GERIATRIC MENTAL HEALTH: THE NEED FOR CHANGE

Focus Group Findings

The Geriatric Mental Health Alliance of New York

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The Geriatric Mental Health Alliance of New York

Written by
Michael B. Friedman, LMSW
Chairman

Kimberly A. Williams, LMSW
Director

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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 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

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Executive Summary

INTRODUCTION AND BACKGROUND

Numerous reports[1] have pointed to significant inadequacies in the current state of service provision for older adults with mental health needs. These include:

- Overuse of institutions
- Limited access to services
- Uneven service quality both in institutions and in the community
- Very limited integration of mental health, health, and aging services
- Neglect of addictive disorders characteristic of older adults
- Very limited capacity to serve cultural minorities
- Lack of adequate family support
- Stigma, ageism, and ignorance about mental illness and its treatment
- Workforce shortages
- Vast financing problems—both amount and structure
- Lack of readiness to meet the mental health challenges of the coming elder boom.

These observations led to the establishment of the Geriatric Mental Health Alliance of New York in January 2004. The goal of the Alliance is to promote changes of practice and policy that will enable older adults with mental health problems to get the help they need.

The Alliance has undertaken many activities to achieve this goal including conducting 24 focus groups with diverse groups concerned with geriatric mental health.

Participants

The focus groups involved over 300 people from many different fields and service settings. They included people receiving services as well as those providing services. They also included researchers, policy analysts, advocates, public officials, and grant makers. Participants came from settlement houses, senior centers, naturally occurring retirement community supportive service programs (NORC-SSPs), adult protective services, case management services, social day care and medical day care programs, nursing homes, adult homes, home health providers, primary health care providers, supportive housing programs, community residences, mental health clinics, continuing day treatment programs, psychosocial rehabilitation programs, mobile crisis services, and more.

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[1] Bazelon Center for Mental Health Law. (2003). *Last in line: Barriers to community integration of older adults with mental illnesses and recommendations for change.* Washington DC: Author

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U.S. Department of Health and Human Services. (1999). *Mental health: A report of the surgeon general.* Rockville, MD: Author.

U.S. Department of Health and Human Services: Administration on Aging. (2001). *Older adults and mental health: Issues and opportunities.* Rockville, MD: Author.

Goals

The goals of the focus groups were to:

1. Gather information about the nature and needs of older adults with mental health problems
2. Gather information about current services
3. Gather recommendations about how to improve practice and policy
4. Gather observations about barriers to improving practice and policy
5. Build awareness about the importance of geriatric mental health issues
6. Provide networking opportunities
7. Add to the membership of the Geriatric Mental Health Alliance
8. Recruit participants in workgroups to develop proposals for changes in practice and policy.

Process

Each focus group posed several fundamental questions, which were discussed for 1-2 hours. The key questions were:

1. What mental health problems do you see among the people whom you serve (or do you or your peers experience)?
2. What do you do to deal with these problems now? Is it effective?
3. What would you if you could do anything?
4. What are the barriers to doing what you think would be best?

The discussions were unstructured. Participants could address any of these questions at any time and were allowed to bring up other issues that they thought were important.

Outcomes

The focus groups provided a staggering array of observations, insights, and recommendations. The groups clearly served a consciousness-raising function in that many of the groups were organized by trade associations or other provider/advocacy groups that had not focused on geriatric mental health prior to the focus group meetings. They also served a networking function for people from similar fields who had either never met before or who had never talked with one another about geriatric mental health despite remarkably similar experiences revealed through focus group discussions. In addition many, if not most, of the participants became members of the Geriatric Mental Health Alliance, and a number of them have been recruited for the specialized workgroups begun in the Fall of 2005.

Findings

Perhaps what was most striking is the number of remarkable, dedicated, and knowledgeable people now working with older adults with mental health problems. It is equally striking that there are virtually no conceptual disagreements among them. Some, of course, place greater emphasis on some issues rather than others; and there is some disagreement about detail. But everyone agrees that the primary goal is to enable older adults to remain in the community. Everyone agrees that there are some very good programs but not nearly enough. Everyone agrees that we need new service models, especially focusing on the integration of health, mental health, and aging services and on cultural competence. And everyone agrees that the way in which the service systems are currently structured and financed create major barriers to expanding and remodeling services.

PART 1: THE MENTAL HEALTH PROBLEMS OF OLDER ADULTS

Part 1 of this report summarizes the observations of focus group participants about the mental health problems of older adults. These include insights about diagnostic categories and prevalence that differ somewhat from standard points of view.

Particularly important are observations about behavioral problems that lead to institutionalization. These include:

- Lack of adherence to treatment regimens
- Belligerence or verbal abuse
- Physical abuse
- Self-neglect
- Unhealthy behaviors such as not eating properly, not cleaning, and hoarding
- Dangerous behaviors such as piling things in passageways creating risks of falls, smoking in bed, leaving stoves on, etc.

In addition, observations of participants have led us to classify the mental health problems of older adults as follows:

- People with long-term psychiatric disabilities who are aging
- People with mental disorders of late life including:
  - —Dementia
  - —Late onset psychoses
  - —Severe anxiety, depressive, and paranoid disorders resulting in social isolation
  - —Less severe anxiety and depressive disorders
  - —Addictive disorders, especially alcohol and prescription drug abuse
- Emotional problems adjusting to old age.

Participants provided a rich array of observations regarding all of these categories. Participants also offered important observations about:

- co-morbid mental and physical disorders
- social isolation
- homebound populations
- elder abuse
- martial conflict
- stigma and ignorance about mental illness and its treatment
- cultural issues
- immigrants
- family issues
- end-of-life issues
- spiritual dimensions of old age.

In addition to problems of old age, focus group participants discussed many opportunities for older adults to maintain health and mental health and to lead satisfying and productive lives.

PART 2: SERVICES FOR OLDER ADULTS WITH MENTAL HEALTH PROBLEMS

Part 2 of the report provides an overview of services currently provided. We learned that a remarkably broad array of services are available through each of the service systems but that the capacity of these services is not nearly sufficient to meet current needs, let alone the needs that will emerge as the aging population grows.

Service types include:

- Public Education
- Information and referral
- Screening and assessment
- Crisis intervention
- Outpatient mental health services
- Peer support
- Outreach and assertive community interventions
- In-home services
- Case management
- Case advocacy
- Family support services
- Elder care management
- Elder abuse services
- Addiction services
- Day programs
- Rehabilitation
- Employment and volunteer opportunities
- Nutrition services
- Transportation services
- Housing programs
- Inpatient services
- Institutional care
- End-of-life service

Part 2 also includes a summary of focus group participants' observations about various approaches to integrating mental health, health, and aging services.

PART 3: SERVICE IMPROVEMENTS FOR OLDER ADULTS WITH MENTAL HEALTH PROBLEMS

Part 3 of the report summarizes the focus group participants' suggestions regarding how to improve services for older adults. These have led us to create a 10-Point Agenda for Change:

1. Help older adults to remain in, or return to, the community
2. Improve access to services
3. Improve quality of services
4. Integrate mental health, health, and aging services
5. Increase the capacity to serve cultural minorities
6. Provide support for family caregivers
7. Provide public education
8. Expand and increase the workforce serving older adults with mental health needs
9. Address the need for new financing models
10. Address the need for governmental readiness

This section of our report covers service needs under categories 1-8. Categories 9 and 10 are covered in the following section, which is on barriers.

PART 4: BARRIERS TO MEETING THE MENTAL HEALTH NEEDS OF OLDER ADULTS

Part 4 of the report provides an overview of the barriers to meeting the mental health needs of older adults. Within the focus group discussions, these observations fell into three broad categories: (1) financing problems, (2) systems fragmentation, and (3) workforce shortages. (In this document we include only those barriers that were discussed in focus groups. There are other barriers, which we will discuss in a document devoted to barriers.)

Financial barriers include:

- Lack of adequate funding
- Lack of knowledge about how to optimize funding sources especially Medicare
- Structural problems that make it difficult to use available funding to use best practices, to be innovative, and to support integration.

Medicare problems include:

- Co-pays are 50% compared to 20% for physical health services. As a result co-pays are more likely to be unaffordable for mental health services. (This problem will disappear as parity is phased into Medicare between 2010 and 2014.)
- There are incentives for geriatric psychiatrists to drop out of Medicare.
- Case management is not covered.
- Transportation costs are covered only for emergencies.
- "Wrap-around" services are not covered.

Medicaid problems include:

- Only 23% of older adults are eligible
- Inadequate rates for home visits
- Difficulty establishing satellites in community settings such as senior centers and NORCs
- Regulatory prohibitions on providing mental health services in health centers and vice versa
- Very low fees to clinicians in private practice
- Regulations making it virtually impossible for nursing homes to provide adequate social work services and difficult to provide the most up-to-date medications.

Focus group participants also provided observations about problems with funding from the aging system, from private insurance, and from foundations.

Fragmentation

Focus groups revealed significant problems of fragmentation both among the components of the public service systems and between public and private service sectors.

Fragmentation of Public Service Systems: Focus group participants spoke of the systems as isolated "silos" and maintained that this interferes with developing ways of pooling funding across systems, of developing comprehensive service packages for people, and of developing ways to integrate practice.

Fragmentation within the Mental Health System: Focus group discussions confirmed observations about the fragmentation of the mental health system itself. The system is structured around discrete service programs without adequate coordination of care or clear responsibility for service recipients.

Fragmentation between Public and Private Service Sectors: Focus group participants observed that it is almost impossible to develop working relationships between a provider—such as a senior center, a NORC-SSP, a home health provider, or a mental health clinic—serving a group of people and the physicians and/or mental health professionals who treat them privately. Yet many older adults prefer to have a physician in private practice or to see a psychotherapist privately. How to engage them in collaborative service plans is a great challenge.

The emergence of elder care managers, who coordinate care, is a potential solution to this problem, but only for those who can afford to hire them.

Workforce Problems

A major barrier to providing needed services, workgroup participants repeatedly told us, is the shortage of people who want to, and are qualified to, provide services for older adults. This includes shortages of clinically and culturally competent geriatric mental health, health, and social services professionals. It also includes shortages of appropriately trained paraprofessional staff in virtually all settings where older adults are served. And it includes shortages of staff who have been trained to understand the workings of all the major systems of care for older adults.

CONCLUSION: OPPORTUNITIES FOR IMPROVEMENT

Opportunities to improve services include:

- **Prevention of the use of nursing and adult homes** through the provision of better management of mental and behavioral disorders and enhanced family support in the community

- **Reconfiguring the community support system** that has been developed for adults with long-term psychiatric disabilities to meet the needs of older adults, including
  - —Increased and reconfigured community housing programs
  - —Improved health care and health maintenance activities
  - —New approaches to psychiatric rehabilitation
  - —Increased support for older adults caring for their adult children with serious, long-term psychiatric disabilities
  - —Increased attention to end-of-life care

- **Improved access** to mental health services through
  - —Service expansion
  - —Increased transportation
  - —Mobile services to homes and community settings
  - —Enhanced cultural competence
  - —Increased affordability

- **Enhanced quality of care in the community** through
  - —Dissemination of state-of-the art practices
  - —Widespread use of screening instruments to flag possible mental disorders
  - —Enhanced suicide prevention efforts
  - —Improved emergency and crisis services
  - —The development of addiction services responsive to the substance abuse problems of older adults
  - —Training regarding geriatric mental health for mental health, health, and aging services workers
  - —Enhanced case management and more widespread use of elder care managers
  - —Enhanced elder abuse and domestic violence services

— Upgrading and reducing caseloads for adult protective services workers
— Linkages between spiritual care and other services for older adults
— Using Naturally Occurring Retirement Community Supportive Service Programs as the hub of service provision in the community
— Preventive interventions to counter social isolation and adverse reactions to aging

- **Enhanced quality of care in institutions** through
  — Providing living arrangements that allow residents personal dignity and choice
  — Routine screening for mental disorders
  — Use of mental health professionals well-trained in geriatric mental health and integrated into the life of the facility
  — Manageable caseloads for social workers
  — Training for all levels of staff, including administrative personnel, regarding mental and behavioral disorders
  — Enhanced advocacy for residents
  — More effective enforcement of regulations in adult homes
  — Improved living conditions in adult homes such as air conditioning

- **Integration of health, mental health, and aging services** including
  — Integrating primary and specialty health care and mental health
  — Linking home health and mental health services
  — Linking aging and mental health services
  — "One-stop shopping" including on-site mental health and health services
  — Development of formal and informal local service networks including private practitioners as well as service organizations

- **Increased capacity to serve cultural minorities** through
  — Location of mental health services in communities where minorities live
  — Co-location of mental health services in indigenous community service settings
  — Extensive outreach into indigenous settings including religious settings
  — Provision of bi-lingual and bi-cultural staff
  — Mental health education for minorities
  — Training to develop cultural competence

- **Increased family support** through
  — Affordable counseling
  — Support groups
  — Respite
  — More responsive crisis services
  — Linkages between family support organizations (such as NAMI) and organizations serving older adults (such as NORC-SSPs)
  — Financial assistance through tax credits or subsidies of health and long-term care insurance

- **Public education** through
  — Mass media campaigns
  — Outreach to community organizations
  — Distribution of written materials in multiple languages
  — Greater use of the internet to make information available
  — Improved information and referral services, especially development of a "one-stop" service addressing all concerns regarding aging

- **Workforce development** including
  — Attracting and retaining larger numbers of mental health, health, and aging personnel
  — Improving the clinical and cultural competence of mental health, health, and aging personnel
  — Developing new paraprofessional and volunteer roles especially for older adults

- **Research and rapid translation of research into practice** especially through partnerships between research and provider organizations

- **New finance models** including
  — Funding of comprehensive service packages
  — Pooled funding across service systems
  — Medicare optimization
  — Reforms of Medicare, Medicaid, and other public funding streams
  — Establishing funding sources for services to immigrants

Introduction and Background

Numerous reports[2] have pointed to significant inadequacies in the current state of service provision for older adults with mental health needs. These include:

- Overuse of institutions
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- Stigma, ageism, and ignorance about mental illness and its treatment
- Workforce shortages
- Vast financing problems—both amount and structure
- Lack of readiness to meet the mental health challenges of the coming elder boom.

These observations led to the establishment of the Geriatric Mental Health Alliance of New York in January 2004. The goal of the Alliance is to promote changes of practice and policy that will enable older adults with mental health problems to get the help they need.

The Alliance has undertaken many activities to achieve this goal including:

- Building a constituency for change,
- Advocating for attention to geriatric mental health by state and local governments as well as professional and provider organizations,
- Advocating for the passage of The Geriatric Mental Health Act of New York (signed into law in August, 2005 and funded in FY 2006-7),
- Organizing presentations on best practices,
- Conducting focus groups with diverse groups concerned with geriatric mental health, and
- Organizing workgroups on special topics to identify best practices, innovative opportunities, and barriers to their use; to develop recommendations to overcome barriers; and to promote innovation and the use of best practices.

This is a report on the findings of our focus groups.

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[2] Bazelon Center for Mental Health Law. (2003). *Last in line: Barriers to community integration of older adults with mental illnesses and recommendations for change.* Washington DC: Author

Friedman, M. & Steinhagen, K. (2004). Issues in geriatric mental health policy. *Community Mental Health Report*, 4 (4), 49-50, 58-64.

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PARTICIPANTS

Between September 2004 and August 2005 we conducted 24 focus groups. (See attached list). These groups involved over 300 people from many different fields and service settings. They included people receiving services as well as those providing services. They also included researchers, policy analysts, advocates, public officials, and grant makers. Participants came from settlement houses, senior centers, naturally occurring retirement community supportive service programs (NORC-SSP), adult protective services, case management services, social day care and medical day care programs, nursing homes, adult homes, home health providers, primary health care providers, supportive housing programs, community residences, mental health clinics, continuing day treatment programs, psychosocial rehabilitation programs, mobile crisis services, and more. (See attached list of participants)

GOALS

The goals of the focus groups were to:

- Gather information about the nature and needs of older adults with mental health problems
- Gather information about current services
- Gather recommendations about how to improve practice and policy
- Gather observations about barriers to improving practice and policy
- Build awareness about the importance of geriatric mental health issues
- Provide networking opportunities
- Add to the membership of the Geriatric Mental Health Alliance
- Recruit participants in workgroups to develop proposals for changes in practice and policy.

PROCESS

Each focus group posed several fundamental questions, which were discussed for 1-2 hours. The key questions were:

- What mental health problems do you see among the people whom you serve (or do you or your peers experience)?
- What do you do to deal with these problems now? Is it effective?
- What would you if you could do anything?
- What are the barriers to doing what you think would be best?

The discussions were unstructured. Participants could address any of these questions at any time and were allowed to bring up other issues that they thought were important.

