

Williams V. Quinn
Case No. 05-4673
(N.D. Ill.)

Annual Report to the Court

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I. Scope of Report

This is the fourth Annual Report to the Court regarding compliance with the Williams Consent Decree. As of December 31, 2014, the State is six (6) months into the fourth year of the five year compliance agreement. This Report will review the mid-year compliance status for year four and (as in past Reports) also discuss systems issues that directly impact overall compliance.

II. Assessment of Current Status and Year-to-Date Compliance for Year Four

A. Outreach to IMD Class Members

DHS/DMH has continued its contract with the National Alliance for the Mentally Ill of Greater Chicago (NAMI-GC) as the primary strategy for outreach to class members. The NAMI-GC role continues to include contacting all new IMD admissions, providing updated information to interested class members, follow-up with class members who have previously declined to participate and assisting with linkage and support to class members during the transition process. The outreach workers continue to perform the initial pre-transition Quality of Life Survey.

There have been multiple positive developments over the past six months as relates to outreach:

- 1) At the Monitor's request, DMH undertook an analysis to determine the unduplicated number (and percentage) of class members who have declined a resident review. Previous data (as reported to the Court) has been the duplicated cumulative percentage of refusals. This percentage has been around 50% refusals over time and has increased slightly year to year. However, the unduplicated cumulative analysis shows a much improved picture – with 31% of class members

refusing a resident review. The major difference is simply a reflection of individual class members saying “no” multiple times over the past 3.5 years of implementation. However, this lower percentage does not obviate the need for continued affirmative outreach efforts for the refusers.

- 2) Beginning in August 2014, DMH put in place a new initiative called Moving on Ambassadors. Ambassadors are class members who have successfully moved to the community and have come forward to assist in sharing their experiences with class members still in IMDs.

With the assistance of NAMI-GC, specific Ambassador community meetings have now been held in all of the 24 IMDs. The focus is for Ambassadors to share their stories and discuss both the positives and challenges they have encountered. The first round of Ambassador meetings has included approximately 580 class members in attendance – with 36 Ambassadors presenting. As a direct result of this initiative, 35 class members requested to be reviewed for possible community placement. Ambassadors receive a small honorarium for their efforts. Subsequent rounds of community meetings will occur over the next six months.

DMH has also – through the NAMI-GC – begun to actively promote the Williams Drop-in Centers. Each Drop-in Center has conducted an “EXTRAVAGANZA” – a social event targeted specifically toward class members who are uncertain or negative about community living. Outreach workers have actively supported these events – providing materials, brochures and resources. Outreach workers have also provided travel guides with specific direction to the individual Drop-in Centers.

3) External Reviews

Two external reviews of the outreach process have recently been conducted. The University of Illinois at Chicago (UIC) is in the process of finalizing a detailed review of class members who have refused to be evaluated. This report should be completed soon and will be discussed with the parties as part of the ongoing discussions about outreach.

The Court Monitor has also contracted with an independent consultant to review outreach activities and factors that might impact refusal rates. This report has been recently submitted, and a copy is attached as Exhibit 2.

Among a number of insightful findings are the following:

- Some class members have become comfortable with the structure and supports of the IMD and are adamant about not moving.
- There are many class members, especially those with long terms of residency in an institution, who need a more intensive and individualized approach of education and support before a decision is made whether to consider transition to the community. This group would benefit from more community experiences, such as shopping for groceries, doing laundry, and visiting the Ambassadors' homes, before and also during any transition. This group has understandable anxieties and fears regarding their abilities to be successful and the level of support they will receive.
- The protracted delays in the transition process have negatively affected Class Members' interest and confidence in moving out of the IMDs.

- The outreach workers' limited time in the IMDs has undermined their effectiveness. Additionally, access issues and the lack of privacy at some IMDs has negatively affected outreach.
- The Ambassadors are a vital resource and should play an expanded role as informed peers – working closely with the outreach workers to afford the community familiarizing experiences which could lead to a more informed decision on the part of class members.

In terms of overall compliance, the Court Monitor continues to find State defendants in general compliance on outreach. DMH has continued to demonstrate a willingness to try new strategies to inform and support class members about their choices. The Ambassador initiative is a very promising model and should be continued and expanded. The external consultation points to the fact that additional work on the front end is needed with some class members who feel fearful about their ability to successfully transition. Overall, the amount of activity in reviewing and expanding outreach activities is impressive and should lead to further success, if expanded as recommended.

B. Resident Reviews

Lutheran Social Services of Illinois (LSSI) and Metropolitan Family Services (MFS) continue, via contract with DMH, to perform all of the Resident Reviews. As of December 8, 2014, a total of 4,602 Resident Reviews had been completed – with 61% having been referred to transition. After factoring in the outcomes of the Clinical Review Teams and the appeal process, however, the cumulative referral rate for transition is at 67% - which, while still

lower than expected, compares favorably to the 59% cumulative rate as of the January 9, 2014 Annual Report to the Court.

