

MEMO

To: Office of Management & Budget

From: Brian J. Hartman, on behalf of the following organizations:

Disabilities Law Program, Community Legal Aid Society, Inc.
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens
State Council for Persons with Disabilities

Subject: Division of Substance Abuse and Mental Health FY 14 Budget

Date: November 13, 2012

Please consider this memo a summary of the oral presentation of Brian J. Hartman, Esq. on behalf of the Disabilities Law Program ("DLP"), the Developmental Disabilities Council ("DDC"), the Governor's Advisory Council for Exceptional Citizens ("GACEC"), and the State Council for Persons with Disabilities ("SCPD"). We are addressing one (1) component of the DSAMH budget, i.e., the need to fund the community-based mental health system to ensure compliance with the 2011 U.S. Department of Justice Settlement Agreement.

Settlement Agreement Requirements

The State of Delaware recently completed its first year under a Settlement Agreement with the U.S. Department of Justice, implemented to divert individuals from institutional care to community-based treatment options, as required by the Americans with Disabilities Act and the Supreme Court decision in *Olmstead*. The Settlement Agreement sets out specific deadlines by which the State must achieve concrete levels of community-based services for individuals with mental illness.¹ The State successfully met the majority of the FY 2012 benchmarks imposed by the Agreement.² The State was praised for this work by Assistant U.S. Attorney General Thomas E. Perez, in his testimony before the U.S. Senate Committee on Health, Education, Labor and Pensions this summer.³ Delaware's progress in creating a consumer oriented mental health system was also commended in the Court Monitor's September 5, 2012 Second Report to the U.S. District Court for the District of Delaware. The Court

¹ An excerpt from the Settlement Agreement, *Implementation Timeline*, Pgs. 10-14 is included as Attachment "A." The full document is available online at <http://dhss.delaware.gov/dhss/admin/files/settlementagreement.pdf>.

² A copy of the *Second Report of the Court Monitor on Progress Toward Compliance with the Settlement Agreement: U.S. v. State of Delaware*, September 5, 2012, is included as Attachment "B." The report is also available online at http://dhss.delaware.gov/dhss/admin/files/monitorreport_usvde.pdf.

³ The testimony submitted by Assistant Attorney General Thomas E. Perez to the U.S. Senate Committee on Health, Education, Labor and Pensions, Washington D.C., June 21, 2012, is included as Attachment "C." It is also available online at <http://www.justice.gov/crt/opa/pr/speeches/2012/crt-speech-120621.html>.

Monitor noted that “the State’s reform efforts are translating into real, palpable changes for individuals with [severe and persistent mental illness].”

However, the level of services required by the Agreement increases every year. By the end of FY14, the Agreement requires the following levels of service be implemented:

- Housing vouchers or subsidies and bridge funding to a total of 550 individuals, an increase of 100 new individuals from the end of FY 2013;
- Supported employment to total of 700 individuals, an increase of 300 new individuals from the end of FY 2013;
- Rehabilitation services to a total of 1100 individuals, an increase of 500 individuals from the end of FY 2013;
- Family and peer supports to a total of 750 individuals, an increase of 250 new individuals from the end of FY 2013;
- 9 Assertive Community Treatment (“ACT”) teams, an increase of 1 additional ACT team from the end of FY 2013; and
- 18 case managers, an increase of 3 additional case managers from the end of FY 2013.

These performance measures show that in addition to providing services to increasing numbers of individuals each year, the State is also responsible for maintaining services to those individuals already receiving them.

It is especially important to ensure that DSAMH has ongoing funds to provide housing in the community to individuals pursuant to the Settlement Agreement. As noted in the Second Report of the Court Monitor, housing vouchers from the State have already enabled 91 individuals to move into the community, with an additional 60 individuals preparing to transition to the community. Of particular note, the Court Monitor reports that 25.5% of those individuals who have received housing vouchers so far are individuals who were formerly homeless or had experienced four or more episodes of homelessness in the past three years.

Recommendation

We respectfully request funding DSAMH at a level sufficient to ensure Delaware will be able to meet the FY 14 benchmarks pursuant to the Settlement Agreement. Funding community-based mental health supports and services is critical to Delaware’s obligations outlined in the Settlement Agreement.

Thank you for your consideration.

Attachments.

G. Family and Peer Supports

1. Family Supports

- a. Family supports are designed to teach families skills and strategies for better supporting their family members' treatment and recovery in the community. Supports include training on identifying a crisis and connecting people in crisis to services, as well as education about mental illness and about available ongoing community-based services.
- b. Family supports can be provided in individual and group settings.

2. Peer Supports

- a. Peer supports are services delivered by trained individuals who have personal experience with mental illness and recovery to help people develop skills in managing and coping with symptoms of illness, self-advocacy, identifying and using natural supports.
- b. Peer supports can be provided in individual and group settings, in person or by phone.

H. The State shall ensure that providers of services listed in this Section (II) have linguistic and cultural competence to serve all individuals in the target population.

III. Implementation Timeline

A. Crisis Hotline

1. By January 1, 2012 the State will develop and make available a crisis line for use 24 hours per day, 7 days per week.
2. By July 1, 2012, the State will provide publicity materials and training about the crisis hotline services in every hospital, police department, homeless shelter, and department of corrections facility in the State. The training will be developed in consultation with the Monitor.

B. Mobile Crisis Services

1. By July 1, 2012 the State will make operational a sufficient number of mobile crisis teams such that a team responds to a person in crisis anywhere in the state within one hour.

2. By July 1, 2013 the State will train all state and local law enforcement personnel about the availability and purpose of the mobile crisis teams and on the protocol for calling on the team.

C. Crisis Walk-in Centers

1. In addition to the crisis walk-in center in New Castle County serving the northern region of the State, by July 1, 2012, the State will make best efforts to make operational one crisis walk-in center in Ellendale to serve the southern region of the State. The crisis center in Ellendale shall be operational no later than September 1, 2012.
2. By July 1, 2013 the State will train all state and local law enforcement personnel about the availability and purpose of the crisis walk-in centers and on the protocol for referring and transferring individuals to walk-in centers.

D. Crisis Stabilization Services

1. By July 1, 2012 the State will ensure that an intensive services provider meets with every individual receiving acute inpatient crisis stabilization services within 24 hours of admission in order to facilitate return to the community with the necessary supports and that all transition planning is completed in accordance with Section IV.
2. By July 1, 2013 the State will train all provider staff and law enforcement personnel to bring people experiencing mental health crises to crisis walk-in centers for assessment, rather than to local emergency rooms or IMDs.
3. By July 1, 2014 the number of annual State-funded patient days in acute inpatient settings in the State will be reduced by 30% from the State's baseline on the Effective Date of the Settlement Agreement as determined by the Monitor and the Parties.
4. By July 1, 2016 the number of annual State-funded patient days in acute inpatient settings in the State will be reduced by 50% from the State's baseline on the Effective Date of the Settlement Agreement as determined by the Monitor and the Parties.

E. Crisis Apartments

1. By July 1, 2012 the State will make operational two crisis apartments.
2. By July 1, 2013 the State will make operational a minimum of two additional crisis apartments, ensuring that the four apartments total are spread throughout the State.

F. Assertive Community Treatment

1. By July 1, 2012 the State will expand its 8 ACT teams to bring them into fidelity with the Dartmouth model.
2. By September 1, 2013 the State will add 1 additional ACT teams that are in fidelity with the Dartmouth model.
3. By September 1, 2014 the State will add 1 additional ACT team that is in fidelity with the Dartmouth model.
4. By September 1, 2015 the State will add 1 additional ACT team that is in fidelity with the Dartmouth model.

G. Intensive Case Management

1. By July 1, 2012 the State will develop and begin to utilize 3 ICM teams.
2. By January 1, 2013 the State will develop and begin to utilize 1 additional ICM team.

H. Case Management

1. By July 1, 2012 the State will train and begin to utilize 15 case managers.
2. By September 1, 2013 the State will train and begin to utilize 3 additional case managers.
3. By September 1, 2014 the State will train and begin to utilize 3 additional case managers.
4. By September 1, 2015 the State will train and begin to utilize 4 additional case managers.

I. Supported Housing

1. By July 11, 2011, the State will provide housing vouchers or subsidies and bridge funding to 150 individuals. Pursuant to Part II.E.2.d., this housing shall be exempt from the scattered-site requirement.
2. By July 1, 2012 the State will provide housing vouchers or subsidies and bridge funding to a total of 250 individuals.
3. By July 1, 2013 the State will provide housing vouchers or subsidies and bridge funding to a total of 450 individuals.
4. By July 1, 2014 the State will provide housing vouchers or subsidies and bridge funding to a total of 550 individuals.
5. By July 1, 2015 the State will provide housing vouchers or subsidies and bridge funding to a total of 650 individuals.
6. By July 1, 2016 the State will provide housing vouchers or subsidies and bridge funding to anyone in the target population who needs such support. For purposes of this provision, the determination of the number of vouchers or subsidies and bridge funding to be provided shall be based on: the number of individuals in the target population who are on the State's waiting list for supported housing; the number of homeless individuals who have a serious persistent mental illness as determined by the 2016 Delaware Homeless Planning Council Point in Time count; and the number of individuals at DPC or IMDs for whom the lack of a stable living situation is a barrier to discharge. In making this determination, there should be due consideration given to (1) whether such community-based services are appropriate, (2) the individuals being provided such services do not oppose community-based treatment, and (3) the resources available to the State and the needs of other persons with disabilities. Olmstead v. L.C., 527 U.S. 581 at 607 (1999).

J. Supported Employment

1. By July 1, 2012 the State will provide supported employment to 100 individuals per year.
2. By July 1, 2013 the State will provide supported employment to 300 additional individuals per year.
3. By July 1, 2014 the State will provide supported employment to an additional 300 individuals per year.

4. By July 1, 2015 the State will provide supported employment to an additional 400 individuals per year.
5. In addition, by January 1, 2012 all individuals receiving ACT services will receive support from employment specialists on their ACT teams.

K. Rehabilitation Services

1. By July 1, 2012 the State will provide rehabilitation services to 100 individuals per year.
2. By July 1, 2013 the State will provide rehabilitation services to 500 additional individuals per year:
3. By July 1, 2014 the State will provide rehabilitation services to an additional 500 individuals per year.

L. Family and Peer Supports

1. By July 1, 2012 the State will provide family or peer supports to 250 individuals per year.
2. By July 1, 2013 the State will provide family or peer supports to 250 additional individuals per year.
3. By July 1, 2014 the State will provide family or peer supports to an additional 250 individuals per year:
4. By July 1, 2015 the State will provide family or peer supports to an additional 250 individuals per year.

