# MEETING THE CHALLENGES OF AGING PEOPLE WITH SERIOUS, LONG-TERM PSYCHIATRIC DISABILITIES

Report of a Workgroup Co-Sponsored by
The Geriatric Mental Health Alliance of New York and The
Urban Institute for Behavioral Health of New York City

MHA OF NYC
your link to health

Mental Health Association of New York City

## 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 URBAN INSTITUTE FOR BEHAVIORAL HEALTH (UIBH)

UIBH is a consortium group of 20 private community based behavioral healthcare providers dedicated to bridging the acknowledged gap between science and practice in the New York City multi-ethnic environment. Combined, UIBH agencies serve in excess of 40,000 consumers annually across multiple program types in the publicly funded behavioral health system of New York City. In aggregate, the agencies cover the gamut of behavioral health services, including but not limited to: clinics, Assertive Community Treatment teams, Continuing Day Treatment Programs, residential and housing services, Intensive Psychiatric Rehabilitation Treatment, homeless outreach, HIV/AIDS services, clinics based services, comprehensive services for intellectual disabilities, physical healthcare, and school based services, provided to consumers from diverse diagnostic categories (e.g. persons with serious mental illness, persons with co-occurring mental health and substance abuse disorders, intellectual disabilities, children with severe emotional disturbance, persons with a history

## 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.

## GMHA-NY FUNDERS

The Geriatric Mental Health Alliance of New York is grateful for the support of the Altman Foundation, the Fan Fox and Leslie R. Samuels Foundation, FJC: A Foundation of Philanthropic Funds, the Stella and Charles Guttman Foundation, the James N. Jarvie Commonweal Service, the New York Community Trust, the van Ameringen Foundation, and the Mental Health Association of New York City.

# MEETING THE CHALLENGES OF AGING PEOPLE WITH SERIOUS, LONG-TERM PSYCHIATRIC DISABILITIES

## Report of a Workgroup Co-Sponsored by The Geriatric Mental Health Alliance Of New York and The Urban Institute for Behavioral Health of New York City

Workgroup Chairs
Peter Campanelli, Psy.D
Carl Cohen, M.D.

Written By
Michael Friedman, LMSW
Kimberly Williams, LMSW

June 2006


MHA OF NYC
your link to health

Mental Health Association of New York City

# Table of Contents

# Executive Summary

As the elder boom unfolds over the next 25 years, the mental health system in the U.S. and in NYS will need to make significant changes to meet the needs of people with severe, long-term psychiatric disabilities who are aging.

Currently services for people with long-term psychiatric disabilities are designed primarily for working age adults and are not geared to respond to the developmental challenges faced by those who are aging. As a result, many aging people with psychiatric disabilities are forced to shift from residential, rehabilitative, and treatment programs in the mental health system to nursing homes and to other programs that stress health care.

In addition, the life expectancy of people with long-term psychiatric disabilities is at least 10 to 25 years less than the general population because of poor health[1] and high rates of suicide and accidents.[2] People with long-term psychiatric disabilities are prone to chronic health conditions such as obesity, hypertension, diabetes, heart disease, and pulmonary conditions. In addition to driving down life expectancy, co-occurrence of these conditions and severe mental illness combined with lack of appropriate treatment drive up the costs of care for this population. Sadly, the chances of getting good treatment are limited because of the fragmentation of the health and mental health systems.

In cooperation with the Urban Institute for Behavioral Health of New York City, The Geriatric Mental Health Alliance established a workgroup on people with long-term psychiatric disabilities who are aging in the spring of 2006.

This workgroup has concluded that, in addition to the provision of good psychiatric treatment, changes in housing, rehabilitation, and health care models could make it possible for many more older adults with psychiatric disabilities to live in the community and to survive and even thrive into old age.

---

1 Colton, C.W. & Manderscheid, R.W. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease, 3* (2), Available from: URL: http://www.cdc.gov/pcd/issues/2006/apr/05_0180.htm.

2 Dembling, B.P., Chen, D.T. & Vachon, L. (1999). Life expectancy and causes of death in a population treated for serious mental illness. *Psychiatric Services*, 50(8), 1036-1042.

