THE CENTER FOR POLICY, ADVOCACY, AND EDUCATION
OF THE MENTAL HEALTH ASSOCIATION OF NEW YORK CITY

SPEAK OUT!

A GUIDE TO ADVOCACY FOR IMPROVED MENTAL HEALTH POLICY

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Dedicated To Improving Mental Health Policy

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CHAPTER ONE

WHAT IS MENTAL HEALTH ADVOCACY?

Who Is This Handbook For?

- This handbook is designed for people who care about mental health and about people who have mental illnesses or psychiatric disabilities, including children, adolescents, and adults of all ages.

- I will use a number of different terms to refer to this population--most often "people with mental illnesses", "people with psychiatric disabilities", and "children and adolescents with serious emotional disturbances", but also "people with mental health problems", "consumers", "recipients", "people with serious and persistent mental illnesses", "person diagnosed with mental illness", etc. Some of the language I use may be controversial. I apologize in advance to anyone who is insulted by my choice of language.

The Value of Speaking Out

- **People who care about mental health can be and have been powerful forces in moving the mental health system in progressive directions.**

- **This includes people with histories in the mental health system--both people with mental illnesses and their families.**

- **It includes concerned citizens.**

- **It includes mental health professionals.**

- **It includes professional mental health advocates.**

- **All people who care about mental health have important stories to tell and information to provide to policy makers.**

- **Public officials--especially elected officials--like to hear directly from the people their decisions will affect.**

Advocacy Regarding Mental Health Policy

- This handbook is about advocacy for changes in the mental health system. This handbook is not about how to advocate for individuals on a case-by-case basis.

- Advocacy for individuals is very important work, but is an art of its own. It focuses on helping people get what they need and want from systems as they are currently structured.

- Systems advocacy is based on the realization that some people cannot get what they need from systems as they are currently structured and that helping them therefore requires working for changes in public policy.

- You and the organizations you are part of need to decide what changes you think are important. Better access to better treatment, better places to live, more opportunities to work, more peer-run

programs, greater respect for people's rights, equal health insurance coverage for mental health, etc. Mental health advocates have identified many needed changes in the mental health system.

- Trying to persuade government or the private sector to make changes in mental health policy so as to help achieve these goals is the kind of advocacy that this handbook is about.

What Is Mental Health Policy?

- Mental health policy consists of laws, regulations, plans, program models, licensing standards, budgets, financing models, organizational policies and procedures, etc.

- These elements of policy are derived from broad visions of the role of society in helping people with mental health problems. For example until the mid-20th century, public mental health policy was institution-based. For the past 50 years, it has been based on a vision of people with mental illnesses leading free and satisfying lives in the community.

Who Makes Mental Health Policy?

- Public mental health policy is made by legislatures, by elected chief executives such as the President, governors, and mayors, by their appointees such as commissioners, and by the courts.

- Some mental health policy is made by the private sector. For example, in the U.S., most people's health benefits are provided by their employers, who decide whether and to what extent to provide mental health coverage.

Why Change Mental Health Policy?

- Most people who are familiar with the mental health system believe that it is inadequate in some important ways. Even people who believe that NYS's mental health system is one of the best in the United States realize that it could be better. In recent years the greatest concerns have related to (1) the failure to reach people diagnosed with mental illnesses who reject traditional treatment, (2) inadequate services for children and adolescents with serious emotional disturbances, (3) lack of readiness for the elder boom, (4) lack of adequate housing, (5) obstacles to work, (6) issues of coercion, (7) access to treatment and medication, and (8) mental health insurance coverage. There are, of course, many other issues.

How To Change Mental Health Policy: The Framework for This Handbook

- You need to **work in advocacy groups to be effective.**

- Effective **advocacy requires planning**.

- A sound advocacy plan rests on **a good assessment** of need, policy, history, cost, and politics.

- A sound advocacy plan has three parts: an **agenda**, a **strategy**, and **tactics**.

- The **agenda** consists of your advocacy goals. Perhaps what you think is important is better access to better treatment, decent housing, family support, access to work for people with psychiatric disabilities, and adequate insurance coverage for mental health treatment. Your "agenda" would include those goals. These are just examples, of course. You may think that other goals are equally important or more important.

- The **strategy** identifies what private or public organizations and officials you are going to try to reach in order to bring about the changes that you want to achieve. It is based on an analysis of who has the power to achieve your goals, of who can influence those with power, and of what will persuade them to do what you want them to. Usually there is more than one person or organization with the power to do what you want. Your strategy is your selection of which point(s) of power to focus your efforts on, your sense of what will motivate them to change policy, and your selection of advocacy partners.

- **Tactics** are the methods that you use to carry out your strategy and to achieve your goals. Once you know what you want to achieve and decide which powers-that-be you want to reach and what you think will motivate them, you need to develop a detailed plan about how to carry out your strategy. Will you organize a letter writing campaign? Will you seek a face-to-face meeting? Will you demonstrate? Will you try to get headlines? These specific actions constitute your "tactics."

- Planning must lead to action, and sometimes action cannot wait for a refined plan.

ADVOCACY IS ACTION

WHAT CAN YOU DO?

Register to vote and vote.

Contact your elected and appointed public officials.

Join an advocacy or an advisory group.

Make a financial contribution to an advocacy group.

Participate in actions organized by an advocacy group such as letter writing or attending lobby days.

Work and provide leadership for an advocacy group.

ADVOCACY PLANNING

ASSESSMENT:

What is the need? The problem?
What is the current policy?
What is the history of the policy and of advocacy to change it?
What is the political context?
How much will the desired change cost?

AGENDA:

What are your goals?

STRATEGY:

Who has power?
Who has influence?
What will motivate them to change policy?
Who can be good advocacy partners?

TACTICS:

How will you persuade the powers-that-be to change policy?
Lobbying?
Public education?
Demonstrations?
Social Defiance?

CHAPTER TWO

ADVOCACY GROUPS

ADVOCACY IS MOST EFFECTIVE IN GROUPS

Why Advocacy Depends on Working in Groups

- On rare occasions, individuals working alone have been able to capture public attention and persuade public officials to make changes in policy. But for the most part, advocacy must take place through groups because (1) in a democracy change only takes place when there are many voters who support change, (2) advocacy takes a lot of work, (3) working in groups helps to test ideas, and (4) groups can capture public and media interest better than individuals working alone.

Join An Advocacy Group

- Advocacy groups need members. Join one.

(See Appendices 1 and 2 for a list of selected local, state, and federal mental health advocacy groups.)

What you can do as a member

- All advocacy groups need money to do their work. Making a financial contribution is very important.
- If you join an advocacy group, you will get mail or E-mail from time to time asking you to write to or telephone certain people. Your letter or call helps to show that many people care about the issue.
- You will also be asked to attend events where it is important that large numbers of people turn out. For example many organizations have lobby days in Albany or Washington, and from time to time there are demonstrations about mental health issues.
- Of course, you can also choose to do much more.
- Advocacy requires a lot of work. You will make yourself very popular and important in your group by volunteering to do anything that needs to be done.
- When you have the opportunity to attend a meeting to discuss an advocacy plan, you should feel free to speak up. But remember that if you are new, listening may be more valuable than speaking. As in all groups, it takes a while to be a fully accepted member whose opinions are welcome and respected.
- Keep in mind that the purpose of discussion is not just for everyone to voice his or her opinion. It is to help the group make a decision about what it will do.

- **ADVOCACY IS ULTIMATELY ABOUT ACTION NOT ABOUT TALK.**

- Once a decision is made, everyone in the group must back it. Differences of opinion are fine in the privacy of the group, but are very damaging if aired in public.

- Effective action requires that people stand together. **"United we stand; divided we fall."**

Leadership functions in advocacy groups

- **Chairing a meeting**: Good meetings allow participants to feel like valued members and enable them to join forces on some plan of action. Most meetings allow for differences of opinions to be expressed, but good meetings also have a sense of order and move to a meaningful conclusion.

- **Building consensus**: To be effective, groups must reach agreement and take action together. There are no general rules about how to build consensus. It is a skill that varies from person to person.

- **Communication and Advocacy Materials:** One of the most important functions in an advocacy group is preparing written materials both for advocacy and for communication within the group.

  - Advocacy materials include letters to public officials, position papers, press releases, etc.

  - Communications materials include letters to members, newsletters, minutes of meetings, etc. Many groups now use E-mail as the major mechanism for communication within their group.

- **Being out front with public officials and the media**: Many people find this frightening. But advocacy groups need people who are able to speak out publicly even if they are nervous about it.

- **Follow through**: If you get the work done that you agree to do, you will be perceived as a leader.

Forming New Groups

If you find that none of the many mental health advocacy groups adequately represents your interests and beliefs, you may decide to form a new advocacy group. What does this take?

- Identify people or organizations with mutual interests.

- Talk with some of them individually before you convene the first meeting of a group.

- Negotiate some issues about goals, and sometimes about leadership roles, with key players before the first meeting.

- Convene an exploratory or planning meeting. At this meeting you should:

  - Identify mutual interests
  - Begin to develop shared positions
  - Begin to develop an agreeable division of labor
  - Develop an action plan

- Follow up on the action plan.

- Convene subsequent meetings consistent with the action plan. But do not have meetings before the actions agreed to at the prior meeting have been undertaken.

- **WORK CONSTANTLY AT BUILDING A CONSTITUENCY**

Constituency Building

- Both existing and newly formed groups need to work constantly to maintain and increase their membership and to build a cadre of people who support their cause.

- This is called "constituency building."

- To build a constituency, a group needs to reach out to people and to try to engage them.

- It is important to identify which people you want to involve in your group. For example if your group represents families of adults with serious mental illnesses, do you want to limit membership to family members or be more inclusive?

  - Bigger groups generally have more impact, but the more diverse the membership the less focused the message.
  - There's no right choice. It's your decision.

- You can reach people through direct contact, through mailings—including e-mail—and through public education activities such as speeches, conferences, websites, and written material.

- From these outreach efforts you need to develop a mailing list.

- Remember that most people do not have time to be active participants in your group, but many will send letters, make calls, or even appear at advocacy events if they know about them.

- Communication is critical. Newsletters, issues alerts, calls for action must go out routinely to give your constituency a sense that your group is active and that they are involved.

ADVOCACY DEPENDS ON WORKING IN GROUPS

- **JOIN A GROUP**
- **MAKE A FINANCIAL CONTRIBUTION**
- **SEND LETTERS AND MAKE CALLS ON BEHALF OF THE GROUP**
- **ATTEND PUBLIC EVENTS ORGANIZED BY THE GROUP**
- **PARTICIPATE IN CREATING THE ADVOCACY PLAN**

AND DOING THE WORK FOR A GROUP

- **BECOME A LEADER OF YOUR GROUP**
- **CREATE A NEW GROUP IF NEEDED**

CHAPTER THREE

CREATING AN AGENDA: SELECTING GOALS

It's Not As Easy As It Sounds

- Since an advocacy agenda is fundamentally a list of your advocacy goals, it sounds like a pretty simple thing to do. It turns out, however, that it's not as simple as it sounds.

The Eight P's

- In general goals need to be carefully thought through and formulated in terms which are clear to potential members of your group, to people who have the power to change policy, and to those who can influence the powers-that-be, such as the press.

- To develop a thoughtful agenda I find it useful to consider each of the following " eight P's".

  - **Population**

    Which population do you want to help? Suppose that your goal is to improve the quality of life for people with mental illnesses. While this is a noble goal, it is vague. Do you mean all people with mental illnesses? Children, adults, and geriatrics? In New York, in the United States, in the world? All diagnostic categories or only those that suggest a serious illness and ongoing disability?

    Suppose that your concern is adults in New York State with long-term psychiatric disabilities. In current policy jargon this population is known as "people with psychiatric disabilities". Your goal then would be to improve the quality of life for people with psychiatric disabilities in New York State.

  - **Problem**

    This is still a nebulous goal. What's wrong with the quality of life of people with psychiatric disabilities? What's the problem? There are many possible answers. One is that people with psychiatric disabilities are too frequently homeless or live in housing which is shabby and dangerous. Another is that they cannot get jobs. Another is that they frequently get no treatment or inadequate treatment. Another is that they are forced to stay in hospitals too long. Or they are forced to leave hospitals before they are ready. Different people have different views.

    Suppose you think the major problems are lack of safe and decent housing, lack of access to high quality treatment, and lack of access to work. Your goals then would be to make more safe and decent housing available for people with psychiatric disabilities in New York State, to assure access to high quality treatment, and to create greater access to work for them. Such goals begin to be specific enough to mount a meaningful advocacy effort.

The Choice of Language in Describing the Population and the Problem

Some people might find the use of the expression "people with psychiatric disabilities" objectionable. They might want to overcome the same problems for the same people but would use other expressions such as "people with severe and recurrent mental illnesses," "people with brain disorders," or "psychiatric survivors." Terminology is very important in formulating your goals. You need to choose terminology that is acceptable to the people in your advocacy group. But you also need to gear your language to the people who have the power to make changes in public policy.

- **Proposed Solution**

  In addition to specifying the population and describing the problem, it is useful to give some idea of how the problem can be overcome. For example, you may believe that the best way to make decent housing available is for The New York State Office of Mental Health to build and fund community residences. Or you may think that rent subsidies are the answer. With regard to work, you may think that it is important to provide job coaches or that Medical insurance must be available. Again these are just examples.