OUTCOMES

The focus groups provided a staggering array of observations, insights, and recommendations. The groups clearly served a consciousness-raising function in that many of the groups were organized by trade associations or other provider/ advocacy groups that had not focused on geriatric mental health prior to the focus group meetings. They also served a networking function for people from similar fields who had either never met before or who had never talked with one another about geriatric mental health despite remarkably similar experiences revealed through focus group discussions.

In addition many, if not most, of the participants became members of the Geriatric Mental Health Alliance, and a number of them have been recruited for the specialized workgroups begun in the Fall of 2005.

FINDINGS

In thinking back on the focus groups and in reviewing our notes, perhaps what was most striking to the two of us who conducted these groups is the number of remarkable, dedicated, and knowledgeable people now working with older adults with mental health problems. It is equally striking that there are virtually no conceptual disagreements among them. Some, of course, place greater emphasis on some issues rather than others; and there is some disagreement about detail. But everyone agrees that the primary goal is to enable older adults to remain in the community. Everyone agrees that there are some very good programs but not nearly enough. Everyone agrees that we need new service models, especially focusing on the integration of health, mental health, and aging services and on cultural competence. And everyone agrees that the way in which the service systems are currently structured and financed create major barriers to expanding and remodeling services.

Everyone also agrees there needs to be more extensive use of evidence-based practices but that there are many important areas of practice for which an evidence-base does not exist. Nevertheless, there is a remarkable degree of consensus about what the best practices are in these areas.

Despite the certainty of vast oversimplification, we have tried to provide an overview of the observations and insights that emerged from the focus groups—regarding the nature of the population, current services, model service possibilities, and barriers.

There are several notable limitations to our findings. First, we did not use a sampling approach that would give even relative assurance that the participants in our focus groups were representative of their fields. Second, there are a number of groups with whom we were not able to arrange focus groups, such as primary care physicians in private practice. Third, almost everyone who participated in a focus group worked, or attended, a program funded primarily by the government. We had very few representatives from the private sector. And fourth, we believe that the focus groups gave many people an opportunity to complain and that, therefore, the groups may have produced excessively critical impressions.

Part 1: The Mental Health Problems of Older Adults

Diagnostic Categories: Participants in the focus groups talked about the full range of diagnostic categories that are reported in prevalence studies including anxiety, depression, bipolar disorder, schizophrenia, dementia, and addictive disorders. But their observations suggest that the standard prevalence figures may be misleading in a number of ways.

For example, serious *depression* may be more common than reported in prevalence studies because some people with symptoms of depression not sufficient to warrant a diagnosis of major depression nevertheless are functionally impaired and even at risk of suicide.

Participants also talked frequently about people with *paranoid ideas*, often of psychotic proportions. Paranoia appears to get very little attention in the professional literature regarding the mental disorders of older adults. But many of the focus group participants who attempt to provide home health and other services to enable people to remain in the community told us that people with paranoid ideation are quite common in their caseloads and among the most difficult to serve.

Participants also expressed concern that the *use of illegal substances*, which prevalence studies show as almost non-existent, may be on the rise both because hard drug users may be living longer and because of different patterns of drug use in the generation now becoming old.

Long-Term vs. Late Life Mental Disorders: When we began conducting focus groups, we drew a fundamental distinction between people with long-term psychiatric disabilities who are aging and people with late onset mental illness. Participants in the focus groups repeatedly told us that many, if not most, of the people we regarded as having late onset mental disorders actually were people who had had mild mental disorders most of their lives but had been able to function "normally" including work, marriage, parenting, etc. In late life, participants told us, events such as physical illness, loss of a spouse, loss of a job, and the development of chronic pain precipitate severe psychological reactions.

Ronald Kessler's[3] recent prevalence studies seem to confirm that there is relatively little late onset mental illness other than dementia. We have concluded that it is important, therefore, to distinguish *not* between long-term mental illnesses and late *onset* mental illnesses but between long-term psychiatric disabilities and *late-life* mental disorders, which are often exacerbations of long-term conditions.

In part because of the discussions in our focus groups, we now categorize the mental disorders of old age as follows:

- People with long-term psychiatric disabilities who are aging
- People with mental disorders of late life including:
  - —Dementia
  - —Late onset psychoses
  - —Severe anxiety, depressive, and paranoid disorders resulting in social isolation
  - —Less severe anxiety and depressive disorders
  - —Addictive disorders, especially alcohol and prescription drug abuse
- Emotional problems adjusting to old age.

[3] Kessler, R.C., et al. (2005). Lifetime prevalence and age-of-onset distributions of *DSM-IV* disorders in the national comorbidity survey replication. *Archives of General Psychiatry*, 62, 593-602.

LONG-TERM MENTAL DISABILITIES

Psychiatric Disabilities: Our conversations with people who provide services for people with long-term psychiatric disabilities and with consumers themselves confirmed that the needs of this population change as they age. Increasing prevalence of chronic physical illness and the development of dementia lead to growing needs for help managing physical disabilities and for ADL supports. Our conversations also confirmed that the desire to work remains strong in some older adults with psychiatric disabilities but that it diminishes in others.

Movement from the Mental Health to the Health System as People with Long-Term Psychiatric Disabilities Age: Observations about people with serious and persistent mental illness also suggested that some of this population moves from getting services from the mental health system to getting them from the health system as they get older.

In part this was not surprising because it is well-known that many people with serious mental illness go to nursing homes. What came as a surprise was that many people with serious mental illness go to nursing homes for short-term rehabilitation for a physical health problem and then cannot leave because the nursing homes cannot find a place to which to discharge them. Social workers in nursing homes also told us that as their population has come to include more and more middle-aged adults with serious mental illness, behaviors characteristic of borderline personality disorder have become more common and are extremely difficult to manage. This includes emotional lability, volatility, and playing staff off against each other.

We were also surprised to learn that some adult medical day programs are now serving significant numbers of people with serious and persistent mental illness. Indeed in some of these programs a majority of patients are from this population, and some of these programs are actively recruiting them.

Hidden Populations: We were very surprised by the number of participants from settlement houses, senior centers, and NORC-SSPs who reported problems dealing with people with serious and persistent mental illness and/or people with mental retardation. They met them primarily through their parents, who had "hidden" them (as one participant characterized it) from the mental health and mental retardation service systems most of their lives. Only as the parents aged and became incapable of continuing to provide care did they ask for help with their disabled, grown-up children. And they seemed to turn not to the mental health and mental retardation systems for help but to senior centers, NORC-SSPs, and the like. It was striking to us that most of the parents were not connected with mental health or mental retardation services or with related family support groups.

We also learned that some of the mentally disabled children tried to take care of their parents as they become disabled. In some cases they fail and become part of the statistics regarding elder abuse. But in some cases they succeed.

Mental Retardation and Mental Illness: Several participants noted that people with co-morbid mental illness and mental retardation are also aging and that virtually no provision has been made to serve this population.

LATE-LIFE MENTAL AND ADDICTIVE DISORDERS

Dementia: Participants in focus groups emphasized that there are stages of dementia and that the common image of a person with dementia as virtually without memory or ability to care for themselves does not apply to the early and mid-stages. In the early stage, they told us, people often feign competence and are sometimes quite successful at disguising their loss of functioning. During this period they also are likely to experience a sense of embarrassment, if not shame, about their diminishing abilities. In the mid-stage it becomes virtually impossible to feign competence, but people often continue to experience distress with their situation and themselves. In both early and mid-stages, people with dementia also frequently experience anxiety—about getting lost, about making fools of themselves, of not being able to manage—and become depressed—with a prominent sense of hopelessness. Some also become distrustful of the people who care for them—both family and paid caregivers—and anger is not uncommon.

Focus group participants also emphasized that some people with dementia exhibit behaviors, such as wandering and abusive outbursts, that are very difficult to manage and that contribute to placement in nursing homes.

Late Onset Psychoses: Although the research literature indicates that about 15% of schizophrenia in late life has late onset (i.e. begins after the age of 44), focus group participants told us that most people they know who become psychotic in old age have had psychological problems all their lives. As noted previously, these problems are exacerbated in old age in what appears to be a reaction to disturbing life events such as loss of a spouse, the development of chronic physical illness, etc. Focus group participants from home health programs, senior centers, NORCs, and supportive housing programs told us that people who become psychotic in late life are among the most difficult to serve because it is difficult to build trust with them (especially with those who become paranoid) and because of prominent behavioral problems. (See below.)

Severe Anxiety and Depressive Disorders: People with severe anxiety and/or depressive disorders were the population most frequently noted in focus groups. It is our impression that depression was the most common concern even though prevalence data indicate that anxiety disorders are much more common than major depression. This may reflect the fact that symptoms of depression are much more common than major depressive disorder. It may also reflect the fact that anxiety and depression are frequently linked.

Focus group participants from community service programs emphasized that anxiety and depression contribute to, and are fed by, isolation and inactivity. (See below.)

Focus group participants also expressed considerable frustration regarding this population because they believe that severe anxiety and depression are treatable disorders but that most people do not get the treatment they need. Focus group participants noted that stigma and ageism result in this population often not seeking treatment even when it is available. They also noted that not seeking treatment seems to link with the negativity and hopelessness that are among the major symptoms of both depression and anxiety.

Mild Mental Disorders: Mild anxiety and/or depressive disorders are the most common late life disorders. Focus group participants confirmed that, although "mild" from the standpoint of psychiatric diagnosis, these disorders are extremely painful to the people who experience them and also contribute to isolation, inactivity, and behaviors that can be difficult to manage.

Addictive Disorders: Participants' observations also confirmed that the misuse or abuse of alcohol and prescription drugs (especially pain killers) are the major substance abuse problems for older adults. Focus group participants stated that the abuse of prescription drugs is sometimes due to unrelieved pain, sometimes due to older adults continuing to take medications their doctor wants them to discontinue, and sometimes due to over-prescription. Participants' observations also suggested that misuse of over-the-counter drugs is a significant problem, that the abuse of illegal substances may be on the rise, that there is a sub-group of older adults who have been on methadone for years who are now using it to manage pain, and that addictive gambling is a problem for some older adults.

Developmental Challenges: Focus group participants confirmed that older adults experience a number of developmental changes that create emotional challenges. Sometimes these challenges reach the proportions of diagnosable disorders; sometimes they do not, but are nevertheless painful periods in the lives of older people. Focus group participants noted a number of common developmental challenges:

- Retirement and the need to develop alternative sources of activity and of self-esteem
- Loss of parenting roles and the need to develop alternative opportunities to nurture future generations
- The development of chronic physical conditions (sometimes including endless pain) and the need to learn to manage and to live with these conditions
- Loss of friends and family and the need to survive grief and to develop new social networks (Several participants noted that the death of a child is the loss that they believe has the most impact on older adults, robbing them of a sense of continuity in life.)

- Loss of some physical and mental abilities and the need to compensate so as to remain independent
- The need to develop a sense of pride in one's past without denying life's personal disappointments
- The need, for some people, to accept dependency
- The need to come to terms with the inevitability of death.

OPPORTUNITIES IN OLD AGE

Despite these common challenges of old age, focus group participants were generally positive about opportunities for aging people—opportunities for work, for social contributions, for relationships, and to maintain health. Most focus group participants see older adults as a relatively untapped source of strength for our society.

PHYSICAL HEALTH

Participants in focus groups confirmed that virtually all older adults with mental illnesses also have chronic physical illnesses. In some cases it is simply a coincidence. Most older adults have chronic health problems such as high blood pressure or arthritis. Some also have a mental disorder such as anxiety or depression.

But mental illness is far more common among people with physical health problems and in some cases clearly linked. For example, major depression affects less than 3% of people who get only routine medical care, but rises to 6-8% of people in the community who have an illness, to 12% or more of people in nursing homes, to 14% of those who need home health care,[4] to 10-30% of those receiving inpatient care[5].

In addition, some participants suggested that anxiety and depression may not be merely common concomitants of illnesses such as Alzheimer's and Parkinson's Disease; they may be an inherent part of such illnesses.

As previously noted, focus group participants also confirmed that people with serious and persistent mental illnesses have significant physical health problems including obesity, hypertension, cardiac disease, diabetes, and pulmonary disease.

One focus group participant noted that there appears to be a link between depression and falls, which are a major cause of serious injuries among older adults.

BEHAVIORAL PROBLEMS

One of the most fundamental insights that emerged from the focus groups is that behavioral problems can make it very difficult to provide community-based and in-home services. They are, therefore, a major reason why some people are placed in institutional settings such as nursing homes and adult homes.

Behavioral problems include:

- Lack of adherence to treatment regimens
- Refusal to leave home
- Belligerence or verbal abuse
- Physical abuse
- Self-neglect

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[4] Bruce, M. (2004, November). *Building an evidence base practice for depressed older home healthcare patients.* Presentation at a best practices lecture on home healthcare and older adults with mental illness sponsored by the Geriatric Mental Health Alliance of New York.

[5] Cole, M. et al. (2006). Systematic detection and multidisciplinary care of depression in older medical inpatients: a randomized trial. *Canadian Medical Association Journal*, 174 (1), 38-44.

- Unhealthy behaviors such as not eating properly, not cleaning, and hoarding
- Dangerous behaviors such as piling things in passageways creating risks of falls, smoking in bed, leaving stoves on, etc.
- Annoying behavior such as repetitive questions or complaints.

Some of these behaviors, focus group participants told us, are products of dementia, depression, anxiety, or psychotic conditions. Some are exacerbated forms of personality traits people have had throughout their lives and which became dysfunctional in old age.

ISOLATION

Isolation was a surprisingly frequent response to our question regarding the most common mental health problems. This appears to reflect the fact that people who are not mental health professionals are likely to think of the people they serve in functional rather than in diagnostic terms.

Isolation, we were told, affects:

- People who are homebound due to physical disability and who have contact primarily with the people who bring them meals and provide services in their homes
- People who refuse to leave their homes because of fear or immobilizing depression
- People who have lost contact with their families
- People whose friends have died or moved away
- People remaining in neighborhoods now occupied by different ethnic and/or socio-economic groups because of either gentrification or ghettoization
- People who reject opportunities for social interaction when they are offered—especially males, who, participants told us, are less likely to participate in social activities than are females.

Participants emphasized that isolation is a vicious cycle. Depression and anxiety foster isolation, which in turn fosters depression and anxiety.

HOMEBOUND

Focus group participants uniformly talked about the needs of older adults who are homebound. They tend to be isolated, as noted above. They also tend not to be able to get access to mental health services because there are so few mobile mental health services available.

ELDER ABUSE AND DOMESTIC VIOLENCE

Concerns about victims of elder abuse emerged in a number of focus groups. Some abuse is physical, but apparently this is relatively rare. Far more common is financial exploitation. Even more common is neglect by informal and formal caregivers, including not getting enough to eat, living in filth, not being bathed, not being given medications and other needed health care, etc. Such neglect particularly affects people who are not capable of self-care because of dementia or other limitations.

It is notable that some neglect occurs when an older adult who has promised to keep his/her spouse out of a nursing home is unable to provide the needed care at home.

We were quite surprised to learn that elder abuse (usually neglect) sometimes occurs when the disabled children of older adults who can no longer provide care try to care for their now disabled parents. Sometimes they simply cannot provide care; sometimes they become abusive when they are frustrated by their inability.

We were also surprised to hear that some women who have been victims of domestic violence throughout their marriages begin to abuse their husbands when they become disabled. It was characterized by one focus group participant as a form of revenge.

MARITAL CONFLICT

Several focus group participants noted severe marital conflict as a significant problem among some couples who had been married for many years.

STIGMA AND IGNORANCE

Focus group participants also noted over and over again that stigma about mental illness has a powerful impact on older adults. They tend to identify mental illness with being "crazy" and refuse to seek mental health services for emotional problems. They also experience mental illness as shameful and do not want to reveal to others that they are having disturbing thoughts and feelings that could be regarded as mental illness. In addition, they tend not to be knowledgeable about concepts of mental health and mental illness or to know that treatment can be helpful to them. And many of those who do seek professional help turn to primary care physicians, who, participants told us over and over again, are generally incompetent with regard to the treatment of mental illness.

However, participants also told us that many older adults will accept mental health services if they are described in a non-stigmatizing way. For example, they will go to social workers who offer to help with a range of problems—both concrete and emotional.

Several participants also noted that, when there is outreach to older adults by sympathetic people who explain mental illness and its treatment, many older adults are happy to have treatment.

Most focus group participants anticipate that stigma will be less among the baby boomers than among the current generation of older adults because they have become more accustomed to concepts of mental health.

CULTURAL ISSUES

Focus groups repeatedly revealed the importance of cultural differences not just of minorities but also of special populations such as the deaf and hearing impaired and the lesbian, gay, bi-sexual, and transgender (LGBT) communities.

With regard to minorities, participants stressed the problems presented by lack of bi-lingual mental health, health, and aging personnel. They also stressed that the concept of mental health is alien to some cultures. For example, we were told that several Asian cultures do not have a concept of mental health at all. Well-being is the closest equivalent.

Minorities are unlikely to seek mental health services. They turn to other resources in their communities; and, we were told, if they are offered mental health services in these indigenous settings, they are more likely to accept professional help.

