



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

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

### **Comments of Equip for Equality in Response to Preliminary Recommendations of Governor's Nursing Home Safety Task Force**

Chicago, Illinois  
January 21, 2010

#### **Introduction**

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 and 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 and direct advocacy to address abuse and neglect of people with disabilities. We wish to thank the Governor and members of the Task Force for their efforts to improve the health, safety, and well being of individuals residing in nursing homes in Illinois. As the work of the Task Force has clearly demonstrated, this issue is multi-faceted and complex. We appreciate being given an opportunity to provide comments in response to the Task Force's preliminary recommendations.

#### **General Comments**

Equip for Equality supports the overall goal of the Task Force to recommend and implement changes that will enhance the quality of care provided to people with disabilities and safeguard them from abuse and neglect. However, it is critical that in doing so equal attention is given to the needs of all persons residing in nursing homes, not just a select population. Many of the problems with Illinois' long term care system identified before this Task Force are long-standing and complex. Illinois has systematically failed to provide adequate community-based resources for people with mental illness that would allow them to live full, productive lives in the community. Moreover, for those individuals with mental illness requiring a nursing level of care, appropriate treatment and services to address *all* of their needs has been minimal or lacking in the institutions to which they are confined. To presume that these problems can be adequately examined, let alone addressed, at the end of a four-month period is neither realistic nor responsible. While the need for reform is unquestioned, it is imperative that the Task Force takes sufficient time to develop and implement

*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@EQUIPFOREQUALITY.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.EQUIPFOREQUALITY.ORG](http://WWW.EQUIPFOREQUALITY.ORG)

recommendations that are meaningful and capable of producing the necessary and sustainable change.

Numerous advocates, providers, and experts testified that the Task Force should focus on ways in which people with mental illness could be served more effectively and eliminating the unfounded stereotype that people with mental illness are violent and in need of segregation. Despite this testimony, a majority of the preliminary recommendations focus only on how to keep elderly residents of nursing homes safe from those with mental illness. The recommendations utterly fail to recognize that people with mental illness are far more likely to be victims of abuse, often at the hands of nursing home employees, than the perpetrators. Prevention of abuse of individuals with mental illness in nursing homes and other settings should be included in the recommendations. The preliminary recommendations totally fail in this regard and thus promote further segregation and stigmatization of people with mental illness.

Furthermore, many of the recommendations, particularly those concerning nursing home standards of care, are duplicative of existing Illinois law. The real problem lies in the lack of enforcement of those laws. Historically, nursing homes in violation of these laws have not faced any repercussions. Unless and until the state commits to enforcing nursing home standards, there is no purpose in creating new ones. Enacting additional laws and regulations without a corresponding commitment to compliance/enforcement will not fix the underlying problem.

Although the Task Force heard testimony from a variety of service providers and advocates about community programs that have been successful in treating those with mental illness, the preliminary recommendations contain very few of these proposed measures. In fact, the preliminary recommendations contain virtually none of the numerous recommendations put forth by those with expertise in treating mental illness. This only reinforces the impression that the true focus of the Task Force is limited to addressing safety concerns related to seniors in nursing homes and does not include a meaningful examination of Illinois' failure to meet the needs of people with mental illness who, as a result of this failure, are warehoused in nursing homes.

We share the concerns expressed by others about the lack of detail in the preliminary recommendations relating to responsibility for implementation and funding sources. Unless adequate funding is secured, the recommendations will be meaningless.

### **Specific Comments**

#### **I. Improving the Pre-Admission Screening & Background Check Process**

This section of the recommendations is primarily focused on separating people with mental illness from elderly residents of nursing homes, resulting in more segregation and stigmatization.