  You will also need to be more specific. For example, if you want more housing for people with mental illnesses, you will need to say how much more.

- **Policy**

  In addition to proposing a solution to the problem you have identified, it is very helpful if you can specify how to change policy. What is the current policy? How should it be changed? How much will it cost?

  The amount of knowledge it takes to do this is daunting to many would-be advocates. Don't hesitate to go to the powers-that-be just because you don't know everything you need to know. They can help you learn, and they can actually help you refine your agenda in ways that will make it more feasible. Besides, it is really the people in government who have the responsibility to take your concerns and shape them into public policy.

  You can also recruit or hire policy experts.

- **Possibility**

  Another consideration in developing an agenda is how idealistic or realistic you want it to be. **Politics is the art of the possible.** Ultimately it takes compromise to get policy changes that approximate your ideal goals. But advocates who insist on achieving certain ideals serve a very useful function on the stage of advocacy. Players at the extreme edges of an issue are necessary to define an acceptable middle ground. Some advocates, therefore, must be stubborn extremists while others are more realistic negotiators. Whether to tilt your agenda towards the extreme or the middle is up to you.

- **Preservation and Development of Your Advocacy Group**

In order to achieve your advocacy goals, you need a strong group. What will it take to keep your group together and active? What will it take to make it stronger and more effective? In addition to desired systems changes, your advocacy agenda may need to include specific goals related to preserving the group, enlarging the group, or improving the group's public image and visibility.

- **Priorities**

  How many issues should be on your advocacy agenda? Some advocates insist that it must be a very few. Others argue that you should address the issues that are very important to the population you are trying to help even if there are a great many issues.

  There is no correct answer. The scope of your advocacy agenda should depend on:

  - How much work can your organization take on? Don't bite off more than you can chew.
  - How many issues will the powers-that-be pay attention to at any given time?
  - How many issues have to be on the agenda to hold the advocacy group together?

- **The Process of Selecting Goals**

  A group's agenda usually arises from a group discussion and debate. The passions of the members of the group and their relationships with each other will have a great impact on the group process, whether agreement is achieved, and what is on the agenda. A good chairperson is essential.

  Some groups end up with long agendas to hold the group together. This is a perfectly good reason to have a long agenda, though it sometimes leads to struggles about priorities later in the process.

Some Current Policy Issues

In New York State, mental health policy issues which are most mental health advocacy agendas include:

- Funding for community-based services for adults with serious and persistent mental illnesses, especially housing, case management, employment, and "assertive" community services.
- Funding for community-based services for children and adolescents with serious emotional disturbances.
- A long-term plan to meet the mental health challenges of the elder boom.
- Improved quality of care and treatment, using state-of-the-art methods.
- Mental health insurance coverage equal to health insurance coverage ("parity").
- Access to psychiatric medications.

Obviously this way of describing the issues does not meet the test of clarity which I have emphasized. It is meant just to give you a taste of prominent mental health policy issues at the moment.
(**A statement of MHA's advocacy agenda is included in Appendix 3.**)

THE 8 P'S OF SETTING AN AGENDA

Population

Who Needs Help?

Problem

What's Wrong?

Proposed Solution

How Do You Think The Problem Can Best Be Overcome?

Policy

What Policies Need To Change?
How Should They Be Changed?
How Much Will It Cost?

Possibility

What's Achievable?
Are You Willing To Compromise?

Preservation and Development of Your Advocacy Group

What Is Needed To Preserve Your Group?
What Is Needed To Make Your Group Stronger?

Priorities

What's Most Important?

Process

Who Needs To Agree?
How Will You Get Agreement?

CHAPTER FOUR

STRATEGY: WHICH POWERS-THAT-BE TO INFLUENCE AND HOW

Power

- It takes power to make change. You must sort out whether the power to bring about change is in the public or the private sector or both. And you must identify specifically which organizations, parts of organizations, offices, and people have power to bring about the changes that you want to achieve.

- If this is a governmental issue, is it a federal, a state, county, or municipal issue? (In NYC, City government provides county and municipal levels of government.)

- Is your issue a legislative, executive, or judicial issue?

- It is likely that more than one level and branch of government have power regarding your goals.

    - Because the Chief Executive usually must sign a law, making law requires cooperation of legislative and executive branches.

    - Governmental budgets are key to carrying out mental health policy and are also joint products of the legislative and executive branches.

- Determining who has power and which of the people or organizations with power to try to persuade to make changes is the first element of developing a strategy.

- **Detailed information about the structure and functions of government in the United States is in Appendix 4. Detailed information about mental health policy making is in Appendix 5.**

Influence

- Some people have "influence" rather than power.

- Powerful people can produce change through their own decision-making, either alone or with others.

- People with influence have access to people with power and may be able to persuade them how to act.

- The chairman of the political party to which the Governor belongs probably has influence. A friend or relative of the Governor may have influence, as may a recognized and trusted expert in mental health policy. A large contributor probably has influence. The news media certainly have influence.

- Determining who has influence is the second element of formulating an advocacy strategy.

Know Your Elected Officials

- Elected officials represent you in the federal, the state, and city governments. The most basic step of advocacy is to know who your elected officials are. (**Appendices 6, 7, and 8 list the most important federal, state, and local elected officials.**)

    - To find out who your elected officials are and where you can reach them call:

- Next you need to sort out which of the elected officials have power, which have influence, and which have neither.

Know The Appointed Officials

- There are public officials in the administrative branch of government who are responsible for mental health services. They include:
  - The NYC Commissioner of Health and Mental Hygiene and The Executive Deputy Commissioner for Mental Hygiene
  - The Commissioner of Mental Health of NYS.
- At the federal level the Secretary of Health and Human Services (HHS) has the highest level of authority for mental health.
  - There are a number of agencies within HHS which deal directly with mental health issues including the National Institute of Mental Health (NIMH), The Center for Mental Health Services (CMHS), and The Centers for Medicare and Medicaid among others.
- **Key appointed officials in Washington are listed in Appendix 9; officials in NYS and NYC are listed in Appendix 10**.

Motivation

- Once you have identified the people with power and influence, you need to figure out what will persuade them to help you.
- Like all of us, people with power or influence have mixed motivations.
- What mix of ideals, values, emotions, self-interest, and politics will help you win over the people you need on your side?
  - Better lives for people with mental illnesses
  - Having a family member or a friend with mental illness
  - The impact a change will have on voters or contributors
  - Building a political reputation of kindness and concern
  - Avoiding bad publicity
  - Doing what the boss wants

Form Strategic Partnerships

- In advocacy greater numbers generally mean greater power, and some advocates and advocacy groups have greater access to power than others.
- For this reason, it often makes sense to work jointly with other advocacy organizations.
- Keep in mind that some people and groups simply cannot work together and that it sometimes takes a very long time to form strategic partnerships.
- Don't lose opportunities for action because you hope for a partnership.

- But don't give up too easily on forming partnerships. Remember "United we stand, divided we fall!"

EFFECTIVE ADVOCACY DEPENDS ON GOOD RELATIONSHIPS

- To be effective at advocacy, you must form good working relationships with people who have power, people who have influence, and people who can be partners in action.

An Example of Advocacy Strategy: The Reinvestment Act of 1993

Towards the end of the 1980's a number of mental health advocacy organizations in New York State became concerned that they were weakening each other's advocacy efforts by advocating for different goals. They decided to formulate a common agenda and to advocate for it together. They formed The Mental Health Action Network of New York State.

After a couple of years of mixed success, they decided to focus on a single theme, which they called "reinvestment." The notion was simple. The state was closing beds in state hospitals and was not providing adequate services for people in the community. Their position was that savings from closing state hospital beds should be reinvested in new services in the community.

In order to move this agenda, they had to choose an advocacy strategy. Achieving a mandate for reinvestment through the courts was clearly not feasible. The policy either could be adopted voluntarily by The Governor and the Office of Mental Health or it could be set in law by the state legislature. The advocates decided reinvestment policy would be more stable as state law than merely as the policy of the current state administration. So they chose a legislative strategy.

They knew that a legislative strategy would require that they get support from the chairs of the mental health committees of the Assembly and the Senate. So they turned to them to sponsor the legislation. Both were impressed with the idea and with the coalition of advocates and agreed to sponsor a bill.

The Governor proved to be more difficult, and his reservations affected not only the likelihood that legislation would be signed but also made it less likely that the legislative house controlled by his party would ultimately support the legislation.

The Mental Health Action Network decided that it needed a media strategy and developed a basic story about the mental health system, stressing the irrationality of closing hospital beds without developing services and supports in the community. The story drew heavily on the fact of homelessness and the widespread belief that there was a clear relationship between homelessness and mental illness. The story stressed that reinvestment could result in community-based services to prevent homelessness at no additional cost to the state. It would simply redirect money from state psychiatric centers to community-based services. The Mental Health Action Network carried the message to newspapers throughout New York State and ultimately got support for reinvestment from virtually every newspaper.

The message was also carried through vigils, rallies, and letter writing campaigns on which people with psychiatric disabilities, their families, and mental health professionals worked closely together.

The idea of addressing a major social problem at no additional cost to the state was politically irresistible. Local state legislators wanted to move ahead, and their desire to pass the law as well as consensus among

the media created more and more pressure on the Governor. Eventually he conceded, after negotiating changes to the bill that focused the bill more clearly on people who were homeless.

This, of course, is a vastly oversimplified telling of the story. But what can we learn from it?

Lessons of the Campaign for Reinvestment

- Strategy begins with identifying who has the power to make a policy change and deciding which of the powers-that-be to target. The Mental Health Action Network decided on a legislative strategy.
- Carrying out a legislative strategy entails getting support from the chairs of the mental health committees in each house, from the leadership of each house, and from The Governor.
- It is important for the most influential members of the entire mental health community--including people with psychiatric disabilities, their families, and mental health professionals--to join forces.
- A persuasive advocacy story has to be formulated which has widespread ideological appeal.
- Media support ultimately carried the day.

STRATEGY

Public or Private Sector?

What Level of Government Has The Power To Change Policy?

Federal? State? County? Municipal?

What Branch of Government Has The Power To Change Policy?

Legislative? Executive? Judicial?

Which Specific Offices and People Have The Power to Change Policy?

Which elected officials?
Which appointed officials?
Which court?

Who Has Influence?

Respected Experts?
Colleagues?
Party Officials and Contributors?
Friends and Family?
The Press?

What Will Motivate Them To Help?

Ideology?
Relationships?
Politics?
A Good Story?
Pressure?

Should You Form A Strategic Partnership?

With whom?
Is It Feasible?
What Compromises Are Required?
Will It Result In Delay?

Have You Developed Good Working Relationships?

CHAPTER FIVE

TACTICS: METHODS TO BRING ABOUT CHANGE

Tactics are specific methods to bring about change. There are four primary ways to bring about change--**lobbying, public education, demonstrations**, and **social defiance**.

TECHNIQUES OF LOBBYING

- "Lobbying" is any effort to **directly influence** elected or appointed public officials. (Legal definitions of "lobbying" vary from state to state. Check lobbying laws to find out whether you have to register as a lobbyist and make reports.)
- Unfortunately "lobbying" has a negative connotation in our society.
- The image of lobbying as a form of political corruption neglects the fact that lobbying is an essential function in a representative democracy.

Meetings

- The term "lobbying" comes from discussions with legislators which used to take place in lobbies outside legislative chambers.
- As the term implies, direct meetings with public officials are a very effective way to lobby.
- Such meetings usually take place in the public official's office, but sometimes you can arrange for the public official to come to a meeting of your group.
- Direct telephone conversations with public officials can also be very useful.
- You should prepare carefully for a meeting with a public official. A written agenda helps.
- Think carefully about what you want to say. Try to formulate your ideas clearly and briefly. Keep in mind that most public officials--especially elected officials--will not be familiar with the issue that concerns you. They have too many issues to deal with to be able to know more than a very few in depth.
- At the beginning of the meeting you should always thank the public official for taking the time to meet with you. These are people who deserve your respect, and you should be sure to show it.
- You should give the public official **a one-page statement** of your positions at the beginning of the meeting with copies for any staff members who are also at the meeting. Written material is important as a reminder of your views after you leave. But it must be brief. **(See sample handout in Appendix 12.)**
- It is not unusual in meetings with public officials not to cover your full agenda or even to drift to topics you hadn't planned to talk about. Don't worry about it as long as the meeting has been

engaging for the public official. That will help you develop a relationship which will make it possible for you to work with the public official over time.

- Working with staff

  - Sometimes it is not possible to get a meeting directly with a public official. Usually you will be able to meet with someone on the public official's staff.

  - Don't be disappointed. Meeting with staff can be very effective. Sometimes it is more effective than meeting with the elected official because the staff member may know more and be the person who will actually develop the official's position.

- Written Material

  - It can be very helpful when you are working with public officials and their staffs to prepare written background information and drafts of desired changes.

Mail, E-Mail, and Phone Campaigns

- Letters in large quantities have a significant impact on public officials.

- Some advocates believe that only personal letters have an impact. It's hard to get people to write personal letters. Since volume counts, I favor form letters or postcards as well as personal letters.

