SUPPLEMENTAL REPORT
In the Matter of
United States of America v. The State of Georgia

Civil Action No. 1:10-CV-249-CAP

March 23, 2014

SUMMARY

Pursuant to the Court's Order of July 26, 2013, this Supplemental Report documents the State of Georgia's efforts to implement Provisions III.A.2.b.iii. (A)-(C) of the Settlement Agreement. These Provisions require the development and implementation of support coordination and an Individual Service Plan for each man or woman with a developmental disability placed from a State Hospital into a community-based residential setting. The Parties requested a delay in the review of these Provisions in order to permit additional time to assess prior Fiscal Year 2013 placements and to design and implement appropriate remedial actions, when necessary.

The Department of Behavioral Health and Developmental Disabilities (the Department) has continued to show good faith, energy and diligence in addressing its obligations to the Court. There have been numerous Parties' meetings and discussions with the Independent Reviewer throughout the months from July 2013 to the date of this Supplemental Report. The Department has invested additional resources and has sought out nationally recognized expert consultants in order to correct the systemic deficiencies that have been discovered through the multiple monitoring activities.

The systemic problems and weaknesses are known. The Department's leadership has acknowledged them, without excuses, and, as of this date, has begun to implement some key corrective actions. While meritorious, these corrective actions are not fully realized and have not yet had a significant impact on the services and supports available to individuals placed from the State Hospitals.

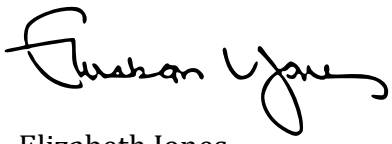
Based on the information documented through extensive site visits, observation, interviews, document review, and examination of the Department's own findings, it is the Independent Reviewer's professional judgment that the State is not yet in compliance with Provisions III.A.2.b.iii. (A)-(C).

Additional time is required for the Department to finalize its plans for the reform of the system of supports for people with a developmental disability, including the implementations of its Home and Community-Based Services Waiver amendments; the restructuring of responsibility and authority at the Regional level; the design and implementation of intensive support coordination for medically fragile individuals; the recruitment and retention of provider agencies with the requisite expertise; and the sustained development of sufficiently rigorous monitoring and oversight strategies. Each of these reform efforts is critical to the health, safety, habilitation and integration of the individuals affected by this Settlement Agreement.

On March 3, 2014, this Report was submitted in draft form to the Parties. On March 7, 2014, a meeting was held to discuss the Report's findings. The Commissioner and

the Deputy Commissioner participated in the meeting and addressed issues of salient concern.

Respectfully Submitted By:



Elizabeth Jones,
Independent Reviewer,
March 23, 2014

BACKGROUND SYNOPSIS

On July 26, 2013, the Court reviewed and approved the Parties' Joint Motion to modify two provisions of the Settlement Agreement relating to individuals with a developmental disability. The Court ordered:

- The Independent Reviewer will not assess the provisions of this section, III.A.2.b.iii. (A)-(C), in her report for the period ending July 1, 2013. Instead, the review period for this section will be extended six months until January 1, 2014, after which the Independent Reviewer will report on this section pursuant to the draft, review, and comment deadlines enumerated in VI.A.;

- Between July 1, 2012, and July 1, 2013, the State shall create at least 250 waivers to serve individuals with developmental disabilities in community settings. The State shall move up to 150 individuals with developmental disabilities from the State Hospitals to the community using those waivers. The remaining waivers shall be used to prevent the institutionalization of individuals with developmental disabilities who are currently in the community. The State shall provide family supports to an additional 500 families of people with developmental disabilities.

From July 1, 2012 until May 14, 2013 (Fiscal Year 2013), the State placed seventy-nine individuals from the State Hospitals into community-based residential settings before it suspended further placements. In addition, it complied with the requirements for the creation and use of waivers referenced in the second Paragraph; its accomplishment was addressed in the report filed with the Court on September 19, 2013. Therefore, this Supplemental Report, submitted to the Parties as a draft on March 3, 2014, is focused on the State's compliance with the Provisions cited in the first Paragraph.

