

**Testimony Regarding Illinois Nursing Homes & People with Severe
Mental Illness**

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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 (including Institutions for Mental Diseases or “IMD” 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 that same period.
- Illinois is also a national leader in spending on institutional care. In Illinois, 59% of the resources for people with severe mental illness are spent on institutional care and only 41% on community care. Of all available resources, 31% is spent on IMDs alone which serve 1% 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 in and nursing homes and IMDs as well as a third case involving people with developmental disabilities.

Illinois’ policy on the use of intermediate care appears to be outside of national and legal standards for appropriate care for individuals with severe mental illnesses. While I do not believe that there are lots of “good guys and bad guys” in this situation, 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. There are at least five reasons to re-examine our use of nursing homes for people with severe mental illnesses.

- **We are placing seniors in nursing homes at risk.** The mixing of young people with seniors in nursing homes creates opportunities for violence towards seniors. The issue is not simply one of people with mental illness mixed with seniors. It is the inherent problems involved in placing large numbers of people under the age of 55 who do not have real medical conditions in institutional settings with vulnerable seniors. It is simply an invitation to difficulties. These difficulties are compounded by the inadequate behavioral health services in most nursing homes, poor screening practices, and a lack of services to individuals who present higher than average risk.
- **We are spending money defending federal lawsuit over the use of institutional care during a time of fiscal crisis and not living up to the spirit or the letter of federal law.** When one reviews the outcome of an Olmstead case decided this fall in New York, it seems likely that Illinois will ultimately lose its Olmstead lawsuits related to people with severe mental illness. We should stop spending tax dollars defending and start developing a settlement of which we can be proud.
- **We are opening too many institutional beds compared to community services.** For example, the number of IMD beds in Illinois increased from 5,400 in 2002 to 6,100 in 2006 and the cost of each bed has climbed by the year. Contrast that to community care. Adjusted for inflation, the

funding base of community funding has shrunk 15-20% over the past five years at the same time that new billing and compliance related administrative costs have skyrocketed. In short, we are shrinking community care and expanding intermediate care for people with severe mental illness. That is simply bad public policy and it is unique to Illinois.

- **We are spending scarce taxpayer money during a time of fiscal crisis on expensive and unnecessary institutional care.** Each nursing home bed costs \$35,000 to \$40,000 per year. This is significantly more expensive than community care. The IMDs are also far more expensive than community alternatives and cannot collect Medicaid for their work because the Federal Government refuses to sanction and support long term, segregated institutional care for people simply because they have a mental illness. The excessive use intermediate care costs Illinois taxpayers at least \$100 million a year in lost Medicaid revenue and excessive costs. It is also worth noting these homes, generally privately owned, can be quite profitable. Some sectors of intermediate care for people with severe mental illness generated an aggregate profit of 22.4% for the period of 2002-2003. That makes them quite different from non-profit community providers which typically achieve margins of 1-2%.
- **We are reducing the quality of life for thousands of Illinois citizens with severe mental illness and reducing their chances for real recovery and a good life** by relegating them to intermediate care. Few people would want to live in an institutional setting if community alternatives are available. We all know that nursing homes, while necessary for some people at some points in their lives, are not a place that we would choose to live. And it would certainly not be our choice if we were in our 40's or 30's or 20's or even younger. In Illinois we routinely place young people in nursing homes simple because they have a mental illness. Thresholds has even taken teenagers out of intermediate care facilities. These are young people who have no underlying medical condition that requires nursing care and for whom community alternatives work better. They have mental illnesses and are in need of community support and recovery services, not in need of being locked away.

In short, it is a bad public policy that spends far more than necessary to serve people with severe mental illnesses. It is a cruel public policy that relegates people with severe mental illness to marginal lives in institutions with limited opportunity. It is a dangerous public policy that all too often places vulnerable seniors at risk. And it is an astonishing public policy to defend these violations of federal law in court. But this is precisely the situation that we face in Illinois. **Illinois citizens who depend on public mental health services as well as their families, friends, and neighbors deserve better. And Illinois taxpayers who fund these services deserve more responsible fiscal management.**

I refuse to point fingers or take cheap shots at any of the parties to this situation. I am sure that when the policies were put into place to create this dependence on intermediate care, the policies made sense. This situation has been years in the making and there are no villains or heroes in the story. That being said, all of us as citizens of Illinois bear some responsibility for the situation and for addressing it. Those of us in this room have particular responsibility for finding a policy solution that serves the citizens of Illinois better than the status quo does. And I believe that we can.

