INSERT TAB: module 4 Script
Hello everyone. Welcome to the NAMI Smarts for Advocacy workshop, *Medication: Protecting Choice*, part of NAMI’s grassroots advocacy series. My name is [name] and I will be facilitating your learning today. And helping us today is [name].

During this workshop, we'll talk about mental health medications as an important part of many people’s recovery. We’ll also discuss the power of your story to impact a person’s ability to get the medication they need. As part of this workshop, we’ll guide you through writing your story in seven short steps.

Medications may not have worked well for you or you may not choose to take them. If that’s the case, you can still use your lived experience—your story—to support other people having choices, including new options that may work better or have fewer side effects.

When you complete this workshop, our goal is that you take with you a version of your story that you can use to raise awareness, inspire others and influence decision makers.

We hope you’re excited. *Are you ready to start?* [Wait for a response, if appropriate] Great, we’ll get started.

To begin, please take out your evaluation form and fill out the first column for question one and two only. You will fill out the rest of the evaluation form at the end of the workshop.

[Give participants about half a min. to fill out the first two questions.]
### Agenda
1. **Learn** why telling your story about medications is important
2. **Hear** tips for telling your story effectively
3. **Listen** to an example
4. **Discover** what makes a story “work”
5. **Write** your own story
6. **Practice** sharing your story

---

### Core Concepts
- Workshop format
  - *First, you will learn* why telling your story about medications is important
  - *Next, you’ll hear* tips for telling your story effectively
  - *Listen to* an example
  - *Discover* what makes a story work
  - *Write* your own story and
  - *Practice* sharing it.

How does this sound to you? [Wait for group to respond.]

Again, today’s workshop is focused on using your story to help people get the right mental health medications easily.

---

### Core Concept
- Turn off electronic devices
- Participate fully
- Hold questions
- Cannot provide medication advice

---

This workshop covers a lot of ground in a short amount of time. In order for everyone to get the most out of this session, I’d like to ask you to agree to the following basic ground rules:

- **Turn off** your electronic devices unless absolutely necessary
- **Participate** fully—be willing to do each of the activities and to stay focused
- Because our time is limited, please keep questions and comments very brief
- This is not “Ask the doctor,” so if you have questions about specific medications, please follow up with a prescriber

To keep us on time, I’ll be signaling you when we need to stop an activity. I’ll let you know by [indicate how you’ll signal participants—voice, hand, chime, etc.] Please be willing to stop even if you are not finished.

If you have questions or comments that aren’t answered during the workshop, feel free to ask them when the workshop is over.

Are you willing to follow these ground rules? [Wait for response] Thank you!

---

Prep:
- Decide how you will signal participants during the workshop (e.g., by voice, raised hand, chime, etc.)
Why Protect Choice?

NAMI cares because:
- Medication can be an important recovery tool
- Medication is often a key part of mental health treatment (but not always)
- One size does not fit all
- Response to mental health medications varies
- When side effects cause problems, a different medication may work better

We’d like to say a word about why this workshop is part of NAMI Smarts for Advocacy. NAMI seeks to build better lives for all who are affected by mental illness or mental health conditions.

We know that medication can be a valuable tool in a person’s recovery. We also know that not everyone takes medication as part of mental health treatment.

But for those who do, we know that one size does not fit all because mental health medications affect people in different ways. Medications that work for one person may not work for another. And, if side effects cause problems another medication, or combination of medications, may work better.

That’s why your lived experience is so valuable to inform the decision makers charged with deciding who can get what kind of mental health medication. Even if medication is not part of treatment for yourself or someone you care about, you can support choice for others.

Warm-up Activity

✓ How has medication helped with your recovery?
✓ What did it take to get the right medication?

To start, let’s think about the role medication has played in your recovery or the recovery of someone you know. What has it taken to get the right medication? Have you had medications that didn’t work for you or had problems getting the medication you need?

I’ll read the first question, then the second. If you’d like to share, raise your hand. Let’s try for a couple of responses to each question.

**Briefly, how has medication helped with your recovery or the recovery of someone you care about?** [Take 2 brief responses]

**Briefly, what did it take to get the right medication? Any challenges?** [Take 2 brief responses, then thank respondents for sharing]

As we start exploring what can get in the way of people getting the medication they need, think about the role medication plays in recovery and what it can take to get the right medication.

Note:
Slide has automation—questions will fade in
Many people get their medication through a health plan. A health plan can be a:

- Commercial health insurance plan, like BlueCross or Aetna
- Health insurance for the military, like TRICARE
- Government-funded health plan, like Medicaid, which covers low-income Americans, or Medicare Part D plans, which cover medications for older Americans and people with disabilities

Throughout this workshop, we'll use the term **health plans** to mean any kind of private or government health insurance or health coverage.

Health plans have to balance…

- How much they charge for a plan (the insurance premium) or the funding they receive with…
- What it costs to provide quality care, including medication, for their members

As part of managing both cost and quality, NAMI believes that health plans should help people get the right medication to aid in their recovery. Without the right medication, people may experience poor health outcomes—and need more costly care, like hospitalization.
<table>
<thead>
<tr>
<th>Slide 7</th>
<th>Approx. .5 min</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core Concept</strong></td>
<td>Health plans may make it difficult to get the right medication</td>
</tr>
</tbody>
</table>

Yet even though the right medication may help with your recovery, health plans may **make it difficult to get the right medication**.

Health plans try to help people recover and stay well while managing costs. But how a health plan manages benefits can affect whether it is easy or difficult for people to get the medication that’s right for them.

<table>
<thead>
<tr>
<th>Slide 8</th>
<th>Approx. 1 min</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core Concept</strong></td>
<td>Health plans may limit choices of medications on its formulary</td>
</tr>
</tbody>
</table>

One of the most common ways health plans may make it harder for people to get the right medication is by **limiting your choice** of covered medications.

Health plans also typically **change their list of covered medications** one or more times a year.

A health plan’s list of covered medications is called a **formulary or a preferred drug list (PDL)**.

We’re going to mention some common terms used by health plans today, but you won’t need to remember them in this workshop. We’ve included a **glossary** of the terms we’re using in your packet for you to read later, if you like.

**Handout: Glossary**

**Helper or Facilitator:**
Hold up a copy of the **Glossary** when it’s mentioned in the script.
### Core Concept

- P&T Committees are often the decision-makers for plan formularies

### Approx. 3 min

You may be wondering who makes the decisions about what medications your health plan covers or what you have to do to get them. In some cases, a health plan’s pharmacy director or pharmacy benefit manager, a company that manages medications for a health plan, decides which medications will be covered and how.

Some plans, like Medicare Part D and Medicaid plans, are required to have a Pharmacy and Therapeutics Committee, more commonly called a P&T Committee. P&T Committees are made up of doctors and other health professionals and sometimes have member or advocate representatives. In 2017, more commercial health plans will be required to have a P&T Committee, too.

P&T Committees review scientific evidence for a medication’s effectiveness, safety, side effects, drug interactions, cost and other factors. The Committee weighs these factors, along with stories or testimony from the public, and then makes a recommendation or decision for coverage by the plan.

We want to point out that health plans may make decisions to not cover a medication or to restrict its coverage because the medication:

- May have dangerous or serious side effects or interactions,
- Isn’t approved for certain health conditions,
- May have limited effectiveness or is effective only under certain conditions or
- Effectiveness or safety may not be well-established or may be in question.

Coverage of a medication may also be limited because:

- A generic version of the medication is available or
- The medication is more expensive than other medications used to treat the same condition.
### Core Concept

**Medication coverage gets more complicated**

We’ve mentioned that health plans can limit your choice of covered medications and can change their list of covered medications one or more times a year. We also noted that, for many plans, P&T Committees are influential or decision-makers on coverage of medications.

**But, it gets even more complicated…** [Pause for a moment]

### Core Concept

**Health plans may put some medications in higher “tier” and charge higher out-of-pocket costs**

Another way health plans may make it harder for you to get the right medication is by putting some medications in a higher “tier” or level on its list of covered medications.

Commercial health insurance plans and Medicare Part D plans usually have tiered drug lists. Drugs on the lowest tier have no or lower out-of-pocket costs compared to drugs on higher tiers.

Out-of-pocket costs may take the form of **copays** (a set amount you have to pay), **coinsurance** (a percentage of the total drug cost) or a **deductible** (an amount you have to pay before coverage will begin or resume).

The tier level of a medication is often listed on a plan’s drug list. However, the list might not tell you what the out-of-pocket cost will be for drugs on different tiers.

**Have you ever had a copay or coinsurance that made your medication unaffordable?** [Take a quick response or two]
### Slide 12

**Approx. 1 min**

**Core Concept**
- Health plans may list medications as “non-preferred” and charge more.

Health plans may also list some medications as “preferred” and others as “non-preferred.” Preferred medications are covered by the plan. Non-preferred medications may be available at a higher cost—or may not be covered at all.

A plan may make a medication “preferred” because it is safer or more effective than a similar medication, but a medication may also be preferred because it is less expensive to the plan than an alternative medication.

*Have you ever needed a medication that was “non-preferred” on your health plan?* [Take a quick response or two]

### Slide 13

**Approx. 1 min**

**Core Concept**
- Health plans may require “prior authorization”.

You may also have problems getting the right medication if your plan requires “prior authorization” or prior approval. Prior authorization means that your doctor must contact your health plan and request coverage of the medication.

If prior authorization, or “PA,” is granted, your plan will cover the drug, but you may have an out-of-pocket cost. Some plans require a new prior authorization every year or even every time you refill your medication.

If prior authorization is not granted, your plan won’t cover the cost of the medication. But, you have the right to appeal your plan’s decision.
<table>
<thead>
<tr>
<th>Slide 14</th>
<th>Approx. 1 min</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core Concept</strong></td>
<td>Health plans may also use “step therapy”—requiring you to try and fail on one or more medications before they will approve coverage for a different medication. For example, a plan may require you to try a generic antipsychotic for several weeks and have your doctor document that it did not work for you before authorizing coverage for a different brand name antipsychotic.</td>
</tr>
<tr>
<td><strong>Have you ever had a bad experience with either prior authorization or step therapy?</strong> [Take a couple of brief responses]</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slide 15</th>
<th>Approx. .5 min</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core Concept</strong></td>
<td>We’ve just talked about:</td>
</tr>
<tr>
<td></td>
<td>• Limited choices of medications on formularies,</td>
</tr>
<tr>
<td></td>
<td>• Tiered lists of covered medications with higher costs at higher tiers,</td>
</tr>
<tr>
<td></td>
<td>• Non-preferred medications that cost more or aren’t covered,</td>
</tr>
<tr>
<td></td>
<td>• Requirements for a doctor to request “prior authorization” and</td>
</tr>
<tr>
<td></td>
<td>• Step therapy requirements.</td>
</tr>
<tr>
<td><strong>Any of these may keep you from getting the medication you need.</strong></td>
<td></td>
</tr>
<tr>
<td>Slide 16</td>
<td>Approx. 1 min</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Core Concept</strong></td>
<td>Not getting the right medication may put people at higher risk for emergency room visits, hospitalization and more...</td>
</tr>
<tr>
<td></td>
<td>Not getting the right medication may <strong>put you at higher risk for emergency room visits, hospitalization or other poor outcomes</strong>.</td>
</tr>
<tr>
<td></td>
<td>According to a ten-state study of Medicaid prescription policies, researchers found that prior authorization of medications were associated with people being:</td>
</tr>
<tr>
<td></td>
<td>- More than twice as likely to be reported homeless and</td>
</tr>
<tr>
<td></td>
<td>- Three times more likely to be hospitalized.</td>
</tr>
<tr>
<td></td>
<td>People who discontinued or temporarily stopped their medications due to problems getting their medications were <strong>more than twice as likely to end up in jail</strong>.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slide 17</th>
<th>Approx. .5 min</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core Concept</strong></td>
<td>More than one out of every 13 emergency department visits involve a mental illness.</td>
</tr>
<tr>
<td></td>
<td>Let’s look at some numbers for emergency department visits. According to hospital data, more than <strong>one out of every 13 emergency department visits among adults involved mental illness</strong>.</td>
</tr>
</tbody>
</table>
### Slide 18
**Approx. .5 min**

**Core Concept**
- Mood disorders a top reason for hospital admissions

For adults, **mood disorders were the top reason for admission** to a hospital after an emergency department visit in 2011.

And mood disorders were the **fourth most common reason for hospitalization of children ages 0-17** (excluding hospital stays for young moms and newborns).

### Slide 19
**Approx. .5 min**

**Core Concept**
- Psychotic disorders also a top reason for hospital admissions

For adults, **psychotic disorders, like schizophrenia, were the fourth most common reason for a hospital admission after an emergency department visit in 2011.**

When people don’t get the health care they need, including the right medication, they’re at **higher risk for poor outcomes like emergency department visits and hospitalization.**

As we’ve just heard, there are serious consequences when people don’t get the help they need. If you’d like to refer to these facts, find the **fact sheet** included in your packet.

**Handout:** Fact Sheet

**Helper or Facilitator:**
Hold up a copy of the Fact Sheet when it’s mentioned in the script.
This quote from the National Institute of Mental Health sums up what many people have experienced: "A medication that works well for one person with schizophrenia often doesn’t work well for another. Genetic variations are thought to play a key role in this difference in response. While patients search for the right medications, their illnesses may worsen.”

This is not just true for schizophrenia. Many people with other mental illnesses, like bipolar disorder, also find that a medication that works well for others doesn’t work well for them.

Do you know someone that has done well on a medication that doesn’t work for you or others, even though you have the same diagnosis? [Take a quick response]

We know that it isn’t always easy to get the right medication and we know what can happen when people don’t get the medication they need. That’s why it’s important to speak up. Your story is a way to let people know how the right medication makes a big difference in not just your recovery or that of someone you love, but also the recovery of other people who live with mental illness.
Research shows that stories that evoke emotion and empathy are far more powerful than facts and figures in shaping the opinions of others. Hearing real stories is one of the best ways to change how health plans cover medications for people living with mental illness.

Best of all: [Pause slightly after each of these concepts to let people process]

1. **Your story is always right**
2. **Your lived experience has value and meaning**
3. **You don’t have to have all the answers—just a clear "ask" of your listeners**

If you think about it, this is very empowering to realize.

However, while your lived experience is meaningful, **how you tell your story** affects your impact. You want to make an impact, so we’ll give you some tips for telling your story about your experience with medication.
<table>
<thead>
<tr>
<th>Slide 24</th>
<th>Approx. 1 min</th>
<th>Core Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tip #1</td>
<td>Keep it brief—stick to the highlights</td>
<td>The 1st tip is to <strong>keep your story brief</strong>.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>We could all tell volumes about what has happened to us. But, you’ll lose your listeners if you spend too much time and give too many details.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Remember, we live in a world of sound bites and Twitter feeds. Keep your story short. <strong>Aim for about 90 seconds</strong>.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Think about a movie trailer—in 30 sec. you get the highlights and want to see more. That is what you want to achieve with your story—give just the highlights about how medication has made a difference in your recovery and leave your listeners eager to know more.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slide 25</th>
<th>Approx. 1 min</th>
<th>Core Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tip #2</td>
<td>Motivate with hope and recovery</td>
<td>Our 2nd tip is to <strong>motivate your listener by using positive concepts like hope and recovery</strong> whenever possible.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hope is a powerful motivator for decision makers. People like to root for those who make it through adversity—use this to your advantage.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>If you struggle to think of your story as hopeful, think about what you hope for or how getting the right medication would help with your recovery or would help others in their recovery.</td>
</tr>
</tbody>
</table>
Facilitator Script for NAMI Smarts for Advocacy, Medication: Protecting Choice

| Slide 26 | Approx. 1 min | Core Concepts | Make an “ask”
| --- | --- | --- | ---
| Tip #3 Make an “ask” that will help you get (or keep getting) the medication you need | Here’s our last tip: **Make an “ask”** of your listener. This is often forgotten when people tell their stories. But as the saying goes, “If you don’t ask, you don’t get.” Besides, decision makers **want** to know what you want them to do, even if they disagree. If you are talking to decision makers, let them know what would help you or others get (or keep getting) the right medication to support recovery. You’ve just heard our three tips. **What was the most meaningful thing you’ve heard so far?** [Take two quick responses]

| Slide 27 | Approx. 5 min | Core Concepts | Make an “ask”
| --- | --- | --- | ---
| With our tips in mind, let's get started... –Listen to the example story and notice your reactions | Now that we’ve gone through our tips, I’m going to share a sample story from the perspective of [choose the sample story you will read]. Your materials include two sample stories—one from the point of view of a peer and one from the point of view of a family member. Your own perspective is unique and you may or may not relate to these sample stories. This story is being told as if the person were talking to a Pharmacy & Therapeutics (P&T) Committee. However, this story format is like a basic recipe; it can be easily adapted to fit other situations or audiences. For now, I’d like you to keep an open mind and notice your reactions and what moves you or has impact for you. **Read the sample story** with expression [you or, ideally, your Helper] **What had impact for you or caught your attention?** [Take two to four responses]

| Prep: Decide which sample story you will use before the workshop | Helper or Facilitator: Practice the sample story out loud several times before the workshop until you can read it smoothly and with expression.

