

THERE'S NO PLACE LIKE HOME:

Recommendations for Improving the Quality of Life in Adult Homes Serving People With Mental Illness



Adult Home Work Group
June 2000



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This report is dedicated to the 11,000 individuals with mental illness
who reside in adult homes across New York State

ACKNOWLEDGEMENTS

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EXECUTIVE SUMMARY

As New York State decreased the size of its large State Psychiatric Hospital system, it increasingly relied on adult homes to provide housing and support for people with mental illness. Currently, 11,000 people with serious mental illness reside in adult homes. They comprise 30% of congregate community housing for people with mental illness. Four out of ten persons living in adult homes have a mental illness.

Over the years, many individuals and groups have decried the deplorable conditions in some adult homes, especially those serving people with mental illness. In response, New York passed laws and regulations to assure quality housing and support services. Despite these efforts, New York State failed to adequately examine the needs of people with mental illness living in adult homes and to develop adequately funded and appropriate services to meet their needs.

In March 1999, the State Communities Aid Association (SCAA) and the National Alliance for the Mentally Ill in New York State (NAMI-NYS), in conjunction with Senator Thomas Libous and Assemblymember James Brennan, hosted "*Finding Solutions that Work*," a symposium on adult homes serving residents diagnosed with mental illness. After the symposium, a stakeholders work group was formed to develop recommendations for improving the quality of life in adult homes serving people with mental illness.

The work group makes the recommendations in this report to improve planning, oversight, financing and coordination by and among the state agencies responsible for monitoring adult homes serving residents with mental illness. The recommendations also address ways to increase resident involvement in adult home life. This work needs to continue. The work group urges the New York State Legislature to create a Stakeholders Advisory Committee to continue to develop and monitor adult homes serving people with mental illness.

Adult homes can provide low-cost supervised housing for people with physical and mental disabilities and should be viewed as an integral part of the continuum of housing options for people with mental illness. In past years, New York increased its investment in more community housing options for people with mental illness. Those efforts are laudable; however adult homes will remain a significant source of housing for the mentally ill. New York State, along with industry providers, mental health providers, consumer advocates and others, must provide the vision and the commitment to create an environment and a program of services, which support the people living in adult homes so that they can live in their communities with dignity and health.

BACKGROUND

The state's 453 licensed adult homes are home to over 28,000 New Yorkers. Licensed by the New York State Department of Health (DOH), adult homes provide housing and supportive services for people who are unable, due to physical and/or mental disabilities, to live independently. Approximately 11,000, or nearly 40%, of those living in adult homes have a diagnosis of mental illness. Although originally designed for the old and the infirm, the number of people with mental illness residing in adult homes has increased 27% since 1979.

Most people with mental illness live in homes where at least 25% of the residents have a mental illness. The Department of Health and the Office of Mental Health refer to these homes as impacted homes.¹ In the past twenty years, the number of adult homes, where at least 25% of the residents have a mental illness, has increased while the total number of licensed adult homes has decreased. In the majority of homes serving the mentally ill, over 40% of the residents have a mental illness.

According to the Office of Mental Health, the characteristics of an adult home resident varies depending on whether or not the person lives in a home with a large population of people with mental illness.

- The "typical" resident of an adult home with few mentally ill residents is a white female between 75 and 84 years of age.
- In contrast, residents of homes with large numbers of people with mental illness are generally younger, male and more likely to be from a minority population.

Approximately 3% of persons in homes with few mentally ill residents are younger than 65 years of age, compared to 69% of the residents in homes with large numbers of persons who are mentally ill.

The "typical" person with mental illness residing in an adult home today is likely to be a male, under age 65. Most of the mental health services utilized by residents are clinic and day treatment programs primarily focused on treatment and management rather than empowerment and recovery. Only 1% of residents are able to access sheltered work or supported employment programs. There are few services available for residents experiencing an alcohol and/or substance abuse problem. In times of crisis, residents are often hospitalized without receiving any therapeutic intervention before the hospitalization.²

Most often people with mental illness move into adult homes after a hospitalization. Many have complex physical as well as mental disabilities that necessitate the supportive living environment and supervision that an adult home provides. Often, people are referred to adult homes because other housing alternatives, especially those licensed and funded by State Office of Mental Health (OMH), are unavailable at the time of discharge or are inappropriate for the person being discharged.

¹ Many find "impacted homes" to be a disparaging term. This term will only be used in the recommendation section in order to save space.

² Delivery of Mental Health Services to Individuals in Adult Care Facilities. OMH, April 1999.

Adult Homes Challenged by Serious Problems for Years

While there are homes that provide adequate, and sometimes exemplary, care for their residents, the adult home industry has long been challenged by serious and deep-rooted problems. In 1977, Charles Hynes, Deputy Attorney General, issued a report entitled *Private Proprietary Homes for Adults* depicting deplorable conditions, unscrupulous financial practices and mistreated residents in many adult homes. This report also highlighted the special needs of residents with mental illness and how limited state funding contributed to the distressing conditions in many of the homes serving the poor and the mentally ill.

In the wake of the Hynes report, legislation and regulations were developed to improve the conditions in adult homes. Legislation requiring the joint visitation and inspection by the Office of Mental Health and the Department of Social Services was enacted in 1977 to address the special needs of people with serious mental illnesses residing in adult homes.