The Provisions included in III.A.2.b.iii obligate the State to provide support coordination to all waiver participants. "For the purposes of this agreement, support coordination shall mean:

(A) Assembling professionals and non-professionals who provide individualized supports, as well as the individual being served and other persons important to the individual being served, who, through their combined expertise and involvement, develop Individual Service Plans, as required by the State's Home and Community-Based Services (HCBS) Waiver Program, that are individualized and person centered;

(B) Assisting the individual to gain access to needed medical, social, education, transportation, housing, nutritional, and other services identified in the Individual Service Plan; and

(C) Monitoring the Individual Service Plan to make additional referrals, service changes, and amendments to the Plans as identified as needed."

There was extensive collaboration among the Parties and the Independent Reviewer during the time frame of the extension granted by the Court. The collaboration included Parties' meetings and discussions, the exchange of documentation and relevant information, site visits, and the implementation of parallel monitoring activities in order to fully evaluate the quality of the community placements, including the Individual Service Plans, implemented under the terms of the Settlement Agreement. Furthermore, as the Department evaluated the community placements, it sought consultation with the Independent Reviewer and consultants with expertise in the design and implementation of community-based supports, including support coordination, health care for medically complex individuals, and the effective use of the Home and Community-Based Services Waiver.

As a result of its own deliberations and the guidance received from its external sources, the Department began to plan and, in some instances, implement a series of initiatives to ameliorate systemic deficiencies and specific situations where the individual's health and/or safety were at risk. For example, the Department removed individuals with a developmental disability from three provider agencies due to unacceptable care and/or oversight. In addition, in Region 4, the Department began to realign and redefine the responsibilities and training of support coordination staff in order to permit earlier engagement during the transition from the State Hospital to a community-based residential setting and to implement intensive case management for medically fragile individuals in Region 4.

These actions and initiatives are critically important but are not yet fully realized or available on a statewide basis. At this time, therefore, the reliable and comprehensive system of support coordination mandated by the Settlement Agreement is not in effect.

Furthermore, as discussed below, the reviews of community placements conducted by both the Department and by the Independent Reviewer document the inadequacy of Individual Service Plans for medically compromised individuals and the failure to implement critical supports required for health, safety and habilitation.

METHODOLOGY

In order to complete the significantly expanded work required for this Supplemental Report, it was necessary to change certain aspects of the monitoring protocol previously used by the Independent Reviewer. Specifically, rather than drawing a random sample of forty-eight individuals placed from the State Hospitals during the Fiscal Year, as done in prior reports, it was determined, with agreement by the Parties, that at least one individual would be reviewed from each of the community residential settings used, for State Hospital placements, during Fiscal Year 2013 and Fiscal Year 2014 to date.

The expansion of the scope of the Independent Reviewer's work required additional funding and technical support. The Department of Behavioral Health and Developmental Disabilities promptly allocated this funding and assisted the Independent Reviewer in accessing any information requested. Although this was a period of considerable pressure for everyone involved, the Department's leadership and staff were very responsive and generous with their time and assistance. Both the Commissioner and the Deputy Commissioner sought out the Independent Reviewer to express interest in her findings as they evolved and to implement remedial actions, as needed, for discrete problems and concerns.

By the end of February 2014, the Independent Reviewer and her clinical consultants had reviewed a total of sixty placements. Either the Settlement Agreement Director or the Assistant Commissioner for Developmental Disabilities accompanied the Independent Reviewer on her own site visits. Regional staff and agency staff were intermittently present during the reviews conducted by her clinical consultants. There were no instances of interference with the site visits by Departmental staff. (On the contrary, they proved to be very helpful when concerns were identified.) However, there were site visits that required rescheduling or that could not be completed because the provider agency failed to be present, as expected.

The monitoring questionnaire, as agreed to by the Parties and as utilized in the past, was relied upon for the gathering of information during the site visits and for the summarization of data conducted by the research associate/statistician retained by the Independent Reviewer from Virginia Commonwealth University.

The Department conducted its own set of monitoring activities in parallel with the Independent Reviewer's evaluation of community placements. The Independent Reviewer participated in the training of the Regional staff assigned to complete those assessments and the same monitoring tool was used. The Department's findings from its seventy-four reviews were submitted to and summarized by researchers at Georgia State University. These findings were shared with the Department of Justice and the Independent Reviewer and are included as Attachment 3. There is concurrence between the findings of both the Department and the Independent Reviewer.