Participants also emphasized the importance of understanding the role of the family in each culture and the shame frequently experienced by both Hispanics and Asians who are cut off from family. There may also be an expectation that family members be included during diagnostic and treatment sessions. For many, confidentiality within the family is a totally alien idea.

Stigma, too, is common among minority cultures; but so far as we could tell it was not especially different from the stigma that is pervasive in the American society.

There was limited discussion of African-American cultural issues in our focus groups. It was noted that African-Americans frequently turn to faith-based organizations for help with personal problems.

Focus group participants concerned about the LGBT community emphasized that in general older gay adults are affected by three stigmas—mental illness, ageism, and homophobia. They also stressed that older gay adults mostly lived their lives "in the closet" and that they are not as comfortable about revealing that they are gay or dealing openly with the issues that arise as they age as are younger gay adults.

Focus group participants familiar with the community of people who are deaf or hearing impaired emphasized the fact that they regard themselves as a distinct culture with its own language—signing—and special needs with regard to mental health services. Focus groups did not produce specific information about their culture and its significance for older adults with mental disorders.

IMMIGRANTS

A number of focus group participants raised special concerns about immigrants. Prevalence studies indicate that immigrants who come to America on their own initiative are less likely to have mental disorders than the general population. But we learned from focus group participants that older adults who have been brought to this country by their adult children frequently experience a sense of isolation and alienation. In part this is because they do not speak English; in part it is because of vast changes in social custom.

In addition older adult immigrants, we were told, frequently feel useless because they find it difficult to get jobs and because neither their children nor their grandchildren respect their wisdom.

Several focus group participants told us that immigrants who have histories of significant trauma are among the most likely to develop mental disorders.

Focus group participants also told us that many immigrants cannot get service because they are not entitled to health and other benefits. But they also told us that many immigrants have difficulty getting the benefits to which they are entitled.

FAMILY ISSUES

Family issues of several kinds arose in our focus groups.

Focus group participants repeatedly confirmed that family caregivers provide most support for disabled older adults and that this takes a considerable emotional, physical, and financial toll on the caregivers, who are at high risk for anxiety and depressive disorders.

Many older adults are caring for other family members including spouses, siblings, children, and grandchildren. These older adults are generally under great stress, which increases as they become older and less able to fulfill the responsibilities they have taken on. What will happen to the people they care for when they can no longer care for them is often their major concern.

It appears that an increasing number of grandparents are raising their grandchildren. Focus group participants told us that they face significant obstacles getting medical and social services for their grandchildren and that they frequently neglect their own physical and mental health because they place their grandchildren first. As a result of stress and self-neglect, these grandparents are at high risk of physical and mental illness.

Some older adults have been largely cut off from their families either because of emotional estrangement or because family members have moved away, died, or become disabled. For these older adults isolation often becomes a significant problem, and they are often saddened and/or ashamed that they are alone. In addition, often they have no source of the extra supports they need to be able to manage in the community. In fact, many focus group participants noted, lack of family support is a major reason for placement in a nursing home.

END-OF LIFE

As we became aware that many people who do not have attentive families face the end of life alone, we began to ask focus group participants what happens as the people they serve approach the end of life. It was striking how many community-based providers did not know. It appears that, as older adults who live at home or in community-based congregate settings become increasingly ill, they are shifted to caregiving facilities such as hospitals and nursing homes and that often they lose touch with the housing, day program, and clinical providers with whom they have developed relationships over many years.

SPIRITUAL ISSUES

For many older adults, participants told us, religious and spiritual beliefs are a profoundly important part of their lives and have a great impact on their mental health. Participants who talked about the religious and spiritual dimensions of the lives of older adults tended to do so in the context of discussions of end-of-life concerns and practices. But they emphasized that religious and spiritual concerns do not arise just in the confrontation with death. For many people they are part of day-to-day reality and an important source of personal satisfaction. Participants emphasized that people who work with older adults need to be prepared to talk with them about the religious and spiritual aspects of their lives and that building linkages with clergy can be an important way to reach older adults who need psychological as well as spiritual help to deal with their emotional problems and/or serious mental disorders.

Part 2: Services for Older Adults with Mental Health Problems

As we noted earlier, through the focus groups we met hundreds of people who serve older adults with great dedication and intelligence. These people work in programs under the aegis of the mental health system, the health system, and the aging system—in clinics, day treatment programs, community residences; in case management, senior centers, and NORCs; in primary health care, home health care, and nursing homes. And more.

From these people we learned that a remarkably broad array of services are available through each of the service systems but that the capacity of these services is not nearly sufficient to meet current needs, let alone the needs that will emerge as the aging population grows. As we learned more about these services we were struck by the fact that while each service system offers services with different names, goals, practices, rules, and financing, there are nevertheless remarkable commonalities.

To capture this we have developed a chart that shows the services offered in the mental health, health, and aging systems organized so as to show what they have in common. We have also developed a glossary to define the abundance of terms that are used to label and describe these services. The chart and glossary can be found at: www.mhaofnyc.org/gmhany/index.html

Service types include:

- Public Education
- Information and referral
- Screening and assessment
- Crisis intervention
- Outpatient mental health services
- Peer support
- Outreach and assertive community interventions
- In-home services
- Case management
- Case advocacy
- Family support services
- Elder care management
- Elder abuse services
- Addiction services
- Day programs
- Rehabilitation
- Employment and volunteer opportunities
- Nutrition services
- Transportation services
- Housing programs
- Inpatient services
- Institutional care
- End-of-life service

In the rest of this section of our report, we provide some highlights of observations about existing services that emerged during the focus groups. These include observations about services that appear to be effective as well as about problems with existing services.

PUBLIC EDUCATION

Focus group participants all agreed that stigma, ageism, and ignorance about mental illness and the effectiveness of treatment result in low utilization of mental health services. They also agree that public education to address these issues is essential. They noted three different kinds of public education—broad media campaigns, targeted education programs, and websites. Broad media campaigns include such efforts as The Mental Health Association's "The Golden Years Don't Have To Be Blue." MHA and other groups, such as the Asian American Federation and the Puerto Rican Family Institute, also go to senior centers, houses of worship, and other community settings to provide mental health education to groups of people. In addition, websites such as cornellcares.com provide information about mental disorders and their treatment. In general, focus group participants regard such efforts positively and voiced concern only about the need for more.

INFORMATION AND REFERRAL

Older adults, their families, and other caregivers frequently find it difficult to negotiate the broad array of services available through the mental health, health, and aging systems as well as the private sector. A variety of information and referral services are available to help them including mental health information and hotlines such as LifeNet and CornellCares.com in NYC, information and referral provided by Area Agencies on Aging, the national Elder Care Locator, a national elder lawyer locator, and more.

We found that many participants in our focus groups were unaware of some of these services. Those who knew about them reported a mix of satisfaction and frustration using them. Each does what it does, but none in the New York City area provides one-stop information and referral. Life Span in Rochester does provide comprehensive information and referral combined with mobile case management for those who need a home visit.

SCREENING AND ASSESSMENT

There was general agreement that screening is a valuable service, that there are instruments available to flag the likelihood of mental illness, that such instruments are useful with minority cultures as well as whites, and that more screening needs to be done so as to identify older adults who may have diagnosable mental disorders. However, because there is such a great shortage of treatment services, there was considerable concern about where to refer people who need professional assessment, diagnosis, or treatment.

In addition, the focus groups revealed some confusion about the difference between screening and assessment. Some participants did not know that there are a variety of screening devices that can be used by people who are not mental health professionals to flag the possibility of a disorder. Nor did they know that this then would need to be followed by a professional assessment and diagnosis.

CRISIS INTERVENTION

1. **Mobile Crisis Services:** Focus group participants who were familiar with mobile crisis services were generally positive about them. One major concern was that they are often slow to respond (up to 2 days) and therefore not useful in real crises. Another was that crisis service personnel often have to provide long-term services in the home because there are few available alternatives.

2. **Emergency Medical Services:** Focus group participants were almost universally negative about crisis services provided by Emergency Medical Services (EMS) and by emergency rooms in New York City. Some emergency technicians are apparently kind and competent. But some participants noted that a response to an emergency by someone who knows the person having a crisis could prevent the trauma created by the crisis intervention process and might help people avoid trips to the emergency room and hospital stays. The emergency room experience was generally described as lengthy and dehumanizing and provided frequently by personnel with inadequate training in mental health or in geriatrics. Some participants complained that emergency rooms too often released people whom they believed needed hospitalization. While that may be true, we had the impression that the perception of the need for hospitalization often reflected lack of community-based services and lack of knowledge by staff in housing and other programs regarding how to work with people experiencing acute psychotic episodes.

3. **Adult Protective Services:** Focus group participants in New York City universally characterized adult protective services workers in the public sector as undereducated, undertrained, and overloaded. Some APS services are contracted out to private, not-for-profit organizations, which got mixed reviews from focus group participants. In general focus group participants in NYC said that they only turned to APS as an absolute last resort. Outside NYC opinions about the competence of APS were more diverse.

In general, focus group participants said that APS has too limited an array of options and too little access to services. As a result, they appear to be referring people to nursing homes who would not need them if alternatives were available.

OUTPATIENT MENTAL HEALTH SERVICES*

In general, focus group participants expressed a high regard for mental health professionals and were optimistic about the effectiveness of outpatient mental health treatment services for typical late life mental disorders, especially anxiety and depression. Medication therapy was seen as effective when used appropriately. In addition, the evidence-based psychotherapies such as cognitive behavioral therapy, problem-solving therapy, and interpersonal therapy were also seen as effective. But there were concerns about the uneven quality of mental health professionals, many of whom, we were told, are not familiar with state-of-the art practices. Focus group participants also expressed great concern about the cultural competence of mental health professionals, especially regarding their ability to speak the language of their clients, to engage people from cultures in which mental health is an alien concept, to make appropriate diagnoses, and to vary treatment in response to cultural differences.

1. **Primary Care Physicians:** Focus group participants repeatedly spoke critically about the fact that most outpatient mental health treatment is provided by primary care physicians. Although some primary care physicians apparently provide adequate mental health treatment, the consensus was overwhelming that in general they do a very poor job—particularly with regard to the prescription of medication. Most focus group participants viewed almost all primary care physicians as lacking the training, or the time, to provide adequate care. And one focus group participant who had conducted research on mental health and primary care physicians told us that her research indicated that even well-trained primary care physicians do not identify mental illness as accurately as mental health professionals or screening instruments.

2. **Mental Health Clinics:** Focus group participants generally believed that mental health clinics could provide better care than primary care physicians. However, they noted that there are very few clinics that specialize in serving older adults and that general clinics frequently:

   - Do not have staff trained regarding geriatric mental health
   - Require people to come to their offices
   - Often have very long waiting lists to get services
   - Frequently are difficult to access because they are not close to where some people in need of services live
   - Frequently do not have culturally competent staff.

3. **Private Practitioners:** Focus group participants noted that it is also difficult to get access to well-trained mental health clinicians in private practice. Some do not accept Medicare (especially geriatric psychiatrists), some will not accept patients who cannot pay the 50% co-pay, and they tend to be concentrated in a few neighborhoods. However, it was also noted that there are social workers and psychologists who could take more older adults into their caseloads, if there were more knowledge about who they are and if they were trained to serve older adults and about how to bill Medicare.

4. **Satellites:** Focus group participants were generally enthused about satellites of mental health clinics on-site at senior centers, NORCs, and other community programs. They noted that many of these programs have figured out how to overcome the problem of stigma by describing their services as providing general help with problems rather than as treatment services. They also noted that over time many of these programs come to be accepted by older adults in the programs where they are located. The major concern about satellites is that there are not enough of them and that they are difficult to establish because they require governmental approval. (This perception may not be accurate according to government officials we spoke with.)

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* In this report "outpatient" mental health treatment refers the provision of medication therapy and/or psychotherapy. Other services classified as outpatient services by NYS OMH are listed here as day programs.

5. **Mobile, Especially In-Home, Services:** Focus group participants were also enthused about the usefulness of mobile services, particularly outreach to people in their homes. They were primarily concerned about the shortage of such services. In addition they noted that some mobile services are defined as short-term crisis services, a great problem because there are rarely other community-based services available to take over when the crisis service withdraws. Despite the consensus about the importance of mobile services, there were some concerns regarding whether they should continue forever or whether they should be designed to encourage people who are psychologically homebound to go to settings outside the home in order to counter their isolation and inactivity.

6. **Addiction Services:** Focus groups provided little information about substance abuse services for older adults. It appears that most substance abuse programs—clinics, detox, rehab and methadone programs–mix older and younger populations. Focus group participants had different opinions about this. Apparently intergenerational programs work for some older adults but not for others. Some special programs have been created such as SPOP's substance abuse counseling program and Odyssey House's eldercare program for older adults with co-occurring severe mental illness and addiction. Staff from Odyssey House told us that their program has not been well attended and they don't know why.

   It was also noted that the patients at methadone programs are aging and that special issues are arising.

7. **Informal Treatment Services:** Older adults with mental health problems who attend senior centers, live in NORCs with supportive service programs, receive case management services, and the like appear to get informal treatment services from providers who are able to form trusting, long-term relationships with them. These services, focus group participants suggested, are often very helpful to people having difficult emotional reactions or who have mild or moderate disorders. But there appeared to be a consensus that more is needed for older adults with serious mental disorders.

8. **Spiritual and Pastoral Counseling:** Several focus group participants spoke positively about the role that the clergy play, although there was concern about clergy over-reaching their ability and their need to know how and when to refer people to mental health professionals. It was also noted that chaplains can often help people face end-of-life concerns. In addition, pastoral counselors are well-trained in psychotherapy and can be particularly helpful to older adults for whom religious and spiritual concerns are paramount.

INTEGRATED OUTPATIENT HEALTH AND MENTAL HEALTH SERVICES

Focus group participants generally believe that integrating health and mental health services would result in far better care than is currently, generally available. They told us about a number of models they believe should be more widespread.

1. **Primary Health Care and Mental Health:** The focus groups revealed a number of ways in which primary health care and mental health treatment are integrated.

   a. **Co-Location in Primary Care Sites:** In some cases mental health professionals are co-located with primary care physicians making rapid consultation and referral possible. For example, some health clinics also provide mental health services. These appear to be most effective when they use an integrated team model—such as at Cornell's Wright Center for Geriatric Medicine. Focus group participants noted that there are few such programs, largely because funding structures do not support them. In addition, most licensed "diagnostic and treatment" (aka "community health") centers are prohibited from providing mental health services unless they are ancillary to treatment of a related physical health condition. Those community health centers that are "federally qualified programs" are permitted to provide treatment for mental health conditions unrelated to physical health problems but apparently have been slow to develop them. . (Regulations in New York State changed in 2008, permitting more mental health services in community health centers.)

b. **Co-Location in Mental Health Sites:** Another approach to integration is for primary care physicians to be located in mental health clinics, as at Greenwich House. No other organization uses this approach because it is generally believed to be prohibited under OMH regulations, and it may well be that Greenwich House in an unreplicable anomaly.

   Other mental health organizations have established partnerships with health care organizations, such as hospitals, to provide health care satellites at the mental health sites.

c. **Specialized Health Clinics:** An alternative approach is for mental health organizations to establish health clinics to serve residents of their housing programs and participants in their day programs or mental health clinics. For example, The Institute for Community Living has taken this approach.

d. **Medical Case Management:** Medical case management can be used with any of the approaches noted above. It involves providing health and mental health education to people with co-morbid mental and physical health conditions and following them in the community to help them to adhere to treatment and to lead a healthy lifestyle.

2. **Mental Health and Wellness:** Concern about the fact that people with serious mental illnesses have a life expectancy that is ten to twenty five years less than the general population and about the fact that they are at high risk of obesity, hypertension, diabetes, cardiac conditions, and pulmonary disease has led some providers of psychiatric rehabilitation services to focus on promoting "wellness." They do this by encouraging people to eat well, to exercise, and to stop smoking as well as to adhere to treatment regimens for hypertension, diabetes, etc.

3. **Home Health and Mental Health:** Focus group participants generally saw home health care as a missed opportunity to help older adults with mental health problems who are homebound. They noted that home health providers could be trained to do screening and to make referrals for mental health intervention—if, of course, referral resources are available. They also believe that some home health workers could be trained regarding how to interact with patients experiencing mental health problems in ways that might ameliorate their symptoms to some extent. They also believe that some home health workers could be trained to work with those older adults whose behavioral problems are most difficult to manage.

OUTREACH AND ASSERTIVE COMMUNITY INTERVENTIONS

Many focus group participants talked about the usefulness of outreach to older adults with mental disorders. For example, one participant described a process in which she began by knocking on the doors of people who were known to be isolated, talking to them through the door, getting them to agree to talk on the telephone, setting up a group via conference call, and ultimately getting people to come to a group in the lobby of their building. The worker believed that the depression and anxiety some of these older people experienced was diminished just by getting them to connect with other people. She also said that she could then do screenings and in some cases persuade people to go for treatment.