In 1979, the Department of Social Services (the agency responsible for adult home licensure at the time) commissioned a report from Welfare Research, Inc. (WRI) entitled *Survey of the Needs and Problems of Adult Home Residents in New York State*. Their survey provided detailed information on the characteristics of the people residing in adult homes and highlighted the need for more case management and supportive services for residents with mental illness (see Appendix B for executive summary). Subsequently, the Department of Social Services developed a plan of action to address those problems (see Appendix C for the recommendations).

In 1990, in response to a request by the New York State Legislature, the Commission on Quality of Care for the Mentally Disabled (CQC) reported on the effectiveness of the joint visitation program in regulating and monitoring adult homes serving people with mental illness (see Appendix D for report recommendations). The similarity between the Hynes report and the CQC report is striking. The CQC report, *Adult Homes Serving Residents with Mental Illness*, found a significant number of homes with serious deficiencies that adversely affected the day-to-day living conditions, safety, supervision and health of residents.

In 1996, New York State implemented the Quality Incentive Payment (QUIP) Program to improve the physical plant in adult homes. QUIP is the first and only direct subsidy the state pays to adult home operators. Payment of QUIP to an adult home operator is based on their compliance history with DOH standards. Funding has totaled between \$1.5 million and \$2.5 million per year. Since its inception, concerns have been expressed about the inadequacy of funds available through QUIP, poor oversight of expenditures and whether or not homes receiving QUIP funds meet DOH standards. In the 2000-2001 NYS Budget \$6 million was included for QUIP although no additional provisions for accountability or resources for residents were included.

In 1997, the New York State Legislature requested the Office of Mental Health to undertake a study of the delivery of mental health services to residents of adult homes. This report, completed in 1999, also includes recommendations for enhancing the coordination and delivery of mental health services to residents of adult homes (see Appendix E for the recommendations).

Finding Solutions That Work

In March 1999, the State Communities Aid Association (SCAA) and the National Alliance for the Mentally Ill in New York State (NAMI-NYS), in conjunction with Senator Thomas Libous and Assemblymember James Brennan, hosted "Finding Solutions that Work," a symposium on adult homes serving residents with mental illness.

For many, the symposium provided the first opportunity to hear a variety of perspectives on the adult home model for people with mental illness. The audience of more than fifty included adult home operators, family members, mental health providers and other mental health advocates, as well as state and local government officials. Although outlooks differed, all were united by the common goal of providing high quality service for people residing in adult homes.

Those attending the symposium acknowledged that while the situation has improved over the past ten years, the quality of life in some adult homes remains distressing. Sadly, many of the problems today are identical to those found in reports completed over the past twenty years:

- Funding mechanisms fail to support services and activities essential to providing high quality residential and mental health services.
- Limited resources for enforcement of state regulations continue to contribute to the poor quality of life in adult homes.
- Service fragmentation and an absence of focus on outcomes and performance have limited the effectiveness of mental health services for persons diagnosed with mental illness residing in adult homes.
- Many residents of adult homes continue to feel powerless over the conditions that determine the day-to-day quality of their lives and they often lack advocates to protect their rights.
- Few adult home residents with mental illness have an opportunity to work or participate in community activities.

After the symposium, SCAA and NAMI/NYS convened a stakeholders work group to develop and promote policies to improve the quality of life for residents of adult homes serving people with mental illness.

Stakeholders Work Group

Members of the work group included representatives from adult homes, mental health providers, local mental hygiene directors, social service commissioners, legal advocates, family members and advocates for the mentally ill. In addition, staff from the Department of Health (DOH), Office of Mental Health (OMH) and Commission on Quality Care for the Mentally Disabled (CQC) provided significant technical assistance to the work group and its subcommittees. The work group met over several months, working through four subcommittees:

- Planning
- Oversight
- Coordination and Service Delivery
- Financing

RECOMMENDATIONS

The Stakeholders Work Group strongly recommends that the efforts they began continue. The work group urges the New York State Legislature to create a Stakeholders Advisory Committee to continue to develop and monitor planning, oversight, service delivery and financing of adult homes serving people with mental illness. This committee should work with DOH, OMH, and CQC and should include stakeholder representation at least as broad as that of this work group. Specific tasks for the Stakeholders Advisory Committee are included in the recommendation section of this report.

Planning Committee

Planning is an important tool in the development of services for people with mental illness benefiting both the residents and operators of adult homes. Planning activities build partnerships in decision-making and help develop a sense of community. Planning should occur at all levels; the individual adult home, the local Community Services Board³ and the state agencies which license or certify the operation of adult homes and the mental health services provided there and at other locations.

Adult homes and the needs of their residents are largely excluded from current state and community planning activities. An example of New York State's failure to adequately address the needs of people with mental illness living in adult homes is the Assisted Living Reform Act (S. 5982), presently before the New York State Legislature. This legislation encourages the development of a variety of options so that physically disabled and elderly residents can "age in place" in an Assisted Living Facility. Adult homes that qualify can become an Assisted Living Facility and receive enhanced Medicaid rates to support more services for residents. However, in order to qualify as an Assisted Living Facility, only 40% or less of the resident population can be diagnosed with a mental illness. Homes with large populations of persons diagnosed with a mental illness will be classified as a residence for adults and will not receive any additional funds.