The July 17, 2014 Amendments to the Implementation Plan (I.P.) outline a number of requirements to enhance the Resident Review process. Among those requirements (and current status) are the following:

- 90 Day Re-approach - The new DMH Participation Agreement with Class Members indicates that Resident Review agencies will re-approach (within 90 days) Class Members who refuse a Review but indicate potential interest in the future. The new Participation Agreement also makes explicit that participating in a Resident Review does not obligate a Class Member to move.
- Neurological/Diagnostic Evaluation – The Amended I.P. calls for the development of State capacity to evaluate Class Members who – as part of the Resident Review – exhibit concerns as to possible dementia or Alzheimer’s disease or severe cognitive impairment. DMH is actively working on the development of an inter-Governmental Agreement (IGA) with the UIC Departments of Psychiatry and Occupational Therapy to perform specialized assessments on the approximately 125 Class Members who fall into these categories. Once the IGA is executed, it is estimated that it will take eight months to complete these assessments.
- LSSI and MFS Disparity Review – DMH conducted a number of probes as to the significant percentage differences between the two agencies in terms of referral rates for community placement. The net result of these efforts has been to identify two operational strategies to ensure greater consistency. The first is enhanced training – which will hopefully be accomplished as a part of the proposed Center for Innovation in Community Integration and Social

Inclusion. This proposed IGA is with the UIC School of Social Work and would include a variety of training and consultative efforts toward all of the Olmstead cases and agencies. The second initiative is for DMH to monitor and refine the class member profiles as developed by the two agencies. As an example, there were noted differences in the randomly sampled reviews as analyzed by DMH staff. One Resident Review agency tended to focus more on historic deficits and current negative symptoms; the other agency reflected a more balanced picture – noting strengths and areas for needed improvement.

The Court Monitor strongly supports the DMH approach of enhanced training and ongoing oversight and review of the two agencies – with a goal of balanced and consistent evaluations. It should be noted that both agencies continue to trend upward in terms of positive recommendations – with one agency having gone from 59% to 65% (over the past six months) and the other from 78% to 84%. The 19% differential continues to be of high concern, but hopefully the DMH interventions will continue to make an impact.

Overall, the Court Monitor continues to find the State in partial compliance as relates to Resident Reviews. The Court Monitor is pleased with the DMH response to the amended I.P. requirements for Resident Reviews. Continued oversight of the Resident Review agencies should yield common strengths-based approaches to the Reviews and increased consistency in terms of outcomes.

C. Transition Coordination and Community-based Services

DMH contracts with eighteen (18) community providers to serve Williams Class Members – with eleven (11) of these providing a full array of services and seven (7) providing transition only

services. DMH has finalized its new contract with a consortium of two agencies in Lake County – precipitated by the decision of the Lake County Health Department/Behavioral Health to not expand its Assertive Community Treatment (ACT) teams beyond current capacity. The New Foundation Center has agreed to provide ACT services for new Lake County IMD Class Members who require such services. The Northpointe Center will assume responsibility for transition coordination and also conducting clinical reviews. The New Foundation Center has hired staff who have completed extensive training via DMH; they are currently using Community Support Services only pending their ACT certification.

As of December 8, 2014, 2,695 Class Members have been referred to a local provider for transition; of this total 1,102 have been “offered placement,” which means that a Class Member has either physically moved to the community or has a signed lease. The year four “offered placement” cumulative requirement is 1,306, which means that DMH will need to offer placement to a minimum of 346 Class Members beyond its June 30, 2014 placement total of 960. DMH will need to average approximately 29 placements per month to achieve its annual requirement; on a year-to-date basis, it is averaging 28 per month. However, there appears to be some slippage in recent months – not unexpected with colder weather and the holidays. It should also be noted that DMH is budgeted to offer placement to 389 Class Members this year – 43 more than the minimum required.

In addition to the slow pace of the transition process evidenced by the numbers of those approved but not yet placed, the State continues to struggle with those Class Members who are currently in the “Unable to Serve” category; this group of Class Members have been recommended for community transition but the selected community provider has responded to DMH that they cannot meet their clinical/support needs. The number of Class Members in the “Unable to Serve” category continues to grow month-to-month and

as of December 8, 2014 was at 212. The DMH, to its credit, has successfully moved twenty (20) Class Members into the first cluster housing project – an intensive housing model with staff on site at all hours. This project has been viewed to-date as very successful. Still, these 212 Class Members are persons who have been found eligible to transition to community living.

A recent meeting was held with the Court Monitor, the parties and four (4) of the larger community providers to discuss the specific reasons for the “Unable to Serve” determination and to explore specific strategies for tackling this problem. In general, the providers present see the need for more intensive living settings with 24/7 staff – which could include supervised residential settings as well as additional cluster housing units. As an outcome to this meeting, the State agreed to put together a workgroup including providers in the near future to develop a series of concrete steps to address the providers’ concerns, and facilitate their acceptance of a higher number of those class members previously found “unable to serve”.

Overall, the Court Monitor continues to find the State is not in overall compliance as relates to transition and community services. The State continues to meet its overall numeric requirements for placement but needs to make serious progress on the “Unable to Serve” population before it can be deemed to be in compliance. The recent discussions with key providers (and the development of a fast-track workgroup) are seen as positive developments. It is also incumbent on the State to move forward with its commitment to contract (via the amended I.P.) with two out-of-state providers who have demonstrated success with this high-need population. The Court Monitor recognizes the need for high-intensity living options, but also believes there are community-integrated ways to achieve this goal.

D. Housing

The cross-agency collaborative housing effort has continued – with the Governor’s office, the Illinois Housing Development Authority (IHDA), DMH, the Corporation for Supportive Housing (CSH) and local providers as full partners. Among the initiatives of the past six (6) months are the following:

- Cluster Apartment Model – As referenced in IIC, the State has successfully implemented the first Cluster Apartment Model of 20 units at Bryn Mawr/Belle Shore Apartments. Thresholds, a large local provider, is providing the 24-hour on site staff. The actual apartments are scattered throughout the buildings. There is currently discussion underway at two other sites – with the potential for adding another 30 units. This model will be specifically targeted toward the “Unable to Serve” Class Members.
- HUD Section 811 – IHDA and HUD have, after significant delays, finalized the Cooperative Agreement that frames the implementation of the Section 811 Program. The overall goal of this initiative is still to produce over 800 permanent supportive housing units for persons with disabilities – including Williams Class Members. However, it does not appear that this program will provide much near-term support for Williams Class Members – largely due to the time lags in developing units and the mismatch between where Class Members want to live and where developers want to develop or rehab units.
- Public Housing Authorities – The State continues its efforts to work with Public Housing Authorities to secure dedicated units for persons with disabilities. There has been ongoing work with the Chicago Housing Authority, which had committed 400 housing vouchers as a part of the 2012 Section 811 application. Most recently, State officials have

attempted to match eligible Class Members with the newly reopened waiting list; it is unclear how many Williams Class Members will be approved as a part of this onerous process. The Housing Authority of Cook County (HACC) has continued its commitment to use up to 10% of its annual turnover for persons with disabilities transitioning from institutional settings.

