

Comments on NYS DOH Proposed Amendment of Personal Care and CDPA Regulations August 2020

About Us

Southern Tier Independence Center, Inc. is a Center for Independent Living in Binghamton, NY, established in 1983. We provide a broad range of programs and services to people with all types of disabilities of all ages across south-central New York State. Our CDPA program, which serves Broome, Chenango and Tioga Counties, began operations in 1999. It is currently serving 466 consumers, and employs 522 personal assistants at this time. We have extensive experience working with managed care insurance plans and county departments of social services in this program. Our Executive Director, Maria Dibble, also has governance experience in the Medicaid managed care field, having served on the board of directors of iCircle, Inc.

General Considerations

The “Legislative Intent” section of the Notice of Proposed Rulemaking (NPR) states that the legislative amendments to the personal care and CDPA services programs include a requirement “that the standards established for the provision, management or assessment of such services meet that [sic] standards set forth in *Olmstead v. LC by Zimring*, 527 US 581 (1999)”. However, several of the proposed regulatory changes (discussed in detail below) actually violate the Americans with Disabilities Act (ADA) as interpreted by the *Olmstead* decision and other case law, as well as federal Medicaid law.

In 2011, the US Department of Justice (DOJ) issued guidance to states on what they must do to comply with the *Olmstead* decision, here: https://www.ada.gov/olmstead/q&a_olmstead.htm.

To summarize:

The *Olmstead* decision requires states that offer any long-term care services and supports to offer them to all eligible individuals in the most integrated settings appropriate to their needs. Any settings that are not the individual’s own home and/or preferred community locations are by definition not the most integrated settings that are, at least, possible. Moving to the question of appropriateness: A functional needs assessment is an example of an objective process that determines the types, durations and intensities of services that are appropriate to the individual’s needs, but, according to the DOJ guidance, it is not the only permissible way to make such determinations. If any appropriate determination methodology finds that an individual needs and can benefit from personal care services, then those services are by definition appropriate to the individual’s needs for ADA purposes.

The *Olmstead* decision applies only two limitations on its requirement: A state may not force an individual to accept a more integrated setting that s/he does not want, and the state need not take actions that would be a fundamental alteration of its long term care programs. The first limitation is self-explanatory.

A claim of fundamental alteration is the only cost-based defense a state may advance against a charge that its long-term care programs violate the ADA. A desire to cut costs does not qualify as

a “fundamental alteration” defense, even in a time of budget difficulties. In fact, ceasing to provide a service to a group of people who previously were offered the service would be a fundamental alteration, whereas continuing to provide that service, or even expanding it, can never be. The DOH guidance, and case law subsequent to *Olmstead*, indicate that cost analyses that do not compare the aggregate costs of serving the universe of eligible people when determining whether one type of long-term care is more or less expensive than another type are not acceptable. Cost analyses that do not consider all of the available or potentially available funding sources, including savings gained from downsizing and consolidating segregated programs, also do not satisfy the standard. Nor does the mere existence of a “state *Olmstead* plan” as a document immunize a state against charges of ADA violations. Only if such a plan effectively, and with reasonable speed over time, expands availability of integrated services and supports and continuously reduces the number of people who are inappropriately segregated against their will, according to specific time frames and in pursuit of measurable goals, can the plan be used in the state’s defense. New York’s *Olmstead* plan is a plan in name only; it does not have specific time frames or measurable goals and the state cannot produce reliable data to demonstrate that the plan is achieving anything of substance.

Federal Medicaid law requires states to provide all services to eligible Medicaid recipients that are “medically necessary”. Personal care services that have been determined by an appropriate authority to be needed by an individual are, by definition, medically necessary. Although the ADA and the *Olmstead* decision do not define medical necessity, they do establish a broad array of acceptable methods for determining what is necessary and appropriate, and DOJ’s guidance is quite clear in stating that minimal compliance with federal Medicaid law does not provide immunity from a charge of violating the ADA in the provision of Medicaid-funded services. Further, the current regulations governing Medicaid managed care, which funds most personal care services in New York, apply the federal regulations for person-centered planning and community-based settings to those services. Although the Centers for Medicare and Medicaid Services (CMS) have permitted delayed implementation of required formal “Community Based Settings Plans”, this does not change the fact that the regulations are in effect now and must be followed now.

