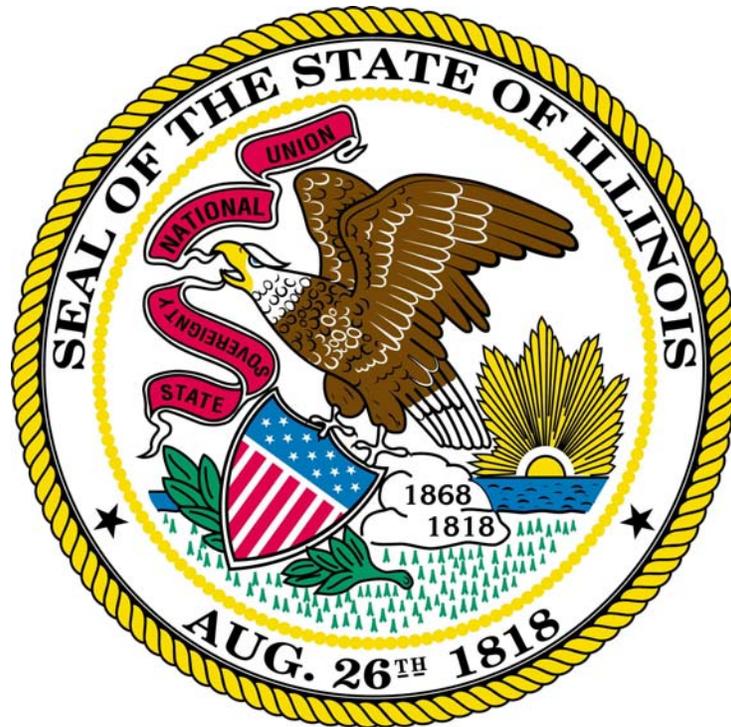


# NURSING HOME SAFETY TASK FORCE



FINAL REPORT  
GOVERNOR PAT QUINN

FEBRUARY 19, 2010



February 19, 2010

Dear Governor Quinn:

On October 3, 2009, you charged this task force to ensure the safety of Illinois nursing home residents. In the face of news reports of violence and inadequate and even harmful treatment, you called on us to investigate the causes and recommend ways to protect our state's most vulnerable citizens. We approached this task as openly and transparently as possible, conducting seven open meetings at which we invited the public to comment, and establishing a web site where all information submitted to the task force is available. We committed ourselves to examine the issues objectively and dispassionately.

Today we submit our final report, confident that our recommendations will lead to a system of long-term care in Illinois that allows each individual to achieve his or her highest level of independent functioning and assures that each receives that care in the most appropriate community-based setting. Emphasis on recovery, therapeutic care, and adequate appropriate housing in the community will significantly reduce the number of younger nursing home residents living with vulnerable older adults in institutional settings and thus significantly reduce the potential for violent interactions.

Our four months of investigation and public meetings included the testimony and comments of approximately 50 nursing home residents, owners, researchers, advocates, and experts from a wide array of disciplines. You should know that every sector involved in this vast and complex issue participated constructively and enthusiastically. There were never two sides to this issue, never a moment when anyone suggested maintaining the status quo. We found remarkable consensus not only on the gaps and weaknesses in the current system of long-term care, but also on the fundamental reforms needed to correct these problems. The task force members visited multiple nursing homes, and researched the laws and regulations of Illinois and other states. We believe that enacting the recommendations in this report will not only increase the safety for nursing home residents, but also help build better systems of treatment for all people who need care in Illinois because of physical or mental illnesses, disorders, or disabilities.

The fact that nursing home residents, owners, advocates, and service providers all support the fundamental changes in our system creates a unique opportunity for Illinois to act quickly and boldly to assure that these problems do not reoccur. Thank you for giving the task force the opportunity to serve our state in this critical task. We look forward to completing the work of implementing these recommendations, for the good of all Illinoisans.

Respectfully submitted,

Michael Gelder, Chair  
Governor Pat Quinn's Nursing Home Safety Task Force

## Table of Contents

<b>EXECUTIVE SUMMARY .....</b>	<b>1</b>
<b>RECOMMENDATIONS.....</b>	<b>3</b>
A. Pre-Admission Screening and Background Check Process .....	4
B. Set and Enforce Higher Standards of Care.....	9
C. Expand Home and Community-Based Residential and Service Options.....	14
<b>NEXT STEPS .....</b>	<b>18</b>
A. Immediate Implementation .....	18
B. Legislation.....	18
C. Rules.....	18
D. Policy .....	19
E. Budget.....	20
F. Workgroups .....	21
<b>APPENDIX 1: TASK FORCE AGENCIES.....</b>	<b>I</b>
<b>APPENDIX 2: BACKGROUND .....</b>	<b>IV</b>
<b>APPENDIX 3: TASK FORCE PROCESS .....</b>	<b>XII</b>
<b>APPENDIX 4: HIGHLIGHTS OF PUBLIC TESTIMONY .....</b>	<b>XVIII</b>
<b>APPENDIX 5: GLOSSARY .....</b>	<b>XXVI</b>

## EXECUTIVE SUMMARY

In response to recent reports of violence, neglect, and sub-standard care in Chicago and downstate nursing homes, the governor charged his senior health policy advisor to convene a task force of executive-branch agencies that serve, protect, fund, arrange for, license and regulate nursing homes, their administrators, and other providers of care. To accomplish this, the task force carefully explored each agency's current responsibilities and potential for expanded efforts to assure safety. The task force convened seven public meetings where it received testimony from more than 50 advocates, experts, provider associations, nursing home residents, and operators, as well as community-based housing providers and developers.

There was universal agreement that nearly all the state's nursing homes, as well as the state's regulations governing them, are designed for older adults who cannot care for themselves. These homes are not appropriate for younger residents with serious mental illness, especially those who also suffer from alcohol or other substance dependencies. The mix of vulnerable and potentially aggressive residents in close quarters is toxic, as the tragic reports of violence highlighted.

Testimony directed the task force's attention to who is admitted to nursing homes, what care and treatment they receive, and what residential alternatives exist in the community. Everyone agrees the state must do a better job preventing residents with violent criminal histories from being admitted to nursing homes that serve vulnerable older adults. There is also remarkable consensus that many people currently admitted to nursing homes with serious mental illness would be better cared for in specially designed and monitored community residential settings. To address this, the task force recommends that the assessment and referral process be significantly enhanced to assure that hospital patients are referred to the residential setting most appropriate for their needs. In the majority of cases, the most appropriate setting will be supported housing in the community. All nursing homes that care for people with serious mental illness must obtain a new special certification. Their residents must be regularly reassessed to assure that they are transitioned to the community as quickly as their condition permits.

The task force also recommends measures to improve the care and treatment for those who need nursing home care. The lower quality of homes serving predominantly minority residents is unacceptable. Adopting and enforcing higher staffing standards for all nursing homes will address this. Older adults, as well as those with serious mental illness, will benefit from more nurses and rehabilitation staff. In addition, recommendations assure that any home that accepts people with mental illness has appropriate and specifically trained staff who can follow care plans designed to help residents achieve their highest level of independent functioning and to prepare them for more appropriate residential settings.

Recommendations also reflect the consensus that the state lacks adequate home and community-based services for older adults as well as people with mental illness. That shortage explains the state's over-reliance on nursing homes. Significantly expanding residential options will assure that nursing homes only serve those who require 24-hour care.

While the details can be challenging, the task force is confident that the array of recommendations will result in a system that uses public and private resources much more

effectively. Better assessments will prevent violent offenders from being mixed with vulnerable older adults. They also will assure that patients with mental illness are referred to the setting most appropriate for their needs and, if admitted to a nursing home, receive care intended to help them rehabilitate, recover, and resume a productive role in society. Higher standards will help restore the public's confidence that every nursing home is a safe, secure facility where adequate and appropriately trained personnel provide quality care around the clock. Additional community-based facilities will provide the alternatives needed by the enhanced assessment process, to avoid loading nursing homes with people who do not need to be there.

Even in this economic downturn, current spending for institutional long-term care, if redirected, can fund many of these recommendations. In addition, the task force calls for an increase in the fees paid by nursing homes to assure the state has adequate resources to carefully regulate and monitor them.

Each of the participating state agencies has taken on specific assignments to convene and participate in workgroups to implement specific recommendations. Some changes already have been implemented. The initial workgroups will report their implementation efforts by April 30<sup>th</sup>, 2010.

## RECOMMENDATIONS

Through a series of incremental decisions over the past several decades Illinois has inadvertently exposed vulnerable residents of nursing homes to potential violence. To improve the safety of all nursing home residents, the state must address who is in nursing homes; the supervision, care, and treatment they receive; and the availability of community-based residential alternatives.

During hearings conducted by Gov. Quinn's Nursing Home Task Force, dozens of stakeholders described state policies that put residents at risk and recommended changes that will result in better outcomes as well as greater safety. The task force learned that many of the younger adult nursing home residents are suffering from serious mental illness. We also learned that nearly all people with mental illness who are covered by Medicaid are admitted to nursing homes when they are discharged from the hospital. The federal Omnibus Budget Reconciliation Act of 1987 requires states to screen hospital patients and divert people with mental illness into appropriate residential settings in the community. Unfortunately, Illinois funds so few supportive housing units that nursing homes continue to be the default option. The combination of younger, active residents with older, frail adults leads to possibilities for violence that could be avoided. This mix of populations becomes more toxic when nursing home residents with mental illness do not receive the care and treatment essential to avoid anti-social behaviors.

The recommendations that follow apply to people with mental illness who occupy more than 10,000 beds in nursing homes once reserved exclusively for frail older adults. The task force's focus on people with mental illness does not reflect any assumption that people with mental illness have a higher proclivity for violence. Indeed, evidence underscores the fact that people with mental illness are much more often the victims of violence rather than perpetrators. But the relatively few mentally ill nursing home residents who exhibit violent behavior, most of them younger adults, have caused significant harm to other residents.

These recommendations call for significant changes and improvements in assessing people before placing them in nursing homes with 24-hour care. We need to determine whether individuals can be appropriately monitored and treated in supportive housing. And we must ensure that the nursing home has the appropriate information when the resident arrives, to assure the safety and security of everyone in the home. Simultaneously, we must raise the standards of nursing home care so that everyone receives the treatment appropriate for their condition. At the same time, we must offer more community-based residential options, so people with serious mental illness can successfully transition to a setting where they have more independence.

It doesn't do any good to carefully assess and refer many people with mental illness for community placement if there aren't enough community alternatives available. Likewise, funding hundreds of new community residential units would be futile if we don't have an assessment process robust enough to place people appropriately. And we must be certain that every one of the thousands of people with serious mental illness currently in nursing homes receives the treatment they need.

Based upon the foregoing, the findings and recommendations of the task force fall into three broad categories: (A) Enhance the Pre-Admission Screening and Background Check Process, (B) Set and Enforce Higher Standards of Care, and (C) Expand Home and Community-Based Residential and Service Options.

## **A. Pre-Admission Screening and Background Check Process**

**1. Ensure that all individuals in need of daily assistance, whether in nursing homes or the community, have a care plan that helps them function as independently as possible in the least restrictive setting.**

**Rationale:** Helping individuals recover and achieve their goals for as much independence as possible should be the basis for every care plan.

Care plans also are essential to identify and address the need for special monitoring and care for those who demonstrate anti-social behaviors, including violence. Violent behaviors reflect a breakdown in the treatment and care of individuals with dementia or substance or alcohol abuse disorders, coupled with certain mental illnesses. Care plans must provide for close supervision and monitoring of such individuals to assure the safety of residents, staff, and visitors to nursing homes and community settings.