- Supportive Residential Expansion – As a part of the overall need for community-based housing, there is ongoing demand by providers and others for 24 hours supervised residential settings. DMH is attempting to meet this need by adding two additional 10-12 bed Supervised Residential Settings – with a target for beginning implementation in February-March 2015. The overall policy intent is to use these Supervised Residential beds as time-limited – with the goal of then transitioning Class Members to integrated Permanent Supportive Housing (PSH) locations. DMH is also conducting monitoring visits to existing Williams Class Members to determine if some of these individuals could, in fact, move to PSH units. To date, most of these Class Members show the need – due to medical complexity – for continued stays in a supervised setting.
- Role of Corporation for Supportive Housing (CSH) – The CSH continues to play a vital role (under contract) for the State. CSH continues to facilitate discussions between and among DMH and housing developers, advocates and investors. CSH also conducts periodic trainings to key stakeholders – including landlords, State level housing conferences and State staff.

Overall, the Court Monitor finds the State in continued compliance as relates to Housing. Despite delays and frustrations on some fronts (e.g. HUD 811), the dedicated housing staff have pressed forward to find new opportunities. The Court Monitor supports the State's efforts

regarding new Cluster Apartment capacity. As relates to Supervised Residential demand, the Court Monitor strongly encourages that DMH critically look at the utilization of Supervised Residential units across the board and not just for Williams Class Members. To the degree that this setting is needed and utilized, it should be reserved only for those persons with very complex needs who would otherwise be confined to an IMD.

E. Service Enhancements

The State has continued its efforts to expand/enrich services via State and/or Federal initiatives. Three of the most notable service enhancements include:

- Balancing Incentive Program (BIP) – As a part of the Affordable Care Act, States that spend less than 50% of their total Medicaid long-term costs on community-based services for 2009 qualify for enhanced Federal Medicaid match. Illinois applied and will receive a 2% enhanced match for July 1, 2013 to September 30, 2015. Specific Williams-related services enhancements include: In-Home Recovery Supports – an intensive peer-driven opportunity for newly-placed Class Members; Drop-in Centers – with the addition of two (2) Drop-in Centers in the Hyde Park and West Loop; and Enhanced Skills Training – targeted toward Class Members who need help with learning basic living skills in order to live more independently. All of these BIP services are scheduled to be available in early calendar year 2015.
- Supported Employment – Illinois has had a very successful evidence-based practice of supported employment since 2005. This program is referred to as Individual Placement and Support (IPS). It works intensively with persons with Serious Mental Illness (SMI) to find and maintain regular jobs of their choice. There are currently 91 Williams Class

Members who are enrolled in IPS and a cumulative total of 42 Class Members who have worked.

DMH has recently received a new Federal Grant to enhance supported employment for persons with SMI in the Chicago Woodlawn and Edgewater neighborhoods. The Court Monitor is hopeful that this grant – along with the recent Illinois Employment First Blueprint – can provide leverage for greater focus on employment for Williams Class Members. At this stage of the Williams case, it is critical that DMH look for ways that Class Members who are interested can move to the next level of community integration. Supported employment has a proven record in promoting self-confidence and enhancing living skills.

- Comparable Services – As discussed in the earlier Reports to the Court, SB 26 (2013) created the opportunity to fund “comparable” community-based services to those authorized for the re-purposed IMDs/SMHRFs. These community-based services include an array of crisis-related services and supports – including crisis assessment/linkage, discharge linkage, transitional living centers and transitional supervised residential. DMH has funded three (3) collaborative programs in Cook County and also in Kankakee and Decatur. The initial report shows that 1,750 total crisis services have been provided and that important linkages have been established with Hospital Emergency Departments (EDs) and Inpatient Psychiatric Units. The Court Monitor is pleased that these programs are up and operating – with the potential for directly impacting admissions to IMDs. In IIIA, the Court Monitor will discuss recommendations for further action in this area.

F. Quality Assurance

As with the July 1, 2014 Interim Report to the Court, the Court Monitor continues to track the multiple aspects of the overall quality assurance program that DMH utilizes for Williams Class Members.

1. Critical Incident Monitoring

Exhibit 1 (attached) details all Reportable Incidents for the six month period of 4/1/14 through 9/30/14. In review of the data it is important to differentiate the continued use of the new three distinct levels as follows:

Level I – Urgent; Critical Incidents: Situations or outcomes that result in adverse occurrences impacting life, wellness and safety.

Level II – Serious Reportable Incidents: Situations or outcomes that could have implications affecting physical, emotional or environmental health, well-being and community stability.

Level III – Significant Reportable Incidents: Situations or occurrences that could possibly disrupt community tenure.

The Court Monitor makes the following comments regarding Exhibit 1 and the other relevant documents:

- The percentages among the three (3) categories are consistent with the prior six (6) month period (October 1, 2013-March 31, 2014) with Level I at 8% of total incidents, Level II at 82.2% and Level III at 9.8%.