Focus group participants from the Asian community spoke very positively about Project Liberty—the post 9/11 effort to provide mental health education and counseling for people adversely affected by the bombing of the World Trade Center. They reported that they were able to reach older Asians who were unreachable with traditional mental health services because Project Liberty funded them to go to community settings where the Asian population customarily goes for help.

Unfortunately, few mental health or other service providers have the time that it takes to do this kind of outreach because they are funded to provide services mostly at sites where mental health or other health and human services are provided.

COMMUNITY-BASED CASE MANAGEMENT

Focus group participants agreed about the importance and value of case management services, which are provided by the mental health and aging systems. Services include screening, assessment, care planning, coordination of care, service arrangement, monitoring, evaluation, and advocacy.

In the mental health system only people with serious and persistent mental illnesses are eligible for case management services. Intensive case management is provided by professionals and is available to recipients 24 hours a day 7 days a week. Caseloads are a maximum of 12. Case managers provide crisis intervention and some verbal therapy as well as advocacy, care planning, and coordination. Supportive case management is provided primarily by paraprofessionals with caseloads of up to 20. There was some disagreement among focus group participants about whether intensive case managers should provide on-going verbal therapy as well as the basic case management functions. But generally both intensive and supportive case management are highly regarded, and focus group participants believe that more should be made available.

In the aging system case management is provided through the Expanded In-Home Services for the Elderly Program (EISEP), the Community Services for the Elderly Program (CSE), and Area Agencies on Aging (AAAs). Staff are generally paraprofessionals whose primary responsibility is to identify, and to arrange to meet, service needs to help older adults to remain in the community. They provide care planning, information and referral, care coordination, and advocacy. Focus group participants said that case managers in these programs need to be better trained regarding health and mental health. They also said that there is a need for a vast increase in the number of case managers. Increased funding, they said, is needed both to enlarge the programs and for higher salaries, which are needed because it is currently difficult to recruit qualified staff.

CASE ADVOCACY AND LEGAL SERVICES

Focus group participants noted that older adults with mental illnesses often face problems getting entitlements and services and that case advocacy and legal services services are often critical. Such services can be provided by the mental health, health, and aging service systems, often as a component of case management services. They also are provided by lay and legal advocacy organizations such as the Coalition for the Institutionalized Aged and Disabled and MFY Legal Services. Services include, but are not limited to advocacy with legal, health, mental health, housing, and crime issues.

Some participants discussed the usefulness of peer advocacy, which, they said, not only helps to de-stigmatize mental health services but also provides advocates who often can develop better working relationships with people with mental illness than professionals can because they have shared the same experiences.

FAMILY SUPPORT

Focus group participants repeatedly confirmed that family caregivers provide most support for disabled older adults and that this takes a considerable emotional toll on the caregivers, who are at high risk for anxiety and depressive disorders. Focus group participants noted a variety of useful supports, particularly counseling, crisis intervention, support groups, and respite services. The literature indicates that what is most effective is a combination of ad hoc counseling for caregivers, family counseling, support groups, and the availability of supportive counselors at times and in places that are convenient for the caregivers.[6] Focus group participants noted that the Alzheimer's Association and the Parkinson's Foundation and other disease-oriented groups, as well as caregiver resource centers in the aging system, provide support groups, but there is a much greater need.

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[6] Mittelman, Mary S. et al. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's Disease. *American Journal of Psychiatry*, 161 (5), 850-856.

Mittelman, Mary S. et al. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's Disease: Results of a randomized trial. *Journal of Gerontology: Psychological Sciences*, 59B (1), P27-P34.

We were surprised to learn that providers serving older adults who care for grown-up mentally disabled children often feel at a loss but have not developed contacts with the National Alliance for the Mentally Ill or similar family support organizations for families with mentally retarded family members. Providers generally did not seem prepared to help parents of mentally disabled adults deal with their most fundamental question—what will happen to my child when I die? For example, in focus groups where the issue arose, no one seemed to be familiar with supplemental needs trusts, a primary mechanism for making provisions for disabled relatives.

In several focus groups, we were surprised that no one talked about family caregivers and their needs. This appears to reflect the fact that a significant proportion of the older adults using publicly funded services are largely cut off from their families. Thus in some cases paid workers have become de facto substitutes for the family.

ELDER CARE MANAGEMENT

In several focus groups participants talked very positively about elder care management, which provides assistance with a broad range of needs for older adults who do not have the capacity to meet their own needs. This can include referral to needed services, taking people to their appointments, arranging in-home help, money management, crisis intervention, and more. In a sense, elder care managers substitute for family caregivers. Often these services are provided by social workers, many of whom have a clinical background. They, therefore, can provide verbal interventions that have therapeutic effect. The major concerns voiced by focus group participants was that this is an expensive service available almost only to people who can afford it. They also noted that the quality of service depends on the abilities of the care manager and that even the best elder care manager cannot fully substitute for family.

ELDER ABUSE SERVICES

Focus group participants identified a number of different elder abuse services including safety planning, crisis counseling, court advocacy, legal guidance, coordination with the police, and community education. Particularly important is providing a safe place to talk.

One participant told us about a new program starting at the Hebrew Home. Through a partnership with the union, they will train building workers to identify signs of elder abuse and to call in reports. The Hebrew Home will send in staff and, if necessary, provide a safe place to live at the Home until the situation is sorted out safely.

Focus group participants noted a number of significant problems regarding elder abuse services. Of course, they said there are not enough. In addition, definitions of elder abuse vary from system to system, creating confusion. For example, the Manhattan District Attorney's Office classifies any crime where the victim is an older adult as elder abuse, but service programs generally define elder abuse as victimization by someone in a position of trust such as a family member or caregiver. A focus group participant who directs an elder abuse program maintained that some elder abuse is really a form of domestic violence but that domestic violence service providers generally are unresponsive to the needs of older adults. It was also noted that adult protective services are often not effective in dealing with situations of elder abuse.

ADDICTION SERVICES

Focus groups have provided little information about substance abuse services for older adults. Some special programs have been created such as SPOP's substance abuse counseling program and Odyssey House's eldercare program for older adults with co-occurring severe mental illness and addiction. Staff from Odyssey House told us that their program has not been well attended and they did not know why.

One focus group participant noted that the patients at methadone programs are aging and that special issues are arising. We clearly need to explore this further.

DAY PROGRAMS

Focus group participants generally confirmed that inactivity and isolation are causes as well as consequences of anxiety and depression. Having something to do during the day and having contact with other people is a key to maintaining, or regaining, mental health. There are a variety of day programs that provide opportunities for activity and contact including: senior centers, NORC-SSPs, adult social day care, adult medical day care, psychiatric rehabilitation, partial hospital programs, and continuing day treatment.

It is striking to us that there are so many different kinds of day programs. Although they are designed to serve different populations and to provide different services, they all have common features, not the least of which is serving a meal every day. They all also provide opportunities for activity and social interaction.

1. **Senior Centers:** Most focus group participants expressed a positive attitude about senior centers because they offer opportunities for activity and social interaction as well as to provide supportive services for people who need help with various problems. They also are seen as places where people can be screened for mental disorders and where mental health services can be offered.

   However, our focus groups revealed some controversy about senior centers. Some participants noted that a small proportion of older adults attend senior centers. Estimates range from 5-20%. So, at least 80% of older adults do not use senior centers. And there is some concern that utilization of senior centers will diminish unless they develop approaches that are more appealing to the next generation of older adults, who may well be more independent than the current generation and not need, or be interested in, going to community centers for older people. If this occurs—and it will be a good sign for the health of the coming older generation if it does—it will become necessary to find other approaches to reaching older adults with untreated mental disorders.

2. **NORC-SSPs:** Supportive service programs in naturally occurring retirement communities (NORCs) are very highly regarded by the participants in our focus groups. This model stresses involving people in activities and in helping roles when they are well and being available to provide help when they need it. Staff include both social workers and nurses, who told us that they do not feel adequately trained to deal with serious mental illness. But, they told us, they are able to form working relationships with people through which they can provide informal mental health assistance for people with mild disorders and can engage people with more serious problems in ways that sometimes result in their accepting the need for psychiatric help. They expressed concern about difficulty getting access to mental health services for people who need, and are ready to accept, them.

3. **Adult Social Day Care:** There are a number of day programs that are unconnected with senior centers and that do not provide medical care. They offer opportunities for activity and social interaction primarily for people in the early and middle stages of dementia. Staff from these programs reported high levels of anxiety and depression among the people they serve and their family caregivers. They believe that activities they provide for people with dementia and the support groups they provide for their families are valuable, but they expressed frustration about not having adequate funding to provide the kind of social supports—including mental health interventions—that many of their participants need.

4. **Adult Medical Day Care:** Unlike adult social day care, adult medical day care programs appear to be well funded via Medicaid to provide a broad array of social and medical services for older adults with a mix of physical health problems and limited cognitive functioning. Some of these programs appear to steer clear of people with serious and persistent psychiatric disabilities because of behavior management concerns. But some programs seek out this population, which is generally eligible for Medicaid and often functionally indistinguishable from people with dementia. Participants in focus groups disagreed about the wisdom and possibility of expanding the use of adult medical day care for people with long-term psychiatric disabilities. Some programs are actively doing this; others are nervous about the population.

The major concern voiced about adult medical day care was that, because it relies on Medicaid funding, it is only available to people who are poor or to those who can afford to pay a fee of about $150 per day.

In addition, some ideological tensions emerged during the focus groups. Some social adult day program providers and some psychiatric rehabilitation providers believe that adult medical day care programs are overly medicalized and do not encourage as much independence as their patients may be capable of.

5. **Psychiatric Rehabilitation:** The mental health system funds a significant number of psychiatric rehabilitation programs, almost all of which are day programs offering a mix of vocational rehabilitation, opportunities for activity and social interaction, and general support to enable people with long-term psychiatric disabilities to live in the community. Psychiatric rehabilitation programs generally do not provide psychiatric or medical services directly, although some are parts of larger agencies that do.

   Discussion with the Board of Directors of the New York Association of Psychiatric Rehabilitation Services (NYAPRS), with program staff, and with people who attend these programs revealed that few of the people in these programs are 65 or over. This probably reflects the fact that the life expectancy for this population is 10 to 25 years less than the general population and the fact that as people with long-term disabilities develop complex physical conditions they migrate to adult homes, nursing homes, and adult medical day care programs.

   Although there are some rehabilitation programs for adults 55 and older, prior to our focus groups most psychiatric rehabilitation programs seem not to have begun to address issues of aging. As the result of our discussions, NYAPRS formed a taskforce on how to meet the needs of people with long-term psychiatric disabilities who are aging.

6. **Continuing Day Treatment:** These programs serve people with long-term psychiatric disabilities; but, unlike psychiatric rehabilitation programs, they provide psychiatric services. In addition their activities tend to be structured under the rubric of therapy. While a rehabilitation program might have an arts group or a discussion group on drugs, a continuing day treatment program would have an art therapy program or a psycho-education meeting. Continuing day treatment providers often maintain that they serve a population more in need of medical model services than those served in psychiatric rehabilitation programs; and one CDT provider told us that they also get referrals of people with chronic medical conditions from psychiatric rehabilitation programs.

   Continuing day treatment programs get mixed reviews. Some people believe that the integration of psychiatric rehabilitation and treatment in one place is ideal; others believe that the use of a medical model impedes the development of independence and of mainstreaming.

   There are a few continuing day treatment programs designed to serve adults 55 and older; and like psychiatric rehabilitation providers, most continuing day treatment providers appear to have given very little thought to how to change their programs to meet the needs of aging patients.

7. **PROS:** While we were conducting focus groups, New York State was in the process of converting psychiatric rehabilitation services and continuing day treatment programs to personal recovery oriented services (PROS). There was considerable debate about whether it will be possible to serve older adults who do not have a goal of work under PROS regulations. Some think the regulations are broad enough to do so; others read them differently.

EMPLOYMENT AND VOLUNTEER OPPORTUNITIES

Participants in focus groups generally agreed that it will be important to develop employment and volunteer opportunities for older adults, most of whom are healthy enough and energetic enough to work. They agreed that if more roles are developed for older adults to help other older adults, many can be part of the solution rather than part of the problem. There are, in fact, a number of programs that currently use older adults to interact with anxious and/or depressed peers, particularly those who will not leave home.

A number of focus group participants commented that they are already employing older adults in a number of helping roles—such as home health—and that they are among their best workers—dedicated, reliable, knowledgeable, and able to work for low pay because it is a supplement to Social Security and pensions. Their availability for low pay stirred concerns among some focus group participants, who worried that this will suppress the pay of younger workers and potentially create conflicts with unions.

RESIDENTIAL PROGRAMS

There are a variety of residential programs serving older adults with mental disorders. Some of these programs are more or less independent but provide some supports. Others are institutional. Focus group participants generally agreed that institutional services—adult homes and nursing homes—should only be used as a last resort, though there was considerable difference about what "last resort" means. There was a consensus that the range of congregate living alternatives is inadequate because there are few small, home-like settings where people can live out their lives.

1. **Community Residences:** NYS OMH funds and licenses a number of different kinds of "community residences" for adults with long-term psychiatric disabilities. Some are group homes; some are structured single room occupancy (SRO) facilities; and some are scatter-site apartments with case management supports. By definition community residences are transitional. There is an expectation that people will stay for a couple of years and then move on to live independently. Although about 6% of community residence beds are filled by people 65 or over, fewer than 1% are in facilities for older adults.

   Focus group participants told us that facilities designated for older adults are not designed to reflect the special needs of older adults. There is still an expectation of transition to independent living; they are not necessarily accessible to people with physical disabilities; and they are not staffed to be able to handle a mix of physical and mental disabilities. They also told us that the expectation of transition to independent living is a problem for older adults with long-term psychiatric disabilities. As a result, focus group participants told us, frequently older adults must be transferred to adult homes or nursing homes.

2. **Supported Housing:** "Supported housing" is a program organized and funded by the NYS OMH. People with long-term psychiatric disabilities, including those with co-occurring addictive disorders, live in apartments alone or with a roommate(s). Case managers visit residents in their apartments to provide whatever supports they need to continue to be able to live in the community. Unlike the OMH community residence program, supported housing is permanent. It appears that relatively few older adults live in supported housing. Focus group participants raised concerns about whether supported housing residents who develop physical disabilities and/or dementia would be able to remain in their homes or would have to be moved to congregate care. Some were convinced that the use of home health services might help them remain, and most participants believed that it would be unfortunate if supported housing residents had to move to adult homes or nursing homes.

3. **Supportive Housing:** Frequently confused with "supported housing", in NYS "supportive housing" refers to housing programs for people with a history of homelessness or who have HIV/AIDS. This, of course, includes some people with mental and/or substance abuse disorders. Some are older adults. While most supportive housing is independent living, in fact almost all of the units are in buildings that are primarily, or even exclusively, supportive housing and which have supportive services on site. There are a few such programs exclusively for older adults.

   Participants in our focus group on supportive housing raised a number of concerns. They were very distressed that their residents often are not admitted to hospitals when they are acutely psychotic. They blamed this both on hospital policies and on what they regard as inadequate provisions under NYS law to hold people in hospitals against their will. (Supportive housing providers were the only group to express a desire for more coercive interventions. Other providers emphasized the need to develop trusting relationships so as to help people accept the treatment they need.) Supportive housing providers also complained about lack of access to outpatient mental health services. The providers with whom we met acknowledged that they had virtually no training in mental health and did not know how to deal with residents exhibiting difficult behavior related to mental illness. (It is important to note that we met with a group of supportive housing staff who happened to be relatively new to their jobs.)

4. **Private Assisted Living Facilities and Lifecare Communities:** Recent research findings indicate that there is a high prevalence of mental disorders in private assisted living facilities and in lifecare communities. Focus groups provided little information about mental health services in these facilities, but indicated that there are few specialized mental health services available except for the treatment of dementia. Other services may be available through onsite health facilities, but we heard of only one program that had a clinical social worker in the health clinic. Otherwise service appears to be provided by primary care physicians or nurse practitioners with visiting or on-call mental health professionals.

INPATIENT SERVICES

Older adults are treated in hospitals for physical, mental and substance abuse conditions; but, focus group participants noted, even when people are hospitalized for physical reasons, significant mental health issues arise.

1. **Treatment for Physical Illnesses and Injuries:** All hospitals have consulting psychiatrists and other mental health professionals to evaluate and provide treatment for people who are being treated for physical illnesses and injuries. But focus group participants expressed concern about the frequent failure to identify the need for mental health services during inpatient stays. They noted that hospital stays tend to be short, focused on dealing with the patient's physical needs, and on making a rapid discharge. Even social work staff do not feel they have time to assess a patient's mental health needs. Screening instruments, which can be administered very quickly, apparently are not used. Therefore, participants told us, diagnosis and assessment for mental health problems is not done unless there is a prominent mental disorder. As a result some patients whom they believe would benefit from psychiatric treatment generally don't get it while they are in the hospital nor is it included in their discharge plans.