Mental health experts unanimously advised the task force that nursing homes are inappropriate places to help individuals recover from mental illness. Living in an institutional environment creates dependencies that thwart psychiatric rehabilitation efforts, which in turn prevent transition to more independent functioning in community settings. This recommendation will require expanding home and community-based housing options for people who have serious mental illness, as well as expanding community-based mental health services, as recommended in section C below.

**2. Enhance the pre-admission screening for mental illness and increase referrals to community-based settings, consistent with care needs.**

**Rationale:** Since 1987, federal law has required that people with mental illness discharged from a hospital be assessed to determine if they require skilled or intermediate care. Only in that case should they be placed in a nursing home. Pre-admission screenings are currently conducted in Illinois, but the vast majority of hospital discharges result in nursing home placements. Deficiencies in the assessment instrument and inadequate training of contracted screeners were cited as causes for the disproportionate use of nursing homes.

**3. Reassess all residents with serious mental illness who are admitted to a nursing home within the first 90 days after admission and again within six months.**

**Rationale:** Evidence supports the value of regular reviews of nursing home residents with mental illness to identify those who can be transitioned to community settings. These reviews are

essential to assure that care plans reflect recovery and independence goals, and are being followed by the nursing homes. This will assure rapid reintegration to community-based alternatives when the need for skilled nursing support is no longer clinically necessary.

**4. Re-train screeners to ensure that they are aware of community-based services and alternative living arrangements appropriate to meet both treatment and rehabilitation needs.**

**Rationale:** The Department of Human Services contracts pre-admission screenings and resident reviews to a large number of community vendors. Testimony revealed that screeners are not fully aware of existing community options nor that those settings could be appropriate for people with serious mental illnesses. When screeners are given comprehensive training in recovery principles, they are more likely to develop a care plan that helps residents transition to community living.

**5. Train hospital discharge planners to utilize community-care settings.**

**Rationale:** Testimony revealed that hospital discharge planners often are expected to arrange the discharge with only a few hours notice. Given the complexity of care needs, such short notice encourages nursing home placements, which are much easier to arrange than community residential placements.

**6. Expand the existing pre-admission screening instrument to include criteria addressing “risk of harm” to others.**

**Rationale:** All nursing home residents, staff, and visitors should be protected from violence. While the task force is aware that people with mental illness are most often victims of violence rather than perpetrators, there is considerable research that some illnesses, when combined with consistent alcohol or substance abuse, may increase the likelihood of violent behaviors when not treated appropriately. The revised assessment instrument will include questions that assist screeners to determine whether the client poses a risk of harm to others. This information will be shared with nursing homes or community agencies upon hospital discharge and incorporated into the interim treatment plan. Thereafter, it is the nursing home’s responsibility to update the risk assessment and incorporate risk mitigation strategies into the care plan, as necessary.

**7. Require hospitals to initiate a criminal background check at the beginning of the hospital discharge planning process.**

**Rationale:** While Illinois has led the nation in requiring criminal background checks upon admission to nursing homes, the value of the checks is diluted if they are not completed before the resident arrives at the home. Delaying the background check also delays the subsequent criminal history analysis, which provides information the nursing home needs to properly treat the resident and protect the safety of others.

The vast majority of nursing home residents are admitted following discharge from a hospital. According to testimony, the average length of stay in a hospital preceding discharge is 5.6 days. If the discharging hospital requests the background check from Illinois State Police electronically, ISP processes it within 24 hours. If the hospital patient is ready for discharge prior to the receipt of the criminal background check results, the hospital can discharge the patient and forward the results as soon as they are available to the referral nursing home or community setting.

**8. Require hospitals and nursing homes to electronically submit criminal background check requests to Illinois State Police, with copies to the Department of Public Health.**

**Rationale:** Paper-based requests sent via U.S. mail take much longer to process because they must first be sent to a payment-processing center before being forwarded to the ISP. Hospitals and nursing homes that submit the background check electronically will receive the reports in 24 hours. The cost for an electronic background check is \$10, a savings of \$6 over the paper-based method. Copying DPH will allow the department to monitor the background checks. DPH will crosscheck the criminal background results against Medicaid claims information to determine whether the background checks are complete.

**9. Authorize the Department of Public Health to sanction nursing homes for failure to initiate a criminal background check within the statutorily required timeframe, regardless of ability to prove that the failure resulted in harm to an individual.**

**Rationale:** Nursing facilities are required to request a criminal background check from ISP for a new resident within 24 hours of admission. The task force recommends revising the definition of Type A and Type B violations so DPH can sanction facilities that violate a specific number of sections of the Skilled Nursing and Intermediate Care Facilities Code. Currently, Type A and B violations are tied to significant resident harm or death, as opposed to failure to comply with the code. Allowing DPH to levy fines for failure to comply with code requirements will deter nursing homes from violating the state's minimum standards.

**10. Authorize nursing homes to admit residents on a provisional basis when background checks and criminal history analyses are not available prior to admission.**

**Rationale:** Under current law, nursing homes are required to serve anyone they admit unless they engage in an involuntary discharge process. This sometimes discourages nursing homes from transferring residents who pose a risk to the general population. Generally, this is an important safeguard to prevent nursing homes from discriminating against certain types of residents or conditions and avoids serious disruptions in care when residents have to move.

The task force recommends establishing a narrow exception so nursing homes could accept a resident on a provisional basis, until all the criminal background check and criminal history analysis are available, and then discharge the resident without going through the involuntary discharge process. If the new resident is determined to be an identified offender for whom the nursing home is unable to provide the necessary security and treatment measures, the facility will be able to transfer the resident to a nursing home certified as described in Recommendation 17. Discharges under this new provision would require the pre-admission screening team to assure residents are transferred to an appropriate facility or setting for their needs.

**11. Determine a mechanism to retrieve information about outstanding warrants, recent arrests on suspicion of a felony, and prior convictions in other states.**

**Rationale:** The Identified Offender program and the Uniform Conviction Information Act restrict ISP from releasing information other than prior Illinois convictions to the nursing homes. Additional information may be necessary for the nursing home to develop an appropriate care plan. More analysis is needed to determine whether this information is valuable and, if so, how the additional criminal background information can be retrieved within the constraints of federal law.

**12. Engage the Illinois State Police, the Attorney General's Office, Clerks of the Court, and Department of Public Health to determine how to conduct a criminal history analysis of identified offenders in a timely manner.**

**Rationale:** Many criminal history analyses are not completed on time and others contain incomplete information. Nursing homes are required to initiate the criminal background check by submitting a request to the Illinois State Police. ISP conducts the check and sends the results to the nursing home. When there are criminal convictions covered under the law (210 ILCS 45/1-114.01), the nursing home must notify DPH, which then conducts a more extensive criminal history analysis by searching conviction and sentencing information to gain insight into the

resident's potential for criminal behavior. Although the DPH process must be completed in 14 days, many are not completed for months if the background check request is not initiated on time or a fingerprint check is required. In other cases, lack of cooperation from local jurisdictions prevents DPH from including all the desired information in the analysis. The task force recommends engaging the Illinois State Police, the Attorney General's Office, Clerks of the Court, and DPH to resolve this problem.

**13. Engage the Illinois State Police, the Attorney General's Office, Clerks of the Court, and local law enforcement agencies determine the appropriate response to residents with outstanding warrants.**

**Rationale:** Generally, law enforcement agencies have the authority to arrest an individual with an outstanding warrant. However, some warrants have geographic limitations set by the issuing jurisdiction. Nursing home residents with outstanding warrants can only be prosecuted by the jurisdiction that issued the warrant. There also is a problem with how to handle individuals with outstanding warrants once they are identified. Many are considered low risk, and the local law enforcement agency may conclude that it cannot accomplish much by taking them from a nursing home to a county jail. Recent raids on nursing homes also demonstrated that many of those with outstanding warrants were not identified as offenders by the initial criminal background checks.

**14. Create an accessible, secure database to capture, report, and facilitate the exchange of appropriate criminal history and criminal analysis data on identified offenders.**

**Rationale:** Every time a resident determined to be an identified offender is admitted to a nursing home, the home must initiate a criminal history analysis of that resident. A centralized database maintained by DPH of appropriate parole and probation information using an offender's unique state identification number would allow DPH to compile the criminal history analysis for nursing homes in-house, eliminating the need for an outside vendor. Access to this database would only be available to state agencies and nursing facilities.

**15. Expand the content of the Consumer Choice Information Report (CCIR)**

**Rationale:** Consumers have complained to the Office of State Ombudsman that the CCIR web site is inadequate to help families compare nursing facilities. CCIR is a joint effort of the Attorney General's Office, Department on Aging, long-term care professional associations, and advocacy organizations to help families with critical information find the appropriate long-term care facility for their aging loved ones.

Expanding the content of the Consumer Choice Information Report will improve the safety in nursing facilities by making the nursing home industry more transparent.

## **B. Set and Enforce Higher Standards of Care**

### **16. Require all nursing homes that provide care to people with serious mental illness (SMI) to obtain a certificate of compliance with state mental health standards.**

**Rationale:** Too many residents with mental illness languish in nursing homes without appropriate therapy or intervention. Nursing home regulations were written for facilities primarily serving older adults and others who need continuous assistance with activities of daily living. A new certificate of compliance will require nursing homes that serve people with serious mental illness to meet enhanced standards consistent with the mental health code. Subparts S and T of the Skilled Nursing and Intermediate Care Facilities Code will incorporate appropriate elements of the Mental Health Code not already included. These standards will define resident care, and requirements for staffing, training, physical plant, mental health programming, alcohol and substance abuse treatment, etc. This certificate of compliance will also apply to the remaining Institutions for Mental Diseases, and will incorporate appropriate standards now contained in Subparts S and T of the rules.

Nursing homes that admit higher-need residents must employ staff that has: (a) expertise in rehabilitation, (b) credentials and history of work experience, and (c) specific performance competencies. Only certified nurse aides who are trained to treat the mentally ill should be permitted to work in facilities that serve SMI residents. DPH should develop and implement certification requirements and criteria for individuals and organizations providing training or continuing education to nursing facility staff.

Requiring a special certificate is consistent with the U.S. Department of Justice admonition that Illinois not recommend separate facilities for people with serious mental illness.

### **17. Establish a new certificate of compliance for nursing homes that offer specialized programs and facilities for people who are at risk of harm to others.**

**Rationale:** Some people with serious mental illness are extremely difficult to treat in regular nursing home settings. If left untreated, they may engage in problematic behaviors that result in repeated transfers to different nursing homes, homeless shelters, unlicensed facilities, and hospitals. This is a very expensive and frustrating process for everyone involved, including neighbors of these nursing homes.

This recommendation will require a new certificate of compliance for nursing homes that offer specialized programs and facilities for people who are a risk of harming others. DPH and DHS will develop rules that specifically identify the conditions under which individuals may be transferred to another facility or another wing of their current facility where they would not have contact with other vulnerable residents or their visitors. Such rules would be based on the

individual's observed behaviors and not on diagnosis or condition. Rules established under this Subpart would require facilities to develop, implement and maintain a plan to address the safety of individual residents. The rule would specify plan components – e.g., admissions policies, marketing practices, environmental issues, screening, facility-wide and individualized prevention and intervention strategies, etc.