- The total reportable incidents for this period (512) were from 260 Class Members. During this 6-month period, there were an average of 931 Class Members who had been transitioned – reflecting the fact that 28% of Class Members accounted for all of the incidents. Conversely, 72% of Class Members were incident free during this 6-month period. This is congruent with the Court Monitor’s Supplemental Report to the Court on November 8, 2013 – which reflected that 70% of Class Members were incident free at that point in time.
- The largest single cause of reportable incidents (352) continues to be for those Class Members who have an unexpected visit to a hospital emergency room and/or an admission. While this is not out of line for persons with Serious Mental Illness (SMI), it nevertheless bears further analysis from DMH to determine if additional preventable actions could be taken.
- There were four (4) deaths during this period. Two were from natural causes, one was ruled an accidental overdose of prescribed medicines and one was ruled a suicide.
- The Court Monitor reviewed over 40 Incident Reports for Levels I and II categories for the time period of May-August 2014. The review was intended to examine issues of timeliness, thoroughness and follow through with providers. From this analysis and discussion with DMH staff, the following action steps are being taken: 1) DMH is seeking to add an additional position to oversee and conduct staffings with provider agencies. The current volume is more than one staff person can handle and has resulted in limited staffings on Level II Reports. 2) Contract with UIC School of Nursing to do mortality reviews. It is

important that an independent review occur for all deaths – looking both at individual deaths but also conducting an aggregate review of all deaths to assess any trends or potential for systemic interventions. This Intergovernmental Agreement (IGA) may also include a similar issue/need for the Illinois Department on Aging (IDoA) regarding the Colbert case.

- The newly constituted SMHRFs are in the process of gaining provisional licenses (see IIIA). In future periods, the Court Monitor will seek to compare and contrast critical incidents between the IMDs/SMHRFs and community settings.

2. Quality Monitoring

DMH continues to employ ten (10) full time Quality Monitors – who visit Class Members at regular intervals post transition (30 days, 3 months, 6 months, 12 months, 18 months). The Quality Monitors continue to play a vital role in facilitating discussion between Class Members and providers if unresolved service issues are presented.

There are now a growing number of Class Members who are beyond the 18-month post transition period. This was originally anticipated to be the end point of Quality Monitor visits; however, DMH has determined that, on a case-by-case basis, some Class Members will continue to receive Quality Monitoring visits.

3. Quality of Life Survey

The standardized Quality of Life Survey continues to be administered to Class Members pre-discharge from the IMD and then at the 6 month, 12 month, and 18th month intervals

post discharge. The Evaluation of Care Survey is a subset of the overall Quality of Life Survey and has been administered to 454 Class Members prior to discharge and 352 Class Members at the 12 month mark as of November 2014. The Evaluation of Care tool elicits responses in seven (7) domains: access to care, quality and appropriateness, outcome, participation in treatment planning, satisfaction, functioning and social connectedness. The overall satisfaction is considered a composite indicator; the most recent analysis shows the continued major gap in overall Class Member satisfaction in the IMDs (65%) versus Class Member satisfaction among those who have transitioned from the IMDs to community settings (90%).

4. Community Tenure

As of November 2014, fully 86% of Class Members who have moved to the community have remained in community settings. This is consistent with prior Reports and is considered a strong indicator that the large majority of Class Members can and do succeed in community settings. There are now 556 Class Members who have been in the community for over a year and 201 over the two year mark. Further study should determine why these Class Members have been successful – and why those who have returned to the IMDs did so (and why they returned to IMDs rather than move to other community settings).

Overall, the Court Monitors finds that the quality assurance system is continuing to operate in a multi-dimensional and acceptable manner. It is critical that additional incident monitoring staff resources be added – given the growth in volume. The mortality review process needs to be done independently to ensure comprehensiveness and full objectivity. The Court Monitor looks forward to the

availability of comparable SMHRF data; this will provide the best source of comparability on key critical incident measures.

G. Decision Support/Information Technology

DMH continues to collect and manage an array of data from providers, including detailed data regarding the transition. The monthly report to the Court Monitor and Parties is excellent – with continued refinements as specific questions come up. The recent report of unduplicated Class Members who have refused Resident Reviews is an example of this internal capacity.

The inability of the current state database system to aggregate and analyze the thousands of Resident Reviews persists – with no apparent resolution. Given the inability to retrieve data, DMH has decided to develop its own module to capture this data. The target date to bring this online is the end of March 2015. Unfortunately the new data module will only capture new Resident Review data, not the previous data files.

H. Budget Support

Final total spending in FY 2014 for the Williams case was \$30.5 million – including \$18.4 million for grant-funded services, \$8.6 million for Medicaid services and \$3.5 million for administrative and operational expenses.

FY 2015, DMH has budgeting approval to spend a total of \$41.7 million – which DMH estimates as its spending total for FY 2015. This amount should provide necessary funds to meet Williams compliance targets.

The looming and unanswered budget question relates to the State tax surcharge which is set to sunset on January 1, 2015. The full

annual revenue impact is estimated at \$4 billion. The newly-elected Governor and the Illinois General Assembly will need to determine how this major shortfall in revenue will be managed. The question is how this potential loss of revenue will impact State agencies like DMH and Williams compliance in particular. The Court Monitor will continue to track these developments and will inform the Court as appropriate.

I. Overall Williams Compliance

As indicated in this Report, the State Defendants are in general compliance as relates to Outreach and Housing – with continued challenges for refinements in both areas. The State is in partial compliance as relates to Resident Reviews – with multiple strategies currently in play that should provide payoff. As relates to placements, the State continues to meet its general numeric targets, but has not come into compliance due to the growing “Unable to Serve” population. Recent discussions provide new hope for concrete strategies to tackle this population. The last six months of year four are critical. The revised Implementation Plan provides an excellent road map toward further progress on all fronts.

III. Assessment of Major Organizational Issues Relative to Williams Compliance

The Court Monitor will continue to evaluate and inform the Court on critical areas that directly impact current and future Williams compliance.