- Generally letters to public officials should be no more than one page. The first sentence should tell the public official what to do. For example "Please vote for S. 1234, a bill that would provide more housing for people with mental illnesses." **(See sample letter in Appendix 11.)**

- You can also fax the letter or send it by E-mail. I believe that a piece of paper received at the official's office has more impact than E-mail.

- Or you can telephone the official's office and leave a message such as "I am calling to ask the Senator to vote for S. 1234, which would provide more housing."

- Mail and phone campaigns require a great deal of organization—including compilation of a mailing list of people who will write or call, compilation of a mailing list of people to be lobbied, writing sample letters or scripts of telephone messages, communication with your fellow "lobbyists", etc.

Lobby Days

- A popular form of lobbying is a "lobby day"—i.e. a day of events at the city where the legislature meets.

- A lobby day generally includes a large assemblage of all the people who have come to lobby. Legislators and other relevant public officials are invited.

- At some events of this kind, representatives of the advocacy group give short speeches, hoping to capture the attention of public officials who attend. At others, public officials speak to the advocates on topics which the advocacy group has asked them to address.

- Public officials tend to wander in and out of these events. For this reason, I believe that it is more effective to ask the public officials to speak than to lecture at them.

- A major purpose of a legislative event is to make an impression, especially to convey a sense of numbers.

- It also may be an opportunity to reach the press.

- One form of lobby day includes a legislative "meal" such as a legislative breakfast, luncheon, or cocktail party.

- A legislative "meal" creates an opportunity for advocates to talk informally with public officials as well as for formal presentations of the advocacy group's agenda.

- Lobby days require tremendous organization and are expensive. You need to have a list of organizers who will bring groups to lobby, have a method of communicating with them rapidly, prepare materials including a handout for legislators, schedule (and confirm and reschedule) meetings, arrange for transportation, reserve a meeting room, arrange for refreshments, schedule speakers, etc.

Giving awards and recognition

- Another effective device in wooing support from public officials is giving them awards and recognition, usually a plaque or some sort of symbolic sculpture similar to an Oscar.

Use of the Internet

- E-mail has made it relatively easy to communicate with people who may join you in advocacy by writing letters, making phone calls, or attending lobby days or demonstrations.

- You can post "action alerts" on a web site, and/or you can create a group E-mail list and notify people when action is needed.

- Some E-mail systems are constructed so as to permit people to send a communication directly. Others require people to cut and paste letters. There is dispute about the effectiveness of E-mailed advocacy communications. I favor asking people via E-mail to send advocacy letters via snail mail.

Testifying at Hearings

- From time to time public officials convene public hearings.

- There are several purposes to hearings--to hear from experts; to gather the public's opinions, whether expert or not; to publicize an issue of concern; and to get media attention.

- A public hearing is quite formal. To speak, you need to call in advance to schedule your testimony, which will be time-limited.

    - Prepare written testimony which you can read in the time that you've been given. It takes two minutes to read one page effectively. **(See sample testimony in Appendix 13.)**

- Say what you have to say briefly, clearly, and forcefully but not with disrespectful anger.

Campaign Contributions

- Elected officials value contributions to their campaign, both tangible and intangible.

- It is illegal for tax-exempt not-for-profit organizations to make political contributions or even to support candidates for office. For-profit organizations and not-for-profit political organizations, which are not tax exempt, are permitted to make contributions and to provide public support.

- Advocates from tax-exempt, non-profit organizations can give support personally. Financial contributions must be from your personal funds and cannot be reimbursed as business expenses or claimed as tax deductions. Work that you do on behalf of a candidate must be on your own time, not on time that is paid for by a tax-exempt organization. You can attend fundraising events, but on personal time and not as a representative of your organization. Any public statement of support must be clearly on your own behalf and not on behalf of your organization.

- There are, of course, ways for organizations to be helpful to political candidates without violating the law. Inviting them to speak at conferences gives them exposure. Putting their pictures in your newsletter or writing an article that features actions they have taken on behalf of mental health can be helpful to a candidate and are legitimate--up to a point.

Using professional lobbyists

- Many organizations that lobby on health, mental health, and social services issues use professional lobbyists, which enables them to have a regular presence with elected officials during the legislative session and saves a great deal of time which otherwise would have to be devoted to building relationships.

TECHNIQUES OF PUBLIC EDUCATION

- Public education is any effort to influence public policy decisions by shaping public opinion or by reaching public officials indirectly.
- The goal of public education is to swing public opinion to support your advocacy goals and to develop a cadre of supporters committed to your cause, i.e. to build a constituency. (See Chap. 2)

Analytic reports and publications

- Studies and analytic reports which document problems that need to be addressed by government can be very effective in shaping public opinion.
- The reports have to be credible and based on professional research and/or expert opinion.
- In addition reports have to be readable. They require professional quality writing.
- Reports must have wide distribution and substantial publicity.
- There must be a follow-up plan to press for the recommendations included in the report.

Conferences

- Another technique of public education is holding a conference to which critical audiences are invited and which hopefully attracts press attention.
- Even conferences designed to educate professionals and others in the mental health community can serve an effective advocacy function.
- In addition to changing public opinion, conferences can be very useful devices to build coalitions of advocates.
- Conferences can also be very effective ways to engage public officials who attend or participate.

Written Material and Internet Web Sites

- People in the general public who have an interest in mental health issues frequently have little access to information. Advocacy organizations typically develop and distribute printed material.
- The Internet has created a wonderful new opportunity to make materials available.

Advertising

- Advertising can be a very effective way to reach both the general public and public officials.
- Ads in newspapers, on radio, and on TV can have a major impact, but of course are very expensive.
- It is sometimes possible to get free help to develop and to place advertising, but free advertising usually ends up being run where or when no one is likely to see it.

Using the Media

- The news media can be a great force in helping to move your agenda.
- The media are a two-edged sword, to be treated with great caution. Historically the media have helped to move the cause of mental health with exposés of horrors in state institutions and of the terrible conditions people lived in after deinstitutionalization. But historically the media have also hurt the cause of mental health with lurid coverage of rare episodes of violence by people with mental illnesses, which have reinforced the fear of people with mental illness that pervades our society.
- The media are motivated by factors which are not as simple as concern about the well-being of people, let alone people with mental illnesses. They need to sell papers or get TV viewers and they are more likely to try to catch people's interests with fear than human interest. Their professional values stress political neutrality. However, journalists often tell stories with a political slant; and, of course, they also write editorials to support one political view or another. But it is hard to get journalists to be advocates for your views.
- There are several basic ways to get coverage:
  - Send out a press release, a short informational piece designed to attract media interest.
  - Call a press conference.
    - Send invitations and **interesting** written material out in advance.
    - New York City is a very tough place to get coverage because there are so many competing stories. In Albany and other places outside NYC, it is frequently easier to get the press to attend a press conference and to write a story.
  - Develop a story and find a reporter who will write it, but remember
    - An advocate's idea of a good story is frequently not a reporter's idea of a good story.
    - Reporters like controversy, scandals, and stories of abuse. They love exposés.
    - On occasion reporters will pursue human-interest stories, more often those that are sad rather than those that show success.

- Stage a media event. Demonstrations with large crowds generally attract attention. Acts of civil disobedience sometimes attract attention. Celebrities attract attention.

- Be prominently involved in an event which will attract press coverage. For example, speaking at public hearings can attract coverage. You need to be provocative to get coverage.

- **Bottom line, dealing with the press is about crafting "soundbites", brief statements which take no more than ten seconds to say and which either are provocative or which seem to sum up a position perfectly.**

- Dealing with reporters

  - Getting your message out through reporters requires experience and skill.

  - The reporter's job is not to convey your beliefs in the way you would want them conveyed. Their job is to tell a story that will catch the interest of their readers, listeners, or viewers. It is usually pointless to try to persuade a reporter to take your side. The reporter will probably be more interested in trying to get you to state your position in a provocative way so as to contrast it with someone else's equally provocative statement of the opposite point of view.

  - Your job is to say over and over again to the reporter what you want to have appear in their story. Do not answer their questions if they do not enable you to say what you want to say.

  - You need to be very careful talking with reporters "on the record", but good reporters are trustworthy if you ask to talk "off the record" or give them "background." "Off the record" means that nothing you say will be quoted. Reporters are willing to go off the record because they can get leads that they could not get on the record. Reporters also like to get background information from knowledgeable people whom they trust even though they cannot quote it.

- Letters to the Editor and OP-ED Essays

  - One great opportunity newspapers provide is to express your opinion publicly and unfiltered by a reporter in a letter to the editor or an OP-ED essay.

  - A letter to the editor sometimes is a response to something that has appeared in the newspaper, but sometimes it is simply a statement someone wants to make.

  - Elected officials all read letters to the editor. It is an excellent way to reach them.

  - A letter to the editor should be no more than 150-250 words. (Different papers have different requirements). It should be very easy to understand. **(See sample letter in Appendix 14.)**

  - Like letters to the editor, OP-ED essays are an excellent way to get the attention of elected officials. They also make good handouts and mailings. The fact that they have been published by a reputable newspaper lends a certain credibility to them that you can't get by sending out a statement on your own stationary.

  - An OP-ED piece is a short essay (about 750 words) which states your opinion about a timely or interesting topic. **(See sample OP-ED piece in Appendix 15.)**

DEMONSTRATIONS

- The purpose of a demonstration is to attract attention and sympathy to your cause. It does no good to get attention which turns the public against your cause. You need the public's support.

- A good demonstration has four key characteristics.

  - First, people must attend. There is nothing sadder and more counter-productive than announcing a demonstration of thousands which is attended by fifty people. Therefore a major part of the effort to hold a demonstration is getting people there. Logistics are as important as your message.

  - Second, the news media have to attend. A demonstration has no meaning without coverage. That means that groundwork has to be done to get reporters interested in covering the event.

  - Third, you need to craft a message that appeals to a constituency whose support you need to move your agenda.

  - Fourth, your message must be communicated clearly, repeatedly, and briefly. The soundbite is the message.

SOCIAL DEFIANCE

- Defiance of normal social order can sometimes be a very effective form of advocacy.

- For example, economic boycotts were used very effectively to advance civil rights.

- Similarly, strikes have been effective both to help workers and to highlight injustices.

- Acts of civil disobedience can also be effective, both at gaining attention from the media and at winning public support.

- However, all acts of defiance are risky, both personally and in terms of public response.

  - You must decide if you are prepared to be gassed, arrested, or sent to jail.
  - You must assess carefully whether your act of social defiance will win or lose support.

ADVOCACY STYLE

- **How to present yourself** is a major decision you need to make as an advocate. Do you want to appear to be tough, principled, and uncompromising, prepared to fight it out? Do you want to be friendly and willing to work together to find a solution that will satisfy most of the players? Do you want to come across as extremely knowledgeable and able to provide expert assistance? Do you want to be "at the table" where decisions are made so that you can influence decisions directly? Do you prefer to be outside the decision-making process so that you can stick to your guns?

- Whether **to work in coalitions** is also a very important choice. Coalitions are usually more effective than advocating alone because there is strength in numbers, but being part of a coalition requires compromise.

- **Your choice will depend primarily on who you are**. If you are confrontational by nature, you will probably work well as an outspoken, critical, demanding advocate. If you are uncomfortable with confrontation, you will probably work best as an advocate who helps to shape compromises. If you have credibility as an expert, you may want to present yourself as a source of information and counsel rather than as an advocate with a strong personal opinion. If you are not usually willing to make compromises, you should not join coalitions.

- Your choice will also depend on your relationships with people in positions of power or influence. If you have good working relationships, you will probably decide to be careful not to jeopardize those relationships by taking harsh positions in public.

- However, **you must be able to adapt your fundamental style for the needs of the moment**. Even a good confrontational advocate must graciously accept a good compromise. And even a congenial, let's-not-fight advocate needs to stick stubbornly to his or her position when a compromise would interfere with achieving the goal. And sometimes you have to take the risk of losing good relationships because the issue is too important and the compromise offered is inadequate.

TACTICS CHECKLIST

Lobbying

Mail
Petitions
Meetings
Relationships
Hearing Testimony
Written Material
Special Events
Awards
Campaign Contributions

Public Education

Reports
Conferences
Written Material
Web Page
Advertising
Media

Demonstrations

Attendance
Press Coverage

Social Defiance

Boycotts, Strikes, Etc.
Civil Disobedience
Risk Assessment

Advocacy Style

Confront Aggressively
Negotiate
Be At The Table
Provide Expert Advice
Work in Coalitions

CHAPTER SIX

PERSISTENCE: THE KEY TO EFFECTIVE ADVOCACY

- Advocacy for changes in public policy is inherently frustrating. Changes usually take place slowly. Occasionally there are dramatic successes, but usually you win some and lose some. Sometimes it seems that you are not getting anyplace.

- It is critical to be persistent despite feeling frustrated.

- Remember that mental health policy has improved a great deal since the mid-20th century.