IV. Transition Planning

A. Assessment and Placement of People Currently in Institutional Settings

1. Each individual, now in or being admitted to DPC or an IMD, shall have a transition team including clinical staff and a representative of a community-based mental health provider.
 - a. Discharge planning shall begin upon admission.
 - b. Discharge assessments shall begin with the presumption that with sufficient supports and services, individuals can live in an integrated community setting.

39 Agreement are infused in public programs statewide for all individuals with disabilities,
40 the sustainability of the reforms that are discussed in this report is heightened.

41 As is detailed below, the State is largely meeting its benchmarks and it is making
42 significant, sometimes ground-breaking, progress in retooling its systems in fulfillment of
43 the ADA. This has not been a simple, linear process. The Settlement Agreement
44 required that in this first year, a multitude of new services and procedures be launched
45 simultaneously, inevitably causing some disruptions, uncertainty and unanticipated
46 challenges. In some instances, these concurrent changes affected the State's ability to
47 meet its implementation target dates, for instance, in recruiting mobile crisis staff in an
48 environment of newly heightened competition for mental health professionals (due to
49 other expansions required by the Agreement). In addition, as is referenced repeatedly
50 below, DSAMH is seriously challenged by fragmented, outmoded and ineffective data
51 systems that are critical to its management of services and future planning.

52
53 Still, at this juncture, things are finally settling into a new—and better—“normal,”
54 whereby longstanding gaps in services (particularly in the southern counties) are being
55 addressed and new initiatives supporting integrated community living are being put in
56 place. Most significantly, the State's reform efforts are translating into real, palpable
57 changes for individuals with SPMI. The Monitor has had an opportunity to meet with
58 several beneficiaries of the Settlement Agreement—all of whom with long histories of
59 institutional segregation, multiple psychiatric crises, homelessness or involvement with
60 criminal justice systems. They are now living in ordinary, scattered-site housing,
61 receiving flexible community-based services and supports. Their days are spent in such
62 mundane activities as shopping, cooking, housekeeping, or working. Given that just a
63 year ago, these individuals would likely be living in hospitals, correctional settings or
64 congregate facilities, this is a remarkable achievement. As contemplated by the
65 Settlement Agreement and, more broadly, the ADA, these individuals are living “like the
66 rest of Delawareans.”¹

67 68 **II. Sources of Information**

69 The findings presented here are based upon a broad set of information sources. They
70 include regular meetings with the leadership of DHSS, DSAMH, various state agencies
71 and providers; peer advocates; local chapters of organizations such as Mental Health
72 America and NAMI; the Delaware Psychiatric Center (“DPC”) and other psychiatric
73 inpatient providers; and individual consumers of public mental health services in the
74 state. In addition, the Monitor has convened or participated in a number of work groups
75 dealing, for instance, with issues such as legislative reform, risk management, discharge
76 planning, housing, and data systems. The Monitor has also reviewed numerous reports,

¹ Settlement Agreement, Section II.E.1.a

77 policies, minutes, inpatient and outpatient case records, data sets and other material
78 relating to implementation. Without exception, the State has continued to provide the
79 Monitor with requested information, facilitated access to any individual or group with
80 whom the Monitor sought contact, and otherwise offered full and helpful assistance in
81 carrying out the monitoring functions delineated in the Settlement Agreement.

82 83 **III. Infrastructure and System Configuration**

84 The Monitor's January 30, 2012 report on implementation during the initial six months
85 referenced two areas not specifically delineated within the Settlement Agreement as
86 requirements, but nonetheless critical to meaningful implementation:

- 87 • Stakeholders' understanding of measures required by the Settlement Agreement and
88 of the ADA and the *Olmstead* decision which underlie these requirements; and
- 89 • Reconfiguration of public systems to comport with the Settlement Agreement,
90 including centralized oversight to ensure that services are least restrictive, most
91 integrating, and meeting the needs of people with SPMI who are served in public
92 programs.

93 The State has made significant progress in each area.

94 95 96 **A. Stakeholders' Understanding of the Settlement Agreement**

97
98 In the initial report, the Monitor found that, notwithstanding the fact that the ADA was
99 enacted over twenty years ago, a meaningful understanding of this pivotal legislation and
100 its implications for practice tended to be limited to managerial staff system-wide. On a
101 direct service level, staff knowledge about the ADA was often superficial, with little
102 evident impact on their interventions with individuals. As a consequence, longstanding
103 practices that are at odds with the ADA and *Olmstead* continued without question.
104 Further, people being served by DSAMH's programs often had at best a vague
105 understanding of their own civil rights. Accordingly, the Monitor recommended training
106 on the ADA, the *Olmstead* decision and the Settlement Agreement with the goal of
107 increasing stakeholders' understanding of the underlying principles and their practical
108 meaning.

109 In the ensuing months, DSAMH has provided relevant training—sometimes involving
110 the Monitor—within DPC (e.g., with Recovery Academy staff, social work staff and
111 medical staff) and externally (e.g., with professional organizations such as the Delaware
112 Organization of Nurse Leaders, police chiefs, judges, the Sussex Mental Health Task
113 Force, the Sussex Interagency Council, and the Delaware Rural Health Initiative). These

114 trainings continue on an ongoing basis. A number of town hall meetings have been held
115 across the state, including representatives from DHSS, NAMI, the Mental Health
116 Association in Delaware (“MHA”), the Delaware protection and advocacy agency,
117 leaders in consumer-run coalitions, consumers, families and other concerned citizens.

118 Furthering these formal training efforts, the local news media has been actively covering
119 the Settlement Agreement’s implementation and related reform efforts (such as the new
120 mental health legislation discussed below), thus increasing awareness of the ADA and its
121 meaning among the general public. Notably, the Summer, 2012 newsletter of MHA
122 included an extensive interview with the Monitor relating to the ADA and the Settlement
123 Agreement; this publication was promulgated as an insert with the state’s major local
124 newspaper, thus getting very wide circulation.

126 **B. System Reconfiguration**

127 The Monitor’s initial six-month report cited two structural aspects of Delaware’s public
128 mental health system that were in conflict with the requirements of the Settlement
129 Agreement in that they have promoted unnecessary institutional segregation, confounded
130 appropriate oversight, and complicated effective community services. These were the
131 poorly controlled use of civil commitment and DHSS’s oversight of psychiatric inpatient
132 care.

134 A. Civil Commitment

135 The Monitor’s last report referenced various gaps in legal protections against the
136 unwarranted detainment, hospital confinement and continuing court oversight of
137 individuals with SPMI. As a consequence, individuals on the Targeted Population List
138 were at unnecessary risk of involuntary hospitalization and the attendant trauma, as well
139 as questionable legal coercion via outpatient commitment orders. As a case in point, the
140 Monitor’s report presented the story of Mrs. L, an individual with SPMI who was
141 actively engaged in community-based treatment. Although not dangerous to herself or
142 others, Mrs. L came to be transported in handcuffs by police from an emergency room
143 (where she had come on her own with delusional physical complaints) to a psychiatric
144 hospital. Notwithstanding the fact that she was not a danger, she was subsequently
145 civilly committed on the basis of dangerousness. The outpatient team that had been
146 providing Mrs. L with comprehensive community based services was not consulted about
147 these actions. There is good news relating to Mrs. L. She is no longer subjected to court-
148 ordered treatment and, in fact, as a beneficiary of the Settlement Agreement, she is now
149 successfully living in her own apartment with continuing community supports.

150 There is also good news to report on a systemic level. The Delaware legislature recently
151 enacted House Bill 311 and House Joint Resolution 17, both signed into law by Governor

152 Markell on July 24, 2012. House Bill 311 rectifies an issue that directly affected Mrs. L;
153 it requires an assessment by a qualified mental health screener before an individual is
154 detained on a 24-hour psychiatric hold, thereby helping to ensure that detainment and
155 hospitalization only occur when it is clinically necessary and that the individual is
156 afforded appropriate access to the less-restrictive alternatives being developed across the
157 state. This legislation also updates the mental health law that had been in effect in
158 Delaware for many decades, incorporating language about community integration,
159 requiring that care be provided on a voluntary basis whenever it is feasible, and removing
160 an unintended incentive for civil commitment whereby in certain circumstances, the State
161 would only underwrite involuntary hospital care.

162 Having thus remedied some immediate critical problems, the companion legislation,
163 House Joint Resolution 17, creates a study group to evaluate the State's mental health law
164 in its entirety and to make recommendations for further reforms. Governor Markell,
165 Cabinet Secretary Landgraf, members of the legislature—in particular, Representative
166 Barbieri—merit great credit for engaging a broad array of stakeholders with very diverse
167 perspectives and quickly moving these important bills to enactment. As the provisions of
168 House Bill 311 become effective, significant “front door” issues that have culminated in
169 unwarranted hospitalization and legal coercion should be rectified. Furthermore, the
170 statewide processes for responding to psychiatric emergencies should become much more
171 aligned with the State's obligations under the Settlement Agreement. The study group
172 that will be formed under House Joint Resolution 17 will have an opportunity to further
173 these gains.

174 The Monitor's initial report also referenced the frequent use of continuing outpatient
175 commitment orders following involuntary hospital care. In conflict with *Olmstead*, these
176 outpatient commitment orders place significant numbers of individuals within the Target
177 Population under questionable legal coercion and at heightened risk of unwarranted
178 rehospitalization. Based upon a review of records and discussion with informants (both
179 within the initial six-months and more recently), the Monitor has found that these orders
180 for continuing court supervision are issued routinely, sometimes in the absence of an
181 explicit clinical rationale and, commonly, without a record of why this is the least
182 restrictive measure appropriate to the individual's circumstances. Furthermore, these
183 court orders can be remarkably vague, not only failing to specify the community provider
184 that is responsible for delivering the court-ordered services, but also failing to specify
185 what these services are. Notwithstanding such ambiguity, these court orders indicate that
186 individuals who are outpatient committed can be re-hospitalized if they are not
187 “amenable” to such treatment.

188 Delaware remains very much an outlier in its use of outpatient commitment, not only in
189 comparison with neighboring states (where such orders are rarely, if ever, used) but also
190 in comparison to New York, where outpatient commitment is used and well studied. As

191 at least a blunt measure of the overuse of court-ordered services in Delaware, following
192 recent discussions with the Monitor, one major community provider determined that it
193 was appropriate to terminate court supervision of about 40% of its clients who had active
194 outpatient commitment orders.