The Assisted Living Reform Act completely fails to address the housing and support service needs of people with mental illness residing in adult homes. The bill also denies people with mental illness the opportunity to age in place. As written, this will provide operators of adult homes with a clear incentive to reduce the number of persons diagnosed with mental illness in their facilities in order to qualify as an Assisted Living Facility.

Additionally, the legislation may be in conflict with the Americans with Disabilities Act of 1990. A recent Supreme Court decision, Olmstead v. L.C. ex. rel. Simring, held that public entities, including states, must administer programs in the most integrated setting appropriate to the needs of individuals with disabilities.

³ Every county in New York State is required by law to have a Community Services Board to advise local commissioners of mental health and to assist in the preparation of annual plans for mental hygiene services in the county.

Planning committee recommendations focus on mechanisms to ensure appropriate planning at the state, local and individual home levels:

- The New York State Legislature should include the needs of people with mental illness in any legislation that impacts adult homes. Specifically, current pending legislation known as the Assisted Living Reform Act should be amended to address the housing needs of people with serious mental illness residing in adult homes in such a way that they are able to age in place and remain in the most integrated setting appropriate to their needs.
- The Stakeholders Advisory Committee should engage in ongoing long-term planning and services development for the residents of adult homes in which 25% or more of the population has a mental illness. Data collected should enable OMH and DOH to provide a description of residents of adult homes with a mental illness, including referral sources and medical and mental health service needs. The confidentiality of all individuals about whom information is collected must be strictly maintained. The aggregate information should be shared with the New York State Legislature, state agencies and local communities.
- DOH and OMH should work together to collect and disseminate data on the population of people with mental illness who are residing in adult homes to support long-term planning and services development.
- OMH should identify residents of adult homes as one of the target populations whose needs should be addressed in annual plans developed by local Community Services Boards.
- Local Community Services Boards, in communities where adult homes in which 25% or more of the population has a mental illness are located, should include both residents and adult home providers.
- Local Community Service Boards should solicit input from adult home residents, operators and service providers when developing local plans.
- Adult home and mental health providers should work together to include residents in planning activities. Examples of planning activities include:
 - Creation and development of a home-like atmosphere.
 - Decisions as to what supportive services are offered in the adult home.
 - How QUIP funds are to be used.
 - Development of social and recreational programs, which residents will enjoy.

Oversight Committee

Oversight of adult homes is dispersed throughout state government. DOH began licensing adult homes in 1998 after assuming this responsibility from the former Department of Social Services. OMH licenses the mental health services provided to residents in mental health homes.

Additionally, Chapter 669 of the Laws of 1977 requires joint visitation and inspection by DOH and OMH in adult homes with a significant number of persons with mental illness and allows OMH to propose supplementary standards for these homes. There currently exists a Memorandum of Understanding (MOU) between OMH and DOH for joint inspections, that states:

“OMH shall participate in the inspection of adult care facilities with a significant number of mentally ill persons. Such participation shall occur after DOH notifies the appropriate OMH...office that after inspection there appear to be issues related to the quality and delivery of services to mentally ill persons...”

In fact, New York State law requires joint inspections as a part of the yearly inspection process because of concerns about quality. Accordingly, the language in the MOU needs to be reviewed for compliance with the law.

CQC administers the Adult Home Advocacy Project providing legal and non-legal advocacy assistance to residents with mental illness in adult homes in New York City and on Long Island. CQC also provides independent oversight of all mental hygiene programs in the state. In addition, three different committees in the New York State Legislature have some oversight responsibility for adult homes.

While many adult homes have improved their operations and physical plant, there remain a number of homes with serious deficiencies. The Oversight Committee was particularly concerned about the number of homes that continue to operate despite repeated deficiencies cited in inspection reports. Weakness in enforcement puts vulnerable residents at great risk. Further, failure to deal with such problems gives the entire adult home industry a black eye. Oversight Committee recommendations focus on improving inspection and enforcement, especially DOH and OMH joint inspections, and oversight of QUIP funds.

- The New York State Legislature should:
 - Significantly increase the amount of QUIP funding for one year as part of an overall program to significantly improve adult homes provided accountability for those expenditures is improved. (This recommendation was developed based on the 1999-2000 QUIP \$2 million.)
 - Improve accountability for QUIP expenditures as part of the experiment by requiring:
 - ◆ Resident input on how to spend QUIP funds in their own home.
 - ◆ DOH to monitor QUIP utilization during annual inspections to ensure consistency with plans submitted to DOH.
 - ◆ Adult home operators to maintain a record of QUIP expenditures.
 - ◆ Provide resources to DOH to enable them to monitor QUIP.

- The Stakeholders Advisory Committee should develop:
 - Eligibility criteria for distribution of QUIP funds to adult homes.
 - A standard questionnaire to measure residents understanding of their rights.⁴

- DOH and OMH should work together to:
 - Conduct joint inspections of adult homes on a regular basis as required by 18 NYCRR, sec. 485.3. The joint inspection need not occur simultaneously. The OMH and DOH Memorandum of Understanding calls for joint inspections only after DOH notifies OMH that there appear to be issues related to the quality and delivery of services to mentally ill persons. This recommendation would bring OMH and DOH into compliance with state law. OMH and DOH should use joint inspections to:
 - ◆ Share information and address concerns surfaced during joint inspections.
 - ◆ Identify areas to target technical assistance efforts.
 - ◆ Ensure that mental health providers and adult home providers exchange information, strictly guarding confidentiality, about resident issues or problems in accordance with 18 NYCRR, 487.7 (7)(2)(iv.).