   In addition it appears that even people with significant histories of mental illness frequently are not identified during inpatient stays. Social workers from nursing homes told us that increasingly nursing homes are taking patients to provide "sub-acute" rehabilitative services with the expectation that the patients will be discharged elsewhere. They find, they told us, that a significant number of people referred for physical rehabilitation in fact have serious mental illnesses not mentioned in the referral material. They find these people both difficult to treat, because they lack expertise in mental health, and difficult to discharge because there are so few community resources. Some social workers in nursing homes believe that the lack of information they receive in the referral reflects a failure to do screening in the hospital. Some are more suspicious and believe that hospital discharge workers purposely mislead them so as to be able to get these patients out of the hospital.

2. **Treatment for Mental and Substance Use Disorders:** There are four kinds of inpatient treatment structures for older adults with mental illness in general hospitals. Some hospitals have specialized geriatric mental health units separated from units for other populations. Some hospitals have specialized geriatric mental health units that share space with other populations. Some hospitals mix the patient populations. And some hospitals put vulnerable older adults with mental disorders on medical surgical units and provide mental health services via consultation. Hospitals also provide inpatient detox and rehabilitation for older adults with addictions to alcohol and/or drugs. We do not know of any that are exclusively for older adults.

   Focus group participants expressed a range of concerns about inpatient treatment of older adults. Some participants—especially those who provide housing—believe that it should be easier to admit older adults with acute mental illness to hospitals. This appears to reflect the fact that if the hospital does not admit them, they will return to housing programs staffed by people ill-equipped to deal with people with acute mental illness.

   Virtually all focus group participants with experience with inpatient services expressed concern about the shortage of specialized geriatric mental health and substance abuse units and about the lack of training in geriatric behavioral health among mental health professionals on general psychiatric units.

   There was also great concern expressed about the quality of discharge planning for people with mental disorders.

INSTITUTIONAL SERVICES

1. **Adult Homes:** Adult homes are congregate living facilities for people who are presumably unable to live independently but who are not eligible for skilled nursing facilities. Most residents are poor, and SSI covers their costs of care. The costs of care of some residents are covered privately. Some homes are small and pleasant; many are large, institutional, and shabby or worse. Some homes (called "heavily impacted") house primarily adults with long-term psychiatric disabilities. Most of these homes have mental health services on site. Medical and mental health services for adult home residents, including home health care, are paid for by Medicaid and Medicare.

   The quality of care in adult homes has been the subject of many exposés over the years. Most focus group participants had a very negative view of adult homes, believing that there needs to be better enforcement of licensing regulations, improved health and safety conditions, improved basic services, and improved health and mental health services. Among advocates and proponents of psychiatric rehabilitation, there is a strong belief that many people with mental disorders in adult homes could be helped to live more independently in the community and that those who cannot live independently should be moved to congregate care programs designed for people with mental disorders and with a goal of recovery.

   Residents of the one adult home we visited did not seem negative about the living conditions or services, and only one or two expressed an interest in leaving the home. Advocates told us that residents are generally reticent about expressing their real feelings and hopes until they develop a trusting relationship.

2. **Nursing Homes:** Focus groups involving home health workers, long-term care ombudsmen, and nursing home staff confirmed that behavioral problems are a major reason for placement in nursing homes and that there is an increasing number of people with mental and behavioral disorders in nursing homes in large part because there are inadequate alternatives in the community. The dominant view in the focus groups was that mental health services are inadequate in nursing homes even though most homes provide psychiatric and psychological services either with staff members or with outside providers. We did, however, hear about a group of psychologists who provide mental health services in nursing homes using a model in which they function as part of the treatment team at the home rather than just as people who drop by, provide treatment, and leave. They coordinate with on-site staff and provide training for them. Those familiar with this model regard it very positively.

All focus group participants who talked about nursing homes agreed that there is a great need to provide training regarding mental illness and behavior management to the line staff and to people in supervisory and administrative positions.

Ombudsmen we spoke with were particularly concerned about the process of entering a nursing home, which—as one participant put it—creates an adjustment reaction disorder to being stripped of dignity.

Despite heavily negative comments about nursing homes, a number of focus group participants maintained that nursing homes are better than remaining at home for some people—especially those who live in utter isolation. And some focus group participants said that some older adults with mental disorders "thrive" in nursing homes. Connecting with the nursing home community, they said, helps some people recover from depressions linked to profound loneliness. Other focus group participants noted that there are efforts underway—such as the Greenhouse model—to change the institutional atmosphere of nursing homes. They maintained that there is not an inherent link between indignity and living in a place where skilled nursing care is provided 24 hours per day

Focus group participants generally agreed that nursing homes are on occasion the most appropriate place for older adults with mental disorders. The fundamental question, they said, should be where the individual will have the highest possible quality of life—in the community or in an institution.

END-OF-LIFE SERVICES

Hospice and palliative care programs appear to have some sophistication regarding mental health. Focus group participants familiar with these services told us that they try to help people deal with the fears and sadness that are a common part of the process of dying.

Focus group participants who work with people with long-term psychiatric disabilities did not raise the issue of end-of-life. It occurred to us that perhaps they are not involved with their clients when they become terminally ill. Most focus group participants confirmed that they lose contact with their clients when they become too physically ill to remain in the housing, rehabilitation, or treatment programs. One participant, however, stated that he and other staff try to stay connected by visiting their clubhouse's members in hospitals, nursing homes, and hospices when they are dying. Another clubhouse told us that they run a housing program for older adults and that residents make it a point to visit former residents when they are ill and/or dying. Nevertheless it is our impression that most people with long-term psychiatric disabilities lose contact with programs that have served them as they approach the end-of-life.

SPIRITUAL CARE

In general, focus group participants confirmed that spiritual matters are very important to most older adults with mental and substance use disorders. Some clinical providers said that they discuss these matters with their patients if they raise them, but some seemed quite uncomfortable getting involved with spiritual concerns. We also heard from several chaplains who stated that they try to be as available to people with mental disorders as to others. One of the chaplains said that she believes that there needs to be geriatric mental health training for chaplains and for other clergy.

Part 3: Service Improvements for Older Adults with Mental Health Problems

We asked each focus group, "What would you do if you could do anything?" An enormous number of ideas emerged in response. Some of their ideas had to do with how to organize and deliver mental health services. But focus group participants did not limit themselves to mental health services. They were clear that services provided through the health, aging, and other service systems are also critical to the mental health of older adults with mental disorders. For example, during the focus group with NORC nurses we asked what would be most helpful for the people with mental disorders they find most difficult to serve. They said that access to professional mental health services would be very helpful, but they also noted the need for friendly visitors for the homebound, telephone reassurance, support groups for older adults and family caregivers, and spiritual counseling. In their view professional mental health services are not enough.

The Geriatric Mental Health Alliance has used ideas emerging from our focus groups, best practices presentations, and other discussions to shape a 10-Point Agenda for Change.

1. Help older adults to remain in, or return to, the community
2. Improve access to services
3. Improve quality of services
4. Integrate mental health, health, and aging services
5. Increase the capacity to serve cultural minorities
6. Provide support for family caregivers
7. Provide public education
8. Expand and increase the workforce serving older adults with mental health needs
9. Address the need for new financing models
10. Address the need for governmental readiness

This section of our report covers service needs under categories 1-8. Categories 9 and 10 are covered in the following section, which is on barriers.

OLDER ADULTS SHOULD REMAIN IN, OR RETURN TO, THE COMMUNITY

A fundamental theme for virtually all participants in the focus groups was that it is preferable for older adults with mental health problems to live in the community rather than in institutions. There are some disagreements about what it means to "live in the community." Does it mean living in your own home or with your own family or does it include some forms of congregate care, particularly those that are small and homelike? And are some people better off in congregate care—even in nursing homes—because otherwise they lead lives of depressed or frightened isolation? If so what are the distinguishing characteristics of people who are better off in congregate settings?

Focus group discussions about living in the community focused on two quite different populations—people with late life mental disorders, particularly dementia, and people with long-term psychiatric disabilities who are aging.

1. Late Life Mental Disorders

According to focus group participants, the widespread impression that older adults end up in nursing homes because of physical illnesses and injuries and because of dementia is only partially true. Four other factors play a significant part—(a) lack of support for family caregivers, (b) social isolation, (c) behavioral problems that are difficult to manage,

and (d) severe mental illnesses including depression, anxiety disorders, delusional states, and paranoia. Focus group participants generally agreed that, to reduce the use of nursing homes, there needs to be more support available to families, more contact provided to isolated older adults, more skill developed in managing difficult behaviors, and increased access to treatment.

a. **Family Support:** Research by Mary Mittelman[7] has confirmed that, when families are provided a combination of individual counseling, family counseling, support groups, and crisis response, their family members with dementia remain in the home up to 18 months longer than if the family does not get such support. The observations of focus group participants support this point of view.

b. **Countering Isolation:** Focus group participants noted that many of the people whom they serve live in isolation and do not have family available to them. Some have been abandoned; some have children who have moved away; some have family who have died. Without family caregivers, isolated disabled older adults must rely on home health services of various kinds. Focus group participants suggested that peer contact would be helpful to such people, some of whom are placed in nursing homes because a judgment is made that they will be better off in a place where they have opportunities for human contact and for activity. For this population transportation to day programs can be key. For those who cannot leave home even when transportation services are available, friendly visitors and telephone support can be extremely helpful.

c. **Behavior Management:** Home health providers who participated in the focus groups emphasized that, despite heroic efforts on their part, some disabled older adults get moved to nursing homes because of behavioral problems including failure to adhere to medical regimens; abusive behavior towards caregivers; hoarding and lack of cleanliness; and dangerous behaviors such as wandering, smoking in bed, not eating, etc. They noted as well that some home health workers are better than others in building trusting relationships and coaxing people to behave in ways that make it possible for them to stay home. They believe that better training for home health workers regarding behavior management could make a big difference.

   Other focus group participants, while agreeing, also suggested that we need to learn more about behavior management and that research in this area is important.

d. **Access to Treatment:** Focus group participants also noted that some people with physical health problems end up in nursing homes primarily because they have severe mental illnesses. In many cases, they believe, they could have recovered from mental illness and been able to avoid placement in a nursing home had psychiatric treatment been available to them in their homes.

2. People with Long-Term Psychiatric Disabilities Who Are Aging

Many, if not most people, with long-term psychiatric disabilities who have not recovered "normal" levels of functioning rely on their families, on the mental health system, and on government supported income maintenance to be able to live in the community. Many live with family, who will become incapable of continuing to care for their mentally disabled adult children as they themselves age, become disabled, and ultimately die. Many live in housing that is funded by the Office of Mental Health, the Homeless Housing Assistance Program, or other governmental housing programs. Many attend day programs such as continuing day treatment and psychiatric rehabilitation, often "clubhouse" programs. Some who work use various forms of job support. Most get psychiatric treatment through the public system of care rather than privately.

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[7] Mittelman, Mary S. et al. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's Disease. *American Journal of Psychiatry*, 161 (5), 850-856.

Mittelman, Mary S. et al. (2004). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's Disease: Results of a randomized trial. *Journal of Gerontology: Psychological Sciences*, 59B (1), P27-P34.

The public system of care for this population is known as the "Community Support Program." Focus group participants noted that it is designed primarily for working age adults and that adaptations are needed to help aging people with long-term psychiatric disabilities to remain in the community. Changes are needed, they told us, in five primary areas—(a) healthcare and health maintenance, (b) housing, (c) rehabilitation, (d) family support, and (e) end-of-life care.

a. **Healthcare:** Research indicates that the life expectancy of people with long-term psychiatric disabilities is 10 to 25 years less than the general population. Focus group participants told us that the people with whom they work also seem physically older than their years and develop chronic medical conditions earlier than the general population. They also told us that most people with long-term psychiatric disabilities get dreadful health care. They often are not welcome even in public health centers because doctors are uncomfortable with them and do not know how to relate to people with histories of significant psychiatric disability, including acute psychoses. They also noted that, in part because of the medications they take, people with long-term psychiatric disabilities are prone to obesity, hypertension, diabetes, cardiac conditions, and pulmonary problems.

   Focus group participants familiar with this population agreed that increasing life expectancy should be a major goal and that this requires improving healthcare. They noted several possible approaches:

   - A major emphasis on "wellness" and consumer self-management, i.e. on prevention of illness via diet, exercise, smoking cessation, and adherence to medical regimens
   - Training primary care personnel in health clinics (Participants mostly were pessimistic about this approach.)
   - Developing primary care personnel with special expertise on serious mental illness
   - Having psychiatrists provide primary health care
   - Establishing primary care satellites in settings that serve people with serious mental illness
   - Developing primary care centers that specialize in serving people with mental disabilities. (The Institute for Community Living uses this approach as do a number of substance abuse agencies and mental retardation agencies.)
   - Disease management approaches, including nurse case managers and peer medical case managers.

   Suicide (mostly by younger people with schizophrenia) and accidents (mostly among older people) are also contributing factors to low life expectancy. Therefore, increasing life expectancy calls for both:

   - Suicide prevention
   - Accident prevention (especially falls prevention).

b. **Housing**

   Expansion: Currently a large number of people with long-term psychiatric disabilities live in adult homes and in nursing homes. Many focus group participants believe that these placements are often inappropriate and that residents should be helped to return to the community. This will require additional community-based housing. In addition a large portion of this population lives with their parents, who will become disabled and ultimately die. New housing will be necessary for them as well. There also may need to be more congregate housing for people who are currently in supported housing.

   Enhanced Housing Programs: As people with long-term psychiatric disabilities age, there will be a need to modify housing models to meet their needs. Most people develop chronic physical conditions as they age, and often they need help to keep track of medications and to adhere to other medical requirements. In addition, older adults become increasingly likely to develop dementia as they age and to need more and more help with ADLs over time. Older adults may also develop problems with mobility and need housing that is physically accessible. In addition, older adults become more prone to falling, which is a major cause of disability. For all these reasons focus group participants stressed the need for housing models to be developed that provide accessibility, falls prevention, medication management, and assistance with ADLs.

This, they suggested, will be a particular challenge for supported housing programs, which currently provide only drop-in case management. But it is also a challenge for community residences, which are not currently funded to provide adequate staff during the day—when younger residents go to program or work—or to provide high levels of medical oversight and assistance with ADLs. In addition, many community residences are not accessible to people with physical disabilities and are not designed to minimize the dangers of falls and other accidents.

Permanent Congregate Housing with a Lifetime Commitment: In addition to changes in physical plant and program design, focus group participants emphasized the need for a change in regulation to make community residences permanent homes for older adults. The expectation of transition to greater independence is, they told us, generally unrealistic, and currently older adults have to move to adult homes or nursing homes as they age because the supports they need if they deteriorate physically are not available in community residences. They suggested that residences for older adults with long-term psychiatric disabilities should be conceptualized as making a lifetime commitment to their residents.

c. **Rehabilitation:** Focus group participants noted that psychiatric rehabilitation programs are generally designed for working age adults and place a heavy emphasis on becoming employed. They are often not suitable to the developmental needs of older adults, many of whom prefer "retirement" at some point. In addition, health needs become more significant issues as people age. For these reasons, modifications are needed in psychiatric rehabilitation models. The New York State Association of Psychiatric Rehabilitation Services (NYAPRS) formed a taskforce to develop recommended changes. The position paper with recommended changes can be found at: www.mhaofnyc.org/gmhany/index.html

   Several focus group participants maintained that more appropriate rehabilitation services can be, and are, provided in adult medical day care programs and that these programs have the additional advantage of integrating health and mental health services. They argued that adult medical day care programs might be more appropriate day programs for older adults with long-term psychiatric disabilities than are either continuing day treatment or psychiatric rehabilitation programs. Other focus group participants worried that adult medical day care is overly medicalized and not geared to recovery. Other focus group participants suggested that some blending of psychiatric rehabilitation and adult medical day care should be explored.

d. **Family Support:** Focus group participants from senior centers and NORC-SSPs alerted us to a hidden population of people with long-term psychiatric disabilities living with their aging parents. They noted that these parents need support to continue to provide the care that they have provided for years and that virtually none of them have contact with The National Alliance for the Mentally Ill (NAMI), which is the major family support group for this population. Focus group participants suggested that NAMI should reach out to senior centers, settlement houses, and NORCs to identify parents in need of support.

   Focus group participants also noted that sometimes adult children with mental disabilities try to reverse roles and care for their parents as they become disabled. Although this sometimes results in sad outcomes, sometimes it works well. SPOP has developed a program to help the adult children play this role. This might well be incorporated into the effort to remodel rehabilitation goals and practices.

e. **End-of-Life Care:** Several focus group participants noted that many older adults with serious mental illness die alone because they have lost family and because programs where they have participated for many years cannot continue to serve them as they become seriously, physically ill. They recommended that efforts be made to incorporate end-of-life care into both housing and rehabilitation services for this population.

