MHANYS
Mental Health Association in New York State

Vibrant Emotional Health

SPEAK OUT!

A GUIDE TO ADVOCACY FOR IMPROVED MENTAL HEALTH POLICY

2023

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ABOUT THIS MANUAL

This manual was originally written in 2000 at the request of The Mental Health Association of New York City (now Vibrant Emotional Health) to help people with histories of mental illness (then called "consumers" or "recipients") speak for themselves and be effective as advocates. Over the next ten years, it went through several revisions and become a manual for anyone who wants to speak out about the need for a better mental health system.

Several social advocacy teachers at Columbia University School of Social Work used the manual as one of several useful frameworks for advocacy. Some have continued to use it even though it was last revised in 2010. John Robertson, one of those teachers, suggested that it needed revision because of the vast increased impact of social media since 2010. He arranged for assistance from Columbia University to support the revision, which has turned out to be more extensive than we originally anticipated. I am grateful to him and Columbia University for encouraging and supporting this work. I am also grateful to the Mental Health Association of New York State and to its advocacy director, John Richter, for their help with revisions. Mr. Richter reviewed the draft in detail and made many useful suggestions.

I am especially grateful to Iliana Rios, a student at Columbia College, who has done most of the heavy lifting for the revision and who became not just an assistant or an editor but a true co-author.

Because Columbia University School of Social Work is in New York City, the appendices of this manual contain information about New York State and New York City as well as about the federal government. People working in other locations are welcome to modify these appendices with information about their state and locality.

We hope that in its revised form the manual will be useful to a new generation of mental health advocates, who will need to carry advocacy efforts into the future. We believe that much progress has been made over the past 50 yers, but much more needs to be done to improve the lives of people with mental illness. We have "miles to go before we sleep."

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CHAPTER 1: WHAT IS MENTAL HEALTH ADVOCACY?

WHO IS THIS HANDBOOK FOR?

This handbook is designed for people who care about mental health and the lives of people of all ages with mental illnesses or psychiatric disabilities—including children, adolescents, adults, and older adults.*

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 a progressive direction.**
- **This includes people with histories in the mental health system—both people with mental illnesses and their families.**
- **It includes concerned citizens, mental health professionals, and professional mental health advocates.**
- **All people who care about mental health have important stories to tell and information to provide to policymakers.**
- **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. It is not about how to advocate for individuals on a case-by-case basis.

Advocacy for individuals is vital work, but it 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 requires changing systems. System change entails change in public or private policy. Trying to persuade the government or the private sector to make changes in mental health policy to help achieve these goals is the kind of advocacy that this handbook is about.

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*I use various 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*," and "*person diagnosed with mental illness*." Some of the language I use may be controversial. I apologize in advance to anyone who is insulted by my choice of language.

WHAT IS MENTAL HEALTH POLICY?

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

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 focused on caring for people with severe psychiatric disabilities in institutions. Since the 1950s, public mental health policy 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 and elected chief executives such as the President, governors, and mayors. It is also made by regulatory agencies, such as the NYS Office of Mental Health, which are headed by officials appointed by the chief executive with legislative approval. They are known as secretaries, commissioners, or directors. Policy is also made by the courts through rulings on constitutionality, precedent setting interpretation of laws, and formal settlements.

Some mental health policies are made by the private sector. For example, in the U.S., most people's mental health benefits are provided by their employers, who also may provide mental health and disability management services directly.

Policies of drug companies also have great impact on people with mental illness who can benefit from psychiatric medication.

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 the mental health system in the U.S. is one of the best in the world realize that it could be better. In recent years the greatest concerns have related to inadequacies in (1) reaching people with diagnosable mental illnesses who cannot or will not use traditional treatment in mental health settings, (2) enhancing capacity, access, and quality of mental health services, (3) enhancing services for children and adolescents with serious emotional disturbances, (4) responding to the elder boom, (5) overcoming racism and racial disparities in the mental health system, (6) supporting unhoused populations, (7) providing housing, (8) reducing use of criminal justice facilities for people with serious mental illness, (9) resolving issues of coercion, and (10) integrating physical health, mental health, and substance use disorder services. 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 early intervention. 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, who can influence those with power, and 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 can focus on government or it can focus on the private sector. Overall, your strategy is your selection of which point(s) of power to focus your efforts on, of who can influence them, 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 an email 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, but 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 sending emails 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 specific goals?*

STRATEGY

- *Who has power?*
- *Who has influence?*
- *What will motivate them to change policy?*
- *Which people or organizations with power and/or influence to form relationships with?*
- *Who can be good advocacy partners?*

TACTICS

- *How will you persuade the powers-that-be to change policy?*
- *Lobbying?*
- *Public education?*
- *News media?*
- *Social media?*
- *Demonstrations?*
- *Social defiance?*

CHAPTER 2: 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 it, (2) advocacy takes a lot of work, (3) working in groups helps to test ideas, (4) groups can capture public and media interest better than individuals working alone, and (5) groups can generally raise more money than an individual working alone.

ADVOCACY GROUPS NEED MEMBERS. JOIN ONE.*

WHAT CAN YOU 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 correspondence from time to time asking you to contact people, usually by email, through phone calls, or by signing a petition. Your email, call, or signature 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 city or state capitals or in Washington, D.C., 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 **and doing it.**

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 their opinion. It is to help the group make a decision about what it will do and to organize action.

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*See appendices 11 & 11 for a list of selected local, state, and federal mental health advocacy programs.

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 damaging if aired in public.

ADVOCACY IS ULTIMATELY ABOUT ACTION, NOT ABOUT TALK.

EFFECTIVE ACTION REQUIRES PEOPLE TO 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 materials both for advocacy and for communication within the group.
    - Advocacy materials include reports, letters/email to public officials, position papers, press releases, op-eds and letters to the editor, podcasts, videos, information and opinion pieces on social media, etc.
    - Communications materials include letters/memos/announcements to members, newsletters, minutes of meetings, etc. Most groups now use email and social media rather than material on paper 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 many 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 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 email, through website postings, etc. **Do not assume that website or social media postings are seen by the people you want to reach.**

Very importantly you can also reach people and build your constituency through **public education** activities such as speeches, training events, webinars, conferences, websites, podcasts, written material (sometimes on paper, sometimes online), etc.

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 some will sign on to letters, send emails, make calls, or even appear at advocacy events if they know about them. **The less they have to do, the more likely they are to do it.**

COMMUNICATION IS CRITICAL.

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

EFFECTIVE ADVOCACY DEPENDS ON WORKING IN GROUPS

- Join a group
- Make a financial contribution
- Send emails and make calls on behalf of the group
- Attend public events organized by the group
- Participate in creating the advocacy plan
- Do the work of the group
- Become a leader of your group
- Create a new group if needed

CHAPTER 3: CREATING AN AGENDA: SELECTING GOALS

IT'S NOT AS EASY AS IT SEEMS

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, it's not as simple as it sounds.

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 take the following steps:

IDENTIFY THE POPULATION OF CONCERN

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 older adults? In your city, your state, the United States, 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, also known as “severe and persistent mental illness.” Your goal then would be to help people with psychiatric disabilities in New York State.

BE CLEAR ABOUT THE PROBLEM

This is still a nebulous goal. What's wrong with the lives of people with psychiatric disabilities? What's the problem? There are many possible answers: people with psychiatric disabilities are too frequently homeless or live in housing which is shabby and dangerous, they cannot get jobs, they frequently get no/inadequate treatment, 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.

PROPOSE A 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 for people with psychiatric disabilities who work. Again, these are just examples. You will need to be still more specific. For example, if you want more housing for people with mental illnesses, you will need to say how much more.

SPECIFY HOW TO CHANGE 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? Where will funding come from?

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. Keep in mind that the people in government have a responsibility to take your concerns and shape them into public policy.

You can also recruit or hire policy experts.

ASSESS THE POSSIBILITY OF SUCCESS

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.

ACT TO PRESERVE YOUR 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.

CHOOSE 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. It is also possible to have a long agenda with a few select priorities.

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?

ESTABLISH A PROCESS FOR DECISION-MAKING

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 leader 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 the U.S., policy issues on most mental health advocacy agendas include, but are far from limited to:

- Funding for community-based services for adults with serious and persistent mental illnesses—especially housing, improved crisis services, and outreach and engagement 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.
- Enhanced workforce
- Addressing racism in the mental health system
- Addressing the needs of people with mental illness in the criminal justice system
- Increased capacity to provide and improved access to services
- Increased or decreased use of hospitals
- Increased or decreased use of involuntary services
- Improved quality of care and treatment, using state-of-the-art methods.
- Improved integration of physical, mental, and substance use services

Obviously, this way of describing the issues is not specific enough for actual advocacy. It is meant to just give you a taste of a few prominent mental health policy issues at the moment.