FINDINGS

All of the information referenced below was obtained through the use of the monitoring questionnaire agreed to by the Parties and utilized in each of the prior years' reviews. The individual reports underlying the data have been submitted to the Parties for their review and any further action, as warranted.

Data was analyzed for nineteen placements made between September 25, 2013 to December 19, 2013 (Fiscal Year 2014) and for forty-one placements made from July 1, 2012 to May 14, 2013 (Fiscal Year 2013). In addition, there were two subsets of Fiscal Year 2013 placements analyzed separately: a group of four individuals who required behavioral supports and a group of twelve individuals who were transferred from a State Hospital in Fiscal Year 2013 but who were not reviewed until late in the monitoring process for this Supplemental Report.

Furthermore, there were fourteen individuals transferred from Southwestern State Hospital, prior to its closure in December 2013, to units located at the Georgia Regional Hospital in Atlanta and two individuals were transferred to East Central Regional Hospital. The Independent Reviewer visited three of the individuals in Atlanta; the nursing attention provided to these three individuals was observed to be caring and attentive. However, they were not reviewed in depth due to their hospital setting. Each of these individuals was projected for a community placement in the future.

Two of the individuals placed in Fiscal Year 2014 died within a short time after their transitions from Southwestern State Hospital. Their deaths were discussed at length with the Department; the Department conducted investigations into the circumstances of their deaths.

Review of Fiscal Year 2014 Placements

The nineteen placements reviewed for the current Fiscal Year occurred after the Department had resumed placements in Region 4 and Region 5 as part of its planned closure of Southwestern State Hospital. This is significant because the Department had instituted a number of proactive safeguards for these placements, including review by Departmental staff, the continued oversight of highly regarded physicians from Southwestern State Hospital and the addition of intensive support coordination in Region 4.

The nineteen individuals reviewed were characterized by histories of lengthy institutionalization, typically from childhood, as well as major medical conditions requiring careful attention by trained professional and paraprofessional staff. These medical conditions included choking risks (95%), seizure disorders (74%), difficulty maintaining or losing weight (63%), bowel elimination problems (100%), limited communication (91%) and immobility, requiring the use of a wheelchair (53%).

Each of the nineteen individuals was assigned a support coordinator. However, it is critical to note that support coordinators did not participate in the discharge planning process from the State Hospital and only assumed responsibility after the community placement had occurred. This is not consistent with expected practice in this field. The early linkage of support coordination is crucial because the support coordinator is responsible for ensuring that the Individual Service Plan is individualized appropriately, is fully implemented, and is modified, after discharge from the State Hospital, to reflect any significant changes in health or wellbeing. When implemented as expected, the support coordinator serves as the linchpin for the delivery of appropriate services and as a safeguard, if problems should arise during the transition or the placement itself. The absence of timely support coordination can jeopardize the stability and responsiveness of the individual's community placement.

The Department is fully cognizant of the need to ensure early engagement of support coordination and has taken action to permit this by preparing an amendment to its Home and Community-Based Services Waiver. On February 28, 2014, the proposed amendment for Intensive Case Management (Support Coordination) was submitted to the Department of Community Health for its review. However, as of this date, the amendment had not been forwarded to the Centers for Medicare and Medicaid Services.

As documented in the attached data summary (see Attachment Two), there were a number of important concerns related to health, habilitation and integration that required attention by the individuals' support coordinators. These areas of concern included:

- Individual Service Plans specified the need to implement prescribed dining and positioning plans for the majority of the nineteen individuals. Nonetheless, dining plans were not implemented for 63% of the individuals reviewed and positioning plans were not implemented for 60% of the individuals. The failure to implement these plans created unnecessary risk for these medically fragile individuals who are highly dependent on staff to meet their basic needs.

- Primary Care Physicians wrote recommendations for thirteen individuals. Timely implementation of these recommendations was not documented for 85% of the individuals. Ensuring that clinical recommendations are implemented is a responsibility of support coordination.

