

**REPORT OF  
ELIZABETH JONES**

**In the Matter of  
Williams v. Blagojevich  
(Case No. 05C-4673)**

August 1, 2008

## I. INTRODUCTORY COMMENTS

The Institutions for Mental Diseases (IMDs) are aptly named. Each facility, regardless of its size, is an institution that exerts significant control over its residents through the consistent and continuous use of restrictive and regimented practices. These practices do not reflect individualized approaches to treatment; they have been designed and implemented to exert deliberate control over a large group of adults with mental illness. Furthermore, the IMDs are segregated settings. That is, though sited within local communities, often adjacent to stores, transportation and other resources, IMD residents are required to comply with burdensome facility rules before access to the community is granted. Almost all services and supports are offered on site or in a day program whose participants have a mental disability. As a result, any interaction with individuals who do not have a disability is extremely limited for most residents. For the majority of time, most IMD residents remain isolated from typical community events, experiences and people.

I am very familiar with institutional settings. In my more than thirty years of experience in the field of mental disability, I have visited and/or evaluated institutions for people with a mental illness and/or developmental disability in nineteen states and five countries.

I have been the Acting Superintendent of a state facility for adults with a developmental disability, the Director of two psychiatric hospitals and the Court-appointed Receiver for another. Also, I have had considerable experience with the management and/or evaluation of community-based systems. I have managed the day to day operations of two community systems.

In my work as an administrator of both state institutions and community systems, I have had a leadership role in the planning, development and implementation of community-based alternatives to institutions. In particular, my work has focused on creating community residential settings for adults with a long history of institutional confinement.

A copy of my resume is attached.

Based on my professional experience, it is my overall conclusion that the IMDs are antithetical to generally recognized approaches for the treatment of mental illness. The isolation, restrictiveness and dehumanizing characteristics of the IMDs are contrary to expected practices in the field of mental health that emphasize inclusion, individualization and informed choice. Residents of the IMDs have relatively few opportunities to socialize and to experience the resources of their communities, to exercise existing skills, and to develop new ones.

## II. METHODOLOGY

Between February 12, 2007 and April 1, 2008, I conducted at least one unannounced site visit to each of the twenty-six IMDs referenced in this litigation. I visited seven facilities twice and two facilities three times. I spent between one and four hours in each IMD.

During each visit, I observed conditions in the living environments. Depending on the hour, I was able to observe mealtimes, the distribution of medication and resident personal needs allowances, and both structured and unstructured activities. I was able to sit with residents in

their bedrooms, the dining room, the smoking areas and the common areas. I observed interactions between the residents and the staff.

In the time available, I spoke with residents about their experiences in the IMD. Often, I had the opportunity to talk with staff about the routines and practices involved in their work.

I spoke with one hundred and five residents in preparation for this report.

Additionally, I read the facility records for each of these residents. I also reviewed deposition transcripts, documents regarding the practices or management of individual facilities and documents from the Illinois Department of Mental Health and certain other state agencies.

Along with Mr. Dennis Jones, I participated in a meeting with providers of residential services in Chicago. The discussion centered on the availability and array of housing and supports for adults with serious mental illness. I also had the opportunity to visit a community day program and supported apartments in Chicago. In the community programs, I spoke with former IMD residents.

My methodology is consistent with standard practices by which institutions are evaluated by monitoring and accreditation agencies.

My conversations with residents, my observations while in the IMDs, and the information obtained from my review of various records form the basis for my opinions in this report.

### **III. FINDINGS**

#### **A. Background**

The IMDs are intermediate care nursing homes licensed by the State of Illinois. They range in capacity from sixty-one to four hundred and seventeen residents. They are located primarily in Chicago and its outlying suburbs, but there are also IMDs in downstate Illinois. In general, the IMDs are near community services such as shops, restaurants, churches and transportation.

Each of these homes is a large congregate facility for residents with mental illness or another disability. Each home has many of the characteristics of a psychiatric hospital.

The IMD residents I met are between twenty-five and ninety-four years old. They have been admitted from state psychiatric hospitals, psychiatric wards in community hospitals, shelters for homeless people, nursing homes, family homes or other such community settings, and other IMDs. The length of stay for the people I interviewed ranged from thirty years to one year or less. At least twelve of those individuals have lived for twenty years or more in their respective IMDs.

Sixty-two of the IMD residents I interviewed are wards of the Office of the State Guardian. Their guardians make decisions about privileges and community placements.