A NOTE ON LANGUAGE:

There are vociferous debates about language. For example, some people find the use of the expression "people with serious and persistent mental illness" objectionable. They might want to overcome the same problems for the same people but would use other expressions such as "people with psychiatric disabilities," "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.

THE STEPS TO SETTING AN AGENDA

IDENTIFY THE POPULATION OF CONCERN

Who needs help?

BE CLEAR ABOUT THE PROBLEM

What's wrong?

PROPOSE A SOLUTION

How do you think the problem can be best overcome?

SPECIFY HOW TO CHANGE POLICY

What policies need to change? How should they be changed? How much will it cost?

ASSESS THE POSSIBILITY OF SUCCESS

What's achievable?
Are you willing to compromise?

ACT TO PRESERVE YOUR GROUP

What is needed to preserve your group? What is needed to make your group stronger?

CHOOSE PRIORITIES

What's most important?

ESTABLISH A DECISION-MAKING PROCESS

Who needs to agree? How will you get agreement?

CHAPTER 4: STRATEGY – WHO TO INFLUENCE & HOW

POWER

It takes power to make change. You must sort out whether the power to bring about change is in the public sector, private sector, or both. 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? 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. You will need to decide whether to develop a federal, state, or local strategy or a combination. And you will need to decide whether to have a legislative, executive, or judicial strategy or a combination.

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.*

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.

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*Detailed information about the structure and functions of government in the United States is in Appendix 1. Detailed information about mental health policy making is in Appendix 2 & 3.

KNOW YOUR ELECTED OFFICIALS

Elected officials represent you in the federal, the state, and local governments. The most basic step of advocacy is to know who your elected officials are.*

To find out who your elected officials are visit *https://www.lwv.org/take-action/find-your-elected-officials* or, in New York call The League of Women Voters at 212-213-5286.

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 each level of government who are responsible for mental health services.**

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 Substance Abuse and Mental Health Services Administration (SAMHSA), the National Institute of Mental Health (NIMH), and the Centers for Medicare and Medicaid Services, among others.

At the state and local levels there are also appointed public officials with substantial impact on mental health policy. In NYS, for example, the commissioners of mental health and health and the director of the Division of the Budget have extensive policy-making power.

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? For example:

- 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 RELATIONSHIPS

All change takes place through relationships, both formal and informal.

- Get to know the people who can help you achieve your goals.
- Develop both working and social relationships if you can.

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*Appendices 13, 15, and 16 list the most important federal, state, and local elected officials.
**Appendix 14 lists key appointed officials in D.C. Appendix 17 lists officials in NYS and NYC.

- Help them achieve their goals including election and/or appointment to public office and help with personal issues when you can.
- Do favors for them when you can do so without violating ethics laws or your own ethical principles
- Ask for favors when you need them.

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 FORMING GOOD WORKING RELATIONSHIPS WITH PEOPLE WHO HAVE POWER, INFLUENCE, OR CAN BE PARTNERS IN ACTION.

STRATEGY

GOVERNMENTAL 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 & PEOPLE HAVE THE POWER TO CHANGE POLICY?

Elected officials? Appointed officials? Court?

WHO HAS INFLUENCE?

Respected experts? Colleagues? Party officials & contributors? Friends & 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 5: TACTICS – METHODS TO BRING ABOUT CHANGE

Tactics are specific methods to bring about change. There are five primary ways to bring about change—**lobbying, public education, use of news media, demonstrations,** and **social defiance**.

TECHNIQUES OF LOBBYING

Lobbying is any effort to directly influence elected or appointed public officials. Although you have a right to lobby, most states require professional lobbyists and lobbying organizations to register as lobbyists and to submit periodic reports. This varies from state to state. Check lobbying laws to find out what guidelines you must follow.

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 and/or email and text 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 know more than a very few in depth. However, many public officials will have personal experience of mental illness or substance misuse. They may be more moved by personal stories than by data.

Be prepared to be asked what specifically you would like the official to do—vote for a particular bill, be a co-sponsor, let the leader of the legislative house know of their support for your position, etc.

At the beginning of the meeting, you should always thank the public official for taking the time to meet with you. These are usually people who deserve your respect, and you should show it.

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*Appendix 6 is a sample handout for meeting with a public official.

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.* It is not unusual in meetings with public officials to not 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 helped you develop a relationship which will make it possible for you to work with the public official over time.**

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.

Always follow up after a meeting with a letter of thanks and a reminder of what they promised to do.

MAIL, PHONE, EMAIL, & SOCIAL MEDIA CAMPAIGNS

Communications from large numbers of people have a significant impact on public officials.

Some advocates believe that only personal communications have a significant impact. I believe that volume matters and that advocates should **make it as easy as possible for people to communicate with public officials.** Systems that require people to simply push a single button to get a message out are most likely to get people to send a message.

Generally, communications with public officials should be very brief. A written statement 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."

Memoranda of support or opposition are a particularly important way to communicate your views on proposed legislation.*** These should be sent to bill sponsors, committee chairs, legislative leaders, the chief executive, and relevant regulatory agencies.

In addition to written communications, 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."

Communication campaigns require a great deal of organization—including: compiling a mailing list of people who will write/call and people to be lobbied, writing sample letters or phone call scripts, communicating with other lobbyists, etc.

Social media is another effective method of directing people to contact their elected officials. Many advocacy organizations have accounts on social media platforms—including Instagram, Twitter, and Facebook. They often provide helpful graphics with contact information and links for petitions to sign, representatives to call, and pre-written emails to send. Social media is able

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*Appendix 6 is a sample handout for meeting with a public official.
**Appendix 5 is a sample letter to an elected official.
***Appendix 7 is a sample memorandum of support.

to reach a widespread group of people and encourage them to contact public officials. But—to repeat—**do not assume that the people you want to reach will look at the social media sites you use.**

WEBSITES

Having a website is important to highlight your group and their advocacy efforts. This website should have:

- The basic information about your advocacy group
- Your advocacy agenda
- Action alerts, preferably with a ready to send advocacy message for public officials
- Background information (including epidemiological data, research findings, recommendations of consensus groups, 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 often includes a large assemblage of all the people who have come to lobby. Legislators and other relevant public officials are invited. Many organizations prepare legislative briefing books for their lobbying days.*

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. You should attempt to meet in rooms that are a little too small for your group.

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.

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*Example of a legislative briefing book: *https://mhanys.org/wp-content/uploads/2023/02/20230130_MHANYS_LegislativeBriefingBook2023-1.pdf*

GIVING AWARDS & 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. ***Public officials are more likely to promote your advocacy efforts, and work alongside you, if they've been honored/acknowledged by your group.***

This should always be done publicly with press in attendance and photos taken that can be distributed both by the advocates and by the person who has been given the award.

TESTIFYING AT HEARINGS

From time-to-time public officials convene public hearings on matters of special interest. In some states (such as Maryland), there are brief hearings on all proposed legislation.

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 usually need to schedule your testimony in advance. Your testimony 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.* Frequently, hearings run long and the people testifying are asked to take less time than originally allotted. Be adaptable and prepared to cut your speech.

Always begin your testimony with your name and the name of the organization you represent. It is very important to give the impression that you are speaking for a great many people. The first sentence after this should state your position in one sentence. Then elaborate.

Say what you have to say briefly, clearly, and forcefully—but not with disrespectful anger, unless your goal is to rile up the press in attendance.

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

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*See sample public hearing testimony in Appendix 8.

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 service issues use professional lobbyists. This enables them to have a regular presence with elected officials during the legislative session and with appointed officials throughout the year. This saves a great deal of time which otherwise would have to be devoted to building relationships and to being on the scene.

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.*

ANALYTICAL REPORTS & PUBLICATIONS

Studies and analytic reports document problems that need to be addressed by the government. They can be very effective in shaping public opinion.

Often, however, they are ignored and end up, as we say, “collecting dust on a shelf."

To be used effectively the reports must:
- Be credible and based on professional research and/or expert opinion.
- Have clear, achievable recommendations.
- Be readable. They require professional quality writing.
- Have wide distribution and substantial publicity.
- Have extensive follow-up to advocate 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 if well-publicized in ways that **make information clear to policy makers.**

Conferences can also be very effective ways to engage public officials who attend or participate.