- Despite community placements in residences located near to community resources (100%), the availability of transportation (90%), and the presence of four or fewer individuals in each residence (100%), there were limited opportunities for community outings on a consistent weekly basis. Less than forty percent of the individuals reviewed had such opportunities and, when

they did occur, they were group rather than individualized experiences. There was little evidence of attendance at religious activities (21%) or of participation in community clubs or organizations (11%).

In response to concerns identified, by its own staff and by others, for the individuals included in the Fiscal Year 2014 placement group, the Department obtained an independent assessment by a nurse consultant from Columbus Community Services. The nurse consultant reviewed activities associated with the Intensive Support Coordination initiative implemented in Region 4. (Her report is included in Attachment 3.)

The report, "Columbus Community Services Consultant Report," dated February 3-6, 2014, identified gaps in communication and information sharing as well as duplicative monitoring strategies that failed to effectively resolve identified concerns. In addition, the nurse consultant found that the Individual Service Plans reviewed were developed while the individuals were still residing at Southwestern State Hospital. Contrary to expected practice, the Individual Service Plans were not revised within thirty days after the transition from the State Hospital; thus, not recognizing that "individuals generally react differently in dissimilar environments." The report also documented that there had been "no revisions made to the current ISP even when individuals have experienced significant changes in status."

In conclusion, for the individuals transitioned most recently from a State Hospital, after reviewing data obtained both from the nineteen monitoring questionnaires completed by nurse consultants to the Independent Reviewer and from documentation provided by the Department, the facts do not support a finding of compliance with the above referenced Provisions. At the end of this Fiscal Year, it will be important to conduct additional fact-finding reviews. These should be completed after the Department has implemented its proposed remedial actions, including the Waiver amendment for Intensive Case Management.

On January 7, 2014, after reviewing its own detailed information about the quality of the Fiscal Year 2014 placements, the Commissioner and Deputy Commissioner informed the Independent Reviewer that they had again suspended, with only limited exceptions for Court-ordered or family requested nursing home placements, any further transitions from the State Hospitals to community-based settings. As of the date of this Supplemental Report, the suspension remains in effect.

Review of Fiscal Year 2013 Placements

Overall, the findings from the review of forty-one placements made from July 1, 2012 to May 14, 2013 were similar to the findings described above. (The summary of the data obtained from the forty-one reviews is included in Attachment Two.)

The data continued to document the location of residences in typical neighborhoods with access to shopping, recreational sites and other desirable resources. In

addition, the Department continued to meet its agreement to limit the number of individuals in each residence to four or fewer. Each individual reviewed had his/her own bedroom; privacy was assured for those without one to one staffing (93%).

Transportation was available, without problems, for the great majority of individuals reviewed (95%). There was documentation to confirm some participation in grocery shopping (60%), clothes shopping (76%), and religious activities (59%). However, membership in community clubs or organizations was very limited (7%) and most individuals (63%) had not met their neighbors.

As in the reviews described above for individuals placed in Fiscal Year 2014, clinical recommendations found in the Individual Service Plans were not implemented as expected: Occupational Therapy was not provided (86%); Physical Therapy was not provided (67%); Speech and Language therapies were not provided (50%); and nutritional supports were not provided (80%). Primary Care Physician's recommendations were not implemented in a timely manner for the majority of individuals (73%).

Ensuring the implementation of clinical recommendations is a responsibility of the support coordinator.

Furthermore, there was evidence that the dining and positioning plans prescribed in the Individual Service Plans were not implemented. Thirty-seven individuals were to receive individualized support at mealtime but more than half of these individuals (51%) did not receive this assistance, as prescribed for them. Eighteen individuals required implementation of positioning plans but the majority (61%) of these individuals did not receive proper positioning.

The failure to implement these important clinical supports placed individuals with a developmental disability at risk and hindered their abilities to develop new or enhanced skills.

The Department recognized the vulnerabilities of its placement protocols and decisions and suspended all further placements in May 2013. The suspension was lifted briefly for the placements from Southwestern State Hospital and was then reinstated on January 7, 2014.