**18. Strengthen the Department of Public Health's regulatory powers to assure high-quality care in every nursing home.**

**Rationale:** Under DPH rules the state must demonstrate harm to individual residents to penalize or revoke a nursing home license. We learned that some nursing homes routinely violate rules, such as the criminal background check; however, without the ability to prove harm to a resident, DPH cannot sanction the home. We also heard repeated testimony and read in DPH reports about “yo-yo” homes. These nursing homes are found non-compliant, bring themselves into compliance for a period of time, and then relapse until a complaint or annual review brings the violations to DPH's attention yet again. This absorbs a significant amount of DPH staff time and resources for monitoring, issuing citations, and handling appeals without achieving continuous compliance with state rules.

This recommendation will enable DPH to revoke the licenses of nursing homes that repeatedly violate state regulations.

**19. Increase the number of Department of Public Health regulators, Department on Aging Ombudsmen, Illinois State Police staff and Guardianship and Advocacy Commission's Human Rights Authority advocates, who will work together to assure the quality of care and safety of nursing home residents.**

**Rationale:** The regulation of nursing homes depends on staff from several departments to regularly visit homes, conduct annual reviews, respond to complaints, and advise homes on interpretation of rules. Due to persistent budget cuts, DPH nursing home surveyor staffing has been reduced in the last 10 years. The reductions in staff, supervisors, and trainers result in inconsistent interpretation of rules, lack of timely responses to inquiries, and delayed hearings to adjudicate fines and penalties. During that period the Long-Term Care Ombudsman program also lost full-time staff and scores of volunteers and no longer meets the federal standard of one full-time ombudsman for every 2,000 residents.

Additional DPH regulators are necessary, but are not the entire solution to better nursing home care. It is important to have a variety of organizations providing oversight for the nursing homes, including regulators, ombudsmen, police, advocates, and the interested public. Ombudsmen can be the eyes and ears of residents and gain their trust. Further, the Human Rights Authority can play an expanded role in protecting the rights of disabled nursing home residents by engaging volunteers to respond to complaints and working with the homes to develop an atmosphere in which the rights of all residents are respected.

**20. Increase penalties for violations of certain regulations.**

**Rationale:** Currently, facilities are fined minimal amounts compared to their annual revenues and for only the most egregious violations. Consequently, owners can budget fines as a cost of doing business and appeal, reduce, and delay their imposition, rather than bring their homes into compliance.

Raising the fines for violations will help motivate owners to comply with standards and ensure an increased quality of care.

**21. Refine and strengthen protocols for the Department of Public Health and the Department of Financial and Professional Regulation to report misconduct by nursing home administrators or other licensed staff.**

**Rationale:** The effort to assure high-quality care in all nursing homes requires the focused efforts of owners and administrators. Both parties must work together to deliver high quality consistently. Efforts to regulate homes must also focus on the homes' administrators. The Department of Financial and Professional Regulation (DFPR) is responsible for overseeing nursing home administrators and other licensed staff. Reports reviewed by the task force revealed that very few nursing home administrators were disciplined by the board despite hundreds of referrals, predominantly from DPH. DFPR can better target resources on problematic administrators if DPH refers cases that more closely indicate administrator responsibility. The two agencies are developing a protocol that will help DFPR target discipline on administrators associated with problems in homes cited by DPH.

**22. Establish agreements between the Department of Public Health and The Joint Commission to exchange information on problems and complaints.**

**Rationale:** The Joint Commission accredits 59 nursing homes in Illinois. It receives complaints about those facilities through the accrediting process. Sharing information about complaints would allow both entities to more efficiently improve nursing home quality.

**23. Require health care institutions, professional associations, professional liability insurers, state's attorneys, and state agencies to report misconduct on the part of nursing home administrators to the Department of Financial and Professional Regulation (DFPR).**

**Rationale:** The Medical Practice Act and Nurse Practice Act require licensees (doctors and nurses) to report misconduct to the DFPR. The same requirement should be applied to nursing home administrators.

**24. Remove the confidentiality restrictions that prevent the Department of Financial and Professional Regulation from referring misconduct cases to appropriate agencies.**

**Rationale:** By law, DFPR cannot refer cases of misconduct by administrators or other licensees to law enforcement or other agencies. Some egregious misconduct has not been pursued as a result.

**25. Provide whistleblower protection to nursing home administrators and staff who make good-faith reports of alleged misconduct.**

**Rationale:** Administrators and other licensed nursing home staff members are not necessarily covered under whistleblower protections when they accuse other staff of misconduct in a nursing facility. This discourages reports that could be very helpful to assure a safe and therapeutic environment in every facility.

**26. Increase minimum staffing requirements to levels consistent with federal government recommendations on nursing home care.**

**Rationale:** One of the most important determinants of quality in nursing homes is the level of staffing (the number of hours of high-level nursing care provided per resident per week). The federal government commissioned a study that proposed appropriate staffing levels (*see "Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes," Phase II Final Report, December 2001*). Illinois's standards are lower than the recommended levels. In more affluent areas of Illinois, nursing homes already meet or exceed these standards because of market demand. In less affluent areas, often with high minority populations, market forces are not creating high-quality nursing home care. By raising the staffing requirement levels, the state can ensure that every nursing home resident receives a high quality of care.

News articles and considerable testimony highlighted the disparate care and staffing between nursing homes serving predominantly poor and minority communities compared to those serving more affluent areas. This is partially explained by the different resources available when nursing homes have a mix of payers, including Medicare, private pay, and insurance, compared to those whose residents are covered only by Medicaid, the payer with the lowest rates. Nonetheless, no licensed facility should operate with insufficient staff or with insufficient training and supervision, regardless of payer.

**27. Provide technical and other assistance to nursing homes that adopt resident-directed care plans and convert nursing home capacity to home and community services.**

**Rationale:** Nursing home representatives advocate creating a separate unit outside the regulatory authority to provide technical assistance to enhance overall quality. Other states have implemented such units to assist nursing homes to change their culture by becoming more responsive to residents' needs. Such technical assistance units can also assist nursing homes to convert unused capacity to fill the need for expanded community resources, such as converting unused open space for adult day care or opening up dining rooms for community meal programs.

**28. Develop a policy to assure proper use of psychotropic drugs for people with serious mental illness and dementia.**

**Rationale:** The task force received many complaints about inappropriate use of psychotropic drugs. Family members said relatives were drugged to the point of unresponsiveness. Others testified that psychotropic drugs were repeatedly used for unapproved indications. Family members specifically complained about the misuse of prescription drugs when orders permitted the nursing home staff to administer the medications “as needed.” Reports show that only a few physicians prescribe the vast majority of psychotropic drugs for people with mental illness in nursing homes covered by Medicaid. The problem for regulators is that the home cannot be cited when there is a valid prescription signed by an Illinois licensed physician.

DFPR will work with DPH, the Illinois State Medical Society, the University of Illinois College of Medicine, and the Illinois Psychiatric Society to determine the standards, monitoring mechanism, and appropriate economic incentives to assure prescribing of psychotropic drugs is appropriate in all cases.

**29. Provide incentives for nursing homes to achieve accreditation with a national accreditation entity, such as The Joint Commission.**

**Rationale:** Few Illinois nursing homes with significant numbers of residents covered under Medicaid are accredited by The Joint Commission or other nationally recognized accrediting organizations. Accreditation offers the state and consumers the confidence that the facility has voluntarily achieved compliance with a set of standards and has passed periodic reviews conducted by peers from throughout the country.

Encouraging nursing homes to meet high quality standards established by respected accrediting organizations would provide another level of assurance for residents and families and allow more state staff time to be directed to non-accredited homes.

**30. Expand criteria for granting certificates of need and licenses to operate a nursing home to include a comprehensive review of all relevant factors, including complaint and violation history.**

**Rationale:** The quality of care in nursing homes is highly dependent on the owner's commitment to providing high-quality care. Current law limits the scope of review to only the most extreme instances of prior bad performance, allowing nursing home owners whose facilities have been repeatedly cited for serious problems to acquire other homes.

**31. Increase nursing home fees and bed taxes to cover costs of licensing and regulation.**

**Rationale:** Businesses in Illinois generally pay for the cost of their regulation through licenses and other fees. The current annual license fee for nursing homes is \$995. Fees have not increased for Illinois nursing homes since 2004. DPH has calculated that on average it costs the department

more than \$17,500 to complete an annual nursing home regulatory survey. Increases will be reported to the federal government, which regulates the amounts nursing homes can be charged.

The nursing home bed tax is another route to raising funds to cover increased costs of regulating and assuring high-quality care in nursing homes.

**32. Adopt payment methodologies to encourage high-quality care for residents with complex clinical conditions.**

**Rationale:** Effective in October 2010, nursing facilities will be required by the federal government to utilize a new instrument to assess resident care, the MDS 3.0. This instrument significantly changes the components used to assess a resident's needs. The release of these recommendations, coupled with the upcoming release of MDS 3.0, provide a unique opportunity for HFS to revise the way it sets rates.

**C. Expand Home and Community-Based Residential and Service Options**

**33. Expand permanent supportive housing options where tenants hold the lease, have full right of tenancy, and receive support services.**

**Rationale:** Permanent supportive housing is a model that best supports recovery of people with mental illness who want to live in a community setting. Both scattered-site and site-management models can be used to implement this recommendation. In a scattered-site model, the tenant holds the lease and has full right of tenancy under tenant/landlord law. The units are self-contained, with a kitchen and bathroom, and individuals have full rights of privacy. The individual chooses the support services he or she wants to receive. The site management model is similar, except that 24-hour support services and enhanced property management are available on the premises for residents who need more care.

Permanent supportive housing includes construction/development financing as well as services and rental/operating assistance funding.

The DHS Division of Mental Health funds 3,911 supervised and supported residential beds statewide. Concurrently, DMH funds 372 supportive housing units through the Supportive Housing Providers Association. DMH also supports 590 permanent supportive housing units through the Bridge Subsidy rental assistance program. The demand for such housing exceeds 10,000 units.

**34. Expand therapeutic housing options for individuals transitioning from a nursing facility to a more independent living situation.**

**Rationale:** This model recognizes that housing arrangements must be available to accommodate those who wish to leave an institutional setting but need more intensive therapy and monitoring before transitioning to permanent supportive housing.

Placement in these step-down settings would be limited to 24 months, and would allow the resident to gain the appropriate skills to transition to a more independent permanent residency. To avoid unnecessary referrals to long-term care, there should be an increase in development of alternatives for individuals who qualify. Qualified individuals would be those who have mental illnesses and who, based on a clinical assessment, do not have complicating medical health care needs that require nursing support, and are likely to respond well to community-based care.

**35. Expand housing resources and funding levels with the support of the Illinois Housing Development Authority.**

**Rationale:** Funding is needed for an enhanced array of evidence-based community service resources, including capital development programs and rental/operating assistance programs, such as IHDA's Rental Housing Support Program, HOME, and the Affordable Housing Trust Fund. Further, the state needs to continue to operate and expand its housing locator program (ILhousingsearch.org) to assist people seeking affordable housing in their communities. This is a free listing service for landlords as well as potential renters. In addition, IHDA needs to continue providing incentives to developers under its Low Income Housing Tax Credit program to set aside 10 percent of units in each approved development for people who need supportive housing populations, including those with mental illness.

However, there are many areas of the state where local service agencies do not have the capacity to develop affordable housing and private developers tend to gravitate towards less complex projects. IHDA is dealing with this problem by funding the Corporation for Supportive Housing to operate an annual Supportive Housing Institute to develop the capacity of local non-profit development teams.

