



## Advancing the human and civil rights of people with disabilities

SELF-ADVOCACY ASSISTANCE ★ LEGAL SERVICES ★ DISABILITY RIGHTS EDUCATION ★ PUBLIC POLICY ADVOCACY ★ ABUSE INVESTIGATIONS

### **Testimony of Equip for Equality Before The Governor's Nursing Home Safety Task Force**

Springfield, Illinois  
October 29, 2009

Equip for Equality is an independent not-for-profit organization designated by the Governor in 1985 to administer the federal Protection and Advocacy System for people in Illinois with physical or mental disabilities. Equip for Equality's mission is to advance the civil and human rights of people with disabilities and is accomplished through self-advocacy training and technical assistance, legal services, and public policy initiatives. In its capacity as an independent watchdog, Equip for Equality also conducts unannounced on-site monitoring visits to programs and facilities, including nursing homes, across the state and engages in systemic investigations to address abuse and neglect of people with disabilities. We appreciate being given an opportunity to provide testimony before the Task Force.

Mental illness cuts across all races, ethnic groups, socio-economic groups, and age groups. It is more common than cancer, diabetes or heart disease. In Illinois, 2.6 to 3.9 million people (20-30% of the population) will be affected by mental illness in any given year. Without treatment and support, the consequences of mental illness to individuals and to the State can be devastating. Frequently, it results in unnecessary hospitalization, unemployment, substance abuse, homelessness, inappropriate incarceration, stigma, and far too often in tragic consequences such as suicide.

In spite of the prevalence of mental illness, Illinois has failed to develop an adequate community based mental health system capable of providing easily accessible and individualized supports and services which would allow people to recover while living their lives in their own homes and communities. Instead, Illinois' grossly under funded community mental health system has meant that services are simply not available to thousands of people in need resulting far too often in people being warehoused in nursing homes and other institutions.

While we appreciate the call to action that has resulted from the articles in the Chicago Tribune, we are deeply troubled by the stigmatizing effect of the articles and the characterization of people with mental illness as dangerous and in need of segregation because of their propensity to commit crimes. This stereotypical notion, while prevalent, has been repeatedly refuted. Studies show that more than one quarter of persons with severe mental illness has been a victim of a violent crime, a rate more than 11 times

*THE INDEPENDENT, FEDERALLY MANDATED PROTECTION & ADVOCACY SYSTEM FOR THE STATE OF ILLINOIS*

DOUG KENSHOL, BOARD CHAIRPERSON    ZENA NAIDITCH, PRESIDENT & CEO

MAIN OFFICE: 20 N. MICHIGAN AVENUE, SUITE 300 ★ CHICAGO, IL 60602 ★ EMAIL: CONTACTUS@EQUIPFORQUALITY.ORG ★ TEL: (312) 341-0022

TOLL FREE: (800) 537-2632 ★ TTY: (800) 610-2779 ★ FAX: (312) 341-0295 ★ MULTIPLE LANGUAGE SERVICES / AMERICAN SIGN LANGUAGE

[WWW.EQUIPFORQUALITY.ORG](http://WWW.EQUIPFORQUALITY.ORG)

higher than the general population.<sup>1</sup> Among persons with severe mental illness, violent victimization is far more prevalent (more than 25% in 2005) than perpetration of violence (4% -13%). Thus, the reality is the inverse of common belief: people with serious mental illness are far more likely to be the victims of violence than its initiators. Blaming the victims is the real danger here because it rationalizes neglect and maltreatment of people with mental illness. Far from being the aggressors, people in nursing homes are much more likely to suffer injury at the hands of staff from poor care, neglect and abuse.<sup>2</sup>

At present, long-term care for people with mental illness in Illinois is primarily provided in institutional settings such as state-operated mental health centers, nursing homes, and Institutions for Mental Diseases (IMDs). The State spends a disproportionate amount of its mental health budget on providing services in segregated settings rather than in the community. The current service system is contrary to the community integration mandate of the Americans with Disabilities Act (ADA) and the Supreme Court's *Olmstead* decision. In addition, it is designed to intervene only *after* these individuals have reached an acute stage of illness. Neither the individuals' quality of life nor the State's economic interests are promoted by such a system.

In Illinois, more than 5,500 individuals with mental illness are housed in large nursing homes referred to as IMDs. These facilities, which are privately owned, are funded 100% by the State. Federal law prohibits the State from recapturing any federal funds for the amount spent on IMDs. If Illinois instead spent these funds on community mental health services, it would be able to recoup at least 40% of the cost in federal Medicaid dollars. Furthermore, individuals living in IMDs, as well as other nursing homes, do not receive sufficient or, in some cases, any services, training or assistance in developing skills that would allow them to live successfully in the community. Equip for Equality's efforts to address the lack of services and the dehumanizing conditions which result from warehousing people with disabilities has been longstanding.