- OMH should:
 - Require mental health teams to articulate the purpose behind their practices and policies: to support empowerment, recovery, and individualized, culturally competent care.
 - Determine if mental health practice is consistent with these principles during inspections.
 - Examine treatment plans of 10% of the adult home population receiving mental health services and hold confidential meetings with the individual residents to determine if the treatment plan is appropriate and being followed.
 - Meet confidentially with Resident Council representatives and any individual resident wishing to meet to discuss their mental health services.
 - Confer with adult home administrators after or during the inspection process to receive their input on mental health services. This communication must not breach any privileged communication between a resident and his/her mental health provider.
 - Ensure that all mental health case managers meet the minimum qualifications established under 18 N.Y.C.R.R. Sec. 487.9(d).
 - Ensure that all mental health providers receive training on residents' rights under Social Services Law and Regulations and inform residents of their rights.

- DOH should:
 - Rigorously pursue enforcement – in an expeditious manner – against all homes that have a demonstrated pattern and practice of substantial noncompliance as evidenced by the regional inspection report.
 - Impose increased civil penalties against homes that have been subject to repeated enforcement for a three-year period.

⁴ See appendix for sample Residents' Rights Measurement Instrument.

- Continue efforts to develop, articulate, implement and assess a plan to promote uniform inspections throughout New York State.
- Conduct frequent inspections of all homes that have repeated deficiencies.
- Require inspectors to attend training sessions. Residents and adult home administrators should have input into the training curriculum.
- Send a copy of the inspection report to the home's Resident's Council.
- Work with the Social Security Administration to ensure the residents receive retroactive payments and monitor those payments during annual inspections to ensure that the funds were properly distributed.
- Review the approach to negotiation and imposition of civil penalties to ensure their impact as a deterrent to continued misconduct and that, when applicable, they are used, with resident input, to improve the quality of life in the home.
- Meet with residents privately to complete the Residents Rights Measurement Instrument to be developed by the DOH/OMH/CQC Stakeholders Advisory Committee.⁵

Coordination & Service Delivery Committee

The Coordination & Service Delivery Committee recommendations seek to expand the range of rehabilitative and recovery-oriented services, improve the overall quality of services and increase and improve communication between adult home operators and mental health providers. Recommendations include:

- The New York State Legislature should:
 - Pass legislation and require regulatory changes to improve medication provision in adult homes. Changes should focus on funding, staff qualification, training and accountability in medication provision.
 - Fund an adequate and appropriate number of adult home staff to meet resident case management needs.
- The Stakeholders Advisory Committee should develop:
 - A standard referral package for adult homes.
 - Release of information procedures to improve coordination and service delivery and encourage coordination and sharing of information between adult home and mental health providers.
 - Collaborative training initiatives.
 - A model adult home program to serve as a Center for Excellence providing adult home providers with the opportunity to learn about and implement new models.
- DOH and OMH should work together to:
 - Sponsor an annual best practice conference for adult home providers, mental health providers and residents.
 - Ensure that all referral sources receive a copy of the DOH "Do Not Place list."

⁵ See Appendix F for draft questionnaire.

- Train referral sources on appropriate referrals, including adult home providers in such training.
 - Provide collaborative training across all systems.
 - Develop a viable dispute resolution process between adult home providers and mental health providers.
 - Ensure technical assistance is provided to adult home operators on accessing mental health resources on behalf of their residents.
- OMH should:
- Include adult homes in OMH's Best Practices Pilot.
 - Add specialized consultation to the array of services that providers can offer to adult homes.
 - Encourage development of Peer Support and MICA-Double Trouble Groups on site in adult homes.
 - Target new supported housing units to residents of adult homes.
 - Emphasize the role of the mental health provider as a resident advocate.
 - Provide technical assistance to mental health providers on adult home regulations.
- DOH should:
- Strengthen Resident Council and leadership training.
- Local Government should:
- Invite and encourage adult home and mental health providers, residents, families and advocates to attend local adult home network meetings to address concerns and foster quality improvement on an ongoing basis.
- Adult home and mental health providers should work together to:
- Encourage resident independence.
 - Reach out to local communities with the goal of blending the facility and residents into the community.
 - Informally educate community members about the services that are provided by the adult home as well as the variety of residents who are members of the community.
 - Encourage residents and staff to attend community activities and patronize community services and businesses in the course of daily living, not necessarily only as part of an institutionalized group outing from the home or mental health program.

Financing Committee

Insufficient funding to support adult home operations and the residents in adult homes continues to undermine quality housing and supportive services to residents.

Adult home providers receive federal and state funds through Congregate Care, Level II SSI. SSI funding is composed of a federal payment and a New York State supplement that is currently \$26.73 per day upstate, and \$27.73 per day downstate. The federal payment is adjusted annually

for changes in the cost of living but the state portion has not been increased since 1988. In order to implement the federal COLA the New York State Legislature acts to increase the amount available to be paid to Adult Home Providers and the amount to be added to the personal needs allowance. (Each resident on SSI currently receives \$115 per month for a personal needs allowance.) The Legislator has allocated the majority of the COLA increases each year to the adult home operator through an increase of room and board. The residents' monthly \$115 PNA is very insufficient because it must cover all personal hygiene items, clothing, public transportation, and use of public telephone.