The state should access other non-IHDA sources including HUD's Section 811 Supportive Housing Program for persons with Disabilities, HEARTH Act funding of permanent supportive housing, specialized set asides of HUD vouchers for people with disabilities through local housing authorities, as well as project-based and tenant-based vouchers that provide rental assistance.

### **36. Increase Medicaid services and rates for home and community-based services.**

**Rationale:** Provider groups testified that they are restricted in providing community mental health services by very low reimbursement rates under Medicaid and DMH programs, limitations on services covered, and burdensome administrative billing procedures.

There is a need to increase Medicaid-covered services, such as Targeted Case Management, to transition individuals identified as candidates for community reintegration, Assertive Community Treatment (ACT) or Community Service Team (CST) and/or other Medicaid Rehabilitation Option Services. Also, the state was urged to develop a supportive living facility demonstration for individuals with SMI. The state should explore opportunities to capture the higher reimbursement under the Money Follows the Person demonstration program to help transition nursing home residents into qualified supportive housing.

### **37. Maximize federal financial resources for home- and community-based options.**

**Rationale:** Many opportunities are available to use federal financial support to expand home and community-based service options. Despite limitations under the federal Medicaid statute, the Secretaries of HHS, through their waiver authority, have strongly encouraged states to expand home care options as an alternative to institutionalization since the Supreme Court's Olmstead decree in 1999. Home and community-based waivers under Section 1915 (c) of the Social Security Act are relatively routine and allow for federal reimbursement of costs to care for people in the community who would otherwise receive care in more expensive nursing homes. The state already has received waivers to cover services for frail older adults, developmental disabilities, and adults with physical disabilities. With substantial Medicaid spending for people with mental illness living in non-IMD nursing homes, the state would be able to meet the federal requirement that care in community settings be no more expensive than nursing home care. The Money Follows the Person demonstration program can assist in financing community services for the first year a nursing home resident transitions to a small residential setting. The program offers up to 82% percent federal cost sharing to transition someone who has lived in a nursing home for at least six months.

The federal government reimburses the state, currently at 62 percent, for services provided to people with serious mental illness who qualify for Medicaid and live in the community. There is no reimbursement for individuals aged 19-64 who reside in mental institutions. The state can realize significant savings when those residents transition to community settings.

### **38. Identify funding sources to permit nursing home residents who plan to transition into the community to keep more than \$30 per month as their personal needs allowance.**

**Rationale:** Nursing home residents retain only \$30 per month of their Supplemental Security Income for personal needs, the minimum allowed under federal regulations. This makes it very difficult for people living in an institution to save any money to establish living arrangements in the community and continues their dependence on social service agencies for assistance.

People with serious mental illness who are discharged from hospitals and nursing homes frequently are not employed and do not have the financial resources to allow them to secure affordable housing on the private market. To transition to community-based housing, these individuals generally need financial assistance.

## **NEXT STEPS**

The recommendations in this document are simply words on the page unless they are implemented. The departments of state government that comprised the task force are committed to making each of these a reality in the days, weeks, and months ahead.

### **A. Immediate Implementation**

- The Department of Public Health is redirecting \$200,000 from Civil Monetary Penalty funds to expand the Ombudsman Program. This will enable the state long-term care ombudsman to recruit additional ombudsman volunteers to visit nursing homes.
- Federal funds have permitted an expansion of the Medicaid Fraud Control Unit. There are now 20 investigators across the state dedicated to abuse and neglect investigations. An additional 37 investigators fulfill a dual role of investigating fraud allegations and cases associated with abuse and neglect.

### **B. Legislation**

- Several of the recommendations will require changes to the Nursing Home Care Act. They include changing Involuntary Transfer and Discharge, Fines, Penalties, and License Revocations, as well as whistle-blower protections for nursing home administrators.
- The Illinois Nursing Home Administrators Licensing and Disciplinary Act will require changes to mirror the Medical Practice Act pertaining to mandatory reporting of alleged misconduct to DFPR by health care institutions, professional associations, professional liability insurers, state's attorneys, and state agencies.
- The Illinois Medical Practice Act and other professional acts will require amendments to enable DFPR to refer cases to appropriate agencies without violating confidentiality provisions.
- Illinois Department of Healthcare and Family Services will need legislative authority to collect additional bed fees from nursing homes and distribute those funds to the Department of Public Health and the Department on Aging as necessary to provide for enforcement of the nursing home regulations.

### **C. Rules**

Several recommendations will require changes to the nursing home regulations. These changes include:

- Increase the focus on the resident care plan.

- Allow for a “provisional admission” that won’t conflict with federal requirements. Also include standards for proper relocation of denied “provisional admissions.”
- Upgrade the Subpart S and Subpart T regulations under the Skilled Nursing and Intermediate Facilities Code, which address nursing homes' responsibilities for caring for people with serious mental illness.
- Require a long-term care facility that accepts persons with mental illness to meet the expanded Subpart S requirements regardless of the number of persons with mental illness admitted.
- Establish a new subpart of the Skilled Nursing and Intermediate Care Facilities Code for people with violent tendencies.
- Establish a special “Certificate of Compliance” for nursing homes accepting residents who require special supervision to prevent harm to other residents, staff or visitors.
- Increase the focus on inappropriate use of psychotropic medications.
- Develop a Certified Nursing Assistant curriculum on mental health and require that CNAs who work in LTC facilities that take persons with mental illness receive this special training.
- Develop a Psychiatric Rehabilitation Coordinator (PSRC) certification program for BA level staff who work in LTC facilities that take persons with mental illness.
- Develop a rule that penalizes nursing homes for not initiating the background check as required.
- Raise the minimum staffing ratios for nurses, CNAs and PSRCs.
- Develop a “Certificate of Compliance” for facilities that serve people with serious mental illness. If the facility fails to get this certificate, it cannot accept persons with mental illness.
- Increase the training requirements for nursing home staff, especially in the area of safety.

#### **D. Policy**

State agencies will make several policy/program changes that reflect the task force recommendations. These include:

- Prioritize creation and use of appropriate care plans.

- Prioritize preadmission screening and resident reviews.
- Prioritize nursing home monitoring to assure resident background checks are conducted in a timely fashion.
- Promulgate standards for the appropriate use of psychotropic medications based on consultation with the Illinois State Medical Society, Illinois Psychiatric Society, University of Illinois College of Medicine, and other potential clinical and academic partners.
- Improve public access to nursing home quality data similar to efforts undertaken with hospitals.
- Develop training curricula for survey staff and ensure that all are trained in the needs of facilities providing support to individuals with serious mental illness.
- Develop a protocol with the Illinois Department of Financial and Professional Regulation for a more effective complaint referral process regarding licensed provider staff.
- Participate in the Advancing Excellence in America's Nursing Homes Campaign Disparities Project.
- Develop a complaint-sharing agreement with The Joint Commission covering its 59 Illinois accredited nursing homes.

### **E. Budget**

Budget issues have often forestalled implementation of previous long-term care improvement recommendations. Some might argue that the current fiscal crisis is cause to delay any new program expansions as recommended here for expanded assessments, higher nursing home standards, and significant expansion of supported housing options.

The task force has considered the costs of proposed changes, as well as the costs of maintaining the status quo. Costs associated with these recommendations fall into two broad categories: service delivery and administration. Overall, expansion of funding for services delivered in the community can be more than offset by decreases in institutional spending for the population that leaves nursing homes. The fear that new residents will fill those vacated nursing home beds is less founded than in the past. These recommendations include efforts to enhance the preadmission screening that will prevent that back-fill. In addition, current occupancy rates continue to drop indicating there is not an abundant supply of new people with mental illness or frail older adults ready to fill those beds. Moreover, the opportunity to capture currently 62% federal matching funds should compel efforts to serve people in the community who are now served in IMDs for which the state has to pay the entire cost of their care.

The task force recommends covering additional administrative costs by modestly increasing licensing fees and bed taxes paid by nursing homes. These additional funds would be dedicated to help cover the state's costs to monitor and regulate and support the state's 1200 nursing homes. These costs include the annual survey, responding to complaints, resolving appeals through the hearing stage, providing adequate ombudsman guardianship and advocacy support, and new costs to support nursing homes for culture change, downsizing, and conversion of bed capacity. Each department assigned to the task force is preparing its budget for FY 2011 and the fiscal impact of the recommendations will be included in the budget request.

## **F. Workgroups**

Under the continued direction of the governor's office, the task force will establish workgroups to implement the recommendations. The workgroups, led by task force members, will prepare detailed plans to assure timely implementation of recommendations that require continued interagency and public participation.

### ***1. Immediate Implementation Workgroups (to be completed by April 30<sup>th</sup>, 2010)***

- **PASRR Enhancement.** DHS and HFS will convene Department on Aging and community housing, care, and assessment providers to develop the enhanced Pre-Admission Screening and Resident Review, determine training needs, establish curriculum for such training, and create an implementation schedule for introduction early in FY 2011.
- **Risk of harm.** DHS will convene appropriate community providers, civil liberty advocates, nursing homes, and state agencies to develop criteria to identify individuals who are at increased risk of harming others, an instrument to assess such risk, and appropriate training for those who assess and identify such individuals.
- **Provisional Admission.** DPH, DHS, and HFS will convene community providers and nursing homes to develop criteria and a narrow definition for provisional admissions.
- **Criminal Background Checks.** The governor's office will convene the Illinois Hospital Association, nursing homes, Illinois State Police, and DPH to resolve issues pertaining to the initiation of the criminal background check and access to its results.
- **Identified Offender Program.** The governor's office will convene the Illinois State Police, the Attorney General's office, DPH, and nursing home safety advocates to plan for the timely retrieval of additional information about previous convictions important for predicting future violent behavior.
- **Mental Health Code.** DHS and HFS will convene mental health experts, nursing homes, and legal advocates to determine the elements of the Mental Health Code that need to be integrated into the Nursing Home Care Act.
- **DFPR investigations.** DPH and DFPR will confer to determine protocols for referral of investigation and complaint information and determine if new legislation or rules are necessary.

- **Psychotropic drugs.** DPH and HFS will convene nursing homes, mental health experts, Illinois State Medical Society, Illinois Psychiatric Society, University of Illinois College of Medicine, Illinois Hospital Association and Illinois Nurses Association to increase physician participation in nursing homes and develop protocols for the appropriate administration of psychotropic medications.
- **Supportive housing expansion.** The governor's office will convene supportive housing providers, IHDA, HFS and DHS to determine the most efficient and effective means of paying for and transferring funding to community support services when residents leave or are deferred from nursing facilities.

## *2. Mid-range implementation (June 30, 2010)*

- **Nursing home technical assistance.** DoA, DHS, and DPH will convene nursing homes to identify their needs for assistance related to culture change, downsizing, and converting resources to support home and community services.
- **MDS 3.0 assessment data use.** DPH and HFS will convene nursing homes to plan for adoption of MDS 3.0 and to determine how to incorporate MDS data into assessments, resident reviews, annual reviews, and special certifications.