- For example, I originally became a mental health advocate in 1978, when I was working in a rehabilitation program for people who had been in psychiatric hospitals for long periods of time. They generally lived in shabby and dangerous places. There were virtually no community residences or supported housing programs. Few people had access to high quality mental health treatment. Most went to State aftercare clinics, which had poor psychiatric staff and outrageously high caseloads. There were only a handful of community-based rehabilitation programs. When people were in crisis, usually they were either hospitalized in poor hospitals for excessively long periods or they were turned away without the services they needed. Many State hospitals at that time were dangerous. People with mental illnesses also had very limited access to health care. They generally did not have enough money to get through a month with enough to eat. Frequently they had only worn out, dirty clothing to wear. Often they had nothing better to do during the day than to wander the streets or to sit on park benches.

- In order to change these conditions, many people fought for specialized housing and community-based treatment and supports.

- Advocacy worked. In 1978, NYS introduced the community residence program and the community support system program. Now there are about 27,500 housing units in New York State. And there has been great growth of rehabilitation programs, outpatient services, local hospital programs, crisis services, and peer support programs. In addition the quality of care in state hospital in-patient and outpatient programs is vastly improved. The mental health system is far better today than it was twenty-five years ago.

- This success reflects the work of coalitions of providers, of family members, and of recipients of services, all of whom consistently spoke to the need for more and better community services.

- Obviously much more needs to be done to create a comprehensive and responsive mental health system. And each year that passes without great improvement creates a sense of disappointment and frustration.

- But, over time, persistent and aggressive advocacy in coalitions works.

- You have a critical role to play. Your experiences, insights, and hard work are vital to effective mental health advocacy in the future. Hang in!

BASIC RULES OF ADVOCACY

Work in Groups

Plan Carefully

Take Action

Build Relationships

Be Persistent

Appendix 1

Selected State and Local Mental Health Advocacy Organizations

American Psychiatric Association NY County District Branch Donna Gajda, Executive Director 400 Garden City Plaza, Suite 202 Garden City, NY 11530 Tel: (212) 685-9633 Fax: (212) 685-9179 E-Mail: executivedirector@nycodbapa.org	Association for Community Living 632 Plank Road Suit 110 Clifton Park, NY 12065 Tel: 518-688-1686 www.aclnys.org
Citizens Committee for Children 105 E. 22nd Street 7th Floor New York, NY 10010 Tel: 212-673-1800 Fax: 212-979-5063 www.cccnewyork.org	Coalition of Institutionalized Aged and Disabled 425 East 25th Street New York, NY 10010 Tel: 212-481-7572 Fax: 212-481-5149 ciadny@aol.com www.ciadny.org
Community Access Advocacy Program 2 Washington Street 9th Floor New York, NY 10004 Tel: 212-780-1400 Fax: 212-780-1412 www.communityaccess.org	Families Together in New York State, Inc. 737 Madison Avenue Albany, NY 12208 Tel: 518-432-0333 Fax: 518-434-6478 info@ftnys.org www.ftnys.org
The Greater New York Hospital Association 555 W. 57th Street 15th Floor New York, NY 10019 Tel: 212-246-7100 Fax: 212-262-6350 www.gnyha.org	Healthcare Association of NYS One Empire Drive Rensselaer, NY 12144 Tel: 518 431-7770 info@hanys.org www.hanys.org
Howie T. Harp Peer Advocacy Center 2090 Adam Clayton Powell Blvd 12th Floor New York, NY 10027 Tel: 212 865-0775 www.howietheharp.org	The Mental Health Association of NYC 50 Broadway, 19th Floor New York, NY 10004 Tel: 212-254-0333 Fax: 212-964-7302 helpdesk@mhaofnyc.org www.mhaofnyc.org
Mental Health Association in New York State 194 Washington Avenue, Suite 415 Albany, NY 12210 Tel: 518-434-0439 Fax: 518-427-8676 info@mhanys.org www.mhanys.org	Mental Health Empowerment Project 116 Everett Road Suite #7 Albany, NY 12205 Tel: 518-434-1393 Fax: 518-434-3823 mhepinc@aol.com www.mhepinc.org

NAMI-APRIL 41 Schermerhorn Street, Suite 229 Brooklyn, NY 11201 718-735-8587	NAMI-NYC/Metro 505 Eighth Avenue, Suite 1103 New York, NY 10018 Tel: 212-684-3365 helpline@naminyc.org www.naminycmetro.org
NAMI-Queens/Nassau 1983 Marcus Avenue, C-117 Lake Success, NY 11042 Tel: 516-326-0797; 718-347-7284 Fax: 516-437-5785 namiqn@aol.com www.nami.org	National Association of Social Workers-NYC 50 Broadway Suite 1001 New York, NY 10004 Tel: 212-668-0050 Fax: 212-668-0305 naswnyc@naswnyc.org www.naswnyc.org
National Association of Social Workers-NYS 188 Washington Avenue Albany, NY 12210 Tel: 518-463-4741 Fax: 518-463-6446 info@naswnys.org www.newyorksocialwork.com	New York Association of Psychiatric Rehabilitation Services 1 Columbia Place, 2nd Floor Albany, NY 12207 Tel: 518-436-0008 Fax: 518-436-0044 www.nyaprs.org
New York State Council for Behavioral Health 155 Washington Avenue Albany, NY 12210 Tel: 518-445-2642	New York State Psychiatric Association 400 Garden Plaza, Suite 202 Garden City, NY 11530 Tel: 526-542-0077 Fax: 516-542-0094 centraloffice@nyspsych.org www.nyspsych.org
New York State Psychological Association 6 Executive Park Drive Albany, NY 12203 Tel: 800-732-3933 Fax: 518-437-0177 nyspa@nyspa.org www.nyspa.org	New York State Rehabilitation Association 155 Washington Avenue, Suite 410 Albany, NY 12210-2332 Tel: 518-449-2976 Fax: 518-426-4329 nysra@nyrehab.org www.nyrehab.org
Schuyler Center for Analysis and Advocacy 150 State Street, 4th Floor Albany, NY 12207 Tel: 518-463-1896 Fax: 518-463-3364 www.scaany.org	Urban Justice Center-Mental Health Law Project 123 William Street, 16th Floor New York, NY 10038 Tel: 646-602-5600 Fax: 212-533-4598 www.urbanjustice.org

Appendix 2

Federal Mental Health Advocacy Organizations

The American Psychiatric Association 1000 Wilson Boulevard Suite 1825 Arlington, VA 22209 888-357-7924 apa@psych.org	The American Psychological Association 750 First Street NE Washington, DC 20002-4242 Tel: 202-336-5500; 800-374-2721 www.apa.org
The Bazelon Center for Mental Health Law 1101 15th Street NW, Suite 1212 Washington, DC 20005 Tel: 202-467-5730 Fax: 202-223-0409 www.bazelon.org	Depression and Bipolar Support Alliance 730 N. Franklin Street, Suite 501 Chicago, Illinois 60654-7225 USA Tel: 800-826 -3632 Fax: 312-642-7243 www.dbsalliance.org
The National Alliance for the Mentally Ill 2107 Wilson Blvd. Suite 300 Arlington, VA 22201-3042 Tel: 703-524-7600 Fax: 703-524-9094 www.nami.org	The National Association of Protection and Advocacy 900 Second Street, NE, Suite 211 Washington, DC 20002 Tel: 202-408-9514 Fax: 202-408-9520 info@ndrn.org www.napas.org
National Association of Social Workers 750 First Street NE, Suite 700 Washington, DC 20002-4241 Tel: 202-408-8600; 800-742-4089 www.socialworkers.org	National Association of State Mental Health Program Directors 66 Canal Center Plaza, Suite 302 Alexandria, VA 22314 Tel: 703-739-9333 Fax: 703-548-9517 www.nasmhpd.org
National Council for Community Behavioral Healthcare 1701 K Street NW, Suite 400 Washington, DC 20006 Tel: 202-684-7457 Fax: 202-684-7472 communications@thenationalcouncil.org www.thenationalcouncil.org	National Empowerment Center 599 Canal street Lawrence, MA 01840 Tel: 800-769-3728 www.power2u.org/
National Mental Health Association 2000 N. Beaurgard Street, 6th Floor Alexandria, VA 22311 Tel: 703-684-7722; 800-969-6642 Fax: 703-684-5968 www.nmha.org	National Mental Health Consumers' Self-Help Clearinghouse 1211 Chestnut Street, Suite 1207 Philadelphia, PA 19107 Tel: 800-553-4539 Fax: 215-636-6312 info@mhselfhelp.org www.mhselfhelp.org

Appendix 3

THE MENTAL HEALTH ASSOCIATION OF NYC

A MENTAL HEALTH AGENDA FOR THE 2ND DECADE OF THE 21st CENTURY

In the first decade of the 20th century, Clifford Beers, the founder of the Mental Health Association movement, articulated the vision which nearly 50 years later became the core mental health policy of the United States. From his own dreadful experiences as a patient in several psychiatric hospitals came a commitment to devote his life to humanizing the conditions in mental hospitals, to preventing the need for hospitalization, and to preventing mental illness and its disabling consequences. He believed that many people with mental illnesses were treated badly because of stigma and ignorance and sought to build national and international organizations through which myths could be dispelled and progressive public policies championed. With the shift from institution-based to community-based mental health policy in the mid-1950s, Beers' vision became the driving force of public mental health policy in the United States.

While deinstitutionalization, the first wave of community mental health, was of great benefit to people who were able to have better lives outside the hospital, it was a disaster for a great many people who were essentially abandoned in the community without the services and supports that they needed. As a result, they lived in terrible conditions and without adequate treatment or became the responsibility of their families, who simply refused to let family members live in danger and squalor.

In the late 1970's, about 10 years after the most aggressive period of deinstitutionalization began, a community support policy was instituted in The United States. This policy shift resulted in a significant expansion of services in the community for adults with serious and persistent mental illnesses including housing, outpatient services, acute inpatient services in general hospitals, crisis services, rehabilitation, case management, and peer support. Many people who would have been living either in State hospitals or in terrible conditions 30 years ago are now leading lives in the community which are far more satisfying than the lives they would have had without the Community Support Program.

At the same time that a community-based system of care was being created for adults with serious psychiatric disabilities, a system of care was also emerging for people with less severe mental disorders such as mild to moderate anxiety and mood disorders. Funded initially primarily from private sources—self-pay, insurance, and philanthropy, over time more and more public funding became available for services to this population, most of it from Medicaid and Medicare. As a result, many people with distressing but not extremely disabling mental disorders have been able to get treatment through a publicly supported mental health system. Recently, new federal and state "parity" laws have mandated that private health plans and Medicare provide equal coverage of health and mental health conditions. This, hopefully, will result in increased access to mental health services in the coming years.

INADEQUACIES OF THE CURRENT MENTAL HEALTH SYSTEM

Despite the improvements which have emerged because of the Community Support Program, Medicaid, Medicare, and parity, there are a number of notable inadequacies with the current mental health system.

1. There are still unmet needs for a broad range of community supports for adults with long-term psychiatric disabilities—particularly for decent housing.

2. About 60% of people who have diagnosable mental disorders do not get mental health services.

3. The quality of services is extremely uneven. The most recent major epidemiological study estimates that 15-20% of people with mental disorders get treatment only from primary care health providers, who provide "minimally adequate" treatment less than 15% of the time. Most others who get treatment get it from mental health professionals, who provide minimally adequate treatment less than 50% of the time.

4. Despite the clarity that has developed about the importance of integrating the delivery of mental health, substance abuse, and physical health services, integrated treatment is still by far the exception rather than the rule.

5. There are still populations that are markedly underserved—including

    a. children and adolescents
    b. older adults
    c. minorities
    d. people with serious mental illnesses who reject or cannot use traditional services
    e. people with co-occurring severe mental, substance use, and physical health conditions
    f. military personnel, veterans, and their families,
    g. and more.

6. Bio-medical research has not yet produced breakthroughs of the kind that have been expected for the past 25 years.

7. The mental health system has not yet begun to prepare for dramatic changes in demography that are now underway in America, especially the rapid growth of minorities and the elderly.

8. Fundamental changes in the "structure" of the mental health system that have taken place due to the reduced role of state psychiatric hospitals, the growth of reliance on Medicaid, and major shifts in employer-based mental health coverage have resulted in a need to rethink and re-organize service delivery, management, finance, and regulation.

To respond to these inadequacies our society will need to provide substantial additional funding for mental health services and supports through both the public and the private sectors. It will also need to engage in substantial restructuring activities including service integration, removal of legal and regulatory barriers to providing state-of-the-art care, the development of revised payment methodologies, and more.

It is possible that some of these issues will be addressed as part of the process of health policy reform now taking place in the United States, but so far it appears that there will be very limited attention paid to mental health needs if health policy reform moves ahead.

Below are specific changes that are needed to improve mental health policy and practice in both the public and the private sectors.

Adults

- A substantial number of **people with recurrent, serious mental illnesses reject, or cannot use, traditional mental health services**. Some people who avoid treatment manage quite well without it, but many end up in crisis and then experience long hospitalizations. An increasing number of them are now in jails and prisons, generally for minor offenses. A very few commit acts of violence which make the headlines that dominate public debate about mental health policy. Many of these episodes of inappropriate treatment and human tragedy could be averted if **relevant and responsive community services** were available.

