

MENTAL HEALTH IS KEY TO LONG-TERM CARE

**Report of a Workgroup on
Behavioral Health and Long-term Care**

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The Geriatric Mental Health Alliance of New York

MHA OF NYC

The logo for MHA of NYC consists of three concentric circles of varying shades of blue, centered behind the text 'MHA OF NYC'.

ABOUT THE GERIATRIC MENTAL HEALTH ALLIANCE OF NEW YORK

The Geriatric Mental Health Alliance of New York (GMHA-NY) was founded in January 2004 with the goal of advocating for changes in mental health practice and policy that are needed to improve current mental health services for older adults and to develop an adequate response to the mental health needs of the elder boom generation. The Alliance's goals are to: 1) advocate for improvements in public policy regarding geriatric mental health and 2) provide information, public education, professional and paraprofessional training, and technical assistance regarding state-of-the-art practices in geriatric mental health. The Alliance works primarily in New York State, but it also offers training and technical assistance in geriatric mental health service, funding, and advocacy nationwide.

ABOUT THE MENTAL HEALTH ASSOCIATION OF NEW YORK CITY

The Mental Health Association of New York City (MHA of NYC) is a private, not for profit, organization whose mission is to provide direct services, access to services, community education, and advocacy for the benefit of people with mental illness. MHA of NYC works to change attitudes about mental illnesses; to improve services for children, adults, and older adults with mental disorders; and to promote mental health in the community. MHA of NYC serves as the mental health information hub for New York City via LifeNet, the 24/7, multilingual, multicultural information and referral hotline and website staffed by mental health professionals. Through a subsidiary corporation, MHA of NYC also operates the National Suicide Prevention Lifeline. For help in NYC, call 1-800-LifeNet or visit www.800lifenet.org. For help nationwide, call 1-800-273-TALK.

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Table of Contents

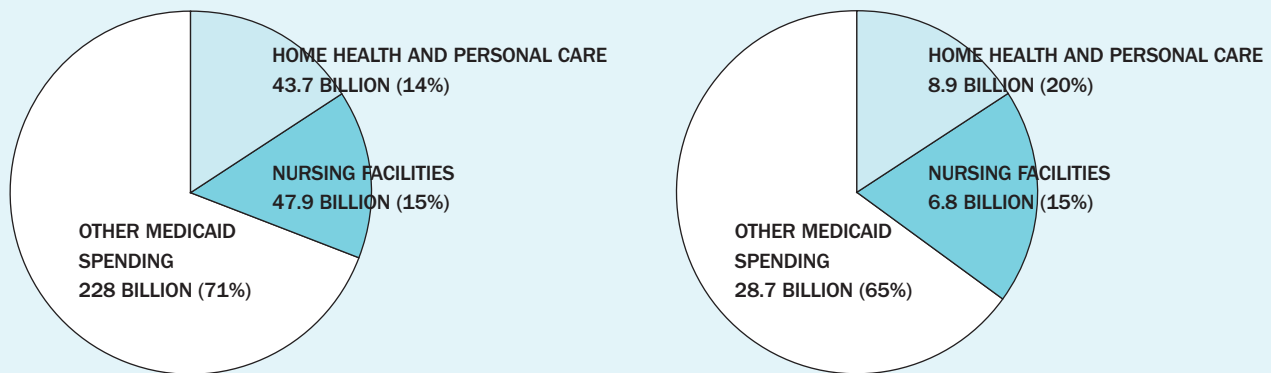
EXECUTIVE SUMMARY AND INTRODUCTION	3
BACKGROUND REGARDING LONG-TERM CARE IN NEW YORK STATE	6
Informal Long-Term Care: Family Caregivers	6
Formal Long-Term Care.....	7
General Observations	7
Case and Elder Care Management	8
Homecare Services.....	8
Day Programs in the Health/Aging Service System.....	9
Day Programs in the Mental Health System	10
Housing	10
Senior Housing.....	10
Naturally Occurring Retirement Community-Supportive Service Programs	10
Assisted Living.....	10
New York State Office of Mental Health (OMH) Housing for People with Serious Mental Illnesses	11
Adult Homes	11
Nursing Homes	12
Hospice and End-of-Life Care	14
Long-Term Care in New York State.....	14
Expanded In Home Services for the Elderly Program (EISEP).....	15
Housing Alternatives to Nursing Homes.....	15
New York Connects	15
Federal-State Health Reform Partnership.....	15
Money Follows the Person Federal Rebalancing Demonstration Program.....	16
Nursing Facility Transition and Diversion Medicaid Waiver	16
Culture Change	16

CONCERNS REGARDING MEETING THE MENTAL HEALTH NEEDS OF RECIPIENTS OF LONG-TERM CARE	17
Shortage of Home and Community-Based Services	17
Inadequate Residential Alternatives	17
Culture Change in Nursing Homes	17
Long-Term Care Workforce.....	18
 RECOMMENDATIONS	 19
Goals	19
How to Achieve These Goals	19
General Recommendations.....	19
Cross-Cutting Themes	19
Workforce Development and Training	19
Finance	20
Governmental and Private Sector Readiness	20
Recommendations to Promote Community Integration	20
Housing	20
Home and Community-Based Mental Health Services	20
Homecare Services	21
Co-Occurring Health and Mental Health Disorders.....	21
Informal Caregiver Support.....	21
Outreach and Public Education	21
Recommendations to Improve Quality of Long-Term Care for Older Adults with Mental Illness	21
General.....	21
To Improve the Quality of Community-Based Long-Term Care Services.....	21
To Improve Quality in Institutional Settings	22
Assisted Living and Lifecare Communities	22
 RECOMMENDATIONS FOR IMMEDIATE ACTION.....	 23

Executive Summary and Introduction

- ◆ The spiraling costs of Medicaid have led to federal and state efforts to hold down these costs, and long-term care has become one of the major areas targeted for cost containment.
- ◆ It is easy to understand why. Nationally Medicaid spending in 2007 for long-term health care was over \$91.6 billion, 29% of total spending. In New York State it was \$15.7 billion, 35% of total Medicaid expenditures..^{1 2}

FIGURE 1: DISTRIBUTION OF MEDICAID SPENDING, 2007



US: Distribution of Medicaid Spending, 2007

NYS: Distribution of Medicaid Spending, 2007

- ◆ One way in which the federal and some state governments are trying to contain these costs is by making it more difficult for people to be eligible for Medicaid. This includes greater limits on transferring assets and holding spouses responsible for payment for long-term care.
- ◆ Another way is through restructuring long-term care which, from a fiscal point of view, means holding down the population of nursing homes by (1) making information available that will help people with disabilities and their families choose not to go to nursing homes, (2) providing alternative home and community-based services, and (3) encouraging efforts to discharge people from nursing homes.
- ◆ NYS's vision is a patient-centered approach to long-term care. The goals are to increase use of home and community-based services, implement right-sizing reforms to ensure quality and efficiency, foster smooth transitions in care, increase availability of supportive housing, increase patient involvement in planning, integrate use of care management services, better address end-of-life care, and develop a qualified workforce.³
- ◆ Current NYS long-term care initiatives include New York Connects, the Nursing Home Transition and Diversion (NHTD) Medicaid Waiver, and more.