195
196 Recommendations:

197 1. Although recent legislative reforms will not come to be fully in effect for another
198 year, pursuant to the Settlement Agreement the State launched a number of service
199 improvements which should have a more immediate impact in reducing
200 questionable hospital admissions and the attendant involvement of the judicial
201 system. As a means of evaluating and improving the impact of these reforms, the
202 Monitor recommends that the State track changes in the following measures:

- 203 a. Involuntary Hospitalizations
- 204 b. Voluntary Hospitalizations
- 205 c. Outpatient Commitment Orders

206 The Monitor recommends that these measures be evaluated not only with respect to
207 the State's own baselines (perhaps using data from the past year or two) but also, to
208 the extent that information is available, population-adjusted data from neighboring
209 states. Such information is not only useful for Performance Improvement purposes,
210 but can also provide stakeholders with an indication of the State's progress towards
211 a more *Olmstead*-oriented service model.

212 Although these measures are fairly basic, the State's ability to collect and analyze
213 such data is currently challenged by its inadequate electronic information systems.
214 A fuller explanation of this problem and the need for immediate remedies is
215 presented in a later portion of this report.

216 2. The State has begun to examine how, within the legislative and policy structures
217 now in effect, it can improve documentation that is presented to Mental Health
218 Commissioners (who issue orders for involuntary psychiatric treatment) so that the
219 basis for court-ordered treatment—whether inpatient or outpatient—is more
220 specific and includes clear information as to why less-restrictive measures are not
221 seen as viable. The Monitor recommends that the State quickly move forward in
222 this initiative, certainly because of its obvious legal implications, but also because
223 requiring more explicit documentation can have the effect of reinforcing *Olmstead*-
224 oriented decision making among the parties involved.² Furthermore, piloting

² The Monitor notes that changes in documentation requirements are having a similar effect in reorienting the system towards housing and service models that promote integration see discussion relating to Section IV.B.1.

225 improved documentation may inform the work of the study group's review of
226 Delaware's mental health laws, pursuant to House Joint Resolution 17.

227 3. In examining the Delaware's decades-old mental health laws, the study group that
228 was created through House Joint Resolution 17 will have the opportunity to make
229 recommendations that build on House Bill 311 in further embedding the values and
230 requirements of the ADA in practices within the State. The Monitor recommends
231 that the diverse stakeholders the study group comprises give careful consideration
232 to how further revisions in Delaware's law can solidify the gains that are now being
233 made pursuant to the Settlement Agreement.

234

235

236 2. Oversight of Psychiatric Hospitalizations:

237 The Monitor's initial report noted that the State's overly-complex arrangements for
238 managing services to people with SPMI posed significant problems in assuring that
239 appropriate interventions are provided, that rights are protected, and that public resources
240 are utilized efficiently. Part of the problem is that there has not been a single point of
241 accountability for public services to people with SPMI; instead, oversight is within
242 DSAMH, within the State's Medicaid program, within both, or shifting between the two
243 entities. The consequences of this arrangement have been evident in a number of ways,
244 including questionable use of hospital emergency departments and inpatient psychiatric
245 beds, poor coordination of outpatient and inpatient services, and inpatient psychiatric
246 admissions of individuals whose fundamental problems are substance abuse. The
247 Monitor found that these problems in managing services not only compromised the rights
248 of individuals on the Target Population List, but also had the effect of drawing on public
249 resources for high-end services (such as hospital care) that are either preventable or
250 unneeded. To a significant degree, the processes that sustain these inefficiencies appear
251 to represent an accumulation of decades of policies and practices, rather than an overall
252 plan to provide effective mental health services in accordance with the ADA and related
253 laws.

254 During the past six months, the Monitor has regularly met with leadership in DHSS and
255 DSAMH to discuss ways of enhancing the management of services and service-dollars.
256 Several of the Monitor's recommendations from the initial report have been addressed,
257 for instance, House Bill 311 addresses financial incentives favoring involuntary
258 treatment.

259 In addition, the State has expanded its staffing of the Eligibility and Enrollment Unit
260 ("EEU") by six staff members. Many of these positions have been filled and recruitment
261 efforts are underway to bring the EEU to full staffing. The expansion in the EEU will
262 allow this unit to apply eligibility and placement criteria to a broader range of services
263 and to begin to perform Utilization Reviews in different service settings. Included will

264 be services to the over 1,300 individuals who were successfully transitioned from
265 existing community programs into the new Assertive Community Treatment (“ACT”)
266 and Intensive Case Management (“ICM”) programs that have been developed pursuant to
267 the Settlement Agreement (they are discussed elsewhere in this report). Finally, with
268 passage of House Bill 311, the EEU will have responsibility for tracking and managing
269 all inpatient psychiatric care and community services for publicly-funded individuals
270 with SPMI.

271
272 Two issues of great importance to meaningful compliance with the Settlement Agreement
273 are currently under discussion with DHSS and DSAMH:

- 274 • The most appropriate format for DSAMH’s system-wide Quality Assurance
275 (“QA”) and Performance Improvement (“PI”) programs. QA and PI are related
276 functions, but with distinct methods and goals; simply stated, QA looks back at
277 services rendered and works to ensure conformity with standards, while PI draws
278 on QA data and other sources with the aim of enhancing outcomes and efficiency.
279 These functions are currently consolidated in a single DSAMH program. Given
280 the new program expansions, changes in service structure, needs for refinement of
281 policies and procedures, and demands for future planning, DSAMH is examining
282 how to most effectively carry out these functions.
- 283 • Establishing a coordinated process for care management. Presently, responsibility
284 for the oversight of services and reimbursement to individuals with SPMI is
285 dispersed among DSAMH, Medicaid and Medicaid Managed Care Organizations.
286 This not only presents problems in monitoring the flow of services and related
287 expenditures, but also in assuring that all individuals on the Target Population
288 List are appropriately afforded access to the array of services that are developed
289 per the Settlement Agreement.

290 As discussions proceed and planning around these issues is solidified, the State will need
291 to address an issue that is frequently referenced in this report: the data systems that are
292 critical to effectively carrying out QA/PI and care management are not in place, and there
293 are apparently bureaucratic hurdles to be overcome if appropriate IT systems are to be
294 established.

295
296 Recommendations Carried Forward from the Initial Report:

- 297 1. In collaboration with the Monitor, the State should begin analyses of inappropriate
298 admissions to DPC and the private psychiatric hospitals (“IMDs”). To further the
299 expanded oversight by the EEU and to provide a basis for root-cause analyses,
300 DSAMH should instruct DPC and IMDs to flag admissions of publicly-funded
301 individuals where the need for inpatient psychiatric care is questionable.

- 302 2. In collaboration with the Monitor, the State should initiate a study of hospital
303 emergency departments and how they deal with individuals who have substance
304 abuse disorders and who do not have justifiable co-existing diagnoses of SPMI. The
305 focus should be on developing a system of care that appropriately addresses their
306 needs and that rectifies the current misuse of public psychiatric beds.

307
308 New Recommendations:

- 309 1. In the coming months, the Monitor plans to engage an expert consultant to evaluate
310 the needs of DSAMH with respect to system-wide Performance Improvement and to
311 make recommendations relating to the scope, key tasks and infrastructure needs.

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313
314 **IV. Progress On Specific Provisions**

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316 **A. Explanation of Ratings**

317 In this section, the Monitor presents brief summaries of the State's progress in fulfilling
318 specific provisions of the Settlement Agreement, particularly those with defined target
319 dates. In accordance with the Settlement Agreement, for each goal the Monitor has made
320 a determination as to whether the State is in "Substantial Compliance," "Partial
321 Compliance," or "Noncompliance" (Section VI.B.3.g defines these ratings). Many of the
322 provisions relate to what will be ongoing processes or interim steps toward long-range
323 goals over the five years of implementation. The ratings presented below represent the
324 State's levels of compliance with each provision during the period July 15, 2011 through
325 July 15, 2012.

326
327 **B. Evaluations of Compliance**

328
329 II.B.1-2 The Settlement Agreement requires the development of a "Target Population
330 List," as follows:

- 331 1. *The target population for the community services described in this section*
332 *is the subset of the individuals who have serious and persistent mental illness*
333 *(SPMI) who are at the highest risk of unnecessary institutionalization. SPMI is a*
334 *diagnosable mental, behavioral, or emotional disorder of sufficient duration to*
335 *meet diagnostic criteria and has been manifest in the last year, has resulted in*

- 336 *functional impairment which substantially interferes with or limits one or more*
337 *major life activities, and has episodic, recurrent, or persistent features.*
- 338 2. *Priority for receipt of services will be given to the following individuals*
339 *within the target population due to their high risk of unnecessary*
340 *institutionalization:*
- 341 a. *People who are currently at Delaware Psychiatric Center, including those on*
342 *forensic status for whom the relevant court approves community placement;*
- 343 b. *People who have been discharged from Delaware Psychiatric Center within the*
344 *last two years and who meet any of the criteria below;*
- 345 c. *People who are, or have been, admitted to private institutions for mental*
346 *disease ("IMDs") in the last two years;*
- 347 d. *People with SPMI who have had an emergency room visit in the last year, due*
348 *to mental illness or substance abuse;*
- 349 e. *People with SPMI who have been arrested, incarcerated, or had other*
350 *encounters with the criminal justice system in the last year due to conduct*
351 *related to their serious mental illness; or*
- 352 f. *People with SPMI who have been homeless for one full year or have had four*
353 *or more episodes of homelessness in the last three years*

354

355 **Partial Compliance.**

356 The Monitor's prior report referenced that, the importance of the Target Population List
357 notwithstanding, constructing and maintaining this list has been a daunting task. As in
358 other states, Delaware's public systems do not have data systems that were designed to
359 communicate with each other. Many rely on outdated software and inefficient modes of
360 data submission. This is the case not only across state departments, but also within DHSS
361 and its various bureaucratic sections.

362 As was verified by an expert consultant hired by the Monitor to assist the State, DSAMH
363 is using information technology that is not only insufficient to address the basic
364 requirements of constructing a Target Population List, but it also lacks a capacity to
365 access timely and accurate data that are essential to the overall monitoring and
366 management of services that are referenced throughout the Settlement Agreement.
367 Among other findings, the consultant noted that DSAMH collects important data that it
368 cannot easily or meaningfully extract for routine oversight or long range planning. Data
369 submission relating to services provided through its programs is a hodgepodge of
370 electronic and paper transmissions, none of it in real time and much of it requiring
371 manual entry and tedious error correction. Lacking an overall unified system, key
372 information (for instance with regard to the disposition of hospital discharges and
373 housing created pursuant to the Settlement Agreement) is maintained in spreadsheets

374 improvised by various staff members. DPC does not yet have a system for electronic
375 medical records and DSAMH confronts bureaucratic barriers to introduce much needed
376 improvements.

377 Based on the report of the Monitor's expert consultant, DSAMH will need help to
378 expedite the procurement and implementation of an electronic health record and redesign
379 of a database that can more appropriately provide data on individuals affected by the
380 Settlement Agreement. The Monitor has learned that the State's restrictive IT security
381 standards complicate the procurement of software products (among them, Electronic
382 Health Records) that can vastly improve the efficiencies of service delivery and
383 oversight.