- A substantial number of people with serious mental illnesses have been **"transinstitutionalized" to jails and prisons, nursing homes, and large congregate care facilities** for poor people who are believed to be unable to live independently in the community. (In New York State they are called "Adult Homes.") Care in these institutions is often poor, sometimes scandalously poor. Solitary confinement and other punishments in forensic facilities are irresponsibly cruel for people with mental illnesses. In addition, adult and nursing homes become dead-ends for people who may be able to live more independently in the community if appropriate housing, services, and supports were available.

- There is **not enough appropriate housing** for people with serious mental illnesses, who often need help finding and paying for decent places to live and who often also need a variety of supports to be able to live in the community. Lack of housing results in homelessness, in living in squalor and danger, in excessive reliance on inappropriate institutions of various kinds, and in family burden.

- Despite decades of talk about providing **integrated treatment services for people who are mentally ill and abuse substances**, such services are still not widely available.

- People with serious mental illness die 10-30 years sooner than the general population in large part because of poor health. In addition, people with chronic physical conditions and mental illness are at high risk for disability, institutionalization, and premature death. They also have far higher medical costs than people without mental disorders. There is a clear need to **integrate physical and mental health care** in primary, specialty, and long-term care.

- Mental health services for adults with serious mental illnesses and their families are often **not based on practice models for which there is research support** because **many mental health professionals are inadequately trained in state-of-the-art models and because regulatory and financing structures are frequently based on outmoded treatment models**.

- Even when they get decent care and treatment, **most people with serious psychiatric disabilities are not employed** despite their desire to work and despite the existence of a

rehabilitative technology which might help them to get and keep jobs. Unfortunately rehabilitative opportunities are not widely enough available.

- **Services provided by people with mental illnesses for their peers**, while growing, remain limited and tenuous despite successful experiences throughout the country.

- There has never been adequate **support for families** of adults with serious mental illnesses even though they provide a large amount of care for their family members. As the current generation of parents providing care for their family members with psychiatric disabilities becomes too old to provide care and eventually dies, a resource on which our society depends informally will be lost.

- **Military personnel, veterans, and their families** have high rates of depression, post traumatic stress disorder, substance abuse, family dysfunction, and suicide. Many of those who would like help from the military or from the Veteran's Administration are not able to get it due to limited capacity, bureaucratic barriers, and stigma. Many, however, will not turn to these channels for help. Unfortunately, the generic health and mental health systems have generally not proved to be good at identifying mental and/or substance use problems or at engaging these people in treatment that is sensitive to their special problems and needs.

- Many adults with mental illnesses, whether mild, moderate, or severe, **cannot get access to mental health services in the private sector.** Parity laws may improve access for those who have not been able to afford treatment.

- But **mental health professionals**, in both the public and the private sector, are in short supply and are simply **not available** in some parts of the country.

Children and Adolescents

- **Children and adolescents with serious emotional disturbances frequently do not get mental health services or do not get the mental health services that would best meet their needs**.

- The average age of onset of a protracted mental illness is 14, but most people do not get treatment until about 10 years after the illness first appears. This **failure of early intervention** probably results in more personal problems and increased risk of disability in adult life.

- There are **not enough mental health services for children and adolescents in the public mental health system or in the private sector.**

- This reflects

    - **Insufficient public funding**
    - **Inadequate insurance coverage**
    - **A shortage of mental health professionals for children and adolescents**.

- Mental health services for children and adolescents are often **not based on practice models for which there is research support** because **many mental health professionals are**

inadequately trained in state-of-the-art models and because regulatory and financing structures are frequently based on outmoded treatment models.

- Outpatient services generally are **not flexible enough** with regard to time, place, and nature of services provided. In addition they generally are **not responsive enough to crises** in the lives of emotionally disturbed children and their families.

- **Inpatient services and residential treatment**, which are critical elements of a comprehensive mental health system for children and adolescents, are **over-utilized because of the absence of a comprehensive system of community-based services which provides a full continuum of services**.

- **Involvement of families in the treatment of their children and support for these families** or caretakers is not nearly as widespread as it should be.

- Children with serious emotional disturbances often are served in several child-serving systems. Little progress has been made in the effort to **integrate child-serving systems.**

Readiness for Demographic Shifts

- The mental health system generally has **not** been **preparing for dramatic demographic shifts** which will take place within the next two decades—especially the growth of older adults (the "baby boom generation") and the growth of cultural minorities.

- As the number of **older adults** grows, so will the number of older adults with significant mental health problems. And they will be more likely to seek out and use mental health services than the current generation of older adults. Nevertheless, meeting the need for more mental health services for this population is not generally included in plans for new mental health services.

- **Minority and immigrant populations** are also growing rapidly. Lack of widespread **cultural competence** will become an ever-greater problem as minority populations grow.

Quality of Care and Treatment

- Despite remarkable improvements in the effectiveness of treatment over the past 25 years and a dramatic shift in attitude among the best practitioners towards recipients of services and their families, **serious problems with the quality of care** remain**.**

- A **human resources crisis** has emerged. Recruitment and retention of well-qualified staff has become exceedingly difficult resulting in serious problems maintaining minimally adequate staffing levels and in providing continuity of care.

- **Many providers are not adequately trained in new treatment methods** and/or in the **need for respect and humanity regarding people with serious mental illnesses and their families**.

- **Research has not yet provided the dramatic breakthroughs in treatment** which have been the central hope for mental health, even though there have been important strides made.

MHA's 12-POINT MENTAL HEALTH POLICY AGENDA

In order to promote a meaningful response to the inadequacies noted above, MHA has formulated the following 12-point advocacy agenda.

1. **Mental health policy reform should be a major component of national and state health policy reform.** This should include: preservation of parity commitments, enhanced integration of mental and physical health care, provisions for workforce development, and revisions of Medicare to cover long-term care and to reflect the special mental health needs of older adults.

2. **Mental health policy should be built on an understanding of the populations** for whom mental health services would be beneficial. There should be a public commitment to meet the mental health needs of these populations by **progressively developing a comprehensive and integrated array of community-based mental health services** including crisis intervention, outpatient services, housing, rehabilitation, case management, peer support services, and inpatient services.

   Progressive expansion of the mental health system should focus particularly on **underserved populations** including (a) children and adolescents, (b) older adults, (c) minorities, (d) people with serious mental illnesses who do not use traditional services, (e) homeless people, (f) people with co-occurring severe mental, substance use, and physical health conditions, and (g) military personnel, veterans, and their families.

   An **empirically based needs assessment and multi-year planning** process should guide this process of development.

3. There should be a multi-year commitment to expand **housing, treatment, support, and rehabilitation and healthcare services for adults with serious mental illnesses** who are not adequately served by the current mental health system, especially those who are:

   - Homeless
   - Living in "adult homes" or nursing homes
   - Involved with the criminal justice system
   - Unwilling or unable to use mental health services
   - Unemployed
   - Substance abusers
   - Veterans.

   This effort should include expanding initiatives which **stress recovery, enhance access to mainstream society, and improve quality of life**.

   It is particularly important to work for better health of people with serious mental illness through improved access to high quality health care and through health promotion activities.

4. There should be a multi-year commitment to **build a comprehensive, community-based system of care for children and adolescents** including:

- **Development of a full range of services**—crisis, outpatient, community support, case management, family support, residential, and inpatient.
- **Expansion and reshaping outpatient and community services** with emphasis on services that are flexible, mobile, and responsive to crisis
- **Increased use of state-of-the-art treatment models**
- Increased attention to children and adolescents who are **victims of abuse or neglect, caught up in the juvenile justice system, or are failing in school.**
- An emphasis on **early intervention** and the provision of services **to build emotional resilience**
- **Improved integration with other child-serving systems.**

5. There should be a multi-year commitment to **prepare for predictable demographic shifts**, especially for:

    - **Older adults** with mental health problems including:

        - The development of long-term, inter-agency plans for geriatric mental health and addiction services at federal, state, and local levels
        - Expansion of geriatric mental health and addictions services especially in home and community settings
        - Improvement of geriatric mental health and addictions services in institutional and community service settings
        - Integration of physical and behavioral health services in primary, specialty, mental health, and long-term care and of behavioral health and aging services
        - Improved funding through optimized use of existing funding streams (especially Medicare), through modification of funding structures to support home and community-based services and service integration, and through increased funding
        - Development of a workforce with clinical, cultural, and generational competence and which is large enough to match the growth of the aging population
        - A research agenda for geriatric mental health that will contribute to improved services in all systems serving older adults with mental and/or addiction problems.

    - **Cultural minorities and immigrants** with mental health problems including:

        - Increased availability of bi-lingual mental health professionals and of good translators
        - Improved access of cultural minorities to high quality service providers in the private as well as the public sector
        - Improved engagement of cultural minorities in mental health programs
        - Improved clinical services to culturally diverse people
        - Workforce development to build cultural competence
        - Fair promotional opportunities
        - Dealing with race relations issues in mental health programs and facilities.

6. **Access to mental health services in the private and public sectors should be improved** by:

    - Making mental health services more available in primary health care, social services, and other community settings.

- Increasing the availability of mental health professionals especially in underserved geographic areas.
- Implementing **parity** between health and mental health insurance coverage as required by new federal and state laws.
- **Assuring that care is available to people without insurance coverage or with inadequate insurance coverage**, including immigrants and undocumented aliens

7. There should be a commitment to enhance quality of care by:

    - Addressing the need for **enhanced clinical and cultural competence** of health and social services providers as well as mental health professionals and paraprofessionals
    - Providing **integrated treatment and collaborative service programs** for people with co-occurring mental, physical, and/or substance use disorders
    - Supporting mental health biomedical, clinical, services, and policy **research** which is **responsive to contemporary mental health policy goals** and which seeks breakthroughs in knowledge and treatment.
    - Assuring **widespread knowledge of state-of-the-art treatment and rehabilitation**
    - **Eliminating abuse** of people with mental illnesses wherever it occurs.

8. **Major workforce development initiatives** should be launched at both the federal and state levels

    - **Addressing the shortage** of mental health professionals, especially for children, older adults, and minorities via
        - Expanded education and training programs
        - Removing barriers such as the high cost of education
        - Creating incentives to become a mental health professional
    - **Developing useful roles for peers, family members, and retired people** as respected providers of services that support and complement professional mental health services.

9. There should be a commitment to a widespread **family support initiative** to assist families who are providing housing and other forms of care for their mentally ill family members including parents of children with serious emotional disturbance, parents of adult children with serious and persistent mental illness, adult children caring for parents with mental disabilities, and grandparents raising their grandchildren.

10. There should be a commitment to **overcome stigma and discrimination** and to educate the public about the realities of mental illness.

11. Federal, state, and local governments should make a **financial commitment** commensurate with progressive mental health policy including:

    - **Maintenance of adequate financial support for core** community mental health services with **routine adjustments for inflation** and **assurance of living wages**.
    - **Progressively increasing funding** for:

        - **Services for populations who are not adequately served by the current system**
        - **Improved education and training** of mental health providers
        - **Research**.

12. Federal, state, and local governments should work together to rethink and re-organize service **structural, regulatory, and financial models so as to support the progressive development of a comprehensive community-based mental health system.**

Appendix 4

THE STRUCTURE AND FUNCTIONS OF GOVERNMENT IN THE UNITED STATES

Levels of Government

- There are four levels of government in the United States--federal, state, county, and municipal.
- Different levels of government have different roles, functions and responsibilities, which vary both from one historical period to another and from one state to another.
- Except for Social Security, SSI, Medicare, and Medicaid, the federal government has very limited responsibility for health and human services. States have primary responsibility.
- The responsibilities of counties for health and human services vary from state to state.
- New York City is confusing because it serves both the county and the municipal functions.

Branches of Government

- There are three branches of government in the United States--legislative, executive, and judicial.
  - At the federal level
    - The legislative branch is the Congress, composed of the Senate and the House of Representatives.
    - The executive branch consists of The President and the members of a Cabinet, who are appointed by the President with the approval of the Senate. Cabinet members head the federal administrative departments, and most are called "Secretaries."
  - In New York State
    - The legislative branch is the State Legislature, consisting of The Senate and the Assembly.
    - The executive branch is headed by The Governor, who--with the approval of the Senate--appoints a Cabinet that includes the commissioners who head NYS's administrative agencies.
  - In New York City
    - The legislative branch is the City Council
    - The Chief Executive is the Mayor, who appoints the heads of various city departments, who are usually called "Commissioners"
- The judicial branch of government exists at all levels of government.
  - There is a very complicated array of types of courts such as criminal courts, family courts, and surrogate courts, etc.

- There is also a hierarchy of local, state, and federal Courts culminating in ultimate courts of appeal in each state and in the United States Supreme Court.

Making Laws: Statutory Law, Case Law, and Constitutional Law

- Laws made by legislatures are called "statutory law."
- Laws made through court rulings are called "case law." Frequently the only way to know what a statutory law means is to know the history of court rulings related to its interpretation.
- Constitutional law is based in the Constitutions of the United States and the individual states.
- Ultimately the courts have the authority to determine whether a law is or is not constitutional.
- The formal process of enacting statutory law is
  - Members of the legislature (called "sponsors") or the chief executive propose a law.
  - After it is introduced, a proposed statute (generally called a "bill") is given a number.
  - The bill is referred to a committee, which usually must approve it before the legislature votes.
  - In addition many bills must go through a finance committee before reaching the floor.
  - The legislative leaders usually have the power to prevent a bill for coming up for a vote.
  - A majority of legislators must vote for the bill, which also must be signed by the chief executive unless his or her veto is over-ridden by a super-majority (usually 2/3).
- The informal process of making statutory law depends very heavily on legislators who become experts in a few areas, on their political parties, and on their staff.