¹ Kaiser Family Foundation. (2007). *State Medicaid fact sheet: New York and United States*. Washington, D.C.: Author.

² Note: These figures omit the amount spent on ICF-MR and mental health facilities.

³ Kissinger, M. (2007, October). Long term care: Overview and issues. Presentation at the New York Academy of Medicine Conference, New York, NY.

- ◆ Because of our concern about the failure to address mental and behavioral issues in all of these initiatives, in the Spring of 2007, the Geriatric Mental Health Alliance of New York convened a consensus development workgroup on mental health and long-term care.
- ◆ This group included advocates, mental health providers, health providers, aging services providers, and others. (See attached list.)
- ◆ Despite the diversity of its membership, the workgroup rapidly reached consensus on a number of core issues.
- ◆ The Geriatric Mental Health Alliance began with the premise that mental health care is key to effective long-term care. The workgroup re-affirmed this premise.
- ◆ We also agreed that the fundamental goals of long-term care restructuring are reasonable. People should be enabled to choose where they want to live, which will almost always be in the community; and both information services and home and community-based services of many kinds should be available so that people can realistically make the choice to live in the community.
- ◆ But we also agreed that some people need skilled nursing care around the clock and that receiving this care in a congregate setting is the best possible arrangement for many of these people.
- ◆ While we share government's goal of holding down costs when this can be done responsibly, we believe that long-term care restructuring should be more about quality of life than cost of care.
- ◆ As a result, we believe that long-term care reform should be about quality of long-term care services as well as about "communitization" of care.
- ◆ We believe that all levels of long-term care can be improved—in-home services, community-based services, and institutional services.
- ◆ We also noted that in NYS, and nationally, there are really three systems of long-term care. One is the system that is being referred to when people talk about "long-term care." It is a combination of services provided by the health and aging systems.
- ◆ The two other systems of long-term care are in the mental health system and in the mental retardation/developmental disabilities system.
- ◆ The mental health system cares for people with serious and persistent mental illnesses (aka long-term psychiatric disabilities), often from late adolescence to the end of life—although, as we will note later, many of these people shift into the health-based long-term care system as they age.
- ◆ The mental retardation system cares for people with developmental disabilities from birth to death. It has a commitment to provide housing and other services for this population for their lifetimes.
- ◆ We will not focus on the mental health⁴ and mental retardation systems in this position paper except to the extent that these populations end up in the health/aging system of long-term care—i.e., getting home-based services, adult social or medical day care, adult protective services, or residential care in adult homes or nursing homes.

⁴ The Geriatric Mental Health Alliance has a position paper on the needs of aging people in the mental health system entitled *Meeting the Challenges of Aging People with Serious, Long-Term Psychiatric Disabilities*, which can be retrieved at http://www.mhaofnyc.org/gmhany/SPMIReport12_2008.pdf

- ◆ The thesis of this position paper is that improved mental health care is key to improved long-term care.
- ◆ Why? It's really quite simple.
- ◆ Many people are admitted to or remain in nursing homes due to:
 - Mental and/or behavioral problems
 - Family burn-out
 - Lack of community-based services and residential alternatives for people with mental and/or behavioral problems.
- ◆ In addition, the failure to address mental health, addictive, and behavioral problems adequately at all levels of long-term care is among the major problems with the quality of these services.
- ◆ We concluded, therefore, that long-term care must:
 - Address mental and behavioral problems at all levels of long-term care
 - Provide family support
 - Develop community-based services and residential alternatives for people with mental/behavioral problems.
- ◆ In what follows we provide:
 - Background information about long-term care and its problems serving people with mental, addictive, or behavioral problems
 - Recommendations regarding how to overcome these problems.
- ◆ Our recommendations are extensive and complex, and we know that they cannot realistically be implemented in the immediate future. But we can get started in ways that will leverage more of the needed change in the future. As starting points we recommend:
 - Establishing a **Center for Excellence on Geriatric Behavioral Health** with an emphasis on training long-term care personnel to serve people with mental, addictive, and/or behavioral problems
 - Funding some home and community-based services demonstrations **specifically targeted to people at risk of placement** in adult homes or nursing homes
 - Appointing behavioral health experts, advocates, and/or consumers to planning and advisory groups dealing with long-term care**
 - Reviewing all current long-term care restructuring proposals** to be sure they include appropriate provisions regarding behavioral health.

Background Regarding Long-term Care in New York State

Long-term care is provided both formally—by those who are paid for their services—and informally—by those who provide the services voluntarily because of their sense of family duty, friendship, or community caring.

INFORMAL LONG-TERM CARE: FAMILY CAREGIVERS

- ◆ Informal caregivers—primarily family members—provide 80% of the care for disabled people,⁵ at great cost to themselves and with great savings to our society.
- ◆ In 1997 a study valued family caregiving at \$190 billion, 18% of all health spending in that year.⁶ That would make it about \$375 billion in 2007, more than the budget for defense prior to the war in Iraq.⁷
- ◆ All of us who have been caregivers for disabled family members know how stressful it is. Over time it becomes unbearable for some of us. We “burn out.” But what does that mean?
- ◆ It means that we become hopeless about the situation. It means that we live on edge, worried about when the next crisis will take place, when the next call will come in the middle of the night or in the middle of a critical meeting. It means that we wonder whether we will ever have a life again.
- ◆ In mental health jargon it means that we become depressed and anxious. And we are also more likely to become physically ill.⁸
- ◆ And eventually some of us—we think *many* of us—give up. We throw up our hands in despair and send our family members to nursing homes not because they “need” to be in a skilled nursing facility, but because the combination of their infirmities and behaviors and our limited availability, skills, and tolerance make it necessary for them to be someplace else.

CASE EXAMPLE 1

Ms. D worked until she was forced into retirement at the age of 62. She had never married and lived with her mother, who died when Ms. D was 70. She had her first psychotic break shortly afterwards. A nephew took responsibility for her. He visited frequently, arranged a friendly visitor from her religious congregation, and arranged and paid for home health aides. But the home health agency was little help in a psychiatric crisis. After ten years of struggling to keep her in her own apartment, he agreed to allow the hospital, to which she had gone after yet another physical and psychiatric crisis, to place her in a nursing home. Although she was physically healthier in the nursing home, she received poor psychiatric care and her episodic depressions became a chronic state. Her story is sadly commonplace. Families provide most care for people with disabilities. The burden on them is enormous and sometimes unbearable. Then families reluctantly send their relatives to institutions, which often provide inadequate psychiatric services.