A. Development of State Policy/Practice to Offer Alternatives to Current Admissions to IMDs/SMHRFs

For FY 2014, there were 885 admissions (new class members with no previous IMD admission) to an IMD – an increase of 98 (12%) over the 787 comparable admissions of FY 2013. It is clear that, despite the advent of the comparable services initiatives (see IIE),

there has been no real impact on the “front door” issue. The State has not yet begun to deal with the reality that in 1.5 years (under the terms of the Consent Decree) all persons must be offered a community alternative prior to being admitted into an IMD.

The Court Monitor strongly encourages the State to begin immediately a planning process that actualizes the language of the Decree. There are multiple service issues (e.g. comprehensive crisis services, housing supports, pre-admission screens) that need to be addressed. The State did a very refined (and fast-track) plan prior to the comparable services initiative – looking, for example, at both the source of IMD admissions and the reasons. Such a process needs to be repeated and updated. Timing is critical as any service enhancements need to be in place well before the end of year five (5) if meaningful community alternatives are to be up and working.

B. State Management, Funding and Oversight of IMDs

The new SMHRF rules are now official and final. The process has begun for current IMDs to obtain provisional licenses for the distinct levels of triage, crisis beds, transition units and rehabilitation. The State anticipates that this process will take 5-6 months for the 24 IMDs to apply for and be granted provisional licenses. The State (via DMH) also intends to have in place a process for prior authorization before the provisional licenses are awarded. In light of the front door issue, the Court Monitor will be anxious to see what impact, if any, the prior authorization process has on SMHRF admission rates.

The Court Monitor believes – with a new Administration soon in place and a budget crisis looming – that now is the time to look at the basic structural question of state organizational responsibility for managing and funding SMHRFs. SMHRFs are nearly 100% full of persons with SMI. The population is totally congruent with

persons who are the responsibility of DMH service agencies and yet SMHRFs exist as an anomalous part of the nursing home program. The Court Monitor would strongly encourage the new Administration to look at placing direct accountability (and budget authority) at DHS/DMH. The need to rationalize a public mental health service delivery system has never been greater; this step could be an important component.

C. Assessment of Cross-Agency Planning

The State has continued its efforts to plan and implement across agency lines. DMH has continued to utilize the Williams service system model for persons with SMI in the Colbert case – another Olmstead case involving nursing facilities in Cook County. The Governor’s office has played an important role in ensuring that issues are discussed and resolved in a conjoint manner.

D. Assessment of Leadership/Management Capacity in the Context of Overall Rebalancing

As noted in earlier Reports, the presence of strong and continuous leadership has been a vital part of the progress in the Williams case. This has, most notably, included the Senior Advisor on Behavioral Health in the Governor’s office and the Interim DMH Director. The obvious concern – with a new Governor – is to maintain maximum continuity and momentum on the multiple issues in play. The Court Monitor has met with several members of the new Administration and is hopeful that continued discussions will lead to awareness and attention to the Williams Decree. As needed, the Court Monitor will advise the Court on transition issues – including budgetary support.

Exhibit 1

Reportable incidents level and categories reported by agencies

Reporting period from 4/1/2014 thru 9/30/2014

Agency	Transitions		Level I - Critical							Level II - Serious					Level III - Significant															
	Total	%	A	B	C	D	E	F	G	H	Total	%	I	J	K	L	M	Total	%	N	O	P	Q	R	S	T	U	Total	%	
Alexian Center For Mental Health	0	0.0	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
Association For Individual Dev.	0	0.0	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
Association House of Chicago	7	3.6	0	1	0	1	0	1	0	0	3	7.3	9	2	0	0	0	11	2.8	0	0	0	0	0	0	0	1	0	1	2.0
Comm Counseling Ctr of Chicago	24	11.8	1	0	0	2	1	0	0	0	4	8.8	37	9	0	0	0	48	10.8	0	0	0	0	0	0	0	0	0	0	0.0
Cornerstone Services	4	2.0	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
Dupage County Health Department	1	0.6	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
Ecker Center	0	0.0	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
Grand Prairie Services	1	0.6	0	0	0	1	0	0	0	0	1	2.4	4	0	0	0	0	4	1.0	1	0	0	0	0	0	0	1	0	2	4.0
Heartland Health Outreach Inc.	8	4.0	0	0	0	0	0	0	0	0	0	0.0	5	0	0	1	0	6	1.4	0	0	1	0	0	0	0	0	0	1	2.0
Heritage Behavioral Health Center	10	6.0	1	0	0	0	0	0	0	0	1	2.4	2	0	0	0	0	2	0.6	0	0	0	0	0	0	0	0	0	0	0.0
Human Resources Dev Inst. Inc.	10	6.0	2	0	0	0	0	0	0	0	2	4.8	8	0	0	0	0	8	1.8	0	0	1	0	0	0	0	0	1	2	4.0
Human Service Center	18	7.9	0	0	0	0	0	0	0	0	0	0.0	68	11	0	0	0	79	18.8	0	0	0	0	0	0	0	0	0	0	0.0
Iroquois County Mental Health Center	0	0.0	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
Kenneth Young Center	1	0.6	0	0	0	1	0	0	0	0	1	2.4	1	0	0	0	0	1	0.2	0	0	0	0	0	0	0	0	0	0	0.0
Lake County Health Dept. MH	8	3.0	0	0	0	0	0	0	0	0	0	0.0	17	6	0	0	0	23	6.6	2	0	0	0	0	0	0	0	0	2	4.0
New Foundation Center	1	0.6	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
PRESENCE HEALTH	0	0.0	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
The Thresholds	88	48.8	0	0	1	11	0	4	1	2	18	48.3	127	16	0	4	3	160	36.8	12	0	8	0	0	0	1	9	30	80.0	
Trilogy Inc.	26	12.4	0	0	0	3	0	4	3	0	10	24.4	74	10	1	6	0	81	21.8	2	0	1	0	0	2	0	7	12	24.0	
TRINITY HEALTH	0	0.0	0	0	0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0.0	0	0	0	0	0	0	0	0	0	0	0.0
	202		4	1	1	18	1	8	4	2	41		362	64	1	11	3	421		17	0	11	0	0	2	2	18	60		

