EAST CENTRAL GEORGIAL REGIONAL HOSPITAL FAMILY COUNCIL

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August 26, 2014

Frank Berry, Commissioner
Georgia Department of Behavioral Health & Developmental Disabilities
Two Peachtree Street, N.W., 24th Floor
Atlanta, GA 30303

Regional Coordinator, Region 2
3405 Mike Padgett Highway, Building 3
Augusta, GA 30906

Re: The Family Council's Response to the Commissioner of Behavior Health and Developmental Disabilities Priority Plan (DRAFT) of June 30, 2014

Dear Commissioner Berry and Region 2 Coordinator,

The East Central Georgia Regional Hospital Family Council offers this input in response to the Department of Behavioral Health and Developmental Disabilities' (the "Department") DRAFT Priority Plan.

1. Families and Legal Guardians as Stakeholders

We remain troubled by the Department's continued insistence that it has regularly included "Stakeholders."

East Central Georgia Regional Hospital residents are among Georgia's most profoundly disabled citizens. Although we are their family and legal guardians, **we have not been consulted, notified, or included as stakeholders.** The minimal interaction we have had with Department officials has come at our request.

The draft Priority Plan is more of the same. Opportunity for input is reactionary and after-the-fact.

Who more than family and legal guardians of the very individuals who are most directly impacted by the Settlement agreement are relevant stakeholders? Our family members have profound intellectual and developmental disabilities, among other medical, physical and behavioral disabilities, and reside at the very State Hospitals (Medicaid-licensed Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID)) that the Settlement Agreement will close if fully implemented.

As families and guardians, we are both morally and legally charged with acting in our best interest of our family members. "[C]lose relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights that should be considered during the involuntary commitment process" (*Heller v. Doe*, 509 U.S. 312, 329 (1993).

Our conspicuous absence from meaningful inclusion as critical stakeholders must stop. We hope the Department's intent to encourage "Stakeholder Partnerships and Involvement" is sincere.

2. Indefinite Moratorium on Transfers Needed to Avoid More Tragedy

While we understand the goals of the Plan’s many monikers – strategic (long term), educational (transparent, inclusive, responsive), persuasive (teamwork), developmental (capacity), and remedial (reactionary) – we remain concerned about the Department’s pace of transfers, based on past actions. In 2012 and 2013 transfers from State Hospitals continued even as alarming data relating to mortality, hospitalizations, injuries and more became known to the Department. When family advocates raised concern with the Department of Behavioral Health and Developmental Disabilities and the Department of Justice, each blamed the other.

“Section III. Planning Based on Individual Needs of Individuals in State Hospitals” (which excludes level of intellectual disability), “Section IV, Individual Needs and Community Resources” and “Section V. Individual Planning and Support Coordination” are nothing more than plans on paper. As shown by past practices, hasty transitions according to quotas and without advance and proper execution of all that is envisioned in these sections and other portions of the plan, will lead to continued and predictable tragedy. Although we recognize that the Department of Justice has imposed a moratorium on transfers, we are gravely concerned by the Department of Behavioral Health and Developmental Disabilities’ silence on the issue of transfers.

The Family Council urges, as part of the plan itself, an express statement of unwillingness by the Department to put more lives in danger until all aspects of its robust Section IV, Section V, and other plan provisions, are fully implemented. Section III must also be amended to provide data with regard to levels of intellectual disability of State Hospital residents, as this information also relates to individualized care needs if and when these individuals are transitioned to community settings.

The affected individuals with intellectual and developmental disabilities deserve assurances that history will not be repeated and that all necessary resources will be available to them when choosing to make the transition from the ICFs/IID to the community.

3. A Safety Net is Needed for People with Profound Intellectual and Developmental Disabilities and Other Severe Disabilities

As confirmed in “Section III, Planning Based On Individual Needs of Individuals in State Hospitals,” a vast majority of current residents experience profound disabilities and have complex needs.

Nationally, 76% of state hospital residents have severe or profound intellectual disabilities, 66% have two or more disabling conditions such as deafness, blindness, cerebral palsy, epilepsy, a psychiatric disorder, and/or a behavioral disorder. 13.1% have autism and 40% or more need help transferring, walking, eating, toileting, and/or dressing (“Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010,” (RISP) University of Minnesota (2012) (note: Georgia did not furnish data for this section of the RISP report)).

While we support the Plan’s inclusion in Section III of the needs and process for identifying individual support requirements, as noted above, level of intellectual disability must be added and we question the ability of community providers and the adequacy of community resources (funding, staffing, and access to health care specialists) to safely and consistently provide necessary supports.

State Hospitals must remain as a safety net for those individuals who choose to remain at home in the licensed facility, or for those who need to return for stabilization or long-term supports after failed community placements. Families are very concerned that, as State Hospitals close, Georgia is losing all the highly specialized resources now available at State Hospitals and not available elsewhere.

4. People with Profound Intellectual Disabilities Require Supports; Families as Primary Decision-makers

Although families strongly support self-determination as a reflection of individual choice, they also recognize that some individuals with profound intellectual disabilities are not capable of self-determination.

First-person statements such as “I am ***making choices*** and setting the direction of my life,” and “I have ***the option of using resources*** (public dollars) to life (sic) my own live (sic) within a given budget,” (page 7) disregard the severe cognitive disabilities experienced by most residents of Georgia’s State Hospitals. As noted above, 76% of state hospital residents nationally have severe or profound intellectual disabilities. In addition, 54% cannot communicate basic desires verbally and 29% cannot understand simple verbal requests (“Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010,” (RISP) University of Minnesota (2012) (note: Georgia did not furnish data for this section of the RISP report)).

In these instances, families and legal guardians must be the primary decision-makers as they know their loved ones’ needs and desires best. As noted above, families and legal guardians are morally and legally charged with acting in their loved ones’ best interest. The Plan must more strongly reflect the important role of families as decision-makers in support of their loved ones’ care.

5. Conclusion

In conclusion, the East Central Georgia Regional Hospital Family Council urges the Department of Behavioral Health and Developmental Disabilities to adhere to the following principles and requests:

A. Schedule regular, pre-scheduled meetings between Department of Behavioral Health and Developmental Disabilities officials and families of each of the State Hospital residents, with the first to be scheduled by the end of October 2014. At least once per year, a statewide meeting of families of State Hospital residents must be held at the remaining State Hospitals on a rotating basis. Even with the reorganization of the Department into regional hospital representation, families – regionally and statewide – deserve the opportunity to meet with the Commissioner, as well as regional directors. Transparency is key and the Department ***will*** benefit from receiving input from individuals most closely informed about the needs of State Hospital residents.

B. Support legitimate choice, including residential choice, for all persons with intellectual and developmental disabilities, no matter where they reside. Georgia must support a continuum of care ranging from skilled nursing care to community based supports depending on choice and needs of individuals, consistent with the letter and spirit of the Supreme Court’s *Olmstead* decision.

C. Recognize and value the State Hospitals unique ability to compassionately accommodate acute health care and support needs. Maintain this care for current residents (no closures) and expand its availability to community-based individuals in need.

D. Provide respite care in the ICFs/IID for community-based individuals, including former ICF/IID residents.

E. Provide for a right-of-return to ICF/IID homes for former residents whose community placement is failing.

F. Provide sensitivity training, including put not limited to education of professionals who provide care to community-based individuals with intellectual and developmental disabilities, including but not limited to direct care staff, health care personnel (e.g., hospital personnel, community-based dentist and doctor office personnel, and EMTs), law enforcement officers, and others.

Thank you for your consideration. We look forward to hearing back from you.

Sincerely,

/s/ Theresa Senior

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