# Recommendations

The Workgroup on Meeting the Needs of People with Long-Term Psychiatric Disabilities Who Are Aging[3] recommends that New York State develop services responsive to its aging population with long-term, severe mental illness. Our recommendations are designed to:

- **Increase the life expectancy** of people with serious and persistent mental illness and
- **Help them to live in the community**, i.e. avoid institutionalization in adult homes or nursing homes.[4]

These recommendations focus on:

- The provision of improved health services
- The development of more appropriate housing
- Adaptations of rehabilitative approaches to respond to challenges of old age
- Expansion of mobile services to help people remain in mainstream, supported, or community-based congregate housing
- Workforce development
- The development of new financing models

## RECOMMENDATIONS TO IMPROVE HEALTH

1. Improve access to good health care by integrating health with mental health services
2. Focus on health maintenance, disease management, and suicide and accident prevention

## RECOMMENDATIONS TO IMPROVE HOUSING

1. Provide more permanent housing
2. Develop housing that is accessible to people with physical disabilities
3. Modify housing to prevent falls and injuries
4. Provide more activities of daily living (ADL) supports
5. Improve health care in housing programs
6. Develop home health care services specifically for people with psychiatric disabilities
7. Develop alternatives to care by family members
8. Develop housing for people with psychiatric disabilities in naturally occurring retirement communities (NORCs) that have on-site supportive services programs

---

[3] **Age:** In response to the ongoing debate about the age at which a person with long-term psychiatric disabilities should be regarded as geriatric, the workgroup recommended 55 rather than 60 or 65. It did so because people with long-term psychiatric disabilities frequently have had hard lives on the streets as well as substance abuse problems and physical illnesses that make them old before their time. The workgroup also believes that 55 makes more sense because the life expectancy of this population is as much as 25 years less than the general population. A great many people with long-term psychiatric disabilities don't survive to 60 or 65.

[4] NYS regards adult homes as community settings. The Workgroup regards them as institutional settings.

## RECOMMENDATIONS TO IMPROVE REHABILITATION

1. Provide choice of non-vocational as well as vocational programs
2. Develop more mainstream opportunities, e.g. access to senior centers and support groups
3. Focus on health and substance abuse in psychiatric rehabilitation
4. Deal openly with issues of death and dying
5. Enhance case management services
6. Focus on suicide prevention
7. Improve access via transportation services and accessibility to people with physical disabilities
8. Provide outreach to people who stop attending programs
9. Provide support for family caregivers
10. Increase staff training regarding aging, health, and cultural competence

## MOBILE SERVICES

As they age, many people find it increasingly difficult to get around or become reclusive. Outreach and mobile services to reach people in their homes or in community settings they will go to, such as houses of worship or doctors' offices are essential to help people remain in community settings. This is particularly true of crisis services. An ambulance ride to an emergency room frequently begins a process of hospitalization and discharge to a nursing or adult home rather than to a community setting. Mobile crisis services help to avert such placements, which often are unnecessary.

## WORKFORCE DEVELOPMENT

The workgroup noted that there is a great shortage of staff qualified to work with older adults with long-term psychiatric disabilities. In general there is a shortage of geriatric mental health professionals. But there is an even greater shortage of those trained to work with people with psychiatric disabilities.

The workgroup recommended that a number of efforts be undertaken to increase the supply of qualified workers including:

1. The development of incentives to enter the field
2. Improved education in professional schools
3. Increased training
4. The development of volunteer and paraprofessional roles that could be filled by older adults and by people with psychiatric disabilities.

## FINANCING MODELS

- The workgroup agreed that there is a need to further explore financing models that support:
- The integration of health and mental health services
- Innovative services and best practices
- Workforce development initiatives

# Introduction

- As the elder boom unfolds over the next 25 years, the mental health system in the U.S. and in NYS will need to make significant changes to meet the needs people with severe, long-term psychiatric disabilities who are aging.
- Currently services for people with long-term psychiatric disabilities are designed primarily for working age adults and are not geared to respond to the developmental challenges faced by those who are aging.
- As a result, many aging people with psychiatric disabilities are forced to shift from residential, rehabilitative, and treatment programs in the mental health system to nursing homes and to other programs that stress health care.
- In addition, the life expectancy of people with long-term psychiatric disabilities is at least 10 to 25 years less than the general population because of poor health[5] and high rates of suicide and accidents.[6]
- People with long-term psychiatric disabilities are prone to chronic health conditions such as obesity, hypertension, diabetes, heart disease, and pulmonary conditions.
- In addition to driving down life expectancy, co-occurrence of these conditions and severe mental illness combined with lack of appropriate treatment drive up the costs of care for this population.
- Sadly, the chances of getting good treatment are limited because of the fragmentation of the health and mental health systems.
- In cooperation with the Urban Institute for Behavioral Health of New York City, The Geriatric Mental Health Alliance established a workgroup on people with long-term psychiatric disabilities who are aging in the spring of 2006.
- This workgroup has concluded that, in addition to the provision of good psychiatric treatment, changes in housing, rehabilitation, and health care models could make it possible for many more older adults with psychiatric disabilities to live in the community and to survive and even thrive into old age.

---

5 Colton, C.W. & Manderscheid, R.W. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease*, 3 (2), Available from: URL: http://www.cdc.gov/pcd/issues/2006/apr/05_0180.htm.