*Recommendation #1, Ensure that individuals have a care plan that facilitates their highest level of independent functioning in the setting most appropriate for the plan. This is required under current law. However, if the thrust of the recommendation is that there will be increased monitoring of the implementation of the care plan so that individuals may live in the least restrictive setting, then Equip for Equality strongly supports it.*

*Recommendation #3, Include a component identifying “risk of harm” to others for inclusion in the pre-admission assessment process. This recommendation is devoid of definition and detail. What does “risk of harm” mean? How will it be assessed? Has the Task Force investigated/identified any best practices for making this type of assessment? Our concern is that this assessment will result in singling out and thus further stigmatizing those with mental illness and not actually ensure better outcomes.*

*Recommendation #4, Reassess nursing home resident’s clinical needs early in their stay and when there is a status change, to ensure that they are in the most community integrated setting. The Nursing Home Care Act and its accompanying regulations already require this. The problem is that this requirement has frequently been ignored by nursing homes and is not being enforced by the Department of Public Health.*

*Recommendation #10, Authorize nursing homes to admit residents on a ‘provisional basis’ when background check and criminal analyses are not available prior to admission. We do not support this recommendation. Procedures already exist to address this issue and provide protections to both the resident and the facility.*

*Recommendation #11, Allow the criminal analysis on an identified offender to include both convictions and arrests in Illinois and out-of state. Under no circumstances should arrests that do not result in convictions be included or considered. To use an arrest, standing alone, as a possible basis for denying an individual admission to a facility would be a violation of his/her constitutional and civil rights.*

## II. Raise and Enforce Higher Standards of Care in All Settings

Given that the General Accountability Office recently released a report stating that Illinois had the second highest number of poorly performing nursing homes in the country, we strongly support efforts directed at obtaining higher standards of care. We agree with the recommendations that will encourage the enforcement of existing law, in order to ensure better care, and have some specific comments.

*Recommendation #1, Require facilities that provide services to people with Severe Mental Illness (SMI) to obtain a newly-created certificate of compliance with state mental health standards. Subchapter S of the Nursing Home Regulations already requires nursing homes and other facilities to provide certain levels of mental health services and to have the expertise in order to do so. Although we support enforcement of the current rules requiring that facilities that receive reimbursement for providing mental health services are actually providing those services in order to eliminate fraud and*

ensure better treatment for people with mental illness, we do not believe that an additional certification requirement is necessary to accomplish these goals. The Departments of Public Health and Healthcare and Family Services do not have the mental health expertise needed to develop and enforce standards designed to ensure adequate treatment of those with serious mental illness. It is unclear how this recommendation would ensure or enhance proper treatment of those with serious mental illness.

*Recommendation #2, The state will employ additional surveyors designed to regulate these facilities with appropriate training in mental health standards.* We agree that the state should employ surveyors with mental health expertise when surveying facilities providing mental health services to ensure compliance with the current standards.

*Recommendation #3, Provide DPH with greater authority to revoke the license of nursing homes that repeatedly violate state regulations. Allow Illinois Department of Public Health (DPH) to sanction and increase fines to nursing homes that violate certain regulations, without the obligation to prove harm to a resident.* While DPH already has such authority, if this recommendation will enhance DPH's ability to effectively enforce current law and ensure that quality care is provided in nursing homes, we support it. For many years, DPH, in large part due to understaffing, has been unable to ensure continued compliance with the standards in the Nursing Home Care Act and accompanying regulations. DPH should use its authority to revoke the license of nursing homes that are found to be repeatedly in non-compliance, although current law largely already provides for this. We also fully support the idea that fines to nursing homes should be increased, because it is well documented that fines must be high enough to ensure that nursing homes do not consider them simply the "cost of doing business" and will comply with required standards of care.

*Recommendation #4, Increase the nursing home fees to fund additional costs related to assuring the safety of nursing home residents by employing additional regulators, ombudsmen, and ISP staff.* We support this recommendation, particularly because it is the only recommendation of the 27 that has a revenue source. Funds should also be available for legal services for nursing home residents whose rights are violated.

*Recommendation #5, Establish protocols for DPH and DFPR to report misconduct by nursing home administrators or other licensed staff.* Although we are concerned about the lack of detail, including the absence of a definition of "misconduct", this may be an important reform if it includes making the investigations and proceedings of the Department of Financial and Professional Regulation reasonably available to the public. For many years, it has been difficult to follow up or obtain any information about DFPR's complaint process and sanctions because of confidentiality provisions. We believe that DFPR should make this information public, in order to ensure accountability for those it licenses.