Making Budgets

- Budgets at all levels of government are made through a process that involves:
  - The administrative department makes a request to the chief executive.
  - The chief executive submits a budget proposal to the legislature.
  - The legislature passes a budget bill which must be signed by the chief executive.
  - The administrative department spends money as provided in the budget.
- At all levels of government there are budget departments, sometimes called an Office of Management and Budget, sometimes called a Finance Department, sometimes called The Division of the Budget.

Executing Laws and Implementing Budgets

- Making Regulations
  - Regulations spell out details which are not included in the laws themselves.

- Regulations have the force of law but they are developed solely by the executive branch.
- In general proposed regulations are issued for information and for public comment prior to being promulgated. Sometimes they are issued on an emergency basis, without public input.
- Regulations can be as important as laws in determining mental health policy. Licensing standards, for example, have a great impact on quality of treatment. Approvals for new programs can foster quick development of needed new programs or slow them to a trickle.

- Planning
  - One of the functions of the executive branch of government is to develop plans.
  - For example federal law requires all state mental health authorities to submit a plan for mental health services for people with serious mental illnesses.
  - New York State law requires a five-year plan for mental health services and annual updates.
  - It also requires local governments to submit local plans to OMH.
  - Planning processes generally require some sort of public review.
  - In NYS the two major planning advisory bodies are The Mental Health Services Council and The Mental Health Planning Advisory Committee.
  - In NYC the major advisory groups are the Community Services Board and The Federation.

- Program Implementation
  - When laws and budgets create or expand programs, the executive branch must implement them.
  - Executive agencies may ask for input about how to develop the new programs.
  - Whether there is a formal process or not, there are usually informal opportunities to influence program development by talking with the staff in charge.

- **Court Action**
  - The courts can also make mental health policy.
  - For courts to make rulings which create case law, a legal action must be taken. Legal actions can either be on behalf of specific individuals or on behalf of classes of individuals ("class action lawsuits").
  - Findings of lawsuits on behalf of individuals apply only to those individuals unless rulings are made which set legal precedents. This often happens through an appeals process.
  - Findings of class action lawsuits apply to all people who are in the class.
  - Sometimes lawsuits are settled without a court finding, but such settlements can create new policy when the executive branch of government agrees to do something new.

- Some settlements are called "consent decrees." The court is part of the agreement and retains authority to make sure that the government does what it has agreed to do.

- Over the years many important mental health policies have been forged in the courts. Issues such as when people can be hospitalized against their wills, the grounds for holding people in hospitals, discharge planning requirements, the right to treatment, forced and unpaid labor by psychiatric patients, and many others have been resolved through court action.

Appendix 5

MENTAL HEALTH POLICY MAKING IN THE UNITED STATES

- It is commonplace to believe that the federal government has greater power than other levels of government on all matters. It's just not so. The Constitution of the United States and more than 200 years of history make it clear that there are areas over which the federal government has little or no authority.

- In order to formulate effective mental health advocacy strategies with government, it is critical to know what level of government and what branch of government are responsible for what mental health policies. In many cases there is overlapping responsibility, and it will be necessary to decide which of the responsible bodies or officials to approach for change.

Federal Mental Health Policy Making

- Mental health policy is an area of governmental responsibility in which the Federal government has a limited role. By tradition, the states have primary responsibility.

- The responsibility of the federal government for mental health includes research, practice leadership, and funding of services through Medicaid & Medicare and several comparatively small grants program, including the Mental Health Block Grant.

- Over the past couple of decades the federal government has also had a significant impact on issues related to the rights of people with serious mental illnesses. For example, The Fair Housing Act and The Americans with Disabilities Act prohibit discrimination against people with mental illnesses in housing and in work.

- The federal government has also weighed in recently on the issue of mental health insurance coverage, has set standards on restraint and seclusion, and has created new requirements for the VA stressing community mental health services for veterans.

Making Federal Mental Health Law

- To make mental health law a bill must be introduced in both the House of Representatives and the Senate by at least one member of each. It is best to have multiple sponsorship including members of leadership.

- Depending on the nature of the legislation, it will be sent to one or more committees. In the House this will usually include The Health Sub-Committee of the Energy and Commerce Committee. In the Senate it will usually include The Health, Education, Labor, and Pensions Committee.

- Any bill with fiscal implications will also be sent to the Ways and Means Committee of the House and the Finance Committee of the Senate.

- The bill generally must be approved by the committees and the leadership to come to the floor for a vote.

- The bill must be supported by a majority of members in both the House and the Senate.

- If the bills passed in each house are different, a House-Senate conference committee will be convened to reconcile the differences. These compromises are generally approved routinely by the House and the Senate.

- To become law The President must sign the bill.

- A veto can be overridden by a 2/3 majority in both the House and the Senate.

- It is very important to have a presence in Washington during the last minute passage of bills.

Making The Federal Budget

- The President submits a budget proposal to the Congress in February.

- Congress develops a budget through its committees using a complex process.

- First, Congress is supposed to pass a Budget Resolution, giving the overall shape of the Federal budget, by April 15. Usually it is late.

- When the budget resolution diverges substantially from current budgetary authority a Budget Reconciliation Act is passed. This Act is stitched together from decisions by committees about how to bring the spending for which they are responsible in line with the Congressional Budget Resolution.

- The Budget Resolution essentially "allocates" specific amounts of money to broad areas of spending, which are the responsibility of specific committees.

- Each committee must make "appropriations" specifying how its allocation will be spent.

- Often appropriations bills are passed shortly before the fiscal year begins on October 1. When the budget process has not been completed on time, "continuing resolutions" are usually passed. Occasionally the government has shut down temporarily.

- To influence the budget, advocates should work with federal departments prior to February and with the Congress and the federal departments after the President's budget is released.

Federal Administration of Mental Health Policies and Programs

- Research and Practice Leadership

    - Mental health research is primarily the responsibility of the National Institute of Mental Health (NIMH), which is part of The National Institutes of Health (NIH.)

    - Practice leadership is primarily the responsibility of the Center for Mental Health Services (CMHS), which is part of the Substance Abuse and Mental Health Services Administration (SAMSA).

        - CMHS tries to stimulate the development of services using state-of-the-art service models by funding demonstration programs and services research.

        - For the most part, it does not provide funding for ongoing service programs.

- Federal Funding for Services
  - The primary sources of federal funding for ongoing service programs are Medicaid and Medicare, which cover a major portion of the public sector's costs of providing mental health care.
  - The Centers for Medicare and Medicaid are responsible for Medicare and Medicaid.
  - Some funds are made available to the states through the Mental Health Block Grant, which is administered by SAMHSA.
- Income Maintenance for People with Disabilities
  - Under federal law, some people with long-term disabilities are eligible for Social Security Disability (SSD) and others are eligible for Supplemental Security Income (SSI). The Social Security Administration administers both of these programs.
- The Department of Health and Human Services
  - NIMH, SAMHSA, The Centers for Medicare and Medicaid, and The Social Security Administration are all parts of The Department of Health and Human Services (HHS) and are ultimaTely responsible to the Secretary of HHS.
- Other Federal Departments
  - Other departments which have major roles with regard to mental health policies and programs include The Department of Housing and Urban Development (HUD), The Department of Education, and The Department of Labor.

Mental Health Policy Making in NYS

- In the United States the states have primary responsibility for care for people with mental illnesses and have a very extensive role in determining mental health policy.
- New York State's functions include the operation of state psychiatric centers, provision of funding for local mental health services directly and through Medicaid, mental health planning, regulation of the mental health system, licensing of mental health programs, approval of new program development, and some research.

Making Mental Health Law in NYS

- Making law in NYS goes through a process that includes the introduction of bills, the gathering of sponsors, approval by relevant committees, acceptance by leadership, passage by The Assembly and The Senate and signature by the Governor.
- It is important in NYS for both the Assembly and the Senate to pass the same bill because, unlike the U.S. Congress, NYS legislature rarely uses a process to resolve differences between the two houses.
- For mental health law the key committees are usually The Mental Health Committee in the Assembly and the Mental Health and Developmental Disabilities Committee in the Senate. Some mental health bills must go through other committees.

- Assembly Ways and Means and Senate Finance Committees must approve bills which involve state spending.

- All legislation must get approval from the Speaker of the Assembly and the Majority Leader of the Senate to get to the floor for a vote.

- In the real process of negotiation that leads to the enactment of a law, the key parties are the committee chairs and their staff, legislative leaders and their staff, the Governor and his staff, the Division of the Budget, and the Office of Mental Health.

- The NYS Legislature convenes in early January and adjourns during the summer.

- It is difficult to pass legislation which is introduced for the first time after the session is convened; therefore it is best to begin work with legislators in November and December.

- It is often important to have a presence in Albany during the last minute passage of bills.

Making the Mental Health Budget in NYS

- The Office of Mental Health submits its request to the Governor (actually the Division of the Budget) in the Fall.

- The Governor submits a budget request to the legislature in mid-January.

- The legislature passes a budget with the approval of the Governor by April 1. (April 1 is the date required by the State Constitution but often the deadline is not met.)

- Prior to agreeing to a budget the Governor and the Legislature generally have protracted, acrimonious negotiations which end in sullen compromises.

- Advocacy about the budget needs to have three phases.

    - In early summer advocates should pressure commissioners of relevant departments, such as the Office of Mental Health, the Department of Health, the Office of Child and Family Services, etc.

    - In November and December advocates should pressure the Governor and the Division of the Budget.

    - From the release of the Governor's budget request until the passage of the budget, advocates need to work with the Legislature, the Governor, the Division of the Budget, and relevant state agencies. Work with the Legislature must be focused on the chairs of the relevant program committees and with the committees which cover finance as well as with the leaders of the Assembly and the Senate.

Administration of Mental Health Policy and Programs in NYS

- Administration of mental health policy and programs in NYS is primarily the responsibility of The Office of Mental Health , which is headed by a commissioner.

- A member of the Governor's staff attends to day-to-day and policy developments in OMH.

State psychiatric centers

- The Office of Mental Health operates the state psychiatric centers, which are a major source of inpatient and outpatient treatment and of community housing and community support programs.
- There are 26 psychiatric centers throughout the state including eight in New York City.
- Directors of state psychiatric centers have a high degree of independence within allocations of staff and funds made by OMH centrally.
- State psychiatric centers are overseen by Boards of Visitors appointed by the Governor.
- Most also have family and consumer advisory committees, consisting of patients and their families.

Funding local programs

- New York State provides funding for mental health programs which are not operated by The Office of Mental Health through a variety of "funding streams." These include Medicaid, local assistance, community support systems (CSS), housing, reinvestment, etc.
- Medicaid funds go directly to licensed service providers, which bill for the services they provide.
- Most other funds go to local governments, which contract for services with local providers or provide services themselves. Some funds are subject to contracts between OMH and a local provider.
- Some of the funds from the state must be matched by local governments or local agencies. For example, federal, state, and local governments share Medicaid costs. And "local assistance" funds require a local match, which in most parts of the state is 50%.

Mental health planning

- State law requires OMH to develop a five-year plan for mental health and update it annually.
- These plans are supposed to link to local mental health services plans, which are prepared by local departments of mental health annually.
- Local and state planning processes both use planning advisory committees, which consist of people with various interests in mental health including providers, families, and recipients.
- At the state level the two primary planning advisory organizations are The Mental Health Services Council, which has members appointed by the Governor with the approval of the Senate and The Mental Health Planning and Advisory Committee, whose members are appointed by The Commissioner of Mental Health.
- These planning advisory committees create opportunities for advocates to have input into mental health planning either by becoming members of advisory committees or by simply attending their meetings, which are required to be open to the public.
- Although state law requires that the OMH plan be distributed by October 1, dates of release have varied in recent years.
- Hearings of various kinds and in various parts of the state are held annually to get input from members of the community.

Regulation

- OMH promulgates regulations covering such matters as licensing standards, requirements for new program development, and procedures for involuntary commitment among many others.
- Regulations are drafted by teams of OMH staff but are the direct responsibility of the Bureau of Policy and Regulation within the OMH Counsel's office.
- All regulations are issued for information and comment before they are issued by the Commissioner, except those that are issued on an emergency basis. Advocates may send written comments to OMH.
- Regulations are also subject to review by the Mental Health Services Council before they are issued.

Certification (Licensing)

- New York State requires many, but not all, mental health programs to be licensed.
- All inpatient and outpatient treatment programs and some housing programs must be licensed.
- To get a license, a program must first get approval to be established (see below.)
- To continue to be licensed, a program must pass inspections which take place periodically. The frequency of inspections depends on findings of OMH certification specialists. If a program is in virtually total compliance with licensing regulations, it can get a license for as long as three years. If a program is not fully in compliance, its license would be for a shorter period of time.
- Certification is not a public process, but it is possible to get copies of certification reports under the Freedom of Information Law (FOIL).
- State licensing was not created to assure that programs are of the best quality but only to assure that a program meets minimum standards.