6 Dembling, B.P., Chen, D.T. & Vachon, L. (1999). Life expectancy and causes of death in a population treated for serious mental illness. *Psychiatric Services*, 50(8), 1036-1042.

# Background

- Since the middle of the 20th century helping people with severe, long-term psychiatric disabilities to live in the community has been the major goal of the mental health system in the United States.
- The first effort to shift from an institution-based mental health policy to a community-based policy was deinstitutionalization.
- Although beneficial to some, for hundreds of thousands of people around the nation and tens of thousands in NYS, deinstitutionalization was a disaster.
- They needed support in order to manage in the community.
- Instead of living independently, upwards of two-thirds moved from hospitals into their parents' homes.
- A great many were transinstitutionalized intentionally to adult homes and to nursing homes; and some were transinstitutionalized unintentionally to jails and prisons.
- A great many did go on to live independently, but most often they lived—with other poor people—in squalid and sometimes dangerous settings. In NYC a very large number moved into single-room occupancy hotels (SROs) that became notorious because of people with psychiatric disabilities were frequent victims of crimes, including a number of highly publicized murders.
- In response to the clear failures of deinstitutionalization, the nation and NYS developed a new mental health policy called "The Community Support Program" (CSP).
- This policy is based on understanding that a great many, if not most, people with long-term psychiatric disabilities need a range of supports to lead satisfying lives in the community.
- In its original form CSP expanded the kinds of interventions provided by the mental health system from treatment alone to a combination of housing, rehabilitation, outpatient treatment, and inpatient treatment in local general hospitals. It also provided case management to coordinate various services and supports.
- Over subsequent years there have been a number of significant modifications including more independent housing models, peer support services, etc.
- Community support policy has been quite successful. In NYS, for example, there are now over 25,000 units of housing for people with psychiatric disabilities. There are also hundreds of rehabilitation programs. There has been a vast increase in outpatient treatment services, some of which have been re-modeled to focus on rehabilitation. In addition, general hospitals have picked up much of the inpatient load that had previously been handled by state hospitals.
- Tens of thousands of people who prior to CSP would have been warehoused in state hospitals or left to their own devices in the community are now reasonably well-served in housing, rehabilitation, and treatment programs.
- However, because CSP has been largely program-based, a significant number of people with psychiatric disabilities who reject mental health services did not benefit from the new services. Over time the system has adjusted to this fact by organizing significant outreach efforts—most notably the Program of Assertive Community Treatment (PACT).
- It too has been remarkably successful.
- But there still is not enough housing, rehabilitation, treatment, case management, or assertive outreach to meet the needs of all people with serious, long-term psychiatric disabilities.

## DEMOGRAPHIC CHANGES

- CSP was created at a time when there had been a great increase in the population of young adults with psychiatric disabilities; therefore, it focused primarily on working age adults.
- With the flow of time, however, people who were in their 30s in the 1980s are in their 50s today, and—if they survive—will be in their 70s in 25 years—at the peak of the elder boom.
- Over the next 25 years the population of older people with long-term psychiatric disabilities will double nationally[7] and increase by 50% in NYS.[8]
- Older adults will increase from about 12% of the total population of people with psychiatric disabilities to about 20%.[9] And the proportion from minority cultures will increase from 16% to 25%.[10]

---

[7] Estimates of the increase range from an increase from 350,000-700,000 to an increase from 1 million to 2 million. The estimates depend on age (55+, 60+, or 65+) and on the definition of psychiatric disability.

[8] Estimates of the increase in NYS range from an increase of 25,000 to 40,000 to an increase from 75,000 to 110,000. The estimates depend on age (55+, 60+, or 65+) and on the definition of psychiatric disability.

[9] U.S. Department of Health and Human Services. (1999). *Mental Health: A Report of the Surgeon General.* Rockville, MD: Author.
U.S. Bureau of the Census. (2000). Population projections of the United States by age, sex, race and Hispanic origin: 1995-2050, *Current Population Reports*, pp. 25-1130.

[10] Ibid

# Older Adults with Long-Term Psychiatric Disabilities and Their Services

## MENTAL STATUS AND PSYCHIATRIC TREATMENT

- Although some people with long-term psychiatric disabilities experience improved mental status and functioning as they age, many continue to have compromised cognitive abilities throughout their lives, even if the primary symptoms of severe mental illness are controlled with medication.

- A small number of the people with serious mental illness who survive into old age have co-occurring substance abuse disorders.[11] Some of them stop abusing drugs as they age, but some do not. There is an expectation that "levels of substance abuse will increase dramatically in the upcoming generation..."[12]

- In addition they are as vulnerable to various forms of dementia as the general population. (The prevalence of dementia doubles every 5 years beginning at age 60.)[13] Therefore, some people with severe long-term psychiatric disabilities experience additional cognitive impairment and, as a result, find it increasingly difficult to manage basic activities of daily living.