## **Appendix 1: Task Force Agencies**

### **Office of the Governor**

Michael Gelder, Senior Health Policy Advisor

Jen Celaya

Tom DeSplinter

Brian Dunn

Amy Lulich

William Maggos

Kendall Marlowe

Justin Slaughter

### **Department on Aging (DoA)**

Director Charles Johnson

Mary Killough

Sally Petrone

### **Department of Financial & Professional Regulation (DFPR)**

Secretary Brent Adams

Daniel Bluthardt

Kristen Strawbridge

### **Department of Healthcare & Family Services (HFS)**

Director Barry Maram

Kelly Cunningham

Theresa Eagleson

Barb Ginder

Jean Summerfield

**Department of Human Services (DHS)**

Secretary Michelle Saddler

Assistant Secretary Grace Hou

Brenda Hampton

Dr. Lorrie Jones

**Department of Corrections (DOC)**

Roberta Fewes

**Department of Public Health (DPH)**

Director Dr. Damon Arnold

Assistant Director Teresa Garate

Bill Bell

Jason Boltz

David Carvalho

Rick Dees

**Guardianship & Advocacy Commission (GAC)**

Dr. Mary Milano

**Illinois Housing Development Authority (IHDA)**

Bill Pluta

**Illinois State Police (ISP)**

Capt. Charlie Maras

Lt. Bill Colbrook

Marcel Reid

**Veterans Affairs (VA)**

Gwen Diehl

Stewart Reeve

## **Appendix 2: Background**

### **A. History**

The phenomenon of people with serious mental illness living in nursing homes began with the downsizing of state mental institutions in the 1950s, and gained momentum in the 1960s with the passage of the federal Medicaid, Medicare and Supplemental Security Income (SSI) programs, which greatly expanded resources available to treat older adult and disabled populations. Disabled populations, including those with mental illnesses and developmental disabilities who had relied on state institutions for care, now had resources available to fund their care in private settings. In 1978, President Carter's Commission on Mental Health stated that severe mental illness should be treated in the least restrictive setting with the "objective of maintaining the greatest degree of freedom, self-determination, autonomy, dignity and integrity of body, mind, and spirit for the individual while he or she participates in treatment or receives services." The Americans with Disabilities Act, signed in 1990, greatly expanded the rights of citizens with disabilities, including mental illness. This right to live in the most community-integrated setting was later reinforced by the U.S. Supreme Court *Olmstead v. LC* decision (1999) that today is the basis for legal challenges to the continued reliance on institutional care for disabled populations throughout the country.

Illinois' initial response to deinstitutionalization was to rely on private nursing homes for persons who were moved from state institutions. This was done at the expense of funding expansion of community-based treatment settings for people with disabilities. In testimony to the task force, Phyllis Mitzen, director of the Center for Long Term Care Reform, stated, "The current crisis evolved over the years because of Illinois' failure to adequately plan for the long-term needs of persons with serious mental illness. Nursing homes stepped in to fill the void and the state responded by adding regulations."

From the 1960s to the 1990s, thousands of persons with mental illness and developmental disabilities moved from state institutions to nursing homes. In Illinois, there were 37,833 residents in psychiatric hospitals in 1955, and only 2,845 in 1994, giving the state an approximate deinstitutionalization rate of 94 percent. A vast majority of these individuals went to nursing homes. According to state statistics, more than 22,000 people with serious mental illness live in nursing homes reimbursed by the state's Medicaid program. Many fewer went to staffed "group home" models and many others had less favorable outcomes. The numbers of persons with serious mental illness in the nation's jails and prisons increased from 1 in 100 of the correctional population in 1950 to 1 in 5 in 2000. In addition, the number of persons with serious mental illness who have become homeless doubled since 1950 and the percentage of juveniles with severe mental illnesses in juvenile detention institutions tripled in the last 50 years (Frank,

2006). These factors all point to significant failures in expanding community-based systems of care nationally. Illinois, unfortunately, is no exception.

Given the high number of persons with mental illnesses in nursing homes, over the past 30 years Illinois has repeatedly tried to reform and improve the long-term care system. In 1979, Illinois passed the Nursing Home Care Act, which at the time was lauded as the most comprehensive legislation in the country regulating the nursing home industry. The Act laid out the requirements nursing homes must meet to provide adequate care, as well as penalties for failing to meet those requirements. The Illinois Department of Public Health (DPH) was empowered to enforce the Act, in the context of regulations from the federal Department of Health and Human Services. Yet a national study by the Institute of Medicine in 1986 questioned the use of nursing homes for the mentally ill, finding the homes “could not provide the specialized services they needed,” and 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.” (Equip for Equality testimony, 10/29/09). A Chicago Tribune series in 1998, “Warehousing the Mentally Ill,” documented the same failures and challenges facing the task force in 2010.

From 2003 to 2005, the Center for Psychiatric Rehabilitation at the University of Chicago trained nursing home staff in providing psychiatric rehabilitation services, yet found “nursing home care, as currently set up, is not an appropriate place for most people with mental illness.” (Alice Virgil testimony, 11/19/09).

In 2004, the American Association of Retired Persons (AARP) worked with the long-term care industry, state agencies, advocates and service providers to address the problem of mixed populations in nursing homes. The group’s core recommendations presaged the recommendations in this report. Two laws concerning ex-offenders were eventually passed, but much of the proposed legislation faltered in 2004 and many of the group’s recommended reforms were never realized. (Health Care Council of Illinois testimony, 10/20/09). The laws that were passed included a 2006 amendment to the Nursing Home Care Act designed to revamp the process to determine a resident’s potential for violence. The amendment required running a criminal background check within 24 hours of admittance. If any prior convictions appeared on the background check, the new law required the nursing home to contact DPH immediately to conduct a thorough Criminal Analysis. In this “identified offender” program, the resident’s criminal and clinical history is evaluated by a forensic psychologist who establishes the level of caution the nursing home must take based on the resident’s level of risk to others.

Illinois’ reliance on nursing home care was successfully challenged for the developmentally disabled population in the class action suit *Bogard v. Bradley*, settled in June 1993. This resulted in moving more than 1,000 individuals with developmental disabilities from nursing homes to less restrictive community-based options over approximately a five-year period. Similar legal challenges that would affect persons with mental illness remain active in the Illinois courts today. (*Williams v. Quinn*; *Colbert v. Quinn*).

## **B. Long-Term Care Services**

In 2010, there will be more than 1,200 long-term care facilities licensed by DPH. These facilities fall into five licensure categories: Skilled, Intermediate, Sheltered Care, Developmentally Disabled, and Skilled Pediatric. Of these, more than 800 facilities are categorized as either skilled or intermediate. Skilled care facilities provide the highest level of care, while intermediate facilities provide less constant monitoring and are most similar to the traditional concept of a nursing home. Among the five categories, there are 121,811 beds, which are roughly 75 percent occupied. There are about 53,000 beds in nursing facilities falling into the skilled or intermediate categories. The average cost to house a resident covered by Medicaid in a nursing home is approximately \$120 per day, or \$3,600 per month. In addition to the Medicaid payment, the home also receives the resident's Supplemental Security or disability income, often amounting to \$674 per month, less the \$30 Illinois allows residents to keep each month.

### **B1. Admissions Process**

The process of admitting a resident to a nursing home consists of several assessments, including a Pre-Admission Screening & Resident Review (PASRR), as well as a screening process called the Identified Offender program.

#### ***B1a. Pre-Admission Screening and Resident Review***

The Pre-Admission Screening and Resident Review is conducted by the Department of Human Services (DHS). The three DHS divisions responsible for conducting pre-admission screenings are: Division of Rehabilitation Services (DRS) for physical disabilities, the Division of Development Disability (DDD) for developmental disabilities, and the Division of Mental Health (DMH), for serious mental illness. Older adults are screened by Case Coordination Units under contract to the Department on Aging.

The pre-admission screening for mental health (PAS/MH) is conducted by DMH's contracted entities. The first step is a Level I screening, which identifies individuals who may have a mental illness. If mental illness is suspected, then a Level II screening should be conducted to determine whether nursing home placement is needed.

#### ***B1b. Identified Offender Program***

In 2006, the General Assembly amended the Nursing Home Care Act to identify potential nursing home residents who had a violent criminal history and to incorporate additional treatment or security measures into their treatment plan.

***B1b. i. Background Check***

Nursing facilities must “within 24 hours of admission, request a criminal history background check pursuant to the Uniform Conviction Information Act for all persons age 18 or older seeking admission to a facility” from the Illinois State Police (ISP). ISP runs the background check based on the name and birth date of the potential resident and return the results to the facility. If the results are inconclusive (e.g., the resident has the same name and birth date as another person), then the facility initiates a fingerprint-based check. If the results of the criminal history background check reveal that the resident is an identified offender, defined as “a person who has been convicted of any [listed] felony offense . . . , is a registered sex offender, or is serving a term of parole, mandatory supervised release, or probation for a felony offense,” then the nursing facility “shall immediately fax the resident’s name and criminal history information to the DPH, which shall conduct a Criminal History Analysis.”

***B1b. ii. Criminal History Analysis***

The Criminal History Analysis is a multiple-step process that must begin as soon as a resident is identified as an offender and must be completed “as soon as practicable, but not later than 14 days after receiving notice from the facility,” according to the statute. The analysis includes consultations, interviews or reviews of: (1) the parole or probation officer; (2) the prosecutor’s office; (3) police reports and facts of the case; (4) the identified offender personally; (5) the facility administrator; (6) the entire criminal history of the identified offender; and (7) additional evaluations if the identified offender is a convicted or registered sex offender.

After this process is completed, a Criminal History Analysis Report is prepared, which includes a risk analysis detailing “whether and to what extent the identified offender’s criminal history necessitates the implementation of security measures within the long-term care facility.” The facility must incorporate security measures into the identified offender’s care plan, or, “if the facility determines that it cannot manage the identified offender resident safely within the facility, it shall commence involuntary transfer or discharge proceedings.” The risk analysis has three categories: high, medium, and low, each requiring certain security measures.

The Criminal History Analysis is administered by DPH and has an annual appropriation of \$2 million. About half of the budget is dedicated to a contract with a private investigation firm to compile the Criminal History Analysis reports, a quarter is dedicated to hiring a forensic psychologist to conduct the Risk Assessments, and a quarter is dedicated to internal administration costs. Between the years 2006 and 2010, DPH completed 5,031 criminal history analyses (2006: 967; 2007: 941; 2008: 1,640; 2009: 1,483). Based on the number of nursing

home admissions per year, the rate of instances in which a potential resident falls under the identified offender program is less than 1 percent per year.

## **B2. Standards of Care**

Nursing homes have a responsibility to provide high-quality care for their residents. The government is responsible for ensuring that the treatment it is paying for is delivered.

### ***B2a. License Requirements***

The Nursing Home Care Act (210 ILCS 45), governs the state's 1200 licensed facilities and enumerates standards they must achieve to receive and maintain a license. To receive payment for residents covered under the Medicaid and Medicare programs, nursing homes must also meet federal certification requirements, which are enforced by DPH.

### ***B2b. Violations & Penalties***

Both the state licensure and federal certification regulations for nursing home anticipate needs of a geriatric population. Since more than 90 percent of the licensed facilities are federally certified, the Nursing Home Care Act allows for the federal survey process to drive the regulation of all licensed and certified facilities. Under both regulatory systems, correction is the primary goal of the enforcement process. License revocation and decertification are a last resort since they result in closure of a facility and necessitate transfer of all residents.

The Nursing Home Care Act establishes three levels of fines and penalties that can be assessed against facilities found to be in violation of the Act. First, an administrative warning requires a plan of correction, but no penalties are assessed. Second, a level B violation will be assessed if there is a direct threat to the health, safety, and welfare of a resident and may result in a fine of not less than \$500 and the issuance of a conditional license. Third, a level A violation will occur when there is a substantial probability that death or serious physical or mental harm may occur and may result in fines of not less than \$5,000, or \$10,000 when serious harm has occurred. Repeat level A violations result in initiation of a licensure revocation action.