Unduplicated count of CMs caused reportable incidents: 260

Total reportable incidents (Level I + Level II + Level III): 512

Legends

Level I - Critical

- A - Death
- B - Suicide Attempt
- C - Sexual Attempt
- D - Physical Assault
- E - Fire
- F - Criminal Activity
- G - Missing Person
- H - Suspected Mistreatment (Abuse, Neglect)

Level II - Serious

- I - Unexpected Hospital Visit/Admission
- J - Nursing Facility(SMHRF (IMD) Placement
- K - Fire
- L - Behavioral Incident
- M - Suspected Mistreatment(Exploitation)

Level III - Significant

- N - Property damage/destruction
- O - Vehicle accident not requiring emergency department visit
- P - Eviction for non-criminal reasons
- Q - Suspected mistreatment
- R - Alleged Fraud/Misuse of funds
- S - Eviction for alleged criminal activity
- T - Missing person
- U - Criminal Activity

Level I: 41 (8.0 %)

Level II: 421 (82.2 %)

Level III 50 (9.8 %)

Transitions Number of Class Members who lease signed or moved-in during reporting period

Total reportable incidents Total # of reportable incidents occurred during reporting period.

Unduplicated Class Members: Unduplicated # of Class Members who caused total incidents. These Class Members may or may not have been transitioned during reporting period.

Exhibit 2

REPORT TO THE COURT MONITOR

In the Matter of

Williams v. Quinn

Elizabeth Jones

Consultant

December 9, 2014

REPORT TO THE COURT MONITOR

In the Matter of

Williams v. Quinn

As a result of the Settlement Agreement in the Williams case, men and women confined to Institutions for Mental Diseases (IMDs) now are entitled to community-based housing and individualized supports. These alternatives to institutionalization offer new and promising possibilities for the development and exercise of skills, including employment, and for participation in expanded social networks in typical community settings. However, these very important opportunities are dependent on the class member's full understanding of the available resources and an expressed interest in accepting them.

As of December 1, 2014, 968 class members have actually transitioned from an IMD in order to live in appropriately designed and supported community housing.

However, despite the availability of information and guidance from trained outreach workers and staff from community-based agencies, a notable portion of the class members has been documented as refusing to leave the IMD. The most recent statistics available, as of November 18, 2014, indicate that, when approached about community housing, 1748 class members (31%), declined this opportunity.

At the request of the Court Monitor, this report focuses on possible explanations for these refusals. In addition, it offers recommendations for consideration by the Court Monitor and the Parties as they strive to ensure that the distinct benefits of the Settlement Agreement are provided to each identified member of the class.

Sources of Information

The preparation of this report was greatly aided by the generous cooperation of staff from the Department of Human Services, Division of Mental Health and its partners in the provision of community-based supports. This assistance expedited access to the IMDs and to the class members living there. It also helped to provide a broader view of the efforts taken to date to implement the terms of the Settlement Agreement.

Information for this report was obtained from several sources:

- On November 6, 2014, meetings were held with the Outreach workers engaged by NAMI and with a group of former residents of IMDs who now serve in the Ambassador initiative. (This initiative is referenced below.)
- On November 6, 2014, consultants retained by the State from the University of Illinois School of Social Work described their initial findings from a study of class members refusing to leave the IMDs.
- On November 6, 2014, a conference call was held with staff from the two agencies that review the class members for community placement. A staff person from one of these agencies initiated a follow-up call, which was held on November 10, 2014.
- On November 7, 11, and 12, 2014, site visits were made to nine IMDs. (The nine IMDs included Clayton Residential Home, Columbus Manor, Grasmere Place, Lydia Healthcare, Monroe Pavilion, Rainbow Beach, Sacred Heart Home, Thornton Heights Terrace, and Wilson Care.) The site visits involved speaking with class members, and one guardian, about their decisions to accept or refuse community housing and supports. With two exceptions, access to the IMD also provided an opportunity to observe interactions between class members and class members and staff. (In both Wilson and Rainbow Beach, staff brought the class member to a conference room.) Outreach workers from NAMI were present for five site visits and members from the Ambassador initiative came to three sites. During these site visits, I spoke primarily with class members who were familiar with the outreach workers or who were documented as having refused community placements. I also spoke with five class members (R.R., M.C-H., T.H., K.K., and P.M.) who were interviewed for my report dated August 1, 2008. (This report was submitted in an earlier stage of this case, prior to the Settlement Agreement, when I served as an expert for the Plaintiffs.)
- On November 19, 2014, a conference call was conducted with the Plaintiffs' counsel.
- On December 2, 2014, a conference call was completed with staff from the eleven agencies that provide transition services.
- The review of data and documentation was limited but included a forty-seven page Refusal Report, dated October 15, 2014, listing class members who were refusing to leave the IMD; the Department's Semi-Annual Report, dated May 30, 2014; and the resumes of the outreach workers.

Overall Observations and Findings

The IMDs are institutions. They exert significant control over the class members by inflexible rules and routines and by limiting access to typical community settings and experiences. Any discussion about the decision to accept or refuse community-based alternatives must be viewed in the current context of the class member's life.

Further, a class member's decision to leave the IMD and to accept community-based housing and other supports depends on a number of critical variables. These variables include the availability of meaningful relationships with family and/or friends; guardianship; the length of time spent in the institution; the nature of the institutional experience, including the level of "privileges" granted by the IMD; previous experiences with community-based services; and the presence or absence of trusted and supportive clinical staff and peers.