After the suspension of placements from the State Hospitals, the Department took a number of corrective actions to ensure greater reliability in the implementation of Individual Service Plans and support coordination. These corrective actions included: training Departmental staff in the expectations for quality placements; initiating its own monitoring processes; enhancing oversight from the Central Office; contracting with external consultants to review support coordination and Quality Assurance strategies; and evaluating its own performance data.

The Department's analysis of its own performance data was conducted through a contract with Georgia State University. The findings from these data, provided from the monitoring questionnaires completed in each Region, are comparable to those described above. The report from Georgia State University, " Georgia DD Community Transition Quality Review Analysis," dated December 2013, is included in Attachment Three.

A Board Certified Behavior Analyst (BCBA-D) retained by the Independent Reviewer reviewed a small group of individuals with histories of lengthy or repeated psychiatric hospitalizations. While the individuals reviewed experienced a number of destabilizing events, including re-hospitalizations, restraints and police interventions, their providers continued to support them and the individuals maintained community residence. Although there was no abuse or neglect found in the reviews, continuing significant concerns were identified related to their behavioral support needs and services. Generalizations cannot be drawn from four individuals. Therefore, a larger sample of individuals with a need for behavioral supports will be included in the next Report.

Finally, a group of twelve individuals, placed during Fiscal Year 2013, were reviewed by nurse consultants to the Independent Reviewer at the end of the period of review for this Supplemental Report. These latest reviews continued to indicate that sufficient corrective actions had not been implemented in order to ensure that the individual's entitlements to community integration and adequate healthcare were met in a timely and comprehensive manner. The failure to implement these aspects of the Individual Service Plan confirmed previously recognized weaknesses in the provision of adequate and individualized support coordination, as required by the Settlement Agreement.

In conclusion, for the individuals transitioned from a State Hospital during Fiscal Year 2013, after reviewing data obtained both from the forty-one monitoring questionnaires completed by nurse consultants to the Independent Reviewer and from documentation provided by the Department, the facts do not support a finding of compliance with the above referenced Provisions.

DISCUSSION OF FINDINGS

In the professional judgment of the Independent Reviewer, the facts do not support a finding that the State of Georgia is in compliance with Provisions III. A. 2.b.iii. (A)-(C). Additional time and expertise will be necessary to implement these obligations.

The Parties to the Settlement Agreement recognize the systemic barriers to compliance, identified in the placements from Fiscal Year 2013 and Fiscal Year 2014. The focus is now on the timely implementation of remedial actions so that Provisions III.A.2.b. iii. (A)-(C) can be fulfilled as expected.

The monitoring activities conducted by the Department and the Independent Reviewer have identified consistent themes that must be addressed in order to ensure adequate health, safety, habilitation and community integration for the individuals with a developmental disability transitioned from State Hospitals to community-based residential settings.

These themes include:

- The immediate need to realign the responsibilities and competencies of support coordinators so that they can perform the duties anticipated by the Settlement Agreement. These responsibilities include ensuring the timely development and implementation of an individualized plan of supports that adequately reflects the needs and choices of the individual.

The Department leadership has initiated efforts to redefine support coordination, permit its early engagement, and retrain the support coordination workforce. However, these initiatives are still in early stages of development and have not been implemented to the extent required for compliance. There have been positive results from the Intensive Support Coordination pilot project with Columbus Community Services in Region 4. There are three dedicated support coordinators working with caseloads no greater than ten individuals. The responsibilities of the support coordinators include ensuring the adequacy of staff training; ensuring and documenting implementation of the Individual Service Plan; and assisting with linkages to community resources, including clinical supports. Oversight monitoring is conducted with a minimum of one face-to-face visit per week at the residential setting and one face-to-face visit at the day program each month. The Department is considering replication of this model in other Regions but no timeframe has been established.

- The continuing need to strengthen the transition process from State Hospital to community-based settings.

Although the Department took several important steps to strengthen the transition process after the suspension of placements in May 2013, these actions proved to be

inadequate in ensuring the expected quality of transitions during Fiscal Year 2014. As noted above, the lack of support coordination involvement was of concern as was the actual ability of provider agencies to implement the Individual Service Plans. The failure to modify the Individual Service Plans to reflect the realities of a community-based, rather than an institution-based, setting was an additional factor. The Department and its consultants continue to examine additional factors that require intervention.