Handout: Sample Stories
### Core Concept

- Compare the sample story with your seven steps checklist

#### Discuss 1st step

- Introduce who you are and where you’re from
- Share how you are affected by mental illness
- State your purpose—what action or decision you want

#### The 1st step of an effective story is to introduce yourself and why you are speaking or writing.

1. Your introduction should begin by letting your audience know your name and what city or town you live in.
2. Share how you are affected by mental illness, whether you live with mental illness, are a family member, caregiver, friend or professional. This establishes your credibility through lived experience.
3. Lastly, let your listener know that you would like to share your story and state your purpose—what action or decision you want from them. This helps your audience focus and be more responsive.

- ➤ Take a moment to mark the phrase in the sample story that lets you know the purpose of the speaker’s story.

#### Handouts:

- Sample Stories
- Seven Steps Checklist
- Story Practice Sheets

#### Helper:

- Help people find worksheets as needed

---

Now that you’ve listened to our sample story and noticed its impact, you’ll need your Sample Stories (pages 3-4), your Seven Steps Checklist (page 5) and your Story Practice Sheets (pages 7-8).

The Checklist lists the elements of a brief, effective story. We’re going to review these seven elements, or steps, and compare them with the sample story you just heard. Then, you’ll use these steps to write your own story.

**Note:** Mark the sentences in your sample story that you want people to mention when answering the questions.
### Discuss 2\textsuperscript{nd} step

- What happened before you received help?
- Should be brief, but vivid

The 2\textsuperscript{nd} step of an effective story is to describe what happened before you got the right medication (or what you are going through now). Keep this very brief--think about the main highlights or most important thing your listener should know about your situation.

Vivid language in this description helps your audience understand what you went through (or are going through).

- Take a moment to mark a line or words in the sample story that moved you or helped you understand what happened to the speaker.

*Who would like to read a line in the second section that moved you or helped you understand what happened?* [Pick a volunteer to read the phrase they think answers the question]

*Did someone else mark a different phrase?* [Pick a volunteer to read a phrase]

Your listeners will vary in what moves them. And, different stories will move different people. This is why it helps for multiple people to share their stories.

<table>
<thead>
<tr>
<th>Handouts:</th>
<th>Sample Stories Seven Steps Checklist</th>
</tr>
</thead>
</table>

### Discuss 3\textsuperscript{rd} step

- What helped in your recovery or what would help?
- Tells the listener what makes a difference

The 3\textsuperscript{rd} step is to describe what helped in your recovery (or for someone you care about) or what would help. By focusing on helped or what would help you or others, you create a sense of hope and help your listener know what makes a difference.

- Take a moment to mark a line in the sample story that helped you realize what helped.

*Who would like to share the line that struck you in the third step?* [Pick a volunteer to read what helped]
<table>
<thead>
<tr>
<th>Discuss 4th step</th>
<th>The fourth step is to describe <strong>how you are different today</strong>. Share what is going right in your life (or in the life of someone you care about) or how you are experiencing recovery. This is how your story inspires. <strong>What language in the fourth step of the story left you feeling hopeful or inspired?</strong> [Ask a volunteer to read the phrase in the fourth section of the story that mentions how the writer is different today.]</th>
<th>Handouts: Sample Stories Seven Steps Checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss 5th and 6th step</td>
<td><strong>In the 5th and 6th steps,</strong> describe <strong>what is the need or problem</strong> and <strong>what will help others</strong>. In step five, transition away from your own concern to what other people need or the challenge they face that is similar to your own. In step six, describe what will help or could help others. This should be what you want a decision maker to do or decide. These steps take you from your personal story to a message that about other people. This helps decision makers who will take actions or decide on policies that will affect many people. <strong>Who would like to share the line that helped you sense the transition?</strong> [Pick a volunteer to share the line they marked.]</td>
<td>Handouts: Sample Stories Seven Steps Checklist</td>
</tr>
<tr>
<td>Discuss 7th step</td>
<td><strong>In the 7th and last step,</strong> make your &quot;ask.&quot; This is a critical step that many advocates hesitate or forget to do. Thank your audience for listening. Then, let them know what action or decision you want them to make on your issue. If your audience gives you a positive response, thank them for their support. If your audience gives you a negative or noncommittal response, don’t take it personally. Thank them, again, and let them know you’d like to serve as a resource on mental illness. ➤ Take a moment to mark a line in the sample story that made an ask. <strong>What strikes you about the &quot;ask&quot; in the sample story? What do you find helpful about the checklist?</strong> [Take 1 to 2 responses]</td>
<td>Handouts: Sample Stories Seven Steps Checklist</td>
</tr>
</tbody>
</table>
Now that you’ve heard a sample story and compared it to the Seven Steps Checklist, you’re ready to **find your Story Practice Sheets** (pages 7-8) and **start writing your own story**.

For help, use your Seven Steps Checklist and the sample story—or ask a question. Remember, the best preparation for telling an effective story is to **know your purpose and your “ask.”**

Here’s the scenario to use for your story. Please pretend you are telling your story to urge decision makers to make it easier for people to get the right medication, just like in our sample stories.

Your “ask” can be the same as in a sample story or you can use your own words.

**You’ll have about 15 minutes to write your story on your practice sheet.** I’ll let you know when you have a few min. left to finish up.

If you don’t finish, don’t worry. This is just a practice. You can finish it on your own time or make edits later. If it’s easier for you, feel free to write your story in “bullet points” instead of full sentences.

If you finish early, practice reading your story silently.

**Circulate:** While participants are writing, walk around the room. If participants finish early, ask if they are willing to let you read their story silently. Let them know what phrases are strong. **Keep in mind participants who have strong stories.**

**Warn participants 5 min. before end and 2 min. before time is up.**

[Use your chime, bell or other prearranged signal]

**Stop participants after 15 min.**

If you didn’t finish your story, feel free to finish in your free time. **What did you learn about writing your story?** [Take one or two responses]

---

**Handouts:**

- Story Practice Sheets
- Seven Steps Checklist

**Helper:** Help people find worksheets and participants with questions or struggles (this will free up Facilitator to circulate and manage time)
You all have a good start on your story. Now, we’ll practice sharing and giving constructive feedback.

Hold onto your story and take out your Constructive Feedback Form. The form has a scale, from one to five, for each step of a story. A “one” indicates an area that could be strengthened; “three” indicates an area that works fine and a “five” indicates an area that is particularly strong or impactful.

Please find a partner and wait for our practice instructions. [Wait for partners to form]

Here are the instructions. In the next ten minutes, we’ll have two five-minute rounds of story-sharing. As a reminder, I’ll let you know when five minutes has passed with [Indicate chime, bell or other signal]. During each round:

- One person will share their story in two minutes or less.
- One person will keep time and stop the storyteller after two minutes. Use a stopwatch function on a cell phone, if available.
- Timekeeper should also listen attentively and, if possible, fill out the Constructive Feedback Form to record impressions.
- After the storyteller’s two minutes is up, provide constructive feedback—specific information about what worked well or worked fine and what could be strengthened and how. Remember that constructive feedback is not intended to be judgmental—it is intended to help you see the strengths of your story and how you could make it even more impactful.

Please begin.

Signal end of round 1 after 5 min.
It’s time to trade roles if you haven’t already.

Signal end of round 2 after 5 min.

How’d that go for everyone? What did you learn about telling your story? [Take 2 to 3 quick responses]
Ask for a volunteer to share their story. Call on a person whom you think may have a good story based on what you heard or read earlier.

Thank you so much for sharing your story. Now, as listeners, what was effective for you and why? [Take two or three responses]
Note: You may ask for another volunteer if you like.

You have all accomplished a lot in just a short time. You’ve written your story and practiced it. Now, you can use your story to help make positive changes for people living with mental illness.

Best of all, the story you wrote is based on a basic structure, or recipe. That means you can make just a few changes in details and the purpose and “ask” and use it for many different issues and audiences.

Let’s learn together—what makes a story really effective?

What was most helpful or impactful for you? [Take a couple responses to each question]

This quote, “Act as if what you do makes a difference. It does.” is a reminder that your story can—and does—influence others.
## Core Concept

**Your story can make a real difference. It can help protect choice of medications.**

### Slide 33

**Approx. .5 min**

- Your story can help protect choice of medications

### Slide 34

**Approx. 1 min**

- Share your story with P&T Committees, pharmacy directors, Medicaid and insurance agencies and elected officials

### One way to make an impact is to share your story with people who can influence medication choices, such as:

- Health plan Pharmacy & Therapeutics (P&T) Committees
- Health plan pharmacy directors
- State Medicaid agencies
- State insurance agencies
- State and Federal elected officials

You can use your story to write a letter or make a call or, for the most impact, meet in person with a P&T Committee or others who are deciding on coverage of medications. Your stories will help decision-makers understand the real life impacts of medications and how they are covered.

NAMI will help keep you informed of opportunities to use your story—and we hope you’ll think of your own opportunities, as well.

(Optional: If host knows of an opportunity, mention Be Heard! handout and any instructions)

---

**Prep:** If there is an opportunity to testify or share stories, fill out Be Heard! handout in advance, print and include in participant packet

**Handout:** Be Heard! (optional)

**Note:** If there are participants with relevant and compelling stories, ask if they’d be willing to testify (share their story) at an upcoming opportunity
**Facilitator Script for NAMI Smarts for Advocacy, Medication: Protecting Choice**

<table>
<thead>
<tr>
<th>Slide 35</th>
<th>Approx. .5 min</th>
<th>What made an impact on you? [Take three responses]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helper and Facilitator:</td>
<td>If possible, bring a portable copier or scanner and scan/copy stories of participants who are willing for you to do so.</td>
<td>Consider taking a picture of the class.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slide 36</th>
<th>Approx. 1 min</th>
<th>Thank you all for giving your time and energy to this workshop. Please give yourselves a round of applause for everything you've accomplished today. [Wait for applause]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prep:</td>
<td>Prepare a container or place for evaluation forms and/or have Helper collect.</td>
<td>Handout: Evaluation Form</td>
</tr>
<tr>
<td>Thank you for your participation!</td>
<td>Before you go, please take half a minute to fill out the remainder of your Evaluation Form and turn it in to [name location or person]. We value your feedback and would like to know if this workshop was helpful to you.</td>
<td></td>
</tr>
</tbody>
</table>
INSERT TAB: Module 4 worksheets
Evaluation Form

Facilitator’s name: _________________________________ Date: ____________

Location of workshop (City & State): ________________________________

My name (optional, but preferred): ________________________________

1. Overall, my **knowledge and skill level** in telling my story about medications is...

   **Before the training:** (Circle your rating)  
   
<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Some</td>
<td>Good</td>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   **After the training:** (Circle your rating)  
   
<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Some</td>
<td>Good</td>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Overall, my level of **confidence** in telling my story is...

   **Before the training:** (Circle your rating)  
   
<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Some</td>
<td>Good</td>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

   **After the training:** (Circle your rating)  
   
<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>Some</td>
<td>Good</td>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. What did you learn that was most meaningful or helpful to you today?

4. Where do you plan to use your medication story?

5. What comments, if any, do you have about this workshop?

6. NAMI seeks to support the entire community.  
To help us track how we are doing, please check all that apply. **I am:**

   - American Indian or Alaska Native
   - Asian American
   - Black or African American
   - Hispanic or Latino
   - Native Hawaiian, Pacific Islander
   - White
   - Multiracial
   - Other: ____________________________

   - Person living with a mental illness
   - Family of adult living with a mental illness
   - Parent or guardian of minor child living with a mental illness
   - Mental health provider, including peer provider
   - Other mental health advocate
   - Military service member, veteran or military family member
   - Other: ____________________________
Sample Family Member Medication Story

1. My introduction
Hello, I’m Keith Jones from Amity. I’m a member of NAMI Springville, part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.

I have a 25-year old son who lives with schizophrenia and my family’s experience leads me here to urge you to make all mental health medications easily available.

2. What happened
I can tell you that the right medication can change lives.

When my son was young, he was bright, loving and happy. But as he grew, schizophrenia took away his joy. Despite mental health services, he ended up in and out of psychiatric hospitals and group homes—and even on the streets. I worried about him every day and wondered if he would ever experience a life without fear again.

3. Getting the right medication
Several months ago, Kevin’s doctor finally got approval for him to try a new antipsychotic. It took weeks to start taking effect, but the difference was amazing. It’s the first medication that has really worked for him.

4. How he/she is different today
For the first time in years, Kevin is living without terror. He’s even moved into his own apartment. He has a peer mentor and wants to become one himself. And for the first time in years, we both have hope.

5. What’s keeping people from getting the right medication
My son is proof that the right medication can change a life. But many people don’t get the right medication because it’s not covered or it’s out of reach.

6. What will help people get the right medication
Making all mental health medications readily available will help more people experience a recovery like Kevin’s and avoid hospital stays and living with unimaginable symptoms.

7. My "ask"
Thank you for listening. I hope I can count on you to protect choice of medications—and the hope of recovery for families like mine.
Sample Peer Medication Story

1. My introduction
Hello, I’m Cynthia Wood from Bothell. I’m a member of NAMI Springville, part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.

I live with major depression and the right medication is critical to my recovery. I’d like to share my story and ask that you protect choice of medications for people living with mental illness.

2. What happened
I’m a family physician, I’m married and I have two beautiful children. I also live with major depression. When I was first diagnosed in my twenties, I was devastated. I thought I wouldn’t make it through medical school, enjoy a career or raise a family.

3. Getting the right medication
I wanted to get better, but my depression was stubborn. Nothing seemed to work. Finally, my doctor and I found the one medication that works for me. It’s expensive, but with it, I made it through med school, became a successful physician, married and started a family.

4. How I’m different today
My depression is under control and I’m able to take good care of my family and my patients. And knowing about my success helps my patients feel like they can recover, too.

5. What’s keeping people from getting the right medication
I want my patients to have what works for them, but as a doctor, I know that when people can’t get the medication they need easily, they often give up—or suffer serious setbacks.

6. What will help people get the right medication
Having choices helps people get the right help at the right time. More choices of medications mean more opportunities for people, like me, to realize their dreams.

7. My "ask"
Thank you. For everyone who lives with mental illness, please protect choice today.
### Seven Steps to Telling Your Story about Medication

The following seven steps will help you craft a succinct and powerful story.

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
</table>
| 1.   | **Introduce yourself**  
  - *Give your name and city or town.* Include your organization. We encourage you to describe yourself as “a member of [NAMI State Org or NAMI Affiliate], part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.”  
  - *Share how you are affected by mental illness.* Are you living with mental illness, a family member, a caregiver? This gives you credibility. |
| 2.   | **What happened?**  
  - *What happened before you received the medication you needed?* Keep this brief—think about the most important thing you’d like your listener to know. |
| 3.   | **Getting the right medication**  
  - *Describe how you got the right medication.* Keep this brief—and add how medication helped in your recovery (or would have helped). If you had problems getting the right medication, share the challenges and the effect on you. |
| 4.   | **How are you different today?**  
  - *Share what is going right in your life or how you are experiencing recovery.* Inspire your audience by sharing the gains you’ve made or what your goals are. |
| 5.   | **What’s keeping people from getting the right medication?**  
  - *Mention the challenges that keep people from getting the right medication.* Think about your listeners and focus on the challenges that are within their influence, like a health plan’s list of covered drugs. |
| 6.   | **What will help people get the right medication?**  
  - *Talk about what will help people get the right medication.* It’s helpful to add why it’s important for people to get the medication they need. |
| 7.   | **Make your "ask"**  
  - *Ask your listener(s) to take the position or action you want.* Thank your audience for listening, then make your “ask.” Feel free to be direct and specific. |
Leave page blank
## Story Practice Sheet
Please refer to your Seven Steps Checklist for additional information.