In addition to changing public opinion, conferences can be very useful devices to **build coalitions** of advocates.

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*See Chapter 2.

WRITTEN MATERIAL, WEBSITES, AND SOCIAL MEDIA

People in the general public who have an interest in mental health issues frequently have little access to information. Advocacy organizations typically create websites on which they post written material, videos, etc.

Many advocacy organizations also use social media platforms to educate the general public on policies and current events. Informational graphics are widely circulated on platforms such as Instagram, Twitter, and Facebook. This information often includes a walkthrough of the topic, timeline of events (when applicable), and action-items. People's ability to like, share, and re-post these tools allows them to reach a wider audience and raise awareness. Public education through social media shot up during the COVID-19 pandemic, when people struggled to remain connected with one another and spent more time online.

ADVERTISING

Advertising can be a very effective way to reach both the general public and public officials.

Ads in newspapers, on radio, on TV, and on social media can have a major impact, but of course are expensive.

It is sometimes possible to get free help to develop and to place advertising, but free advertising often ends up being run where or when no one is likely to see it.

USING THE NEWS 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 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 concerns about the well-being of people, let alone people with mental illnesses. They need to sell papers or get TV viewers. They are more likely to catch people's attention with fear than with 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 and which either are provocative or seem to sum up a position perfectly.**

In addition to getting coverage of a particular issue or event, it can be valuable to develop ongoing relationships with reporters, who need contacts with people who have expertise and/or inside knowledge.

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." 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 otherwise. Reporters also like to get background information from knowledgeable people whom they trust even though they cannot quote them.

LETTERS TO THE EDITOR & 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 is usually a response to something that has appeared in the newspaper, but sometimes it is simply a statement someone wants to make.

Elected officials 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 but different publications have different requirements.

The letter should also be very easy to understand.*

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 creates credibility.

An Op-Ed piece is a short essay (about 750 words) which states your opinion about a timely or interesting topic. Limitations on length vary from newspaper to newspaper.**

SOCIAL MEDIA

Many news media outlets also have social media accounts. In addition to reaching out to traditional news media, you can attempt to get coverage on their social media accounts. Sometimes, coverage on social media results in coverage on traditional news media, giving the issue broader attention.

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:

1. **People must attend.** There is nothing sadder and more counter-productive than announcing a demonstration of thousands which is only attended by fifty. Therefore, a major part of the effort to hold a demonstration is getting people there. Logistics are just as important as your message.
2. **The news media must be present.** A demonstration has no meaning without coverage. That means that groundwork has to be done to get reporters interested in covering the event.
3. **You need to craft a message that appeals to a constituency** whose support you need to move your agenda.
4. **Your message must be communicated clearly, briefly, and repeatedly**. The soundbite is the message.
5. **Social media to support effective demonstrations.**

SOCIAL MEDIA FOR DEMONSTRATIONS

Social media have become effective ways of spreading the word about a demonstration. Posts about upcoming demonstrations are quickly and easily shared, allowing thousands to learn of the event and attend. Several student-led demonstrations, including gun-control rallies and walkouts, have been organized almost entirely through social media.

It's important that demonstrations shared on social media focus on engaging their audience. This includes not only posting one announcement about the demonstration, but several reminders leading up to it.

Organizers can usefully go live on social media platforms at their event to document their action and reach more people.

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*See sample letter to an elected official in Appendix 5.
**See sample Op-Ed essay in Appendix 10.

SOCIAL DEFIANCE

Defiance of the 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 to both help workers and 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, uncompromising, and 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 of advocacy groups is also a very important choice. Coalitions can be more effective because there is strength in numbers. Being in a coalition, however, requires compromise. If you are not usually willing to make compromises, you should not join coalitions.

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.

Your choice will also depend on your relationships with people in positions of power or influence. If you have good working relationships, you may 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.

A NOTE ON SOCIAL MEDIA:

Social media are constantly changing and evolving and the ways in which social media are used for advocacy will continue to change. Advocates should use different social media platforms to engage different audiences. Younger generations, for example, may be less reachable on platforms such as Facebook. Age, and other demographics, are key to deciding what type of social media advocacy you engage in.

TACTICS: TO CONSIDER

LOBBYING

- *Meetings*
- *Direct communication via mail, email, telephone, & petitions*
- *Formal & informal relationships*
- *Written material*
- *Special events/lobby days*
- *Awards*
- *Campaign contributions*
- *Professional lobbyists*

PUBLIC EDUCATION

- *Reports*
- *Conferences*
- *Hearing testimony*
- *Written material*
- *Web page*
- *Advertising*
- *News media*
- *Social media*

DEMONSTRATIONS

- *Attendance*
- *Press coverage*
- *Soundbites*

SOCIAL DEFIANCE

- *Boycotts, strikes, etc.*
- *Civil disobedience*
- *Risk assessment*

ADVOCACY STYLE

- *Confrontation*
- *Negotiation*
- *Compromise*
- *Reliable Expert*
- *Influential Relationships*

CHAPTER 6: 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, in the mid-1970s many, perhaps most, people who had been in state psychiatric hospitals for long periods of time generally lived in shabby and dangerous places or with overburdened families; there were virtually no community residences or supported housing programs. Few people with severe mental illness had access to high quality mental health treatment; most went to clinics that had poor psychiatric staff and outrageously high caseloads. There were only a handful of community-based rehabilitation programs. When people were in crisis, they usually went to emergency rooms that were inadequately prepared to deal with psychiatric crises. Some went to 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, the concept of community support programs (CSP) emerged and since then there has been great growth of housing and rehabilitation programs, outpatient services, case-management, local hospital programs, crisis services, and peer support programs for people with serious mental illnesses. In addition, the quality of care in state hospitals is vastly improved. The mental health system is far better today than it was forty-five years ago.

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

BASIC RULES OF ADVOCACY:

- **Work in groups**
- **Plan carefully**
- **Take action**
- **Build relationships**
- **Be persistent**

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!

GOVERNMENT STRUCTURE IN THE UNITED STATES & NEW YORK

STRUCTURE AND FUNCTIONS OF GOVERNMENT IN THE USA & NEW YORK

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 have shifted from one historical period to another and continue to vary from state to state.

Although the federal role with regard to health and human services has grown over time, federal authority and responsibility are limited by the Constitution. The states have substantial responsibility and power, particularly regarding mental health.

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**.

- The legislative branch at the federal level is the Congress—composed of the Senate and the House of Representatives. Each state also has a legislature, as do counties and municipalities.
- The executive branch at the federal level 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. Most are called Secretaries.
- State executive branches are headed by Governors who appoint Cabinets with legislative approval. The heads of state departments have different titles such as Secretary or Commissioner, depending on the state.
- Local executive branches are headed by Mayors, County Executives, etc.
- The judicial branch of government exists at all levels of government. There is a very complicated array of various types of courts—such as criminal courts, family courts, and surrogate courts. There is also a hierarchy of local, state, and federal courts culminating in ultimate courts of appeal in each state and federally, in the United States Supreme Court.

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*.

MAKING LAWS: STATUTORY LAW, CASE LAW, & 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 Constitution of the United States and the Constitutions of 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.
- Additionally, 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 must also be signed by the chief executive unless his or her veto is over-ridden by a super-majority (usually two-thirds).

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 processes that include:

- Administrative departments submit requests 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 & IMPLEMENTING BUDGETS

MAKING REGULATIONS

Regulations spell out details that 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. Required approvals can allow the quick development of 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 The State Office of Mental Health.

Planning processes generally require some sort of public review.

In NYS the two major planning advisory bodies are the Behavioral Health Service Advisory Council and the Regional Advisory Committees. The major local advisory groups are the Community Services Boards.

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.

In order for courts to make rulings—which create case law—legal action must be taken. This legal action can either be on behalf of specific individuals or on behalf of a group of individuals (known as class action lawsuits).

Findings from lawsuits on behalf of individuals only apply to those individuals, unless rulings are made which set legal precedents. This often happens through an appeals process.

Lawsuits can also be "settled." Such settlements can create new policy. This happens when the government agrees to change its current practice.

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, including: criteria for involuntary hospitalization, requirements regarding discharge planning, bans of unpaid labor by psychiatric patients, the right to treatment, and more.