384 That said, and acknowledging the significant effort required of DSAMH's IT staff, the
385 State's Target Population List includes 6,373 unduplicated names as of May 31, 2012.
386 The list includes individuals with SPMI who are receiving state-funded inpatient
387 psychiatric care or who were admitted to such care during the two-year period prior to the
388 date the Settlement Agreement took effect (representing about 3,000 admissions). For
389 this same period, it includes 990 individuals with SPMI who have been homeless.
390 Drawing from Medicaid claims data, it also includes information about 1,638 individuals
391 who were admitted to emergency departments of general hospitals, apparently for
392 treatment of issues attendant to SPMI (this required some inference based on diagnostic
393 information, since there is apparently no distinct coding that would flag psychiatric
394 emergency care in these settings). Although individuals who have received treatment at
395 DPC under forensic orders are included on the Target Population List, DSAMH has not
396 yet established mechanisms to access data relating to criminal justice involvement by
397 individuals with SPMI. This is a significant gap in the database. And again, the status of
398 DSAMH's IT systems is such that generating the critically important information to
399 maintain and utilize the Target Population List is a labor-intensive enterprise, using
400 information that is not consistently current.

401

402 Recommendations:

403 Because issues relating to information technology are central to this provision of the
404 Settlement Agreement and are also intertwined with other provisions, the following
405 recommendations have bearing on the State's fulfillment of other sections, as well.
406 DHSS is aware that its IT systems are antiquated and siloed. A Department-wide
407 overhaul of IT systems is already underway, with the goals of vastly improving access to
408 information needed for oversight and decision making, and integrating information across
409 DHSS's various Divisions. Because of the complexity of this process, the planned
410 creation of a State Data Hub and other IT elements needed to fully achieve the
411 Department's goals will not be immediate. At the same time, fulfillment of the

412 Settlement Agreement requires that some data issues be immediately addressed, likely
413 through temporary measures as the State's longer-range IT improvements proceed.

- 414 1. DHSS should quickly move forward in resolving restrictions to accessing data from
415 other state agencies, particularly the State's Department of Justice and Department
416 of Corrections. Not only is this essential to fully meeting requirements relating to
417 the Target Population List, but real-time criminal justice data about individuals on
418 that list can enable mental health providers to intervene to prevent arrests and
419 further involvement with the legal system. The Monitor is aware of electronic
420 systems that are able to carry out this function while protecting the confidentiality
421 of individuals receiving mental health services.
- 422 2. DHSS should consider the recommendations of the consultant engaged by the
423 Monitor as it continues to refine plans for an upgrade of IT systems within DSAMH
424 and other related Divisions.
- 425 3. Within the next few months, DHSS and DSAMH, in collaboration with the
426 Monitor, should establish a working blueprint for addressing data requirements
427 presented by the Settlement Agreement, including issues to be addressed in the
428 long-range rebuild of the State's data systems and interim measures that will
429 address the immediate IT needs.

430
431 III.A.1 *Crisis Hotline: By January 1, 2012 the State will develop and make available a crisis*
432 *line for use 24 hours per day, 7 days per week.*

433
434 **Substantial Compliance.**

435 The Crisis Hotline is in place and is operational around the clock, as evidenced by
436 random quality checks. DSAMH has promulgated information about the Crisis Hotline
437 by distributing postcards through its peer-specialist and provider networks, and through
438 advertising panels at major shopping malls in the state.

439
440 III.B.1 *Mobile Crisis Services: By July 1, 2012 the State will make operational a sufficient*
441 *number of mobile crisis teams such that a team responds to a person in crisis*
442 *anywhere in the state within one hour.*

443
444 **Partial Compliance.**

445 During the initial four months of this calendar year, mobile crisis teams responded to a
446 monthly average of 40.5 emergencies statewide, 70% of which occurred in New Castle
447 County with the remainder roughly equally divided between the two southern counties.
448 The State has not been tracking the specific time it takes for mobile crisis staff to

449 physically arrive to intervene in emergencies, but it reports that staff members are
450 deployed on average within 13 minutes of the a request for assistance and they return to
451 base on average within about two hours. Assuming that a face-to-face intervention lasts
452 around one hour, and considering the State's small geographic size, it is possible that the
453 state is meeting the one-hour requirement specified in the Settlement Agreement.
454 Looking forward, the State should directly measure compliance with this provision.

455 The Monitor notes that there are as many as seven vacancies for related positions within
456 the Kent and Sussex Counties, in large part as a result of the competition for qualified
457 mental health staff associated with the new programming that is being developed there
458 under the Settlement Agreement and the reality that such positions are hard to fill due to
459 the level of education and experience required. It is unclear how these vacancies are
460 affecting the mobile crisis response in those counties, where requests now average only
461 slightly more than one per week, and how demand may change as the Ellendale facility
462 (discussed immediately below) reaches its full impact in the region.

463 Recommendations:

- 464 1. As referenced in the above section, the State needs to improve its capacity for data
465 collection and management, including its ability to capture data reflecting the time
466 between receipt of a request for crisis intervention and the arrival of staff on the
467 scene.
- 468 2. In order to ensure that resources are appropriately in place statewide, data relating
469 to response times should be tracked on a county-by-county basis, including day,
470 time of day, and specific responders.

471

472 III.C.1 *Crisis Walk-in Centers: In addition to the crisis walk-in center in New Castle County*
473 *servicing the northern region of the State, by July 1, 2012, the State will make best*
474 *efforts to make operational one crisis walk-in center in Ellendale to serve the southern*
475 *region of the State. The crisis center in Ellendale shall be operational no later than*
476 *September 1, 2012.*

477

478 Substantial Compliance.

479 Renovations to the Ellendale Crisis and Psychiatric Assessment Center ("CAPAC") were
480 completed on June 25, 2012. The State contract for the program was awarded to
481 Recovery Innovations and, as of the time of this report, that new provider is training staff.
482 In keeping with the timeline in the Settlement Agreement, CAPAC will be fully
483 operational by September 1, 2012. The Ellendale site is now providing at least limited
484 crisis services on a 24-hour basis, 7 days per week to Delaware's southern counties, in
485 partnership with the State's Mobile Crisis Intervention Team.

486

487 III.D.1 *Crisis Stabilization Services* By July 1, 2012 the State will ensure that an intensive
488 *services provider meets with every individual receiving acute inpatient crisis*
489 *stabilization services within 24 hours of admission in order to facilitate return to the*
490 *community with the necessary supports and that all transition planning is completed*
491 *in accordance with Section IV.*

492

493 **Substantial Compliance.**

494 Currently, crisis stabilization services occur within Crisis and Psychiatric Emergency
495 Services (“CAPES”), the psychiatric crisis center serving northern Delaware that is
496 located within Wilmington Hospital-Christiana Care. As is discussed above, in
497 September, 2012, a crisis center serving the lower counties will open in Ellendale.
498 CAPES presently has a bed capacity of 5 beds, and CAPAC will have 6 beds.
499 Approximately 75% of individuals who are admitted to CAPES stay less than eight
500 hours. When individuals are being served by community programs, staff at CAPES
501 consults with the providers as a part of the assessment process and the determination of
502 an appropriate disposition. Based on the Monitor’s review, individuals are receiving
503 appropriate transition planning. The Monitor will review practices at CAPAC when that
504 facility is operational.

505

506 III.E.1 *Crisis Apartments:* By July 1, 2012 the State will make operational two crisis
507 *apartments.*

508

509 **Substantial Compliance.**

510 As of this report, community providers statewide have a capacity to access up to six crisis
511 apartments and to provide associated short-term services, thereby exceeding the capacity
512 required by the Settlement Agreement. As new services come to be fully operational (for
513 instance, statewide mobile crisis) and new and existing providers assume roles in the
514 reorganized system, the Monitor will evaluate how these crisis beds are being used.

515

516 III.F.1 *Assertive Community Treatment:* By July 1, 2012 the State will expand its 8 ACT teams
517 *to bring them into fidelity with the Dartmouth model.*

518

519 **Substantial Compliance.**

520 The State is exceeding the requirements of this provision, having awarded contracts for
521 ten ACT teams statewide, all under contract and fully operational as of this report. The
522 parties to the Settlement have agreed that in place of the Dartmouth operational

523 standards, these teams will demonstrate program fidelity through the Tool for
524 Measurement of Assertive Community Treatment (“TMACT”), a newer assessment
525 instrument with enhanced requirements for person-centered services and recovery
526 planning. During the coming year, the Monitor will evaluate the performance of the new
527 ACT teams, some of which represent new providers in the state.

528

529 III.G.1 *Intensive Case Management: By July 1, 2012 the State will develop and begin to utilize*
530 *3 ICM teams.*

531

532 **Substantial Compliance.**

533 The State has surpassed this target. As of mid-May, contracts for five Intensive Case
534 Management teams had been awarded. As of this report, these teams are fully functional
535 in New Castle County and have begun operations in Kent and Sussex Counties. During
536 the coming year, the Monitor will be evaluating their performance.

537

538 III.H.1 *Case Management: By July 1, 2012 the State will train and begin to utilize 15 case*
539 *managers.*

540

541 **Partial Compliance.**

542 In late 2011, the State issued a Request for Proposals (“RFP”) for Targeted Care
543 Management (“TCM”) in fulfillment of this provision, but received only one response.
544 In March, it reissued an RFP with revised specifications, and a contract with a provider is
545 currently being finalized to provide for 11 case managers with caseloads to be at a level
546 of 1:25. These caseloads are much lower than had been anticipated, but they reflect
547 DSAMH’s assessment of the complex needs of the individuals being served. As a result
548 of contracting issue, there has been an understandable delay in fully implementing TCM
549 statewide—not attributable to the State’s lack of effort—until the beginning of
550 September, 2012. At the same time, 4.5 TCMs are active on the acute care units of DPC,
551 serving as liaisons to the community for approximately 90 individuals at any point in
552 time. In addition to these 15.5 TCM positions, DSAMH’s contracts with ACT providers
553 include a requirement for peer specialists (one per team), whose work complements that
554 of the case managers.

555

556 III.I.1 *Supported Housing: By July 11, 2011, the State will provide housing vouchers or*
557 *subsidies and bridge funding to 150 individuals. Pursuant to Part II.E.2.d., this housing*
558 *shall be exempt from the scattered-site requirement*

559 III.1.2. *By July 1, 2012 the State will provide housing vouchers or subsidies and bridge funding*
560 *to a total of 250 individuals.*

561

562 **Substantial Compliance.**

563 As was reported in the prior report, the State has identified 150 individuals who live in
564 semi-integrated housing and it continues to provide supports allowing these individuals to
565 live successfully in these settings. In some instances, individuals in this group have been
566 able to move to more integrated supported housing.