<table>
<thead>
<tr>
<th>1. My introduction</th>
<th>Include your name and city and organization, if applicable. Add how you are affected by mental illness and the position or action you want your listener(s) to take.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. What happened</td>
<td>Aim for 3-5 sentences. Briefly describe the most important and compelling thing(s) about your situation.</td>
</tr>
<tr>
<td>3. Getting the right medication</td>
<td>Aim for 2-4 sentences. Briefly describe how you got the right medication and how it helped in your recovery. If you had problems getting the right medication, share the challenges and the effect on you.</td>
</tr>
<tr>
<td>4. How I'm different today</td>
<td>Aim for 1-3 sentences. Share what is going right in your life or how you are experiencing recovery. Inspire by sharing the gains you’ve made or what your goals are.</td>
</tr>
<tr>
<td>---------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>5. What’s keeping people from getting the right medication</td>
<td>Aim for 1-3 sentences. Mention the challenges that keep people from getting the right medication. Focus on challenges within the influence of your listeners.</td>
</tr>
<tr>
<td>6. What will help people get the right medication</td>
<td>Aim for 1-2 sentences. Talk about what will help people get the right medication. It’s helpful to add why it’s important for people to get the medication they need.</td>
</tr>
<tr>
<td>7. My &quot;ask&quot;</td>
<td>Aim for 1-2 sentences. Thank your listener for listening to you. Then, ask your listener(s) to take the position or action you want. Feel free to be direct and specific.</td>
</tr>
</tbody>
</table>
Constructive Feedback Form
In the space below each scale, identify where the **story was strong or impactful** or what would strengthen the story.

<table>
<thead>
<tr>
<th>Section</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would benefit from strengthening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Works fine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very strong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What happened?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would benefit from strengthening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Works fine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very strong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Getting the right medication</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would benefit from strengthening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Works fine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very strong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>How are you different today?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would benefit from strengthening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Works fine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very strong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What’s keeping people from getting the right medication?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would benefit from strengthening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Works fine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very strong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What will help people get the right medication?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would benefit from strengthening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Works fine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very strong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Make your &quot;ask&quot;</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would benefit from strengthening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Works fine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very strong</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Glossary

**KEY TYPES OF HEALTH PLANS**

**COMMERCIAL OR PRIVATE INSURANCE/HEALTH PLAN:** Coverage for certain health care costs in exchange for premiums paid for by you, your family or an employer.

**MEDICAID:** A health care coverage program for low-income families, children, pregnant women, seniors and people with disabilities. Medicaid typically covers a wider range of benefits and has lower out-of-pocket costs than Medicare or commercial health insurance.

**MEDICARE:** A federal health insurance program for people who are 65 or older and for younger people with disabilities who receive Supplemental Security Disability Income (SSDI). Medicare Part A and Part B cover hospital and outpatient care.

**MEDICARE PART D:** Part D is Medicare coverage for medications.

**BRAND NAME DRUG:** A medication developed by a pharmaceutical company and sold under a brand name. When a brand name drug’s patent expires, generic versions of the medication may be sold.

**COINSURANCE:** A percentage you must pay of the cost of your medication or health care (for example, your plan may pay 80 percent and you pay 20 percent coinsurance).

**COPAYMENT OR COPAY:** A fixed amount (for example, $20) you pay for covered medication or health care.

**COST SHARING OR OUT-OF-POCKET (OOP) COSTS:** Costs that aren’t covered by your health plan, such as premiums, deductibles, coinsurance, copayments and non-covered services and supplies.

**DEDUCTIBLE:** The amount you pay in a year before your plan covers costs. For example, if you have a $1,000 deductible, you will pay $1,000 for health care before your plan begins covering any costs in one year.

**EXCEPTION FOR PSYCHIATRIC MEDICATIONS:** An instance when a health plan approves a member or doctor’s request to provide or cover a medication in a different way than is typical for the plan. Some sample requests are to:

- Cover a drug that is not covered on the plan’s formulary or PDL
- Waive prior authorization or step therapy requirements for a drug that works for you
- Provide a higher-tier drug at a lower tier cost because lower tier drugs do not work for you

**EXEMPTION FOR PSYCHIATRIC MEDICATIONS:** A freedom from requirements, such as prior authorization, step therapy, generic substitution, for one or more types of mental health medications.

**FORMULARY:** A list of generic and brand name medications covered by your health plan (may also be called a Preferred Drug List or PDL).
**GENERIC DRUG:** A medication with the same active ingredients and in the same amounts as a brand name counterpart. Generics are usually less expensive than a brand name drug, but may have different fillers, additives or different timing of the release of active ingredients.

**NON-PREFERRED:** A medication that a health plan may not cover or that has higher cost-sharing or other requirements.

**PHARMACY BENEFITS MANAGER (PBM):** A managed care organization that specializes in providing medications through mail order and/or a network of pharmacies for Medicaid and other health plans.

**PREFERRED DRUG LIST (PDL):** A list of generic and brand name medications covered by your health plan (may also be called a Preferred Drug List or PDL).

**PRIOR AUTHORIZATION:** A requirement by your health plan to review a medication request before approving or denying. Your plan may require prior authorization because a medication has dangerous side effects, may interact with other drugs, is often misused or abused or when your plan thinks a different or less expensive drug might work as well or better.

**QUANTITY LIMITS:** A limit on the amount of a medication your plan will cover over a period of time.

**STEP THERAPY:** A requirement to try one or more drugs first—sometimes for specific lengths of time—before your plan will cover a certain medication.

**TIER:** A level of coverage on your health plan’s formulary. Medications on lower tiers have lower cost sharing, while medications on higher tiers have higher costs and may have more restrictions.

**UTILIZATION MANAGEMENT (UM):** Techniques, such as preferred drug lists, prior authorization, quantity limits, tier levels or step therapy, that may be used to improve safety and/or quality, ensure appropriate use or to control costs.

<table>
<thead>
<tr>
<th>KEY HEALTH PLAN DECISION-MAKERS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HEALTH PLAN MEDICAL AND PHARMACY DIRECTOR:</strong> Executives who oversee medical services and medications for a health plan and who make decisions about coverage and exceptions.</td>
</tr>
<tr>
<td><strong>STATE INSURANCE COMMISSIONER:</strong> State official responsible for regulating insurance offered in his/her state, including commercial health insurance plans.</td>
</tr>
<tr>
<td><strong>STATE MEDICAID DIRECTOR:</strong> State official responsible for the entire Medicaid program in his/her state.</td>
</tr>
<tr>
<td><strong>MEDICAID MEDICAL AND PHARMACY DIRECTOR:</strong> State officials who oversee medical services and medications for the state Medicaid program and who make decisions about coverage or exceptions.</td>
</tr>
<tr>
<td><strong>PHARMACY &amp; THERAPEUTICS COMMITTEE (P&amp;T COMMITTEE):</strong> A committee of experts that weighs effectiveness, safety, side effects, costs and other factors in making decisions about medications for a health plan or pharmacy benefit manager.</td>
</tr>
</tbody>
</table>
Access to Mental Health Medications

Why NAMI Cares
The right medication is a key to recovery for many children and adults with mental health conditions. Yet, in a 2015 study of private health plans, NAMI found that coverage of antipsychotic and antidepressant medications was inadequate.1 People need choices because individuals react differently to different medications and because the effects of not getting the right mental health medication can be costly and dangerous.

Mental health medications are unique.

- While mental health medications work in similar ways, individual responses vary greatly.1
  - About a third of those with depression improve after treatment with an SSRI antidepressant. Others get better with different or added medication.2 Lack of treatment success with one SSRI does not predict the same effect with another.3
  - Effectiveness of medications for ADHD varies markedly between patients depending on such factors as symptoms, presence of other conditions and family situation.4
  - An antipsychotic medication that works well for one person with schizophrenia will not necessarily work for another.5

- Psychiatric medications differ, even within the same class, with varying side effects, drug interactions and effectiveness.
  - Some mental health medications have side effects that may pose serious health risks in persons with common chronic disorders such as heart disease or obesity.
  - Some children may only be able to tolerate a long-acting or liquid form of ADHD medication.
  - An antipsychotic that is sedating may help an agitated or sleepless person, but not someone who is withdrawn and lacks energy.
  - Some antipsychotics have significantly shorter half-lives (a few hours), which means symptoms may return quickly with a skipped dose.

People with mental health conditions are at high risk.

- More than one out of every 13 emergency department visits involves a mental illness.6

- Mood disorders are the top reason adults 18-64 years old are admitted to a hospital after an emergency department visit and psychotic disorders are the fourth most common reason.7

- Two out of three Medicaid beneficiaries with disabilities who have common chronic conditions also have a mental illness. The hospital admission rates for those with mental illness are 46% to 70% higher than for those without.8
 Restricting medications shifts costs to the wrong places.
Preferred drug lists, prior authorization and other restrictions pose substantial risks for people with serious mental health conditions. Medication failures can lead to emergency department visits, hospitalization, school failure, job loss—even incarceration or suicide.

- In a 2009 ten-state study of Medicaid prescription drug policies, prior authorization requirements were associated with people being 2.1 times more likely to be reported homeless and 3.1 times more likely to be hospitalized.⁹
- Preferred drug lists were associated with 1.8 times higher rates of emergency department visits and 2.3 times higher rates of hospitalization.¹⁰
- People who stopped taking medications because of access problems were more than twice as likely to end up in jail.¹¹

Preserving choice can achieve better outcomes and cost savings.
Preserving choice in medications can achieve better health outcomes through more effective care and cost savings by reducing unavoidable emergency department visits and hospital stays.

- Five percent of Medicaid beneficiaries with disabilities account for more than 50 percent of overall Medicaid costs. In this highest-cost group, mental illness is in three of the top five most prevalent pairs of diseases.¹²
- According to a 2015 research study, better adherence to antipsychotics alone could yield an annual net savings of $3.2 billion to states, an average of $1,580 per enrollee per year.¹³

² Ibid.
³ Ibid.
⁸ Boyd C; Leff B; Weiss C; et al. (Dec. 2010). Clarifying Multimorbidity Patterns to Improve Targeting and Delivery of Clinical Services for Medicaid Populations. Center for Health Care Strategies, Inc.
¹⁰ Ibid.
¹¹ Ibid.
¹² Kronick, Rick, PhD, Bella, Melanie & Gilmer, Todd P., PhD. (October 2009). The Faces of Medicaid Iii: Refining the Portrait of People with Multiple Chronic Conditions. Center for Health Care Strategies, Inc.
Insert Tab: Module 5 Script
Hello everyone. Welcome to this workshop on parity, or fairness in health insurance coverage for mental health and addiction care. This is part of NAMI’s grassroots skill-building program, *NAMI Smarts for Advocacy*.

My name is [name] and I will be your facilitator. And helping us today is [name].

During this workshop, we'll define the term, ‘mental health and addiction parity’. We'll talk about the laws that require insurance companies to provide fair mental health coverage and how to spot problems in your health plan. You'll learn how and where to file a complaint. Then we'll share some stories to help you learn how to identify possible parity issues. Finally, we'll practice completing a complaint form to show you how simple it can be to start the process for yourself or someone you care about.

Are you ready to start? [Wait for response] Great!

[Skip if part of a longer training:]

Before we begin, please look at the first two questions on your evaluation form. Take half a minute to circle the number in the left-hand column for questions 1 and 2 that best matches your level of knowledge about parity and confidence in asserting your parity rights.
<table>
<thead>
<tr>
<th>Slide</th>
<th>Time</th>
<th>Script</th>
<th>Handouts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ground Rules</strong>&lt;br&gt;• To help everyone get the most out of this training, we ask you to agree to the following:&lt;br&gt;• Participate fully&lt;br&gt;• Help keep us on time&lt;br&gt;• Turn off cell phones</td>
<td>1 min</td>
<td><strong>This training covers a lot of ground in a short amount of time.</strong> To help everyone get the most out of this training, I’d like to ask you to agree to the following basic ground rules:&lt;br&gt;• Participate fully&lt;br&gt;• Keep us on time (avoid getting side-tracked or involved in conversations)&lt;br&gt;• And turn off your cell phones.&lt;br&gt;By “participate fully,” we mean being willing to do each of the activities. It also means putting away distractions so you can be focused and take in this training.&lt;br&gt;To keep us on time, I’ll be signaling you when we need to stop an activity.&lt;br&gt;[indicate how you’ll signal participants—voice, hand, chime] Please be willing to stop even if you are not finished.&lt;br&gt;We encourage comments at times during the training. That said, we ask you to hold longer or unrelated comments, questions or opinions until after the training.&lt;br&gt;<strong>Are you willing to follow these ground rules?</strong> [Ask for a show of hands.]</td>
<td><strong>Parity Overview</strong></td>
</tr>
<tr>
<td><strong>What is Parity?</strong>&lt;br&gt;Mental health or substance use treatment must be covered by health insurance at the same level as other types of medical care:&lt;br&gt;• Treatment limits&lt;br&gt;• Out of pocket costs&lt;br&gt;• Review for treatment approval</td>
<td>1 min</td>
<td><strong>We’ll start by defining the term, ’mental health and addiction parity’ also known as ’mental health and substance use parity.’ Either way, it’s quite a mouthful, but the basic idea is simply that health insurance plans must cover mental health and addiction care at the same level as other medical conditions.&lt;br&gt;This includes treatment limits such as the number of treatment visits or hospital days, out of pocket costs, and the way treatment requests are reviewed.&lt;br&gt;The reason we need to know about mental health parity is that mental health and substance abuse care has long been shortchanged by the health insurance industry. In the past, if health plans covered mental health care at all:&lt;br&gt;• mental health visits were more limited,&lt;br&gt;• out of pocket costs were higher,&lt;br&gt;• care was denied more frequently, and&lt;br&gt;• plans were cancelled when people used high cost care like psychiatric hospital or intensive outpatient treatment.</strong></td>
<td></td>
</tr>
<tr>
<td>Slide</td>
<td>Time</td>
<td>Script</td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>------</td>
<td>--------</td>
<td></td>
</tr>
<tr>
<td>It's the law of the land</td>
<td>30 sec</td>
<td>Because of this history of inequality, three federal laws were passed requiring most health plans to must cover mental health conditions and addiction the same way they cover other medical conditions. The information I'm talking about is included on the Parity Overview handout on page 1. We will also define some insurance terms during this workshop. They are included for later reference in a glossary at the end of your handouts.</td>
<td></td>
</tr>
<tr>
<td>Major Parity Laws</td>
<td>30 sec</td>
<td>Now, back to parity laws: The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act, or MHPAEA [meh-PEE-ah], passed in 2008. The Patient Protection and Affordable Care Act of 2010, or the ACA. This is a health insurance reform law that also strengthens the parity requirements of MHPAEA. The 21st Century Cures Act of 2016, which is a broad health service and research law that has some parity provisions. Let’s take a closer look at these laws.</td>
<td></td>
</tr>
<tr>
<td>Mental Health Parity &amp; Addiction Equity Act (MHPAEA)</td>
<td>30 sec</td>
<td>The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, or MHPAEA, applies to health plans from large employers and Medicaid managed care plans (which is most Medicaid plans). MHPAEA does not require health plans to provide mental health or addiction benefits, but if they do, treatment limits and out of pocket costs must be at the same level as other types of medical care.</td>
<td></td>
</tr>
</tbody>
</table>
The Patient Protection and Affordable Care Act of 2010, or ACA, is designed to reform health insurance. This law helps people who need mental health or substance abuse care in several ways.

It sets consumer protection standards. For example, under this law health plans can no longer turn people down or charge more for having a long-term condition such as mental illness. The law also bars health plans from having lifetime or annual limits for addiction treatment or mental health care.