### ***B2c. Staffing***

One of the most important determinants of quality in nursing homes is the level of staffing and how many hours of high-level nursing care is provided per resident per week. For a skilled nursing home, a minimum of 2.5 hours of licensed and direct care staff must be provided daily to each resident. This standard requires that 20 percent of the 2.5 hours be combined RN and LPN time. The remaining 2 hours must be provided by CNAs.

According to a December 2001 report by the Centers for Medicare and Medicaid Services improvements in quality of care can be realized at staffing levels of 3.55 to 4.1 hours of CNA and combined RN/LPN care per resident daily.

***B2d. The Mental Health Code***

Under the Mental Health Code, (405 ILCS 5) “mental health facilities” are defined as “any licensed private hospital, institution or facility or section thereof, and any facility, or section thereof, operated by the state or a political subdivision thereof for the treatment of persons with mental illness and includes all hospitals, institutions, clinics, evaluation facilities and mental health centers which provide treatment for such persons.” (405 ILCS 5/1 114)

The Mental Health Code requires a detailed treatment plan that must be prepared within three days of admission that includes “an assessment of the recipient’s treatment needs, a description of the services recommended for treatment, the goals of each type of element of service, an anticipated timetable for the accomplishment of the goals, and a designation of the qualified professional responsible for the implementation of the plan. The plan must be reviewed and updated at least every 30 days, or as warranted by the individual's condition. (405 ILCS 5/3 209)

***B2e. Funding***

The Department of Healthcare and Family Services (HFS), as the single state Medicaid agency, is responsible for reimbursing nursing facilities for services provided to Medicaid-eligible residents. Medicaid reimbursement rates for long-term care facilities are calculated based on three components — nursing, capital, and support — that together comprise the facility’s per diem rate. Capital and support components are based on a cost report, and the nursing component is based on both a cost report and clinical information gleaned from the federally required Minimum Data Set (MDS) assessment instrument, described in more detail below.

Nursing facility payment rules adopted in January 2007 require that the state's payment for the nursing component of the reimbursement rate correlate to a resident’s clinical needs. In support of this requirement, HFS performs data-driven, onsite monitoring protocols in nursing facilities to ensure that MDS coding is accurate and that services are delivered in accordance with federal requirements. These protocols include monitoring of rates connected to services for persons with severe mental illness.

The federal government defines an Institution for Mental Disease (IMD) as a hospital, nursing facility, or other institution of more than 16 beds that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services. A facility is deemed an IMD if it was established and is maintained primarily for the care and treatment of individuals with mental diseases, whether or not it is licensed as such. (42 CFR 435.1009) The federal government will not reimburse the state for individuals 22-64 years old residing in IMDs. In Illinois, 26 licensed nursing facilities serving

approximately 4,000 residents are designated as IMDs. Five of these IMDs participate in a demonstration program operating under special DPH regulations relating to provision of specialized services, training, technical assistance, and admission restrictions.

***B2f. Fraud, Abuse, and Neglect Investigations***

In order to investigate and prosecute fraud, neglect, or abuse associated with the Medicaid program, the Illinois State Police, along with the Office of the Illinois Attorney General, has formed the Medicaid Fraud Control Unit (MFCU). In addition, the MFCU also reviews allegations of abuse or neglect in health care facilities receiving payments under the state Medicaid plan. The MFCU has 20 investigators statewide dedicated to abuse and neglect investigations, with an additional 37 investigators fulfilling a dual role of investigating fraud and cases associated with abuse and neglect. The Attorney General's office also has ten attorneys assigned to the MFCU. These attorneys are dedicated to prosecuting cases initiated by or referred to the MFCU. Cases may also be referred to the local state's attorney's offices for prosecution.

The MFCU receives referrals of alleged criminal conduct from multiple sources. They include the Ombudsman program staff and volunteers, the public, local law enforcement agencies, HFS and DPH. The MFCU and DPH have a Memorandum of Understanding allowing the two agencies to share critical information and resources to investigate abuse and neglect. Although the MFCU primarily reacts to complaints of fraud, abuse and neglect, it has been proactive in providing training on abuse and neglect issues at nursing homes as part of the in-service training staff must receive.

**B3. Home and Community Options**

***B3a. Housing***

There are several community-based living alternatives to address the residential needs of persons who have severe mental illness. The Division of Mental Health has funded traditional supervised and supported therapeutic residential models, which are either 24-hour staffed settings or settings without overnight staff. DMH has pursued the development of Permanent Supportive Housing (PSH) but at this time PSH is only available for individuals who have severe mental illness, who fall within one of the identified priority populations, and who have been assessed as able to function in an independent living environment without 24-hour staffed support. The existing model of PSH is scattered-site, community-based rental units. Each unit must be self contained with a kitchen and bathroom. The renter holds the lease and has full rights of tenancy under tenant-landlord law.

***B3b. Services***

Support services are not a condition of residency; however support services are available as flexible, wrap-around services tailored to meeting the client's individual treatment needs. Services can be made available in the home and community through options such as Targeted Case Management, Assertive Community Treatment (ACT) or Community Service Team (CST) and other Medicaid Rehabilitation Option Services.

***B3c. Funding***

Housing development and rental assistance are two components for funding community-based housing. There are federal and state funding sources for both. Programs for capital development under IHDA include Illinois Affordable Housing Capital Fund, the HOME Program, and the Affordable Housing Trust Fund.

Capital development programs under the Department of Commerce and Economic Opportunity and IHDA include CDBG Disaster Recovery Program, the HUD-Section 811 Supportive Housing for Persons with Disabilities Program and the HEARTH (Homeless Emergency Assistance and Rapid Transition to Housing) Act.

HUD rental/operating assistance, programs include Section 8 Housing Choice Vouchers, Operation Mainstream vouchers, project-based vouchers, Section 811, HEARTH Act, DHS/DMH-Bridge Rental Subsidy Program, and the IHDA Rental Housing Support Program.

Under the "Money Follows the Person" program, eligible persons transitioning to the community who have been in a nursing facility for six months or longer have limited dollars available for one-time transition expenses for security deposits, utility connections, and other necessary items to establish a household; however, rent and utilities are not covered under this service.

### **Appendix 3: Task Force Process**

On Oct. 3, 2009, Governor Pat Quinn established the Nursing Home Safety Task Force to look into news media reports of threats to the safety of nursing home residents in Illinois. He appointed his Senior Health Policy Advisor, Michael Gelder, as Chair of the task force. "We will make sure Illinois' nursing homes offer a safe haven for residents, many of whom are among our most vulnerable and needy," said Governor Quinn. "The Nursing Home Safety Task Force will address this critical issue with all deliberate speed." The Governor invited the department heads to participate directly as well as identify specific individuals in their departments to participate throughout the task force process.

The task force acknowledges the significant contribution of journalists to this work, both in shining the light of public attention on these issues and informing the task force's debates. They are: David Jackson, Gary Marx, and Sam Rowe of the *Chicago Tribune*, Carla K. Johnson of Associated Press, Jeff Kelly Lowenstein of the *Chicago Reporter*, and Christina Jewett of ProPublica. These reporters and their news organizations devoted substantial time and resources to their investigations, to the benefit of the public they serve.

#### **A. Public Meetings**

The task force held seven public meetings in which it heard more than twenty hours of testimony from over forty witnesses from throughout the nursing home industry, including resident patient advocacy groups, government representatives, industry leaders, parents of patients with mental illnesses, owners of nursing homes, children of elderly parents, professional accreditation agencies, local and regional ombudsmen, home and community care providers, and law enforcement officials, among others.

##### **A1. First Public Meeting**

At the first meeting, held on Oct. 8, 2009, in the Thompson Center in Chicago, each of the representatives from the agencies on the task force explained the role their department played in regulating the nursing home industry. They gave their first impressions of problems that they recognized and stated their commitment to working towards finding adequate solutions. The following people testified:

Pat Comstock, Health Care Council of Illinois

Wendy Meltzer, Illinois Citizens for Better Care

## **A2. Second Public Meeting**

The second public meeting was held on Oct. 20, 2009, and was mainly dedicated to hearing testimony about safety problems in nursing homes from stakeholders as well as any interested individual during open public comment period. The following people testified:

Troy Warfield, Resident, Greenwood Care (Evanston)

Nancy Flowers, Regional Ombudsman, Evanston Health & Human Services

Jennifer Walling, Chief of Staff for Sen. Heather Steans

Monica Hammer, Office of Ald. Mary Ann Smith

Wendy Meltzer, Illinois Citizens for Better Care

Mark Heyrman, Mental Health America of Illinois

Jennifer Thomas, Access Living

Phyllis Mitzen, Health & Medicine Policy Research Group, Center for Long Term Care Reform

David Vinkler, AARP

Tony Zipple, CEO of Thresholds

Arnie Kanter and Randy Walker, Barton Management

Pat Comstock, Health Care Council of Illinois (HCCI)

## **A3. Third Public Meeting**

The third public meeting was held in Springfield on Oct. 29, 2009. The meeting provided an opportunity to for organizations and individuals in central and southern regions of the state to describe nursing home safety problems. The following people testified:

Barbara McGoldrick, Parent of a nursing home resident

Fred Friedman, Next Steps and former nursing home resident

Linda Virgil, Board of Directors, National Alliance on Mental Illness

Nancy Funk, AARP

April Verrett, Executive Vice President, SEIU Healthcare

Lore Baker, Supportive Housing Providers Association

Cheryl Jansen, Legislative Policy Manager, Equip for Equality

Pat Comstock and Terry Sullivan, Health Care Council of Illinois

Jamie Freschi, Regional Ombudsman in Springfield

Sally Petrone, Illinois Long-term Care Ombudsman

Violet Radwill, Wife of a nursing home resident

Margaret Niederer, Retired Ombudsman

#### **A4. Fourth Public Meeting**

The fourth public meeting was held on Nov. 19, 2009, in Chicago, and included testimony focused on the treatment of persons suffering from mental illness and licensing of nursing homes and their administrators. The following people testified:

Mark Epstein, J.D., Epstein and Epstein

Patrick Knepler, Legal and Legislation Liaison, DMH

Daniel Bluthardt, Director of Division of Professional Regulation

Marylynn Clarke & Kathleen Pankau, Illinois Hospital Association

Lore Baker, Supportive Housing Providers Association

Cheryl Jansen, Legislative Policy Manager, Equip for Equality

Pat Comstock & Terry Sullivan, Health Care Council of Illinois

Jamie Freschi, Regional Ombudsman in Springfield

Sally Petrone, Illinois Long-term Care Ombudsman

Violet Radwill, wife of a nursing home resident

Margaret Niederer, retired Ombudsman

Ms. LeeJoy Hoofnagle

Ms. Rebecca Catalano, New Beginnings

Joe Zimmerman, Nursing Home Owner

#### **A5. Fifth Public Meeting**

The fifth public meeting was held on Dec. 16, 2009, in Chicago, and focused on the accreditation process of nursing facilities and the placement procedures by county officials. The task force

members also had a lengthy discussion about their experience visiting nursing homes as part of the investigation process. The following people testified:

Gina Zimmerman, Executive Director Home Care and Long-term Care Accreditation, The Joint Commission

Jennifer Hoppe, Associate Director State and External Relations for The Joint Commission

Doug Schenkelberg, Associate Director, Policy and Advocacy, Heartland Alliance for Human Needs and Human Rights