## **B. The IMDs are Segregated Institutions**

Psychiatric institutions are congregate facilities typically characterized by restrictive rules and practices that prohibit or severely limit opportunities for interaction with non-disabled individuals. As a result, institutionalized individuals exercise little or no control over their personal lives, possessions, or space. There are few opportunities to participate in community events or activities. There is little opportunity for developing relationships with non-disabled people.

Institutions are designed to manage or control large numbers of people. They exercise that control by eliminating choice and personal autonomy, establishing inflexible routines for the convenience of staff, restricting access, implementing measures that maximize efficiency, and penalizing residents who break the rules.

Every IMD is characterized by restrictive practices that curtail autonomy, participation in community opportunities, and interactions with people without a disability.

### **1. IMD residents lack choice.**

For virtually all residents, the lack of meaningful choice is evident in nearly every aspect of daily life. Residents are required to get up in the morning and retire to their rooms at night by a certain time. They must follow the schedule for medication distribution. Meal times are at fixed hours; the failure to be on time can result in the loss of a meal. Residents may be required to share a room with as many as three other individuals they don't know.

The routine of the day is non-negotiable. There is scant flexibility or spontaneity. There are lines — long lines for medication, meals and personal needs allowances. Residents wait because the schedules are for the institution's convenience, not theirs. For example:

- Abbott House has up to one hundred and six residents. Meals are served in shifts. Each resident is assigned a shift. There is half an hour allotted for each meal. Breakfast is from 7:00 to 7:30 a.m.; lunch is from 11:30 until noon; dinner is from 5:00 to 5:30 p.m. Snacks are served at 2:00 p.m. and 7:30 p.m. Coffee time is from 1:14 to 2:30 p.m.
- Medications are distributed four times a day at Abbott House. You must be present at your scheduled time.
- At Somerset Place, the approximately four hundred residents are called to the dining room by floor. Residents on the "eating program" eat in the first half hour; for breakfast and lunch, all other residents eat in the remaining hour and three quarters. There is only an hour and three quarters allocated for the entire dinner meal.

Additionally, the individuals now living in the IMDs required a residential placement in order to leave a psychiatric hospital or nursing home or to avoid being homeless. A number of residents with whom I spoke were not given an informed choice about admission to the IMD. Rather, decisions were actually made for them or heavily influenced by hospital social workers, psychiatrists, family members, staff of their then current residential program or a guardian. The alternative living options presented were very limited.

For example:

- Administrative staff at Rainbow Beach and Albany Care informed me that residents did not see those IMDs before admission. These two IMDs have a capacity of two hundred and four hundred and seventeen residents respectively.
- T.S. said he wanted an apartment and was offered four IMD options instead. He was required to select one of the four in order to have a place to live.
- J.P. was taken for a ride from Abbott House to Bayside Terrace. Without any notice and without her consent, she was told that she would live at Bayside Terrace from now on. She lost all of her belongings in this move.
- There was no informed choice for M.C., R.R., I.P., B.C., B.P., M.A., J.J., Z.J., and J.H.

The lack of choice about placement has created emotional stress and trauma for many residents. In our conversations, residents told me of their discomfort and their fears that the IMD would be a permanent placement. Residents described their feelings of hopelessness and loss of autonomy. They explained to me that the lack of choice has resulted in lethargy and despair. In contrast, a former resident explained the renewed energy and confidence he gained when he left the IMD for a community placement.

These troubling emotions are identical to those described to me by individuals once confined, for as much as decades, to the psychiatric hospitals I supervised.

## **2. IMD residents lack privacy.**

In addition to the lack of choice, there is an uncomfortable lack of privacy. Telephones are in public areas and conversations can be overheard. Some residents share a bathroom with eight or more people; some IMDs have the bathrooms in the hallway rather than adjacent to the bedroom. Doors do not always lock. Staff may enter without knocking. Storage space for personal belongings is very limited. Privacy curtains around beds are used in several of the IMDs, limiting personal space even more. The common areas are noisy and crowded. As a result, many residents simply remain in their rooms, often lying on the bed. These environmental conditions are not conducive to recovery from a mental illness.

## **3. There are constraints on social interactions in IMDs.**

The environment, the control and the lack of choice impact residents in other important ways. There are extremely limited opportunities to participate meaningfully in community life.

Because of the restrictions on access at certain facilities, some residents are not able to leave the institutional setting. For example:

- D.S. has not left the building in a year except to go to her day program.
- Five years ago, D.W. went to McDonalds. He has not gone anywhere since then.

- J.C. is not allowed to go outside; she is not certain of the reason for this decision.