The ACA allows states to enroll anyone in Medicaid whose income is at or below 138% of the federal poverty level - about $16,400 per year for one person. Over half of the states have expanded Medicaid.

This law extends parity requirements to all individual and small group health plans whether they are sold in the health insurance exchange or not. It also requires parity in private health plans used in Medicaid expansion and Children's Health Insurance Plans, or CHIP.

The ACA sets up health insurance exchanges in every state to offer health plans that meet quality standards. The law provides for up-front tax credits to make the plans affordable.

The ACA also requires all individual and small group plans to cover 10 essential health benefits, or EHB. ‘Behavioral health’ is one of the EHB categories. It includes mental health and substance use care.

EHBs must meet MHPAEA standards, not only within the ‘behavioral health’ category, but also in other categories such as emergency care.

So, the ACA requires insurers to cover mental health and substance use care for individual and small group plans. This is stronger than the if/then standard of MHPAEA which applies to large employer-sponsored plans.

Finally, the ACA makes care more affordable by setting limits on how much consumers pay out-of-pocket (OOP) per year.
### Slide 9

**Time**: 1 min

**Script**

If these laws have been on the books for years, why do we still have so many problems with parity?

Part of the problem is that it took years to produce the rules that spell out what insurers must do to comply with the law. The final rules weren't issued for private insurers until 2013 and for Medicaid and CHIP until 2016.

Another problem is that the different types of health plans are overseen by different state and federal agencies, so it wasn’t clear which agencies were charged with enforcing the law.

Insurers haven’t had incentive to comply with those laws because it is not being monitored and enforced, so unless told otherwise they cut costs to turn a profit for their shareholders.

### Slide 10

**Time**: 30 sec

**Script**

The 21st Century Cures Act tries to clear up what is required of health insurers and sort out how federal and state government agencies must enforce parity.

Parity is only a small section of this broad law but it strengthens mental health and addiction parity in general. 21st Century Cures also has a section on eating disorders, which are often treated unequally.

### Slide 11

**Time**: 1 min

**Script**

Some types of plans don’t have to follow federal parity law. **Take a look at your handout on page 2.**

Medicare, the federal health program for seniors and people with disabilities, is not under parity law. State Medicaid fee-for-service programs also don’t have to comply.

Small state and local government plans with 50 or fewer employees don’t have to follow parity, although many have chosen to opt in. And health plans for employees of faith organizations such as churches, synagogues or mosques, can opt out of parity.

Finally, small group and individual plans purchased before 2010 do not have to comply with parity IF the plan hasn’t changed since the ACA was passed. These are known as grandfathered plans and there are very few left.
The fact is that most Americans are covered by health plans that are under one or more federal parity laws.

Federal law protects parity in several types of care.

**Turn to your Parity Protections handout on page 3.**

- Inpatient or hospital care must be covered equally in or outside the health plan network,
- Outpatient care in and out of network,
- Residential treatment,
- Emergency care, and
- Prescription drugs.

Parity also applies to cost sharing such as co-pays, co-insurance, deductibles and out-of-pocket cost limits. The goal is that consumers should not have to pay more for mental health or substance abuse care than for general medical care.

Health plans are required to have enough mental health and substance use outpatient providers and mental health hospitals to serve members close to home. And, provider payment rates for mental health must be on the same level as other types of care.

Finally, standards used to approve or deny treatment requests must be no stricter for mental health and addiction than for medical or surgical care.

**We’ve just gone through quite a bit of information. What have you learned about federal parity law that stands out for you?**

[Take a couple of quick responses.]

You may be wondering how to tell whether a health plan is following parity law. Let’s go through some common warning signs.

**Look at the parity violation warning signs handout on page 4.**
Under parity law, health plans can’t cover fewer visits for mental health or addiction treatment than for other types of care. So, if there is no limit on the number of visits to an endocrinologist for diabetes, there should be no limits on visits to a psychiatrist, therapist or addiction counselor.

And, the number of covered days in psychiatric hospital must be equal to days for other kinds of inpatient treatment.

These are called ‘quantitative treatment limits’ or QTL. Health plans usually comply with QTLs because they are written into the health plan proposals reviewed by the government.

Back to signs of parity issues, a health plan may be violating parity law if it doesn’t cover residential treatment or partial hospitalization for mental health or addiction, but does cover step down care in a skilled nursing facility after a stroke or heart attack.

Some health plans will not pay for mental health or addiction care if the member quits before the treatment is complete. This may be a parity violation if the plan doesn’t place the same requirement on other types of care.

Health plans cannot charge more to their members for mental health or addiction treatment than for medical or surgical care. Out of pocket costs include copayments, co-insurance and deductibles.

A deductible is how much you have to pay in medical bills before the health plan begins to pay. Added deductibles for mental health and addiction care are not allowed under parity law.

A copayment, or copay, is a set fee that health plan members must pay for each visit. Parity law requires copays for mental health or addiction treatment to be the same as for similar types of care for other conditions.

Be aware that co-insurance and copayments are not the same. Copayments are a set fee per visit, while co-insurance is a percentage of the total cost of the treatment.

For example, a plan may have a $20 co-pay for doctor’s appointments, but the pharmacy benefit may require a 20% co-insurance. If the total cost of medication
<table>
<thead>
<tr>
<th>Slide</th>
<th>Time</th>
<th>Script</th>
</tr>
</thead>
</table>
| 17    | 2 min| Another type of treatment limit involves how health plans review requests for mental health or addiction treatment compared to other types of care. Treatment reviews are done for three main reasons:  
1. To make sure the best type of care is being provided,  
2. To prevent the wrong type of care from being provided and  
3. To reduce the health plan’s costs.  
Health plans decide whether care is ‘medically necessary,’ when deciding whether to approve or deny care. They may deny care because it:  
- Is not approved for certain health conditions;  
- May only work under certain conditions;  
- Effectiveness or safety may be in question;  
- Or, the treatment costs more than treatments for the same condition.  
These types of limitations are called Non-Quantitative Treatment Limits or NQTL, and this is where parity problems usually appear. The way insurers do this for behavioral health care is often more strict than for other types of care. Under parity law health plans must share the standards used to approve or deny care if the member asks for the information. The plan must also share with a provider acting on behalf of a member. |
### Slide 18

**Time:** 1 min

Prior authorization and step therapy are other examples of non-quantitative treatment limitations (NQLT).

Prior authorization or prior approval (PA) means that the member or provider must contact the health plan to request coverage of treatment. If PA is granted, the plan will cover the treatment, although the member may still have an out-of-pocket cost. Some plans require a new prior authorization every year or every time a member reaches a certain number of visits.

If prior authorization is not granted, the plan won’t pay for the treatment.

Step therapy, or fail first, is a type of prior authorization. With step therapy, the member must first try a more common, less expensive treatment or medication that has been proven effective for most people with a given condition before they can “step” to the recommended treatment.

### Slide 19

**Time:** 4 min

Provider credentialing is another NQTL in which health plans contract with a limited number of providers who meet the plan's quality standards. Providers must go through a review process and may or may not be accepted into a given health plan network. In return for client referrals, these providers agree to work for a reduced rate and follow plan procedures. If the insurer does this differently for mental health than other types of providers, that may be a parity violation.

Narrow networks allow health plans to pay the provider less per visit because they can guarantee a higher number of referrals to each provider in the network. This strategy also makes it easier for health plans to monitor the quality of care given by their providers.

The problem is that members often have a really hard time finding an in-network mental health or addiction treatment provider. Health plan provider directories may be out of date; even those that are on line. The directory may list providers who are no longer practicing or who aren’t taking new patients.

And, it may look like the plan has a provider in the area, when in reality the provider practices at a number of clinics and only takes a few health plan patients from a given town.
<table>
<thead>
<tr>
<th>Slide</th>
<th>Time</th>
<th>Script</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>It is true that it's hard for health plans to keep directories up to date when providers come and go quickly. The health insurance industry is working on a technical solution, but it may be awhile before this problem is solved.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>In any case, narrow networks mean that consumers pay higher out of pocket costs for out of network providers. This extra financial burden may be a parity violation. Because of this, if no in-network providers are available in a local area, parity law requires health plans to pay the full cost for an out-of-network provider.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Let's stop here for a brief discussion. Have you or someone you care about experienced any of these situations? If so, what happened? [Take a couple of quick responses.]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Now, we’d like to talk about what to do when you believe a health plan may be out of compliance with parity law.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Look at your handout on Complaints and Appeals on pages 5 and 6.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The member - or the provider on behalf of the member - has the right complain about a health plan decision or to ‘appeal’ a denial of care. An appeal is a formal written request for a different decision.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Members and providers hesitate to file a complaint for fear that the health plan may drop them or get even in some other way. Rest assured that is strictly against the law to retaliate, and health plans know it. Also, state insurance departments – who receive most of the calls – say that complaints and appeals are filed all the time as a standard part of the insurance business.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Complaints and appeals to state and federal agencies are important, because the government bases enforcement of parity law on the number and type of complaints and appeals received. So, by filing a complaint or appeal with the government, the member is helping themselves and everyone else who isn’t getting the care they are entitled to under parity law.</td>
</tr>
<tr>
<td>Slide</td>
<td>Time</td>
<td>Script</td>
</tr>
<tr>
<td>-------</td>
<td>------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>2 min</td>
<td>It is a good idea to contact the state health insurance department even if the complaint or appeal needs to go to a federal agency because states are responsible to monitor and enforce parity laws. This helps them track the number of complaints and appeals filed from people in the state. And, state insurance departments have consumer assistance staff who work with members to make sure the paperwork is completed and filed correctly. They can also contact the health plans on your behalf to request a change in the decision. Let’s go through the Complaints and Appeals handout to see how the process works. [Read through ‘How to prepare a complaint’ and ‘What happens when a complaint is filed?’] What questions do you have about this process? [Take a couple of quick responses.]</td>
</tr>
<tr>
<td></td>
<td>3 min</td>
<td>Before filing a complaint or appeal, the member and the provider should discuss the recommended treatment and how the denial of care affects the member. Be specific about treatment goals. If the health plan has proposed an alternative, discuss how it falls short and why the original prescribed treatment is still preferred. The next step is to complain to the health plan’s consumer service department. Often, the health plan will change the decision if the reasons for the change are explained in detail. If customer service representatives still deny the treatment request, the provider or member can complete and submit a written appeal form to the insurance plan, usually by fax or email. Although most people don’t bother to file an appeal, it is well worth the time and effort because health plans usually decide appeals in favor of the member. If the health plan denies the appeal, that’s not the end of the story. The member or provider can still appeal to the state insurance department and/or the federal agency in charge of the particular type of plan.</td>
</tr>
</tbody>
</table>
Slide 23

<table>
<thead>
<tr>
<th>Time</th>
<th>Script</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 min</td>
<td>If you feel overwhelmed by how complicated this is, you are not alone. In response to requests from people across the country, the U.S. Department of Health and Human services set up a web-based clearinghouse for parity information and complaints. By checking a couple of boxes and answering a few questions, the website links you to the correct governmental agency responsible for the complaint or appeal. <strong>Have you tried to file a parity complaint or an appeal for yourself or someone you care about? How did it go?</strong> [Take a couple of quick responses.]</td>
</tr>
</tbody>
</table>

Page 6 of the **Complaints and Appeals** handout has a chart showing which government agencies handle appeals for different types of health plans.

- The U.S. Department of Labor is responsible for self-insured health plans sponsored by employers with 50 or more workers. That means the employer covers its own health benefits.
- The state health insurance department handles complaints and appeals about plans purchased by individuals or small groups under 50 people, whether the plan was sold inside or outside a state health insurance exchange or the federal health insurance marketplace.
- Health insurance exchange plans are also the responsibility of the federal Centers for Medicare and Medicaid Services, or CMS.
- Appeals about Medicaid managed care plans should be filed with the state Medicaid program and CMS.
Now let's look at three brief stories that illustrate how common parity violations look from the member viewpoint.

In your handouts, look at Sample Story 1 on page 7. [Co-teacher] will read a sample story, then we'll discuss it as a group.

[Teachers, circulate and help participants find the right pages]

Are you ready? Great!

[Co-teacher] please read the first sample story.

[Co-teacher reads sample story.]

Does this story have parity issues? If so, what are they? [Take a couple of responses. If not mentioned, go through the following points.]

Answers:

- There may be a parity problem with to prior authorization because medical care is treated differently.
- Medical necessity may or may not be a problem. We need more information about medical necessity criteria for other conditions.

What is the first step she should take? [Wait for a response.]

Answer: After talking with her provider, she should contact her health plan.

What government agency should she contact? [Wait for a response.]

Answer: She should contact the state department of insurance because this is a small employer health plan.
Thanks everyone. Let's go on to the second story.

[Co-teacher name] please read sample mental health story number 2.

[Co-teacher reads sample story.]

Does this story have parity issues? If so, what are they? [Take a couple of responses. If not mentioned, go through the following points.]

Answers:

- It makes a difference whether the medications for diabetes and mental health are generic or brand name. If both are brand name, there may be a parity violation. If the diabetes drug is generic and the mental health drug is brand name, there may not be a parity issue because health plans have the option to place more expensive drugs on higher tiers.
- The step therapy requirement may violate parity if it only applies to his psychiatric medications.
- Regardless, he would have standing to appeal the step therapy requirement since he has already gone through step therapy twice.

What is the first step he should take? [Wait for a response.]

Answer: After talking with his provider, he or his provider should contact his health plan.

What government agency, or agencies, should he contact? [Wait for a response.]

Answer: He should contact the state department of insurance and CMS because this is an individual health plan purchased on the state exchange.
<table>
<thead>
<tr>
<th>Slide</th>
<th>Time</th>
<th>Script</th>
</tr>
</thead>
</table>
| 26 | 5 min | Thanks everyone. Let's go on to the third story.  
[Co-teacher name] please read sample mental health story number 3.  
[Co-teacher reads sample story.]  
**Does this story have parity issues? If so, what are they?** [Take a couple of responses. If not mentioned, go through the following points.]  
**Answer:**  
- This appears to be a parity issue because the psychiatric residential treatment was reviewed more often than the rehab facility for her injury.  
**What is the first step she should take?** [Wait for a response.]  
**Answers:**  
- After talking with the provider, her daughter or the provider should contact the managed care plan.  
- If she has a medical power of attorney or other legal standing to act on behalf of her daughter, she can contact the managed care plan directly.  
**What government agency, or agencies, should she contact?** [Wait for a response.]  
**Answer:** She should contact the state Medicaid program and CMS. |
<table>
<thead>
<tr>
<th>Slide</th>
<th>Time</th>
<th>Script</th>
</tr>
</thead>
</table>
| 27    | 16 min | Now it’s your turn to practice filing an appeal. Please pair up with another person. One of you will play the health plan member and the other will play the mental health care provider.  
- **Here’s the situation:** Your request for individual therapy for posttraumatic stress disorder, or PTSD, has been denied. The health plan requires group therapy first, but the member is nervous around strangers.  
- You’ll have 15 minutes to complete the Sample State Health Insurance Complaint Form on page 10 and 11. When it’s your turn to fill out the form, write your name and contact information. Pretend you’re the person with PTSD.  
- We will circulate around the room to answer any questions you may have.  
- We’ll let you know when it’s nearly time to give you a chance to wrap up.  
[Both teachers circulate around the room. When only 3 minutes remain, tell participants it’s time to wrap up.]  
Thank you, everyone. It’s time to lay your pencils down. |
| 28    | 2 min | Please give yourselves a pat on the back for working through this exercise. Let’s talk about the experience.  
**What did you learn from filling out this form?**  
**What was most helpful for you?**  
**How will you use what you have learned?**  
[Take a few responses to each question] |
### Slide 29

**Kennedy Forum Complaint Portal**

- This website, [www.ParityRegistry.org](http://www.ParityRegistry.org), has excellent information in plain language to help you learn more about parity. Sponsored by the Kennedy Forum and the Scattergood Foundation, ParityTrack is collecting stories of people who have experienced parity violations to help fight for stronger enforcement of state and federal parity law.

By submitting your story on the ParityTrack website in addition to filing with the proper agency, you’ll help the overall struggle for parity. You can give your name or not, it’s up to you.

### Slide 30

**Consumer Resources**

- If you would like more information or assistance, this slide and your handouts include some helpful state and national resources.