567 The Settlement Agreement requires that as of July 1, 2012, the State fund integrated
568 housing for an additional 100 individuals. As of this report, the State has exceeded this
569 goal. Funding for an additional 151 vouchers has been approved for individuals on the
570 Target Population List through a combination of programs through HUD, DSAMH, and
571 the Delaware State Rental Assistance Program (“SRAP”). These vouchers have enabled
572 91 individuals to move into integrated housing, and the additional 60 individuals are in
573 various stages of transition. The Targeted Population List provides some information as
574 to which priority subpopulations (defined above in relation to Section II.B.2) have
575 benefited from these housing expansions (Individuals may be reflected in more than one
576 category):³

577	DPC.....	21.9%
578	IMD.....	23.8%
579	Emergency Department Treatment.....	19.2%
580	Homeless.....	25.2%
581	Inpatient History + Inappropriately	
582	Housed per Community Program	33.8%

583 The Monitor’s visits to several such individuals in New Castle County have affirmed that
584 housing and related supports are, indeed, consistent with the requirements of the
585 Settlement Agreement. Individuals with SPMI who would otherwise be living in
586 institutions or congregate settings that segregate them from the community mainstream
587 are now living in nice, scattered-site apartments in ordinary apartment complexes with
588 the flexible array of community supports that is helping them meet their personal goals.
589 It is evident that these individuals (and the providers who assist them) rightly feel a sense
590 of pride in making the goals of the ADA something beyond mere aspirations and
591 demonstrating the true capacities of these Delawareans. During the coming year, the
592 Monitor will continue to assess the State’s progress with respect to this pivotally

³ As discussed elsewhere, criminal justice information is not yet incorporated in the Target Population List

593 important provision, particularly in the southern counties where housing and supports
594 have historically been a special challenge.

595 Comment:

596 It is noteworthy that the DHSS and DSAMH have not only been working to fulfill the
597 quantitative requirements of the Settlement Agreement relating to integrated housing, but
598 they have also taken a leadership role in ensuring that relevant policies and practices are
599 aligned across State departments. For example, Cabinet Secretary Landgraf and
600 Delaware State Housing Authority (“DSHA”) Director Anas Ben Addi successfully
601 negotiated changes in the SRAP program to remove barriers that particularly
602 disadvantaged individuals on the Target Population List in qualifying for housing
603 vouchers.

604
605 Furthermore, Secretary Landgraf and Director Huckshorn have been instrumental in
606 launching an initiative to examine existing congregate housing in order to identify
607 opportunities to “retool” this housing stock to comport with the ADA’s integration
608 requirements. The development of much of this housing either pre-dated the ADA or was
609 based on funding programs that were not structured around the ADA. Because federal
610 disability protections apply to a larger population of Delawareans than is the focus of the
611 Settlement Agreement, the State has broadened discussions about housing
612 reconfiguration to include individuals with developmental, intellectual and physical
613 disabilities, as well as stakeholders concerned with older adults and homeless individuals.
614 DHSS has engaged leadership from DSHA and the federal Department of Housing and
615 Urban Development in this initiative. The goal is to develop an ADA-consistent master
616 plan for integrated housing that spells out actions that can be taken long-range and in the
617 more immediate term to expand opportunities for ordinary mainstream housing.

618
619 These two initiatives have great significance. The changes in SRAP policy reflect the
620 goals of the Governor, the Cabinet Secretary and other leadership in the State to not only
621 fulfill the State’s specific obligations under the Settlement Agreement, but to also ensure
622 that public programs in Delaware comply with the ADA’s wider requirements. The
623 development of an *Olmstead*-oriented master plan for housing individuals with
624 disabilities speaks to the enduring commitment of the State to promote meaningful
625 integration of its citizens with disabilities well beyond the expected five-year period of
626 implementing this Settlement Agreement. Leadership within Delaware should be
627 commended for these measures.

628

629 III.J.1 *By July 1, 2012 the State will provide supported employment to 100 individuals per*
630 *year.*

631

632 **Substantial Compliance.**

633 The State is surpassing this requirement. Because DSAMH's contracts with Community
634 Continuum of Care Programs ("CCCPs"), included supported employment as a part of
635 the service package, a majority of the 1,300 individuals they served received these
636 services. Pursuant to the Settlement Agreement, these programs reformulated as ACT
637 teams, with supported employment services remaining a contractual element. The
638 Delaware Department of Labor, Division of Vocational Rehabilitation has contracted
639 with each of the ACT teams to strengthen the supported employment services provided.
640 It is noted that supported employment is included among the services offered to the 151
641 individuals for whom new integrated housing was funded (see discussion of Section
642 III.I.1-2).

643 The success of these programs is evidenced in the number of individuals currently in
644 competitive employment. As of July 1, 2012, 49 individuals on the Target Population
645 List have been in supported employment for 90 days, and an additional 79 individuals
646 have been in supported employment for at least 10 days. Although on their face, these
647 numbers may appear small, unemployment among people with SPMI is astronomically
648 high nationwide and the State is building on an admirable record of making vocational
649 services and employment opportunities available to this population. There is an
650 expectation that DSAMH's data collection regarding supported employment will improve
651 in the coming year as a function of the reporting requirements of the new ACT and
652 Community Re-Integration Project ("CRISP," discussed in Section IV.A) programs. The
653 Monitor plans to conduct interviews with a sample of individuals in supported
654 employment during the coming months.

655

656 III.K.1 *By July 1, 2012 the State will provide rehabilitation services to 100 individuals per*
657 *year.*

658

659 **Substantial Compliance.**

660 As is the case with regard to supported employment, DSAMH's core database relating to
661 rehabilitation services is derived from reports of providers working under the old CCCP
662 contracts. These generic reports show that 1,395 individuals with SPMI received some
663 level of community-based rehabilitation services. Unlike supported employment, where
664 the impact of services can be measured at least bluntly in the number individuals in
665 gainful employment, the existing data capacities with respect to rehabilitation services are

666 very limited. Information regarding the provision of rehabilitation services and service
667 outcomes should improve through reporting by the new ACT teams (which replaced the
668 CCCPs) and CRISP, particularly if the State makes the much needed improvements in its
669 IT systems that are referenced throughout this report. Although information about the
670 provision of rehabilitation services over the past year is general, the State has met its
671 numeric targets. The Monitor plans to conduct more targeted assessments of this service
672 requirement during the coming months.

673

674 III.L.1 *By July 1, 2012 the State will provide family or peer supports to 250 individuals per*
675 *year.*

676

677 **Substantial Compliance.**

678 The State is exceeding its targets with respect to family and peer supports. Between the
679 July 1, 2011 and the date of this report, a total in excess of 416 individuals have received
680 or are receiving such services. These include: 30 inpatients at DPC and served by the
681 hospital's peer program; 49 individuals receiving the services of Bridge Peers, who assist
682 in transition to community living; 250 peers served at the peer-operated Rick VanStory
683 Center in Wilmington; 57 peers served at the Open Door Peer Support Center in
684 Wilmington; 30 individuals receiving supports through the Sussex Drop-in Centers; and
685 an additional number of individuals (unavailable as of this report) who receive supports
686 through the drop-in center located in Dover.

687 During the past six months, the Monitor has had an opportunity to visit the Rick
688 VanStory Center and to meet with its director, to hear first-hand from individuals now
689 living in integrated housing about the benefits of Bridge Peers, and to meet fairly
690 regularly with the Peer Specialists at DPC. The State has made considerable strides in
691 expanding the role of peers in these settings, as well as in its new ACT teams.

692 The Peer Specialists at DPC have been active advocates, not only in individualized work
693 with people who are hospitalized, but also in identifying systemic issues, such as those
694 relating to questionably restrictive practices and poor coordination in implementing
695 arrangements for discharge. Under the leadership of Gayle Bluebird, the DPC Peer
696 Services Director (who is nationally known for her work), they also are doing impressive
697 work in the area of trauma, producing a plain-language booklet illustrated with works by
698 peer artists, entitled "What You Need to Know About Trauma."

699

701

702 **Not Rated.** (Ratings of provisions in Section IV with specific implementation milestones
703 appear below.)

704 This section of the Settlement Agreement lays out processes for evaluating the
705 capabilities and needs of individuals who are institutionalized, with the goal of moving
706 people who do not require an institutional level of care into community settings that
707 maximize integration. During the initial six months of implementation, DSAMH's
708 "Barrier Busters" committees—comprising DPC staff, community providers and peers—
709 focused on individuals who are on the hospital's long-term care units. Typically, these
710 individuals have very longstanding problems attendant to SPMI, often with co-occurring
711 physical health issues, substance abuse and legal challenges. Consistent with the
712 Settlement Agreement, Barrier Busters was highly successful in not only problem-
713 solving, but also reorienting transition planning for this population towards a strength-
714 based model of community integration. The Barrier Busters committees (one for New
715 Castle and one for the two southern counties) strengthened the collaboration between
716 hospital staff, community providers and peer specialists and laid the groundwork for the
717 mindset that is now gaining traction system-wide, whereby an individual is presumed
718 appropriate for integrated supported housing unless otherwise demonstrated.

719 Understanding the sometimes unique needs of the long-term care population that was the
720 focus of Barrier Busters—reflecting not only clinical complexities, but also dependencies
721 that are encouraged by protracted institutionalization—the State developed a new
722 program model for the community integration of these individuals, issuing contracts to
723 two providers. The Community Re-Integration Project ("CRISP") is a capitated, shared-
724 risk initiative which allows these community providers great flexibility in delivering
725 traditional and innovative services and supports in integrated settings. Part of the CRISP
726 contracts, which were modeled after another state's successful initiative, hold the
727 involved providers financially responsible for any post-discharge visits to emergency
728 rooms or admission to inpatient psychiatric care. CRISP will become fully operational
729 during the coming months, with each program serving 50 individuals. It is anticipated
730 that the program will result in at least 50 additional discharges from DPC's long term
731 care units. CRISP will also support other individuals with SPMI who may be in the
732 community, but who are high risk for hospitalization at DPC because they have had
733 difficulties engaging in recovery services. As is discussed below, the introduction of
734 CRISP, as well as new processes attendant to transition planning has resulted in DSAMH
735 restructuring how it carries out the centralized special transition functions that had been
736 the focus of Barrier Busters.