SSI can be the sole source of reimbursement an adult home receives from indigent residents, and may be the only source of income in homes with large populations of people with mental illness although adult home providers often receive additional funds from family members of residents as well as through other mechanisms. The state does not regulate payments from family members and there is no data on how much adult home providers receive.

Adult home providers are required to furnish room and board (three meals per day), 24-hour supervision, personal care, case management, medication assistance, structured activities, laundry and housekeeping under this reimbursement schedule. As stated previously, adult homes also may receive QUIP payments depending on compliance with DOH standards. QUIP was created to reward exemplary homes. Adult home providers are to use QUIP funds to:

- enhance the quality of life for residents, including renovations;
- enhance activity programs;
- increase salaries for direct care staff.

QUIP has not been adequately funded nor has there been adequate oversight to ensure that QUIP funds are used appropriately. QUIP is not permitted, under New York State law, to simply be a subsidy to adult home operators although without oversight, it is probably used in that way. Since QUIP funding was tripled in the 2000-2001 Final Budget, assuring accountability, resident input, and compliance with DOH requirements will become paramount.

Mental health services are purchased from mental health agencies and are reimbursed through Medicaid. While the services that are required to be provided by the adult home provider should promote wellness through a supportive living environment and the early detection of problems, they are insufficiently funded. Adult home providers are unable to access Medicaid funding for many needed services because federal law prohibits federal participation of Medicaid for any services rendered to individuals who live in an Institution for the Mentally Diseased (IMD). An IMD is defined as a facility with more than 16 beds in which 50% or more of the population has a diagnosis of mental illness. The state is concerned that using Medicaid to fund these crucial services in adult homes with large numbers of people with mental illness will risk federal financial participation in Medicaid for all of the residents of the adult home. Accordingly, Medicaid is not available to support needed services in these homes.

Advocacy services for residents of adult homes are supported by federal and state funds and are administered by CQC. According to CQC, state funding for advocacy services for residents of adult homes totals less than \$200,000 per year and only supports services in New York City and Long Island. The limited resources for advocacy programs make it hard to effectively respond

to the many complaints received from this disabled population. For example, there is only one attorney available to respond to the residents of 58 homes in New York City, one Resident's Council coordinator in New York City and one attorney in Long Island. The disabled residents must have access to top quality, readily available advocacy support in every home in New York State.

CQC also administers the federally funded Protection and Advocacy for people with Mental Illness (PAMI) program. This program funds legal and non-legal advocacy services for people with a mental illness living in any type of supported living facility, including adult homes. These services are available throughout the state although services to persons living in adult homes are a very small part of their work.

These funding mechanisms do not provide adequate incentives or oversight to insure that quality will improve with increased funding. The Finance Committee strongly urges the state to develop new funding mechanisms in conjunction with appropriate oversight structures to assure quality housing and access to appropriate treatment and support. Re-directing funds could minimize the need for additional state funding to support adult homes. For example, some Medicaid funds currently spent on hospital services could be re-directed toward crisis intervention services in adult homes to reduce the reliance on hospitalizations in times of crisis.

Recommendations include:

- The New York State Legislature should:
 - Increase funding to support residents through creation of a clothing allowance for adult home residents on SSI and Safety Net/Welfare.
 - Increase adult home residents' personal needs allowance.
 - Increase funding for advocacy services so that they can be available throughout the state and City of New York.
 - Require increased accountability and resident input in QUIP decisions. This recommendation takes on greater significance in view of the Legislatures willingness to increase QUIP in the 2000-2001 Budget. See associated recommendations in Oversight Committee recommendations.
 - Increase funds for DOH staff to carry out the inspection process.
- The Stakeholders Advisory Committee should thoroughly examine the issues surrounding adult homes serving people with mental illness and design a program with enhanced funding that will encourage a more home like setting, and increase quality of life, choice and competition.
- OMH and DOH should fund an annual best practices conference for adult homes serving people with mental illness.
- OMH should:
 - Work with local mental hygiene directors and mental health providers to insure that new mental health funding initiatives (especially case management) are targeted toward residents of adult homes with mental illness.

- Provide funding to support specialized consultation to adult homes by mental health providers.
- Provide funding for licensed providers to work with adult home providers, staff and residents to develop demonstration projects that increase attention to the needs of people with mental health diagnoses in adult homes.

CONCLUSION

The following tables summarize committee recommendations for each of the state and local entities involved in the adult home arena. These recommendations were developed and are supported by a broad range of stakeholders. We hope that our successful experience working together will inspire New York State to continue this important work. Without leadership from the state, these recommendations will do nothing to improve the quality of life for the people living in adult homes. For over twenty years, good, solid recommendations have been made to improve adult homes. In response, New York has passed laws and regulations to improve the quality of life in adult homes. Laws and regulations are just one part of the solution. New York must also provide the resources necessary for implementation. It is time for the state to make a sustained effort to make adult homes a viable community housing option for people with mental illness.