- Also, there is increasing evidence that people with long-term psychiatric disabilities frequently become depressed as they age,[14] compounding emotional and cognitive problems.

- Although there are no formally sanctioned evidence-based practices for the treatment of older adults with schizophrenia, there is a consensus that atypical anti-psychotics are effective (albeit in different doses than for younger adults).[15]

- There is also consensus that depression in older adults with schizophrenia can be treated effectively with anti-depressant medications and with cognitive behavioral therapy.[16]

- A number of experts on schizophrenia in old age believe that family psycho-education—an evidence-based practice for younger adults—could also be effective for older adults but that the technique would need to be modified for this population.[17]

---

11 Schoos, R. & Cohen, C.I. (2003). Medical comorbidity in older persons with schizophrenia. In C. Cohen (Ed.), *Schizophrenia Into Later Life* (pp. 128-138). Washington, D.C.: American Psychiatric Publishing, Inc.

12 Patterson T.L. & Jeste D.V. (1999). The potential impact of the baby boom generation on substance abuse among elderly persons. *Psychiatric Services* 50, 1184-1188.

13 Ibid

14 Meeks, S. & Depp, C. (2003). What are the service needs of aging people with schizophrenia? In C. Cohen (Ed.), *Schizophrenia Into Later Life* (pp. 179). Washington, D.C.: American Psychiatric Publishing, Inc.

15 Bartels et al. (2002). Evidence-based practices in geriatric mental health care. *Psychiatric Services*, *53* (11), 1419-1431.

16 Liberman, R.P. (2003). Biobehavioral treatment and rehabilitation for older adults with schizophrenia. In C. Cohen (Ed.), *Schizophrenia into Later Life.* (pp.238-9) Washington D.C.: American Psychiatric Publishing, Inc.

17 Personal communications with Carl Cohen and with William McFarland.

## HEALTH AND LIFE EXPECTANCY

- Although some older adults with long-term psychiatric disabilities remain healthy and vigorous throughout their lives, most have chronic physical conditions including obesity, hypertension, diabetes, heart disease, and pulmonary disease as well as dementia.

- Sadly, people with serious, long-term psychiatric disabilities generally have limited access to quality health care[18] because health care providers generally do not understand their psychological problems and are often uncomfortable caring for them.

- Poor health and poor health care contribute to the low life expectancy of people with serious long-term psychiatric disabilities, whose lives on average are at least 10 shorter than the general population.[19] [20] A recent study puts it at about 25 years.[21]

- Lower life expectancy is also due to suicide and accidents.[22] (Falls are a major cause of disability and death among older adults.)

- Poor health, lack of access to good health care in the community, and the lack of the capacity of mental health programs to address the physical health problems of their clients as they become more severe frequently results in a shift of the population to nursing homes or to adult medical day care facilities as they become more frail.

- Sadly, this often results in separating people with serious, long-term psychiatric disabilities from the communities to which they have often been attached for many, many years.

- And it appears that it also results in many people with serious, long-term psychiatric disorders being alone as they reach the end of life.

### Integrated Health and Mental Health Services

- Integrated health and mental health care offers the hope of improved health care and improved health.

- One approach is to integrate psychiatric services into primary health settings. However, this approach probably will not be helpful to the vast majority of people with serious and persistent mental illness because they generally get very poor primary care and do not have a stable relationship with a primary care physician.
- For this population it makes more sense to integrate primary care into mental health settings.

---

[18] Horvitz-Lennon, M., Kilbourne, A., & Pincus, H. (2006) From Silos to Bridges: Meeting The General Health Care Needs of Adults With Severe Mental Illnesses, *Health Affairs*, 25 (3), 659-669.

[19] Friedman, M. (2004). Baby boomers with schizophrenia and other long-term psychiatric disabilities: Prepare now. *Mental Health News*, p.13.

[20] Bartels, S. (2004). Caring for the whole person: Integrated health care for older adults with severe mental illness and medical comorbidity. *American Geriatrics Society*, 52 (12), 249-257.

[21] Colton, C.W. & Manderscheid, R.W. (2006). Congruencies in increased mortality rates, years of potential life lost, and causes of death among public mental health clients in eight states. *Preventing Chronic Disease*, 3 (2), Available from: URL: http://www.cdc.gov/pcd/issues/2006/apr/05_0180.htm.

[22] Dembling, B.P., Chen, D.T. & Vachon, L. (1999). Life expectancy and causes of death in a population treated for serious mental illness. *Psychiatric Services*, 50 (8), 1036-1042.

- Some mental health organizations (such as The Bridge, Inc.) have done this by establishing satellite health clinics in mental health programs.

