

Advocacy  
and the Adult Home Resident  
Slide 1

Introductory remarks

In this introductory session, I hope you come to appreciate that you have many of the skills you need, to be just as effective as advocates for people with psychiatric disabilities as you are for older adults in nursing homes. You may not have all the knowledge yet that you want to be able to do that effectively, but you have most of the requisite skills.

(Click)



Goals  
Slide 2

The goals of this training are two fold: first, to increase the personal comfort and confidence of ombudsman in their abilities to work effectively with residents living in adult homes with multiple, chronic health problems (both mental and physical); and by doing so, to increase their ability to advocate effectively *for* and *with* residents. It is expected that this advocacy will occur at both the individual and systems levels.

Objectives  
Slide 3

At the end of this particular module, you will be able to:

Describe situations you are likely to encounter in adult homes.

Describe how they might be different from what ombudsmen are used to in nursing homes and to describe the ways in which they are similar.

(Click)

You will also be able to name the key mental health organizations and resources in your community that are needed to address mental health issues at both the individual and systems level.

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Underlying assumptions  
Slide 4

The approach throughout the entire mental health training manual is based on the beliefs that: (Click)

The mind/body split is invalid

We have a problem in our language. We have had it forever. (Or at least since Descartes); I’m referring to the mind/body split or “the physical versus mental” split. We think that everything physical happens from here down (gesture below the chin) and everything mental from here up. (Gesture above the chin).

Well, those of us who work with seniors of course know there is very little separation. If a frail senior living in a nursing home gets a urinary tract infection, it will likely show up as confusion and may cause the person to appear as if they have Alzheimer’s disease.

(Click)

- 2) Mental health is as important as physical health and (click)
- 3) Physical health effects mental health and vice versa

For example, we now know that people with depression have more problems with heart disease. Another example would be the common problem of urinary tract infections causing increased confusion in nursing home residents

Ask participants to think of similar examples from their own experiences or from something they may have read

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Underlying Assumptions  
Slide 5

One of the frustrations faced by individuals with mental illness is the tendency for others to see everything that happens as resulting from the person’s mental illness.

It will often fall to the ombudsman to remind care providers that having a mental illness doesn’t explain everything.

People with mental illness have good days and have bad days  
Just like you and me.....

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Working in adult homes will require overcoming a number of obstacles:  
[Click once: the words will automatically appear; you can just keep reading/talking]

Adult home setting  
Slide 6

You are up against stigma, you are up against demoralized residents and you are up against demoralized care givers. You are up against direct care workers and facility operators who have been in the spotlight and feel nobody appreciates the job they do. You are up against people who are doing a good job being lumped in with people who are not doing a good job and feeling resentful and a little defensive. When a good job IS being done, you need to acknowledge the effort, especially under difficult conditions.

You are also up against the fact that many communities are more than a little ambivalent about having folks with psychiatric disabilities in adult homes in their communities. There are a lot of people who would like to see separate psychiatric facilities in a “less visible” location.

Individuals with mental illness may exhibit many types of behaviors such as extreme sadness and irritability, or suffer from hallucinations and total withdrawal. Instead of receiving compassion and acceptance, individuals with mental illness may experience hostility, discrimination, and stigma.

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Why does stigma still exist?  
Slide 7

Why does stigma still exist? There are many possible explanations.

The media certainly plays a role. Newspapers, in particular, often stress a history of mental illness in the backgrounds of people who commit crimes of violence.

National advertisers use stigmatizing images as promotional gimmicks to sell products.

Television news programs frequently sensationalize crimes where persons with mental illnesses are involved.

Comedians make fun of people with mental illnesses, using their disabilities as a source of humor.

[Think of examples you may know. Ask others to give some examples.]

How can you combat this?

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Who’s Who in Adult Homes  
Slide 8

One way to combat stigma is to focus on real people. Who are the folks in adult homes? (click once: words on the left will automatically appear)

First and foremost, they are people.

They are people with stories of success and of failure.

In adult homes, you are going to see people who have had a lot of trauma. That trauma may have been from physical abuse or sexual abuse or abusive relationships. In those homes that cater to an older veteran population, you are going to see people with post-traumatic issues from military service. So you're going to see people who have lives that have, in large measure, shaped who they are, as is true for all of us.

You are more likely to encounter individuals in adult homes who have some history of incarceration than you are in nursing homes. This is likely due in part to the fact that our prison systems have become alternative placements for people with mental illness.

There are also folks who, just like folks in long-term care, come to adult home living with a lot of loss. They lose some of their hopes and dreams for a life without having mental illness. Maybe they have lost their homes. They may have lost their family connections.

