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Ms. Kerry Delaney  
Commissioner  
Office for People With Developmental Disabilities  
44 Holland Avenue  
Albany, NY 12208

Dear Ms. Delaney:

I am writing in regard to the transformation panel draft recommendations. Let me begin by thanking you and the panel for your service to individuals with developmental disabilities and their families.

The recommendations contained within the draft provide a framework of values from which to build a comprehensive system to meet the needs of all individuals with developmental disabilities.

Significant challenges remain in predicting what will result, based on the recommendations made, at an operational level. Without significant additional detail, it is unclear as to how effective the system will be in meeting the needs of all the individuals for whom it is intended. In order to determine that, it is imperative that the recommendations, which are vague in their current form, be precisely developed into actionable goals. Many questions need to be answered in order for stakeholders to be able to make informed comments. For example:

- Has an analysis been performed to determine the level of funding needed to carry out each of the objectives?
- What is the timeline for implementation of each recommendation?
- What financial commitments have been made by the state?
- Who are the parties designated to oversee implementation?
- What opportunity do stakeholders have to formally disagree with determinations made and what is the process to file for grievance? How are stakeholders informed of this?
- How will the system be designed to ensure flexibility and the ability for stakeholders to have as much autonomy as is appropriate?

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- What continuum of options will be available to meet the needs of an extraordinarily diverse population?
- What safeguards are in place to ensure that the most vulnerable individuals have their needs met?

These are just a few of the many critical questions that remain. All quantitative and qualitative factors necessary to achieve the objectives set forth in the report and to serve individuals in a meaningful way should be made available to stakeholders.

In addition, with respect to the last question, it was recently discovered that a number of ventilator dependent children have few, if any, appropriate residential placements to transition into upon aging out. My understanding is that the particular individuals in this situation on Long Island were simply overlooked due to no mechanism tracking them in the system. If that is an accurate assessment, we need to invest in information technology capable of providing real-time data and create procedures to ensure that all individuals have been accounted for.

I would like to point out that I volunteer on the Long Island Family Support Services Advisory Council. What I have learned during my short time as a member is that there are individuals with significant needs unable to find a permanent residential placement and have been living in crisis respite facilities. I am confident that this is a well-known problem as well as confident that the agency continues to make efforts to rectify it. However, it should be noted that fiscal constraints as they currently exist will be exacerbated by the need for significant upfront investment to transition to managed care and other planned measures. How will the agency simultaneously serve those already in dire need, create the infrastructure necessary for home and community based services, and execute a transition to managed care? That said I have grave concerns whether the budget appropriated will be sufficient to successfully carry out those objectives, particularly since the budget is determined by those outside of the agency.

I look forward to the solutions to be proposed. Please do not hesitate to contact me if I can be of assistance.

Respectfully yours,  
Denise M. Lombardi