- Other mental health organizations (such as the Institute for Community Living) have established primary healthcare clinics that specialize in serving people with mental disabilities.

- Other mental health organizations (such as Fountain House) have established linkages between mental health and primary healthcare providers in the community.

- Other possible approaches include:

  — Applying the disease management model to follow up with, for example, people with serious mental illnesses who have diabetes

  — Establishing home health providers who specialize in serving people with psychiatric disabilities

  — Using psychiatrists to provide primary health care.

## HOUSING

- Currently in NYS the Office of Mental Health (OMH) provides housing for people with long-term psychiatric disabilities including some older adults

- However, many older adults with long-term psychiatric disabilities live with their families, in adult homes, in nursing homes, or are homeless.

- OMH housing is based on three different models—community residences, SROs, and supported housing.

- All three models of housing need to be adapted to the realities of the lives of older people with long-term psychiatric disabilities.

### Community Residences

- "Community residences," which may be congregate living settings or scatter-site apartments, are designed to be transitional living situations. Residents are expected to move on to live independently or with limited supports.

- Most residences work on the assumption that residents need very limited assistance with basic activities of daily living and that they can leave the residence during the day to work, go to school, or attend rehabilitation or day treatment programs. Funded staffing levels are based on these assumptions.

- Funded staffing levels are based on these assumptions.

- Currently 7% of people in community residences are 65 or over, but less than 1% are in facilities designated for older adults.[23]

[23] Personal communication with Doug Cooper, Deputy Director Association for Community Living.

- And facilities for older adults are, unfortunately, not funded to provide additional staffing needed to provide ADL supports and medication management or to adapt the residential setting to the needs of people with physical disabilities or at risk of falls.

### SROs

- SROs provide single room occupancy apartments in buildings that also have minimal on-site services.
- They are designed on the assumption that residents will have an "extended stay," but they do not provide "permanent" housing.
- Older adults in SROs are eligible for a variety of home-based services, but virtually none of these services are designed to meet the mental health needs of older people with serious and persistent mental illnesses.

### Supported Housing

- "Supported housing" is permanent housing in the community subsidized by OMH. Case managers visit residents as needed.
- Few supported housing units are accessible to people with physical disabilities.

### Alternative Design

- There is a need for alternative housing models to take into account the complexity of co-occurring disorders, the need for more ADL supports, and the need for safe and accessible housing.
- There is also a need for congregate housing that is home-like and located in local communities but that is not officially transitional. At some point it simply makes no sense to establish an expectation for an older adult to move from a congregate, supportive setting to independent living.
- Such models are key to avoiding unnecessary use of adult and nursing homes.
- A number of organizations have developed model programs for older adults with long-term psychiatric disabilities, including Rehabilitation Support Services (RSS), Fountain House, and The Bridge.
- In addition, 30-40% of people with serious, long-term psychiatric disabilities live with their parents.[24] As their parents die or become disabled, they need alternative housing and sources of care and support.

## PSYCHIATRIC REHABILITATION, CONTINUING DAY TREATMENT, AND ADULT DAY CARE

- Psychiatric rehabilitation services currently are available in psychiatric rehabilitation programs using a variety of models and in "continuing day treatment" (CDT) programs licensed by OMH.
- Both types of programs are largely designed for middle-aged populations and focused to a large extent on work as a goal.
- Although some older adults want to work their entire lives, others decide that it is time to "retire."

---

[24] Grosser, R. & Conley, E. (1995). Projections of housing disruption among adults with mental illness who live with aging parents. *Psychiatric Services*, 46: 390-394.

- This creates a challenge for psychiatric rehabilitation organizations that have worked hard to promote recovery and to help people lead lives that they find meaningful and satisfying.
- It is not enough, from this point of view, to provide a place to hang out, drink coffee, and play a few games. It means creating opportunities for older adults to engage in activities that they find meaningful.
- This can include volunteer work of a kind that other older adults engage in when they are retired.
- It can also include educational activities.
- It can also include opportunities for socialization and recreation.
- New York Association for Psychiatric Rehabilitation Services (NYAPRS) has organized a Task Force to develop recommendations regarding how to serve older adults for whom activities designed for younger adults are not meaningful or satisfying.[25]
- In addition, adult medical day care programs and, to some extent, adult social day care programs have welcomed older adults with long-term mental illnesses into their programs.
- Although these programs are designed primarily for older adults with dementia and/or severe physical disabilities, focus groups conducted by the Geriatric Mental Health Alliance revealed that some medical adult day care programs are not only including people with long-term psychiatric disabilities but are actually recruiting them.
- In part, this appears to be happening because most people with long-term psychiatric disabilities are eligible for Medicaid—the primary funding source of adult medical day care.
- But it is also happening because some people with long-term psychiatric disabilities develop dementia or severe physical handicaps that cannot be handled in psychiatric rehabilitation or continuing day treatment programs. Adult medical day care provides some needed medical services.
- From the standpoint of the need for integrated rehabilitative, medical, and psychiatric services, adult medical day care has the advantage of providing a full range of services.
- But from the standpoint of using a "recovery" model, adult medical day care may be built too much on the expectation of the inevitable decline of dementia.
- Therefore, it may be more appropriate to incorporate health care into all programs that provide psychiatric rehabilitation.