(Click)

They are people with mental illness, (click).

People who are marginalized,

(click) people who are stigmatized.

*[The instructor may wish to reiterate how difficult it is to think about individuals if we use words or phrases like the mentally ill, the elderly as a sort of class, as though they are all the same. ]*

(\*Click)

Ombudsman role  
Slide 9

As ombudsman for people with mental illness who are living in adult care home or in nursing homes, your role is not just to enforce standards and make sure facility operators are doing what they are supposed to be doing. It is to really **SEE** the individuals for whom you are advocating. That you TALK with them as individuals. That you hear their stories.

There is often anxiety about mixing people with major mental illness in the same setting as frail elders. So there may not even be support for making things work. When they are not working, the focus must be kept on: ‘Can *this placement* work for *this individual* in *this home* at *this time*?’ not “you can’t mix *the mentally ill* with *the elderly*”

I also encourage you to support the recovery movement, which you'll hear more about in another module.

Ask the participants how this role might (or might not) differ from working with someone *without* mental illness in a nursing home

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What’s different?  
What’s not?  
Slide 10

[To the instructor: The point in the next three slides: “What’s different? What’s not?” Is to help the ombudsman think about what they already know as well as what they don’t know. You will want to reassure the ombudsmen that they know more than they think they know about addressing needs of individuals with mental illness, who, like seniors in nursing homes, have been historically marginalized.]

Define stigma: ask participants to give examples of how both older adults and persons with mental illness might experience this on a daily basis.

You will be up against not only the stigma in the community but you are up against the fact that you hold some of those views yourselves. And you will be up against what is called internalized stigma. This means that many individuals with mental illness believe the stereotypes themselves; believe the most negative things about themselves. So you have to overcome the community stigma, your own stigma, the individual stigma and work cooperatively to consciously challenge stereotypes and myths about this population. It is frankly a tall order. (Click) Imagine what it would be like if every time you saw somebody, instead of saying hello, how are you doing, they would say *‘I see you solved your weight problem. Or worse, I see you haven’t solved your weight problem! Why aren’t you dieting?’* And yet do you know that the first question people with mental illness are often greeted with in adult homes is *“Are you taking your medication?”* As soon as someone looks like they are having a bad day: *‘Are you taking your medication?’ ‘Have you seen your doctor?’* Imagine what it would be like if somebody greeted you with *why are you letting yourself go like that?* Instead of *how are things going?*

Try to rid yourselves of the idea that people with mental illness are fundamentally different in some way from people with physical illness. If you have serious cardiac disease, diabetes or, multiple losses, you are as likely to become depressed as somebody who has an underlying major depressive disorder.

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What's different? What's not?  
Slide 11

Individuals with schizophrenia have felt the impact of that disorder life long, particularly those who are older, and began treatment when the illness was less well understood. Living in a group situation, including a nursing home may be in some ways less stressful than the older adult who has had a lifetime of social connection now abruptly shut off.

The other thing that you need to understand about people who have had life long mental illness is that they may have few memories of a time when we were doing better to help them get through difficult times. People who have achieved a certain amount of satisfaction either as parents, as spouses, as friends, in the work place, as students, can tap into that sense of success when they are feeling down and bolster their self-esteem.

People with mental illness who have not had experiences of being involved in their communities in similar ways so they can look back and say *I'm not so bad* are at a real disadvantage when they are having a bad day, because they don't have those internal resources to draw on. And when you pit that against the fact that other people are treating them as second-class citizens and you get some of the idea of the magnitude of the problem because they need to bolster themselves every day, and the reservoir is very limited.

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What’s different? What’s not?  
Slide 12

Unlike many cognitively impaired and frail elders in nursing homes, adults with mental illness in group homes will want to be partners in advocating for themselves, but will need your help in knowing how to do this.

One of the biggest similarities may be in the limits on self-determination imposed by involuntary care through commitment, in the case of individuals with psychiatric disabilities and through guardianship with older adults.

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Mental illnesses are...  
Slide 13

What do we mean by mental illness? Most simply, mental illnesses are disorders of *thought, feeling* and/or *behavior* which result in an inability to cope with life’s ordinary demands and routines

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Mental illnesses are NOT  
Slide 14

Mental illnesses are not:

(\*Click -- each phrase will appear automatically after the first click; don’t click again)

Evidence of a character weakness, a punishment from God, an individual’s “fault” anymore than getting cancer is, or the result of a poor upbringing.

Mental illnesses are illnesses, and like any illness: diabetes, heart disease or high blood pressure, may be influenced by our genes, our environment, our health behaviors.