To the best of my knowledge, there are restrictions on community access in every IMD.

Bayside Terrace requires signing in/out, and community passes are limited to three hours before the 6:30 p.m. curfew.

At Thornton Heights, a resident must earn points to go outside.

The policy at Skokie Meadows defines a visit to the community as a privilege, not a right.

Kankakee Terrace, Rainbow Beach, Lake Park Center, and Sacred Heart have much stricter controls including, in some of these facilities, petitioning for community privileges, requirements for accompaniment by a peer, and limited hours for community outings.

At Rainbow Beach, a resident who returns fifteen minutes late may be given a ten-day restriction; more than fifteen minutes incurs a fourteen-day restriction on community access.

The restrictions are relatively limited at Abbott House, Belmont Nursing Home, Greenwood Care and Margaret Manor. But even these IMDs, which are unlocked, require compliance with a curfew and a sign-in/out procedure.

The lack of full access to community-based resources and experiences is detrimental to recovery from mental illness, especially since the treatment program options for IMD residents are so limited.

During my site visits, the majority of residents I observed were sitting with little or nothing to do. In virtually every IMD, residents sat in the day rooms unengaged or watching TV. Residents sat in the hallways and in the smoking areas. At Sacred Heart, residents stood by the front door but did not leave the building. Residents sat in their rooms. With the exception of Sharon Health Care Woods, I saw very few residents outside the confines of the facility. My overwhelming impression is of prolonged inactivity.

The majority of available programs or treatment groups are conducted within the IMD setting. Although there appear to be group activities scheduled each day of the week, in fact, these groups are very brief (usually thirty minutes) and consist of repetitive instruction. I observed that some planned activities did not occur as scheduled. There is didactic instruction on community living skills but very little opportunity to actually practice those skills in a community setting.

Relatively few residents attend outside day programs. For example, only twenty one out of one hundred and ninety eight residents of Wilson Care attend an outside program. The administrator at Rainbow Beach informed me that attendance at outside day programs has significantly declined and that most programming occurs on site. Although residents appear to enjoy the opportunity to leave the IMD, there is little evidence that treatment goals and outcomes are coordinated across treatment settings.

Some residents work on housekeeping and other facility-tasks within the IMD. For example, in exchange for a stipend or non-monetary rewards, they collect trays in the dining room or wipe

tables after meals. Very few residents have the option of competitive employment in a community business. This is particularly unfortunate because research has demonstrated that competitive employment is a powerful tool for recovery from mental illness. Many of the residents I spoke with desired to be employed with a meaningful wage. Rules regulating employment create very substantial disincentives for IMD residents to seek gainful employment and develop skills and relationships associated with the work environment. This is a significant disadvantage for IMD residents who are interested in exercising self-determination, maximizing social relationships, and moving aggressively toward independence.

#### **4. There is evidence of dehumanizing practices in IMDs.**

There are obvious reminders of confinement and control. The outdoor area at Sacred Heart is surrounded by a metal fence topped with razor wire. Mail is opened for the residents at Monroe Manor. Residents at Belmont Nursing Home were noted to be subdued and passive. A former resident of Belmont explained to me that staff were particularly harsh.

At Wilson Care, the progress notes for R.G. revealed a prison guard-like attitude by staff. An April 24, 2007 note stated “. . . resident was loitering in the lobby waiting for an opportunity to escape” and, later, on May 31, 2007, “Resident escaped the facility this month.”

During my three hour visit to Sharon Health Care Woods, staff were playing pool with each other while many of the residents slept. Some residents appeared groggy and detached. Clothing was filthy and some residents lacked shoes. There were minimal furnishings, little personalization of rooms, and constant noise. Most residents must remain at the facility; they do not go to outside day programs.

At Decatur Manor, staff intimidation of residents was documented in a Department of Public Health inspection survey. Staff paged the code “Mr. Bubbles” so that other staff, including maintenance men, could present a show of strength and force a resident to bathe. (Other serious risks have been documented in inspection reports, including falls and other injuries, high medication error rates, and the failure to treat life-threatening health conditions.)

Loudspeaker noise is deafening in certain IMDs, including Lydia Healthcare Center with the capacity for four hundred and twelve residents. It is extraordinarily difficult to hear, speak or think.

In these often chaotic institutional environments, the crowding, noise, lack of private space, poor supervision and lack of meaningful activities create emotional stress and physical discomfort for the residents. Overall, it is my strong observation that the IMDs are not “safe havens” for people with serious mental illness.