## WORKFORCE

- There is a vast shortage of mental health professionals and paraprofessionals with special training regarding the geriatric population and about health care issues.
- And most who are trained in geriatrics do not have expertise regarding people with long-term psychiatric disabilities.
- In addition, workers in the health and aging systems generally are not prepared to work with older adults with mental illnesses, let alone to work with those with long-term psychiatric disabilities.

---

[25] The report can be accessed at http://www.mhaofnyc.org/gmhany/NYAPRSGeriatricTask ForcePositionPaper.pdf

- And throughout all the service systems there is a vast shortage of workers who are culturally competent. There is a great need for clinically competent providers who speak the language of people who are not proficient in English and who understand cultural perspectives regarding the kinds of problems in people's lives that are characterized as mental illness in industrial societies but often characterized in different ways in other societies.

## FINANCE

- There are a variety of models for funding health, housing and rehabilitation services for people with long-term care psychiatric disabilities.

- There are also a variety of funding sources including Medicaid, Medicare, Social Security Disability Income (SSDI), Social Security Income(SSI) and more.

- Providers frequently find ways to cobble together different funding models from different sources to cover the costs of services.

- Often this results in funded services that are far less than ideal, do not support best practices, coordination of care, innovation, or the cultivation of a clinically and culturally competent workforce.

- This workgroup did not focus on the problems of financing, recommending that a separate workgroup be developed for this purpose.

# Recommendations

- The Workgroup on Meeting the Needs of People with Long-Term Psychiatric Disabilities Who Are Aging[26] recommends that New York State develop services responsive to its aging population with long-term, severe mental illness. Our recommendations are designed to:

- **Increase the life expectancy** of people with serious and persistent mental illness and

- **Help them to live in the community**, i.e. avoid institutionalization in adult homes or nursing homes.[27]

These recommendations focus on:

- The provision of **improved health services**

- The development of **more appropriate housing**

- **Adaptations of rehabilitative approaches** to respond to challenges of old age

- Expansion of **mobile services** to help people remain in mainstream, supported, or community-based congregate housing

- **Workforce development**

- Development of **new financing models**.

## HEALTH

### 1. Access to good health care

People with long-term psychiatric disabilities generally do not get access to good health care and this contributes to their poor health status and their low life expectancy. The workgroup, therefore, recommended that a variety of efforts be made to improve access to good health care. This includes primary, specialty, and home health care.

a. **Primary care:** There are various models that appear to be viable to provide good primary care for this population, including
   — Clinics that specialize in serving people with psychiatric and/or developmental disabilities
   — On-site satellites of community health centers or hospital outpatient clinics
   — Carefully cultivated linkages with community-based health providers
   — Health care managers who can promote communication between patients and health providers and ensure that the patients' medical conditions are being treated adequately. This role could be played by peers.

---

[26] Age: In response to the ongoing debate about the age at which a person with long-term psychiatric disabilities should be regarded as geriatric, the workgroup recommended 55 rather than 60 or 65. It did so because people with long-term psychiatric disabilities frequently have had hard lives on the streets as well as substance abuse problems and physical illnesses that make them old before their time. The workgroup also believes that 55 makes more sense because the life expectancy of this population is ten years less than the general population. A great many people with long-term psychiatric disabilities just don't survive to 60 or 65.

[27] NYS regards adult homes as community settings. The Workgroup regards them as institutional settings.

It has also been suggested that psychiatrists could provide primary health care, although there are some doubts whether most psychiatrists have adequate skills to do so.

b. **Quality specialty care:** People with long-term psychiatric disabilities who get decent primary care often find it difficult to get access to good specialty care. Getting access appears to depend heavily on cultivating linkages with providers in the community because community health centers generally do not have specialists on staff and many of the specialists accessible through public clinics at hospitals are in-training or of uneven quality.

c. **Specialized home health care:** Current home health care providers are rarely trained to serve people with serious mental illness. Training and the development of specialized home health care services are necessary so that home health services can be effectively provided for people with serious mental illness.