IMPROVE ACCESS TO SERVICES

Perhaps the most frequent concern we heard from focus group participants was the difficulty getting access to geriatric mental health services. By lack of access they meant:

- There are no geriatric mental health services available in some neighborhoods.
- There are often very long waits for service.
- Transportation to and from mental health services is often difficult or non-existent.
- There are few home-based geriatric mental health services available.
- There are few geriatric mental health services available on-site in senior centers, NORC-SSPs, and other community settings where older adults go for help
- Many mental health professionals who serve older adults are not culturally competent—not bilingual, not skilled at engaging cultural minorities, and/or not sensitive to cultural differences.
- Services are often not affordable.

Problems of access exist in the private as well as the public sector. For example, one of New York's leading geriatric psychiatrists said that his practice is entirely full and that he routinely tells people to "call your Congressman."

In order to improve access to services, focus group participants suggested:

- **A Major Expansion of Geriatric Mental Health Services** is needed in both the public and private sectors. This would require both increased public funding and a significant increase of the workforce trained in geriatric mental health. Some focus group participants suggested that some social workers and psychologists in private practice, who may be willing to accept the Medicare rate with less than a full co-pay, could ease the workforce shortage in the private sector if they were trained in geriatric mental health.

- **Increased Transportation** is needed to and from geriatric mental health service settings. Several focus group participants noted that the issue is not just providing transportation but providing transportation that is tolerable to people. Some van services pick up a number of individuals along the way and can take several hours. Many older adults find this more than unpleasant.

- **Increased Mobile Services** are needed to
  —Respond to crises,
  —Provide treatment to people in their homes, and
  —Provide services in the community settings to which people go for help.

Focus group participants gave particular emphasis to home-based services and to providing services in community settings—especially senior centers, ethnic "clubs", NORCs, and houses of worship.

With regard to home-based services, there was general agreement that they should last as long as people need them, but that they should be structured to encourage people to leave home and to go to settings where they will have contact with other people.

With regard to mental health services in community settings, focus group participants were enthusiastic about the opportunity that they provide to reach people who, because of stigma, would otherwise not seek services. Many suggested that it is important to describe these services as offering general help rather than only clinical help so as to attract people to use them, but others said that they can be successfully incorporated into the culture of a community setting even when described as psychotherapy services.

- **More Culturally Competent Providers** are needed so as to more effectively engage minorities with mental health problems. Especially important are bilingual and bicultural workers who are well trained in geriatric mental health. Focus group participants also stressed the importance of active outreach into the community and of outposting mental health workers in indigenous community settings such as houses of worship.

- **Geriatric Mental Health Treatment Services Also Need To Be More Affordable**. Currently, Medicare requires a 50% co-pay, which is out of reach for many older adults. This could be changed by developing a cadre of well-trained providers (e.g. social workers) who are willing to accept Medicare without the full co-pay. It could also be changed by state and local government and philanthropies underwriting the co-pay. It will be addressed by a change of Medicare rules beginning in 2010. We will discuss these financing issues in the next section.

IMPROVE QUALITY OF SERVICES

Focus group participants expressed great concerns about the uneven quality of service available in both the private and the public sectors and in both the community and institutions. They also maintained that there are opportunities for preventive interventions to counter social isolation and adverse reactions to the developmental challenges of aging.

Improving Community Services: With regard to the quality of community services, they were concerned about services in the mental health and substance abuse systems, the health system, and the aging system. Concerns included:

- The fact that so many of the mental health and substance abuse providers who serve older adults in both the public and the private sector do not have special training in geriatric mental health and are unfamiliar with evidence-based and other state-of-the-art interventions
- The inability of most primary care and specialty physicians to identify mental and addictive disorders and to provide adequate interventions or make appropriate referrals
- The failure to pursue opportunities to improve identification and treatment of mental and addictive disorders via home health care and community services under the aegis of the aging system, including senior centers, case management, and more
- Inadequate crisis and emergency services for acute mental illness
- The inadequacy of Adult Protective Services, especially in New York City
- Inadequate suicide prevention efforts
- The lack of addiction services geared to older adults
- Lack of cultural competence in all service systems.

To address these concerns, focus group participants recommended:

- Training regarding geriatric mental health and the dissemination of best practices for mental health professionals, health providers (including primary care, specialty care, and home health providers), aging providers, and adult protective services workers
- Widespread use of screening instruments to flag possible mental disorders
- Improved integration of health, mental health, and aging services (discussed below)
- Enhanced suicide prevention efforts
- The development of alternatives to ambulances and emergency rooms to respond to mental health crises
- The development of addiction services using a harm reduction model and responsive to the substance abuse problems of older adults including the misuse of alcohol and prescription and over-the-counter drugs as well as excessive gambling
- Upgrading adult protective services workers and reducing caseloads
- Upgrading case managers in the aging system and reducing caseloads
- Training people who come in contact with older adults in the community such as people who serve meals on wheels, work in local stores, provide janitorial services, etc. as "gatekeepers" who can alert local providers about people in need
- Developing linkages between spiritual care and other services for the aging

- Using NORC-SSPs as the hub of service provision in the community
- Enhanced services for cultural minorities (discussed below).

Improving Services in Institutions: With regard to institutions and other congregate care facilities, focus group participants were concerned about:

- The loss of human dignity that is part and parcel of life in many nursing homes
- The failure to provide the amount of mental health service that many nursing home residents need
- The uneven quality of mental health services in nursing homes
- The huge caseloads of social workers in nursing homes
- The lack of training regarding mental health and behavioral issues for nursing home staff at all levels
- Poor living conditions in adult homes
- The uneven quality of mental health services in adult homes
- The failure in both nursing homes and adult homes to facilitate greater "integration" into the community
- Lack of mental health services in assisted living facilities and lifecare communities, despite high prevalence of mental disorders.

To improve quality of care for residents with mental disorders in nursing homes, focus group participants recommended:

- Changes to entrance processes so as not to dehumanize residents
- Individualized schedules for sleeping, eating, and activities
- Routine screening for mental disorders,
- Use of mental health professionals well-trained in geriatric mental health and integrated into the life of the facility
- Manageable caseloads for social workers
- Training for all levels of staff, including administrative personnel, regarding mental and behavioral disorders.
- The development of alternatives to nursing homes for people with mental disorders who do not need skilled nursing care for a physical health problem.

To improve quality of care in adult homes, focus group participants recommended:

- Enhanced advocacy for residents
- More effective enforcement of regulations
- Improved living conditions, especially air conditioning
- Improved mental health and substance abuse services
- More activities that connect residents of adult homes with the mainstream
- Case managers and "peer bridgers" to help residents explore alternative living arrangements that are more "integrated" with the mainstream community.

To improve quality of care in assisted living facilities and lifecare communities, focus group participants recommended:

- Acknowledgement of recent research findings that mental disorders are widespread in assisted living facilities
- Routine screening for mental disorders
- Readily available high quality treatment for mental disorders.

Preventive Interventions

Focus group participants tended to believe that it is possible to prevent social isolation and adverse reactions to the developmental challenges of old age in some people. Suggested approaches include:

- Immediate outreach to people known to be becoming isolated

- Engagement of people in activities and socialization
- Education for older adults to help them prepare for the developmental challenges they will face when they retire, when they experience losses, and when they are approaching death.

INTEGRATE MENTAL HEALTH, HEALTH, AND AGING SERVICES

The need to integrate mental health, health, and aging services was apparent to everyone who participated in our focus groups, and a variety of approaches to integration emerged from our discussions.

Integrating Primary Health Care and Mental Health

As previously noted, primary care physicians provide most treatment for mental health problems among older adults, yet most of them are not well-prepared to do so. Although some people advocate for all psychiatric treatment to be provided by psychiatrists, most realize that there are not now, and never will be, enough psychiatrists to provide services to all who need it. In addition, it is clear that many people prefer getting treatment from their primary care physicians. The key question, therefore, is how to improve the quality of care provided by primary care physicians.

Training: Some focus group participants recommended more training in mental health for primary care physicians, but many participants were skeptical about this approach because primary care physicians have so little time and have to have some degree of expertise in so many different areas.

Some focus group participants advocated for a more targeted approach to training primary care physicians focused on the use of screening instruments, guidelines for pharmaceutical treatment, and guidelines for referral to mental health professionals.

Co-Location in Primary Care Settings: Another basic approach to integrating primary health care and mental health involves co-locating mental health professionals and primary care physicians. This is comparable to having a nutritionist on-site. Some focus group participants were enthusiastic about this idea. Others were skeptical because co-location is not the same as integration.

Integrated Treatment Teams: We learned from our focus group with Cornell and from one of our best practices presentations about the treatment team approach used at the Wright Center of Geriatric Medicine at Cornell School of Medicine. Not merely co-location, this approach involves the creation of a treatment team combining health and mental health professionals. The problem with this approach, focus group participants told us, is that it is costly and may not be practicable except for service providers that can draw in grants and other sources of support beyond fee income.

Medical Case Management: Focus group participants who were familiar with it were also enthusiastic about the use of medical case managers to follow up with patients diagnosed as depressed by their primary care physicians. Research indicates that this approach improves symptom reduction in about 50% of those served.

Telephone Consultation: Another approach suggested by focus group participants involves telephone consultation. Primary care physicians would be able to place a call to a geriatric psychiatrist to discuss a complicated case and get a call back within a very short period of time.

Primary Care in Mental Health Service Locations: Most discussions of integrating mental health and primary health care focus on integrating mental health into health settings. Focus group participants noted, however, that it is also possible to integrate health care into mental health settings. Particularly those who work with people with serious mental illness pointed out that this population gets very poor service in primary care settings. It may make sense, they said, to focus on putting mental health into primary health care settings for people who get good physical health care there, but for people with serious mental illness the opposite is true.

There are a number of ways to integrate health in mental health settings.

In a Mental Health Clinic: Greenwich Neighborhood House provides primary health care in its mental health clinic. Most focus group participants maintained that this is contrary to regulations and that it is the exception to the rule. Regulations were subsequently changed to permit this.

Health Clinic Dedicated to People with Mental Disorders: The Institute for Community Living and several mental retardation and substance abuse agencies operate health clinics dedicated to their clients with mental illness, mental retardation, and/or addictive disorders. Focus group participants who were familiar with it were enthusiastic about this approach.

Health Satellite: Some mental health organizations serving people with long-term psychiatric disabilities such as The Bridge, have developed linkages with hospitals or community health centers that provide primary health care satellites on site at mental health programs. Focus group participants who were familiar with it were also enthusiastic about this approach.

Mental Health and Specialty Health Care

Integration of mental health and specialty health care appears to be neglected in most discussion of integrating health and mental health. Focus group participants noted that mental disorders affect the outcome and cost of treatment of a number of physical mental illnesses, most notably cardiac problems. The cost of treating cardiac illness is significantly higher for those patients who have depression. Yet, focus group participants noted, little has been done to integrate mental health care with specialty treatment. It appears to be limited to referral to mental health professionals or, in the hospital, to calling in consulting psychiatrists. Focus group participants suggested much more is possible, but they did not offer possible new models.

Linkages of Home Health and Mental Health Services

Home health care, focus group participants said, provides a significant opportunity for the identification of mental and addictive disorders, referral to mental health professionals (where they are available), and for humane interactions that can help to ameliorate anxiety and depression. Participants emphasized the importance of helping recipients of home health services to control behavioral problems. Home health workers, they said, generally need special training to learn how to provide screening, to make appropriate referrals, to provide humane interactions, and especially to manage difficult behavior.

Several focus group participants suggested that it would be useful to try to develop local systems to improve mental health treatment for home health recipients and to reduce the use of nursing homes. Such a system would include hospital discharge planners, home health providers, local health providers, local mental health providers, local senior centers and NORC-SSPs, etc.

Psychotherapy in Senior Centers and Other Community Settings

Focus group participants from senior centers, settlement houses, and other community settings where older adults go for meals, recreation, and assistance were all enthusiastic about having mental health professionals providing psychotherapy on-site in their programs. Many had had experience with such programs and believe that they work well despite some problems with stigma, which we have noted elsewhere.

There are several ways in which such services can be incorporated including:

- Satellites of mental health clinics or health clinics
- Visiting mental health professionals who bill privately
- Mental health professionals, especially clinical social workers, on the staff of the aging services program

Some focus group participants expressed concern that there is over-reliance on senior centers as sites where older adults can be reached, screened, and treated. They observed that senior centers currently serve at most 20% of the older adult population and that utilization may decline as a new generation ages.

One Stop Shopping Including Health and Mental Health Professionals

Most one-stop shopping service centers provide a broad range of services including recreation, nutrition, entitlements advocacy, housing search, etc. Some also include mental health and/or health services.

Many focus group participants like the idea of having centers where older adults can go for virtually all of their service needs, but in one focus group we heard an important cautionary tale. A center in Queens added a physician to their staff. After a while no one used the physician—because he/she was perceived as providing poor care.

Choice

From this and other stories we have concluded that it is absolutely critical when planning programs to keep in mind that clients make their own choices about whom they want to serve them. They may prefer "fragmented" care because they like particular service providers or because they like privacy. It is also critical to keep in mind that not all providers are equal. Simply designing a program with a physician and a mental health professional does not make it a desirable or desired program. It depends on who the actual people providing service are.

Network Development

At several focus groups during which participants complained about their clients' not being able to get access to services they needed, it became apparent that they had not done the most basic kind of network development—i.e. getting to know the people to whom they were making referrals. We discussed this observation in several focus groups, and participants noted a number of possible approaches to integrating providers within local neighborhoods. These included formal and informal approaches. Formal approaches are one variation or another of developing local "coalitions" and holding regular meetings to share information, provide training, discuss how to work together better, and/or to discuss very problematic cases. Informal approaches simply stress the importance of people from different programs and service systems getting to know each other over lunch, drinks, or even friendly telephone conversations.

INCREASE THE CAPACITY TO SERVE CULTURAL MINORITIES

As noted in the first section of this report, focus group participants repeatedly talked about the importance of cultural differences not just of minorities but also of special populations such as the deaf and hearing impaired and the lesbian, gay, bi-sexual, and transgender (LGBT) communities. The Geriatric Mental Health Alliance organized special workgroups on Asian and on Hispanic geriatric mental health. These workgroups developed recommendations regarding best practices and innovative opportunities. Therefore, in this report we provide just a few bullets about what emerged as service needs for cultural minorities. They include:

- Mental health services located in communities where minorities live
- Mental health services co-located in community service settings to which minorities commonly turn for help
- Extensive outreach into indigenous settings including religious settings
- Linkages with indigenous providers of help
- Provision of bi-lingual and bi-cultural staff
- Education for minorities about mental illness, about its treatment, and about where to go for help
- Training to develop cultural competence.

A common issue that emerged in the discussion groups is whether there need to be special settings for minorities and for the LGBT and deaf communities or whether they can be served in programs for people from different cultures and people of different ages. The consensus among focus group participants was that some people need special settings and some people are comfortable going to settings serving the general population.

PROVIDE SUPPORT FOR FAMILY CAREGIVERS

The need to support family caregivers applies to three different populations.

- Caregivers of older adults with mental and physical disabilities
- Older family members caring for adult children with mental disabilities
- Grandparents raising grandchildren.

Caregivers of Older Adults: Family members who provide care for older adults with mental and physical disabilities, focus group participants told us, are under tremendous stress both emotionally and financially. In some families a family member who does not work (usually a woman) takes primary responsibility for providing care, but often this person also has responsibilities for taking care of children and of maintaining the family household. In other families, family members are juggling all of this and paid work. To help families with these burdens, focus group participants suggested that a variety of services and supports should be available including:

- Affordable counseling at times and places that work for people whose days and nights are generally crowded with responsibilities
- Support groups, also at workable times and places
- Respite to enable caregivers to have time off for a little relaxation whether for an evening or even for a vacation
- More responsive crisis services
- Financial assistance in the form of tax credits or subsidy of home health care.

Older Family Members Caring for Adult Children with Mental Disabilities: Older family members providing care for their adult children with mental disabilities find it increasingly difficult to provide care as they age and become less capable of managing the multiple tasks caregiving requires. Many of these family caregivers, we learned from focus group participants, do not get support for themselves from either the mental health or the mental retardation systems. And in some cases, their adult children are also not getting services they could use.

Focus group participants suggested that both the mental health and the mental retardation systems should conduct outreach programs to reach these families and help them develop appropriate service plans. They also suggested that NAMI should reach out to the families of people with serious, long-term psychiatric disabilities.

Also, as previously noted, some mentally disabled adults try to care for their parents when they become disabled. Focus group participants who knew about the SPOP effort to help them perform this function thought that more efforts of this kind should be made.