Again, we recommend going to your state department of insurance in addition to the other things you do. That will make sure your parity complaint is registered with the state, which will help strengthen the parity law for everyone.

### Slide 31

**We value your feedback**

*Please turn in your evaluation form*

Thank you all for giving your time and energy to this workshop. Please applaud yourselves for everything you’ve accomplished today.

*Please remember to fill out your post-training evaluation and turn it in to (name location or person).*

### Slide 32

**Authors**

- Angela Kimball, NAMI
  - National Director of Policy and Advocacy
  - akimball@nami.org

- Sita Diehl, NAMI
  - Director, State Policy & Advocacy
  - sdiehl@nami.org

If you would like more information on *NAMI Smarts for Advocacy*, contact your local or state NAMI organization.
Insert Tab: Module 5 Worksheets
Overview

What is parity?
Parity means ‘at the same level’. Mental health and addiction treatment parity requires health insurance plans to cover mental health and substance abuse treatment at the same level as other types of medical care.

Why is parity important?
Health insurance should help millions of Americans get the mental health or addiction treatment they need, yet too many health plan members face lower visit limits, higher out of pocket costs and stricter rules on how care is reviewed than for medical and surgical benefits.

Federal Parity Laws
The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA)
MHPAEA applies to large group and self-insured health plans and Medicaid managed care plans. MHPAEA does not require health plans to provide mental health or addiction benefits, but if they do, treatment limits and out of pocket costs must be at the same level as medical and surgical care.

The Patient Protection and Affordable Care Act of 2010 (ACA)
The ACA strengthens coverage for mental health and addiction through:

- **Consumer protections:** Health plans can’t turn people down or charge more for having major illnesses such as mental health or substance use conditions. The law does not allow lifetime or annual treatment limits. Parents can include adult children on their health plan up to age 26.

- **Medicaid expansion:** States have the choice to expand Medicaid eligibility to any household with an income at or below 138% of the federal poverty level ($16,400/year for one person).

- **Health insurance exchange:** Every state must have a state or federally run health insurance exchange with health plans that meet certain standards. Exchange plan premiums are partly covered by up-front tax credits up to 400% of the federal poverty level ($97,200 for one person).

- **Parity in individual and small group plans:** Requires all individual and small group health plans to meet MHPAEA parity requirements whether or not they are sold through an exchange. Requires parity in private health plans that cover people in Medicaid expansion and Children’s Health Insurance Plans (CHIP).

- **Essential Health Benefits:** All individual and small group plans must cover 10 Essential Health Benefits (EHB). Behavioral health is one EHB category. EHBs must meet parity standards, not only within the ‘behavioral health’ category, but also in other categories such as emergency care.

The 21st Century Cures Act of 2016
The parity section of this law requires the U.S. Department of Health and Human Services to:

- Issue new guidance on how to comply with federal parity laws
- Hold a public meeting on state and federal agencies coordination regarding parity
- Publish a report on federal parity investigations - issued each year for five years
- The Government Accountability Office (a federal watchdog) will study enforcement of federal parity law.
- New resources are required on eating disorder treatment parity. Health professionals will be educated about eating disorders and effective treatment.
Not all types of health coverage must meet parity requirements, and conditions under which parity applies vary. The following chart shows the types of health plans that must comply with federal parity law and the conditions that apply.

<table>
<thead>
<tr>
<th>Type of Plan</th>
<th>Parity?</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employer Sponsored</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Large employer &gt; 50 employees</td>
<td>Yes</td>
<td>Not required to provide mental health or addiction benefits, but if they do, coverage must be on par with other medical benefits.</td>
</tr>
<tr>
<td>Small employer 2 to 50 employees</td>
<td>Depends</td>
<td><em>If created after 3/23/2010,</em> must provide mental health benefits. Required to follow federal parity law.</td>
</tr>
<tr>
<td>Federal Employee Health Benefits Plan (FEHBP)</td>
<td>Yes</td>
<td>Must provide mental health benefits; required to follow federal parity law.</td>
</tr>
<tr>
<td>Non-federal government</td>
<td>No</td>
<td>Some health plans for state or local government workers can opt out of federal parity law.</td>
</tr>
<tr>
<td>Faith-based organizations</td>
<td>No</td>
<td>Plans for employees of faith-based organizations can opt out of federal parity law.</td>
</tr>
<tr>
<td>Retiree only</td>
<td>No</td>
<td>Plans that only cover retirees can opt out of federal parity law.</td>
</tr>
<tr>
<td><strong>Government Programs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>No</td>
<td>Federal health plan for people who are age 65 or older and people with disabilities. Federal parity law does not apply.</td>
</tr>
<tr>
<td>Children’s Health Insurance Program (CHIP)</td>
<td>Yes</td>
<td>Government health plan for low to middle income children. Federal parity law applies.</td>
</tr>
<tr>
<td>Medicaid</td>
<td>Depends</td>
<td>Government health plan for certain low-income children and adults. Federal parity law applies to Medicaid managed care plans, but not Medicaid Fee-for-Service (FFS) plans.</td>
</tr>
<tr>
<td>TRICARE</td>
<td>No</td>
<td>Federal health care program for uniformed military service members and their families</td>
</tr>
<tr>
<td><strong>Individual Plans</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual health plans (You buy for self or family)</td>
<td>Depends</td>
<td>If created after 3/23/2010 or changed since, must provide mental health benefits; required to follow federal parity law.</td>
</tr>
</tbody>
</table>

---

2. Federal law restricts the use of Medicaid dollars for service to adults between the ages of 21 and 64 in certain types of free standing psychiatric hospitals and residential facilities. 42 U.S.C. 1369(d).
Parity Protections

Federal parity law protects health plan members by requiring the same level of coverage for mental health and addiction treatment as for other types of medical and surgical care.

Types of care:

- Hospital or residential treatment
- Outpatient visits
- Emergency or crisis care
- Prescription drugs
- Both in-network and out-of-network

Out-of-Pocket Costs: Costs for mental health or addiction treatment must not be greater than costs for most other medical care

- Co-pays: Flat fee per visit or service
- Co-insurance: Percentage of total service cost
- Maximum out-of-pocket costs: What you pay before the plan pays 100%
- Deductibles: What you pay before the plan begins to pay
- Annual or lifetime dollar limits: The most a plan will pay in a year or lifetime

Treatment limits: The number of visits or days for mental health or addiction treatment must be no less than limits for most other medical care

- Number of outpatient visits
- Number of days in hospital or residential care
- Limits on prescription medications
- Excluded types of treatment or situations

Other limits: Other types of limits must not be more restrictive for mental health or addiction treatment than for other types of medical care

- Prescription drug costs or requirements
- Prior-approval requirements
- Clinical standards used to approve or deny care
- Availability of providers
### Warning Signs: Parity Violation?

<table>
<thead>
<tr>
<th>Fewer visits or days for MH/SUD care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Warning sign:</strong> The health plan covers fewer office visits or inpatient days for mental health or addiction treatment than for other types of medical care.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MH/SUD residential or partial hospital care not covered</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Warning sign:</strong> The health plan does not cover residential treatment or partial hospital care for mental health or addiction treatment, but similar care is covered for other medical conditions.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Higher out of pocket costs for mental health/addiction care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Warning sign:</strong> The health plan charges more for mental health and addiction care:</td>
</tr>
<tr>
<td>• Added deductible for mental health and substance abuse care</td>
</tr>
<tr>
<td>• Higher copay for services (set fee per visit or prescription)</td>
</tr>
<tr>
<td>• Higher co-insurance (percentage of total cost)</td>
</tr>
<tr>
<td>• Medication or treatment placed on a higher tier (percentage of total cost)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care denied unequally: Not medically necessary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Warning sign:</strong> The health plan reviews requests for mental health or addiction treatment more often or in a stricter way than for other types of care.</td>
</tr>
</tbody>
</table>

Health plans approve or deny requests for care based on *medical necessity*. A treatment request may be denied because:

| • It is not approved for certain health conditions |
| • The treatment may only work under certain conditions |
| • Effectiveness or safety may be in question |
| • The cost is higher than other types of care for the same condition |

<table>
<thead>
<tr>
<th>Having to ask permission more for mental health or addiction care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Warning sign:</strong> The health plan requires prior approval more often for mental health and addiction treatment than other types of care.</td>
</tr>
</tbody>
</table>

With prior authorization or prior approval (PA) the member or provider must contact the health plan to ask permission before starting treatment. If PA is granted, the plan will pay.

Step therapy means the member must try a common, less expensive treatment or medication that is proven effective for a given condition before “stepping” to the prescribed treatment.

<table>
<thead>
<tr>
<th>Can’t find in-network mental health or addiction providers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Warning sign:</strong> It is hard to find local mental health or addiction treatment providers in the health plan network, but other types are available. Provider directory not up to date.</td>
</tr>
</tbody>
</table>

To keep premiums low, health plans contract with a limited number of providers who meet quality standards. In return for client referrals, providers go through a review process, agree to work for a reduced rate and follow plan procedures. This is called a provider network.
Complaints and Appeals

When care is denied, a health plan member or provider has the right to complain (about the quality of care or coverage) or to ‘appeal’ (ask for a different decision). Complaints and appeals are a standard part of the insurance business. State and federal agencies need complaints and appeals because they are helpful in finding out where the problems are and making the parity law stick.

How to prepare a complaint:

1. Member and provider discuss the reason for the complaint or appeal. Write down the details.
2. Member or provider contacts the health plan customer service office to ask for a different decision.
3. If not resolved, the member or provider files a written complaint with the health plan.
4. At the same time, the member or provider contacts the state health insurance department:
   - For information
   - For help filing a complaint with the health plan
   - To file a complaint with the correct government agency.

What happens when a complaint is filed?

1. Fill out a complaint form and attached documents, if any, that provide details.
2. Submit the completed complaint form and attachments by U.S. mail, fax or email.
3. When the state insurance agency receives the form, you will receive a written notice that your complaint has been received. A file number will be assigned which you should use any time you contact them about your complaint.
4. The state insurance agency will forward the complaint to the health insurance company or agent and request a response. The company or agent has a limited time to respond, usually 30 days.
5. When the state receives a response one of the following will happen:
   a. If the complaint has been resolved, the file will be closed. You’ll get a letter.
   b. If an insurance law has been violated, they will be asked to correct the problem.
   c. If the company is not abiding by the policy, they will be asked to correct the problem.
   d. If the insurer or agent has not responded to all questions or has not looked into the complaint in detail, they will be required to do so.
   e. If no violation is found, you will get a letter explaining why the case is closed.
6. It takes about 45 days from the time a complaint is received to when the problem is solved. A complex complaint could take longer.
Complaints and Appeals, continued.

This chart shows the government agencies responsible for different types of health plans. If you are not sure where to file a complaint or appeal, visit the HHS parity complaint website shown below. At the same time, contact your state insurance department.

<table>
<thead>
<tr>
<th>Type of Health Plan</th>
<th>Government Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employer-based plans: Large group or self-insured</td>
<td>Department of Labor (DOL)</td>
</tr>
<tr>
<td>Individual health plan: Federal Marketplace or State Exchange</td>
<td>State Health Insurance Dept. Centers for Medicare &amp; Medicaid Services (CMS)</td>
</tr>
<tr>
<td>Individual or small group Non-exchange plan</td>
<td>State Health Insurance Dept.</td>
</tr>
<tr>
<td>Medicaid Managed Care or Children’s Health Insurance Plan (CHIP)</td>
<td>State Medicaid Program CMS</td>
</tr>
<tr>
<td>Federal Employee Health Benefit plan (FEHB)</td>
<td>U.S. Office of Personnel Management</td>
</tr>
</tbody>
</table>

**Not sure where to file?**

Federal HHS parity complaint website


- Information
- Links:
  - Federal agencies
  - State insurance departments
Sample Mental Health Story 1: Worksheet

A 38-year-old married woman covered by her husband’s small group employer-sponsored health plan:

“My health plan requires prior authorization for mental health, but not for medical care. The doctor prescribed TMS * for my depression, but my health plan denied the service as ‘not medically necessary’ despite the fact that I’ve tried everything.”

Discussion questions:

Does this story have parity issues? If so, what are they?

What is the first step she should take?

What government agency or agencies should she contact?

* TMS: Transcranial Magnetic Stimulation is used for treatment-resistant depression
Sample Mental Health Story 2: Worksheet

A 59-year-old man with an individual health plan purchased through the state health insurance exchange:

“My brand name diabetes medication is on tier 1 with no coinsurance, but my mental health medications are on tier 3 and I can’t afford $240.00 out of pocket every month.

I have to ‘step up’ by taking less expensive psych meds for 6 weeks. I only get the one I need if the other doesn’t work. I changed health plans twice before and had to ‘step up’ each time. Why can’t they look at my record and approve the right drug from the start?”

Discussion questions:

Does this story have parity issues? If so, what are they?

What is the first step he should take?

What government agency or agencies should he contact?
Sample Mental Health Story 3: Worksheet

A 20-year-old single woman with Medicaid managed care.
Her mother is speaking:

“Our Managed Care Organization (MCO) evaluated medical necessity for day hospital treatment almost on a daily basis. That made no sense because the decision to admit our daughter to this type of treatment was based on her receiving residential care for four weeks. Care was denied several times while she was there and it was a constant struggle to extend the stay.

I don’t understand why this is different than her stay in the rehab facility after she broke her leg.”

Discussion questions:
Does this story have parity issues? If so, what are they?

What is the first step she should take?

What government agency or agencies should she contact?
Sample Consumer Complaint Form
National Association of Insurance Commissioners

Required fields are marked with an asterisk (*)

Complainant’s information:
* First name ___________________  Middle ___________________  *Last name ___________________

*Address ___________________________________________________________

*City ___________________  *State ______  *ZIP ___________

County ___________  Country ______  International ZIP ______

Email address: _____________________________________________________

Please re-enter email address as verification: __________________________________

*Phone number: ________  ________  ________  Extension: ___________

*Alternate phone number: ________  ________  ________  Extension: ___________

How do you want to be contacted? _______________________________________

Insured Information (if different than above)
* First name ___________________  Middle ___________________  *Last name ___________________

Other parties involved in this problem:
* First name ___________________  Middle ___________________  *Last name ___________________

*Type of Insurance
Annuity  Auto  Commercial  Dental  Disability  Group health  Home  Individual  Life  Long term care  Medicare supplement  Other  Title  Workers comp

*Reason for Complaint
Agent handling  Cancellation  Claim delay  Claim denial  Delays/no response  Information requested  Misrepresentation  Nonrenewal  Other  Premium & rating  Premium notice/billing  Premium refund  Unsatisfactory settlement offer

Other desc. ___________________________________________________________

Other desc. ___________________________________________________________
*Details of complaint

*What do you consider to be a fair resolution?

Maximum fair resolution length: 4,000 characters.  Characters left: 

Note: After the final submission of this form, you will be provided an opportunity to attach supporting documents. Will you be mailing or attaching additional supporting information?

To download form: https://sbs-tn.naic.org/Lion-Web/servlet/org.naic.sbs.ext.onlineComplaint.OnlineComplaintCtrl?spanishVersion=N
Resources

State:

Dept. of Commerce & Insurance: State insurance agency staffed to answer insurance questions and assist with complaints and/or appeals.

Phone: ______________
Email: _________________
Download complaint form: ______________________________________________

Medicaid:

• Customer service line: ______________
• Complaints and Appeals: ______________

State Mental Health Authority: State agency responsible for mental health and addiction services.

Phone: _______________ Information & Referral, M-F, 8:00am – 4:30pm

Federal:

U.S. Department of Health and Human Services (HHS) Parity Portal. Website to file parity complaints and appeals with the correct government agency.

www.hhs.gov/mental-health-and-addiction-insurance-help

U.S. Department of Labor (DOL)

• EBSA (Employee Benefits Security Administration): Federal agency responsible for employer sponsored and large self-insured health plans.
  Phone: 866-444-3272
  www.dol.gov/agencies/ebsa/about-ebsa/ask-a-question/ask-ebsa

CMS (Centers for Medicare and Medicaid Services): Federal agency responsible for Medicare, Medicaid and health insurance exchange or federal Marketplace health plans.