It is well documented that individuals with long histories of institutionalization may find it difficult to break their learned dependence on that setting, although it is also documented that these same individuals will do very well in community-based housing, if appropriately individualized supports are provided. It is also firmly established in the mental health field that the presence of peers, people with a shared life experience, can be instrumental to the decision to leave an institution for more independent housing with supports. Peers are valuable allies in the process of recovery.

Upon observation in the IMD, there are clearly established social groups clustered in the courtyards or in the indoor common areas. There are also individuals who sit alone, who are unconnected to the activity surrounding them, or who remain in their rooms. When approached, some class members are immediately responsive while others do not make any eye contact or walk away. Unless specific arrangements are made, there is scant privacy for conversation. These characteristics are found in each of the nine IMDs visited for this report.

The class members residing in the IMDs are a diverse group of adults when age, behavior and history are considered. Therefore, the strategies for approaching them about community alternatives must be diverse and individualized as well.

In the preparation of this report, these observations led to specific findings and recommendations about the current protocols for determining whether a class member wishes to leave the IMD in order to receive community-based supports.

These findings and recommendations are summarized below:

- The current approach to seeking a decision about community placement may be inadequate for class members with long histories of institutionalization or prior negative experiences with community-based services. A number of the class members interviewed for this report actually seemed interested in leaving the IMD but were afraid to do so. Their reluctance stemmed from several factors, including the awareness that skills had eroded due to the lack of opportunity to use them; the concern that support would be inadequate; the fear of loneliness; the opposition of family; and the doubt that resources would be adequate for the cost of living in an apartment. The class member's length of stay in the IMD heightened these fearful thoughts. These are not concerns that can be erased in an abstract way by describing community resources or offering words of reassurance. After years of confinement, the class members with this level of doubt must be given experiences that demonstrate, repeatedly and consistently, the opportunities that will be available to them, including the specific types of housing in their neighborhoods of interest and the possible options for socialization and companionship. The members of the Ambassador initiative understand these dynamics perfectly. They discussed their own hesitations prior to leaving the IMDs and repeatedly offered to be of assistance to the class members expressing doubt. They volunteered to go with other class members to the grocery store, the laundromat, and, even, to their very own apartments so that a class member, after years of institutionalization, could make an informed choice. In fact, the Ambassadors concurred that it would be preferable if these community experiences could be provided even before the choice to leave the IMD was discussed.

In addition to experiential learning, the establishment of a trusting relationship is the other key ingredient in helping this subset of class members to decide to choose community supports rather than continued institutionalization. Many class members have lost the ties to their families and friends; they need to develop relationships that will not only help with the initial transition to the community but will be present in the years ahead. Again, peer supports are a valuable resource but there are other potential resources as well. One class member said that she would like to be part of a church; another elderly class member described the recent death of her best friend in the IMD and her wish to develop other close friendships. Her expression brightened up at the mention of senior citizen centers. If relationships were already established at a church or neighborhood program for elders, it is very possible that these two class members would feel less risk in leaving the IMD and would choose to do so.

RECOMMENDATION: In order to maximize truly informed choice about community placement, it is recommended that there be more frequent and varied community experiences offered prior

to discussing the actual decision; that opportunities to form trusting relationships be developed through reliance on appropriate community resources; and that the Ambassador initiative be expanded to permit greater involvement of peers with class members currently refusing community supports due to their doubts, fears and lack of current knowledge.

- Problems with access to class members need to be resolved in certain IMDs. Transition team members identified several sites that curtailed access to class members. During the site visits conducted for this report, one IMD (Rainbow Beach) did not permit access to the common areas and another IMD (Wilson) brought class members to a conference room. Access was not restricted in the other seven IMDs. However, the agency staff working with class members on transition to the community described problems with access in Wilson, Belmont, Albany Care, and Monroe. Furthermore, the transition team staff described barriers to meeting with medical staff working in one IMD (Monroe Pavilion) and to having privacy in discussions with class members (Grasmere and Clayton). The lack of unrestricted access may create barriers to forming trusting relationships with class members and may impede the timely transmittal of important information.

RECOMMENDATION: The formation of trusting relationships with class members is important to informed choice and to timely and accurate communication. The concerns cited by transition team members require further discussion, investigation, and remedial action, as appropriate, by the Department and by the Court Monitor.

- Strategies for Guardians may need revision in order to permit class members to exercise their expressed desire to leave the IMD. The reason for a refusal may be related to a Guardian's preference, rather than the preference of the class member. The issue of Guardian refusals for community placement has been a substantial deterrent in other cases and in other jurisdictions. For example, the refusal of parents and Guardians to agree to community placement has been a longstanding constraint in the field of developmental disabilities as States seek to replace institutions with community-based residential settings. A number of the Williams class members categorized as "refusing" to leave the IMD are, in fact, agreeable to moving but the Guardian's refusal to consent is an intractable barrier. There were two class members (J.W. and T.H.) interviewed for this report who exemplified this problem. Each of them could describe the level of supports needed for transition; each class member was confident that the transition was possible, with assistance; and each class member was eager to begin the process. In each case, however, the Guardian had either refused or had failed to follow through on the requisite paperwork.

RECOMMENDATION: The strategies for involving Guardians in the decision-making process should be examined to ensure that their ward's expressed interest in community-based support is fully explored. If a conflict persists without reasonable cause, challenges to the Guardianship should be considered and an advocate assigned to the class member. Expanded opportunities for Guardians to be educated about supported housing should be provided on a continuing

basis. These opportunities should include discussions with other Guardians, who are experienced in transitioning from an IMD.