Grandparents Caring for Grandchildren: Grandparents caring for grandchildren are also under tremendous stress and at high risk of developing depression and anxiety disorders. Like other family caregivers they need a mix of emotional and financial supports. Focus group participants suggested:

- Affordable counseling and treatment for grandparents and their grandchildren
- Support groups
- Respite

- More responsive crisis services
- Financial assistance to cover the cost of health and mental health care for both grandparents and their grandchildren
- Tax credits to subsidize some of the costs of raising children, for whom there is no obligation of support.

PROVIDE PUBLIC EDUCATION

The need for public education about mental illness arose in virtually every focus group. Participants noted repeatedly that most older adults, their families, their spiritual leaders, and even their primary care physicians are ignorant about mental and substance use disorders and their treatment. They share in the stigma about mental illness, which is pervasive in our society, and they are given to a form of ageism according to which mental disorders among the aging—especially depression and dementia—are regarded as a normal part of aging. Focus group participants could not have been clearer about the importance that they place on overcoming stigma, ageism, and ignorance about mental illness and its treatment.

Participants of focus groups were also very concerned about the difficulty they and the people they serve encounter trying to get information about resources including mental health treatment, housing options, elder law, etc.

Suggestions for public education included:

- Mass media campaigns including television advertising, posters in mass transportation, and the like
- Outreach to community organizations including houses of worship, senior centers, clubs, etc.
- Distribution of written materials in multiple languages
- Greater use of the internet to make information available
- Improved information and referral services.

Focus group participants were quite clear about the limits of each of these approaches. Affordable television advertising tends to occur when few people watch television. Posters in mass transportation cannot reach older adults who are essentially homebound. This is also true of outreach approaches that depend on going to places in the community. Written material, even in multiple languages, often goes unread. And internet-based information assumes that older adults have, and can use, computers. Still, each of these approaches, they believe, is useful to some portion of the older population and their families.

Information and referral raised a particular concern—the absence of a comprehensive service in the NYC area. Focus group participants noted that there are a number of good information and referral services—both telephonic and internet-based—such as 1-800-LifeNet and Cornellcares.com. But they also noted that each appears to have limited information and that there is no "one-stop" information service regarding the needs of older adults and their families. The development of such a comprehensive information and referral service was seen as of enormous potential value.

WORKFORCE DEVELOPMENT

All focus group participants were concerned about current and prospective problems with the workforce serving older adults with mental health problems. Their concerns include numbers of workers and their clinical and cultural competence. To address these concerns focus group participants pointed to three types of actions that are needed:

- Attracting and retaining larger numbers of mental health, health, and aging personnel who are trained to work with older adults with mental, behavioral, and addictive disorders
- Improving the clinical and cultural competence of mental health, health, and aging personnel
- Developing new paraprofessional and volunteer roles that can be fulfilled by older adults themselves under the supervision of professionals.

Attracting Staff: To attract more staff to work with older adults, focus group participants suggested:

- Providing incentives to become geriatric mental health, health, and social service professionals, especially for people who are bilingual and bicultural. This could include providing scholarships, loan forgiveness, higher compensation, and career ladders.
- Building a better image about working with older adults

- Working with professional schools of medicine, nursing, social work, and psychology to provide better general education about geriatrics and to provide more specialized courses on geriatrics, all emphasizing state-of-the-art practices
- Providing mentors for students who show an interest in working with older adults. Mature professionals would pair with students and provide them with advice, work experience, networking contacts, and access to good jobs.

Improving the Clinical and Cultural Competence of Staff: Focus group participants emphasized the need for programs to promote the use of state-of-the-art practices, especially evidence-based practices, and for programs that promote cultural competence.

They also recommended the development of widespread training programs for mental health, health, and aging services personnel as well as clergy and others to whom older adults are likely to turn for help.

Innovative Use of Paraprofessionals and Volunteers, Especially Older Adults: Focus groups all were concerned about how there can possibly be a large enough workforce to serve the baby boomers as they age. There are not enough now, and the working age population will shrink as a percentage of the overall population as the population of older adults doubles. But focus group participants also noted that most older adults are under the age of 75, are healthy, and are able to work. They could be mobilized into an important part of the workforce of the future playing such roles as:

- Friendly visitors
- Telephone support
- Respite
- Peer counselors
- Home health workers
- Outreach workers
- Community educators
- Peer advocates
- Peer case managers
- Peer bridgers
- Peer medical case managers
- Food service
- Activities program management
- Administrators
- Etc.

Older adults could also be trained as professionals.

RESEARCH AND RAPID TRANSLATION OF RESEARCH INTO PRACTICE

Many focus group participants noted that there still is much to learn about how to effectively treat older adults with mental and addictive disorders and that increased research on geriatric mental health is needed to develop techniques that will reduce mental, behavioral, and addictive disorders. It is also became clear that the current research agenda—which is dominated by depression and dementia—is too limited. Research about such conditions as paranoia that influence being able to live in the community need much more attention.

Part 4: Barriers to Meeting the Mental Health Needs of Older Adults

As the prior section hopefully makes clear, focus group participants had a great many ideas about how to improve services and supports to meet the mental health needs of older adults and their families. Many of the services recommended already exist but are in very limited supply. Some recommendations are for promising innovations.

In order to get some insight into what the barriers are to providing services focus group participants think are best, we asked why they were not providing the services they thought would be so useful. Although we spent relatively little time on this question in most of the focus groups, a number of important observations emerged. These observations fell into three broad categories: (1) financing problems, (2) systems fragmentation, and (3) workforce shortages. (In this document we include only those barriers that were discussed in focus groups. There are other barriers, which we discuss in a document devoted to barriers. The document can be found at http://www.mhaofnyc.org/gmhany/BarriersReport12_2008.pdf

FINANCIAL BARRIERS

There are two fundamental kinds of financial barriers to providing the kinds of services that focus group members thought would be best. Most focus group participants believe that there is **not enough money** available to develop needed programs, but some believe that there would be enough money if it were allocated more rationally.

In addition, focus group participants noted a number of ways in which **limits on the use of available funds** interfered with providing needed services.

Ignorance of Financing Opportunities: It is important to note that focus group participants were not always correct regarding limits on the availability of, or limits on the use of, funding for services. For example in one focus group, a participant maintained that her organization could not bill Medicare unless the co-pay was collected. She was sitting next to the head of another organization, which was billing Medicare without any problems because they make a good faith effort to collect co-pays using a sliding fee scale . During that same focus group, a social worker from a Y said that they could not bill for clinical services that they provide. Other participants in the focus group told them what to do so that they could bill Medicare. It turned out that their organization was reluctant to bill for services because providing clinical services ran counter to its culture

Ignorance about what is reimbursable and how to bill appears to be a major barrier to funding geriatric mental health services. We believe that there are untapped opportunities to use Medicare to fund treatment services in home and community settings.

Medicare: Virtually all older adults in the United States are eligible for Medicare, which pays for mental health services, and Medicare is an entitlement through which all reimbursable services for eligible individuals are covered no matter how much the total cost. Nevertheless, focus group participants noted a number of very significant restrictions on Medicare funding.

- Co-pays are 50% (compared to 20% for physical health services). As a result co-pays are more likely to be unaffordable for mental health services. (In 2008 federal law changed to provide parity in Medicare, which will phase in over 4 years beginning in 2010.)
- Medicare will only pay providers who have enrolled as a Medicare provider and agreed to limit their charges to below market rates. Many providers (especially geriatric psychiatrists) can get much higher rates from patients who pay for themselves; therefore, providers who are in high demand often drop out of Medicare and serve only wealthy people.
- Medicare does not cover case management.
- Medicare covers transportation costs only in an emergency.

In general, focus group participants observed, Medicare uses a medical model and pays a discrete rate for discrete medical services—psychotherapy session, medication monitoring visit, etc. It does not pay for the organization of packages of services and supports that are often necessary to help people with mental disorders to live in the community rather than to be moved to institutions.

Medicaid: Focus group participants generally regard Medicaid as a better funding source for services to meet the mental health needs of older adults because it covers a broader range of services. But Medicaid, they told us, created a variety of obstacles.

- It is only helpful to those who are eligible for Medicaid, a relatively small proportion of older adults. (23%)
- As NYS has shifted away from program budget ("deficit") financing to Medicaid so as to increase the federal share of mental health funding and to decrease state and local shares, providers have been forced to look for clients/patients who are Medicaid eligible to the neglect of those who are not.
- Although Medicaid permits unlimited home-based services, it does not pay a higher rate, which creates a de facto disincentive to serve older adults in their homes.
- Medicaid permits a limited number of "off-site" services, i.e. services outside a clinic site. But when visits are made regularly to a community setting such as a senior center, the clinic must formally establish a satellite, a difficult process designed to slow program expansion, according to many focus group participants.*
- Program development is limited by what is known as "Medicaid neutrality", which requires that the state decide to allow increased Medicaid expenditures before a new program is started. (This regulation was dropped in 2008.)
- The growth of Medicaid managed care has created some problems, especially regarding inpatient care. Not only are managed care entities often reluctant to authorize a hospital stay, they also do not contract with all local hospitals.
- Medicaid covers mental health services provided in health clinics and health services in mental health clinics to a very limited extent, effectively blocking major opportunities to integrate health and mental health services. (This was changed in 2008.)
- Medicaid pays very low fees to clinicians in private practice, which has effectively eliminated their availability to serve people who often cannot get service in overloaded clinics.
- Rules regarding Medicaid funding for nursing homes make it virtually impossible for nursing homes to provide adequate social work services.
- They also make it difficult to provide nursing home residents the most up-to-date medications.

Aging Services Funding: Focus group participants generally agreed that some aging services could be more responsive to the mental health needs of older adults—if it were possible to pay higher salaries and reduce caseloads for professional staff and to provide more training. For example, there are case management positions in senior centers, which, if filled by clinical social workers, could provide needed mental health services. But salaries are set at paraprofessional levels and caseloads are high. Only those organizations able to raise philanthropic funds have been able to upgrade these positions. Similarly there are case managers who work with people in their homes in an effort to help them remain in the community. But focus group participants told us, they too are underpaid, overloaded paraprofessionals.

Grants: Focus group participants told us that their best and most innovative services are supported by time-limited philanthropic and/or government grants. They told us that they are very appreciative of these funding opportunities, but they often are not able to continue to operate grant funded programs because they do not have continued operating support. Philanthropic organizations, they noted, often will not give grants unless there is reason to believe that they are sustainable after the foundation removes support. This, of course, substantially limits experimentation with new service models that require new sources and methods of finance.

* Representatives of the NYS Office of Mental Health said that this perception is out-of-date and that satellites can now be established fairly easily.

SYSTEMS FRAGMENTATION

Focus groups revealed significant problems of fragmentation both among the components of the public service systems and between public and private service sectors.

Fragmentation of Public Service Systems: Throughout our focus group discussions the importance of integrating mental health, substance abuse, health, and aging services was entirely clear. But it was also clear that these systems of care have very little overlap in fact. Yes, there are examples of cross-system integration, such as the operation of satellite mental health clinics, depression screenings, and mental health education in senior centers. And Oneida County has integrated its county departments of aging and mental health. But by and large focus group participants indicated that they didn't know much about service programs outside their own service system and that they did not know the people who worked in other service systems, even though they frequently made referrals back and forth. In addition, the focus groups made clear that each of the service systems had its own set of goals, practices, regulations, funding structures, etc. As has become popular over the past decade or so, focus group participants spoke of the systems as "silos" and said that the silos needed to be broken down. Although we find the metaphor a bit puzzling—are we talking about grain silos or silos of nuclear weapons?—it was clear that there is a powerful and pervasive view that the service systems are fragmented and that this interferes with developing ways of pooling funding across systems, of developing comprehensive service packages for people, and of developing ways to integrate practice.

Fragmentation within the Mental Health System: Focus group discussions confirmed observations that have been made for years about the fragmentation of the mental health system itself. The system is structured around discrete service programs. Each type of program is governed by a specific set of rules regarding eligibility, service, and funding. Inpatient providers, day programs, housing providers, clinics, private practitioners, etc. each do what they do without adequate coordination of care or clear responsibility for service recipients.

At our focus group with Gouverneur Health Care Services, we learned of a particularly unfortunate example of the problem of fragmentation. Gouverneur operates a number of different mental health programs, which serve an ethnically diverse population of adults of all ages. No one of them includes a full range of services or the full range of languages spoken by its polyglot clientele. As a result someone may be admitted to the clinic but need a service or language only available in the continuing day treatment program or vice versa. Participants in this focus group believed strongly that they could provide services much more effectively, and with a lot less paperwork, if their clients were simply admitted to their outpatient center and got the services they need without regard to artificial program categories.

Fragmentation between Public and Private Service Sectors: Almost all of the participants in our focus groups were from the public service sector. But a few also had their own private practices as therapists or elder care managers. This led us to develop a sense of a deep schism between the public and private sectors, both with regard to the possibility of working together and with regard to the nature of thinking about service.

It is exceedingly difficult to develop cooperative working relationships between say a mental health housing provider and a community health agency. It is almost impossible to develop working relationships between a provider—such as a senior center, a NORC-SSP, a home health provider, or a mental health clinic—serving a group of people and the physicians and/or mental health professionals who treat them privately. Yet many older adults prefer to have a physician in private practice or to see a psychotherapist privately. How to engage them in collaborative service plans is a great challenge.

The emergence of elder care managers, who coordinate care, is a potential solution to this problem, but only for those who can afford to hire them.

In addition, it is extremely difficult—perhaps impossible—to engage people in private practice in processes of community planning. They generally do not think of this as part of their professional responsibility, and they do not have time to attend meetings—except those that generate business—because it entails loss of income for them personally.

WORKFORCE PROBLEMS

A major barrier to providing needed services, workgroup participants repeatedly told us, is the shortage of people who want to, and are qualified to, provide services for older adults. As previously noted, this includes shortages of clinically and culturally competent geriatric mental health, health, and social services professionals. It also includes shortages of appropriately trained paraprofessional staff in virtually all settings where older adults are served. And it includes shortages of staff who have been trained to understand the workings of all the major systems of care for older adults.

Conclusion: Opportunities for Improvement

Although we know that this report must seem impossibly long and excessively detailed, we also know that it doesn't do full justice to the richness of the discussions in the focus groups themselves. We are sure that it is hard to believe, but in fact we have left out some very interesting material.

We hope that what we have summarized here provides a sense of the vast number of opportunities there are to improve services and supports for older adults with mental health problems.

These include:

- **Prevention of the use of nursing and adult homes** through the provision of better management of mental and behavioral disorders and enhanced family support in the community

- **Reconfiguring the community support system** that has been developed for adults with long-term psychiatric disabilities to meet the needs of older adults, including
  - — Increased and reconfigured community housing programs
  - — Improved health care and health maintenance activities
  - — New approaches to psychiatric rehabilitation
  - — Increased support for older adults caring for their adult children with serious, long-term psychiatric disabilities
  - — Increased attention to end-of-life care

- **Improved access** to mental health services through
  - — Service expansion
  - — Increased transportation
  - — Mobile services to homes and community settings
  - — Enhanced cultural competence
  - — Increased affordability

- **Enhanced quality of care in the community** through
  - — Dissemination of state-of-the art practices
  - — Widespread use of screening instruments to flag possible mental disorders
  - — Enhanced suicide prevention efforts
  - — Improved emergency and crisis services
  - — The development of addiction services responsive to the substance abuse problems of older adults
  - — Training regarding geriatric mental health for mental health, health, and aging services workers
  - — Enhanced case management and more widespread use of elder care managers
  - — Enhanced elder abuse and domestic violence services
  - — Upgrading and reducing caseloads for adult protective services workers
  - — Linkages between spiritual care and other services for older adults
  - — Using Naturally Occurring Retirement Community Supportive Service Programs as the hub of service provision in the community.
  - — Preventive interventions to counter social isolation and adverse reactions to the developmental challenges of aging.