APPENDICES

- Appendix A: Recommendation Tables
- Appendix B: WRI Executive Summary
- Appendix C: DSS 1979 Action Steps
- Appendix D: CQC Recommendations from 1990 Study of Adult Homes Service Residents with Mental Illness
- Appendix E: Recommendations from 1999 OMH Report to the Legislature on the Delivery of Mental Health Services to Individuals in Adult Care Facilities
- Appendix F: Resident's Rights Questionnaire
- Appendix G: Work Group Participants

Appendix A:

Recommendation Tables

Appendix B:

WRI Executive Summary

***Adult Home Stakeholders Work Group Recommendations for:
The New York State Legislature***

Planning	Oversight	Coordination & Service Delivery	Financing
<i>Create a Stakeholders Advisory Committee to continue to develop and monitor planning, oversight, service delivery and financing of adult homes serving people with mental illness.</i>			
<p>Include the needs of people with mental illness in any legislation that impacts adult homes. Specifically, current pending legislation known as the Assisted Living Reform Act should be amended to address the housing needs of people with serious mental illness residing in adult homes in such a way that they are able to age in place and remain in the most integrated setting appropriate to their needs.</p>	<p>Significantly increase the amount of QUIP funding for one year as part of an overall program to significantly improve adult homes provided accountability for those expenditures is improved. (This recommendation was developed based on the 1999-2000 QUIP \$2 million.)</p> <p>Improve accountability for QUIP expenditures as part of the experiment by requiring:</p> <ul style="list-style-type: none"> • Resident input on how to spend QUIP funds in their own home. • DOH to monitor QUIP utilization during annual inspections to ensure consistency with plans submitted to DOH. • Adult home operators to maintain a record of QUIP expenditures. • Provide resources to DOH to enable them to monitor QUIP. 	<p>Pass legislation and require regulatory changes to improve medication provision in adult homes. Changes should focus on funding, staff qualification, training and accountability in medication provision.</p> <p>Fund an adequate and appropriate number of adult home staff to meet resident case management needs.</p>	<p>Increase funding to support residents through creation of a clothing allowance for adult home residents' on SSI and Safety Net/Welfare.</p> <p>Increase adult home residents' personal needs allowance.</p> <p>Increase funding for advocacy services so that they can be available throughout the state and City of New York.</p> <p>Require increased accountability and resident input in QUIP decisions. This recommendation takes on greater significance in view of the Legislature's willingness to increase QUIP in the 2000-2001 Budget. See associated recommendations in Oversight Committee recommendations.</p> <p>Increase funds for DOH staff to carry out the inspection process.</p>

***Adult Home Stakeholders Work Group Recommendations for:
The Stakeholders Advisory Committee***

Planning	Oversight	Coordination & Service Delivery	Financing
<p>Engage in ongoing long-term planning and services development for the residents of adult homes in which 25% or more of the population has a mental illness. Data collected should enable OMH and DOH to provide a description of residents of adult homes with a mental illness, including referral sources and medical and mental health service needs. The confidentiality of all individuals about whom information is collected must be strictly maintained. The aggregate information should be shared with the New York State Legislature, state agencies and local communities.</p>	<p>Develop eligibility criteria for distribution of QUIP funds to adult homes.</p> <p>Develop a standard questionnaire to measure residents understanding of their rights.*</p>	<p>Develop a standard referral package for adult homes.</p> <p>Develop release of information procedures to improve coordination and service delivery and encourage coordination and sharing of information between adult home and mental health providers.</p> <p>Develop collaborative training initiatives.</p> <p>Develop a model adult home program to serve as a Center for Excellence providing adult home providers with the opportunity to learn about and implement new models.</p>	<p>Thoroughly examine the issues surrounding adult homes serving people with mental illness and design a program with enhanced funding that will encourage a more home like setting, and increase quality of life, choice and competition.</p>

* See Appendix F for sample Residents' Rights Measurement Instrument

Adult Home Stakeholders Work Group Recommendations for:

Joint Initiatives to be Undertaken by the New York State Department of Health (DOH) and Office of Mental Health (OMH)

Planning	Oversight	Coordination & Service Delivery	Financing
<p>Collect and disseminate data on the population of people with mental illness who are residing in adult homes to support long-term planning and services development.</p>	<p>Conduct joint inspections of impacted adult homes on a regular basis as required by 18 NYCRR, sec. 485.3. The joint inspection need not occur simultaneously. The joint inspections should be used to:</p> <ul style="list-style-type: none"> * Share information and address concerns surfaced during joint inspections. * Identify areas to target technical assistance efforts. * Ensure that mental health providers and adult home providers exchange information, strictly guarding confidentiality, about resident issues or problems in accordance with 18 NYCRR, 487.7 (7)(2)(iv.) 	<p>Sponsor an annual best practice conference for adult home providers, mental health providers and residents.</p> <p>Ensure that all referral sources receive a copy of the DOH "Do Not Place list."</p> <p>Train referral sources on appropriate referrals, including adult home providers in such training.</p> <p>Provide collaborative training across all systems.</p> <p>Develop a viable dispute resolution process between adult home providers and mental health providers.</p> <p>Ensure technical assistance is provided to adult home operators on accessing mental health resources on behalf of their residents.</p>	<p>Fund an annual best practices conference for adult homes serving people with mental illness.</p>

Adult Home Stakeholders Work Group Recommendations for:

The New York State Office of Mental Health (OMH)

