

August 9, 2017

Howard Zucker  
Commissioner of Health  
Corning Tower  
Empire State Plaza  
Albany, NY 12237

Kerry Delaney  
Acting Commissioner of OPWDD  
44 Holland Avenue, 4th Floor  
Albany, New York 12229

Via E-Mail ONLY [HHIDD@health.ny.gov](mailto:HHIDD@health.ny.gov)

Dear Commissioner Zucker and Acting Commissioner Delaney:

On behalf of DDAWNY, the Developmental Disabilities Alliance of Western New York, these comments are being submitted in response to the draft Health Home Application to Serve Individuals with Intellectual and/or Developmental Disabilities

DDAWNY is a collaborative group of member voluntary agencies providing supports and services to people with developmental disabilities. While honoring individual agency missions, it is the intent of the Alliance to assist agencies to develop relationships, promote unified strategies and share risks for the mutual aim with and for the benefit of people with disabilities.

DDAWNY member agencies employ over 22,400 individuals in the seventeen Western and Finger Lakes counties of New York State providing supports and services to over 33,000 individuals with developmental disabilities and their families and/or circle of supports. DDAWNY has also formed a Family Committee to give voice to the people served in the disability arena, but who are often unheard.

DDAWNY has reviewed and is pleased to provide comment on the State's draft application.

First, DDAWNY strongly supports the comments submitted by our sister provider associations, NYSACRA and NYSRA, in particular the concerns expressed by these associations regarding an implementation schedule which seems wholly unrealistic and the need to provide a more deliberate, phased approach to implementation, in order to identify best practices, barriers to implementation and allowing stakeholders from each region of the state to be more deeply involved in ensuring the ongoing transformation effort is successful and serves the needs of the individuals we serve.

DDAWNY shares the concerns of our sister provider associations regarding the role of the I/DD provider agencies in this new health home construct and the need to focus not just upon the health care needs of the individuals we serve, but also on the supports and services we provide which allow people with I/DD to live meaningful and fulfilling lives in the community.

Quality measures need to be outcome based and measure the satisfaction of individuals with I/DD in where they live work and play. Merely importing health based quality measures regarding appropriate medical services for people with I/DD in order to satisfy DSRIP outcomes, outcome measures developed with little thought or input from the I/DD community, does not serve to enhance the lives of people with I/DD. The state and by extension the CCO/HH needs to measure consumer satisfaction with where individuals with I/DD live, work and play. Asking CCO/HH to collect data on employment, without identifying employment, as a valued outcome of the individual is counter productive and the opposite of a person centered approach. For individuals with I/DD who have not graduated high school, but merely aged out of an education system that did not begin to prepare the individual for the world of work, using employment as a quality metric is a disturbing and failing metric.

Quality metrics forming the foundation of a valued based payment system must measure those things of value to the individual. Going to a ball game, working out or swimming, learning to paint, interacting with others may be even more important than finding a job. The CCO/HH needs to measure these metrics of Quality and be rewarded for helping to make the life of an individual with I/DD fulfilling. Similarly moving from a certified IRA to an uncertified setting may be valuable to CMS or the State of New York, but if the individual has lived for 20 years with the same friends in a certified housing situation, his decision to continue to live there should not be a basis for reducing payments to a CCO/HH because there has not been movement to an uncertified setting.

DDAWNY is critically concerned regarding the use of IT, the cost of necessary IT upgrades and the top down approach to IT as contained in the draft application. As has been pointed out by several commentators, unlike, hospitals and physicians, I/DD providers have received very limited EHR investment dollars from the State of New York. The key to a successful transformation agenda will require a far greater investment of State and Federal dollars in upgrading the capacity of DDAWNY member agencies. Our agencies currently lack the capacity to produce the type of reports that will be critical to the success of the transformation and we simply do not currently have resources available to meet the very large investment in technology capital and IT personnel necessary to successfully function in a managed care environment. DDAWNY strongly feels investment in IT at the provider level as well as at the CCO/HH level is a critical and necessary component of a successful transition to managed care under a health home model.

DDAWNY also shares the concerns of our sister provider agencies NYSRA and NYSACRA regarding the critical need to create an IT system based upon common national standards for health information and exchange. Currently the Children Health Home requires knowledge of three separate platforms or portals. There is a need for uniformity and a reduction in the complexity of the IT structure. IT middleware can allow information using common data sets to function transparently. Simplification and standardization across platforms is cost effective and will improve the collection of valuable data and outcomes.

DDAWNY appreciates the opportunity to comment on the draft Health Home Application to Serve Individuals with Intellectual and/or Developmental Disabilities and continues to work as a partner with OPWDD and other State and Federal authorities to improve the lives of individuals with Developmental Disabilities, their families and their circle of supports.

Respectfully Submitted

DDAWNY, the Developmental Disability Alliance of Western New York

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