#### **C. The Vast Majority of Residents I Spoke with About their Residential Placement Would Choose to Leave the IMDs. However, Discharge Planning is Virtually Nonexistent.**

In my opinion, discharge from the IMDs appears elusive. I spoke with seventy-seven individuals about their residential preferences. Sixty-six individuals told me clearly and emphatically that

they would decide to live elsewhere, if given a choice. An apartment with supports was the residential choice mentioned most frequently.

It is important to note that most of the individuals who were uncertain or hesitant to leave the IMD at this time cited concerns about benefits, were undecided about making a change now, were fearful of a setback, or felt vulnerable or afraid. In my experience, these are understandable and not uncommon concerns of institutionalized individuals. These concerns usually evaporate after placement occurs. Otherwise, they can be addressed through a trusting relationship, by first hand knowledge of community-based options, and by the availability of flexible supports that can be tapered-off or adjusted once the individual feels more confident.

I know from my own work with institutionalized adults that there must be strong support throughout the discharge phase. The successful transition from an institutional setting to one that is more integrated and less restrictive requires individualized discharge planning, responsiveness to any problems or concerns and encouragement from professional staff and significant others. Institutional staff cannot be permitted to undermine the community placement.

Unfortunately, the discharge planning in most of the cases I reviewed is seriously flawed. I reach that conclusion after reviewing one hundred and five records to determine the nature and extent of discharge planning in the twenty-six IMDs.

Meaningful discharge planning is virtually non-existent for most IMD residents. In fact, some residents' records did not even contain any discharge planning forms.

#### **1. Staff make improper decisions about discharge planning.**

Improper discharge planning decisions by IMD staff have contributed to residents being unable to leave the IMDs. I note the following examples of such decisions about the implementation of discharge planning:

- Skokie Meadows uses a scoring system for discharge planning. C.H. received a score of 62% instead of the mandatory 80% score. His discharge planning was discontinued. This resident is reported as capable of unsupervised pass privileges, and was willing to work hard to find gainful employment and to learn new skills. According to his record, his score was decreased because he lacked the presence of a support system, lacked self-sufficiency in independent living skills, used tobacco, and didn't have a wellness lifestyle.
- G.P. is an elderly woman who wishes to leave Lydia Healthcare Center. She has many documented strengths including physical functioning, care of possessions and living space, social acceptability, money management, shopping, use of leisure time, self-medication, following directions, completing tasks, seeking help, knowing her diagnosis and medications, and not using alcohol or drugs. Her treatment priorities are bathing and interpersonal relationships. There are no discharge goals. Her weaknesses are described as grooming, bathing and preventing falls. She is also cited for lacking employable skills, even though she is nearly eighty years old.



- S.T.'s discharge potential is described in his record as fair to poor; that is, he asks repetitive questions of staff on a daily basis. He requires verbal prompts to change his clothes and to complete his personal hygiene and care. He also requires verbal prompts to attend programming and to participate in group activities. He is said to lack insight into his mental illness as well as lacking medication knowledge. He repeatedly goes into the community and eats foods that are not in his diet.

From my many years of experience, I know that all of these identified concerns could be addressed in the community with the appropriate supports. These individuals are very similar to the hundreds of individuals with mental illness that I have seen successfully placed in community-based residences during my career as an administrator in the field of mental health. As demonstrated by the research of Stein and Test, it is well known and accepted in the field of mental health that it is simply unnecessary to first learn skills in an institutional setting; indeed it is contrary to expected practice.

## 2. Discharge planning does not occur in a timely fashion.

In my professional work, comprehensive discharge planning should begin at the time of admission to a psychiatric facility. All constraints and needs should be identified, strengths and resources should be described, and any treatment goals should be focused on discharge. In the IMDs, discharge planning does not take place at the time of admission.

For example:

The discharge plan for S.T. was first drafted in 1999 ----- three years after his admission. The same discharge plan is reviewed each quarter; it has not been revised or updated.

During my review, I also noted a serious lack of urgency in establishing timelines for discharge. This contributes to many residents languishing for years in IMDs.

For example:

- Grasmere staff thinks that J.D. may be capable of increased independence in a group home in three to five years. He needs assistance with medication management and budgeting. Both of these supports are available now in community programs.
- The record for C.N. documents his wish to be discharged and states that he has a support person who is positive about his community placement. Yet, discharge is anticipated to be more than one year away.

These two residents have been living in these IMDs continuously for six years and eight years respectively.

Some of the IMD residents I spoke with are deeply affected by these delays. They told me:

- I would like to leave because I don't have my freedom.