Planning	Oversight	Coordination & Service Delivery	Financing
<p>Identify residents of adult homes as one of the target populations whose needs should be addressed in annual plans developed by local Community Services Boards.</p>	<p>Require mental health teams to articulate the purpose behind their practices and policies to support care that will support an individual's recovery.</p> <p>OMH inspections should determine if mental health practice is consistent with these principles during inspection.</p> <p>Examine treatment plans of 10% of the adult home population receiving mental health services.</p> <p>Hold confidential meetings with the individual residents to determine if the treatment plan is appropriate and being followed.</p> <p>Meet confidentially with Resident Council representatives and any individual resident wishing to meet to discuss their mental health services.</p> <p>Confer with adult home administrators after or during the inspection process to receive their input on mental health services.</p> <p>Ensure that all mental health case managers meet the minimum qualifications established under 18 N.Y.C.R.R. Sec. 487.9(d).</p> <p>Ensure that all mental health providers receive training on residents' rights under Social Services Law and Regulations and inform residents of these rights.</p>	<p>Include Adult homes in OMH's Best Practices Pilot.</p> <p>Add specialized consultation to the array of services that providers can offer to adult homes.</p> <p>Encourage development of Peer Support and MICA-Double Trouble Groups on site in adult homes.</p> <p>Target new supported housing units to residents of adult homes.</p> <p>Emphasize the role of the mental health provider as a resident advocate.</p> <p>Provide technical assistance to mental health providers on adult home regulations.</p>	<p>Work with local mental hygiene directors and mental health providers to insure that new mental health funding initiatives (especially case management) are targeted toward residents of adult homes with mental illness.</p> <p>Provide funding to support specialized consultation to adult homes by mental health providers.</p> <p>Provide funding for licensed providers to work with adult home providers, staff and residents to develop demonstration projects that increase attention to the needs of people with mental health diagnoses in adult homes.</p>

***Adult Home Stakeholders Work Group Recommendations for:
The New York State Department of Health (DOH)***

Oversight	Coordination & Service Delivery
<p>Rigorously pursue enforcement – in an expeditious manner – against all homes that have a demonstrated pattern and practice of substantial noncompliance as evidenced by the regional inspection report.</p> <p>Impose increased civil penalties against homes that have been subject to repeated enforcement for a three-year period.</p> <p>Continue efforts to develop, articulate, implement and assess a plan to promote uniform inspections throughout New York State.</p> <p>Conduct frequent inspections of all homes that have repeated deficiencies.</p> <p>Require inspectors to attend training sessions. Residents and adult home administrators should have input into the training curriculum.</p> <p>Send a copy of the inspection report to the home’s Resident’s Council.</p> <p>Work with the Social Security Administration to ensure the residents receive retroactive payments and monitor those payments during annual inspections to ensure that the funds were properly distributed.</p> <p>Review the approach to negotiation and imposition of civil penalties to ensure their impact as a deterrent to continued misconduct and that, when applicable, they are used, with resident input, to improve the quality of life the home.</p> <p>Meet with residents privately to complete the Residents Rights Measurement Instrument to be developed by the Stakeholders Advisory Committee.*</p>	<p>Strengthen Resident Council and leadership training.</p>

* See Appendix F for draft questionnaire.

Adult Home Stakeholders Work Group Recommendations for:
Local Government

Planning	Coordination & Service Delivery
Ensure that local community services boards in communities which impacted adult homes* are located include both residents and adult home providers in their membership and that the local community service boards solicit input from adult home providers, residents operators and service providers when developing local plans.	Invite and encourage adult home and mental health providers, residents, families and advocates to attend local adult home network meetings to address concerns and foster quality improvement on an ongoing basis.

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* Impacted home is the term used by OMH and DOH to refer to a home where 25% or more of the population has a mental illness.

Adult Home Stakeholders Work Group Recommendations for:

**Joint Initiatives to be Undertaken by Adult Home
and Mental Health Providers**

Planning	Coordination & Service Delivery
<p>Include residents in planning activities. Examples of planning activities include:</p> <ul style="list-style-type: none">* Creation and development of a home-like atmosphere.* Decisions as to what supportive services are offered in the adult home.* How QUIP funds are to be used.* Development of a social and recreational program which residents will enjoy.	<p>Encourage resident independence.</p> <p>Reach out to local communities with the goal of blending the facility and residents into the community.</p> <p>Informally educate community members about the services that are provided by the adult home as well as the variety of residents who are members of the community.</p> <p>Encourage residents and staff to attend community activities and patronize community services and businesses in the course of daily living, not necessarily only as part of an institutionalized group outing from the home or mental health program.</p>

Appendix B:

WRI Executive Summary

Appendix C:

DSS 1979 Action Steps

DSS 1979 Action Steps

- Action 1. The Department of Social Services will promote the development of a continuum of residential care facilities and admissions criteria and controls to assure that individuals are appropriately placed within that continuum.
- Action 2. The development of case management for adult home residents will be a priority for the Department of Social Services.
- Action 3. The admission process should at minimum require a completed, standardized medical examination form that includes not only a physical assessment but also an assessment of ability to exercise daily living skills, with the signature of the examining physician; the assessment should be updated annually thereafter.
- Action 4. Each DCF should be required to have a written agreement for emergency medical services with a local hospital, medical group, or physician.
- Action 5. Each DCF will be required to have a written agreement with a psychiatric center, a community mental health council, or a voluntary agency for episodic and continuing psychiatric services, including rehabilitation.
- Action 6. Administration and self-administration of medications will be immediately addressed.
- Action 7. The Department of Social Services will review training needs for the case managers, DCF administrators and staff, and all professionals who work with or place DCF residents. Where appropriate, direct sponsorship of training programs will be undertaken. Licensure requirements for adult home administrators will also be evaluated.
- Action 8. The Department of Social Services will develop programs to coordinate and enrich existing recreation and rehabilitation services offered to DCF residents by both public and voluntary agencies.
- Action 9. The Department of Social Services will add a health component to its field inspection process and will work closely with the Department of Health to maximize that agency's intervention in adult homes.
- Action 10. The Department of Social Services will join with the Department of Health to develop mechanisms that would provide efficient methods of transfer between DCFs, HRFs, SNFs, and acute care hospitals as well as to lower levels of care.
- Action 11. The Department of Social Services will continue to support applied research in adult homes and the service delivery system that directly relates to the homes.

Appendix D:

CQC Recommendations from 1990 Study of Adult Homes Serving Residents with Mental Illness

Appendix E:

Recommendations from 1999 OMH Report to the Legislature on the Delivery of Mental Health Services to Individuals in Adult Care Facilities

Appendix F:

Resident's Rights Questionnaire

Draft Resident's Rights Questionnaire

- Did you receive a copy of your admission agreement?
- Did it have a statement of rights attached to it?
- Has anyone explained your rights to you? If yes, who?
- Have you had a complaint concerning the home within the last year? If yes, what?
- Did you tell a staff member about the problem? If yes, who and was the problem resolved?
- Would you bring a problem to the home's attention again? Why or why not?
- Within the past year, have you complained to someone outside the home about a problem at the home? If yes, who, and was the problem resolved?
- Does the staff treat you with respect and courtesy?
- While you were in your room, has a staff member ever entered your room without knocking and waiting until you gave him/her permission to do so within the past year?
- While you were in your room, has a staff member ever removed any of your belongings without permission within the past year?
- Are you allowed to have visitors during regular business hours?
- Has someone at the home opened your mail without permission within the past year?
- Do you have a Resident's Council at your home?
- How often does it meet?
- Are you told of the date and time of the meetings? How and by whom?
- Do you attend meetings?
- Is the Council effective?
- Is there anything else that you would like to tell me?

Appendix G:

Work Group Participants

Adult Home Work Group Participants

Peter Ashenden, Mental Health Empowerment Project
Eric Bettelheim, New York Psychotherapy & Counseling Center
William Bode, Nassau/Suffolk Law Services
Eleanor Mallach Bromberg, DSW, State Communities Aid Association
Veronica Coppola, Coppola Ryan McHugh
Gail DeRienzi, Catholic Charities
Colleen Gillespie, Center for Health & Public Service Research, NYU
George Gitlitz, Coalition of Institutionalized Aged and Disabled
Sherry Janowitz Grenz, National Alliance for the Mentally Ill in NYS
Margaret Hadad, Long Term Care Ombudsman's Office
Patricia Harrison, NYC Dept. of Mental Health, Mental Retardation & Alcoholism Services
Wayne Herron, National Alliance for the Mentally Ill in NYS
Michael Katch, Federation of Employment & Guidance Services
Geoffrey Lieberman, Coalition of Institutionalized Aged and Disabled
Harvey Lieberman, Institute for Community Living
Wendy Lukas, NYS Conference of Local Mental Hygiene Directors Inc.
Judith Maier, Sullivan County Division of Health & Family Services
Lisa Newcomb, Empire State Association of Adult Homes & Assisted Living Facilities
Michael O'Leary, Columbia County Department of Mental Health
Julia Price-Rosner, Mobilization for Youth Legal Services, Inc.
Davin Robinson, State Communities Aid Association
Joshua Rubin, Coalition of Voluntary Mental Health Agencies, Inc.
Sheri Sanduski, NYS Conference of Local Mental Hygiene Directors, Inc.
Karen Schimke, State Communities Aid Association
Lynn Videka-Sherman, School of Social Work, Rockefeller College
Lenore Warsoff, Rockland County Office for the Aging
Florence Weil, National Alliance for the Mentally Ill in New York State

Adult Home Work Group

Catholic Charities
Center for Health & Public Service Research – NYU
Coalition of Institutionalized Aged and Disabled
Coalition of Voluntary Mental Health Agencies, Inc.
Columbia County Department of Mental Health
Empire State Association of Adult Homes & Assisted Living Facilities
Federation of Employment & Guidance Services
Institute for Community Living
Long Term Care Ombudsman’s Office
Mental Health Empowerment Project
Mobilization for Youth Legal Services, Inc.
Nassau/Suffolk Law Services
National Alliance for the Mentally Ill in NYS
New York Psychotherapy & Counseling Center
NYC Department of Mental Health, Mental Retardation & Alcoholism Services
NYS Conference of Local Mental Hygiene Directors, Inc.
Rockland County Office for the Aging
School of Social Work - Rockefeller College
State Communities Aid Association
Sullivan County Division of Health & Family Services

(INSIDE BACK COVER)

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Appendix C:

DSS 1979 Action Steps

**Report
to the
Legislature**

April 1999