- The urgent need to ensure competent and sufficient health practitioner oversight of individuals who are medically fragile and require assistance with most aspects of their daily lives.

This may be one of the most challenging obstacles that the Department must resolve. There are a number of critical resources that must be in place, including well-trained direct support staff who can implement instructions consistently and accurately; primary care nurses assigned to each residence; regional nurse capacity to provide technical assistance and monitor trends; a statewide Quality Assurance/risk team that is focused solely on working with high risk individuals and their providers; and capacity for immediate response when necessary.

The Department is exploring the means to develop the requisite knowledge and performance competencies of its healthcare workforce but these actions have not been fully conceptualized or implemented.

- The critical need to define the authority and responsibility of the Regions for the ongoing oversight of the development and implementation of Individual Service Plans for those individuals with a developmental disability transitioning from State Hospitals to community placements.

The Department is exploring the use of expert consultants to assist them in this set of tasks. Fragmentation of authority and responsibility and patterns of inconsistent communication appear to be a partial explanation for the incomplete implementation of the Department's strategies to ensure adequately supported community placements.

- The critical need to develop and implement sustainable strategies for the ongoing monitoring and evaluation of community placements.

The Department and the Independent Reviewer are working collaboratively to design and implement a joint review process to be implemented by Summer, 2014. This process will complement other Quality Assurance initiatives already underway by Departmental staff. These initiatives include a training and implementation plan for a revised Individual Service Plan that is projected to be more person-centered in its approach to developing supports for an individual. It is hoped that this revised process and format will lead to increased community integration. The full

implementation of these initiatives should assist the State of Georgia to achieve full compliance with the relevant Provisions of the Settlement Agreement.

RECOMMENDATIONS

The following recommendations are derived from discussions with Departmental staff and from the observations made during the site visits conducted in preparation for this Supplemental Report:

- As referenced earlier, there is an urgent need to develop and implement sufficient health practitioner oversight of the medically fragile individuals transferred from State Hospitals to community settings. Other state jurisdictions have had to confront similar challenges. As a result, there is a solid base of knowledge to draw from in designing appropriately individualized supports for this group of high-risk individuals. It has been recommended that the Department explore the development of a Medical Safeguards Project, such as those implemented in Pennsylvania and Massachusetts, to assist in the building of its oversight capacity. In addition, there needs to be further examination of the availability of clinical expertise in the community, including occupational and physical therapists, in order to ensure the availability of appropriate supports.

- The Department took decisive action in removing individuals from poorly performing or negligent provider agencies. However, the options for new placements were limited and, thus, constrained the smooth and timely transition to other residential settings. The need for additional resources should be explored in order to ensure sufficient capacity for emergency situations involving an entire provider agency. In addition, the experiences with these three provider agencies should be the catalyst for additional review of provider agency qualifications once problems/concerns are initially discovered.

- The Department's efforts to strengthen the transition process have identified the clear need to obtain a more complete understanding of those individuals still placed in State Hospitals. An updated assessment would permit more accurate planning for the development of community resources. It is recommended that these assessments be conducted on a regional basis and that the findings be compared against the current availability of requisite resources, including clinical expertise.

- The Department should retain an independent consultant/consultant group to conduct mortality reviews for individuals placed under the Settlement Agreement. Independent review of any such deaths would strengthen the Department's knowledge about provider agencies and the availability/provision of critical supports.

- The Department and the Independent Reviewer have agreed to develop a joint review process under the supervision of the Independent Reviewer.

Details of team composition are still in the discussion stage but the process is anticipated to begin by early Summer 2014, in time for the preparation of the next Annual Report by the Independent Reviewer. The Department has increased the Independent Reviewer's budget to permit this work to commence.

Completion of this Supplemental Report required extensive cooperation and assistance from each of the Parties to this Settlement Agreement. This collaboration is greatly appreciated.

On March 7, 2014, a Parties' meeting was held to discuss the findings to this Report. The Commissioner and the Deputy Commissioner participated in this discussion and outlined their immediate actions for implementing the requisite reforms. The Parties have agreed to continue these discussions.