New York Self-Determination Coalition

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January 5, 2017

Comment on Medicaid Program: Request for Information: Federal Government Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services.

*New York Self-Determination Coalition is a group of families and a few professionals. We support self- directed services for people with intellectual and developmental disabilities by disseminating information, informally mentoring families, and advocating at the state and local level. We are not affiliated with any government or voluntary agency, are not a 501(c)(3), and are not paid for the work we do.*

*The members of our Advocacy Committee come from all over the state and have children of varying ages and Intellectual and Developmental Disabilities*.

We appreciate the opportunity to comment on the Medicaid RFI, “Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services.”

As parents and advocates, we applaud the continuing movement of CMS towards guaranteeing people with I/DD the rights guaranteed to all citizens under the US Constitution and Bill of Rights, as well as, more recently, under the ADA and the Olmstead decision.

We, and many families we speak with are extremely satisfied with NYS OPWDD’S Self-Directed Services with budget and employer authority. We’re encouraged that self-direction is gaining momentum and increasingly being seen as the default option. However, for Self-Directed Services to work for everyone, CMS must ensure that states fund it adequately and monitor it effectively, in order to safeguard the integrity of the program.

A. What are the additional reforms that CMS can take to accelerate the progress of access to HCBS and achieve an appropriate balance of HCBS and institutional services in the Medicaid LTSS system to meet the needs and preferences of beneficiaries?

CMS should assure that funding for people with significant disabilities who choose self-direction is adequate to meet their needs.

We applaud the establishment of the HCBS settings rules. However, we’ve seen both state and voluntary agencies, using the progressive terms to disguise the same old traditional congregate services and settings.

Funding should be rebalanced to facilitate real community integration, not only by moving people from nursing homes to “homes in the community” (which continue to be owned, managed and staffed by an agency) but also incentivizing people to move from any agency-run congregate setting, to regular, non-certified housing, chosen by the individual through self-directed services. This can be done by establishing realistic rental subsidies and giving people adequate funding to pay for the level of support they need to be successful.

Self-direction should not be a hardship choice; there should not be an artificial funding ceiling for people who self-direct. This is even more important in the current environment, so that states cannot cut funding levels in the name of increasing self-direction., while continuing to pay higher prices for more institutional type settings, and for services/settings that redirect money towards provider agencies rather than towards self-hired staffing in non-certified community settings.

**Recommendation:**

 As the Waiver requires that expenditure for HCBS may not exceed the cost of an institutional placement, funding for people who SD with employer and budget authority should also be limited only by that same standard, i.e., people should be funded for the level of services they need to successfully self-direct in their community, as long as the amount doesn’t exceed money that would be used in non-self-directed services. The “cost neutral” requirement should not set lower cost ceilings for people who self-direct their community based services.

Please note: we also made a recommendation related to access (medication administration) in answer to question B. below, as it relates to both access and health/safety.

B. What actions can CMS take, independently, or in partnership with states and stakeholders, to ensure quality of HCBS and beneficiary safety?

A significant percentage of people with I/DD take medications regularly, and/or require assistance with routine activities, such as tube feeding, and that number will increase as the population ages.

A current barrier to using SDS in NYS is the Nurse Practice Act, which arbitrarily disadvantages people who self-direct through OPWDD’s 1915(c) Waiver. People hired as direct support staff through the Waiver are prohibited from carrying out routine health maintenance activities (procedures that the individual would do for him/herself if they were not disabled). This is not a safety issue for the state, because people who self-direct using Consumer Directed Personal Assistance Services have the ability to hire, train, and supervise unlicensed people to perform these activities.

**Recommendation**: This issue can, and has been addressed in other programs by exemptions to the Nurse Practice Act. It would be helpful to have federal encouragement and guidance (with a reminder of Olmstead provisions) to assist states to address the political pressures they are under in this area.

C What program integrity safeguards should states have in place to ensure beneficiary safety and reduce fraud, waste and abuse in HCBS?

1. We are distressed by seeing the increased use of the words “choice,” “individualized”, “person-centered”, and especially “self-directed” to describe agency offerings that are none of those things. This is a particular concern with the Agency with Choice model, offered as a way to “self-direct” with employer authority.

In some cases, these agencies impose significant restrictions on staffing that make a mockery of the guarantee of “employer authority.”

**Recommendation:**

CMS should require states to assure that the Agency with Choice model actually gives participants full employer authority.

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**Recommendation:**

 Agency with Choice organizations should be transparent in their policies. (This will also enable Individuals who receive services and their families to knowledgably choose service providers).

For example, the state could be required to have each Agency with Choice publicly post answers to these questions:

Can the participant decide which of the Agency’s staff they wish to hire?

Does the agency limit the number of hours a participant can work with a particular staff member? (This should be a negotiation between the participant and staff).

Does the participant have the freedom to set the time of day or length of shift they hire staff for?

Does the Agency with Choice require the participant to receive brokerage services from that agency?

Does the agency limit the number of hours a person can receive of community habilitation, for example, even if the person’s budget can support more time.?

2. In New York State, Fiscal intermediaries for Self-Directed Services have been given broad discretion to choose which SD Waiver services they offer, and the ability to reject plans funded above a certain number. For example, some FIs will not allow the paid neighbor option for example, while others set a cap on plans they will accept. Both limitations deny people needed services, and often prevent them from moving out of the family home, even if OPWDD has allotted adequate funding.

**Recommendation**

We believe that CMS should be clear in its guidance that a Fiscal Intermediary for Self-Directed Services with budget and employer authority, must agree to administer all services the State’s 1915 (c) Waiver authorizes to be self-directed.

Further, since Fiscal Intermediaries do not provide direct services nor directly supervise staff, they should not be allowed to cherry pick plans based on budget size, number of employees, etc., and should be required to take all comers.

D. What specific steps could CMS take to strengthen the HCBS home care workforce?

Budget authority is meaningless if ability to hire, and retain staff is taken away. People with I/DD who self-direct (often with significant involvement of a parent or guardian), need direct support staff who are responsible, flexible, problem solvers, as they are often working alone with an individual, without co-workers or supervisors present. Further, the job is not just to care for the individual, but to actively facilitate their inclusion in community, often a complex task. Direct support staff should be paid a competitive wage.

We are especially concerned with direct support workers’ wages as we move to managed care, as we’ve seen an example of this with Consumer Direct Personal Assistance Services in New York. When CDPAS in Nassau and Suffolk Counties became part of MLTC, wages for staff dropped significantly, and staff quit, threatening the ability of some people to avoid institutionalization.

**Recommendation**

Under NYS’ new minimum wage law, flipping burgers would be a step up in salary to that paid by MLTC companies for direct support staff, an outrageous state of affairs. Direct support staff must be paid a competitive wage. CMS should require states to closely monitor MLTC companies to require that wages are paid that are adequate to hire and retain competent staff.

Sincerely,

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