More importantly, this is by no means a new problem. In 1986, a report authored by the Institute of Medicine on improving the quality of care in nursing homes suggested that people with severe mental illness who were deinstitutionalized from state mental health hospitals were discharged to nursing homes that could not provide the specialized services they needed.<sup>3</sup> The report also raised concerns that even the former state hospital patients who needed a nursing level of care were not receiving the minimally necessary level of mental health treatment in nursing homes.<sup>4</sup> The federal Omnibus Budget

---

<sup>1</sup> Linda A. Teplin, et al., *Crime Victimization in Adults with Severe Mental Illness: Comparison with the National Crime Victimization Survey*, 62 Archives of General Psychiatry 914 (2005) ("People associate mental illness with violence. Crime and mental illness are linked, but not in the way people think. People with severe mental illness are terribly vulnerable to victimization.").

<sup>2</sup> *Abuse in Nursing Homes*, National Center on Elder Abuse Newsletter (National Center on Elder Abuse, Washington, D.C.), May 2002, at 10.

<sup>3</sup> Institute of Medicine, *Improving the Quality of Care in Nursing Homes* (1986).

<sup>4</sup> A GAO report from 1982 documented the same problem. "Often . . . mental conditions remain undiagnosed because nursing homes are not equipped and have little incentive to provide mental health diagnosis or treatment. Left undiagnosed and untreated, mentally ill nursing home residents have limited

Reconciliation Act of 1987 was a major policy reform directly addressing the lack of appropriate mental health services in nursing homes. Despite regulations requiring mandated screening for mental illness, studies have reported low rates of implementation of recommended mental health services. A study conducted in 1997 found that among nursing home residents with an identified psychiatric diagnosis, only 36% received any mental health visits that year. More recent data indicate that approximately one-fifth of all nursing homes receive a deficiency citation each year for problems with or a lack of mental health care as part of the federal survey and certification process. As recently as August of this year, the Government Accountability Office published a report stating that Illinois had the second highest number of poorly performing nursing homes in the country.<sup>5</sup>

Equip for Equality's onsite observations and investigations of the quality of mental health services provided by nursing homes confirm the findings identified in the studies cited. Not only do nursing homes routinely fail to provide meaningful mental health services, often there are simply none. Our investigation of programs that nursing homes send people to, along with the investigations of other investigatory agencies, documented that since 2002, millions of taxpayer dollars have been wasted in payment of services allegedly provided by doctors to address the mental health needs of those involved in the programs. In spite of the amount of public funds that have been spent, the services and programs did not resemble any form of actual mental health services. Rather, as one program administrator best described, the programming offered was "abysmal" adding that "programming" at many of the sites consisted of nothing more than smoke filled rooms, television groups, and poorly trained staff.<sup>6</sup>

The key to improving the State's mental health system is to increase funding and support of quality community mental health services that are readily available and easily accessible. While currently resources are few, there are some community programs that have been successful in maintaining people with schizophrenia, bipolar affective disorder, and other serious mental illnesses in the community. With sufficient resources, the best community programs could expand these activities, which, in turn, would alleviate many of the problems associated with mental illness. Although at present such resources are scarce, there are things that can be done for individuals with mental illness (such as crisis intervention teams, intensive outreach, and peer programs). These measures seek to engage individuals with mental illness, including homeless people with mental illness, who are not connected to any services and to develop a relationship of trust with them, so they choose to become involved in treatment. Individuals who seek treatment voluntarily are far more likely to benefit from the treatment, thereby improving their long-term prognoses.

---

prospects for improvement." U.S. Gen. Accounting Office, *The Elderly Remain in Need of Mental Health Services* 5 (1982).

<sup>5</sup> U.S. Government Accountability Office, *Nursing Homes: CMS's Special Focus Facility Methodology Should Better Target the Most Poorly Performing Nursing Homes, Which Tended to Be Chain Affiliated and For-Profit* 15 (2009).

<sup>6</sup> Equip for Equality, *Ensuring the Safety of Children and Adults with Disabilities: Filling the Gaps in Illinois' System that Investigates Allegations of Abuse and Neglect* (2008).

As currently structured, the mental health system in Illinois does not meet the needs of the individuals it is intended to serve. To create and sustain an effective, cost-efficient and person-centered long-term care system, it is necessary that the State: 1) decrease its reliance upon institutional care for people with mental illness; 2) increase its funding and support of community mental health services; 3) take a proactive rather than reactive approach to mental health care; 4) provide people with mental illness with a variety of services to meet their needs, including adequate acute care when needed, that will allow them to live more productive, fulfilling lives in the community; 5) provide flexible and individualized pharmaceutical care; and 6) maximize its ability to capture federal Medicaid dollars for the mental health services it provides.