737

738 IV.B.1 *Implementation of Transition Assessments and Placement: Within 30 days of the*
739 *signing of the agreement the State will re-assess all individuals currently in*
740 *institutional settings.*

741

742 **Substantial Compliance.**

743 The provisions of the Settlement Agreement relating to transition planning are
744 particularly significant to the State's efforts to reorient its systems in support of the
745 community integration required by the ADA. In Delaware (and elsewhere), longstanding
746 practices relating to service planning were built around a "levels of care" framework
747 whereby an individual with SPMI would be matched to the setting regarded as most
748 consistent with his or her needs—for instance, group homes, nursing homes, or
749 supervised apartments. At least in theory, the individual would move through the
750 established levels of care as needs changed. The Settlement Agreement reflects the
751 recognition that this outdated service model tends to perpetuate institutional segregation,
752 in part because service planning is constructed around settings that were state-of-the-art
753 well before the ADA was enacted and when the principal goal was downsizing massive
754 state hospitals.

755 Consistent with the ADA's goal of ending segregation based on disability, the Settlement
756 Agreement specifies a very different model, requiring that "...assessment shall begin
757 with the presumption that with sufficient supports and services, individuals can live in an
758 integrated community setting."⁴ The Settlement Agreement clearly describes an
759 integrated setting as one where "...people with SPMI can live like the rest of
760 Delawareans, in their own homes, including leased apartments, homes or living with
761 family"⁵ and includes specific parameters to prevent the new development of settings
762 where people with SPMI are intentionally clustered with other individuals who have
763 disabilities. These requirements are a departure from many of the housing, service and
764 assessment models that have been utilized in Delaware and nationwide over the past
765 decades.

766 Pursuant to the Settlement Agreement, the State has developed an innovative protocol for
767 assessing individuals based first on a presumption of integrated living and, when this is
768 not feasible (e.g., in light of the intensity of an individual's needs) or consistent with the
769 individual's informed choice, for analyzing and reviewing alternative plans. The
770 consequence has been a dramatic, laudable shift in how service planning is being
771 conducted; this is evidenced in the growing number of individuals with SPMI moving
772 from segregated settings to integrated supported housing (see discussion below relating to
773 Sections III.I.1-2).

⁴ Settlement Agreement, Section IV.A.1.b

⁵ Settlement Agreement, Section II.E.1.a

774 This change in culture and practice can be fairly described as cutting-edge. It has
775 required creative thought, input from a variety of stakeholders, and flexibility to change
776 approaches midstream. While the State's efforts relating to assessment and transition
777 planning properly remain a work in progress, the traditional "defaults," whereby
778 individuals with SPMI were routinely placed into segregated specialized settings clearly
779 have been supplanted by planning that is oriented towards integration.

780 At the same time, implementation of the Settlement Agreement over the past year has
781 revealed a need to clarify how some provisions will be addressed if the shift toward
782 integrated living is to be fully realized. DPC serves two different populations:
783 individuals with SPMI who are on long-term care units and have sometimes been
784 hospitalized for years, and individuals who are admitted for short-term acute care.⁶ The
785 IMDs, which account for the largest number of hospital admissions in the state,
786 essentially serve the latter population. Individuals in these settings are in acute mental
787 health crises and have lengths of stay of approximately 5-7 days.

788 The Monitor has found that the protocol for integrated transition planning that was
789 developed at DPC is working well, particularly on its long-term care units. There is an
790 increasingly collaborative (and well documented) partnership of DPC staff, community
791 providers and the person being served to construct and implement supported housing
792 plans. As the State's new CRISP program, which targets this population, ramps up, it is
793 anticipated that larger numbers of individuals on the long-term care units will be moving
794 to settings that maximize community integration.

795 Piloting this model within acute care settings (both at DPC and in the IMDs) has worked
796 less well. The Monitor conducted random reviews of clinical records of individuals
797 recently admitted to DPC for acute inpatient care. In 100% of the cases, the new protocol
798 for transition plans based on a presumption of integrated living was completed with
799 participation by the individual being served and the community provider. At the same
800 time, individuals are in these settings only briefly and, given that they are in immediate
801 psychiatric crises, they may not be in a position to meaningfully participate in person-
802 centered planning regarding their preferred integrated setting. Although many may be
803 desirous of and appropriate for integrated supported housing, their immediate concern is
804 likely to be getting back home, even if that home is a non-integrated setting.

805 Considering all of the above, the Parties agree that requirements of the Settlement
806 Agreement relating to transition planning and access to supported housing can be
807 meaningfully achieved if operationalized as follows:

- 808 a. The assessment and transition planning for individuals on DPC's long term care
809 units will continue as is.

⁶ DPC also serves a forensic population, which is not being considered here.

- 810 b. For individuals receiving publicly funded acute inpatient care in DPC or an IMD,
811 the designated community provider will take on greater responsibility for
812 conducting and implementing a person-centered assessment, including an
813 integrated housing assessment that is consistent with the protocol in use on DPC's
814 long-term care units. Depending upon an individual's circumstances, this
815 assessment may occur while the individual is hospitalized or subsequently, but in
816 all instances the hospital record will show how, by whom and when the transition
817 planning is to be conducted.
- 818 c. For individuals who are receiving publicly funded acute inpatient care and who
819 lack appropriate housing upon discharge, the designated community provider will
820 assure access to alternatives [such as "Haven Housing" (transient housing in
821 unused group home beds) or crisis apartments] where they can live while
822 integrated housing needs are assessed and plans are implemented.

823

824 Recommendation:

- 825 1. Through its system-wide Quality Assurance ("QA") program, DSAMH should
826 carefully monitor transition planning and implementation, particularly in instances
827 where such planning occurs in the community following discharge from acute
828 inpatient care. In all instances, the hospital record should either include a transition
829 assessment consistent with what is being successfully utilized at DPC, or else a
830 specific plan for carrying out such an assessment shortly following discharge.
- 831 2. Through its system-wide QA, DSAMH should monitor discharge arrangements
832 from acute inpatient care (both at DPC and the IMDs) to ensure that individuals are
833 not being discharged to homelessness, shelters or unstable housing situations and
834 that Haven Housing, crisis apartments and other arrangements are being
835 appropriately used while permanent housing needs are evaluated and addressed.
- 836 3. Data from the QA monitoring of the use of such temporary housing arrangements
837 should be used to inform DSAMH about the adequacy of its current capacity to
838 prevent discharges to homelessness, shelters or other unstable living arrangements
839 and whether additional development is needed.
- 840 4. Given the positive impact of the new transition planning protocols at DPC, both in
841 individual service planning and in supporting a shift in culture towards an *Olmstead*
842 orientation, DSAMH should promote the routine use of these assessments (or a
843 variation thereof) within the community programs it funds.

844

845 IV.B.2. *Within 60 days of the signing of the agreement the State will make operational*
846 *transition teams including community provider and peer representatives.*

847

848 **Partial Compliance.**

849 The Monitor's review of records within DPC and discussions with Peer Specialists and
850 other informants confirm that transition teams are operating with participation by
851 community providers and peer representatives. DSAMH currently monitors
852 hospitalizations for individuals who are admitted to DPC or involuntarily admitted to
853 IMDs. In the coming year, its oversight will be expanded to all publicly-funded
854 individuals with SPMI who are admitted to these facilities.

855

856 **Recommendation:**

- 857 1. As a part of its system-wide QA, DSAMH should expand its monitoring to ensure that
858 transition teams in IMDs appropriately include community providers and peer
859 representatives for all publicly-funded hospitalizations for individuals with SPMI.
860

861 IV.B.3. *Within 60 days of the signing of the agreement the State will make operational a*
862 *central specialized transition team including community provider and peer*
863 *representatives.*

864

865 **Substantial Compliance.**

866 As was discussed in regard to Section IV.A, Barrier Busters was phased out as the central
867 specialized transition team. DSAMH meets regularly with the ACT and CRISP providers
868 to resolve problems in care. In addition, it is building on an effective model that it has
869 devised at DPC to ensure that individuals who present challenges in discharge to an
870 integrated setting are identified, that additional consultation is provided as needed, and
871 that discharges to living arrangements that are not integrated are appropriately reviewed.
872 Other than for individuals who are returning to their congregate living arrangement
873 following brief hospitalization, DPC has initiated a special addendum to its transition
874 planning packet (discussed above, and including participation by the individual being
875 served and the community provider) in instances where a disposition of a non-integrated
876 setting is being recommended. This form, in combination with other information relating
877 to discharge planning, is the basis for reviewing either problems in implementing an
878 appropriate plan or a proposed discharge to a setting such as a group home. It documents
879 the types of community living arrangements that were discussed with and offered to the
880 individual, and the reasons (including the individual's informed choice) that integrated
881 housing is not being pursued. It specifically requires information relating to "serious

882 medical physical illness that requires consistent monitoring including, but not limited to:
883 inability to ambulate, problems with other bodily functions, chronic orthostatic
884 hypotension, brittle diabetes, wounds requiring frequent care, dementia..." that might
885 justify a special living arrangement. The form is reviewed by a Peer, a Peer Supervisor,
886 the Director of Professional Services and the Director of DPC before it is forwarded to
887 the DSAMH Director and the Court Monitor. At any point, when further information or
888 discussion is required a meeting of relevant parties can be convened. The Monitor has
889 found that this overall process not only affords appropriate protections against the
890 inappropriate reliance on segregated living arrangements for individuals on the long term
891 care units of DPC, but it has also had the additional advantage of encouraging staff and
892 other stakeholders to critically examine what had been engrained practices that are in
893 conflict with the ADA.

894 As is discussed in regard to Section IV.B.1, this process will now be extended to
895 individuals with SPMI receiving publicly-funded inpatient services at IMDs, with the
896 designated community providers taking a prominent role.

897

898 Recommendations:

- 899 1. DSAMH should expand its QA functions to assure that transition planning in all
900 inpatient settings occurs in compliance with the Settlement Agreement and that
901 reviews and assistance by the centralized transition team are occurring system wide.
- 902 2. DSAMH should improve its electronic data systems to ensure that it is capturing real-
903 time information relevant to transition planning, including such factors as individuals'
904 living arrangements at the time of hospital admission, whether the discharge is to an
905 integrated setting and whether reviews of discharges to non-integrated settings are
906 taking place appropriately.

907

908 IV.B.5 *By July 1, 2012 the State shall develop a program to educate judges and law*
909 *enforcement about community supports and services for individuals with mental*
910 *illness on forensic status.*

911

912 Substantial Compliance.

913 DSAMH leadership met with all of the superior court judges and commissioners who are
914 routinely involved with DSAMH clients at their annual retreat in April, 2012, presenting
915 information on the ADA, the Settlement Agreement and changes underway in the service
916 system. In June, Superior Court Judge Jan Jurden, who oversees the mental health court,
917 hosted a meeting including the Monitor, leadership from DSAMH, legal advocates and
918 court personnel. The intent was to review the implementation of the Settlement
919 Agreement and its implications for the probation and diversion cases that come before

920 Judge Jurden's court. The meeting served as a beginning to what is expected to be an
921 ongoing a dialogue around the factors that bring individuals with SPMI—and many with
922 co-occurring substance abuse—into contact with the criminal justice system and how
923 mental health programs might improve their effectiveness in averting this outcome.