APPENDIX 2

MENTAL HEALTH POLICYMAKING IN THE USA

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 250 years of history make it clear that there are areas over which the federal government has little to 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 government responsibility in which the Federal government has a limited role. By tradition, the states have primary responsibility, although over time the federal government has taken an increasing 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 Community Mental Health Services Block Grant (MHBG).

Historically, 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 on issues such as mental health insurance coverage, standards on restraint and seclusion, overcoming homelessness, mental health services for veterans, inclusion of children with mental illnesses in mainstream education, and many more.

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 body. It is best to have multiple sponsors including leadership members.

Depending on the nature of the legislation, it will be sent to one or more committees. In the House this will usually include the Subcommittee on Health 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 appropriate committees. For the House, this includes: the Ways and Means Committee, the Financial Services Committee, and the Committee

on Appropriations. For the Senate, this includes: the Finance Committee, the Committee on the Budget, and the Committee on Appropriations.

Generally, the bill 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. For some Senate bills, at least 3/5 of the members must vote to limit discussion prior to voting, so some bills require a supermajority to pass.

If the bills passed in each body are different, a House-Senate conference committee will be convened to reconcile the differences. These compromises are usually approved routinely by the House and the Senate, but that's not always the case.

To become law, the President must sign the bill. A veto by the President can be overridden by 2/3 majority in both the House and the Senate.

In the last-minute passage of bills, it is very important for advocates to have a presence in DC.

MAKING THE FEDERAL BUDGET

The President submits a budget proposal to Congress in February. Congress develops a budget through its committees using a complex process, summarized below:

First, Congress is supposed to pass a Budget Resolution, giving the overall shape of the Federal budget, by April 15—though it's usually late.

If the budget resolution diverges substantially from current budgetary authority, Congress may enter the budget "reconciliation" process. This can produce a reconciliation bill (ex: American Rescue Plan Act of 2021 and Inflation Reduction Act of 2022) which is stitched together from committee decisions about bringing the spending they are responsible for 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.

Appropriations bills are often 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. The government has shut down temporarily due to delays in passing appropriations bills.

In order to influence the budget, advocates should work with federal departments prior to February. They should continue to work with Congress after the President's budget is released.

FEDERAL ADMINISTRATION OF MENTAL HEALTH POLICIES & PROGRAMS

RESEARCH & 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 (SAMHSA).

SAMHSA 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.

The Health Resources and Services Administration (HRSA) also funds research related to mental health services.

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 (CMS) 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.

Some funds are made available through demonstration grants and the like.

INCOME MAINTENANCE FOR PEOPLE WITH DISABILITIES

Under federal law, some people with long-term disabilities are eligible for Social Security Disability Income (SSDI) and others are eligible for Supplemental Security Income (SSI). The Social Security Administration administers both of these programs. SSDI is 100% federal funding and totally under federal control. SSI includes some state funding and its rules vary from state to state.

THE DEPARTMENT OF HEALTH & HUMAN SERVICES

NIMH, SAMHSA, HRSA, 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 Center for Disease Control and Prevention (CDC), The Department of Housing and Urban Development (HUD), The Department of Education, The Department of Labor, and more.

MENTAL HEALTH POLICYMAKING IN NYS & NYC

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 Committee on Mental Health in the Assembly and the Mental Health 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 their 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 no later than November or 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.

- During the summer, advocates should advocate for specific funding proposals with the 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 advocate for specific proposals with the Governor (program staff) 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 of the committees which cover finance as well as with the leaders of the Assembly and the Senate.

ADMINISTRATION OF MENTAL HEALTH POLICY & PROGRAMS IN NYS

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

But Medicaid is the responsibility of the Department of Health (DOH), where there is a Deputy Commissioner for Medicaid as well as a Commissioner of Health.

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

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, state aid to localities, community support systems (CSS), housing, reinvestment, etc.

Medicaid funds go directly to licensed service providers, which bill for the services they provide, or to Medicaid Managed Care Organizations, which serve as intermediaries between service providers and the state.

Some funds go to local governments, which contract for services with local providers or provide services themselves.

Some additional 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 service recipients (recently known as “people with lived experience”).

At the state level the two primary planning advisory organizations are the Behavioral Health Service Advisory Council, which has members appointed by the Governor with the approval of the Senate, and Regional Advisory Committees with members appointed by OMH.

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.

Hearings of various kinds, in various parts of the state, and on the internet, 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, Regulation, and Legislation within the OMH office.

All regulations are issued for information and comment before they are promulgated by the Commissioner, except those that are issued on an emergency basis. Advocates may speak at hearings or send written comments to OMH.

Regulations are also subject to review by the Behavioral Health Service Advisory 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 the findings of prior inspections. Programs can get a license for as long as three years.

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, which are established by OMH.

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, reduce, 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 Behavioral Health Service Advisory 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.

SAMPLE MATERIALS

APPENDIX 4

SAMPLE ADVOCACY AGENDA

*THE GERIATRIC MENTAL HEALTH ALLIANCE OF NEW YORK**

HOW TO MEET THE COGNITIVE AND BEHAVIORAL HEALTH NEEDS OF OLDER ADULTS IN THE UNITED STATES

1. Enable older adults with cognitive or behavioral health conditions to **live where they prefer**, generally in the community rather than in institutions.
2. **Improve long-term care** including nursing homes, assisted living, and home and community-based services.
3. **Enhance support for family caregivers.**
4. Increase cognitive and behavioral health **service capacity** to keep pace with the growth of the older population and address current shortfalls.
5. Enhance **access to care**, particularly with **extensive use of telehealth** and **increased outreach and engagement** efforts such as assertive community treatment teams (ACT).
6. **Improve quality of care and treatment**, emphasizing clinical, cultural, and geriatric competence in service design and delivery.
7. **Increase and improve the professional and paraprofessional workforce** in primary care, long-term care, behavioral health, and aging services.
8. **Enhance integration of care** within and between service systems—dementia care, behavioral health care, primary care, long-term care, and aging social services.
9. Address **social "determinants" of behavioral health** such as racism, poverty, and social isolation.
10. Address **racial and economic disparities.**
11. **Increase "preventive" interventions** so as to reduce the incidence of cognitive and behavioral disorders, relapse, institutionalization, and suicide.
12. **Promote mental well-being in old age** via assistance in preparing for retirement, adapting to the empty nest, maintaining old and developing new relationships, finding engaging activities, living with chronic illness, tolerating dependency if necessary, achieving reconciliation with one's past, and dealing with mortality.
13. Improve **public and professional education.**
14. Increase and redesign **funding** to meet the needs of older adults.
15. Compile **epidemiological, services, and financial data** and the create a publicly accessible **data dashboard.**

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*Provided by the Geriatric Mental Health Alliance of New York.

APPENDIX 5

SAMPLE LETTER TO AN ELECTED OFFICIAL

AD HOC GROUP OF EXPERTS ON COGNITIVE AND BEHAVIORAL HEALTH OF OLDER ADULTS IN MARYLAND

250 President Street Suite 513, Baltimore, MD 21202

443-835-2539 cbhexpertsMD@gmail.com

Michael B. Friedman, LMSW (co-chair) **Constantine G. Lyketsos, MD (co-chair)**

Dear Governor-Elect Moore:

Congratulations on your election as Governor.

We are writing to urge you to make addressing the cognitive and behavioral health needs of older adults a priority for your administration.

Older adults in Maryland do not currently have adequate cognitive, mental health, and substance use disorder services. In addition, the older population of Maryland will grow about 30% over the next decade from about 1 to 1.3 million people. Barring an unexpected breakthrough in the prevention or treatment of dementia, mental illness, or addictions, the population of people with cognitive or behavioral disorders will also grow 30%. It will be a great challenge to keep pace with population growth, while also addressing the current shortfalls in service.

In October of 2021, the Departments of Health and of Aging submitted a report to the General Assembly identifying unmet need and calling for the development of a comprehensive plan to meet the cognitive and behavioral needs of older adults.

Part of the needed plan has been completed by the Alzheimer's and Related Disorders Council. It will be important to provide multi-year funding to implement its recommendations.

It will also be important to provide funding to develop a comprehensive plan to respond to mental and substance use disorders among older adults.

In addition, we urge you to conduct a review of the current advisory groups in Maryland that have missions relevant to the cognitive and behavioral health needs of older adults. We believe that their current mandates should be modified to focus greater attention on geriatric cognitive and behavioral health and that mechanisms of communication and coordination should be established to enable them to develop common goals and work in unison rather than at cross purposes. (See attached report).