- **Enhanced quality of care in institutions** through
  - Providing living arrangements that allow residents personal dignity and choice
  - Routine screening for mental disorders
  - Use of mental health professionals well-trained in geriatric mental health and integrated into the life of the facility
  - Manageable caseloads for social workers
  - Training for all levels of staff, including administrative personnel, regarding mental and behavioral disorders
  - Enhanced advocacy for residents
  - More effective enforcement of regulations in adult homes
  - Improved living conditions in adult homes such as air conditioning

- **Integration of health, mental health, and aging services** including
  - Integrating primary and specialty health care and mental health
  - Linking home health and mental health services
  - Linking aging and mental health services
  - "One-stop shopping" including on-site mental health and health services
  - Development of formal and informal local service networks including private practitioners as well as service organizations

- **Increased capacity to serve cultural minorities** through
  - Location of mental health services in communities where minorities live
  - Co-location of mental health services in indigenous community service settings
  - Extensive outreach into indigenous settings including religious settings
  - Provision of bi-lingual and bi-cultural staff
  - Mental health education for minorities
  - Training to develop cultural competence

- **Increased family support** through
  - Affordable counseling
  - Support groups
  - Respite
  - More responsive crisis services
  - Linkages between family support organizations (such as NAMI) and organizations serving older adults (such as NORC-SSPs)
  - Financial assistance through tax credits or subsidies of health and long-term care insurance

- **Public education** through
  - Mass media campaigns
  - Outreach to community organizations
  - Distribution of written materials in multiple languages
  - Greater use of the internet to make information available
  - Improved information and referral services, especially development of a "one-stop" service addressing all concerns regarding aging

- **Workforce development** including
  - Attracting and retaining larger numbers of mental health, health, and aging personnel
  - Improving the clinical and cultural competence of mental health, health, and aging personnel
  - Developing new paraprofessional and volunteer roles especially for older adults

- **Research and rapid translation of research into practice** especially through partnerships between research and provider organizations

- **New finance models** including
  - — Funding of comprehensive service packages
  - — Pooled funding across service systems
  - — Medicare optimization
  - — Reforms of Medicare, Medicaid, and other public funding streams
  - — Establishing funding sources for services to immigrants

List of Focus Groups

- Leaders of senior centers and case management programs which are members of the Council of Senior Centers and Services (CSCS)
- Leaders of senior centers, aging services, and mental health services which are members of United Neighborhood Houses (UNH)
- Leaders of social services programs in "naturally occurring retirement communities" (NORC-SSPs)
- Nurses of (NORC-SSPs)
- Leaders of home-based services programs operated by the Visiting Nurse Services of New York (VNS)
- Staff from supportive housing programs which are members of the Supportive Housing Network (SHN)
- Members of the Queens Geriatric Mental Health Committee
- Staff from a mental health clinic operated by FEGS which serves primarily older, Russian immigrants
- Participants in the annual conference of the New York Association of Psychiatric Rehabilitation Services (NYAPRS)
- Residents of an adult home
- UJA Federation providers working with older adults
- Service providers associated with the Weill/Cornell School of Medicine
- Staff from NY Service Program for Older People (SPOP)
- Providers of Gouverneur Health Facilities
- Housing providers who are members of the Association for Community Living (ACL)
- Providers of the New York State Adult Day Services Association (NYSADSA)
- Participants in the annual New York State Area Agencies on Aging Conference
- Participants in the NYC Dept. for the Aging Conference on Integrating Mental Health, Health, and Aging Services
- Participants in the Westchester Mini-White House Conference on Integrating Health and Mental Health
- Volunteers with the Long Term Care Ombudsman Program in Westchester
- Members of a Psychosocial Rehab Program for Adults with Severe and Persistent Mental Illness
- Members of the Healthcare Association of New York State (HANYS)
- Members of Region 7 Adult Day Health Care Council
- Members of New York Association for Homes and Services for the Aging (NYAHSA)

List of Focus Group Participants

Leaders of senior centers and case management programs which are members of the Council of Senior Centers and Services

Naomi Altman
SADS Caregiver Service

Rose Marie Borg
Sunnyside Community Services Home Care and Adult Day Services

Donna Corrado
Catholic Charities

Cheryl Glenn
Brooks Senior Center

Rhonda Grand
Special Services for Senior Citizens

Joanne Gray
Stanley M. Issacs Neighborhood Center

Cheryl Kamen

Hudson Guild
Stavroula Joannidis
HANAC Inc.

Linda Leest
Services Now for Older Adults (SNAP)

Nikki Odlivak-Wright
Community Agency for Senior Citizens (CASC)

Eileen Resnick
Project SOS, Bronx Community College

Bill Weber
Jewish Association for Services for the Aged (JASA)

Judy Willig
Heights and Hill Community Council
Kathleen Zvarych
CSCS

Leaders of senior centers, aging services, and mental health services which are members of United Neighborhood Houses

Houika Ablin
Greenwich House Senior Citizens Health and Consultation Center

Martha Bruce
Weill-Cornell School of Medicine

Michele Buono
Goddard Riverside Community Center

Diana Cruz
Sunnyside Community Services Senior Center

Rose Dobrof
Brookdale Center on Aging of Hunter College

Janet Fischer
Henry Street Settlement

Cheryl Fuller
Educational Alliance

Aileen Gitelson
JASA

Melissa Gorton
Hamilton-Madison House

Nancy Harvey
SPOP

Cheryl Kamen
Hudson Guild

Marina Kaneti
Hamilton-Madison House

Susan Kingsland
University Settlement Society

Jenny Lopez
Henry Street Settlement – NORC

Rebecca Mushkin
Lenox Hill Neighborhood House

Elizabeth Olofson
Guttman Foundation

Eriko Teutsch
Goddard Riverside Community Center

Robert Tobing
University Settlement Society

Chung Wai
Chinese American Planning Council

Jessica Walker
United Neighborhood Houses

Barbara Zeni
NYC Dept for the Aging

Leaders of social services programs in "naturally occurring retirement communities" (NORC-SSPs)

Sherba Austin
Rochdale Village Social Services, Inc.

Dena Bock
Alliance Volunteer

Kay Boonshoft
Parkchester Enhancement Program (PEP) for Seniors

Amy Chalfy
JASA

Willing Chin-Ma
Grand Street Settlement

Barbara Chocky
Spring Creek Senior Partners

Jennifer Cinelli
Big Six Towers NORC

Catherine Cronin
Hamilton-Madison House
Knickerbocker Village Senior Center NORC

Darlene Dindial
NORC-WOW

Bonnie Errico
Co-op Village Senior Care

Evelyn Gottlieb
Forest Hills Co-Op NORC

Gayle Kolidas
Deepdale CARES

Risa Liskov
Amalgamated/ Park Reservoir NORC

Lynn Millheiser
Phipps NORC

Patricia Palmer
Sheepshead Nostrand Supportive Services Program

Rebecca Robinson
West Side NORC

Josephine Roman
Phipps Plaza West NORC Program

Karin Stieber
Warbasse Cares for Seniors

Fredda Vladeck
United Hospital Fund

Jessica Walker
United Neighborhood Houses

Nurses of NORC-SSPs

Dale Chaikin
NORC-WOW

Inna Feyman
Visiting Nurse Service of New York

Pamela Hayes
Visiting Nurse Service of New York

Jung Ja Hong
Pelham Parkway House NORC Program

Pamela Kalmanson
Spring Creek Senior Partners

Rachelle Kammer
MHA of NYC

Jane Linker
Public Relations Consulting

Marie Phillips
Morningside Retirement and Health Services

Helen Roman-Bruzese
Jewish Home and Hospital

Leaders of home-based services programs operated by the Visiting Nurse Services of New York (VNS)

Mary Beaudet
Acute Care

Eileen Campbell
Bronx Regional Administrator

Marki Flannery
Partners in Care

James Garafalo
Brooklyn Acute Care Region

Ron Goralewicz
Adult Mental Health Service

Regina Hawkey
Congregate Care Program

Leila Laitman, M.D.
In-Home Geriatric Mental Health Program

Katherine Levine
Bronx Borough Director

Florence Marc-Charles
Long Term Home Health Care Program

Rebecca Morales
Geriatric Mental Health/Mobile Crisis Unit

Andresa Person
AIDS Services

Neil Pessin
Community Mental Health Services

Rayna Taylor
VNS Choice

Linda Wayne
Manhattan Geriatric Outreach

Jacklynn Williams
Manhattan Community Mental Health

Staff from supportive housing programs which are members of the Supportive Housing Network

Tom Alexander
Jasmine Court

Dena Bock
Alliance Volunteer

Tricia Dawson
Catholic Charities

Yusselffy Denize
Amber Hall

Amy Glover
Supportive Housing Network

Michael Golub
Supportive Housing Network

Jonathan Margolies
Aurora Residences ACTORS Fund

Jeannette Vega
CIDR

Linda Whittle
Jericho Project

Lorraine Wynne
Caring Communities

Members of the Queens Geriatric Mental Health Committee

Adeline Brand
Community Advisory Program for the Elderly (CAPE)

Ravinder Dhillon
Creedmore Psychiatric Center

Katia Fernandez
New York Urban League

Shirley Fischer
CAPE

Shashana Garber
Pride of Judea

Yvonne Gelbord
NORC-WOW Program of
Samuel Field Y

Betty Hankin
CAPE

Joan Serrano Laufer
Queensboro Council for Social Welfare

Karen LoPresti
Club Pride – Jewish Board of Family and Children Services (JBFCS)

Susan Melchion
Hillside Geriatric Center

Barbara Perkin
CAPE

Maureen Rizzo
SAVOY of Little Neck

Phyllis Schwartz
Deepdale Care NORC

Maggie Silver
Senior Support Solutions

Arezoo Termechi
Builders for the Family and Youth

Christine Washington
Jamaica Service Program for Older Adults (JSPOA)
Friendship Center

Staff from a mental health clinic operated by FEGS which serves primarily older, Russian immigrants

Alla Bazay
Brooklyn Resource Center
FEGS

Amy Dorin
FEGS

Dalia Glauberson
Brooklyn Resource Center
FEGS

Nina Kononchuk
Brooklyn Resource Center
FEGS

Teri Messina
Brooklyn Resource Center
FEGS

Dina Trakhtenberg
Brooklyn Resource Center
FEGS

Participants in the annual conference of the New York Association of Psychiatric Rehabilitation Services (NYAPRS)

28 Participants (we do not have a list of the names)

Residents of an adult home (first names only to protect confidentiality)

Alvin
Ernestine
Erwin
Fredda
Gilbert
Harry
John
Kristin
Merrill
Phil
Ruth
Sam
Sin Fan Yuen
Tanya
Wendy

Geoff Lieberman
Coalition of Institutionalized Aged and Disabled (CIAD)

Rebecca Wulf
Coney Island CSS - JBFCS

UJA Federation providers working with older adults

Jane Bardavid
CAPE

Lisa Bennet
JCC of the Greater Five Towns

Becky Bigio
Selfhelp

Alan Cohen
UJA Federation

Stephanie Dickstein
JBFCS

Richard Gersh
JBFCS

Rick Greenberg
JBFCS

Judith Gordon
JASA

Alene Hokenstad
United Hospital Fund

Nelly Katsnelson, MD
Montefiore Medical Center

Roy Laird
FEGS

Rita Landberg
JBFCS

Paula Marcus, MD
Montefiore Medical Center

Alessandra Scalnati, MD
Montefiore Medical Center

Lisa Stern
JCC of the Greater Five Towns

Beth Zeidel
Selfhelp

Service providers associated with the Weill/Cornell School of Medicine

Risa Breckman
Weill Medical

Margery Elson
Memorial Sloan Kettering

Rhoda Meador
Cornell Institute for Translational Research on Aging (CITRA)

Harriet Mischel
Clinical Psychologist

Deirdre Mole
The Wright Center on Aging

Ken Onaitis
Burden Center on Aging

Donna Rosenstiel
The Wright Center on Aging

Amy Stern
New York Presbyterian Hospital

Elaine Wethington, Ph.D.
Cornell University

Staff from NY Service Program for Older People (SPOP)

Andrew Beecher
Clinic

Amy Berg
Adult Day Services

Carola Chase
Clinic

Ken Cooper
Adult Day Services

Barbara Danish
Widowed Persons Service

Nancy Harvey
Executive Director

Tara Isserman
Adult Day Services

Maryann Kenney
Clinic Director

Lauren Taylor
Clinic

Providers of Gouverneur Health Care Services

Judith Birch
Nursing and Adult Child Behavioral Health

Judith Blanshard
Older Adult Clinic

Peggy Coaxum
Nursing and Adult Child Behavioral Health

Solangel Griffith
Coordinating Manager

Griselda Kelin
Senior Community Liaison Worker

Mary Palmer-Rosa
Head Nurse

Edgar Velazquez, M.D
Behavioral Health

Diana Marsi
Intern

Housing providers who are members of the Association for Community Living (ACL)

Diana Andres
Mercy Haven

Kate Burns
Project Renewal

C. Castoire
Unique People Services

Vincent Cipriano
Project Renewal

Doug Cooper
ACL

Catherine Coppolino
The Educational Alliance

Joan Douglas
Heritage Housing

Leslie Goldberg
JSI

Tony Guarino
GEEL Community Services

Cynthia Isaac
Unique People Services

Carol Lashley
MTI Residential Services

Nicole Lewis
The Association for Rehabilitative Case Management and Housing (ACMH)

Erie Lusterman
JSI

Erika Maximo
Supported Housing Bronx

Michele Miller
Beacon of Hope

Jim Mutton
Project Renewal

Craig Retchless
The Bridge

Amy Schneider
Odyssey House

Tracy Sherman
Bowery Residents Committee

Sandy Stocker
Fountain House

Serge Toitchin
Heritage Housing

Arnie Unterbach
Odyssey House

Marjorie Walters
Heritage Housing

Claudette Williams
Heritage Housing

Calvin Williamson
Unique People Services

James Woods
Heritage Housing

Michael Zuriff
The Bridge

Providers of the New York State Social Adult Day Services Association (NYSADSA)

Phillip Bentley
NYSADSA

Miriam Burns
Selfhelp Community Center

Rebecca Carel
Fort Washington Houses Services Elderly

Susan Holodak
ADHCP Jewish Home

Iris Hudis
VIP Health Care Services

JoAnn Mason
Isaacs Stanley

Antonette Mentor
Day Care – Jewish Home and Hospital

Ann Michitsch
Ridgewood Bushwick Senior Citizens Council (RBSCC)
Respite Care Program

Marianne Nicolosi
Park Slope Geriatric Day Center

Deborah Stricoff
VNS Choice Adult Day Center

Participants in the annual New York State Area Agencies on Aging Conference

Participants in the NYC DFTA Conference on Integrating Mental Health, Health, and Aging Services

Antonio Almoguerra Abad, M.D.
Bellevue Medical Center

Judy Birch
Gouverneur Health Care Services

Antoinette Emers
Food Change

Paul Feuerstein
Barrier Free Living

Janet Fischer
Henry Street Settlement

Bob Goldblatt
MHA of NYC

Clair Hall
The National Caucus and Center on Black Aged – NYC Chapter

Terry Kaelber
Senior Action in a Gay Environment (SAGE)

Maxine Metersky
Visiting Nurse Service of New York

Joanna Miller
Wurzweiler School of Social Work

Catherine Patrin
Hamilton-Madison House

Beth Stubenbold
Fountain House

Fredda Vladeck
United Hospital Fund

Pia Roper
Murray Hill SRO

Carolyn Wolfe
VISIONS/Services for the Blind and Visually Impaired

David Nardacci
Gouverneur Health Care Services

Pearl
Gouverneur Health Care Services

Yolanda Bruno
Coler/Goldwater Specialty Hosp. & Nursing Facility

Participants in the Westchester Mini-White House Conference on Integrating Health and Mental Health

Jennifer Brennan
MHA of Westchester

Donna Bucci
Maple House

Marlene Cartaina
National Alliance for the Mentally Ill (NAMI)

Yemaja Jubilee
Doles Senior Program

Margaret Manousoff
Hofstra Law / My Sisters' Place

Miki Mardit
Montrose VA

Diane Neff
Sarah Lawrence College

Carla Quail
MHA of Westchester

Mariann Russell
Caretaker

John Sullivan
Fordham University

Volunteers with the Long Term Care Ombudsman Program in Westchester (first names only to protect confidentiality)

Bert
Cynthia
Eunice
Felicia
Frank
George
Joe
Josephine
Lorraine
Lotti
Margaret
Maria
Marilyn
Martina
Patricia
Rena
Ron
Richard
Rosalie

Members of a Psychosocial Rehab Program for Adults with Severe and Persistent Mental Illness (first names only to protect confidentiality)

Al
Carlos
Cynthia
Danin
Debbie
JC
Kirby
Leccio
Robbin
Ron
Sunshine

Sean Pica
Community Access

Members of the Healthcare Association of New York State (HANYS)

Diane Ashley
Rochester Regional Healthcare Association

Eric Garfinkel, Ph.D.
St. Cabrini Nursing Home

John Graziadei
Samaritan Hospital

Janice Korenblatt
Montefiore Medical Center Home Health Agency

Carol Podgorski
Strong Memorial Hospital

JoAnn Wolcott
Rome Memorial Hospital

Members of Region 7 Adult Day Health Care Council

Carolyn Andrews
Beth Abraham Adult Day Health Care Center

Lucille Bowen
GuildCare

Lois Cartica
Cabrini Adult Day Health Services (Westchester and Manhattan)

Twila Evanson
Brooklyn United Methodist Church Home Adult Day Health Center

Jack Friedman
Palm Gardens Adult Day Health Center

Betsey Hochhauser
Adult Day Services Program of Westchester and the Bronx (Hebrew Home and Hospital)

Phyllis Howard
Ludington Adult Day Health Services

Toni Levato
Providence Rest Adult Day Health Center

Sheila Merolla
Village Adult Day Health Center

Patricia Rincon
Isabella Geriatric Center Adult Day Health Care

Josephine Tramontana
Sunrise Adult Day Health Center

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