



Association for Individuals with Intellectual Disabilities



Save Residents' Homes at Developmental Centers

February 23, 2015

HCBS Rules
c/o Lowell Arye, Deputy Commissioner
NJ Department of Human Services
P.O. Box 700
Trenton, NJ 08625-0700

Submitted by email: mahs.hcbs@dhs.state.nj.us

Re: Opposition to the proposed New Jersey Statewide Transition Plan

Dear Deputy Commissioner Arye,

We are submitting this testimony in opposition to the proposed New Jersey Statewide Transition Plan (STP) as part of the public comment process for the Final Rule recently released by Centers for Medicare & Medicaid Services (CMS).

Overall, the STP is deeply flawed. The STP does not take into consideration the wide range and severity of intellectual and developmental disabilities (I/DD) exhibited among the individuals needing HCBS services and supports.

New Jersey Should Not Be Proposing Unnecessary Changes to Law and Policy Before Hearing from the Public

Throughout the STP, New Jersey indicates its intent to first change policy and then law, purportedly to achieve compliance with the Final Rule. As the STP indicates, while certain settings (see below) may be presumed HCBS ineligible, New Jersey could and should, consistent with public input, encourage CMS to overcome such presumptions of ineligibility by demonstrating that these settings meet the Final Rule’s criteria. Determining prior to public comment that policy and law changes are needed – which the Final Rule clearly indicates are not needed – shows New Jersey’s disregard for public input and its lack of concern for individuals who will lose services. The proposal completely negates public input yet to come and makes assumptions that are not required by the HCBS Rule.

Lack of Adequate Public Notice

New Jersey has not provided information about these important changes in plain language as an alternative for assisting individuals with I/DD to understand and respond to the proposed STP. New Jersey offered only two in-person “input sessions,” one of which was scheduled less than a day after the release of the STP and the other just one week later. This is not enough time for individuals with disabilities and other stakeholders to read, plan to attend, and offer public comment at an input session.

The STP Rejects Living Arrangements Allowed by the Rule: The STP Must Consider and Allow Innovative Partnerships as Allowed by the Federal CMS Rule

The STP fails to consider innovative partnerships between ICF/IID settings and HCBS waiver providers, negating opportunities for individuals to be served in service settings of their choice with access to necessary services. For example, individuals receiving HCBS services (group homes, day programs or workshops) on or near ICFs/IID will be required by the state to relocate to “community integrated” settings by June 30, 2016, even though settings adjacent to public institutions are not prohibited in the Final Rule. A unilateral decision by the State, without regard to public comment or the needs and choices of those individuals impacted by the proposed STP, demonstrates no appreciation for the highly specialized needs of those fragile individuals who would benefit from a community setting with access to specialized care at ICF/IID homes.

The STP’s failure to support innovative residential solutions such as farmsteads and planned residential communities now benefiting from HCBS funding (settings which are not prohibited in the Final Rule) again denies opportunities for individuals to have access to necessary services and be supported in service settings of their choice.

The STP Contains Harmful Arbitrary Quotas Which Completely Negate Individual Choice and Need, Contrary to the Final Rule

The STP also contains arbitrary numbers and percentages to define level of integration. The STP arbitrarily decides that 75 percent is the right amount of time that people with disabilities should spend “in the community, not at the facility” day programs. 75% is not person-centered, will be contrary to individual choice in many cases, and has nothing to do with individual outcomes, as required by CMS.

The STP also limits home sizes to 4 people and indicates that a 25% “density rule” will apply to unlicensed, independent housing settings, such as apartment buildings, requiring that no more than 25% of units in a living setting serve people with disabilities. We seriously question the legitimacy of these size limits. Seniors, college students, religious communities, ethnicities, and even families with more than four members, are not subjected to quotas of similarly situated individuals with whom they live and associate by choice. The STP’s arbitrary quotas inappropriately trump individual choice, contrary to the Final Rule.

Reliance Solely on Provider Self-Assessments Prevent Necessary Public Input

Finally, we object to the lack of meaningful public input opportunities. According to the STP, providers will self-assess their compliance with the Final Rule. The true stakeholders, the individuals and their families who value and depend on these programs and services must also be part of the assessment process and provide input about whether their homes, service sites and workplaces meet the necessary “community” criteria.

Conclusion

In summary, the State is making assumptions, prior to public input and contrary to the Final Rule without regard to individual choice, without consideration of outcomes, and without the nature and quality of the individuals’ experiences. The STP indicates that the state “must strive to offer individuals a choice of housing from a spectrum of options.” That spectrum should not be a limited menu otherwise

available to individuals without disabilities. That spectrum must not be restricted based on physical characteristics, the amount of time spent in a day program, the location of services nor the density of individuals with disabilities living at a site. This STP must be challenged as this non-evidence oriented criteria is directly contrary to the letter and intent of the Final Rule.

Respectfully Submitted,

Tamie Hopp

VOR, Director of Government Relations & Advocacy

605-399-1624

thopp@vor.net

VOR is a national nonprofit organization advocating for high quality care and human rights for people with intellectual and developmental disabilities.

Joanne St. Amand

President, Association for Individuals with Intellectual Disabilities, Inc. (AIID)

President, Save Residents' Homes at Developmental Centers 908-272-0399

Jrst.amand@verizon.net

association4iid@gmail.com

AIID is a nonprofit organization advocating for quality care for the residents of NJ who have intellectual disabilities completely funded by private donations.

Save Residents' Homes at Developmental Centers is a coalition of families, friends and caregivers of the residents of New Jersey's Developmental Centers. The Mission of Save Residents' Homes is to keep all of New Jersey's Developmental Centers open as a life-saving choice for our most severely intellectually disabled individuals and their families.

Cindy Bartman

President, Association for Hunterdon Developmental Center (AHDC)

201-819-6996

CEB528@aol.com

AHDC is a non-profit organization advocating for the responsible care of people with intellectual and developmental disabilities.