⁵ Spillman, B. and Pezzin, L. (2000). Potential and actual family caregivers: Changing networks and the “sandwich generation”. *Milbank Quarterly*, 78 (3), 347-374.

⁶ Arno, P.S., Levine, C., & Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs*, 18 (2), 182-188.

⁷ Houser, A., & Gibson, M. (2008). *Valuing the invaluable: The economic value of family caregiving, 2008 update*. Washington, D.C.:AARP.

⁸ Evercare. (2006). *Evercare® study of caregivers in decline: A closeup look at the health risks of caring for a loved one*. Author.

- ◆ This is a very important and fundamental point about the “need” for care or the “difficulty” of a problem. It is not something inherent in the person who has problems; it is in the relationship between the person and their caregiving environment.
- ◆ We said earlier that some people go to nursing homes because of their behavioral problems. It would have been more precise to say that they go to nursing homes because the people who are caring for them cannot cope with their behavior problems.
- ◆ Often a person with greater skill or tolerance could cope with the problem.
- ◆ That’s why it is so important for us to focus a great deal of attention on caregiver education and support.
- ◆ Caregivers cannot appropriately care for their loved ones alone. They need appropriate supports to help their family members age in the community.
- ◆ Counseling and support for informal caregivers are known to relieve their depression as well as help them cope better with patient’s behavioral problems. This leads, at the very least, to delaying nursing home placement, as much as 18 months, which is a substantial portion of the average length of stay in nursing homes.⁹

FORMAL LONG-TERM CARE

GENERAL OBSERVATIONS

- ◆ Formal long-term care is provided through case management, elder care management, home-based services, day programs, community-based supported and congregate housing, assisted living, life care communities, adult homes, nursing homes, and hospice programs.
- ◆ In NYS, and nationally, there are really three systems of long-term care. One is the system that is being referred to when people talk about “long-term care” restructuring. It is a combination of services provided by the health and aging systems.¹⁰
- ◆ The two other systems of long-term care are in the mental health system and in the mental retardation/developmental disabilities system.
- ◆ The mental health system cares for people with serious and persistent mental illnesses (aka long-term psychiatric disabilities), often from late adolescence to the end of life—although, as we will note later, many of these people shift into the health-based long-term care system as they age.
- ◆ The mental retardation system cares for people with developmental disabilities from birth to death. It has a commitment to provide housing and other services for this population over their lifetimes.
- ◆ We will not focus on the mental health and mental retardation systems in this position paper except to the extent that these populations end up in the health/aging system of long-term care—i.e., getting home-based services, adult social or medical day care, adult protective services, or residential care in adult homes or nursing homes.

⁹ Mittelman, M.S., Haley, W.E., Clay, O.J., & Roth, D.L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer’s disease. *Neurology*, 67, 1592-1599.

¹⁰ One could argue that this is really two systems of care because there are two different state agencies and different federal and state laws involved, but we think it is important to emphasize the connection made between the two systems in developing long-term care plans.

- ◆ Older adults who receive long-term care due to disabilities are much more likely to have mental health conditions than older adults who are not disabled. For example, approximately 3% of older adults in the community without a chronic physical condition have major depression as compared to 7% of those with a physical condition treated in primary care, 14% of those receiving home health care, and approximately 30% of people in nursing homes¹¹.
- ◆ Currently long-term care services for older adults with co-occurring physical disabilities and behavioral health problems are generally inadequate, as we detail below.
- ◆ Funding is also inadequate. Medicare, Medicaid, and even private long-term care insurance cover only some of the kinds of services that older adults with mental disabilities need.

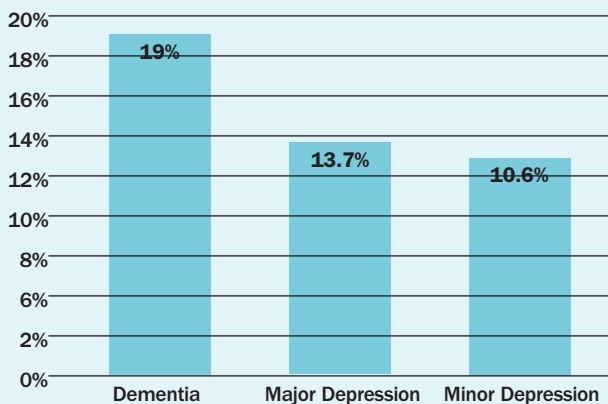
CASE AND ELDER CARE MANAGEMENT

- ◆ Case management is available through the aging services system. For people with serious and persistent mental illness, it is also available through the mental health system. Neither system provides enough funding to meet the full need for case management.
- ◆ Case management provided by the aging services system relies on case managers with limited education and training, virtually no knowledge of mental health or addiction problems, and little skill in dealing with difficult behaviors.
- ◆ Case management provided through the mental health system relies on case managers who generally have not had education or training regarding older adults or the management of chronic health conditions.
- ◆ Elder care management is a relatively new profession. Care managers serve essentially as a supplement or even a substitute for family caregiving. They arrange services in and out of the home, keep in regular contact with their clients, and are usually available when there is a crisis.
- ◆ Many elder care managers are clinical social workers and nurse practitioners by training, and they often have some sophistication with regard to mental health issues.
- ◆ But elder care management is generally available only to those people who can afford to pay for it.

HOMECARE SERVICES

- ◆ Homecare services include a variety of home health services, a variety of home assistance services, and some home-based mental health services.
- ◆ In a 2002 study of home health care patients, 19% suffered from dementia, 13.7% suffered from major depression, and an additional 10.6% suffered from minor depression. Of those with major depression, only 12.3% received adequate treatment.¹²
- ◆ Home health and other home care providers generally are not prepared to screen for mental illness, to make appropriate referrals, or to provide adequate mental health services in the home.

FIGURE 2: PERCENTAGE OF MENTAL ILLNESS AMONG HOME HEALTH CARE PATIENTS



¹¹ Hybels, C.F. & Blazer, D.G. (2003). Epidemiology of late-life mental disorders. *Clinics in Geriatric Medicine*, 19, 663-696.

¹² Bruce, M. et al. (2002). Major depression in elderly home care patients. *American Journal of Psychiatry*, 159, 1367-1374.