• Helpline: 877-267-2323 extension 61565
  • phig@cms.hhs.gov

SAMHSA (Substance Abuse and Mental Health Services Administration): Federal agency responsible for mental health and substance use services.

• Helpline: 800-662-4357

Advocacy Organizations:

Depression Bipolar Support Alliance (DBSA): Organization of individuals and families affected by mood disorders. Provides help, support, and education. www.dbsalliance.org

Mental Health America (MHA): Addresses the needs of people with mental illness and promotes the mental health of all Americans. http://www.mentalhealthamerica.net

National Alliance on Mental Illness (NAMI): Organization of individuals and families affected by mental health conditions. Provides support, education, advocacy, awareness.

Helpline: 1-800-950-6264, info@nami.org Parity information: www.NAMI.org/parity

ParityTrack: Helps people with mental health and substance use disorders understand and exercise their rights under parity law. www.paritytrack.org
Glossary

**Appeal:** If a health plan will not pay a claim or drops a member from coverage, the member has the right to appeal for a different decision and have it reviewed by a third party. Insurers must explain why the claim has been denied or coverage has been dropped.

**Children’s Health Insurance Program (CHIP):** CHIP provides health coverage for eligible children, through both Medicaid and separate CHIP programs. CHIP is funded with federal and state dollars and operated by states under federal rules.

**Co-insurance:** The health plan member shares the cost of a covered service. Co-insurance is a percent (for example, 20%) of the allowed cost of service. For example, if the allowed amount for an office visit is $100 and the member has met the deductible, the co-insurance payment of 20% would be $20. The health plan pays the remaining allowed amount.

**Complaint:** If a health plan member has reason to believe that the plan is not providing benefits as required in the health plan policy or the law, the member can file a complaint with the health plan or the state or federal government agency in charge the plan.

**Consumer protections:** Health care law offers rights and protections that make coverage more fair and easy to understand. Some protections may apply to plans in the Health Insurance Marketplace, other individual plans, job-based plans, and some apply to all health coverage.

**Copayment, copay:** A fixed amount (Example: $20) the health plan member pays for a covered service, usually at the time of service. The amount can vary by the type of covered health care service.

**Credentialing:** The process deciding whether a professional will be included in a health plan network. The health plan usually reviews education, clinical privileges, experience, licensure, accreditation, certifications, professional liability insurance, malpractice history and professional competence.

**Deductible:** How much the member owes for covered health care services before the health insurance begins to pay. The deductible does not apply to preventive services such as annual check-ups or mental health screening, meaning that the plan will pay even before the deductible has been met.

**Essential Health Benefits (EHB):** Under the Patient Protection and Affordable Care Act, all individual and small group health plans (except grandfathered plans) must cover 10 types of care: (1) outpatient services; (2) emergency services; (3) hospital care; (4) maternity and newborn care; (5) behavioral health services; (6) prescription drugs; (7) rehabilitation; (8) lab services; (9) preventive and wellness services; and (10) children’s services, including dental and vision. All EHB must comply with federal parity law.

**Formulary:** A list of prescription drugs covered by a prescription drug plan or another insurance plan offering prescription drug benefits. Also called a preferred drug list (PDL).

**Grandfathered health plan:** Health plans that existed on March 23, 2010, and haven’t cut benefits or increased member costs. Grandfathered do not have to offer parity or other protections required under the Affordable Care Act. Insurance companies must notify members who have grandfathered plans.

**Individual health plan:** Health coverage purchased by an individual for self or family either through a health insurance exchange, or directly from the health insurance company.

**Medical necessity, medically necessary:** Health care services or supplies needed to prevent, diagnose, or treat a condition, and that meet accepted standards of medicine.

**Narrow network:** To lower costs, health plans contract with a limited number of service providers, hospitals, labs and pharmacies. The monthly premium may be lower, but members pay more if they use out-of-network care.
Glossary

**Out of pocket cost (OOP):** The amount owed by a health plan member during a policy period before the health insurance plan begins to pay 100% of the allowed amount. This limit does not include the premium, balance-billed charges or costs for benefits not covered under the plan.

**Parity (Mental Health and Addiction):** Most health insurance plans are legally required to cover mental health and addiction treatment at the same level as other types of medical care.

**Provider Network:** Facilities, providers and suppliers contracted with a health plan to provide care to members. The health plan covers more of the cost of care for in-network providers. However, for a given type of care, if no in-network provider is available within a certain distance from the member’s home, the health plan is required to pay for an out of network provider.

**Prior authorization, prior approval (PA):** A decision by the health plan that a health care service, treatment plan or prescription drug is medically necessary. Sometimes called preauthorization, prior approval or precertification.

**Medically necessary, medical necessity:** Health care services or supplies needed to prevent, diagnose or treat an illness or condition and that meet accepted standards of medicine.

**Non-quantitative treatment limits (NQTL):** Standards used to review treatment requests for type and duration of care that do not involve the number of visits or days. NQTLs include prior approval, step therapy and other techniques to decide whether a service is medically necessary. Under the ACA, an NQTL must not limit mental health or addiction treatment more than medical or surgical care.

**Quantitative treatment limits (QTL):** Standards that limit the number of visits, days or costs. Examples include the number of visits or inpatient days, copays, coinsurance or annual dollar limits. Under the Patient Protection and Affordable Care Act (ACA), QTL must be no more restrictive for mental health or substance use care than for medical surgical care.

**Self-insured/self-funded health plan:** A health plan in which the employer assumes the financial risk for providing health care benefits to its employees.

**Small group health plan:** Employer-sponsored health insurance offered by an employer with 2 to 50 employees.

**Step therapy, fail first:** A type of prior approval in which the member must try and fail to respond to certain treatments that are less expensive, but effective for most people with a given condition, before they can “step” to a different treatment. For example, the plan may require a generic drug, then a less expensive brand-name drug from its formulary, before covering a similar, more expensive brand-name prescription drug.

**Substantially all:** If a type of cost requirement or treatment limit applies to substantially all medical/surgical benefits in a class, then that requirement or limit may apply to mental health or substance use disorder benefits if it is on par with two-thirds or more of the medical/surgical benefits for the same class of treatment.

**Tier:** A level of health coverage for a given type of care. For example, health plan members would pay more out of pocket costs for a prescription drug on tier 3 than for a medication on tier 1.

**Utilization management (UM):** Array of procedures used by insurers to evaluate whether requested care is medically necessary, efficient and in line with accepted medical practice. Examples of utilization management practices include prior authorization and step therapy.
Evaluation

Presenter Name: ___________________________   Date: ____________

Location of Presentation (City & State): ____________________________

Your Name (optional, but preferred): ____________________________

1. Overall, my knowledge and skill level about health insurance parity is...

   Before the training: (Circle your rating)  
   After the training: (Circle your rating)
   
   1     2     3     4     5     6     7     8    9    10
   None        Some        Good        Excellent

2. Overall, my level of confidence about asserting parity rights is...

   Before the training: (Circle your rating)  
   After the training: (Circle your rating)
   
   1     2     3     4     5     6     7     8    9    10
   None        Some        Good        Excellent

3. What did you learn that was most meaningful or helpful to you today?

4. How do you plan to use what you have learned in this training? What will you do differently?

5. What comments, if any, do you have about this training?

6. We seek to support the entire community. To help us track how we are doing, please check all that apply. I am:

   □ American Indian or Alaska Native  
   □ Asian American  
   □ Black or African American  
   □ Hispanic or Latino  
   □ Native Hawaiian, Pacific Islander  
   □ White or Caucasian  
   □ Multiracial  
   □ Other: ____________________________

<table>
<thead>
<tr>
<th>Mental Health</th>
<th>Substance Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with condition</td>
<td></td>
</tr>
<tr>
<td>Family caregiver of adult</td>
<td></td>
</tr>
<tr>
<td>Parent/guardian of child or youth</td>
<td></td>
</tr>
<tr>
<td>Service provider</td>
<td></td>
</tr>
<tr>
<td>Peer provider</td>
<td></td>
</tr>
<tr>
<td>Advocate</td>
<td></td>
</tr>
<tr>
<td>Military, veteran or mil/vet family</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>
Insert Tab: Advocacy Day Script
Advocacy Day: Changing Hearts & Minds

<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
<th>Prep/handouts</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 min</td>
<td>Welcome to NAMI Smarts for Advocacy: NAMI’s grassroots skill-building program. In this workshop we'll help you cook down your lived experience into a powerful advocacy message that can be used when connecting with policymakers. We'll also give you some tips and tools to have an effective meeting with your legislator. [Teachers introduce themselves very briefly.]</td>
<td>Prep: Have workshop handouts, notepads &amp; pencils at each place. Before the training, Practice the meeting script and story aloud.</td>
</tr>
<tr>
<td>1 min total: 2 min</td>
<td>This training covers a lot of ground in a short time, so to get the most out of this training, we'll ask you to agree to the following ground rules: • Participate fully • Keep us on time • Silence your cell phones. Do you agree? [Show of hands.] Super! Today we'll explore why advocacy is important and how it affects our lives • We'll talk about why your story is a valuable tool to change minds • [Name] will tell [his/her] powerful advocacy story in less than 2 minutes. • You'll get to jot down your own story and practice it with a partner • Then you'll see how to work it into a legislative meeting • And we'll provide some tools to help you prepare for the meeting. We hope you'll come away confident and ready to meet your legislators.</td>
<td></td>
</tr>
<tr>
<td>30 sec. total: 2.5 min</td>
<td>We'll begin by talking about why advocacy is so important. It's because every American with a mental health condition deserves the opportunity for recovery. “Recovery,” doesn’t need to mean symptom-free. Rather, we think of it as the ability to manage a mental health condition while leading a full, satisfying life. Elected officials are faced with a host of issues and interest groups. Your personal relationship—and a well-crafted message—can make the difference in their attention to and support of mental health issues.</td>
<td></td>
</tr>
<tr>
<td>Slide/time</td>
<td>Script</td>
<td>Prep/handouts</td>
</tr>
<tr>
<td>-----------</td>
<td>--------</td>
<td>---------------</td>
</tr>
<tr>
<td>slide 4</td>
<td>30 sec. Total: 3 min&lt;br&gt;&lt;br&gt;Your story shows that <strong>mental health conditions are common and recovery is possible</strong>, especially when our needs are met and we feel valued as a whole person. Yet, too few <strong>people get the care they need.</strong>&lt;br&gt;&lt;br&gt;<strong>There is an average delay of 8 to 10 years</strong> before people get an accurate diagnosis. And fewer than half of children and adults with mental health conditions receive <em>any</em> treatment at all. Finally, those who do receive treatment often don’t get the types of services and supports that are proven effective.</td>
<td></td>
</tr>
<tr>
<td>slide 5</td>
<td>30 sec. Total: 3.5 min&lt;br&gt;&lt;br&gt;And without mental health care, we all pay the price. One way is with <strong>school failure</strong>. Students with serious mental health conditions have the highest dropout rate of any disability group. <strong>We also pay a high price in unemployment.</strong> Very few adults with mental health conditions get the supports they need to get a job and stay employed. <strong>In homelessness.</strong> Over one in four people who are homeless has a mental health condition. <strong>And in criminalization.</strong> Untreated mental illness can get people into trouble with the law. Our jails are filled with people who would not be there if they had the care they need. <strong>Lastly,</strong> without mental health care, we sacrifice our future to <strong>suicide.</strong> Every thirteen minutes, we lose one life to suicide.</td>
<td></td>
</tr>
<tr>
<td>slide 6</td>
<td>30 sec. Total: 4 min&lt;br&gt;&lt;br&gt;So, what can you do to change this situation? Talk to your legislator! Legislators respond best to people they know who live in their district. Hundreds of bills land on their desk every session, so a personal story from a constituent increases the chance that they will take action.</td>
<td></td>
</tr>
<tr>
<td>Slide/time</td>
<td>Script</td>
<td>Prep/handouts</td>
</tr>
<tr>
<td>-----------</td>
<td>--------</td>
<td>---------------</td>
</tr>
<tr>
<td><strong>Why Advocate?</strong></td>
<td>Building good relationships with your legislators is important because they make key decisions about laws &amp; budgets that control who can get what type of care, for how long and at what cost.</td>
<td></td>
</tr>
<tr>
<td>slide 7</td>
<td>30 sec.</td>
<td>Total: 4.5 min</td>
</tr>
<tr>
<td><strong>Why Advocate?</strong></td>
<td>So your personal experience, if brief, focused and well told, will support our legislative “ask” which will save lives and save taxpayer dollars.</td>
<td></td>
</tr>
<tr>
<td>slide 8</td>
<td>30 sec.</td>
<td>Total: 5 min</td>
</tr>
<tr>
<td><strong>Your story is advocacy GOLD</strong></td>
<td>Now let’s look at the valuable role you can play as grassroots advocates. One reason people don’t contact their legislator is that they don’t think they know enough. But according to research, stories that help the listener stand in your shoes are far more powerful than facts and figures. Any lobbyist will tell you that <strong>real stories, if brief and sincere, are advocacy gold.</strong> They are one of the surest ways to gain support for mental health care and break the stigma of mental health conditions. Keep these thoughts in mind: 1. Your story is always right 2. Your lived experience has value and meaning 3. You don't have to have all the answers--just a clear &quot;ask&quot; [Pause slightly after each of these statements to let people process.] If you think about it, this is very empowering.</td>
<td></td>
</tr>
</tbody>
</table>
**Advocacy Day: Changing Hearts & Minds**

<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
<th>Prep/handouts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tip #1</strong> Keep your story brief, Just the highlights</td>
<td>Here are four tips for telling a story that will move your legislator... The first tip is to keep your story <strong>brief</strong>. We live in a world of sound bites and text messages, and legislators are very busy, so <strong>aim for a minute or two</strong>. We all could tell volumes about what has happened to us, but, you will lose your listeners if you give too much detail. Think about a movie trailer—in 30 seconds you get the highlights and want to see more. That is the effect you want to achieve.</td>
<td></td>
</tr>
<tr>
<td>slide 10 30 sec Total: 6.5 min</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tip #2</strong> Paint the picture</td>
<td>We mentioned that stories that evoke emotion are powerful. Use vivid language to place the listener in your shoes. Paint a picture of what you went through, what helped and what life is like now. However, if your story causes you to cry, it will overwhelm others and they will shut down. But if your story brings out emotion—without causing you to tear up—you will move others. If you find your story hitting too close to home, focus on the parts that don’t bring up as much pain or use language that allows you to maintain composure. The more you practice, the easier it will get.</td>
<td></td>
</tr>
<tr>
<td>slide 11 30 sec Total: 7 min</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tip #3</strong> Motivate with hope and recovery</td>
<td>Another tip is to use positive concepts like hope and recovery, if possible. If your story doesn’t have a hopeful aspect—someone or something that helped—then describe what would have helped or what could help others. Hope is a powerful motivator for policy makers. Because they want to invest taxpayer dollars effectively, they need to know that recovery is a real possibility.</td>
<td></td>
</tr>
<tr>
<td>slide 12 30 sec Total: 7.5 min</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Advocacy Day: Changing Hearts & Minds

<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
<th>Prep/handouts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tip #4 Make an “ask”</td>
<td>Last, but not least: Make an “ask” of your listener. This is a critical step that many advocates leave out. Thank your listener for hearing your story. Then, put them on the hook by asking if you can count on them to support your issue. If your listener answers with a clear “yes”, thank them for their support. If your listener answers with a clear “no” or a vague response, thank them for taking the time to meet with you and let them know you’d like to serve as a resource on mental health. Regardless of the response, plan on following up often and to politely build a relationship. This will help you gently shift opinions or, in the case of a supporter, help them become a legislative champion.</td>
<td></td>
</tr>
<tr>
<td>slide 13 30 sec Total: 8 min</td>
<td>Now we’ll show you how these tips can be used to tell a powerful story – with an advocacy ask - 2 minutes or less. [Name] will tell [his/her] story and I will track the time just to prove that it can be done. The story is told as if [he/she] were giving testimony at a legislative hearing. But, this basic format can be easily adapted to fit other situations. As you listen, keep an open mind. Notice your reactions, what moves you. [Co-teacher] tells story with the mental health budget ask. [Teacher keeps time. Thanks speaker and calls for applause.] What language moved you? What really caught your attention? [Take one response.]</td>
<td>Handout: Sample Story</td>
</tr>
<tr>
<td>slide 14 3 min Total: 11 min</td>
<td>Now that you've listened to the sample story and noticed its impact, look at the Seven Steps Checklist on page 2, which show the parts of a brief, effective story. We're going to review these seven steps now. Then, you'll use them to draft your own story. [Teacher reviews checklist, referring to sample story.]</td>
<td>Handout: Seven Steps Checklist</td>
</tr>
</tbody>
</table>

Rev. Mar. 2017
NAMI Smarts for Advocacy: Teacher Script
© 2013 NAMI, Inc.
Now you're ready to use your **Story Practice Sheet** on pages 3 and 4 to start writing your own story. For help, use your Seven Steps Checklist and the sample story. Remember, the best preparation for telling an effective story is to **know your “ask.”**

Here’s the scenario: You’re telling *your* story to urge your legislator to support HB 39 the mental health budget.

