



# The Family Support Coalition of New Jersey

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February 24, 2015

Deputy Commissioner Lowell Arye  
Deputy Commissioner Dawn Apgar  
NJ Department of Human Services  
P.O. Box 700  
Trenton, NJ 08625-0700

Dear Deputy Commissioners Apgar and Arye,

Members of the Family Support Coalition of New Jersey consist of families who are caring for a family member with an intellectual/developmental disability (I/DD) at home and provider agencies throughout the state. On behalf of our members please find comments for your review and consideration in amending the Draft Statewide Transition Plan as provided to stakeholders on January 27, 2015.

It is stated in the draft plan that “Under the HCBS setting requirements, the PCP process needs to be as follows: driven by the individual; help the individual to direct his/her process to the best possible extent, and is both timely and convenient. The PCP must identify the services and supports that are necessary to meet the person’s identified needs, preferences and quality of life goals.”

As stated above, the intent of the new rule is to assist individuals with I/DD in directing their PCP while instituting and executing their plan. As stakeholders who provide services and supports, whether through direct care as family members or paid staff or provider programs, the proposed policies and regulations as outlined in the draft plan puts forth many mandates that do not promote self-direction in a number of areas. It is our opinion the plan does not recognize the broad spectrum of abilities and disabilities of the population it is meant to serve. Setting restrictions in the amount of time one spends participating in certain activities or the composition of individuals living in a residence do not provide options or individual choice. There is a disconnect between what is stated in the new rule to meet desired outcomes for community living and what individuals with I/DD, their families and providers are currently doing on a day-

to-day basis to fulfill identified PCP goals versus some of the proposed policy changes in the draft plan. Below are top areas of concern.

1. Day programs requirements:

- a. At least 75% of time will be spent in the community and not at the program site: For individuals with medical and/or behavioral challenges often precludes spending this amount of time in the community. Even for those without these challenges, barriers to assisting individuals with personal hygiene in the majority of community settings is equally unrealistic.
- b. Program may not be co-located in a facility where other services/supports are provided. Again for individuals with significant challenges the ability to stay within one building may be needed to prevent exposure to weather changes, lack of appropriate supports and safe transportation to another site.
- c. A requirement to spend a specified amount of time in the community does not ensure the individual will engage in meaningful activities while in the community. Too often community outings are not well developed, designed or adequately staffed to provide a true inclusive community experience. For example, going to the mall to walk around without a specific purpose, riding in the van to deliver food donated by a restaurant and delivered to a food bank/homeless shelter while the staff leave the van to pick up/drop off the food, are not inclusive experiences.
- d. Transportation: Increased community participation requires transportation options and availability to meet individual preferences, particularly for those with medical/behavioral challenges. Current transportation options, whether county, public or provided by a program, are extremely limited and costly. The expectation that transportation services can be expanded and provide the flexibility needed to accommodate numerous individualized needs based on PCP is unrealistic and financially impossible under current resources. Despite 1.5 years of reviewing rates for every service under the new system rates related to transportation have yet to be determined by DDD.
- e. Lack of choice

2. Residential settings:

- a. Change in policy that will require only 25% of a residence is set aside for individuals with I/DD:

- i. Many individuals currently live in residential settings where all permanent residents have I/DD, eg group home, or within an apartment complex or building designed and built to accommodate individuals with I/DD and co-occurring medical/physical disabilities and behavioral challenges. If this policy is adopted, at the least, a grandfather clause is needed to protect those already living in such a residence.
- ii. This restricts individuals in the number of residences and type of residence. The general public including senior citizens, individuals from one ethnic background, individuals with the same religious beliefs, etc are free to choose where and with whom they live. Why should these types of restrictions be placed on individuals with I/DD?
- iii. Moratorium on developing group homes: Many individuals prefer this type of residential setting within a neighborhood. This choice should not be prohibited moving forward. In many cases this feels much more like a home with a “family” as opposed to living a single, solitary life in a one-bedroom apartment; this is community. Various housing models should be allowed, individuals with I/DD must have options like all citizens. Currently, thousands of individuals with I/DD are in need of residential placements as their parents now in their 60’s, 70’s and beyond can no longer safely care for their adult children as they themselves face new health concerns. Options should be expanded to meet the growing crisis for residential placements.
- iv. Lack of choice

The focus on PCP is to be applauded for a population of who has had a limited voice throughout history. We believe this PCP is the right thing to do. However, to implement individual plans under the Medicaid system based on a medical model generally does not provide a high level of flexibility. The intent of the new HCBS rule is to provide additional flexibility in how long-term services are delivered within a community based setting while ensuring health and safety. The proposed plan is more restrictive than current practices

As stakeholders we have serious concerns about how individualized PCP can be met with limited resources for increased staffing needs and funding. To ensure that PCP is fully integrated in “real” world settings the need for flexibility as well as the quality of how plans are executed is paramount. Supporting individuals with I/DD in their communities means more than taking them there; it requires staff that are well trained, compassionate and respectful toward those they are supporting. This demands a living wage for direct support staff and sufficient funding for providers to provide more training, creativity in designing programs and finding solutions to the significant transportation issues that will only magnify in order to fulfill PCP goals.

Equally important is the opportunity for stakeholders to review and comment on assessment tools to be used in the evaluation of licensed settings as well as data collected. We recommend that the division establish a stakeholder advisory group that can meet on a regular basis during this major transition period to discuss in greater detail critical issues and concerns.

Finally, we believe the timeline for achieving compliance does not provide sufficient time to fully review draft/revised plans or gather ongoing input from stakeholders. While the initial plan is due to CMS on March 17, 2015, full compliance with the new HBCS rule is required on or before March 17, 2019. Every piece must be carefully and thoughtfully reviewed by policy makers, those who provide services/supports and, most importantly, the recipients of services and their families. We sincerely hope you review all input and move forward in a well thought out manner so that adults with I/DD living in NJ can experience the meaningful lives they desire in the communities of their choice.

Sincerely,  
Bonnie Brien, President  
On behalf of the Family Support Coalition of New Jersey

Cc: Elizabeth Shea, Assistant Commissioner  
NJ Department of Human Services  
Department of Developmental Disabilities