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Major Mental Illness  
Slide 15

Often a distinction is made between so-called “major” and “minor” mental illness. The distinction is important to ombudsman only insofar as most states limit the public role and responsibility to those with *major* mental illness.

Major mental illness is also referred to as serious and persistent mental illness and includes psychotic disorders such as schizophrenia and delusional disorders as well as major depression, bipolar disorder (formerly known as manic depression) and severe personality disorders. Many individuals with major mental illness also abuse alcohol and other drugs. Let's define “psychosis” or “psychotic disorders”

Psychosis is a term we use to describe a very specific set of symptoms and a very specific problem, and that is the problem of “breaking with reality”.

The primary manifestations of psychosis, whether the psychosis is from depression, schizophrenia, dementia or from ingesting hallucinogens are the same: hallucinations and delusions. What's a hallucination? A hallucination is when you hear something when no one is speaking. When you see something that isn't there, taste something when there is nothing in your mouth, feel something crawling on your skin when there is nothing there, and when you smell something that nobody else can smell. In other words, hallucinations are disturbed perceptions: You see, smell, hear, taste, and feel something that isn't there. This is also an example of a break with reality about the external world.

For people with schizophrenia, the most common kind of hallucination is auditory. They hear people speaking when no one is speaking.

For people with substance problems, particularly during withdrawal, they are more likely to see things than to hear things and to feel things crawling on their skin. Many of you have seen movies where they depict rum fits or the Delirium tremens (DTs)? Well, that's what they are portraying when they talk about seeing pink elephants, feeling things crawling and start seeing spiders in their bed.

[To the instructor: The following anecdote is not necessary to include but may be helpful for you to be aware of if someone asks about macular degeneration. You can also get visual hallucinations if you are 92 years and have macular degeneration. A typical story goes like this: "My family thinks I'm crazy; my doctor thinks I'm crazy, and you're going to think I'm crazy too but here's what

happens: I see little girls in my room at night feeding a cat, and everybody tells me they are not there and I see them. I’ve never had a mental illness. Never had any mental health problems. I don’t take drugs. I’ve never even been depressed. I’ve had a pretty non-stressful life. Now I’m living in this facility and the staff think I’m crazy because I want them to get that little girl out of my room”.

The psychiatrist who told this story described how she responded. She said: of course you're seeing a little girl with a kitten at the foot of your bed. I just don't know why. I don't know why you see it and nobody else sees it. I know that people who have macular degeneration sometimes get this. I think that because people with macular degeneration can no longer see as well, the brain will start making images. When the brain is starved, it hallucinates.

And so we start talking about loneliness and little girls and cats, and I say to her, you know, you're never going to convince people that you see these things so you may want to just talk about it with me. What we are going to do is try to figure out whether or not it's worth it for you to take some medication that might block your brain from doing that, or whether you can get used to not being frightened by that and learn to treat it like a movie”]

Common interventions  
Slide 16

Mental illnesses are illnesses, and like any illness: diabetes, heart disease or high blood pressure, they can be treated and managed, though not often cured.

This slide lists many of the interventions that are used in the treatment of serious and persistent illness like schizophrenia.

You will have an opportunity to learn more about each of these during the rest of the course through reading materials and discussion

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Advocacy  
Slide 17

What do you bring to address the issues we’ve been discussing?

Your most valuable resource is you. I mean that quite sincerely. Ombudsmen bring incredible optimism. You bring conviction that you are doing the right thing. You see things that can and must get better. You have energy. You have commitment. You have increasing knowledge and you already have communication skills that are built on knowing how to listen.

What you bring to the adult home, what you bring to the psychiatrically disabled person are all of these skills. You also bring your own prejudices, your fears, and your anxieties. Many of you may not want to go into adult homes. I have heard some ombudsman say: *I don't know if this training is going to help. Some people just don't want to go in those places. Some people can't stand that squalor. Some people are afraid of people with mental illness.* Please keep an open mind. Some people don’t like to even go to fine nursing homes. They find them frightening, depressing, and oppressive. But many more of us at least have had the experience of going to nursing homes to visit a family member or friend there and find nursing homes less “scary”.

So go to adult homes in teams. Find partners. One obvious partner for you is the recovery movement. Another may be any of the survivor movements of people who have lived in adult homes and moved on.

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Advocacy  
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In addition to a positive attitude, you also bring knowledge.

Your manual should include a list of local and national resources as well as copies of the relevant State regulations regarding adult homes, involuntary treatment and reporting tracks

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Let’s solve some problems!  
Slide 19

Let’s solve some problems. Introduce the exercise: *Identifying resources*