The solution to this situation is straightforward. It does not take more money. In fact it saves money. It does not require developing exotic community services. Eighty-five percent or more of the residents of intermediate care who are there simply due to mental illness could be served in the types of community services that already exist if only Illinois were willing to fund more of them. Thresholds now routinely moves people with severe mental illnesses out of intermediate care, and we could help many more by shifting funding from intermediate care to community care and increasing Illinois' commitment to assertively leading the development and management of community care alternatives.

We need to get the large majority of people who do not have significant medical needs out of intermediate care facilities and reduce intermediate care capacity for people with severe mental illness. And we need to develop community alternatives to intermediate care. I do not believe that many people would dispute that we have too many institutional beds, too few community beds, and a need to balance the service system. The conversation should be one of "how quickly can we accomplish this" rather than can we or should we. I suggest the following four points as a framework for the conversation.

1. **Consider a Joint Settlement of the Two Olmstead Cases Involving Plaintiff with Mental Illness:** The two Olmstead cases now in federal court have similar requirements for settlement. Both cases require reduced intermediate care capacity and both require significant increases in community capacity to serve people with mental illnesses. The settlement in each case should include attention to the other case in order to avoid unanticipated transfer of individuals between the IMDs and nursing homes. In addition, coordinated and focused activity to develop community capacity will be required and should be done as a single project. While it would be a mistake to hold up one case waiting for the other, the state should consider an assertive and rapid settlement offer for both cases.
2. **Eliminate Most Uses of Regular Nursing Homes for People with Mental Illnesses:** Illinois should take this opportunity to settle the Olmstead nursing home lawsuit and establish clear and firm regulations that prevents anyone under the age of 55 who does not have a specific medical diagnosis that requires significant skilled nursing support from living in a nursing home. In addition, Illinois should limit by regulation the total number of people who can be in any nursing home as a result of mental illness to less than 5% of the daily census of the home. At least 85% of the savings from reduced use of intermediate care should be transferred to the development and operation of community services. These steps to reduce population mixing and risk of violence towards seniors could be phased in over a period of five years. The best IMDs could be strategically engaged in this process to provide placement opportunities for the small percentage of nursing home residents who cannot be easily relocated to the community.
3. **Reduce IMD Capacity by 50-80%:** Illinois should take this opportunity to settle the IMD Olmstead lawsuit. IMD capacity should be reduced by an average of approximately 500-800 beds a year for the next five years and transfer at least 80% of the savings from associated general revenue funding and potential Medicaid match to developing community services. The speed of the capacity reduction should be informed by the efforts to reduce the use of

nursing homes for people with severe mental illnesses. At the end of five years, we will still have approximately 1000 to 2500 IMD beds available for people with unique needs who have been difficult to place in the community. It should be noted that some IMDs offer better services than others. The state should preserve the best of the IMDs to serve individuals who are difficult to place in other settings. After five years, Illinois and the court can evaluate the ability of the state to further reduce the number.

4. **Build Stronger Community Services Infrastructure:** Eliminating most intermediate care for people with severe mental illnesses in Illinois and developing good community alternatives is a substantial project involving the creation of capacity for at least 10-12,000 individuals over the next five years. This project can be successfully completed if Illinois is committed to its success. It will require an investment in infrastructure at the Division of Mental Health and in provider organizations but it will save money over the coming few years. A small working group endorsed by the Governor, led by the Division of Mental Health, supported by the Legislature, and overseen by the court be assembled to lead this project. Outside consultation should be engaged to assist in the planning and execution of the project and to provide a national perspective on strategies for a successful project.

For far too long, Illinois has pursued a policy of institutional care that is overdue for change. The current policy is not in the interest of its taxpayers or its citizens with severe mental illnesses. We need to reverse that course. We have the money and the programmatic leadership to create exceptional community services if we have the courage to act. It is the right fiscal thing to do. It is the right clinical thing to do. It is our legal obligation. It is the right public policy to implement. And it is the right thing to do for our friends, neighbors, and loved ones who have severe mental illnesses. Let us make a real commitment to their recovery and fund community mental health services instead of institutional care. Our citizens deserve better public policy in this area.