2. Prevention

a. **Health maintenance:** Issues related to the kinds of chronic health conditions common among people with long-term psychiatric disabilities can be addressed to some extent with good nutrition, exercise, and smoking cessation. The workgroup recommended that health maintenance activities be built into both housing and day programs.

b. **Disease/Care management:** Failure to adhere to treatment and dietary restrictions for chronic conditions such as diabetes is a major contributor to the development of life threatening conditions, disability, and death. The use of disease/care management techniques, in which a person monitors adherence and provides health education, could reduce the serious consequences of chronic illnesses. Usually this kind of service is provided by a health professional, such as a nurse. But the workgroup suggested that it could also be provided by "peer medical care managers."

c. **Suicide prevention:** Suicide rates are highest among older adults and contribute to the low life expectancy of people with severe, long-term psychiatric disabilities.[28] In addition, depression becomes more common among people with schizophrenia as they age. For these reasons, the workgroup recommended that all providers for this population focus more attention on efforts to identify depression and suicide risk and to intervene quickly.

d. **Accident prevention:** Falls are a major cause of disability and death among older adults, and accidents (including medication overdoses) are a major contributor to the low life expectancy of people with long-term psychiatric disabilities.[29] The workgroup, therefore, recommended that falls prevention and medication monitoring be a major focus of providers—especially housing providers.

## HOUSING ADAPTATIONS

There is a shortage of housing for older adults with long-term psychiatric disabilities.

In addition, most current housing programs for people with long-term psychiatric disabilities are not suited for those who are older especially those with chronic physical conditions. The workgroup recommended a number of ways in which OMH housing programs should be modified for older adults.

1. **Permanence:** For some people with long-term psychiatric disabilities congregate housing is preferable to supported, scatter-site housing. But for older adults some congregate housing needs to be permanent; these residents need to be in the place they will stay for the rest of their lives.

---

[28] Dembling, B.P., Chen, D.T. & Vachon, L. (1999). Life expectancy and causes of death in a population treated for serious mental illness. *Psychiatric Services*, 50 (8),1036-1042.

[29] Ibid

2. **Accessible:** Many older adults cannot manage stairs and may need walkers or wheel chairs to get around. For these older adults housing needs to be handicapped accessible with wide enough corridors and large enough bathrooms to accommodate walkers and wheel chairs.

3. **Safety:** Since falls are a major risk for older adults, housing needs to be constructed to try to reduce falls—for example, by providing grab bars—and to minimize the risks of injuries when people fall—for example, by using soft floor surfacing.

4. **ADL Supports:** For those older adults whose activities of daily living skills are deteriorating due to cognitive impairments, housing needs to be available that provides assistance with activities of daily living. This does not necessarily mean round-the-clock skilled nursing. The workgroup believes that by building ADL supports into OMH housing programs and/or by providing access to homecare services in these programs, nursing home placements could be averted.

5. **Health Care:** Congregate, mental health housing programs also need to be able to address the complex health care needs of their residents. This includes health maintenance activities, medication management, disease management, on-site nurses or home healthcare, and linkages to good health care providers.

6. **Home Health Care:** Helping people with serious long-term psychiatric disabilities to remain in scatter-site, supported housing may depend on the development of specialized home health care providers, who are knowledgeable about mental illness and working with people with psychiatric disabilities as well as with the physical conditions to which they are prone.

7. **Alternatives to Family Caregivers:** A large percentage of adults with serious, long-term psychiatric disabilities live at home with their parents. When their parents become disabled or die, alternative housing needs to be made available. The workgroup recommends that priority for housing in the community be given to people who have lost their families.

8. **NORC-SSPs:** Some NORCs have on-site supportive services programs that provide opportunities for activities, socialization, voluntary assistance to neighbors, on-site primary care by nurses, and on-site social work services. The workgroup was very excited about the possibility that OMH could locate some supported housing in such sites and develop arrangements with the on-site supportive services programs to provide support to these residents. It would combine strong support oriented to older adults with an opportunity to live in the mainstream.

## REHABILITATION

The workgroup noted that rehabilitation for older adults with long-term psychiatric disabilities can be available in psychosocial rehabilitation programs, continuing day treatment programs, or adult social or medical day care programs. In addition some older adults with long-term psychiatric disabilities could benefit from senior centers and NORC-Supportive Services Programs.

But, the workgroup recommended, whatever the aegis, social and rehabilitative programs need to make adaptations to meet the needs of older adults. These include:

1. **Choice:** Not all older adults are alike. Some want to work; others do not. Some are interested in education; others are not. For this reason, the workgroup recommended that day programs for aging people with long-term psychiatric disabilities offer a range of choices including work, education, peer support and wellness groups, and social/recreational activities.

2. **Mainstream Opportunities:** Many senior centers and social adult day care programs are reluctant to serve people with serious, long-term psychiatric disabilities because of their concerns about behavior. But other programs have welcomed some of this population. The workgroup recommended further exploration of opportunities in services in the aging system.