- The data collected about refusals may require additional review and verification. Class members described as “refusing” may wish to leave the IMD but may require or request additional support to do so. Although it is recognized that conversations may change from time to time, depending on the circumstances surrounding the interview or the class member’s frame of mind on a given day, there were inconsistencies between the data reviewed for certain class members in the Refusal Report, dated October 15, 2014, and their expressed choices during the interview for this report. For example, on November 11, 2014, P.M. stated that, after fourteen years, he wants to leave the IMD but was refused the opportunity after the initial interview. He is able to describe the level of support he needs and is also able to discuss his interests in rebuilding his life. The information from the Department, dated November 24, 2014, reported that P.M. declined the opportunity to leave the IMD. On November 7, 2014, M.C.-H. stated that she did not say “no” but did not understand the process. She wants to leave the IMD and wishes to seek employment. (She does housekeeping at the IMD.) Both of these class members would like to be reviewed again soon and both are interested in seeing apartment sites.

RECOMMENDATION: The data regarding refusals should be re-examined and there should be a process instituted for substantiating the refusal. It is also suggested that the Refusal Report only include absolute refusals, not denials by Guardians or notations regarding the need for additional supports. (The reason stated for the refusal by S.E. is “resident is wheel chair bound.”) Reasons such as, “Because I have no idea about the outside of IMD” and “Who would take me to the doctor, cook and give medicine?” are not truly refusals but legitimate expressions of concern that should trigger a prompt response and the beginning stages of a trusting relationship.

- The delays in the transition process warrant attention. Class members may need more information about denials. During the site visits, the Outreach worker for three of the IMDs was repeatedly asked about the various delays experienced by the class members who were prepared to move to supported housing. These class members were articulate and distressed that more information about the transition timetable was not available to them. The lack of current information creates an uncomfortable situation for the Outreach worker, who was unable to respond to these questions. The delays in the process were reported to be undermining confidence in the transition process, thus causing doubt in the mind of some class members yet to decide about leaving the IMD.

RECOMMENDATION: There was insufficient time to fully examine the delays in the various stages of the transition process. This issue will continue to warrant close attention by the Department and by the Court Monitor so that the lack of timeliness does not become a major cause of refusals, especially among the class members who socialize together and share information about their transition status.

- Outreach workers have a particularly important role in the decision-making process for class members. They are capable of developing trusting relationships with class members in the IMDs. The schedule for the Outreach workers involves successive days in one week every month. As a result, four weeks elapse before the Outreach worker returns to the IMD. This stretched-out timetable impedes the development of trusting relationships with the class members, especially those hesitant about leaving the IMD. Furthermore, this schedule does not allow for timely responses to class members' questions about their transition status. The Outreach worker's assignments would benefit from an expanded relationship with the peers involved in the Ambassador initiative. The ongoing presence of a peer, working alongside the Outreach worker, would maximize the time spent on site and enable more interaction with class members, especially those requiring additional attention and support.

RECOMMENDATION: The schedules for the Outreach workers should be reviewed to permit more on-site presence in each IMD throughout the entire month. The Ambassador initiative should be expanded so that peers work along with the Outreach workers at each IMD. A primary focus of their attention should be directed towards class members with long histories of institutionalization or who are reluctant to leave the IMD.

It was reported that staff at certain IMDs attempt to negatively influence class members' decisions about supported housing. Although there was no evidence of retaliation observed or documented during the site visits for this report, staff from the community agencies assigned to help with the transition process described instances of negative influence or pressure by staff in certain IMDs. These actions were reported to be deterrents to a class member's decision to choose supported housing. For example, certain IMD staff were said to exaggerate the likelihood of psychiatric hospitalization in community placements or to stress those instances when a class member was returned to the IMD.

RECOMMENDATION: It may be useful to re-issue instructions to all Outreach workers, Reviewers and Transition Staff that any instance of perceived pressure or negative influence by IMD staff should be reported immediately to the Department and the Court Monitor so that the allegation can be investigated and action taken, as appropriate.

There were two issues that were noted during the preparation of this report that warrant inclusion, although they do not deal directly with the issue of refusals. First, as of December 1, 2014, the Department has confirmed that 101 class members have been returned to IMDs from their placements in supported housing. It would be important to examine and analyze the reasons for these unsuccessful community placements in order to identify both root causes and remedial interventions. Second, during the site visits, brief interviews were held with two class members who had been placed in the IMD after a course of psychiatric hospitalization. Both class members were visibly unstable. Both were upset that they had lost their apartments. It is not clear why these class members were returned to an IMD rather

than being placed in more intensively supported community residences. In both instances, they need reassurance that they can return to supported apartments and will be given the assistance required to do so.

Concluding Comments

It is readily apparent that the Settlement Agreement has provided important opportunities for class members who have chosen to live in supported housing. They are now able to access community resources and re-establish skills that were lost or diminished. There is the possibility of enriched social networks and meaningful relationships.

Class members who now live in IMDs may decline these opportunities for a number of reasons. Based on interviews and observation, it is clearly evident that some class members have become comfortable with the lifestyle afforded by the IMDs. They are adamant in their refusal to leave. There are other class members, however, who do not agree to move to supported housing because they lack confidence in their abilities, fear loneliness, or are worried that sufficient resources will be available in the long term. These class members require a more individualized approach to decision-making. They require direct experiences with community resources before being asked to decide. They require a trusting relationship so they do not feel alone.

In order to minimize the likelihood of refusals, it would be beneficial to redesign some of the approaches and resources currently available to the class members. In particular, the role of peers should be considered for expansion so they can work in partnership with the Outreach workers assigned to the IMDs. In addition, given the age and health status of some class members, it is reasonable to expect that the array of housing models will need to be expanded to provide more ongoing support.

Elizabeth Jones, Consultant

December 9, 2014