924
925 V.B.4-5 *Quality Assurance and Performance Improvement: If harm occurs despite these*
926 *measures, the responsible State, IMD or community provider will complete a root*
927 *cause analysis within 10 days. Using the results of the root cause analysis, the State,*
928 *IMD or community provider will develop and implement a corrective action to prevent*
929 *future harm.*

930 931 **Substantial Compliance.**

932 At the time the Monitor's initial six-month report was being finalized, a serious event
933 occurred at DPC, involving a patient-on-patient assault that did not result in life-
934 threatening injuries. DSAMH had not yet completed its root cause analysis at the time
935 the report was issued. This analysis, which was provided to the Monitor shortly
936 thereafter, was thorough and well done. It did not identify an underlying systemic
937 problem at DPC, and staff on the unit evidently responded quickly and competently to the
938 resultant medical emergency.

939 No other significant incidents of harm have been since reported at DPC or the IMDs.
940 During the review period, DSAMH received a total of 7 reports of possible abuse, neglect
941 or harm in community programs through the State's "PM-46" process. Three of the
942 associated investigations determined the allegations to be unsubstantiated; the remaining
943 four remain under investigation. All occurred in group home settings, and none involved
944 issues of serious harm.

945 946 **V. Summary**

947 As is clearly evidenced in this report, the State of Delaware has made impressive gains
948 over the past year, not only in achieving the specific intermediate targets required by the
949 Settlement Agreement, but also in taking steps to establish enduring ADA-oriented
950 practices in its service systems. Although this Settlement Agreement focuses specifically
951 on individuals who have serious mental illnesses, the State's increasing actions to engage
952 in implementation efforts other populations covered by the ADA (e.g., individuals with
953 physical, developmental or intellectual disabilities) and relevant divisions of state
954 government beyond DHSS and DSAMH demonstrates an appreciation of the importance
955 of the ADA among Delaware's leadership.

956 Because of the scope of new programming and other organizational changes required in
957 the first year of implementation, this has been a challenging period. The coming years
958 require far less in terms of launching new types of programs, and much more in regard to
959 refining the State's new array of services and bringing these services to full fruition.
960 Important to this undertaking will be a continuation of the ingenuity and effort that
961 Delaware's stakeholders have shown during the past year.

962

963 Respectfully Submitted,

A handwritten signature in cursive script, appearing to read "Robert Bernstein".

964

965 Robert Bernstein, Ph.D.

966 Court Monitor

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JUSTICE NEWS

**Assistant Attorney General Thomas E. Perez Testifies Before the
U.S. Senate Committee on Health, Education, Labor and Pensions**

Washington, D.C. ~ Thursday, June 21, 2012

Good morning Chairman Harkin, Ranking Member Enzi and members of the Committee. Thank you for holding this hearing about implementation of the Supreme Court's landmark *Olmstead v. L.C.* decision. The Court's ruling has often and properly been called the *Brown v. Board of Education* of the disability rights movement.

As the thirteenth anniversary of the *Olmstead* decision approaches, I am pleased to testify today about the Civil Rights Division's *Olmstead* enforcement work and about the Department's active role in ensuring that people with disabilities can realize their full potential. As you know, in *Olmstead*, the Supreme Court recognized for the first time that the civil rights of people with disabilities are violated when they are unnecessarily segregated from the rest of society. The Court's decision acknowledged that segregating individuals with disabilities in institutional settings deprives them of the opportunity to participate in their communities, interact with individuals who do not have disabilities and make their own day-to-day choices; it also recognized that unnecessary institutionalization stigmatizes people with disabilities, reinforcing misunderstanding and negative stereotypes.

The *Olmstead* decision was heralded as the impetus to finally move individuals with disabilities out of the shadows, and to facilitate their full integration into the mainstream of American life. Over the several years following the decision, through advocacy and policy and programmatic changes at the State and Federal level, there was some progress toward this goal. But the hoped-for sea change in the lives of people with disabilities has not come to fruition. More than a decade after *Olmstead*, many individuals across the country who can live in the community and want to live in the community remain unnecessarily institutionalized.

For that reason, when I became Assistant Attorney General in 2009, I identified enforcement of the *Olmstead* decision as one of the Division's top priorities. In the last three years, the Division has been involved in more than 40 matters in 25 states. We have also significantly expanded our collaborations with other federal agencies, including the Departments of Health and Human Services (HHS), Housing and Urban Development and Labor, recognizing that community integration can only be successful if people have access to necessary community services and housing. Through our *Olmstead* work, we help states comply, not only with their legal obligations under the ADA, but also with their fiscal obligations to taxpayers, by moving from expensive institutional care to more cost-effective community-based services that allow the state to leverage federal dollars most effectively. As importantly, *Olmstead* implementation serves states' broader interest in serving people with disabilities in the way most conducive to independence and full participation in community life.

The Division's *Olmstead* enforcement efforts have been driven by three goals: (1) people with disabilities should have opportunities to live life like people without disabilities; (2) people with disabilities should have opportunities for true integration, independence, recovery, choice and self-determination in all aspects of life including where they live, spend their days, work, or participate in their community; and (3) people with disabilities should receive quality services that meet their individual needs. We have learned many important lessons from the past. Chief among them is that it is not enough to move people out of institutions; we must ensure that individuals have the support and services that they need to lead successful

lives in the community.

We have used a variety of different tools in our *Olmstead* work, including reaching system-wide settlement agreements to expand community opportunities for thousands of people in several states; filing statements of interest in private litigation when questions arise regarding the ADA's legal requirements when necessary, bringing suit in court against noncompliant states and other public entities; and developing guidance documents and a website on *Olmstead* enforcement to help people understand their rights and to help public entities understand and implement their obligations. We have engaged in work on behalf of persons with a variety of disabilities, including developmental disabilities, intellectual disabilities, mental illness, and physical disabilities, and on behalf of both adults and children. This work assists people unnecessarily segregated in institutions as well as those at risk of segregation. We have challenged unlawful segregation in a wide range of settings, including state-run institutions, privately-run institutions, such as nursing homes and board and care homes, and other non-residential settings.

Matters Regarding State-run Institutions

The initial focus of our *Olmstead* work was on states that unnecessarily segregate individuals in public institutions or that place people at risk of entering public institutions. Our work focuses, not just on getting people out of these facilities, but also on the systemic reforms needed to ensure that public agencies do not put people at risk of unnecessary institutionalization.

Most recently, in Virginia we entered into a landmark settlement, to resolve the Department's finding that Virginia's system for serving people with intellectual and developmental disabilities violates the ADA by placing people in or at-risk of unnecessary institutionalization. The agreement will shift Virginia's developmental disabilities system from one heavily reliant on large, expensive, state-run institutions to one focused on safe, individualized, and cost-effective community-based services that promote integration, independence and full participation by people with disabilities in community life. The agreement expands and strengthens every aspect of the Commonwealth's system of serving people with intellectual and developmental disabilities in integrated settings, and it does so through a number of services and supports.

Among other things, the Settlement Agreement:

- Adds thousands of new Medicaid Home and Community Based Waiver slots for individuals to transition to the community from state-run and privately run institutions and for people on waitlists for community services;
- Creates a new family support program to help care for persons with disabilities in their own homes or a family members' home to prevent their unnecessary institutionalization;
- Requires the development of a comprehensive crisis system that will help divert individuals from unnecessary institutionalization;
- Provides for an integrated housing fund because we recognize that housing is a critical barrier to giving full force to the *Olmstead* decision;
- Requires the development and implementation of an Employment First Policy, prioritizing integrated, competitive-wage supported employment and the expansion of integrated employment and day activities; and
- Requires the development of a robust and comprehensive community quality assurance system.

Throughout the investigation that led to the Virginia settlement, we met with stakeholders across the Commonwealth, to learn their views about what was and was not working for people with developmental disabilities. We heard their problems and concerns, and ideas for addressing them, as well as their successes. We heard from families who were barely hanging on while their loved ones sat on long waitlists for community services and from self-advocates wanting more opportunities to work and live

independently. We also heard from the families of persons now living in institutional settings who worried whether the needs of their loved ones could ever safely be met in community settings. We took these perspectives to heart, and incorporated them into our agreement.

These stakeholder views have been shared, not only with the Department, but also with the Federal judge who is considering whether to permanently approve the agreement. In responding to the Court's invitation to submit comments on the agreement, several hundred Virginians movingly described the real-life impact of the shortcomings in the Commonwealth's current developmental disability service system, and explained why transformation of that system is so important. Some of these individuals also submitted affidavits supporting the agreement.

For example, a single mother who is caring for a pre-adolescent son with severe autism, developmental and behavioral needs, and who faces an eight-year waiting list for home and community based waiver services, told the Court that she is "overwhelmed by the thought of the years ahead" and not sure how she can continue to care for her family without the types of behavioral supports provided by the Virginia agreement. This woman wrote that receiving waiver supports would "dramatically improve" her well-being, the well-being of her son, and the well-being of his non-disabled brother. The parents of a 21-year-old with multiple disabilities who has always lived at home expressed their gratitude for recently-received waiver services that allowed them to avoid institutionalization and to continue to allow their son to "enjoy his life to the fullest." These parents urged the Court to approve the Agreement for the benefit of many other families who "desperately" need services but do not currently have them. Another parent, whose six-year-old daughter is one of approximately 7,000 individuals on a wait list for waiver services, described her joy in seeing that her child "thrives in the community" and her hope that her daughter can live in the community as an adult. She added, however, that at present, her family and many others "live in crisis" waiting for needed services.

I have also spoken with a number of parents of people living in the Commonwealth's training centers and they were very concerned, as they wondered what sort of quality control would be in place if or when their child moved into a decentralized setting in the community. I respect this concern. The *Olmstead* decision recognized that people with disabilities will move to appropriate community-based settings if they do not oppose such placement. For too long, people with disabilities have not been given meaningful choices or appropriate information to make informed choices about community services. Moving to the community will not be a realistic option for persons with disabilities if they and their families do not believe that the transition will be made in a thoughtful, respectful manner, and if they cannot feel confident that persons with disabilities will have the support needed to be safe and to thrive in the community. That is why the Virginia agreement includes a discharge planning process that includes family and community providers, and provides the opportunity to thoroughly explore community alternatives. Our consideration of the concerns expressed by family members is one of the reasons why the Virginia agreement includes enhanced protections for any person transitioning from a training center to the community.