- ◆ Home health providers report that the people most difficult to serve are those who exhibit significant behavior problems, such as distrust/paranoia, anger/belligerence, rejection of or non-adherence to treatment, poor hygiene, hoarding, wandering, and annoying behaviors such as complaining and repetitive questions.¹³
- ◆ They also report that they encounter a severe shortage of mental health services in the community, especially mobile mental health services.
- ◆ Funding for homecare services is inadequate. Medicare provides limited coverage for home health services and no funding for home assistance. Medicaid provides more extensive coverage but only for those who are poor.

CASE EXAMPLE 2

Mrs. B, who is 71, lives in a rent-controlled apartment with no elevator. Her husband died five years ago. For a while she kept up with friends, but then she developed a heart condition and managing the stairs became dangerous for her. Over time she has become increasingly isolated, anxious, and depressed. She has a home attendant four hours a day, three days a week to help with shopping and cleaning and the like. A visiting nurse stops in from time to time. Neither is prepared to help Mrs. B with her emotional problems. Mrs. B is not unusual. A recent study indicated that 14% of older adults receiving Medicare home health care have major depression, more than double the prevalence among the general population of older adults.¹⁴

DAY PROGRAMS IN THE HEALTH/AGING SERVICE SYSTEM

- ◆ Day programs include senior centers, adult social day care, adult medical day care, continuing day treatment, and psychiatric rehabilitation programs such as clubhouses.
- ◆ Senior centers are generally not funded adequately to provide mental health services or to serve a significant number of people with disabilities requiring assistance. However, some senior centers have satellite mental health clinics on site or similar arrangements, which appear to be quite helpful.
- ◆ Social day care is far too poorly funded to provide mental health services.
- ◆ Medical day care programs are far better funded, and some have developed a specialty in serving people with serious mental illnesses. Some are also serving people with mental retardation/developmental disabilities, many of whom have a co-occurring psychiatric diagnosis. But most are geared to serving people with physical disabilities and/or dementia.
- ◆ Some programs have established on-site mental health services to better serve these populations, while others have wanted to establish on-site mental health but have not been able to due to the shortage of mental health staff.

CASE EXAMPLE 3

Mr. J, a 60 year old consumer who lives with family and attends a day program operated by the mental health system, has a history of serious mental illness, head trauma, seizures, heart trouble, and gout. Increasingly, program staff have been spending a lot of time assisting Mr. J with various health-related issues including access to benefits and obtaining proper assistive devices. A few weeks ago, Mr. J had a series of medical hospitalizations due to seizures/strokes. He was ordered to have bed rest for two weeks and scheduled for physical therapy three days a week, which preclude him from attending the day program. Staff and fellow consumers are reaching out to Mr. J via telephone. They report that "he is very confused" about his medical condition, and doesn't really understand what is going on. He also is very "down" that he is unable to make it to the program due to the therapy and other medical appointments. He sees the program as a great social outlet.

¹³ Friedman, M., & Williams, K. (2006). Geriatric mental health – *The need for change: Focus group findings*. Retrieved from http://www.mhaofnyc.org/gmhany/FocusGroup12_2008.pdf.

¹⁴ Ibid Bruce, M. et al. (2002).

- ◆ It appears that increasing numbers of people in adult medical day care have serious and persistent mental illnesses because:
 - Mental health programs cannot care for people with co-occurring serious mental illness and major physical disabilities.
 - Some adult medical day care programs are recruiting people with serious and persistent mental illness, almost all of whom are Medicaid eligible.¹⁵

DAY PROGRAMS IN THE MENTAL HEALTH SYSTEM

- ◆ Continuing day treatment (CDT) programs are designed for people with long-term psychiatric disabilities—primarily middle-aged people. CDTs provide a combination of treatment and rehabilitation services, but generally do not have resources to manage physical conditions.
- ◆ Psychiatric rehabilitation programs are largely designed for middle-aged populations, and work is a primary goal. New York Association for Psychiatric Rehabilitation Services (NYAPRS) has developed recommendations for adapting psychiatric rehab to older adults including providing program participants choice as to whether or not they want to work, allowing for mainstreaming opportunities with the aging service system, focusing on health and substance abuse, and providing case management, accessibility, outreach, support for caregivers and staff training.

HOUSING

Senior Housing

- ◆ Organized housing programs for seniors include active adult communities, supportive housing for older adults, enriched housing, continuing care retirement communities, shared living residences, naturally occurring retirement communities (NORCs), intergenerational housing, and single room occupancies.
- ◆ Some have on-site supports, but most do not have on-site mental health services.
- ◆ In fact, most of the housing for older adults is not designed to address the mental health needs of their residents.

Naturally Occurring Retirement Community-Supportive Service Programs (NORC-SSPs)

- ◆ Many older adults live in NORCs—apartment houses or complexes in which a majority of residents are older adults.
- ◆ Some NORCs have supportive service programs (NORC-SSPs). On-site services often include case management, health care management, education, socialization, recreational activities, and volunteer opportunities.
- ◆ Some provide on-site mental health services, but most are not prepared to deal with the serious mental health problems of their residents. Many of them report difficulty getting access to community-based mental health services.¹⁶

Assisted Living

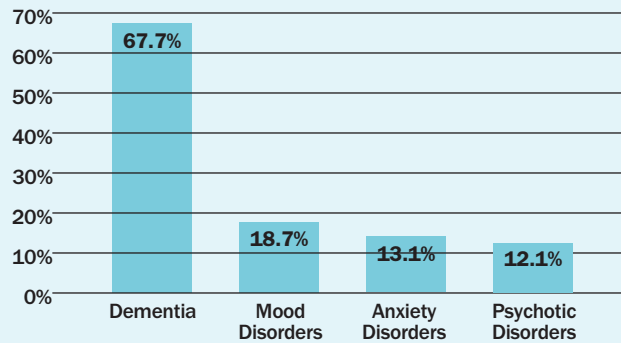
- ◆ Assisted living facilities (ALFs) and lifecare communities are generally designed for people who have some degree of physical disability and/or dementia but who do not need 24 hour skilled nursing care. They are not designed for people who have a history of serious mental illness.

¹⁵ Ibid Friedman, M., & Williams, K. (2006).

¹⁶ Ibid.