Jane Addams Senior Caucus

Terry Worman, Chicago Task Force on LGBT Aging

Margeret Niederer, retired Ombudsman

Wendy Meltzer, Illinois Citizens for Better Care

Rob Moon, Cook County Sheriff's Office

Mariam Smith

Alexandria Willis, Student, UIC School of Public Health

#### **A6. Sixth Public Meeting**

The sixth public meeting was held on Jan. 14, 2010, in Springfield, and focused on the presentation of the task force's preliminary recommendations. The following people testified:

Pat Comstock, Health Care Council of Illinois

Gina Zimmerman

Violet Radwill

Lore Baker

LeeJoy Hoofnagle

Margeret Niederer, retired Ombudsman

#### **A7. Seventh Public Meeting**

The seventh public meeting was held on Jan. 21, 2010, in Chicago. The purpose was to hear comments on the preliminary draft recommendations. The following people testified:

Pat Drennan, Jane Addams Senior Caucus

Kathleen Pankau, Illinois Hospital Association

Pat Comstock & Terry Sullivan, Health Care Council of Illinois

Janet Hasz, Supportive Housing Providers Association

Wendy Meltzer, Illinois Citizens for Better Care

Bill Kasper, Senior Life Service

Rev. Elaine Bellis, Community Renewal Society

Sen. Jacqueline Collins

Sen. Susan Garrett

Sen. Heather Steans

Merle Sosa, Illinois Psychiatric Society

Alan Lurie, nursing home resident

Nancy Flowers, Regional Ombudsman, Evanston Health & Human Services

LeeJoy Hoofnagle

Susan Aarup, Access Living

## **B. Website Comments**

The task force also created a website ([www.nursinghomesafety.illinois.gov](http://www.nursinghomesafety.illinois.gov)) in order to improve communication with the public. The website was used to post documents related to the public meetings, including the meeting agendas, minutes, and copies of written testimony. There were links available to watch or listen to webcasts of the public meetings online. The website also offered a comment section designed to allow members of the public to offer their opinions and recommendations to the task force to help in its work. To date, the task force has received more than 130 comments on the website. They have ranged from the concerns of family or friends of loved ones residing in problem nursing homes, to personal accounts of failures encountered during a resident's stay, to the opinions of long-time advocates for better health and long-term care, to recommendations from lay people and skilled experts on how the task force could accomplish its goal of protecting the safety of nursing home residents. The dozens that described tragic examples of abuse and neglect in nursing homes were referred to DPH, state police and other appropriate agencies.

### **C. Nursing Home Visits**

Members of the task force visited several nursing homes throughout the state, including in Springfield, Chicago, and the surrounding suburbs. These included facilities that predominantly house aging seniors; facilities where most residents have been diagnosed as having a mental illness; and standard and demonstration IMDs, which exclusively serve people with serious mental illness. The task force members shared their thoughts and reactions from their visits at the fifth public meeting.

### **D. Joint Legislative Hearing**

The task force members appeared before a joint hearing of the State Senate Human Services and Public Health Committees on Thursday, Nov. 5, 2009, and testified about its work to protect nursing home residents in Illinois. The chairperson explained the task force's mission and process to recommend solutions to the safety problem. Each of the members testified and answered questions from the legislators, acknowledging that the admissions process and regulations are in need of revision, and expressing their desire to work with the General Assembly to address these issues. Senators Mattie Hunter, William Delgado, and others stated specific areas that they wanted to see addressed, including the effect of having a large concentration of nursing homes in a particular district, the racial disparity between higher-rated nursing homes in wealthier areas and lower-rated nursing homes serving poorer areas, and the housing of violent ex-convicts in nursing facilities. Several of the senators stated that they wanted to see legislation proposed by the February session and offered to sponsor the legislation.

## **Appendix 4: Highlights of Public Testimony**

### **A. Violence in Nursing Homes**

**People with violent histories who present a risk of harm to others are inadequately screened and inappropriately placed into the same nursing homes as vulnerable, elderly residents.**

Thomas Donovan, a 63-year-old amputee suffering from diabetes, kidney failure and schizophrenia, spent a quarter-century in nursing homes. Months after he moved into Burnham Healthcare, he was dead. State authorities allege that Donovan died April 1 after being beaten by mentally ill housemates in two incidents. His case, still unresolved, sheds a harsh light on the dangerous population mix inside Illinois' new breed of nursing home... Diana O'Connell is still stunned by what happened to her brother. "It wasn't like he could stand up and protect himself; he was in a wheelchair," she said. "When a person is put into a facility, you would hope it would be a safe, caring and protective environment." (Chicago Tribune, 09/29/09.)

"The typical nursing home is not equipped to handle ex-offenders and people with violent behavior. These individuals need specialized services and staff trained to respond to their specific needs. Nursing homes should not be the housing of last resort for people who could pose a threat to other residents." (AARP, 10/20/09).

The current system for screening potentially violent nursing home residents and ensuring the safety of those around them is seen as inadequate even when performed promptly and correctly. A more thorough assessment of risk of harm to others is recommended: "We do not believe it is possible to assess "dangerousness" without evaluating the person's medical history, behavioral history while being treated for mental illness, current diagnoses, medication and other therapy recommendations, and the person's history of and current compliance with those recommendations." (Illinois Citizens for Better Care testimony). The risk assessment as currently performed has allowed, for example, a person with a history of repeated violations of orders of protection, violent felonies, and arson to be classified as "medium risk."

Numerous logistical obstacles also thwart the process, as background checks are often not initiated promptly as required by law, and may not be completed until months later. Current law requires the pursuit of information that may or may not be relevant or available, while other critical information is omitted. Available criminal histories contain convictions but not arrests, and some residents commit crimes against other residents that are neither reported nor tracked as residents move from nursing home to nursing home.

Even when the risk assessment is completed, the measures recommended to safeguard fellow residents are inherently inadequate. The common recommendation is to place a "high-risk"

resident “in a room nearest the nurse’s station,” a precaution one advocate labeled “ridiculous.” (Illinois Citizens for Better Care testimony, 10/29/09).

The task force researched similar laws in others states, though few have addressed the issue:

Most states have no regulations governing the admission of ex-offenders to nursing homes and long-term care facilities. There is little consistency among the few states that do regulate the admission of ex-offenders. The burden to act shifts between the government, the facility, and the offender, depending on the state. The crimes that require notification differ, and only a handful of states require facilities to notify residents if an offender lives in the center.”

Minnesota has one of the most stringent set of requirements regarding ex-offenders in nursing homes, though they focus on a limited number of very violent crimes such as murder, kidnapping, and sex offenses. Minnesota has also established a “forensic nursing home” for just these “predatory offenders.” (“Forensic Nursing Home Opens,” St. Peter Herald, 11/26/09).

Problems with violence and crime in and around nursing homes also affect the surrounding community. Local legislators in districts with a high number of problematic nursing homes regularly receive complaints from community members about panhandling, drug dealing and even violence arising from nursing home residents. In the 7<sup>th</sup> State Senate District, local police receive 6,500 such complaints per year, draining local law enforcement resources.

It is important to distinguish between two populations currently living in nursing homes in Illinois: people with severe mental illnesses, and people with violent histories who present a risk of harm to others. They are not the same. “Most persons with mental illnesses are not dangerous and are not criminals,” and “Most criminals are not mentally ill.” (Mark Heyrman/Mental Health America of Illinois testimony, 10/20/09).

Even objective news coverage of harm to nursing home residents can reinforce an unfair and inaccurate stereotype of predatory “mentally ill criminals,” stigmatizing good people who are striving to recover from mental illness and regain their place as productive members of their community. “The reality is the inverse of common belief: people with severe mental illness are far more likely to be the victims of violence than its initiators.” (Equip for Equality testimony, 10/29/09).

## **B. Treatment of Persons with Mental Illness**

**Nursing homes as currently operated are not an appropriate treatment and recovery setting for people with serious mental illness. These residents often are inappropriately placed into the same nursing homes as vulnerable, elderly residents.**

The task force heard testimony from many residents, advocates and service providers on this issue, all calling for an end to the practice in Illinois of placing persons with mental illness in inadequate or inappropriate institutional settings. “Most persons with chronic mental illness don’t “need” nursing home care... Helping them move to places they want to live, with supportive services that Medicaid will actually match, needs to become a priority.” (Illinois Citizens for Better Care testimony). “Illinois is really unique in its blurring of long-term care and mental health resources,” Harvard Medical School associate professor David Grabowski told the *Chicago Tribune*, “Many of these patients were not appropriate for placement in a nursing home – yet Illinois didn’t have an alternative for them.” (Chicago Tribune, 09/29/09).

Anthony Zipple, CEO of Thresholds, a leading provider of mental health services, summarized our state’s standing:

“Illinois is in a nearly unique position with regard to its preference for inappropriate, unnecessary, and expensive institutional care for people with severe mental illnesses.

- Illinois is a leader in the use of nursing homes... for people with severe mental illness. More than 15,000 of the 125,000 people nationally who are in nursing homes simply due to mental illnesses are Illinois citizens. This is particularly tragic since we have increased spending for intermediate care for people with severe mental illnesses in the past five years and cut the base funding for community alternatives to intermediate care in the same period.
- Illinois is also a national leader in spending on institutional care... 59 percent of the resources for people with severe mental illness are spent on institutional care and only 41 percent on community care. Of all available resources, 31 percent is spent on IMDs alone, which serve 1 percent of the population. In spite of recent efforts to rebalance the system Illinois is still, perhaps, the most imbalanced system of care in the nation.
- Finally, Illinois is a leader in federal lawsuits over institutional care. Illinois has two active Olmstead lawsuits in federal court related to people with severe mental illness.

I am convinced that the thousands of individuals who are inappropriately placed in nursing homes and the taxpayers of Illinois who cover the cost of these placements deserve better.” (Anthony Zipple testimony, 10/20/09).

This “imbalance” against community-based and home-based care is exacerbated by payment schemes of both federal and state governments. “The rates paid by the state and the failure to provide adequate mental health care services in nursing homes means that nursing homes *make* money on every client... Compare this to our mental health care system. The Medicaid rates and the things our Medicaid system is (un)willing to pay for mean that community mental health providers *lose* money on every client and almost every service.” (Mark Heyrman, 10/23/09 letter.)

The preference for institutional care, even for younger persons with mental illness who do not require nursing care, means that Illinois has the highest number of persons age 22 to 64 living in

nursing facilities, as reported by the Associated Press (AP article, “Mentally Ill a Threat in Nursing Homes,” 3/22/09). Yet these individuals often do not receive adequate care in a nursing home. A local legislator’s survey of her district found “an almost universal lack of comprehensive care programs for those with mental illness.” (Jennifer Walling, aide to State Senator Heather Steans, testimony 10/20/09).

As stated by social worker Alice Virgil, “In my experiences providing training to nursing home staff, there are currently no indications that staff behaviors contribute in any way to an individual’s recovery, but rather, tend to do quite the opposite.” The problem is not the staff themselves, the social worker adds, but their lack of mental health training and an organizational culture in many nursing homes that is simply incompatible with the recovery model of mental health treatment. Instead, “community care is better, far less expensive and, most importantly, more humane, and implies societal respect for the individual with mental illness. (Alice Virgil testimony, (11/19/09.))

Lack of community-based care alternatives for people with mental illness “slams the door on their recovery” while it opens the potential for violence in long-term care facilities. “Safety or the lack of it, and the inadequate continuum of care for many nursing home residents with a serious and persistent mental illness are systemically linked.” (Community Behavioral Healthcare Association testimony, 10/29/09.)