The requirements in the Virginia agreement build and expand upon settlements we've reached in the past. For example, in October 2010, the Department, the HHS Office for Civil Rights, and Georgia reached a comprehensive, court-enforceable agreement regarding the Georgia system for serving people with developmental disabilities and mental illness. As a result of the agreement, Georgia is putting into place community-based services and supports for more than 1,000 individuals with developmental disabilities and expanding home and community-based waivers for individuals transitioning out of the State's developmental disabilities facilities and for people who are at risk of institutionalization. The State is also developing services and supports for more than 9,000 people with mental illness.

In the first year of the agreement, Georgia provided supported housing to more than 100 individuals with

mental illness, and will provide the same supports for an additional 400 individuals with mental illness this year. The State increased its existing community services to 20 Assertive Community Treatment (ACT) teams; two intensive case management teams; two community support teams; and maintained a crisis hotline, case management services, five crisis stabilization units, and peer support services. One State psychiatric hospital was closed, and the State negotiated agreements for the provision of services in community hospitals. Among the individuals who benefit from these actions is a man with a mental health diagnosis had been chronically homeless and was living in a tent. Initially, the ACT team worked with this man to find temporary housing at an extended stay hotel. Once his housing voucher was approved, the ACT team helped him search for a suitable apartment until he chose one he liked and moved in. He continues to live this stable environment.

For individuals with developmental disabilities, since signing the agreement, Georgia has ceased admissions to its State hospitals, transitioned 247 people out of these hospitals, funded an additional 100 community waivers, and created six mobile crisis teams and five crisis respite homes. The State provided family supports to 450 families of individuals with developmental disabilities this fiscal year. These changes helped a 9-year-old with developmental disabilities, who had spent her entire life living in one of the State hospitals, to move to the community. As a result of the agreement, this child is now living in a host home with a family and a nurse who is available to provide 24-hour-a-day care; in the fall, she will attend a new school where she will have the opportunity to relate to other children her age.

In July 2011, we signed a comprehensive agreement with Delaware to transform that State's mental health system. Over the next five years, Delaware will prevent unnecessary hospitalization by expanding and deepening its crisis services, including a hotline, crisis walk-in centers, mobile crisis teams, crisis apartments and short term crisis stabilization programs. Delaware will also provide community treatment teams and case management to individuals living in the community who need intensive levels of support. Our agreement also provides for scattered-site supported housing for everyone in the agreement's target population who needs it. Finally, Delaware will offer supports to enable persons with mental illness to lead integrated daily lives, including supported employment, rehabilitation services and peer and family supports. I'm pleased to report that Delaware is well on the way to meeting the agreement's July 2012 compliance benchmarks, including for crisis services, treatment, family support, supported housing and supported employment.

In a recent Delaware monitoring visit, a Civil Rights Division attorney met with several people who, as a result of the agreement, have moved from Delaware's State psychiatric hospital into their own apartments in the past year. These individuals include a formerly homeless woman; a man who had many years of involvement with the criminal justice system; and a long-term psychiatric hospital resident. Our attorney also met a 21-year old woman who, due to recently enhanced peer counseling, is now preparing to move from the State hospital to her own apartment in the community. These individuals described the positive change that our agreement had made in their lives. They said:

"It's one more day closer to Christmas;"

"I'm no longer invisible, people see you and say hi to you;"

"Independence means being able to accept friendship from other people;"

"I now have the right to just live and the freedom to open and close doors;" and

"Thank you for giving me back my life."

There are so many other places where we are doing significant *Olmstead* work and where such work is necessary. In December 2011, we issued findings that the State of Mississippi is violating the ADA and *Olmstead* in the operation of its mental health and developmental disabilities system. We are currently negotiating with Mississippi to change its service delivery system from one that unnecessarily

institutionalizes thousands of adults and children to one that provides real opportunities to people unnecessarily institutionalized or at risk of unnecessary institutionalization. In New Hampshire, we issued findings in April 2011 that New Hampshire unnecessarily segregates individuals with mental illness in institutional settings and places individuals with mental illness living in the community at serious risk of institutionalization. We recently intervened in private *Olmstead* litigation to address these violations.

Matters Regarding Privately Owned Segregated Settings

States' *Olmstead* obligations are not limited to people who are forced to live in publicly-run institutions. As many states have been decreasing their reliance on publicly run institutions, we have seen more and more individuals with disabilities inappropriately segregated by states in privately owned or operated institutions, including nursing homes. We have been very active in *Olmstead* enforcement in this area. For example, in July 2011, the Division moved to intervene in private litigation filed on behalf of a class of approximately 4,000 individuals with developmental disabilities in or at risk of entering nursing facilities in Texas. Many of the class members had lived in the community successfully, but ended up in a nursing home because of the way the state administers its program of services for individuals with developmental disabilities.

Additionally, after a lengthy investigation of North Carolina's mental health service system, the Division issued a findings letter in July of 2011 concluding that the State is violating *Olmstead* by administering its system in a manner that unnecessarily segregates persons with mental illness in large, privately-owned adult care homes. The Department recommended that the State implement certain remedial measures, including the development of scattered site supported housing and the provision of adequate, community-based support services for people with mental illness who are unnecessarily institutionalized, or at risk of unnecessary institutionalization, in adult care homes. Currently, the Department is negotiating with North Carolina to resolve these findings.

The Division also continues its participation in *Disability Advocates, Inc. v. Cuomo*, a case in which a federal court in New York found, after a trial, that New York discriminates against persons with mental illness by operating its mental health service system in a manner that confines them to large, for profit adult homes, when they could and want to receive services in community settings. After the Second Circuit vacated the trial court's decision on jurisdictional grounds, the Division is considering its options for how to proceed in the case and, as with any case, seeks to resolve the case without resorting to litigation.

In other instances, we have learned of states that are segregating children in private nursing homes, depriving them of the opportunity to live with their families and in the community. In Virginia, we learned of almost 200 such children in private nursing homes and private developmental disability facilities, and our agreement provides community relief for them. We currently have an investigation in another state regarding children with physical and developmental disabilities in or at risk of entering nursing homes. We also have an open investigation into whether a state is unnecessarily placing people with physical disabilities at risk of being forced into nursing homes.

Statements of Interest

The work I have described above is in addition to the Division's participation in dozens of private lawsuits concerning the right of persons with disabilities to receive services in the most integrated setting appropriate to their needs. We have filed briefs in 27 other matters in 17 states supporting private litigation regarding people who are unjustifiably confined to institutions or at risk of being segregated in an institutional setting unnecessarily.

Guidance and Website

The Department also has developed resources to help people to understand their rights and to help states understand and implement their obligations. In June 2011, we issued the Division's first technical assistance document on *Olmstead* enforcement. In this document, we describe the requirements of the ADA's integration mandate and provide a series of questions and answers on a range of topics. Among other things, this document makes clear the Department's view that both the mandate of *Olmstead* and the appropriate remedy to unnecessary segregation apply to the full range of settings in which individuals with disabilities live, work, and receive services. We also have a website dedicated to *Olmstead* enforcement, which includes links to settlements, briefs, findings letters, and other materials.

Interagency Collaboration

In 2009, on the tenth anniversary of the *Olmstead* decision, President Obama launched the "Year of Community Living" directing all relevant federal agencies, including the Departments of Justice, Health and Human Services, and Housing and Urban Development ("HUD"), to work together to make the promise of *Olmstead* a reality for Americans with disabilities. We have embraced this directive and worked in partnership with HHS, HUD, the Department of Labor, and other agencies that have primary responsibility for programs that are essential to community integration.

We have worked with HHS, particularly the Centers for Medicare and Medicaid Services and the Substance Abuse and Mental Health Services Administration, to aid states in making the systemic changes necessary to provide community-based services to individuals who would be in, or at risk of, institutional placement. We have also worked with the HHS Office for Civil Rights (OCR) in matters where we have a shared enforcement interest. For example, in Georgia, the State failed to comply with a voluntary resolution agreement between OCR and the State to resolve longstanding *Olmstead* complaints and DOJ worked with OCR and the State to achieve a comprehensive, court-enforceable settlement. DOJ is currently investigating a matter in another state where OCR was unable to secure voluntary compliance. Moreover, as evident from the relief we sought in Virginia, Delaware, Georgia and other cases, we know that the lack of affordable housing is one of the biggest barriers to community living. So, we have been working with HUD to help identify for states federal resources for affordable integrated housing.

We have also collaborated with HHS and HUD on policy development, and we continue to work with HHS, including its newly-aligned Administration for Community Living, and HUD to develop and disseminate policies that can promote integration in a consistent and comprehensive way.

Ongoing and Future Work

The Department's *Olmstead* enforcement activities are dynamic and ongoing. We have several ongoing investigations, and are addressing new issues, including: the segregation of children with disabilities, people with disabilities inappropriately in nursing homes, and the segregation of people with disabilities in day-time activities, including segregated work. With regard to employment, the Division has expanded its *Olmstead* work to look beyond just where people live to examine how people live and spend their days. Simply moving someone from an institution to a community-based residence does not achieve community integration under *Olmstead* if that person is still denied meaningful integrated ways to spend their day and is denied the opportunity to do what so many people do – pursue competitive employment in the community. And so, in a federal case in Oregon, we recently filed an amicus brief supporting private plaintiffs who asserted that *Olmstead* applies to a situation in which individuals seek integrated supported employment services but are instead placed by the State in employment settings in which they have little or no opportunity to interact with non-disabled workers or to learn valuable skills that would assist them in

working in competitive employment. In addition, our settlement agreements in Virginia and Georgia require the states to expand supported employment opportunities for individuals receiving services under those agreements; and our findings letters in Mississippi and New Hampshire noted a lack of integrated day opportunities, including supported employment opportunities, for individuals receiving services in the State.

As I consider the Department's *Olmstead* accomplishments to date, and our plans for the future, I continue to take inspiration from people with disabilities, their families and their caregivers. These individuals express the harm of segregation and the value of integration more eloquently than any lawyer's brief ever could. They are the heroes of this civil rights movement. And so, I end this testimony with the words of a family member who wrote urging the Court to approve our Virginia agreement. This woman, who initially raised her son at home, very reluctantly sent him to a State institution for lack of community alternatives, and most recently has seen him make great strides upon returning to community living, told the Court:

In my view, it is good for all of us to be able to see that people with disabilities are a part of our society and belong to us. We can respect them, admire them, interact with them, have admiration and compassion for some of the challenges they face – and we can be inspired. People with disabilities are part of us – and should not be put in isolation, unseen and unappreciated.

The Department of Justice will continue to do all we can to ensure that our *Olmstead* enforcement lives up to these words.

Thank you.