Your “ask” can be the same as the sample story or you can put it in your own words.

**You'll have 15 minutes to fill out your story practice sheet.** I’ll let you know when you have a few min. left to finish up.

If you don’t finish, don’t worry; this is just a practice and you can fine tune it in your own time. Also, if it’s easier, write in “bullet points” instead of full sentences.

If you finish early, practice reading your story silently.

[Circulate while participants are writing. For those who finish early, ask if they would let you read their story. Praise them for the strong phrases.]

**Warn participants 2 minute before time is up.**

**Stop participants at 15 min.**

If you didn't finish your story, feel free to finish in your own time.

**What did you learn about writing your story?** [Take one response.]
### Advocacy Day: Changing Hearts & Minds

<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
<th>Prep/handouts</th>
</tr>
</thead>
<tbody>
<tr>
<td>slide 17</td>
<td>You have all finished or have a good start on your story. Now, we'll practice sharing them and giving constructive feedback.</td>
<td></td>
</tr>
<tr>
<td>10 min</td>
<td>To get ready, please have your <strong>Story Practice Sheet</strong>, a note pad and a pencil.</td>
<td></td>
</tr>
<tr>
<td>Total: 42 min</td>
<td>Each of you will have a chance to share your story with a partner. You will try to <strong>tell your story in two minutes or less</strong>.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The other person will <strong>keep time</strong> and stop the storyteller at two minutes. While you time, also listen to the story.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Notice your reaction to the flow, words or phrases that move you and areas that could be strengthened. If you like, on the note pad jot down what came across as strong or suggestions to make the story even stronger.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>After the storyteller's two minutes are up, the listener should provide brief <strong>constructive</strong> feedback. Say what worked in the story, and how it could be improved.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Remember that constructive feedback should help you see what is powerful about your story and how you could make it even better.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Please turn to your neighbor and let me know when you're ready by looking at me.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>[Wait until everyone is in a pair.]</td>
<td></td>
</tr>
<tr>
<td></td>
<td>You'll have just 4 minutes for each round for storytelling <strong>and</strong> feedback, so use your time wisely. If you finish early, tell your story again.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Stop round 1 after 4 min.</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>It's time to trade roles and begin with another storyteller and feedback.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Stop round 2 after 4 min.</strong></td>
<td></td>
</tr>
</tbody>
</table>
|            | **How did that go for everyone?**  
**What did you learn about telling your story?** [Take a response or two] |

**Handout:**  
**Story Practice Sheet**

**Supplies:**  
**Notepads**  
**Pencils**
### Advocacy Day: Changing Hearts & Minds

<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
<th>Prep/handouts</th>
</tr>
</thead>
</table>
| In-person meetings… | **Help you build a relationship**  
Now that you’ve drafted your story, you can polish it up and use it as a foundation for advocacy. And, with just a few changes, you can target your story to different audiences and a range of issues.  
Your story drives the point home by helping the legislator understand what it is like to live with a mental health condition. Most important, by helping an elected official see through your eyes, your story builds a relationship.  
And building a connection is far more important than powering through a number of people or points, because a good relationship increases the odds that the legislator will act on your requests in the future. | |
| slide 18  
30 sec.  
Total: 42.5 min | However, we would like our meetings to make as strong an impression as possible. Think about an effective meeting you’ve been part of, especially with a legislator.  
**In one word, who can describe what helps a meeting work?**  
**What can lead to a disappointing meeting?**  
[Take one response to each question. Paraphrase what you heard.]  
Great response! Thank you. Keep these thoughts in mind as we go through a few tips and tools to strengthen your meetings. | |
| But, some meetings **make a stronger impression** than others  
slide 19  
1 min  
Total: 43.5 min | Take a look at your handout, **Making Your Case**. I’ll go over 4 tips now and you can review the rest in your own time.  
The first tip is to **know your issue**. Your policymaker will expect you to be meeting with him or her about an issue—not just to chat.  
Having clarity about your issue and what position or action you want your legislator to take is vital to an effective meeting. | Handout:  
**Making Your Case** |

Rev. Mar. 2017  
NAMI Smarts for Advocacy: Teacher Script  
© 2013 NAMI, Inc.
Advocacy Day: Changing Hearts & Minds

<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Briefing Sheet</td>
<td>A briefing sheet help you organize the basic information on page [page]. What do you notice about the sample briefing sheet in your packet? [Take a couple of responses. Paraphrase, then walk through the briefing sheet.] We’ve provided a blank form for you to use in future meetings with legislators or policymakers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prep/handouts</th>
<th>Handout: Briefing Sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td>slide 21</td>
<td>1 min Total: 45 min</td>
</tr>
</tbody>
</table>

| Tip #2 Know your legislator | The second tip is to know your policymaker. You can build a stronger connection (and a more targeted message) by knowing and understanding your elected official. Knowing your policymaker can help you choose what you say and how you say it—and may help you choose who to bring to a legislative visit. |

<table>
<thead>
<tr>
<th>Prep/handouts</th>
<th>Handout: Making Your Case</th>
</tr>
</thead>
<tbody>
<tr>
<td>slide 22</td>
<td>30 sec Total: 45.5 min</td>
</tr>
</tbody>
</table>

| The Backgrounder | We’ve provided another tool, called a Backgrounder to help you research your legislator. A simple web-search on the legislator’s name will bring up the information you need. Then you can just copy and paste into the sheet like we have done in this sample. What do you notice about the backgrounder that would help you during the meeting? [Take one response. Paraphrase, then walk through the backgrounder.] And again, there is a template for you to use. |

<table>
<thead>
<tr>
<th>Prep/handouts</th>
<th>Handout: Backgrounder</th>
</tr>
</thead>
<tbody>
<tr>
<td>slide 23</td>
<td>1 min Total: 46 min</td>
</tr>
</tbody>
</table>
## Advocacy Day: Changing Hearts & Minds

<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
<th>Prep/handouts</th>
</tr>
</thead>
</table>
| Tip #3  
Plan your visit  
 Slide 24  
30 sec  
Total: 46.5 min | The third tip is to **plan your visit**. Meeting with your policymaker can be intimidating. Planning will help you feel more confident.  
There is another reason to plan. You may find yourself in a group meeting with a policymaker. The more people in a group, the more complicated the “flow” and the greater the chance of people going “off message.”  
Fortunately, the solution is simple. **Prepare**. | **Handout:**  
Making Your Case  
Handout:  
Meeting Roles |
| Meeting Roles  
Handout:  
Meeting Roles  
Slide 25  
1 min  
Total: 47.5 min | Take a look at the **Meeting Roles** handout in your packet. There are three basic roles to keep in mind.  
1. **The lead** starts the conversation, makes the ask and closes the meeting on a positive note.  
2. **The messenger** lays out facts and talking points to support the ask.  
3. **The storyteller** brings the issue ‘off the page’ by relating personal experience to the issue.  
If you are visiting a legislator by yourself, you’ll take all three roles. **Going to a meeting as a pair is effective** because the legislator forms the third leg of a “triangle” which encourages productive dialogue. In that case, one person may take the lead and the messenger role while the other is the storyteller.  
A larger group can make a strong impression, but it’s important to have one lead, to identify other roles in advance and to remember that it isn’t necessary for everyone to speak. |
<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
<th>Prep/handouts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tip #4 Make an “ask”</td>
<td>Here's our last tip: <strong>Make an “ask”</strong> of your listener. If you are talking to a legislator, let them know what would help others (such as the Centers for Excellence) and then, ask them if you can count on their support. This puts them on the hook by asking them for a commitment. This will tell you a lot. If they commit, you have a supporter. If they say no or they are noncommittal, you know where they stand and that you need to follow up and nurture the relationship to build support. Don’t take a negative or noncommittal response personally. Your legislator may be under pressure to take a particular position on your issue or may be being cautious. Take it in stride and work to build a positive relationship.</td>
<td>Handout: Making Your Case</td>
</tr>
<tr>
<td>slide 26 30 sec Total: 48 min</td>
<td></td>
<td></td>
</tr>
<tr>
<td>With our tips in mind, let’s get started…</td>
<td>To help you see how these tips and tools work, we’re going to demonstrate a <strong>meeting with a policymaker and two constituents</strong>. I’ll play the Senator while [Name] and [Name] will be constituents. While you listen, notice the roles the two constituents play and where you hear our tips in action. Also listen for facts and a story highlight. <strong>Demonstrate a meeting using Meeting your Legislator demo script.</strong> [Prep: arrange 2 helpers. Ask them to read through the script ahead of time]</td>
<td>Fact sheet in bright green folder 3 copies of <strong>Demo: Meeting Your Policymaker</strong></td>
</tr>
<tr>
<td>slide 27 6 min Total: 54 min</td>
<td><strong>Did you notice how much was conveyed in just a few short minutes?</strong>  <strong>What did you notice about the roles people played and the flow?</strong>  <strong>[Take a response]</strong>  <strong>Did you notice the policymaker spinning the conversation in a different direction? What did you note about the response?</strong>  <strong>[Take a response]</strong></td>
<td></td>
</tr>
<tr>
<td>Slide/time</td>
<td>Script</td>
<td>Prep/handouts</td>
</tr>
<tr>
<td>------------</td>
<td>--------</td>
<td>---------------</td>
</tr>
<tr>
<td>slide 28</td>
<td>Turn to the <strong>Meeting Your Legislator Checklist</strong> on page 13. This handout breaks down the steps of meeting a policymaker. Notice that the checklist has three parts: Stage 1: Make a Connection, Stage 2: Deliver your Message, Stage 3: Close on a Positive Note [Walk through the points in each section] Always remember to send a thank you note or email after your meeting. It’s not only polite, but it will leave a positive impression and give you another chance to make your ask. There is a simple thank-you worksheet in your handouts.</td>
<td><strong>Handout:</strong> Meeting Your Legislator Checklist</td>
</tr>
<tr>
<td>slide 29</td>
<td><strong>What did you take away from this experience today?</strong> <strong>What does this change for you?</strong> <strong>Where do you plan to use your story?</strong> [Take a couple of quick responses] Thank you all for taking the time to build your advocacy skills. Give yourselves a round of applause.</td>
<td></td>
</tr>
<tr>
<td>slide 30</td>
<td>This workshop is part of NAMI Smarts for Advocacy, NAMI’s grassroots skill building program. If you’d like to know more about the program, see me after the workshop.</td>
<td></td>
</tr>
</tbody>
</table>
## Advocacy Day: Changing Hearts & Minds

<table>
<thead>
<tr>
<th>Slide/time</th>
<th>Script</th>
<th>Prep/handouts</th>
</tr>
</thead>
<tbody>
<tr>
<td>slide 31</td>
<td>Before you go, please take a minute to complete your evaluation. We look at these closely because we always seek to improve the program. And now I'll turn it over to [moderator].</td>
<td>Handout: Evaluation form</td>
</tr>
</tbody>
</table>

We value your feedback
Please turn in your evaluation form

2 min Total: 65 min
Demo: Meeting Your Policymaker
(Two Constituents)

Meeting Stage 1: Make a connection

Introductions

**Senator Walker:** “Good morning, everyone. Thank you for coming.”

**John (Lead):** (shakes hand) “Hello, Senator. I’m John Adams from Spring Valley. We’re members of NAMI Springville, part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.

We really appreciate your taking the time to meet with us—we know you’re very busy.”

**Jenny (Storyteller):** (shakes hand) "It's a pleasure to meet you, Senator. I'm Jenny Jones from Springville."

**Senator Walker:** “It's a pleasure to have you here. I know NAMI; you’ve always done a great job bringing up mental health issues."

Show appreciation

**John (Lead):** "Senator Walker, before we talk about some important issues affecting your constituents who live with mental illness, we'd like you to know that we appreciate your many years of service in our legislature."

**Senator Walker:** “Thank you, I've spent twelve years in public office, now." 

**Jenny (Storyteller):** "We also appreciate that, as a doctor, you value the health of your constituents and have provided important leadership on the Medicaid Health Plan and health care issues in our state."

**Senator Walker:** "Well, I’ve seen too many people in emergency rooms with issues that could have been prevented for pennies, including a lot of people who needed mental health care."

Issue and position

**John (Lead):** "I'm glad you mentioned that, Senator. We're here because we want to urge you to support mental health services in HB 39, the mental health budget."
Meeting Stage 2: Deliver your message

The need or problem

John (Lead): “More families than ever are seeking help from our mental health centers. But with budget cuts, people can’t get the mental health services they need.”

Senator Walker: “I’ve always been a supporter of mental health; I was a co-sponsor on NAMI’s parity bill. But, it’s going to be an extremely tight budget this year. There are serious revenue shortfalls and we’re still figuring out where we can find savings. We’ve got to get spending under control.”

Talking points

John (Lead): “We understand, Senator. It’s going to be challenging, but the people of our state deserve the opportunity to be productive and healthy. To have that opportunity, they need access to mental health care.

Also, if we don’t protect mental health services, it’s going to cost us more in other places.

When our children can’t get help for mental health conditions, they fall behind in school and families struggle.

When adults can’t get treatment, costs shift to jails, emergency rooms and hospitals.”

Senator Walker: “Isn’t that the truth. Like that kid involved in that police shooting—they’re saying he has a mental illness. I can’t believe those parents of his didn’t do something before a tragedy happened.”

Story

Jenny (Storyteller): “Yes, there’s a lot of speculation around that. I just wish the media would talk about stories of recovery, like mine, instead of focusing on sensational news.

I’m here because my life is affected by mental illness. My son, Andy, lives with bipolar disorder and I can tell you that treatment can make the difference between despair and recovery. Today, Andy’s living on his own, working as an artist and making me proud. I never thought I’d see him experience this kind of recovery.

But, it wasn’t always that way. Before he got the treatment he needs, I saw him in the back of police cars and held him in my arms after a suicide attempt. No child should have to go through this.”

Senator Walker: “I really appreciate your story, Jenny, and I’m so happy to hear your son is doing well. Is Andy showing his art anywhere?”

Talking points

Jenny (Storyteller): “Yes, a gallery is representing him. But, what I’m worried about is that there are thousands of others in our state just like my son, except most don’t get the help they need.”
More than one in ten youth and about one in seventeen adults lives with a serious mental illness, so it’s more common than most people think. Many of our returning service men and women are experiencing mental illness, too."

**What will help others**

**Jenny (Storyteller):** “We need more mental health services, not fewer. It’s an investment in health and productivity. If people can get the right care at the right time, they can be successful, like my son.”

**The “ask”**

**John (Lead):** “The people of our state need your vote to protect mental health care. Can we count on your support of HB 39, Senator?”

**Senator Walker (standing):** “You’ve both made some excellent points and I’ll keep them in mind. I know how important mental health services are and I’ll think about this as we’re working on the budget.”

**Meeting Stage 3: Close on a positive note**

**Say thank you**

**John (Lead):** (shakes hand) “Thank you so much, Senator Walker. We appreciate you taking the time to hear about our issues.”

**Provide information**

**Jenny (Storyteller):** “Thank you for meeting with us, Senator. We know your time is limited, so we’d like to leave you with this packet that contains a fact sheet and NAMI’s other legislative priorities. We hope we can count on your support for them.”

**Offer to be a resource**

**John (Lead):** “Please know that we’d welcome the opportunity to be a resource to you in the future. We’d also like to follow up and see how you intend to vote on our issues.”

