New York Self-Determination Coalition Position Paper:

Preserving the Rights of People with Developmental Disabilities in the People First Waiver

As OPWDD moves closer to completing the People First Waiver and submitting it to CMS, we are concerned that by primarily focusing on the technical issues of the transformation to managed care, we are losing sight of its potential to transform people's lives. As members of People First Waiver Design Teams and the Waiver board, we were encouraged by OPWDD’s stress on the principles of person-centeredness, choice, quality and community during the planning process. However, for these goals to be realized it is imperative that a mechanism for an independent ombudsman be written into the waiver.

Currently, the Medicaid Service Coordinator has a dual role, serving to both coordinate care and act as an advocate for the people she serves. Although this system isn’t perfect, people with disabilities and families identify their MSC as the person to call when they need help handling a problem with one of their services or supports. Further, mandated visits from the MSC provide an occasion to bring up pressing issues, and also can serve to uncover instances of abuse or neglect. Conversely, in managed care, the care coordinator functions primarily as a gatekeeper, not an advocate. Without advocacy, the people OPWDD serves will be deprived of the ability to shape their own lives.

We recognize that managed care organizations and Medicaid have complaint, grievance, and appeal procedures, which are usually initiated after a denial of supports or services. What if, instead, we could create a proactive system to correct inadequacies before they develop into serious problems, and to give people with disabilities real access to the already existing appeal processes? Dealing with problems at the “front end” would enhance peoples’ lives and also be cost effective.

There are two major reasons why the currently available processes would not adequately serve to accomplish OPWDD’s goal of improving (or at least, maintaining) quality of life for people with developmental disabilities

First, by definition, a formal grievance process takes place after a problem has arisen. Common sense would seem to suggest that many issues that arise in peoples’ lives could be worked out by a series of conversations, rather than a formal complaint. Although a small number of self-advocates are able to express their needs clearly and negotiate with those who have enormous control over their lives, the vast majority of people with developmental disabilities cannot.

Second, it is not reasonable to expect a person with significant developmental disabilities to be able to navigate informal or formal complaint, grievance and appeal procedures that were designed for “typical” adults. A few hypothetical situations will make this clear.

For example: You are a person with an intellectual disability, and you want something to change in your life: a paying job, a roommate who doesn’t keep you up all night, more friends. Or maybe you’re being emotionally abused, and are becoming depressed, but are unable to communicate this in words.

Here’s what you have to know and do to improve your situation:

        Be aware that your life can be different than it is now, or that how you are being treated is wrong,

        Know that there’s a way to resolve your issues (that you have rights)

        Find out whom to speak to in order to begin the process

        Contact and communicate with the appropriate person by phone, mail, or email

        Receive documents by mail or email

        Read and understand what you are being asked to do or submit

        Fill out required forms

        Follow up on your complaint or appeal

In addition, many people with significant intellectual disabilities also carry diagnoses of psychiatric disease, behavior disorder, sensory impairment, communication differences, and/or motility difficulty. They often live in settings where the only non-disabled people they interact with are agency staff, and where use of the phone and/or computer (if available) is limited.

And of course, people with significant disabilities are often almost completely dependent on the very staff and system that may not be adequately serving their needs.

This issue should be addressed by establishing a dedicated, funded, independent ombudsman program. Creating an ombudsman was, in fact, the formal recommendation of the OPWDD led Access and Choice and Care Coordination Design teams and approved by the People First Waiver Steering Committee.

The role of an ombudsman is clearly explained in a joint paper from the National Senior Citizens Law Center and the Disability Rights and Education Defense Fund:

*A key beneficiary protection, particularly for LTSS services, is the availability of an independent, conflict-free entity to serve as an ombudsman for participants. The ombudsman would provide individuals with free assistance in accessing their care, understanding and exercising their rights and responsibilities, and in appealing adverse decisions made by their plan. Through this individual assistance the ombudsman can also identify systemic problems and work with state and plan officials to raise and resolve issues. Although the ombudsman can address any issues that arise for MCO members, it is anticipated that most issues would involve LTSS and the ombudsman should have particular LTSS expertise.*

From: Long-Term Services and Supports: Beneficiary Protections in a Managed Care Environment

The ombudsman role could be filled by funding an existing advocacy organization or organizations. Another idea is to attach the ombudsman function to the not yet developed Justice Center. The ombudsmen could be a "Justice Center extender," able to assist people BEFORE significant problems occur. We have more specific ideas about how an ombudsman could function in the managed care system and would be happy to share them.

As New York State and OPWDD work to transform the system of care for people with developmental disabilities, it would be unacceptable to leave society’s most vulnerable individuals, without the protection of an advocate whose sole goal is to be their voice.

Sincerely,

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New York Self-Determination Coalition