- ◆ The majority of ALFs do not provide onsite mental health services, but many permit private practitioners to come on site to provide mental health services.
- ◆ ALF staff generally have not been trained to recognize mental health needs of residents or to deal with behavioral problems even though recent studies indicate high prevalence of mental disorders. For example, a recent study revealed that 67.7% of residents in assisted living have some form of dementia and 26.3% have some other mental disorder – 18.7% have mood disorders, 13.1% have anxiety disorders and 12.1% have psychotic disorders.¹⁷ The study also showed that, of the assisted living residents with non-dementia mental disorders, 42% are not properly diagnosed.¹⁸

FIGURE 3: PERCENTAGE OF MENTAL ILLNESS AMONG ASSISTED LIVING RESIDENTS



New York State Office of Mental Health (NYSOMH) Housing for People with Serious Mental Illnesses

New York Office of Mental Health (OMH) Housing for People with Serious Mental Illnesses

- ◆ Community-based supportive, supported, and congregate housing is provided through the mental health system, homeless housing assistance, and other programs. It consists of many different housing models ranging from virtually independent living to supervised group living.
- ◆ In general, these housing programs are not designed with older adults in mind. For example, while 6% of the housing units funded by OMH are occupied by people 65+, very few are designated for older adults—and they are not staffed or funded differently from other units.¹⁹
- ◆ These programs and others should be designed to be accessible to people with physical disabilities, to prevent injuries due to falls, to assist with activities of daily living (ADLs), to manage numerous medications, and with appropriate requirements regarding activities during the day.
- ◆ Because OMH housing programs are generally not designed for older adults with mental and behavioral problems, older adults are often referred too quickly to adult and nursing homes.

Adult Homes

- ◆ Because of the state's reliance on adult homes to house deinstitutionalized adults with serious and persistent mental illness, many adult homes have a very large number of residents with serious mental illness ("impacted homes"). In NYS 12-15,000 people with serious and persistent mental illnesses live in adult homes, many of them 55 or older.²⁰ In addition there are many older adults in these homes who do not have lifelong mental illness but have developed significant mental health problems as they have aged.

¹⁷ The percentages do not add up to 26.3% due to co-occurring disorders.

¹⁸ Rosenblatt, A. et. al. (2004). The Maryland assisted living study: Prevalence, recognition, and treatment of dementia and other psychiatric disorders in the assisted living population of Central Maryland. *Journal of the American Geriatrics Society*, 52 (10), 1618-1625.

¹⁹ New York State Office of Mental Health. (2007). *Patient characteristics survey*. Albany, NY: Author.

²⁰ New York State Office of Mental Health. (2004). *2004 – 2008 statewide comprehensive plan for mental health services*. Albany, NY: Author.

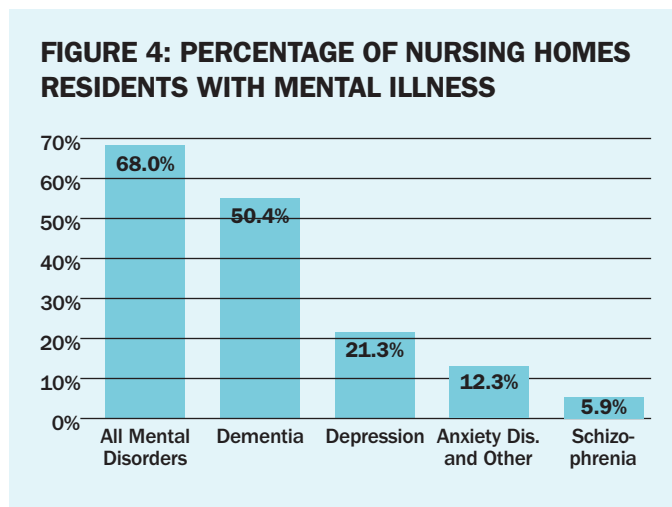
- ◆ Most impacted homes have on-site mental health services, which in some homes are quite good. But there is a widespread impression that in most homes mental health services are inadequate, living conditions are very poor, and health care is not of decent quality.
- ◆ It is likely that many adult home residents with mental illness could live in more “integrated” settings, but adult homes are not geared to promote recovery or movement to more independent settings.

Nursing Homes

- ◆ Most people in nursing homes have chronic physical illness or have failed to recover from injuries. Yet at least 50% of this population has co-occurring mental illnesses—especially dementia, depression, and anxiety disorders.
- ◆ In fact, mental and behavioral disorders are among the major reasons that people go to, and remain in, institution-based long-term care settings.
- ◆ Many people in nursing homes have dementia, which is commonly thought of as a physical rather than a mental disorder—a view that reflects a totally antiquated Cartesian mind-body dualism.
- ◆ Sometimes what is diagnosed as dementia is actually unrecognized depression. And many people correctly diagnosed with dementia have co-occurring depression and anxiety disorders that, in many cases when treated, improve the patient’s cognitive functioning.

- ◆ Current data from the Center for Medicare and Medicaid Services indicate that the prevalence of mental and behavioral disorders in nursing homes in NYS is high and increasing. These data indicate that 46% have dementia, often with emotional and behavioral complications; 35% are clinically depressed; 17% have other psychiatric diagnoses; and 23% have behavior problems associated with mental illness.²¹

- ◆ There are reasons to believe that these estimates are low. For example, a 1996 study estimated that 68% of nursing home residents have some mental illness—59% have schizophrenia, 21.3% have depression, 50.4% have dementia and related disorders, and 12.3% have anxiety and other disorders.



- ◆ This study also found 16.6% of nursing home residents have a primary diagnosis of mental illness other than dementia, second only to circulatory diseases.²² These are people who cannot care for themselves and do not have family or friends to take care of them at home.
- ◆ In addition, during the heyday of deinstitutionalization a large number of people with serious and persistent mental illness were discharged to nursing homes. This was official state policy. During the 1980s a change in federal law prohibited the practice of referring people with a primary diagnosis of mental illness to nursing homes. This may have

²¹ Center for Medicare and Medicaid Services. (2007). *CMS OSCAR data current surveys: Medical condition-mental status*. Retrieved from http://www.ahcancal.org/research_data/oscar_data/NursingFacilityPatientCharacteristics/MC_mental_status_Jun2007.pdf

²² Mechanic, D. & McAlpine, D. (2000). Use of nursing homes in the care of persons with severe mental illness: 1985 to 1995. *American Psychiatric Association*, 51, 354-358.

slowed this process, but it certainly did not stop it. Exceptions are permitted. And many older adults with serious mental illness also have physical disabilities.

