ADVOCACY TO IMPROVE CARE FOR OLDER PEOPLE WITH COGNITIVE AND/OR BEHAVIORAL HEALTH DISORDERS

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By
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Thank you for inviting me to speak at this remarkable annual conference again this year. It's amazing that it has continued for over a quarter of a century and that it has retained its vitality. It's a tribute to Dr. Kennedy and to Montefiore, for sure. But it's also an indication of the stubborn resistance of illnesses of the mind—of cognitive, mental, and substance use disorders—to either prevention or cure.

Obviously, that means that there need to be continuing biomedical research that hopefully one day will lead to true breakthroughs in prevention and treatment. But I, for one, am not optimistic that that will happen in the next few years.

In the meantime, we need to devote more attention to the psycho-social dimensions of cognitive and behavioral health conditions.

And, in my view, we need to pay considerable attention to the link between cognitive and behavioral health disorders.

There are good historical reasons why a field of cognitive disorders—dementia and cognitive impairment—split off from the field of treating mental illnesses. State hospitals prior to deinstitutionalization were 30% older people with "organic brain syndrome" as it was called at the time. Deinstitutionalization could not be the same for them as for people with greater functional capacity. At that time, there was also an erroneous diagnostic distinction between "organic" and "functional" conditions of the mind. In addition, as the populations of state hospitals began to decline, Medicaid was created, and it funded nursing homes but not long-term psychiatric hospitals. The transinstitutionalization of people with serious and persistent mental illness to nursing homes became a scandal and was wisely discouraged but with scandalously insufficient housing alternatives. Outpatient services split between adult medical day care in the long-term care system and various forms of clinics, day treatment, and rehabilitation programs in the mental health and substance abuse systems. Thus, a schism emerged between treatment for people with so-called brain disorders and for those with mental and/or substance use disorders.

This is obviously a false trichotomy. Over the years, mental illnesses and substance use disorders have increasingly been understood as brain disorders with powerful psycho-social dimensions. And, research studies have made it entirely clear that virtually all people living with dementia will at some point during their progressive cognitive decline also have behavioral disorders—generally referred to as "neuro-

psychiatric symptoms"—including anxiety, depression, psychosis, substance misuse, behavior problems, etc. 98% is the number reported in recent research.

We also know that the mental and substance use disorders are frequent precursors of the development of dementia. In fact, they may be the early phases of as yet unnamed conditions of the mind that begin with psychiatric symptoms and end with an admixture of cognitive and behavioral disorders.

What difference does this make for policy? It suggests to me that we ought to re-conceptualize the service systems from the standpoint of the unity of the mind rather than a fictitious fracturing. Ideally, systems of care should be remade emphasizing early identification and intervention with entry into a compassionate continuum of care rather than as non-communicative and competitive "silos", as they are often called.

At the very least, the long-term care system should develop expertise in serving people with co-occurring cognitive and behavioral health conditions, and the mental health and substance abuse systems should develop expertise in serving people who also have, or will develop, cognitive impairments.

Let's stop shifting people from one system to another without regard to continuity in their lives. Let's stop fitting people to the system rather than vice versa.

To do this requires a re-conceptualization of Medicaid and Medicare, a story for another time.

All of this also suggests to me that advocates for the various silos ought to make an effort to work together to promote better lives for people with cognitive and/or behavioral disorders. That's hard to do when there is such intense competition for limited resources, of course. But it is possible.

I have dwelled this morning on one neglected aspect of very complex policy issues regarding people with cognitive and/or behavioral disorders. Let me close by rapidly ticking off of some of the other major issues.

- America is aging rapidly; services need to expand to keep pace with population growth.

- There is a workforce crisis with regard both the quantity and quality.

- The long-term care system has been in need of improvement for decades. Sadly, advocates and providers too often negate each other in the political arena rather than joining forces.

- There needs to be more support to age in the community and more residential alternatives to institutions.

- Family caregivers need more support.

- Racial and economic disparities need to be addressed.

- There needs to be more public and professional education.

- There needs to be more attention to opportunities for prevention by promoting healthy aging, which has just been added as a goal to the National Alzheimer's Plan.

- There needs to be more research, especially psychosocial and epidemiological research.

- There needs to be an accessible and reliable source of data for systems transformation, planning, and program development.

- Last, but not least, we need to **learn the lessons of the pandemic** about the extreme vulnerability of older adults with cognitive and/or behavioral health conditions.

Clearly, we have "miles to go before we sleep".

Thank you again for the opportunity to speak today.

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