- I want (to leave) with all my heart . . . . I have had enough. I want to go where I am not a patient.
- Nursing homes do not tolerate people who want to leave.
- I don't like it at all. The quicker I go home the better I'll be. (This resident has lived at Rainbow Beach for twenty years.)

Only three of the one hundred and five residents I interviewed are receiving assistance with discharge planning from a community agency. The record for one of these three, O.C., however, does not reference collaboration with the community provider. The progress notes for another of the three, M.S., indicate that he is being reviewed for independent living by a case management agency but there is no indication of any specific plans or options.

Only five of the individuals I met have since been discharged. Four of these residents were discharged to other institutional settings:

- Two elderly women, one who was ninety-four years old, were discharged to another nursing home. Both were described as anxious and tearful at the time of departure. There is no evidence in their records that indicates that trial visits or other supports were offered to them. There is no evidence that they participated in the decision about their relocation.
- One male resident was discharged to a hospital for medical treatment after experiencing abdominal pain and several months of significant weight loss.
- One younger resident was discharged, apparently after transfer to a psychiatric hospital.
- One woman went to court and had her guardianship dissolved. She then moved to her own apartment. There is no evidence in the record that she received support from the IMD or any community agency.

The Minimum Data Set (MDS) is standardized information describing the individual resident of an intermediate care nursing home. Information is reported at the time of admission, quarterly and whenever there is a significant change. My review of the records indicates that the MDS information about discharge preferences (Section Q) is unreliable and should not be the basis for estimating discharge-related needs on either an individual or systemic level. Conflicting information about discharge was evident in numerous records, including those for thirty-four of the residents who expressed to me their distinct preference for community placement. Nonetheless, the MDS data I reviewed indicates that at least twenty-nine of the residents I spoke with about their residential preference would prefer to return to a community placement.

If the individual choices of IMD residents who desire discharge are to be respected, discharge practices must be changed.

#### IV. CONCLUDING REMARKS

Based on my observations and my experience, it is my professional opinion that the twenty-six IMDs I visited during the course of my review are segregated institutions. In fact, the State of Illinois agrees that these facilities are institutions.

The controls exercised over the IMD residents are clearly evident:

Access to resources and social opportunities in the community are often curtailed. The IMDs segregate residents from their communities by their restrictions on autonomy, choice, privacy and access to sustained and meaningful contact with people who are not disabled. The inflexible and controlling practices of the IMDs prevent residents from exercising independence in their everyday routines.

Discharge planning is non-existent for the majority of residents. The IMDs have established requirements that skill development must occur prior to discharge. These are unnecessary requirements when community supports are individualized and available. Delays in discharge are counterproductive and create frustration and a sense of hopelessness for IMD residents who wish to live in a supported apartment or its equivalent. Additionally, there is the risk that skills will be eroded.

Individualized approaches to care and treatment are not available for most IMD residents. Practices are designed to manage large numbers of adults with a mental illness.

Treatment options are inadequate. Residents rarely have the opportunity to be employed and fulfill their desire for productivity and economic self-sufficiency. Group activities are limited and repetitive. There is weak coordination, at best, between the IMD and any community-based day program. Residents do not have the opportunity to practice skills across settings.

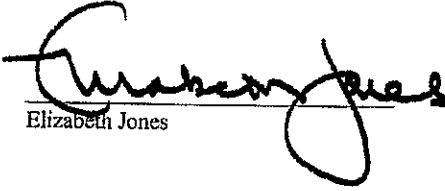
The institutional setting is dehumanizing. Privacy is extremely limited as are the opportunities for choice in activities of daily living. There is unacceptable risk in the environment caused by such factors as crowding, confinement, poor supervision, and the lack of meaningful activities.

The majority of residents I interviewed would prefer to live in a supported apartment or its equivalent. Placement in a supported apartment would enable each resident to receive more appropriately individualized treatment for his/her mental illness. Such a placement would be consistent with the policies of the State of Illinois that promote independence, self-determination and recovery from mental illness. Such a placement would permit social interactions with non-disabled peers, employment with appropriate supports, and use of mainstream community services and housing.

In the end, it is my professional opinion that the Institutions for Mental Diseases are outdated models for the treatment of mental illness. They are truly reminiscent of the substandard back wards in state hospitals that I encountered early on in my professional work. My review also indicates that these institutions are operated as if they were very long term placements.

In every aspect of their nature and practice, the Institutions for Mental Diseases are clearly not representative of contemporary expected practices in the field of mental health.

Dated: August 1, 2008

  
Elizabeth Jones