**Senator Walker:** ”Certainly. Please give my staff your contact information before you leave so they can get hold of you.”

**Make a request**

**Jenny (Storyteller):** (shakes hand) "Thank you, Senator. If you have time, we would be honored if you would have your picture taken with us for our newsletter."

**Senator Walker:** "I think I can take a moment for a picture. And please tell Andy "hello" for me, will you?"

**Jenny (Storyteller):** "Of course, Senator. Thank you. That will make his day."
Insert Tab: Advocacy Day Worksheets
Sample Family Member Story

1. My introduction
Hello, I’m Jenny Jones from Springville. I’m a member of NAMI Springville, part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.

I’m also the proud mother of a 23-year-old son who lives with bipolar disorder. I’d like to share my story with you and ask for your support of mental health services.

2. What happened
When my son was still a toddler, I had a thought that no mother should have: I wondered if my beautiful boy would be in juvenile detention on his 16th birthday. He just did not respond the way other children did to requests, to routines, to daily life and love.

As he grew, we never knew what would be broken, who might be hurt or when it would happen.

3. What helped
In fifth grade, my son’s teacher said, "Jenny, honey, I’ve taught hundreds and hundreds of kids. I know when a boy is misbehaving and I know when something is wrong. And something is wrong. You just keep looking for help."

When Andy was finally diagnosed with bipolar disorder, our lives changed. With treatment, he started smiling, enjoying school and making friends.

4. How I’m different today
On his sixteenth birthday, Andy wasn't in juvenile detention; he was creating art. Today, he’s enjoying life, working hard and making me proud.

5. What is the need or problem
My son is proof that treatment works. But, not everyone gets the help they need.

6. What will help others
A strong mental health system will help children and adults get the right care at the right time.

7. My "ask"
Thank you for meeting with me and listening to my story. Can I count on you to protect mental health services—and give families the hope of recovery?
### Seven Steps: Telling Your Story Checklist

The following seven steps will help you craft a brief and powerful story.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong></td>
<td><strong>Introduce yourself</strong></td>
</tr>
<tr>
<td><strong>Give your name and city or town.</strong> Include your organization. Describe yourself as “a member of NAMI [State Org or NAMI Affiliate], part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.”</td>
<td><strong>Share how you are affected by mental illness.</strong> Are you living with mental illness, a family member, a caregiver? This brings a &quot;real face&quot; to mental illness.</td>
</tr>
<tr>
<td><strong>State your issue and position.</strong> Let your listener know what you want them to support or oppose (or do). This helps your listener focus.</td>
<td><strong>What happened?</strong></td>
</tr>
<tr>
<td><strong>What happened before you received the help you needed?</strong> Keep this brief—think about the most important thing you’d like your listener to know.</td>
<td><strong>What helped?</strong></td>
</tr>
<tr>
<td><strong>Describe what helped in your recovery (or would have helped).</strong> This adds a hopeful tone and helps show the value of services and supports.</td>
<td><strong>How are you different today?</strong></td>
</tr>
<tr>
<td><strong>Share what is going right in your life or how you are experiencing recovery. This concludes your personal story on a positive note that inspires.</strong></td>
<td><strong>What is the need or problem?</strong></td>
</tr>
<tr>
<td><strong>Mention the problem or need you want addressed.</strong> Transition to the challenge(s) faced by people living with mental illness.</td>
<td><strong>What will help others?</strong></td>
</tr>
<tr>
<td><strong>Talk about what will help.</strong> Let your listener know what will address the need or problem you described.</td>
<td><strong>Make your &quot;ask&quot;</strong></td>
</tr>
<tr>
<td><strong>Ask your legislator if you can count on their support (or opposition). Include a bill number, if possible. Thank your legislator for his or her time.</strong></td>
<td></td>
</tr>
</tbody>
</table>
### 1. Introduction

Include your name and city. Describe yourself as *a member of NAMI [State or Affiliate], part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.* Add how you are affected by mental illness, your issue and position.

### 2. What happened

Aim for 3-9 sentences. Briefly describe the most important and compelling thing(s) about your situation.

### 3. What helped

Aim for 1-5 sentences. Briefly describe what helped in your recovery (or what would have helped). Aim for a hopeful tone that helps show what is helpful.
### 4. How I'm different today
Aim for 1-3 sentences. Share what is going right in your life or how you are experiencing recovery. This concludes your personal story on a positive note that inspires.

### 5. The need or problem
Aim for 1-2 sentences. Transition to the challenge(s) faced by people living with mental illness that you want addressed.

### 6. What will help others
Aim for 1-2 sentences. Talk about what will help. Let your legislator know what will address the need or problem you described.

### 7. My "ask"
Aim for 1-2 sentences. Thank your legislator for listening to you. Then, ask your legislator for a commitment. Be specific.
# Making Your Case:
## Tips for Legislative Advocacy

## Prep for success

| ✓ Know your issue. | Identify your issue, describe the problem, talking points, your story, the solution and your “ask.” Use a **briefing sheet** to stay organized. |
| ✓ Know your legislator. | Research your legislators online. Read their bios. Find out what committees they are on, their interests and any action on your issues. Use a **backgrounder** to note important details. |
| ✓ Plan your meeting. | If meeting as part of a group, identify roles and coordinate what you will say. A group of two is often the most effective. Use the **Meeting Roles** worksheet as a guide. |
| ✓ Dress respectfully. | Business or business casual is best; no jeans, no revealing clothing. T-shirts are fine if part of an advocacy campaign. |
| ✓ Be Prompt. | Legislators are busy. Arrive a few minutes before the appointed time. Be prepared to wait. Committee hearings or meetings may run overtime. |

## During the meeting

| ✓ Speak respectfully. | Address the legislator by their title and last name: Senator or Representative [last name]. Don’t argue. Respond politely, even to uninformed or stigmatizing comments. |
| ✓ Be truthful. | If you don’t know the answer to a question, say so. Offer to find the information, then contact your NAMI office if you need help. |
| ✓ Manage spin. | Don’t get caught up in side issues. Practice bringing the focus back to where it belongs—on people living with mental health conditions. |
| ✓ Expect resistance. | Practice positive responses to challenging comments and questions. Use facts to support your statements, if possible. |
| ✓ Make an Ask. | Ask your legislator whether you can count on their support (or opposition). Include a bill number, if possible. |

## Follow up

| ✓ Send a thank you note. | A brief thank you note or email is not only polite, it will leave a positive impression and allows you to **repeat your ask**. |
| ✓ Check back regarding position. | Write, call or email a polite inquiry a week or two after your meeting. |
| ✓ If needed: Follow through on a request. | If the legislator asks for more information, follow up immediately. Ask NAMI for help if you need it. |
The Briefing Sheet Example

A "briefing sheet" is a tool to prepare for meetings with legislators; it is not appropriate to leave behind. Provide elected officials or staff with separate fact sheets or materials outlining legislative priorities.

<table>
<thead>
<tr>
<th>The issue</th>
<th>The “ask”</th>
<th>The need or problem, talking points and solution</th>
<th>Committee Sponsors</th>
</tr>
</thead>
<tbody>
<tr>
<td>House Bill 39 (mental health budget)</td>
<td>Vote to protect mental health services in HB 39</td>
<td>The need or problem: More individuals and families than ever are seeking help from our mental health centers. But with budget cuts, people can't get the mental health services they need.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Talking Points:</strong></td>
<td>Joint Ways &amp; Means Committee</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• People deserve the opportunity to be productive and healthy.</td>
<td>Co-Chair Sen. Johnson</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To have that opportunity, they need access to care.</td>
<td>Co-Chair Rep. Mark</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• When children can't get help for mental health conditions, they often fall behind in school and families struggle.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• When adults can't get treatment, costs shift to jails, emergency rooms and hospitals.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• More than one in ten youth and about one in seventeen adults live with a serious mental illness, so it's common.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Thousands of men and women who've served our country experience mental illness.</td>
<td>Human Services Subcommittee</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• When people get the right care at the right time, they can be successful and experience recovery.</td>
<td>Co-Chair Sen. Greenly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Mental health care is an investment in health and productivity.</td>
<td>Co-Chair Rep Henry</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>The solution (what will help):</strong> Support HB 39. Preserve mental health funding will ensure that mental health services are there when people need them.</td>
<td>No sponsor—agency budget bill</td>
</tr>
</tbody>
</table>
### Briefing Sheet Template

**Finding information**
- Consult your NAMI State Organization for the information you need. If information is not available, consider the following sources:
- For the committee assignment and sponsors, search for the bill on the legislature website or call the legislature’s information line.
- For talking points, consider using facts from www.nami.org or other reputable sources.
- Your “ask” should align with NAMI’s policy platform at www.nami.org and your NAMI State Organization’s position.

<table>
<thead>
<tr>
<th>The issue</th>
<th>The “ask”</th>
<th>The need or problem, talking points and solution</th>
<th>Committee, Sponsors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>The need or problem:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Talking Points:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>The solution (what will help):</td>
<td></td>
</tr>
</tbody>
</table>
## Backgrounder Example

<table>
<thead>
<tr>
<th><strong>Elected official</strong></th>
<th><strong>Committee assignments</strong></th>
</tr>
</thead>
</table>
| **Senator David Walker, M.D.**  
D-Spring Valley  
First elected to Senate in 2004  
Deputy Majority Leader | **Ways & Means**  
Co-Chair, Ways & Means Subcommittee on Human Services |

<table>
<thead>
<tr>
<th><strong>Contact info</strong></th>
<th><strong>Notes</strong></th>
</tr>
</thead>
</table>
| 900 Court St NE, S-205  
Salem, OR 97301  
**Phone** (503) 555-5555  
**Email** sen.dwalker@somewhere.state.us  
**Website** www.walker4ever.com |  
- Strong proponent of expansion of health care coverage  
- Concerned about reigning in health care costs |

<table>
<thead>
<tr>
<th><strong>Personal info</strong></th>
<th><strong>Bio</strong></th>
</tr>
</thead>
</table>
| **Marital Status:** Married to April  
**Residence:** Spring Valley, Oregon  
**Occupation:** Doctor  
**Previous Political Experience:** Oregon House of Representatives, 2000-2004  
**Education:** BA, Oregon State University, 1969  
DO, College of Medicine, Richmond, Virginia, 1973  
**Birthdate:** August 2, 1946  
**Religion:** Protestant |  
- Enlisted in the US Army and served one tour of duty in Vietnam  
- Attended medical school at the College of Medicine  
- In private practice in rural Spring Valley for the last 30 years  
- Former Chief of Medicine at Deep Valley Medical Center  
- Served three terms on the Spring Valley School Board  
- Governor's Quality in Education Task Force  
- Appointed to the Health Services Commission in 1989, which was instrumental in designing the Oregon Health Plan. |

Where do you see potential areas of connection or shared interest?  

Do you see or know of any potential concerns or areas of resistance to your issue?
# Backgrounder Template

**For basic information:**
- Go to www.nami.org/advocacy, enter your zip code
- Click on your state legislator’s name
- Click on the Bio tab for basic information
- Click on the Committee tab for info about committees
- Click on the Contact tab for a link to legislator’s website

**Options for more information:**
- Visit your legislator’s website for more information
- Visit www.votesmart.org/officials
- Google your legislator’s name

<table>
<thead>
<tr>
<th>Elected official</th>
<th>Committee assignments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copy &amp; paste photo</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Contact info</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal info</th>
<th>Bio</th>
</tr>
</thead>
</table>
Meeting Roles

Before your group meeting, determine what role each participant will play. Note: Role descriptions are suggestions; refer to your Meeting Your Legislator checklist and make sure a participant is identified for each part you expect to cover.

### Role descriptions

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
</table>
| **Lead**  | - Introduces self or the group  
             - Introduces issue and position  
             - Makes the "ask"  
             - Closes the meeting          |
| **Messenger** | - Gives talking points  
                  - Describes the need or problem  
                  - Describes the solution  
                  - Gives legislative packet at meeting close |
| **Storyteller** | - Adds highlights of personal story or local perspective of issue's impact |

### Size of meeting

<table>
<thead>
<tr>
<th>Division of roles</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>One-on-one meeting</strong></td>
</tr>
<tr>
<td><strong>Two-on-one meeting</strong></td>
</tr>
<tr>
<td>(two constituents and legislator)</td>
</tr>
<tr>
<td><strong>Three-on-one meeting</strong></td>
</tr>
<tr>
<td>(three constituents and legislator)</td>
</tr>
</tbody>
</table>
| **Group of four or more** | Three people in the group should take on one role each. Other participants should serve as “eyes and ears” during the meeting.  
Note: If there are two or three issues to discuss, participants may switch roles for second and third issue, if desired. |
### Meeting Your Legislator Checklist

#### Stage 1: Make a connection

- ✓ **Address your legislator by their elected title.** Add their last name, if you like.
- ✓ **Give your name and city or town.**
- ✓ **Include your organization.** We encourage you to describe yourself as “a member of NAMI [State Org or Affiliate], part of America’s largest grassroots mental health organization, the National Alliance on Mental Illness.”
- ✓ **Thank your legislator for his/her time.** Mention something positive he or she has done or touch on a shared interest or connection.
- ✓ **Describe the issue.** State the position or action you want your legislator to take.

#### Stage 2: Deliver your message

- ✓ **State the problem or need you want addressed.** Transition to the challenge(s) faced by people living with mental health conditions.
- ✓ **Add talking points.** Talk briefly about the issue and/or why the bill is needed.
- ✓ **Describe what will help others.** Let your legislator know what will help address the need or problem you described.
- ✓ **Ask your legislator for their support (or opposition).** Be specific about the action or position you want them to take. Include a bill number, if possible.
- ✓ **Describe your next issue.** Repeat the process.

#### Stage 3: Close on a positive note

- ✓ **Thank your legislator.** Let your legislator know you appreciate their time and attention.
- ✓ **Optional: Provide written information.** Leave a fact sheet, legislative packet or summary of your issue(s) or bill(s). Ask for support on your other issues, if applicable. Include information on your organization and its programs.
- ✓ **Optional: Offer to help.** Tell your legislator that you are willing to serve as a resource on mental health issues.
- ✓ **Request a picture or extend an invitation.** Ask your legislator to pose for a group photo or ask him/her to visit a local program or event, like the NAMI Walk.
Evaluation
NAMI Smarts: Changing Hearts & Minds

Presenter Name: ___________________________ Date: ____________

Location of Presentation (City & State): ____________________________________________

Your Name (optional, but preferred): ____________________________________________

1. Overall, my knowledge and skill level about advocacy is...

   **Before the training:** (Circle your rating)  
   
   1 2 3 4 5 6 7 8 9 10  
   None Some Good Excellent  

   **After the training:** (Circle your rating)  
   
   1 2 3 4 5 6 7 8 9 10  
   None Some Good Excellent

2. Overall, my level of confidence about advocacy is...

   **Before the training:** (Circle your rating)  
   
   1 2 3 4 5 6 7 8 9 10  
   None Some Good Excellent  

   **After the training:** (Circle your rating)  
   
   1 2 3 4 5 6 7 8 9 10  
   None Some Good Excellent

3. What did you learn that was most meaningful or helpful to you today?

4. How do you plan to use what you have learned in this training? What will you do differently?

5. What comments, if any, do you have about this training?

6. We seek to support the entire community. To help us track how we are doing, please check all that apply. I am:

<table>
<thead>
<tr>
<th>Mental Health</th>
<th>Substance Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with condition</td>
<td></td>
</tr>
<tr>
<td>Family caregiver of adult</td>
<td></td>
</tr>
<tr>
<td>Parent/guardian of child or youth</td>
<td></td>
</tr>
<tr>
<td>Service provider</td>
<td></td>
</tr>
<tr>
<td>Peer provider</td>
<td></td>
</tr>
<tr>
<td>Advocate</td>
<td></td>
</tr>
<tr>
<td>Military, veteran or mil/vet family</td>
<td></td>
</tr>
<tr>
<td>Other: ____________________________</td>
<td></td>
</tr>
</tbody>
</table>

   □ American Indian or Alaska Native  
   □ Asian American  
   □ Black or African American  
   □ Hispanic or Latino  
   □ Native Hawaiian, Pacific Islander  
   □ White or Caucasian  
   □ Multiracial  
   □ Other: ____________________________