Approval of New Program Development

- Licensed programs and programs which depend on public funding must get permission to establish a new program or to significantly expand or close an existing program.
- Generally new program development is subject to public review both at local and state levels.
- In NYC, local reviews take place in the various committees of the Federation.
- For NYS public review is done by The Mental Health Services Council.
- The local commissioner decides whether or not to recommend the establishment of a new program to the state commissioner, who decides whether or not the program can be established and expanded.

Role of the Field Office:

- Its field offices carry out some functions of OMH. This includes making recommendations regarding certification, new program development, local planning, and funding for local services.

The NYC Field Office of OMH is located at 330 Fifth Avenue, New York, NY 10001.
Telephone: 212-330-1650.

Research

The Office of Mental Health also operates two research institutes. The NYS Psychiatric Institute is located in New York City and is affiliated with Columbia University. The Nathan Kline Institute is located in Rockland County and is affiliated with New York University.

Other State Departments Which Affect People with Mental Illnesses

- The population for which OMH is responsible has substantial overlap with the populations for which The Office of Mental Retardation and Developmental Disabilities (OMR/DD) and The Office of Alcoholism and Substance Abuse (OASAS) are responsible. Services for people with what are now called "co-occurring" disorders are very much affected by tensions, conflicts, and the failure of integration among these three departments.

- These three departments are all subject to review by The Commission on the Quality of Care, which has wide authority to inspect mental health, mental retardation, and chemical dependency programs and to issue reports about the quality of care and about the organization of the systems of services.

- The Department of Health (DoH) has overall responsibility for Medicaid and is involved with the development of mental health rates and funding regulations.

- DoH also licenses primary health care clinics and centers, many of which also provide mental health services.

- The Department of Education

  - is responsible for vocational rehabilitation and oversees a number of programs which serve people with mental illnesses who want to go to work,

  - oversees school related services to children and adolescents with serious emotional disturbances,

  - licenses or certifies mental health professionals.

- The Office of Children and Family Services is responsible for the child welfare and juvenile justice systems, through which many youngsters with serious emotional disturbances are served.

- Department of Insurance has responsibility for health insurance, including mental health insurance.

- The Office of Temporary and Disability Assistance in the Department of Family Assistance and The Department of Housing are also important.

Mental Health Policy Making in NYC

NYC's mental health functions include planning, contracting with local providers, providing city tax levy funds to match state and federal funds, and service provision by the Health and Hospitals Corporation.

Making Mental Health Laws and Budgets in NYC

- Local governments play virtually no role in making mental health laws in the United States.

- The role of the City Council regarding mental health is limited to the making of the city budget.

- The City budget process has two components-- (1) a preliminary budget, which provides a projection of spending and revenues for four years and (2) an annual budget.

- The Mayor submits the preliminary budget in mid-January. The Mayor submits an annual budget proposal at the end of April.

- Negotiations take place until the budgets are adopted, no later than June 21.

- The Council's Mental Health Subcommittee of the Health Committee can have significant impact on the budget for mental health.

City Funding for Mental Health Services

- New York City uses funds which it derives from city taxes ("NYC tax levy funds") to provide the matching funds required by NYS to receive "local assistance" from the state.

- NYC also uses its tax levy funds to pay its share of Medicaid.

- NYC tax levy funds are also used to provide some funding for The Health and Hospitals Corporation (HHC).

- In addition NYC sometimes uses its tax levy funds to cover the costs of special programs, which it believes to be important enough to do even without federal or state financial participation.

Administration of Mental Health Policies and Programs in NYC

- The administration of mental health policies and programs in NYC is primarily the responsibility of The Department of Health and Mental Hygiene, which is headed by a Commissioner. Reporting to the Commissioner is an Executive Deputy Commissioner for Mental Hygiene, who has responsibility for mental health, mental retardation, and substance abuse services.

- The functions of the department are primarily mental health planning and contracting.

  For information call 212-219-5400.

The Local Planning Process in NYC

- Local planning in NYC includes two major elements--the annual mental health plan and review of proposals for new program development.

- These plans are subject to review by one or both of two planning advisory groups--The Community Services Board and The Federation for Mental Health, Mental Retardation, and Alcoholism Services.

- The annual mental health plan is supposed to link with NYS's mental health planning process and to link as well with decisions regarding state funding for NYC.

- The city is also required to make recommendations regarding proposals to establish new programs, to significantly expand existing ones, or to close programs. DOHMH sends its recommendations to OMH, which must make the decision to approve or to reject proposals.

- For its Annual Plan, the city uses The Federation to fulfill the state requirement that local plans be subjected to review by planning advisory groups which consist of consumers, providers, and interested citizens.

- The Federation is an independent organization. NYC's Executive Deputy Commissioner of Mental Hygiene appoints its chair, but the Federation itself selects all other officers and members.

- The Federation has a citywide interdisciplinary disability committee with citywide subcommittees for each disability and additional subcommittees by borough and by special population.

- Some Federation sub-committees have become quite active as mental health advocates and some have taken on projects related to public education.

- For more information about The Federation, call DOHMH's Bureau of Mental Hygiene Policy, Planning and Clinical Affairs at 212-219-5617.

Contracting with providers

- In New York City, DOHMH does not provide any direct mental health services. Instead it contracts with local providers--almost all of which are not-for-profit--to provide needed mental health services.

- DOHMH also monitors programs, both to be sure they provide the amount of service agreed to in the contract and to assure that the service of acceptable quality.

Direct service via HHC

- HHC operates an extensive system of outpatient and inpatient mental health services.

- Historically it has tended to serve most of the poor people in NYC because it provided free care.

- Each HHC facility has a department of psychiatry which operates with some degree of independence, but HHC facilities are now linked into networks of hospitals covering certain geographic areas. The purpose of the networks is to coordinate care and to reduce duplication

- There is also a central department of psychiatry for HHC, which is now called the Department of Behavioral Health. It has overall responsibility for the quality of psychiatric care in HHC facilities and attempts to provide leadership in new program development.

Other City Departments Which Affect People with Mental Illnesses

- The Human Resources Administration is responsible for the administration of income maintenance in New York City. Many people with mental illnesses connect with HRA for disability assessments and for income maintenance.

- The Department of Homeless Services is responsible for services for homeless people in NYC. 30-40% of homeless people have serious and persistent mental illnesses.

- The Department of Housing Preservation and Development manages housing for NYC. It plays a major role in developing housing for homeless people with serious and persistent mental illnesses.

- The Administration for Children's Services is responsible for child protection, foster care, and prevention of foster care services in NYC. Many of the children it serves have serious emotional disturbances and some of the group residences it contracts with provide residential treatment.

Appendix 6

KEY ELECTED FEDERAL OFFICIALS

The President

Barack Obama
The White House
Washington, DC 20500
202-456-1414

The Majority Leader of the Senate

Harry Reid
Washington, DC
522 Hart Senate Office Bldg
Washington, DC 20510
Phone: 202-224-3542
Fax: 202-224-7327
Toll Free for Nevadans:
1-866-SEN-REID (736-7343)

Speaker of The House

Nancy Pelosi
H-232, US Capitol
Washington, DC 20515
(202) 225-0100

Chairman of Senate Finance Committee

Max Baucus
219 Dirksen Senate Office Building
Washington, DC 20510-6200
(202) 224-4515

Chairman of Ways and Means

Charles Rangel
Committee on Ways & Means
U.S. House of Representatives
1102 Longworth House Office Building
Washington D.C. 20515
Phone: (202) 225-3625
Fax: (202) 225-2610

Chairman of Senate Health, Education, Labor and Pensions Committee

Vacant
Committee on Health, Education, Labor and Pensions
428 Senate Dirksen Office Building
Washington, DC 20510

Chairman of Health Sub-Committee

Frank Pallone, Jr.
WASHINGTON, DC
237 Cannon Building
Washington, D.C. 20515-3006
Phone: (202) 225-4671
Fax: (202) 225-9665

To Find Out Who Represents You In Washington

www.congress.org

Appendix 7

Key Elected Officials in NYS

The Governor

David Paterson
The Executive Chamber
The NYS Capitol
Albany, NY 12224
518-474-8390

The Majority Leader of the Senate Pedro Espada, Jr. Albany Office 420 Capitol Albany, NY 12247 Tel: (518) 455-3395 Email: espada@senate.state.ny.us	**The Speaker of the Assembly** Sheldon Silver 932 Legislative Office Building Albany, NY 12248 518-455-3791
The President Pro Tempore of the Senate Malcolm A. Smith 909 Legislative Office Building Albany, NY 12247 Tel: (518) 455-2701 Fax: (518) 455-2816 Email: masmith@senate.state.ny.us	
The Chairman of the Finance Committee of the Senate Carl Kruger 913 Legislative Office Building Albany, New York 12247 Tel: (518) 455-2460 Fax: (518) 426-6855 Email: kruger@senate.state.ny.us	**The Chairman of the Ways and Means Committee of the Assembly** Herman D. Farrell, Jr. 923 Legislative Office Building Albany, NY 12248 518-455-5491
The Chairman of the Standing Committee on Mental Health of the Senate Thomas Duane 430 State Capitol Building Albany, NY 12247 Tel: (518) 455-2451 Fax: (518) 426-6846 Email: duane@senate.state.ny.us	**The Chairman of the Mental Health, Mental Retardation and Developmental Disabilities Committee of the Assembly** Peter Rivera LOB 826 Albany, NY 12248 518-455-5102

To Find Out Who Represents You In The State Legislature
Call the League of Women Voters
212- 213-5286

Appendix 8

KEY ELECTED OFFICIALS IN NEW YORK CITY

The Mayor

Michael Bloomberg
City Hall
New York, NY 10007
212-788-3000

The Public Advocate

Betsy Gotbaum
Municipal Building 15th Floor North
1 Centre Street
New York, NY 10007
212-669-7200

THE CITY COUNCIL

The Speaker of the City Council

Christine Quinn
City Hall
New York, NY 10007
212-788-7210

Chair, Health Committee

Joel Rivera
250 Broadway, 18th Floor
New York, NY 10007
212-788-6966

Chair, Mental Health, Mental Retardation, Alcoholism, Drug Abuse and Disability Services Committee

G. Oliver Koppell
250 Broadway, 18th Floor
New York, NY 10007
212-788-7078

To Find Out Who Represents You In The City Council

Call the League of Women Voters
212- 213-5286

The Borough Presidents

The Bronx Borough President

Ruben Diaz, Jr.
Bronx County Building Room 301
851 Grand Concourse, 3rd Floor
Bronx, NY 10451
718-590-3500

The Brooklyn Borough President

Marty Markowitz
209 Joralemon Street
Brooklyn, NY 11201
718-802-3700

The Manhattan Borough President

Scott M. Stringer
Municipal Building 19th floor
1 Centre Street
New York, NY 10007
212-669-8300

The Queens Borough President

Helen Marshall
120-55 Queens Blvd.
Kew Gardens, NY 11424
718-286-3000

The Staten Island Borough President

James P. Molinaro
120 Borough Hall
Staten Island, NY 10301
718-816-2000

Appendix 9

KEY FEDERAL ADMINISTRATIVE OFFICIALS

Department of Health and Human Services

Kathleen Sebelius, Secretary
200 Independence Avenue SW
Washington, DC 20201
202-619-0257
www.dhhs.gov

The National Institute of Mental Health

Thomas R. Insel, Director
6001 Executive Boulevard
Bethesda, MD 20892-9663
1-866-615-NIMH (6464), toll-free
www.nimh.nih.gov

The Substance Abuse and Mental Health Services Administration

Eric Broderick
1 Choke Cherry Road,
Rockville, MD 20857
301-443-4795
www.samhsa.gov

The Center for Mental Health Services

A. Kathryn Power, Director
5600 Fishers Lane
Rockville, MD 20857
301-443-2619
www.mentalhealth.samhsa.gov

The Center for Medicare and Medicaid Services

Charlene Frizzera, Administrator
7500 Security Blvd.
Baltimore, MD 21244
410-786-3000
www.cms.hhs.gov

Appendix 10

Key Mental Health Officials in New York State

The New York State Office of Mental Health

44 Holland Avenue
Albany, NY 12229
518-474-4403
800-597-8481

- The Commissioner of Mental Health: Michael F. Hogan
- Executive Deputy Commissioner Bruce E. Feig
- Senior Deputy Commissioner Robert Myers
- Director, NYC Field Office Anita Appel
  330 Fifth Avenue, New York, NY 10001
  212-330-1650

Key Mental Health Officials in New York City

The New York City Department of Health and Mental Hygiene

93 Worth Street
New York, NY 10013
212-219-5400

- The Commissioner of Health and Mental Hygiene Thomas Farley, M.D.
- Executive Deputy Commissioner for Mental Hygiene Adam Karpati, M.D.
- Chief Operating Officer Andrew Rein
- Assistant Commissioner, Bureau of Mental Health Trish Marsik
- Assistant Commissioner, Bureau of Mental Hygiene Policy, Planning and Clinical Affairs Lily Tom

Appendix 11: Sample Handout for a Meeting with an Elected or Appointed Official

THE MENTAL HEALTH ASSOCIATION OF NEW YORK CITY

MENTAL HEALTH POLICY PRIORITIES FOR 2010

The Mental Health Association of New York City supports the incremental development of a comprehensive, community-based mental health service system in New York State. Progress in 2010 will be difficult because of the state's budget problems. **Fighting against cuts is our major priority for 2010**. However, we will also pursue improvements through targeted increased funding, reinvestment strategies, regulatory change, planning, and initiatives that can be implemented at little or no cost.

