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## **HOW ABOUT RECOVERY FOR PEOPLE WITH PSYCHIATRIC DISABILITIES IN LONG-TERM CARE?**

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Happily, the concept of “recovery” has become a powerful force in the mental health system. We talk now about a “recovery-oriented system” and “recovery-oriented services.” In doing so we express our sense of hope—our conviction—that people with serious, long-term psychiatric disabilities can lead satisfying and meaningful lives despite mental illness.

Unhappily, the concept of recovery is not a significant organizing principle in systems other than mental health where large numbers of people with serious, long-term mental illness are incarcerated or cared for—not, for example, in the penal system and not, for example, in the long-term care system.

By “long-term care system” we mean the spectrum of services that are the responsibility of the health and aging services systems and include: home-based health and personal care services, in-home case management, adult protective services, social and medical adult day care, assisted living, and nursing homes.

This system is conceptualized in terms of the needs of frail elderly people and of people with physical disabilities—including dementia, which from a policy point of view is regarded as a physical rather than a mental disorder just because it has a readily identifiable physical cause. (Strange, of course, to make such a hard and fast distinction in a period of psychiatric history dominated by organic theories of mental illness; but Cartesian mind-body dualism, which has been antiquated for at least a century, is still alive and kicking.)

It is unfortunate that the long-term care system is conceptualized solely in terms of physical disability because a majority of people getting, or in need of, long-term care have co-occurring mental disorders. Many, in fact, are in long-term care solely because of mental or behavioral disorders.

Shouldn't the concept of recovery apply to them as well as to people with serious, long-term mental illness served in the mental health system? We are—it seems to us—denying the advantages of recovery-oriented services to a very large number of people just because they are cared for outside the mental health system.

Keep in mind that about half of people in long-term care have a mental disorder other than dementia, often co-occurring with dementia or with physical disabilities. And about 10-15% of people in nursing homes are there primarily because they have mental illnesses with behavioral symptoms that make it difficult for them to be served in

community settings or cared for by their families. And let's not forget that one of the ways we reduced the census of state psychiatric hospitals was by discharging older adults with serious mental illness to nursing homes and adult homes—trans-institutionalization rather than deinstitutionalization.

Now they are out of the mental health system, but that does not mean they don't have the same needs and same potential as those who are in the mental health system. It does not mean that recovery is not a hope of them.

There is, of course, a widespread sense that needing long-term care is a terminal state—that hardly anyone who meets the criteria for long-term home health care, let alone for nursing home care, will be able to live independently ever again. Recovery is not possible, it is widely believed.

No doubt people in long-term care have profound problems, but some of them do return to independence. And, more importantly, the beauty of the concept of recovery in mental health is that even people who continue to have serious mental illnesses can develop lives that are satisfactory and meaningful to them. Recovery, in this sense, does not mean that the illness and some of its disabling consequences are gone; it means that a decent life is possible nevertheless.

What specifically would the concept of recovery bring to people with serious mental and behavioral problems in the long-term care system?

Recovery oriented systems and services would convey a strong sense of hope for a satisfying life. In addition, the concept of recovery rests on respect for the person with a psychiatric disability and on a sense of their right to dignity and self-determination. Choice, that is to say, is a key dimension of recovery. This means that individuals should have the opportunity to define their personal goals and that they should get the support that they need to achieve these goals. This is the essence of psychiatric rehabilitation, which includes help for people to develop the skills they need to achieve their own goals, the removal of environmental obstacles—such as discrimination or inflexible requirements for access to a life in the community, and ongoing support of the life they choose for themselves.

Some of these themes, it is important to acknowledge, are implicit in recent efforts at long-term care reform, which focus on opportunities for choice, culture change in institutions—un-institutionalizing them as it were, nursing home diversion and transition, and the use of resident and family councils to bring a consumer perspective to long-term care.

But, to support recovery, more is needed. This includes a recovery-oriented staff in long-term care—i.e. a staff that understands psychiatric disability and how to interact with people with respect and in a way that supports as much autonomy as an individual is capable of. Recovery also calls for the use of psychiatric rehabilitation model that engages people to achieve their highest possible level of functioning. Long-term care, like the mental health system, would also benefit from peers in program planning and in service delivery. They are messengers of hope and models for alternatives that often seem impossible. Families play a critical role in caring for people with disabilities in the

community. They need and deserve far more support than they get as well as a much more meaningful voice in the service system.

In addition, there is a need for housing alternatives to institutional settings, especially for people who have co-occurring physical and mental disabilities. The mental health housing and community support systems are usually overwhelmed by people with complex physical disorders. It does not need to be that way. A recovery orientation calls for integration of health and mental health services in the “most integrated setting”, and models already exist for doing this.

At this moment in the history of mental health policy, recovery has become a central theme but, as we have said, only for people served by the mental health system. Sadly, the mental health system—to overstate just a bit—washes its hands of people with psychiatric disabilities when they develop serious, chronic physical disabilities. And just as sadly, the health care system that then takes responsibility for them has done little to prepare itself to serve these people well. Both systems need to step up and take responsibility together for people with psychiatric disabilities who are in, or need to be in, long-term care.

That is why we at the Geriatric Mental Health Alliance are pressing for passage of The Behavioral Health, Chemical Dependency, and Long-term Care Act, which would require New York State to face the fact that, without attention to behavioral health, long-term care reform is incomplete and, in fact, impossible. It is time, we believe, that people with behavioral health conditions have the same opportunity for recovery in the long-term care system that they are gradually getting in the mental health system.

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