We, of course, will be happy to assist your administration in plan development and implementation and in a review of current advisory structures.

Please do not hesitate to ask for our help.

Sincerely,

Michael B. Friedman
mf395@columbia.edu

Constantine Lyketsos
kostas@jhmi.edu

SAMPLE HANDOUT TO A PUBLIC OFFICIAL

William T. Gettman, Jr., MPA
Board Chair

Glenn Liebman, MA
CEO

MHANYS 2023 Legislative Priorities*

Mental Health Workforce Funding: MHANYS strongly supports a State Budget that includes an 8.5% COLA based on the Consumer Price Index (CPI) for OMH and OASAS providers. This COLA funding should become a permanent funding stream for every year, and should include Health Home Care Managers.

Housing: The Governor's budget proposal includes $39 million, which will help to pay staff an adequate wage and to enhance programs for housing residents with multiple medical and mobility challenges. MHANYS is calling on the Governor to add an additional $57 million (for a total investment of $96 million) to help close a funding gap for existing NYSOMH sponsored/licensed/funded mental health housing programs in New York.

Mental Health and Schools: MHANYS supports four proposals in response to the mental health needs of schools including:

- Support the Governor's budget proposal to expand school-based satellite clinics and enhance school-based wraparound services through an investment of $30 million;
- S.5294 (Fernandez) would require teachers, teaching assistants and school administrators to receive three hours of mental health training annually;
- S.3179 (Hoylman-Sigal) would amend the education law, in relation to providing for absences from school for the mental or behavioral health of minors, and;
- S.1537 (Hoylman-Sigal) would require all New York school boards to adopt a policy on student suicide prevention, intervention, and post-vention for grades 7 to 12.

Pension and Retirement Plans: Pass legislation to establish a study group to evaluate and make recommendations regarding a pension and retirement plan for employees of not-for-profit human service providers.

Mental Health and Higher Education: Pass legislation to increase mental health literacy on campuses and encourage whole health parity. Include $500 thousand in the budget for student, faculty and staff mental health training.

Veterans and Military Families: MHANYS appreciates that Governor Hochul included $7.7 million in the 2023/24 Executive Budget to support existing Dwyer programs in all counties in the state. We urge the Legislature to continue to support the Dwyer Project in the state budget. We also advocate for greater involvement of families within the funding model.

Workplace Mental Health: S.1860 (Brouk) directs the commissioner of labor to create and distribute to employers a poster, pamphlet, or other written materials regarding mental health and wellness of employees to be posted in the workplace. The legislation also directs voluntary guidelines for employers to put in place strategies and programs to support the mental health and wellness of their employees.

Provided by Mental Health Association in New York State (MHANYS). For more information: *https://mhanys.org/action/*

SAMPLE MEMORANDUM OF SUPPORT

William T. Gettman, Jr., MPA
Board Chair

Glenn Liebman, MA
CEO

Memorandum in Support

A.6804 (Gunther)/S.7236 (Brouk)

AN ACT to amend the education law, in relation to improving student mental health and mental health literacy in institutions of higher education in the state, and requiring the adoption of related protocols, policies and programs.

The Mental Health Association in New York State, Inc. (MHANYS) strongly supports A.6804/S.7236, which would promote policies to increase mental health literacy on campuses and encourage whole health parity.

There's evidence of a college mental health crisis dating back to at least 2007. Data from an April of 2022 Active Minds study showed a 135% increase in depression and 110% increase in anxiety among college students between 2013 and 2021, and in 2021 60% of college students met the criteria for one or more mental health conditions.

A survey college presidents conducted by Inside Higher Ed, found that over 90 percent of presidents reported being very or somewhat concerned about student mental health during the COVID-19 crisis, making it their top concern. The American Council on Higher Education found that over 66 percent of all presidents are reporting an increase in the utilization of mental health services due to COVID-19.

This crisis is not limited to college students, but pervades the mental health and wellness of the whole college, including faculty, staff and students. More than half of college faculty report signs of professional burnout with 40% considering leaving their current jobs as a result of COVID changes. While stress was high at the onset of the pandemic, research has found that faculty anxiety appears to be increasing, with more faculty reporting peak stress now than at the beginning of the pandemic.

There are two ways to immediately support the mental health needs of colleges. First, targeted training is needed to raise mental health literacy on campuses tailored to the unique needs of students, faculty and staff. In addition, colleges need resources to improve their policies and practices for responding to student mental health challenges (i.e., whole health parity). These policies include, but aren't limited to, leave of absence and return to campus policies, as well as policies for suicide prevention, intervention and post-vention. This legislation would accomplish these goals.

For these reasons MHANYS strongly supports A.6804/S.7236 and urges the Legislature to pass this bill into law.

Healthy Minds For A Healthy New York

194 Washington Avenue • Suite 415 • Albany, New York 12210-2314
518-434-0439 (P) • 518-427-8676 (F) • MHANYS.org

SAMPLE PUBLIC HEARING TESTIMONY

AD HOC GROUP OF EXPERTS ON COGNITIVE AND BEHAVIORAL HEALTH OF OLDER ADULTS IN MARYLAND

250 President Street Suite 513, Baltimore, MD 21202
443-835-2539 cbhexpertsMD@gmail.com
Michael B. Friedman, LMSW (co-chair) **Constantine G. Lyketsos, MD (co-chair)**

My name is Michael Friedman. I am the Co-Chair of The Ad Hoc Group of Experts on the Cognitive and Behavioral Health of Older Adults in Maryland. Our group consists of psychiatrists, psychologists, social workers, administrators, and advocates, who work on behalf of older adults.

Thank you for the opportunity to speak with you today and to urge you to provide $250,000 to complete a comprehensive, long-term plan to address the cognitive and behavioral health needs of older adults in Maryland, which was mandated by the General Assembly in 2021.

These funds would be used to address the behavioral health components of the mandated plan. The cognitive health components were addressed by the Alzheimer's Disease and Related Dementias Council in 2022.

Why is this important?

- About 1 in 10 people 65 and older have some form of dementia, most likely Alzheimer's disease. Dementia was the 7th leading cause of death in the United States in 2020.
- And **virtually all people with dementia develop** behavioral health conditions (aka "neuro-psychiatric symptoms") such as depression, anxiety, or psychosis.
- As many as 1 in 5 older adults suffer from depression, anxiety, or psychosis. Suicide was the 12th leading cause of death in 2020, and suicide rates are high among older adults.
- About 1 in 25 suffer from addiction, 4 and as many as 1 in 5 dangerously misuse alcohol and medications. For example, between 2015 and 2019, there were about 140,000 alcohol-related deaths per year in the United States.
- Many older adults experience emotional distress in response to challenging life circumstances such as the pandemic, social isolation, economic instability, racism, and poor health.
- All this contributes to personal and familial dysfunction, premature disability and death, avoidable institutionalization, high rates of suicide, and the very high costs of healthcare.

For all of these reasons, it is very important to address the needs of those people who experience mental problems in old age.

It is all the more important because Maryland like the rest of **America is aging rapidly**. Over the next few decades, the proportion of adults 65 and older will come to exceed the proportion of children under 18—an historic first. And as the number of older adults in Maryland grows from approximately 1 million today to 1.5 million in 2045, so will the number of older adults with cognitive impairment, mental and/or substance use disorders, autism and other developmental disabilities, and emotional distress. Unless there are long hoped for breakthroughs in treatment

and preventive interventions, the number of older people with mental illnesses in Maryland will grow from about 140,000 in 2020 to about 210,000 in 2045. And the number of older people who misuse alcohol and other drugs will grow from about 200,000 to 300,000.

As noted in a report submitted to the General Assembly in 2021 by the Departments of Aging and of Health, Maryland **is not prepared to meet the challenges of supporting mental well-being in older adults**. The services that are currently available in the health, long-term care, mental health, substance use, developmental disabilities, and aging services systems **fall very short of meeting the need** and are **dysfunctionally fragmented**. Many older people are **not able to live where they would like to live**, whether a family home or a retirement community, because they cannot get the services and supports that they need. **People with cognitive impairment** living in the community have a **range of unmet needs** including **"neuropsychiatric behavior management and caregiver support**. Those living in nursing homes and assisted living facilities often **get inadequate treatment** for cognitive and behavioral health disorders, which are highly prevalent among residents in these facilities. **Fewer than half of older adults with mental or substance use disorders get any treatment at all because of limited service capacity and access**. As a result, treatment for mental illnesses is too often provided by **primary care physicians without adequate training or by mental health professionals without geriatric expertise**. Only about 1 in 3 people who get treatment get even "minimally adequate treatment."