1. **Reject Funding Cuts for Community Mental Health Services**

   - Preserve funding for programs funded by Medicaid and those not-funded by Medicaid
   - Ensure that the restructuring of clinic reimbursement does not result in reduced service capacity
   - Preserve existing, and move ahead with previously funded, housing programs with priority for adult home residents pursuant to the recent Federal Court ruling
   - Preserve funding for child mental health services and provide funding to begin implementation of the interagency child mental health plan
   - Preserve funding for geriatric mental health demonstration programs
   - Preserve of funding for centers of excellence in cultural competence
   - Preserve funding for suicide prevention programs
   - Preserve funding for planned initiatives related to co-occurring disorders
   - Preserve the carve-out of psychiatric medications from the Medicaid preferred drug program

2. **Promote integration of mental health and primary, chronic, and long-term health care**

3. **Address the mental health needs of veterans**

4. **Provide necessary supports for consumers to gain and maintain employment**

5. **Address workforce shortages**
   a. **Address the crisis regarding social work licensing**
   b. **Remove regulatory obstacles to licensing qualified immigrants to provide mental health services**

Appendix 12: Sample Letter to a Legislator

Mailed on letterhead for MHA, which includes a list of board members.

May 15, 2009

Senator Thomas Duane
NYS Senate
Legislative Office Building Room 430
Albany, NY 12247

Dear Senator Duane:

I am writing in support of the **Behavioral Health, Chemical Dependency and Long-Term Care Act of 2009 (A.7027/S.3341),** a bill to lay the groundwork for addressing the behavioral health needs of older adults with disabilities and their family caregivers in NYS's long-term care system.

With health care reform on the horizon, there is a unique opportunity to ensure that our long-term care system adequaTel:y responds to the mental health and substance abuse needs of older adults receiving, or in need of, long-term care and their family caregivers. Failure to do so will impede the state's long-term care reform initiatives. By promoting a planning process, assuring that behavioral health information is available, requiring that people who work in long-term care get appropriate training, and more, this legislation begins the process of addressing the critical relationship between behavioral health and long-term health care.

Thank you for your commitment to addressing the needs of older adults with behavioral disorders in NYS. I look forward to working with you to ensure passage of this important legislation.

Sincerely,

Giselle Stolper, CSW
Executive Director

Appendix 13: Sample Hearing Testimony

Cover page is on MHA letterhead, which includes a list of board members

ADULT HOMES: A CRISIS OF CONSCIENCE

Testimony to

A Hearing of the New York State Assembly

May 10, 2002

Presented by

Michael B. Friedman, CSW
Public Policy Consultant

For further information contact Mr. Friedman
12 Old Mamaroneck Road, White Plains, NY 10605
914-686-2886
mbfriedman@aol.com

ADULT HOMES: A CRISIS OF CONSCIENCE

My name is Michael Friedman. I am the Public Policy Consultant for the Mental Health Association of New York City and the Mental Health Association of Westchester County. Both of these organizations are dedicated to advocacy, community education, and direct services to meet the needs of people with mental illnesses and to promote mental health. We appreciate your committees' joining together to sponsor this hearing and are grateful for the opportunity to speak today. My testimony today will present the views of the two Mental Health Associations. It is also a personal statement of moral regret.

The recent *New York Times* coverage of the dreadful conditions in some adult homes in New York State did not surprise me. For those of us who have been active in mental health over the past 30 years or so, it's an old story that makes new headlines every few years.

This time, however, the revelations provoked a personal crisis of conscience. I realized that I have paid too little attention to adult homes as an advocate and that I did too little about them when I was Director of the Hudson River Region of the New York State Office of Mental Health at the end of the Cuomo administration.

During those years I took pride in moving people to the community from the state hospitals for which I was responsible. We considered adult homes part of the community, even though it was obvious then, as it had been obvious for many years, that the large adult homes are institutions, albeit institutions that are different from state psychiatric institutions.

Of course we took steps that were meant to be protective. Staff from my office visited the adult homes to which we sent residents. We stopped referrals to those which were poor and did not improve care quickly. We encouraged, and funded, working relationships between adult homes and local mental health providers to be sure that people with mental illnesses got the mental health care they needed.

Many people got quite decent care. But the fact remains that by our actions we supported a mental health policy that is fundamentally wrong. Many years ago John Talbott called it a policy of "transinstitutionalization" in contrast to the professed policy of deinstitutionalization. Community mental health is about integrating people with mental illnesses into the community. Transinstitutionalization is about meeting arbitrary goals in one institutional system by transferring people to another institutional system. In the beginning it was a policy of desperation, a policy adopted because there was no decent housing in the community for people with mental illnesses who needed some degree of supervision or support. Once New York State developed a policy of providing housing for people with mental illnesses in the community, the use of adult homes became a policy of convenience, making it possible to reduce the perception of the need for more community-based housing.

When I say that housing people with serious mental illnesses in adult homes is the wrong policy, I mean that putting people in large, congregate living facilities--even if they are well supervised--violates the most fundamental insights and goals of the community mental health movement. The goal of community mental health is to help people lead decent lives as full-fledged members of the general community. Well-supervised adult homes do not, and cannot, fulfill that goal; and, therefore, reforming adult homes by making sure that they are safer and that they provide more services is not enough.

It's an obvious truth, so obvious that I wonder how I have missed it until the most recent set of revelations about scandalous conditions.

Coincidentally, I have just read Jonathan Glover's book *Humanity: A Moral History of the Twentieth Century*. In it he reviews many of the atrocities committed over the course of the past century and explores what made it psychologically possible for apparently decent people to participate in atrocities. Two of his observations are very important for understanding why good people agree to carry out bad--even shameful--social policy.

First, he notes that fragmentation of decision-making results in no one being, or feeling, responsible for the overall policy. We each do our piece, making the best of a situation which is beyond our control. I took pride, for example, in the extent to which my Regional Office instituted some protections. I had done the best I could.

Glover also notes a process of what he calls "moral drift". The making of a decision to pursue the lesser of evils makes it easier to make other decisions between the lesser of greater evils until ultimaTel:y one has agreed to something truly awful.

I don't think that the adult home situation rises to the level of evil of the atrocities that Glover explores, and the current state of adult homes does not reflect exactly the same kind of moral drift. In this case it's more a drift to moral complacency. Each revelation leads to a minor reform and a period of pride in minimal achievement. This contributes to our growing reconciliation with a policy which is fundamentally wrong.

Can understanding why we continue to face the same basic issues about adult homes that first surfaced 30 or so years ago help us make it better? I think it can. We need to be clear that what we need is not the kind of patching of a flawed system that is now being proposed in response to the *Times* expose. **We need a fundamental change in policy.** We should move towards responsible deinstitutionalization of adult homes. The goal should be for all people with serious mental illnesses who need supervised or supported housing in the community to get housing in small, homelike settings or in independent living settings with supports. These settings should have a rehabilitative structure designed to promote recovery, independence, and full integration into the community.

Obviously it will take years to achieve these goals. But some actions can be taken immediaTel:y which will move in the right direction. The Mental Health Associations of NYC and Westchester recommend:

First, the New York State Office of Mental Health (OMH) should take full responsibility for adult homes with a preponderance of people with mental illnesses. (Proposals of the kind that are now emerging for state agencies to share responsibility are futile because state agencies hardly ever work together effectively.)

Second, OMH should establish a policy that rejects the use of adult homes for people with serious mental illnesses.

Third, OMH should develop a long-term plan to create appropriate housing. Some small adult homes can become good community residences. It may be possible for some large adult homes to be renovated into apartment buildings providing independent living units. But some adult homes will not be usable in the context of a policy to provide real, community-based housing. Therefore, the long-term plan will need to include new housing as well as conversions of existing adult homes.

Fourth, while moving towards the creation of appropriate housing for people who now are in adult homes, OMH should institute model programs emphasizing rehabilitation and recovery in the adult homes which remain open.

Fifth, OMH should be responsible for developing adequate systems of oversight and enforcement.

Each time terrible conditions in adult homes have been revealed in the past, we have tinkered with the system. I realize now that I had become inured to it and cynical about it, as have many others. It has been a bipartisan moral failure. This time I hope we will all face the truth, that a major change in policy is the only reform that will make a long-term difference.

Thank you once again for the opportunity to testify today.

Appendix 14: Sample Letter To The Editor

Published in The New York Times, October 2, 2007

To the Editor:

It is striking that neither your Sept. 23 editorial, "The Battle Over Health Care," nor any of the letters that you published on Sept. 25 about the health policy proposals of the presidential candidates mentioned mental health despite the fact that mental and substance abuse disorders are second only to cardiac conditions as a cause of long-term disability.

In addition to the suffering inherent in mental illness, untreated depression vastly complicates the treatment of cardiac and other conditions, resulting in increased risks of disability and premature death as well as vastly increasing the costs of medical treatment.

Nearly a decade ago, the surgeon general observed that there is no health without mental health. Apparently the message hasn't gotten through.

Michael B. Friedman
New York, Sept. 25, 2007
The writer is Director, The Center for Policy, Advocacy, and Education, Mental Health Association of New York City.

Appendix 15: Sample OP-ED article

Published in *The Journal News* on May 02, 2008

What The Presidential Candidates Should Say About Mental Health

By
Michael B. Friedman, LMSW
Lloyd I. Sederer, MD
Patrick Runnels, MD

It is the final debate of the Presidential race in 2008. As a follow up to his question on health care, Jim Lehrer asks, "As we all know, mental health is critical to human well-being. What would you do to promote mental health in America if you become President?"

Here's what we'd like to hear a Presidential candidate say:

"*Thank you, Mr. Lehrer for raising that question. For far too long mental health has been a distant afterthought in health policy debates. But as the Surgeon-General said a decade ago, 'There is no health without mental health.' Mental and substance abuse disorders are second only to cardiac conditions as causes of long-term disability. Untreated depression vastly complicates the treatment of diabetes, heart disease, and other chronic medical conditions, increasing the likelihood of disability, early death, and the cost of medical treatment. Mental illness reduces the productivity of American workers and the chances for educational success of our nation's children. Mental illness also contributes to avoidable institutionalization for as many as half the people in nursing homes. But sadly, the American health care system pays scant attention.*

Did you know, Mr. Lehrer, that more than one in four Americans suffer from a mental or substance use disorder each year, and one in two over their lifetimes? And do you know that only 40% get treatment and that our children, minorities, and older adults are even less likely to get the service they need.

All this must change, Mr. Lehrer. Here's what I'd do. First, I would end the stalemate in Congress regarding parity of mental health coverage. People should have the same coverage for mental health as they do of physical health, and my plan to phase in universal health coverage builds that in.

But parity alone is not enough. A recent national study revealed that primary care physicians provide "minimally adequate mental health care" less than 13% of the time and that mental health professionals achieve that standard less than 50% of the time. We need to ensure that primary care physicians and mental health professionals consistently provide excellent care. That means better translation of current research findings into everyday practice as well a research agenda dedicated to improving the chances of recovery.

Improving existing care starts with ensuring that mental disorders are identified. Easy-to-use screening tools are available for depression and other common and treatable conditions. They

should be used as a standard part of annual health examinations as is the case for heart disease, cancer and diabetes. The federal government could advance this through quality standards in Medicare and Medicaid.

We also need to build mental health service into our nation's system of long-term care. Too many individuals end up in nursing homes because of unidentified and/or untreated mental disorders and behavioral problems that become unmanageable for formal and family caregivers. Our nation relies on family caregivers to help people with disabilities remain in their home, but they are prone to depression, anxiety, and physical disorders. They burn out. Jim, do you know that the financial value of the care families provide is about $350 billion a year? If families can't keep it up, the cost to our nation will be enormous. Families need support and people with mental illnesses need treatment, and when I am President I'll see that they get it."

In addition, our society has a profound obligation to people with severe mental disabilities—people with serious and persistent mental illnesses, people with developmental disabilities including children with autism, and people with Alzheimer's disease and other dementias. Investment in home and community-based care has helped, but we have much more to do to meet our obligations to integrate these populations into our communities."

We also have a responsibility to our veterans, whose suicide rate, by the way, is double the general population's. This reflects serious emotional problems in response to war that we as a nation can and must help them overcome.

The above is what we would like to hear a Presidential candidate say. Impossible? Until recently, few believed that a woman or a black man could be elected President. 2008 is a time of change. Let it also be the year when the Presidential candidates lead America to break down the barriers that have prevented mental illnesses from receiving their proper place in mainstream medicine despite the compelling evidence of the prevalence and burden of mental illness. Let's not stop at the margins when we know we can do so much for so many.

(Michael Friedman is Director of the Center for Policy and Advocacy of The Mental Health Associations of NYC and Westchester. Lloyd Sederer is the Medical Director of the NYS Office of Mental Health. Patrick Runnels is a fellow in the Public Psychiatry program at Columbia University. The opinions expressed are their own and do not necessarily represent the views of the organizations for which they work.)