   In addition, the workgroup recommended exploring the possibility that people with long-term psychiatric disabilities could participate in support groups for people with similar physical conditions, developmental challenges, or history (such as being veterans).

3. **Focus on health and substance abuse:** The workgroup believes that all programs for older adults with psychiatric disabilities should focus on health and substance abuse and that this should include:

   - Health maintenance via good nutrition, exercise, and smoking cessation
   - Disease management, particularly using peer medical care managers
   - Health care personnel on-site
   - Integrated treatment for mental illness and substance abuse

   The need for health care personnel on-site in day programs suggests, the workgroup noted, the need for a day program model that integrates health and mental health services in one site. The workgroup recommended that the development of an amalgam of psychiatric rehabilitation, continuing day treatment, and adult medical day care be explored.

4. **Deal with death and dying:** Apparently it is rare for service programs to deal openly with issues of death and dying. The workgroup recommended that all providers:

   - Assist people with serious long-term psychiatric disabilities with future care directives
   - Develop ways to maintain contact with clients who have become terminally ill so that they do not die alone.

5. **Case management and coordination of care:** The workgroup recommended that programs serving older adults with long-term psychiatric disabilities assist their clients with the coordination of health and mental health services, access to assistive technology, and access to entitlements.

6. **Suicide prevention:** Day program providers have frequent opportunities to observe their clients. Screening for depression as well as sensitivity to mood swings could help to identify suicide risks and to intervene.

7. **Accessibility:** Access to day programs can become increasingly difficult as people age. They may not be able to manage public transportation, so special arrangements such as vans and taxis can be very important. In addition they may not be able to attend a location that is not handicapped accessible, particularly to people whose mobility is limited or who need walkers or wheel chairs.

8. **Outreach:** Over time people with psychiatric disabilities who have participated in psychiatric rehabilitation, continuing day treatment, or adult medical day programs may become homebound, institutionalized, or homeless. The workgroup recommended that "bridger" programs be developed whereby other program participants and staff visit former program participants at home or in their institution to provide them with ongoing companionship and to explore how they could return to the program if they choose.

9. **Support for caregivers:** Many people with psychiatric disabilities who attend day programs live with their families, who often could benefit from supports of various kinds, such as respite. The workgroup recommended the development of family support initiatives by day program providers.

The workgroup also noted that some people with long-term psychiatric disabilities attempt to take care of their disabled parents. Sometimes this results in virtual elder abuse—usually inadvertent. But sometimes it can be successful. The workgroup recommended that rehabilitation providers include care of elderly parents among the skills that they help their clients to develop. Service Program for Older Persons (SPOP) has developed such a program, apparently with some success.

10. **Staff training on aging, health, and cultural competence:** Staff in psychiatric rehabilitation and continuing day treatment programs generally have little expertise in serving older adults, and staff in adult medical day care generally have little expertise in serving older adults with long-term psychiatric disabilities. Mental health workers tend to be particularly ignorant regarding health issues, and health care workers tend to be particularly ignorant about mental health issues. All staff tend to lack cultural competence.

    The workgroup recommended that special training be provided for staff in programs serving increasing numbers of people with long-term psychiatric disabilities.

## MOBILE SERVICES

As they age, many people find it increasingly difficult to get around or become reclusive. Outreach and mobile services to reach people in their homes or in community settings they will go to, such as houses of worship or doctors' offices, are essential to help people remain in community settings. This is particularly true of crisis services. An ambulance ride to an emergency room frequently begins a process of hospitalization and discharge to a nursing or adult home rather than to a community setting. Mobile crisis services help to avert such placements, which often are unnecessary.

## WORKFORCE DEVELOPMENT

The workgroup noted that there is a great shortage of staff qualified to work with older adults with long-term psychiatric disabilities. In general there is a shortage of geriatric mental health professionals. But there is an even greater shortage of those trained to work with people with psychiatric disabilities.

The workgroup recommended that a number of efforts be undertaken to increase the supply of qualified workers including:

- The development of incentives to enter the field
- Improved education in professional schools
- Increased training.

The workgroup was particularly interested in the **development of volunteer and paraprofessional roles that could be filled by older adults and by people with psychiatric disabilities.** These roles could include providing respite, home visiting, providing home health care, serving as medical care managers, and more.

## FINANCING MODELS

The workgroup recommended establishing a workgroup to explore the development of new financing models that support:

- The integration of health and mental health services
- Innovative services and best practices
- Workforce development initiatives.

THE GERIATRIC MENTAL HEALTH ALLIANCE OF NEW YORK
50 BROADWAY, 19TH FLOOR, NEW YORK, NY 10004
PHONE: (212) 614-5753
FAX: (212) 964-7302

EMAIL: CENTER@MHAOFNYC.ORG
WWW.MHAOFNYC.ORG/GMHANY