- ◆ According to the CDC, there are roughly 43,000 people with schizophrenia in nursing homes nationally. Nursing homes are the primary source of institutional care for older adults with schizophrenia, accounting for 89% of those institutionalized²³ (other than prisons).
- ◆ In addition, in 2003 (the most recent available figures) approximately 6.2% of spending on direct mental health services was in nursing homes.²⁴
- ◆ Nursing home staff and long-term care ombudsmen have both reported a rise in the number of people in nursing homes with serious mental illness, substance abuse, and severe behavior problems. Much of this rise appears to be related to the trend to reduce length of stay in hospitals by transferring patients to nursing homes for short-term rehabilitation.²⁵
 - Once rehab is complete, many patients with mental illness cannot be discharged due to lack of community services, especially housing.
 - Popular alternatives to nursing homes, especially assisted living, will not admit or keep people with severe mental or behavior problems.
- ◆ One of the critical takeaway messages of all these data is that a great many people who are in nursing homes putatively because of dementia or physical illnesses or injuries are actually there because of their mental and behavioral disorders.
- ◆ Home care workers, case managers, and—most importantly—their families could manage their physical problems in the community if they had the skill and assistance to deal with such behavioral problems as:
 - Distrust/Paranoia
 - Verbal or physical abuse of caregivers
 - Refusal or inability to adhere to treatment
 - Not eating properly
 - Dangerous behaviors such as smoking in bed
 - Wandering
 - Lack of personal and/or household cleanliness
 - Hoarding
 - Being wildly annoying—such as constant complainers or questioners.
- ◆ Of course, what really results in their placement in nursing homes is not their problematic behavior alone. It is the inability of people to manage their behavior in the community. Better trained, more skilled, more tolerant caregivers in the community could probably prevent many of these placements.
- ◆ Lack of skill in dealing with mental, addictive, and behavioral problems is also common in nursing homes.
- ◆ There are different ways to provide mental health services in nursing homes. Some nursing homes have mental health professionals on staff, some contract with mental health professionals in private practice, and some have a mix of both.
- ◆ Some of these services are quite good.

²³ Jones, A. (2002). *The national nursing home survey: 1999 summary*. National Center for Health Statistics. Vital Health Stat 13 (152). Washington, DC: U.S. Department of Health and Human Services.

²⁴ Mark, T. et al. (2007). Mental health treatment expenditure trends, 1986-2003. *Psychiatric Services*, 58 (8), 1041-1048.

²⁵ Ibid Friedman, M. & Williams, K. (2006).

- ◆ But in general it appears that line staff, physicians, and administrators often do not have the knowledge they need to work effectively with residents with behavioral health problems.
- ◆ It is also difficult for nursing homes to provide enough mental health services because of Medicare and Medicaid rules that limit the use of social workers and which can delay the use of new medications for years.

Hospice and End-of-Life Care

- ◆ Generally, mental health providers do not have the resources to deal with people with serious and persistent mental illness at the end-of-life. As a result, they often transfer people to health providers, who are strangers.
- ◆ In some cases, hospice services are provided in community settings, but this seems to be quite uncommon.²⁶

LONG-TERM CARE IN NEW YORK STATE

- ◆ The hard work of developing viable alternatives to nursing home care began in New York State in 1977 with the passage of the Lombardi Nursing Homes Without Walls Act.²⁷ This made it possible for an individual who was eligible for a nursing home but who could remain at home with assistance that cost no more than 75% of the average cost of a nursing home to have Medicaid pay for needed health care and assistive devices in the home.
- ◆ Since that time, New York has introduced nearly a dozen other Medicaid programs that provide alternatives to nursing home care for thousands of New Yorkers. These include: the Program for All Inclusive Care for the Elderly (PACE), the Consumer-Directed Personal Assistance program, the Traumatic Brain Injury program, the Care at Home program for Medically Fragile Children, the Medicaid Assisted Living program, and most recently the Nursing Home Transition and Diversion Medicaid Waiver. Each new program has built on the successes and limitations of previous efforts, and was designed to address the unique needs of very different subpopulations.
- ◆ In several of these programs, the State has experimented with capitated financing for community-based long-term care services. Various organizations have accepted overall responsibility for the care of older adults at something less than the average cost of nursing home care in the same county. There are currently 18 managed long-term care plans in New York State serving 20,000 seniors. From a quality of care perspective this approach appears to be effective.²⁸
- ◆ Despite these early and ongoing efforts, the State—and many others—are convinced that there are significant numbers of people in nursing homes who would not be there if appropriate services were available in the community.
- ◆ Key elements of long-term care restructuring include:
 - Single points of entry (information)
 - Home renovation for accessibility and safety
 - In-home services such as home health care and case management
 - Community-based services
 - Residential alternatives to nursing homes
 - Culture change in nursing homes.
- ◆ Some specific initiatives include:
 - Expanded In Home Services for the Elderly Program

²⁶ Ibid.

²⁷ Melvin, T. (1987, July 12). 173 beds for the elderly approved. *New York Times*.

²⁸ Hokenstad, A. & Haglanger, K. (2004). *Keeping care at home: Strategies for expanding Medicaid managed long term care*. New York, NY: United Hospital Fund.

- Housing Alternatives
- New York Connects
- Federal State Health Reform Partnership (F-SHRP)
- Money Follows the Person Demonstration Program
- Nursing Home Transition and Diversion Medicaid Waiver
- Culture Change, such as the Greenhouse Model

EXPANDED IN HOME SERVICES FOR THE ELDERLY PROGRAM (EISEP)

- ◆ EISEP provides access to non-medical in home services for older adults who are at risk of institutional care. Most of the recipients are non-Medicaid eligible and are required to pay a fee, based on their annual income. Funding is provided for home services, case management, respite, and ancillary services.
- ◆ The providers of these services have limited education with no knowledge or training regarding mental health. This program will be expanded as part of long-term care restructuring.

HOUSING ALTERNATIVES TO NURSING HOMES

- ◆ The NYS budget for 2007-8 included \$2.5 million for the development of housing alternatives to support nursing home diversion or transition—a small step in the right direction.

NEW YORK CONNECTS

- ◆ “NY Connects” is the new name for an initiative that was originally called “the single point of entry.” It is one of the requirements of F-SHRP. (See below.)
- ◆ When first proposed, it appeared that the state wanted to control admission to nursing homes by creating an entry point where an evaluation would be done, efforts would be made to divert from placement, and decisions would be made whether and where to place someone in need of skilled nursing care 24 hours a day.
- ◆ This interpretation of the proposal aroused great concerns about the potential for a bureaucratic bottleneck and for vastly limited choice by a person with disabilities and/or their families.
- ◆ It has since been made clear that the “single point of entry” is intended to be a single source of comprehensive and unbiased information for people of all ages in need of long-term care services. Its use is optional—at least for now.
- ◆ A local government agency or organization will be responsible for the coordination of the program in each county.
- ◆ Such local agencies have the option of including mental health as part of the other long-term care information they provide; however it doesn't appear that many counties are planning to include it. Most likely the “single-point of entry” will refer mental health issues out to mental health information and referral services, which are designed to respond to people with long-term psychiatric disabilities or to people who can benefit from traditional clinical services but not for people who may need skilled nursing care 24 hours a day or for their families, who need support.