*Recommendation #9, Require nursing homes to regularly train staff on how to provide appropriate care and treatment to all of its residents.* This is already required under

current law. The fact that nursing homes are failing to train staff on how to care for those it serves is not a result of lack of regulation in this area, but simply a failure to enforce compliance. In addition, without further detail it is difficult to determine whether it will achieve any real improvements in the quality of life for those residing in nursing homes.

### III. Expand Home & Community Based Housing Options for People with Serious Mental Illness

Unfortunately, the recommendations contained in this section, which in our opinion, would do the most to solve the problems identified by so many providing comments to the Task Force, are the fewest in number and include the least amount of detail. The failure to more fully explore and develop recommendations regarding increased housing options for people with mental illness underscores the perception that the primary focus of the Task Force is to address the health and safety of elderly nursing home residents, not those with mental illness. It appears that the Task Force did not heed any of the recommendations made about ways to effectively serve those with mental illness in the community.

*Recommendation #4, Maximize federal financial resources for home and community-based options, using supported living waiver and/or Medicaid home and community based services waiver.* One way the State can maximize federal financial resources is by moving individuals out of Institutions for Mental Diseases (IMDs), which are funded 100% by the state. Federal law prohibits the state from recapturing any federal funds for the amount spent on IMDs. If Illinois moved the more than 5,500 individuals residing in IMDs and instead spent these funds on community mental health services, it would be able to recoup a significant amount of the cost in federal Medicaid dollars. Any discussion of maximizing federal resources should include a discussion of the large amount of money the state loses by housing individuals with mental illness in IMDs instead of providing community-based options. It is critical that the state develop and adequately fund quality and readily accessible community mental health services. As previously noted, successful community-based programs for people with serious mental illness exist and need to be expanded using any and all financial options available to the State. The final recommendations of the Task Force should include concrete provisions for making this a reality.

### IV. Issues still under consideration

The issues still under consideration contain some of the most important subjects for the Task Force. We are very interested in hearing any additional recommendations that stem from additional consideration of the topics listed.

*Issue #1, Determine how the Mental Health Code applies to nursing facilities and home and community based settings.* This issue does not need any further consideration because of the Illinois Appellate Court's decision in *Muellner v. Blessing Hospital*, 335 Ill. App. 3d 1079 (4th Dist. 2002). This decision held that residents of nursing homes are

entitled to the protections offered by the Mental Health and Developmental Disabilities Code. The state of Illinois should enforce this decision.

*Issues #2 and #3*, relating to segregated “specialized programs” for people with mental illness is contrary to the community integration mandate of the Americans with Disabilities Act and the Supreme Court’s *Olmstead* decision. The State already spends a disproportionate amount of its mental health budget on providing services in segregated settings rather than in the community. Creating additional segregated settings instead of investing in community resources that facilitate recovery and enable successful community living is both counterproductive and illegal. It also serves to further stigmatize people with mental illness.

*Issue #4, How do we properly monitor use of psychotropic drugs for people with serious mental illness served in state-funded programs and settings?* This issue requires additional consideration and is much broader than identified. The issue of delivery of and access to appropriate medication for treating mental illness is complex and extends beyond administration in state-funded programs. Equally important is the ability of people with mental illness to access and maintain medications that work for them. Limiting or excluding certain medications based upon formularies, without regard to the effectiveness and/or serious side effects to the individual, can be detrimental to the health of the individual and, in the long run, more costly to the State.

*Issue #6, How do we inform and empower the public about nursing home safety?* Part of the Task Force’s effort in this regard should be educating the public about the facts of mental illness and dispelling the myths. In Illinois, 2.6 to 3.9 million people (20-30% of the population) will be affected by mental illness in any given year, compared with 92,000 people residing in nursing homes. As we noted previously, people with mental illness are far more likely to be abused than be abusers. While the goal is certainly to ensure that all individuals with disabilities receive appropriate care in the most integrated setting, more of an effort should be made to educate and empower the public about people with mental illness who are capable of recovery with appropriate treatment and supports. This would go a long way toward reducing the stigma of mental illness.

It is our understanding that the recommendations will be revised before final submission to the Governor and possible implementation of the proposed reforms. We urge the Task Force to reconsider the primary focus of the recommendations, and consider putting forth more precise solutions that will effectively protect and serve not only seniors in nursing homes but also those with mental illness in Illinois.

Thank you for your consideration.