And very importantly, our **systems of care are plagued by racial and economic disparities** in the prevalence of disorders, access to care and treatment, and rates of death.

It is important to note that while the risks to mental health are great in old age, **the opportunities to experience mental well-being are also great**. Addressing cognitive and behavioral struggles will almost certainly result in a significant increase in the number of **older adults in Maryland who are aging well** and **can help the state of Maryland to thrive in the coming decades**.

What should a comprehensive plan seek to achieve? Here are 15 key goals for Maryland.

1. Enable older adults with cognitive or behavioral health conditions to **live where they prefer.**
2. **Improve long-term care.**
3. **Enhance support for family caregivers.**
4. Increase **service capacity.**
5. Enhance **access to care** particularly with **extensive use of telehealth** and **increased outreach and engagement** efforts such as assertive community treatment teams (ACT).
6. **Improve quality of care and treatment.**
7. **Increase and improve** the professional and paraprofessional **workforce**.
8. **Enhance integration of care**
9. Address **social "determinants" of behavioral health.**
10. Address **racial and economic disparities.**
11. **Increase "preventive" interventions**
12. **Promote mental well-being in old age.**
13. Improve **public and professional education.**
14. Increase and redesign **funding** to meet the needs of older adults.
15. Create a publicly accessible **data dashboard** including **epidemiological, services, and financial data.**

As noted earlier, in 2021 the state budget included a planning mandate and subsequently, the Alzheimer's Disease and Related Dementias Council submitted comprehensive recommendations. In addition, $3.5 million was included in the Supplemental Budget to begin to implement the ADRD's recommendations.

But to date, there has not been work done to develop comparable plans and recommendations regarding behavioral health.

That is why today we are asking for $250,000 in this year's budget for the Department of Health or the Department of Aging to hire consultants to complete a plan focused on behavioral health.

The population of older adults in Maryland is aging rapidly. There should be no further delay in addressing their mental health needs.

APPENDIX 9

SAMPLE LETTER TO THE EDITOR

MARYLAND NEEDS A PLAN TO REDUCE SUICIDE

The Baltimore Sun, March 1, 2022

To the editor:

In his excellent essay on criminal justice, (Maryland's Public Safety System Is Broken 2/22/22), Wes Moore notes, as have many others, that the homicide rate in Maryland is dreadful and unacceptable. He is right.

But in recent times, the suicide rate in Maryland has been higher than the homicide rate. According to the CDC, from 2011 through 2020 there have been 5164 homicides and 5977 suicides. During this decade, there have also been 4569 drug overdose deaths. Together, then, there have been over 10,000 "deaths of despair", as suicide and overdoses are frequently called.

The obvious implication is that in addition to addressing the inadequacies of the criminal justice system, Maryland needs to address the inadequacies of its response to mental and substance use disorders. Hopefully, candidates for state office, including Mr. Moore, will make improving our behavioral health system a top priority.

Michael B. Friedman, LMSW
Adjunct Associate Professor Columbia University School of Social Work

Paul A. Nestadt, MD
Psychiatrist

SAMPLE OP-ED ESSAY

OPINION: COERCION AND INSTITUTIONALIZATION WON'T FIX IN NY'S MENTAL HEALTH CRISIS

By Harvey Rosenthal

City Limits, March 30, 2022

“ I spent six weeks in a psychiatric hospital on Long Island in 1970. I hadn’t slept or eaten in many days, had isolated myself for many more, and was increasingly suspicious of others. The medication and “therapy” groups left me empty and gave me little reason for hope. I thought my life as I knew it was lost forever.

Several years later, I went to work at the local state psychiatric center in Albany to try to give encouragement to people like me, who were essentially being told that their lives were over.

I worked as a mental health service provider for the next 18 years and as a mental health advocate for the last 30. I have seen New York’s mental health system at its worst and at its best.

I have seen us fail to provide the time and the will to find out how best to engage people in great need, only to place the blame on them and label them as “non-compliant.”

I’ve seen us give up on people because they wouldn’t accept medications without even trying to first address their most immediate needs, like food, shelter, and clothing. Now I’m seeing the state move to forcibly confine people in psychiatric wards because we haven’t found a way to get them to accept those same things.

I’ve seen people and politicians complain about and decry the “homeless mentally ill” and then fail to provide the specialized housing and supports necessary for people to voluntarily leave the streets and subways for help that they can trust, even as we have 2,500 empty supported housing units in New York City.

I’ve seen us fail time after time to skillfully engage and support BIPOC individuals with serious mental illnesses, as powerfully demonstrated by the finding that nearly 4 out of 5 Kendra’s Law coercive treatment orders are applied to Black and Brown people in New York City.

I’ve seen the sharp rise in public fears about the “violent mentally ill” even as the data is clear that the people I support are 11 times more likely to be victims of violence and five times more likely to be victims of murder.

We must reject policies that single out, scapegoat, and sweep away the rights of our neighbors with mental illness.

But I’m also seeing extraordinarily promising successes.

Just a few days ago, I saw New York's Legislative Black, Brown, Puerto Rican and Asian Caucus reject the Hochul Administration's proposal to expand the use of coercive treatment orders in favor of extending more and more appropriate services to those same communities.

I'm seeing programs send peer counselors out again and again to Queens tenements, White Plains bus stations, and Rochester homeless shelters to successfully and voluntarily engage people who would have otherwise been levied with Kendra's Law orders that are supposed to be used as a last resort, but often aren't.

I'm seeing the launch of crisis response models in New York State that offer a peer homeless outreach program in New York City, a center offering an array of crisis responses under one roof in Buffalo and the success that forensic peer team members are having in Westchester County.

I'm seeing the success of "low threshold" housing programs that take in and support people who were initially unwilling to stop using drugs or to start taking medications of choice.

Today, after many years of getting the wrong kinds of treatment, I deeply appreciate the medication, therapy, and peer support that I rely on because they were the right fit and introduced in the right way by the right people—and I had the choice to use them.

Years ago, a provider told me of how a worker had gone out again and again to unsuccessfully engage a person in severe need with a particular medication and treatment plan and asked me, shouldn't we respect people's right to refuse care? I answered, before you give up, send out someone else and offer them something better.

We must go forward and make these voluntary support and housing models available to all and stop any moves backward to the policies of coercion and institutionalization.

Harvey Rosenthal is CEO of the New York Association of Psychiatric Rehabilitation Services."

Harvey Rosenthal. "Opinion: Coercion and Institutionalization Won't Fix NY's Mental Health Crisis." City Limits (2022). *https://citylimits.org/2022/03/30/opinion-coercion-and-institutionalization-wont-fix-nys-mental-health-crisis/.*

ADVOCACY ORGANIZATIONS

APPENDIX 11

SELECT FEDERAL ADVOCACY GROUPS

The American Psychiatric Association ⭐ *Represents psychiatrists* 800 Maine Avenue SW, Suite 900 Washington, DC 20024 Phone: (888) 357-7924 Email: apa@psych.org *https://www.psychiatry.org/* Saul Levin, CEO	**The American Psychological Association** ⭐ *Represents psychologists* 750 First St. NE, Washington, DC 20002 Phone: (800) 374-2721 https://www.apa.org/ Sebrina Barrett, Executive Director
Bazelon Center for Mental Health Law ⭐ *Litigation & public policy advocacy* 1090 Vermont Avenue NW, Suite 220 Washington, DC 20005 Phone: (202) 467-5730 Email: communications@bazelon.org *https://www.bazelon.org/* Holly O'Donnell, CEO	**Depression and Bipolar Support Alliance** ⭐ *Support for people with bipolar disorder* 55 E Jackson Blvd, Suite 490 Chicago, IL 60604 Phone: (800) 826-3632 Fax: (312) 642-7243 *https://www.dbsalliance.org/* Michael Pollock, Chief Executive Officer
Mental Health America ⭐ *Mental illness prevention & treatment* 500 Montgomery Street, Suite 820 Alexandria, VA. 22314 Phone: (703) 684-7722 https://mhanational.org/ Schroeder Stribling, President	**National Alliance on Mental Illness** ⭐ *Mental health support for individuals & families* 4301 Wilson Blvd., Suite 300 Arlington, VA 22203 Phone: (703) 524-7600 *https://nami.org/home* Daniel H. Gillison, Jr., Chief Executive Officer