FEDERAL-STATE HEALTH REFORM PARTNERSHIP (F-SHRP)

- ◆ Federal-State Health Reform Partnership is a Medicaid 1115 demonstration program that requires NYS to restructure its health care system. The reform initiatives include:
 - Rightsizing the acute care system

- Reforming long-term care, which includes rightsizing long-term care, implementation of a single point of entry, a home modification program, and a tele-home care program to help individuals remain at home
- Improvement in primary/ambulatory care

- ◆ Mental health services are not included as part of this demonstration program.

MONEY FOLLOWS THE PERSON FEDERAL REBALANCING DEMONSTRATION PROGRAM

- ◆ This demonstration grant will provide enhanced federal matching funds for select Medicaid services to persons who transition to community-based care after having been in a nursing home under the NHTD Medicaid Waiver. The additional federal revenue is to be used to offset the cost of projects designed to rebalance the long-term care system. NYS plans to use the funds for:
 - Establishment of a Housing Taskforce to address housing related barriers to community reintegration. OMH is participating on the Taskforce.
 - Discussion with nursing home residents about community integration opportunities
 - Coordination with other long-term care efforts including the Department of Health (DOH) Discharge Planning Work Group, NY Connects, and others.
 - Establishment of OMH and Office of Mental Retardation and Developmental Disabilities procedures to assure that individuals with mental illness and/or developmental disabilities are provided information regarding community-based options
 - Provision of assistive devices

NURSING FACILITY TRANSITION AND DIVERSION MEDICAID WAIVER

- ◆ The NHTD Medicaid Waiver will allow about 2,500 Medicaid beneficiaries over a period of five years, who would otherwise be institutionalized in a nursing home, to live and receive services in the community. Recipients will have access to regular Medicaid services as well as additional services including case management, independent living skills training, assistive technology and other services needed to maintain independence. There are unresolved issues as to how the waiver program will work with the mental health system. It will be critical to have cooperation from mental health providers on how to deal with clients with mental illnesses.

CULTURE CHANGE

- ◆ Culture change is a movement to transform the institutional approach of traditional long-term care institutions into a care delivery model that is person centered. Components of the person-centered approach include individualized care, collaboration between residents and staff to better reflect resident's needs and wants, a home-like environment, and a sense of community.
- ◆ An example of the culture change movement is the Greenhouse Model, which is a nursing home model that alters the physical environment, the staffing model, and the philosophy of care to make nursing home life more home-like. The homes are small with at most ten older adults, each with private rooms and bathrooms and a shared communal space. Front line staff are known as universal workers that perform a variety of job duties including cooking meals, providing personal assistance, doing laundry, etc. A visiting clinical support team is made up of nurses, doctors and other professionals. We need to learn more about how mental health issues are addressed in this model.
- ◆ As part of this initiative, some nursing homes are also reducing beds and using the additional funds for community-based services.

Concerns Regarding Meeting the Mental Health Needs of Recipients of Long-term Care

As noted above, NYS's long-term care restructuring initiatives barely recognize the importance of mental and behavioral health services. Specifically these initiatives fail to address the problems noted below.

SHORTAGE OF HOME AND COMMUNITY-BASED SERVICES

- ◆ No state proposal regarding expansion of in-home services has addressed the need for staff to have knowledge about mental health beyond community integration counseling for those transitioning from institutions and to have staff who specialize in serving people with mental or behavioral problems.
- ◆ There are no plans to:
 - Expand in-home mental health services
 - Expand mental health services on-site in aging services programs such as senior centers, senior housing, NORCS, or social day care programs
 - Enhance adult medical daycare to meet the mental health needs of patients with serious mental illnesses in addition to dementia
 - Modify continuing day treatment or psychosocial rehabilitation programs to meet the needs of older adults with physical as well as mental disabilities
 - Expand family support.

INADEQUATE RESIDENTIAL ALTERNATIVES

- ◆ The state appears to regard adult homes as community-based residential settings. We regard most of them as institutions that are not acceptable alternatives to nursing homes.
- ◆ Although there are a couple of new mental health community residences designed for older adults with co-occurring psychiatric and physical disabilities, OMH does not have a plan to develop more. Maybe they will and maybe they will not.
- ◆ It is not clear what the impact of the assisted living regulations will be regarding the development of affordable assisted living for people with mental disorders. Basic assisted living requirements do not address issues of mental health.
- ◆ There are no plans to train current staff regarding mental and behavioral disorders.
- ◆ OMH will be participating in the housing workgroup of the Money Follows the Person Demonstration Program. We will monitor this process for outcomes impacting older adults with mental illness.

CULTURE CHANGE IN NURSING HOMES

- ◆ The Greenhouse model offers skilled nursing care 24 hours per day in a non-institutional environment. Expansion of such approaches could promote the individualization of care and life in nursing homes.
- ◆ Mental health training programs for nursing homes could improve quality/humanity of care and promote enough recovery for some residents to return to the community. But no training program is planned.

LONG-TERM CARE WORKFORCE²⁹

- ◆ While the state has mentioned the development of mechanisms to support the workforce, it has not yet articulated a plan as to how it will enhance and expand a qualified, stable long-term care workforce.
- ◆ Such a plan needs to include the use of able, older adults as paid or volunteer members of the workforce because, as the population grows, there will not be enough working age adults to provide needed care.
- ◆ Such a plan should also recognize the contributions made by informal caregivers and should address their needs for support.
- ◆ Efforts must be mounted to determine what training, skill, competency, and preparation the future long-term workforce will need, which must include the support of mental health across the continuum of care.
- ◆ These efforts must pay particular attention to the need to develop both clinical and cultural competence.
- ◆ They also must include the conceptualization of new roles that are responsive to the needs of older adults with mental and behavioral disorders and which can be performed by a workforce that includes older adults returning to the workforce among others.
- ◆ For example, The New York Academy of Medicine has proposed the development of a care coordination function which would provide an assessment-based, comprehensive, longitudinal, and multidisciplinary approach to care for older adults³⁰ and be available in all long-term care settings. Addressing mental health must be a core component of the care coordination model.

²⁹ The Geriatric Mental Health Alliance of New York has developed a position paper on workforce development entitled *Workforce Development to Meet the Mental Health Needs of Older Adults*, which addresses in greater detail the mental health related workforce needs in long-term care.

³⁰ Social Work Leadership Institute. (2007). *Redefining Long-Term Care: A Clear Role for Social Workers in Care Coordination for Older Adults*. New York, NY: Author.

Recommendations

GOALS

Addressing the mental and behavioral issues of older adults and their family members is critical to helping older adults to age in the community. Therefore NYS's long-term care initiatives must include mental health.