### **C. Inadequate Staffing & Racial Disparity**

#### **Staffing is inadequate at many nursing homes, resulting in inferior and sometimes unsafe care, especially at nursing homes primarily serving African Americans.**

“I have a parent in a nursing home... There are times when my parent can’t get needed medication because there are too few employees for the number of residents in her facility... from the nurses to the CNAs. The staff doctors are very seldom at the facility.” (Public comment to Nursing Home Safety website, 11/07/09)

“The [patient to staff] ratio is too high... I’m in the healthcare field as well and it broke my heart when I had to put my dad in a nursing home because of his Alzheimer’s.” (Public comment to Nursing Home Safety website, 11/22/09)

“From a nurse’s point of view... sometimes we may miss something because we are in such a hurry. Also we have too many residents to take care of. I am responsible for 60 to 67 residents.” (Public comment to Nursing Home Safety website, 10/29/09)

Sufficient levels of staffing are acknowledged by experts as “important in providing quality care in a nursing home,” (The Chicago Reporter July/August article) and as “a critical factor in protecting the vulnerable.” (Chicago Tribune 09/29/09). The task force heard testimony on a wide variety of nursing homes, including high-quality facilities with appropriate numbers of

well-qualified staff. Yet often, testimony included descriptions of missing or inattentive staff in lower-quality facilities, leading to poor care and harm to residents. The nursing home industry itself has proposed some increase in staffing levels. (HCCI testimony, 11/19/09).

The fact that low staffing levels seem concentrated in nursing homes primarily serving African Americans was deeply disturbing to the task force, legislators, and community members. The Chicago Reporter series examined this phenomenon in depth:

“Illinois is arguably the worst state in the nation for black senior citizens seeking quality nursing home care. There is just one home in Illinois rated “excellent” by the federal government when more than 50 percent of the home’s residents are black. In Illinois, these facilities get the worst federal ratings and on average have more violations than facilities where a majority of residents are white. And in Chicago, on average, these homes have more medical malpractice and personal injury lawsuits. People in white homes got better care than those in black homes, even if both were poor... Staff at Illinois’ black nursing homes spent less time daily with residents than staff at facilities where a majority of the residents are white. Of that time, black residents got a smaller percentage of time with more-skilled registered nurses than facilities where the residents were white.... Some say the disparities are the result of staffing levels and qualifications. Nearly 85 percent of the black homes in Chicago received the lowest mark for nursing staff hours. About 21 percent of the white homes got the same score.” (The Chicago Reporter, July/August 2009).

At a joint hearing of the State Senate Committees on Human Services and Public Health, legislators committed to ending these racial disparities, and discussed looking to Tennessee laws prohibiting bias and Florida laws mandating staffing levels.

Racial disparities in the quality of care may also be partly due to differing payment sources and corporate structures; 97 percent of Chicago’s majority-black homes are for-profit, compared to 71 percent of homes where the majority of residents are white. White-majority homes are also more likely to have more patients paying for their own care, while black-majority homes are more likely to rely on Medicaid payments for their revenue. While a for-profit home is not necessarily any less effective or caring than a non-profit home, the task force heard that the lack of non-profit homes that can solicit donations to support enhanced care has diminished the quality of nursing home care in Chicago’s black communities.

#### **D. Psychotropic Drugs**

**Psychotropic drugs are often over-prescribed to nursing home residents and inadequately monitored, and regulators lack the information and authority to correct this practice.**

“Just eight hours after he moved into the nursing home, state inspection records show, Lloyd Berkley was approached by four employees, one of whom had a needle behind her back. While three of them held down the 74-year-old man, the fourth injected him with a high amount of the anti-psychotic drug Haldol, which quickly sedated him, according to state records. Several hours later, Berkley fell in his room, hurt his head and died at a hospital. The worker with the needle,

investigators discovered, was not licensed as a nurse and did not have a doctor's order to give the man the medication." (Chicago Tribune, 10/27/09).

"A friend of mine died from nursing home abuse and neglect and the side-effects of the numerous psychotropic drugs he received at several Illinois care facilities... He did not have a mental illness... He was given numerous life-threatening psychotropic drugs not FDA approved for Alzheimer's patients for the sole purpose of chemically restraining him so he would not try to escape." (LeeJoy Hoofnagle testimony, 11/19/09).

"People are overmedicated, under medicated, or do not understand the reasons for taking the medications they are currently prescribed... Residents should be reviewing their medications monthly with a psychiatrist. This is not happening." (Access Living testimony, 10/20/09).

The use of psychotropic drugs for nursing home residents with severe mental illness is seen as potentially effective and appropriate treatment when the prescribing physician has properly diagnosed the patient, the patient understands the prescription and has given consent, and medication use is professionally supervised and monitored. Yet the public told the task force that the legally required procedures for use of these drugs were often not followed in many nursing homes:

"State inspection records show that nursing home staffs often bypass the step of trying to calm residents and instead call a patient's doctor seeking a psychotropic drug. The doctors frequently OK the request over the phone without seeing the patient." (Chicago Tribune, 10/27/09).

These incidents are not limited to poorly performing nursing homes; similar incidents also occur at highly rated homes. (Chicago Tribune, 10/28/09). And it was clear from testimony that psychotropic drugs are often prescribed inappropriately and unnecessarily.

State regulators are also constrained by law in what they can do to stop a doctor misusing or over-prescribing drugs for nursing home residents. One Illinois doctor has prescribed one psychotropic drug more often than all the doctors in the state of California (or Florida, or Texas) combined. One researcher suggested the doctor's prescription rate was "70 times greater than what would be expected of even a busy psychiatrist. Yet state regulators' efforts to exclude the doctor from receiving Medicaid reimbursement have failed, twice. (Chicago Tribune, 11/10/09). As stated by a former regulator who co-owns nursing homes himself, "There's no downside for the physicians," who are seldom fined.

Even if a psychotropic drug is at first appropriately prescribed to a nursing home resident, "inadequate understanding of and monitoring of use" of that medication going forward can defeat attempts to treat a resident's mental illness. (Mental Health America of Illinois testimony, 10/20/09).

## **E. Regulatory Enforcement**

### **State regulators lack the necessary authority and staffing to require compliance with existing laws and stop repeat violators.**

“If you are really serious about ending abuse in nursing homes and psychiatric facilities in Illinois, those agencies and officials to whom we are told we should report abuse must be empowered to act. They cannot just be given fancy titles so that it looks like the government is doing something for the elderly... And there need to be strong penalties for those who violate the law. Crimes that occur in nursing homes need to be treated as crimes and not just demerits on the annual Health Department Survey.” (LeeJoy Hoofnagle testimony, 11/19/09)

Even when Department of Public Health regulators cite nursing home operators for violations, fines limited in amount by law and prosecutions that require harm to a specific resident often mean that conditions found in violation of the regulations remain uncorrected. As stated by an aide to State Sen. Heather Steans, who represents a district with a high concentration of nursing homes:

“This past summer, I sent several interns from our office to read (DPH) survey reports and visit all of the nursing homes with mental health patients in our district. At most facilities, the interns observed filthy, disgusting conditions, often in nursing home facilities that had just two months before been inspected and fined by the Department of Public Health. The (DPH) survey reports at most facilities were full of incidents of medical neglect...” (Jennifer Walling testimony, 10/20/09).

“Penalties need to be meaningful to prompt real change.” (AARP testimony, 10/20/09). The maximum fine for nursing home violations in Illinois is \$10,000, an amount seen by Monica Hammer, aide to Chicago Ald. Mary Ann Smith as no more than “a small cost of doing business for nursing homes in our community that gross tens of millions of dollars every year.” (Monica Hammer testimony, 10/20/09).

Ineffective enforcement mechanisms also mean that some nursing homes fall into a repeated pattern of noncompliance. Said State Senator Jacqueline Collins, “There’s a yo-yo pattern – they come into compliance and then fall back into noncompliance, [and] we see the egregious behavior and the problems still continuing.” (Chicago Tribune, 11/6/09)

## **F. Residents' Rights**

### **Nursing home residents aren't aware of their rights, and too few advocates are available on their behalf.**

The task force repeatedly heard testimony that nursing home residents are unaware of their rights, including their right to leave a facility and exercise choice over where they live. While required materials on resident rights are routinely handed out to new nursing home residents, an outside advocate is seen as necessary to ensure those rights become reality.

Illinois' Long-term Care Ombudsman Program was developed to give residents information and independent advocacy to meet their needs. The program "provides advocacy on behalf of long-term care facility residents living in licensed nursing homes, assisted living and shared housing establishments and supportive living facilities. Throughout Illinois, ombudsmen investigate and resolve resident complaints, work to ensure residents are treated with dignity and respect, assist residents and families through education and information, help facilities through consultations and trainings, and represent the interests of residents before government agencies." (Nancy Flowers testimony, 10/20/09).

"Ombudsmen are the eyes and ears of residents and sometimes, they may be the only ones trusted by residents." (Sally Petrone testimony, 10/29/09). Yet they are too few; only 260 certified ombudsmen statewide, of whom only 47 are paid, full-time employees. The DPH functions of investigators and a central complaint hotline are understaffed, causing more referrals to already overloaded ombudsmen.

The Ombudsman Program is seen as a valuable but underfunded tool to advocate on behalf of individual nursing home residents of any age, though most concentrate only on elderly clients. "Most of the ombudsmen never go into the kind of nursing homes the Trib is writing about, because representing residents younger than 60 is optional, and they don't have the time or the training." (Wendy Meltzer, Illinois Citizens for Better Care testimony, 10/20/09).

In addition to the ombudsmen, the Illinois Guardianship and Advocacy Commission's Human Rights Authority has played a role in protecting the rights of patients and residents in nursing homes. This is a citizen-based, low-cost, statewide structure that affects both individuals and systems.

**Appendix 5: Glossary**

ACT	Assertive Community Treatment
CNA	Certified Nursing Assistant
CDBG	Community Development Block Grants
CFR	Code of Federal Regulations
CST	Community Service Team
DCEO	Department of Commerce and Economic Opportunity
DDD	Division of Developmental Disabilities (in DHS)
DFPR	Department of Financial and Professional Regulation
DHS	Department of Human Services
DMH	Division of Mental Health (in DHS)
DON	Determination of Need
DRS	Division of Rehabilitation Services (in DHS)
HCBS Waiver	Medicaid Home and Community-Based Services Waiver
HCCI	Health Care Council of Illinois
HEARTH Act	Homeless Emergency Assistance and Rapid Transition to Housing Act
HFS	Department of Healthcare and Family Services
HHS	U.S. Department of Health and Human Services
IHA	Illinois Hospital Association
INA	Illinois Nurses Association
ILCS	Illinois Compiled Statutes
IMD	Institution for Mental Disease
ISMS	Illinois State Medical Society
LPN	Licensed Practical Nurse
LTC	Long-term care

MDS	Minimum Data Set
MFCU	Medicaid Fraud Control Unit
NAMI	National Alliance on Mental Illness
PAS	Pre-Admission Screening
PAS/MH	Pre-Admission Screening for Mental Health
PASRR	Pre-Admission Screening & Resident Review
PSH	Permanent Supportive Housing
RAP	Resident Assessment Protocol
RN	Registered Nurse
SEIU	Service Employees International Union
SLF	Supportive Living Facility
SMI	Serious Mental Illness
SSI	Supplemental Security Income