National Association of Social Workers
⭐ *Represents social workers*

750 First Street, NE Suite 800
Washington, DC 20002

Phone: (202) 408-8600.
https://www.socialworkers.org/

Anthony Estreet, Chief Executive Officer

National Association of State Mental Health Program Directors
⭐ *Represents mental health directors*

675 N Washington St Ste 470
Alexandria, VA 22314

Phone: (703) 739-9333
https://www.nasmhpd.org/

Brian Hepburn, Executive Director

National Council for Mental Wellbeing
⭐ *Represents mental health organizations*

1400 K Street NW, Suite 400
Washington DC, 20005

Phone: (202) 684-7457
https://www.thenationalcouncil.org/

Charles Ingoglia, President

National Disability Rights Network
⭐ *Legal advocacy for people with disabilities*

820 First St. NE, Suite 740
Washington, DC 20002

Phone: (202) 408-9514
Fax: (202) 408-9520
https://www.ndrn.org/

Marlene Sallo, Executive Director

National Empowerment Center
⭐ *Public policy & education resources*

599 Canal St.
Lawrence, MA 01840

Phone: (800) 769-3728
https://power2u.org/

Oryx Cohen, Chief Executive Officer

National Mental Health Consumer's Self-Help Clearinghouse
⭐ *Technical assistance & resource center*

737 Madison Avenue
Albany, NY 12208

Email: selfhelpclearinghouse@gmail.com
https://www.mhselfhelp.org/

Joseph Rogers, Executive Director

APPENDIX 12

SELECT ADVOCACY GROUPS IN NEW YORK CITY & NEW YORK STATE

New York State Psychiatric Association ⭐ *Represents psychiatrists* 400 Garden City Plaza, Suite 202 Garden City, NY 11530 Phone: (516) 542-0077 Fax: (516) 542-0094 Email: centraloffice@nyspsych.org *https://www.nyspsych.org/* Rachel A. Fernbach, Executive Director	**Association for Community Living** ⭐ *Represents mental health housing providers* 28 Corporate Drive, Suite 102 Clifton Park, NY 12065 Phone: (518) 688-1682 Fax: (518) 688-1686 Email: admin@aclnys.org https://aclnys.org/ Sebrina Barrett, Executive Director
Citizens' Committee for Children of New York ⭐ *Advocates for children in NYC* 14 Wall Street, Suite 4E New York, NY 10005 Phone: (212) 673-1800 *https://cccnewyork.org/* Jennifer March, Executive Director	**Coalition of Institutionalized Aged and Disabled** ⭐ *Represents residents of adult homes in NYC* 425 East 25th Street New York, NY 10010 Phone: (212) 481-7572 *https://ciadny.org/* Geoff Lieberman, Executive Director
Community Access ⭐ *Advocacy by people with lived experience* 64 Beaver Street, #109 New York, NY 10004 Phone: (212) 780-1400 *https://www.communityaccess.org/*	**Families Together in NYS** ⭐ *Represents families of children & adolescents* 737 Madison Avenue Albany, NY 12208 Phone: (518) 432-0333 Fax: (518) 434-6478 Email: info@ftnys.org *https://www.ftnys.org/* Paige Pierce, Chief Executive Officer

<table>
<tr>
<td>The Greater New York Hospital Association
⭐ Health care & patient care advocacy in NY

555 W 57th Street
15th Floor
New York, NY 10019

Phone: (212) 246-7100
Email: info@gnyha.org
https://www.gnyha.org/

Kenneth E. Raske, President</td>
<td>The Healthcare Association of New York State
⭐ Represents healthcare organizations in NYS

One Empire Drive
Rensselaer, NY 12144

Phone: (518) 431-7600
https://www.hanys.org/

Bea Grause, President</td>
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<td>Howie The Harp, a program of Community Access
⭐ Peer advocacy center

2090 Adam Clayton Powell Jr. Blvd., 12th Floor
New York, NY

Phone: (212) 673-1800
Email: hthtraining@communityacces.org
https://www.communityaccess.orghowietheharp</td>
<td>Vibrant Emotional Health
⭐ Mental health advocacy & support

50 Broadway, 19th Floor
New York, NY 10004

Phone: (212) 254-0333
Email: info@vibrant.org
https://www.vibrant.org/

Kimberly Williams, President</td>
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<td>Mental Health Association in New York State
⭐ Mental healthy awareness & recovery

194 Washington Avenue, Suite 415
Albany, NY 12210

Phone: (518) 434-0439
Email: info@mhanys.org
https://mhanys.org/

Glenn Liebman, Chief Executive Officer</td>
<td>Mental Health Empowerment Project
⭐ Represents recipients of mental health services

3 Atrium Drive, Suite 205
Albany, NY 12205

Phone: (518) 434-1393
Fax: (518) 434-3823
https://mhepinc.org/

Isacc Brown, President</td>
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National Alliance on Mental Illness - NY State	National Association of Social Workers - NYC
⭐ *Mental health support for individuals & families* 150 Broadway, Suite 406 Menands, NY 12204 Phone: (518) 462-2000 Fax: (518) 245-9227 Email: info@naminys.org *https://www.ftnys.org/* *visit for other NY locations *Sharon Horton, Executive Director*	⭐ *Represents social workers in NYC* 305 Seventh Avenue, Suite 13A New York, NY 1000 Phone: (212) 668-0050 Email: contactus.naswnyc@socialworkers.org *https://www.naswnyc.org/* Claire Green-Forde, Executive Director
National Association of Social Workers - NYS ⭐ *Represents social workers in NY State* 188 Washington Avenue, Albany, NY 12210 Phone: (518) 463-4741 Email: info.naswnys@socialworkers.org *https://naswnys.org/* Samantha Fletcher, Executive Director	**New York Association of Psychiatric Rehabilitation Services** ⭐ *Provide recovery-based mental health services* 194 Washington Avenue, Suite 400 Albany, NY 12210 Phone: (518) 436-0008 Fax: (518) 436-0044 *https://www.nyaprs.org/* Harvey Rosenthal, Chief Executive Officer
NYS Council for Community Behavioral Healthcare ⭐ *Recovery-focused mental health services* 911 Central Ave, Albany, NY 12206 Phone: (518) 461-8200 *https://nyscouncil.org/our-team/* Lauri Cole, Executive Director	**New York State Psychiatric Association** ⭐ *Organization of psychiatrists* 400 Garden City Plaza, Ste 202 Garden City, NY 11530 Phone: (516) 542-0077 Email: centraloffice@nyspsych.org *https://www.nyspsych.org/* Rachel A. Fernbach, Executive Director

New York State Psychological Association ⭐ *Aimed at advancing psychology* 330 West 38th Street, Suite 1105 New York, NY 10018 Phone: (518) 437-1040 Fax: (518) 437-0177 Email: nyspa@nyspa.org *https://www.nyspa.org/* Lori Sales Cutler, Executive Director	**New York Alliance for Inclusion & Innovation** ⭐ *Advocacy & training organization* 240 Washington Avenue Extension, Suite 501 Albany, NY 12203 Phone: (518) 795-3590 *https://nyalliance.org/* Michael Seereiter, President & CEO
Schuyler Center for Analysis and Advocacy ⭐ *Policy analysis and advocacy organization* 540 Broadway Albany, NY 12207 Phone: (518) 463-1896 Fax: (518) 463-3364 *https://scaany.org/* Kate Breslin, President	**Urban Justice Center | Mental Health Project** ⭐ *Ending the criminalization of mental health* 40 Rector Street, 9th Floor New York, NY 10006 Phone: 1-877-647-5291 Email: mhp@urbanjustice.org *https://mhp.urbanjustice.org/* Demetrius Thomas, Managing Director

PUBLIC OFFICIALS*

*As of May 2023. For up-to-date information, contact the League of Women Voters or visit their website.