The Consensus Group identified three fundamental goals:

- ◆ **Raise consciousness about the importance of mental health** across long-term care systems
- ◆ **Increase access to, and integration of**, mental health, health, and aging community-based services so as to
 - Help older adults with mental and/or substance abuse disorders to live where they want to live
 - Prevent unnecessary institutionalization
 - Make the most efficient use of resources.
- ◆ **Improve the quality of long-term care services.**

HOW TO ACHIEVE THESE GOALS

GENERAL RECOMMENDATIONS

- ◆ NYS's long-term care restructuring initiatives should be recast to recognize the importance of mental health.
- ◆ All advisory and planning groups on long-term care should include experts on geriatric mental health and geriatric mental health "consumers" including family members.

Cross-Cutting Themes:

- ◆ **Person-centered care:** Provide care that allows patients choice of where they want to live, who they want to provide the services, and how they want the service delivered.
- ◆ **Integration of mental health, health, and aging services**
- ◆ **Stigma:** Address mental health stigma experienced by older adults, their caregivers, and providers.

Workforce Development and Training:

- ◆ Increase the size of the workforce
- ◆ Build clinical competence
- ◆ Build cultural competence
- ◆ Provide cross training
- ◆ Offer mentoring opportunities

- ◆ Develop and make use of new service roles such as the “universal worker” and care coordination
- ◆ Foster changes in professional education
- ◆ Develop cadres of home care, day care, and case management providers in the mental health, health, and aging systems well-trained in working with older adults with mental disorders, especially those with severe behavior problems.
- ◆ Provide training for informal caregivers
- ◆ Develop new paraprofessional and peer roles
- ◆ Provide incentives to enter the workforce serving older adults with mental disorders such as loan forgiveness, scholarships, credentialing, and career ladder.

Finance: Need changes of structure as well as more funding.

- ◆ Develop financing models that support care coordination, home-based mental health services, services in community settings such as senior centers and NORCs, day programs integrating health and mental health services, and housing alternatives to nursing homes for older adults with co-occurring physical and psychiatric disabilities.
- ◆ Optimize the use of Medicare funds in NYS.
- ◆ Advocate for Medicare reform including parity and payment for the kinds of services that make it possible for older adults with mental health problems to live in the community.

Governmental and Private Sector Readiness:

- ◆ Develop appropriate leadership
- ◆ Develop plans
- ◆ Provide funding to meet the mental health needs of our growing population of older adults.

RECOMMENDATIONS TO PROMOTE COMMUNITY INTEGRATION

Housing:

- ◆ Provide alternative congregate housing for people with co-occurring physical and mental illnesses so as to reduce admissions and increase discharges from institutions.
- ◆ Develop outreach support services to enable people to live independently if that is what they prefer.

Home and Community-Based Mental Health Services:

- ◆ Increase access to, and quality of, community-based mental health services for older adults with mental illness. It is particularly important to make services more available in people’s homes and in the community settings that they go to for other purposes, such as senior centers, social day care, NORC-SSPs, etc.

Homecare Services:

- ◆ Re-conceptualize homecare as services to address mental health and behavioral problems as well as health problems. This will require some training in mental health for all home health workers, but it will also require the development of cadres of home health care workers who specialize in working with people with mental or behavioral problems.

Co-Occurring Health and Mental Health Disorders:

- ◆ Provide consumers with maximum choice of where to get services
- ◆ Develop the capacity to provide mental health services in the health system—in primary care, specialty care, home health care, medical day care, adult homes, and nursing homes.
- ◆ Develop the capacity to provide health services in the mental health system.
- ◆ Increase the capacity of the mental health system to serve people with serious and persistent mental illnesses who develop serious, physical conditions so as to maintain the continuity of important relationships.
- ◆ Promote dialogue between mental health and health providers about various forms of day care including psychiatric rehabilitation, continuing day treatment, and adult medical day care.

Informal Caregiver Support:

- ◆ Provide support and treatment for informal caregivers.

Outreach and Public Education:

- ◆ Provide public education and outreach to help the general public—including minority populations, clergy, members of benevolent associations and the like, and other people who serve older adults—to understand mental illness, its treatment, and where to find resources. It is also important to address ageism and stigma.

RECOMMENDATIONS TO IMPROVE QUALITY OF LONG-TERM CARE FOR OLDER ADULTS WITH MENTAL ILLNESS

General

- ◆ Increase research to foster the development of evidence-based practices, particularly with regard to mental conditions, behavioral problems, and psychosocial needs for which evidence-based practices currently do not exist.
- ◆ Promote the use of evidence-based and other state-of-the-art practices.
- ◆ Address end-of-life issues with an emphasis on helping people continue their important relationships when they are severely ill and on using palliative care.

To Improve the Quality of Community-Based Long-Term Care Services

- ◆ Review current regulations to assure that they are appropriate for older adults and make necessary changes.
- ◆ Provide needed training in best practices for staff in the mental health, health, and aging systems.

To Improve Quality in Institutional Settings

To improve the quality of mental health care in nursing homes in NYS, it is critical to:

- ◆ Review regulations, including staffing regulations
- ◆ Provide rigorous enforcement
- ◆ Study psycho-behavioral units
- ◆ Promote culture change: Promote individualization of care.
- ◆ Provide mental health training: Provide training in the identification and treatment of mental illness and in the management of behavior problems for staff at all levels.

To improve the quality of life in adult homes, it is critical to:

- ◆ Actively enforce regulations designed to protect adult home residents
- ◆ Improve living conditions in adult homes, such as assuring that all residents have air conditioning in their rooms
- ◆ Conduct a study of the quality of mental health services for adult home residents
- ◆ Review and revise roles of DOH, OMH, and the Office for the Aging
- ◆ Develop training and networking opportunities for mental health professionals serving adult home residents
- ◆ Focus on opportunities for discharge to more independent living settings.

Assisted Living and Lifecare Communities

- ◆ Facilitate enhanced capacity of assisted living and lifecare communities to deal with mental illness and behavior problems.

Recommendations for Immediate Action

- ◆ Our recommendations are extensive and complex, and we know that they cannot realistically be implemented in the immediate future. But we can get started in ways that will leverage more of the needed change in the future. As starting points we recommend:
 - Establishing a **Center for Excellence on Geriatric Behavioral Health** with an emphasis on training long-term care personnel to serve people with mental, addictive, and/or behavioral problems
 - Funding **demonstration projects specifically targeted to people at risk of placement** in adult homes or nursing homes
 - **Appointing behavioral health experts, advocates, and/or consumers to planning and advisory groups dealing with long-term care**
 - **Review all current long-term care proposals** to be sure they include appropriate provisions regarding behavioral health.

Notes

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