KEY FEDERAL ELECTED OFFICIALS

PRESIDENT OF THE UNITED STATES
Joseph Biden The White House Washington, DC 20500 (202) 456-1414 *https://www.whitehouse.gov/contact/*

HOUSE OF REPRESENTATIVES	SENATE
Speaker of the House: **Kevin McCarthy** H-232, The Capitol Washington, DC 20515 Phone: (202) 225-4000 *https://kevinmccarthy.house.gov/*	**Senate Majority Leader:** **Chuck Schumer** 322 Hart Senate Office Building Washington, DC 20510 Phone: (202) 224-6542 *https://www.schumer.senate.gov/*
Ways & Means Committee Chairman: **Jason Smith** 1011 Longworth House Office Building Washington, DC 20515 Phone: (202) 225-4404 *https://jasonsmith.house.gov/*	**Senate Finance Committee Chairman:** **Ron Wyden** 221 Dirksen Senate Office Building Washington, DC 20510 Phone: (202) 224-5244 *https://www.wyden.senate.gov/*

HOUSE OF REPRESENTATIVES	SENATE
House Budget Committee Chairman: Jodey Arrington 1107 Longworth House Office Building Washington, DC 20515 Phone: (202) 225-4005 *https://arrington.house.gov/*	**Senate Budget Committee Chairman: Sheldon Whitehouse** 530 Hart Senate Office Building Washington, DC 20510 Phone: (202) 224-2921 *https://www.whitehouse.senate.gov/*
Health Sub-Committee Chairman: Brett Guthrie 2434 Rayburn H.O.B. Washington, DC 20515 Phone: (202) 225-3501 *https://guthrie.house.gov/*	**Health, Education, Labor, and Pensions Committee Chairman: Bernie Sanders** 332 Dirksen Building, Washington, D.C. 20510 Phone: (202) 224-5141 *https://www.sanders.senate.gov/*

KEY FEDERAL ADMINISTRATIVE OFFICIALS

DEPARTMENT OF HEALTH & HUMAN SERVICES

Secretary: Xavier Becerra
200 Independence Avenue, S.W.
Washington, D.C. 20201
Phone: (877) 696-6775
https://www.hhs.gov/

THE NATIONAL INSTITUTE OF MENTAL HEALTH

Director: Joshua A. Gordon
6001 Executive Blvd
North Bethesda, Maryland 20852
Phone: (866) 615-6464
https://www.nimh.nih.gov/

THE SUBSTANCE ABUSE & MENTAL HEALTH SERVICES ADMINISTRATION

Assistance Secretary: Miriam E. Delphin-Rittmon
5600 Fishers Lane
Rockville, MD 20857
Phone: (877) 726-4727
https://www.samhsa.gov/

THE CENTER FOR MENTAL HEALTH SERVICES

Director: Anita Everett

5600 Fishers Lane

Rockville, MD 20857

Phone: (240) 276-1310

https://www.samhsa.gov/about-us/who-we-are/offices-centers/cmhs

THE CENTER FOR MEDICARE & MEDICAID SERVICES

Administrator: Chiquita Brooks-LaSure

7500 Security Boulevard

Baltimore, MD 21244

Phone: (800) 633-4227

https://www.cms.gov/

KEY ELECTED OFFICIALS IN NYS

THE GOVERNOR
Kathy Hochul New York State Capitol Building Albany, NY 12224 Phone: (518) 474-8390 *https://www.governor.ny.gov/*

Senate Majority Leader: **Andrea Stewart-Cousins** Legislative Office Building, Room 907 Albany, NY 12247 Phone: (518) 455-2585	**Speaker of the Assembly:** **Carl E. Heastie** Legislative Office Building, Room 932 Albany, NY 12228 Phone: (518) 455-3791
Chair of the Senate Finance Committee: **Liz Krueger** Capitol Building, Room 416 Albany, NY 12247 Phone: (518) 455-2297	**Chairman of the Ways & Means Committee of the Assembly:** **Helene E. Weinstein** Legislative Office Building, Room 923 Albany, NY 12248 Phone: (518) 455-5462
Chairman of Senate Mental Health Committee: **Samra G. Brouk** Legislative Office Building, Room 812 Albany, NY 12247 Phone: (518) 455-2215	**Chairman of the Mental Health Committee of the Assembly:** **Aileen M. Gunther** Legislative Office Building, Room 826 Albany, NY 12248 Phone: (518) 455-5355

KEY ELECTED OFFICIALS IN NYC

THE MAYOR	THE PUBLIC ADVOCATE
Eric Adams City Hall New York, NY 10007 Phone: (212) 639-9675 *https://www.nyc.gov/office-of-the-mayor/*	**Jumaane D. Williams** 1 Centre Street 15th Floor North New York, NY 10007 Phone: (212) 669-7250 *https://www.pubadvocate.nyc.gov/*

THE CITY COUNCIL	
The Speaker of the City Council: **Adrienne Eadie Adams** City Hall New York, NY 10007 Phone: (212) 482-6731 *https://council.nyc.gov/adrienne-adams/*	
Chair of the Health Committee: **Lynn Schulman** 250 Broadway Suite 1873 New York, NY 10007 Phone: (212)788-6981 *https://council.nyc.gov/lynn-schulman/*	**Chair of the Committee on Mental Health, Disabilities, & Addiction:** **Linda Lee** 250 Broadway, Suite 1744 New York, NY 10007 Phone: (212) 788-7075 https://council.nyc.gov/linda-lee/

THE BOROUGH PRESIDENTS
The Bronx Borough President: Vanessa L. Gibson 851 Grand Concourse, 3rd Floor Bronx, New York 10451 Phone: (718) 590-3500 *https://bronxboropres.nyc.gov/*
The Manhattan Borough President: Mark Levine 1 Centre Street, 19th floor New York, NY 10007 Phone: (212) 669-8300 *https://www.manhattanbp.nyc.gov/*
The Staten Island Borough President: Vito J. Fossella 10 Richmond Terrace Staten Island, NY 10301 Phone: (718) 816-2000 *https://www.statenislandusa.com/*
The Brooklyn Borough President: Antonio Reynoso 209 Joralemon Street Brooklyn, NY 11201 Phone: (718) 802-3700 *https://www.brooklyn-usa.org/*
The Queens Borough President: Donovan Richards 120-55 Queens Boulevard One Claire Shulman Way Kew Gardens, NY Phone: (718) 286-3000 *https://queensbp.org/*

APPENDIX 17

KEY MENTAL HEALTH OFFICIALS IN NYS & NYC

THE NEW YORK STATE OFFICE OF MENTAL HEALTH	
Commissioner: **Ann Marie T. Sullivan** 44 Holland Avenue Albany, NY 12229 Phone: (518) 474-4403	**Executive Deputy Commissioner:** **Moira Tashjian** 44 Holland Avenue Albany, NY 12229 Phone: (518) 474-7056
Medical Officer: **Daniel Silverman** 44 Holland Avenue Albany, NY 12229 (212) 330-1650	**Senior Deputy Commissioner:** **Robert Myers** 44 Holland Avenue Albany, NY 12229 (518) 486-4327
New York City Field Office: 330 Fifth Avenue, 9th Floor New York, NY 10001 Phone: (212) 330-1650	

THE NEW YORK CITY DEPARTMENT OF HEALTH & MENTAL HYGIENE	
Commissioner: **Ashwin Vasan** 125 Worth Street New York, NY 10013	**Executive Deputy Commissioner:** **Deepa Avula** 125 Worth Street New York, NY 10013
Chief Operating Officer: **Emiko Otsubo** 125 Worth Street New York, NY 10013	**Chief Medical Officer:** **Michelle Morse** 125 Worth Street New York, NY 10013

BIOS

MICHAEL B. FRIEDMAN, LMSW

Over the course of his 55-year career as a social worker, Michael Friedman has served as a direct service provider, an administrator, a government official, an educator, and a social advocate. He retired in 2010 from his position as Director of The Center for Policy, Advocacy, and Education of The Mental Health Association of New York City, which he founded in 2003. He also retired as Chair of the Geriatric Mental Health Alliance of New York, which he co-founded in 2004, and as the Facilitator of the Veterans' Mental Health Coalition in NYC, which he co-founded in 2009.

Mr. Friedman has served on numerous advisory and advocacy groups at the federal, state, and local levels.

After retirement, Mr. Friedman continued teaching health policy and mental health policy at the Columbia School of Social Work.

He moved to Baltimore in 2019 to be closer to his daughter and grandchildren. There, he has served as a volunteer mental health advocate with AARP MD, the Maryland Mental Health and Aging Coalition, Johns Hopkins Department of Psychiatry, NASW of MD, and others.

Mr. Friedman has published over 250 essays, articles, lectures, and book chapters. Many are on his website, *www.michaelbfriedman.com.*

ILIANA RIOS

Iliana Rios is a student at Columbia College in the City of New York. She is double-majoring in Political Science and Ethnicity and Race Studies, planning to graduate in 2025. She was an intern in the Office of Senator Jacky Rosen of Nevada in the summer of 2022. She has also worked on many political and community service projects.