Specific Issues

1. “Not the individual’s attending physician”

The proposed rule requires that personal care services can only be provided if approved by a “qualified and independent physician” who is “not the individual’s attending physician” (changing 18 NYCRR Section 505.14(a)(1)).

If this requirement results in people being denied personal care in their own homes and preferred community locations when their attending physicians or other authoritative sources would approve such services, it will violate the DOJ guidance, which states, in relevant part:

“An individual may rely on a variety of forms of evidence to establish that an integrated setting is appropriate. A reasonable, objective assessment by a public entity’s treating professional is one, but only one, such avenue. Such assessments must identify individuals’ needs and the services and supports necessary for them to succeed in an integrated setting. Professionals involved in the assessments must be knowledgeable about the range of supports and services available in the community. However, the ADA and its regulations do not require an individual to have had a state treating professional make such a determination. People with disabilities can also present their own independent evidence of the appropriateness of an integrated setting,

including, for example, that individuals with similar needs are living, working and receiving services in integrated settings with appropriate supports. This evidence may come from their own treatment providers, from community-based organizations that provide services to people with disabilities outside of institutional settings, or from any other relevant source. Limiting the evidence on which *Olmstead* plaintiffs may rely would enable public entities to circumvent their *Olmstead* requirements by failing to require professionals to make recommendations regarding the ability of individuals to be served in more integrated settings.”

Although not necessary to demonstrate that the proposed regulation will violate the ADA on its face, we would like to point out that medical professionals who are experienced in working with people with disabilities know that assessment tools, in and of themselves, do not necessarily provide a complete and accurate picture of the individual’s abilities and needs. This is why, for example, the assessment protocol used for the TBI and NHTD waivers allows for the input of people who know that individual well. Peremptorily excluding the input of the attending physician in the manner contemplated here violates not just best practice, but standard practice for reliable assessments.

2. “Cost effectiveness”

The proposed rule requires a “cost effectiveness” determination by means of comparing the costs of serving an individual among all types of available long-term care services and imposing the least expensive type on each individual in each case (18 NYCRR Section 505.14(a)(3)(iii)).

If, solely as the result of such a comparison, an individual is forced to accept a setting that is less integrated than s/he prefers, it would violate the ADA. This is because the only cost-benefit analyses that federal courts have accepted in such cases are those that compare the costs of serving people in the aggregate, not on an individual basis. It matters not at all to the state’s fiscal soundness if some individuals’ personal care services in their own homes and preferred community locations cost more than serving them in a segregated setting that is not their own home, including assisted living centers, adult care or personal care homes, or nursing facilities, if the state’s aggregated cost to serve all of its eligible citizens with fully integrated personal care remains less than the state would have to pay to serve them all in segregated settings.

As regards cost-cutting, the DOH guidance states:

“The relevant resources for purposes of [cost effectiveness] consist of all money the [state] allots, spends, receives, or could receive if it applied for available federal funding to provide services to persons with disabilities. Similarly, all relevant costs, not simply those funded by the single agency that operates or funds the segregated or integrated setting, must be considered. . . . Moreover, cost comparisons need not be static or fixed. If the cost of the segregated setting will likely increase, for instance due to maintenance, capital expenses, environmental modifications, addressing substandard care, or providing required services that have been denied, these incremental costs should be incorporated into the calculation. Similarly, if the cost of providing integrated services is likely to decrease over time, for instance due to enhanced independence or decreased support needs, this reduction should be incorporated as well. . . . Even in times of budgetary constraints, [states] can often reasonably modify their programs by re-allocating funding from expensive segregated settings to cost-effective integrated settings.”

We don’t support use of individually-based cost comparisons under any circumstances, because they completely omit the individual’s preferences from the equation, and those preferences have

legal standing under the ADA and federal Medicaid regulations (see item 3, below) and must be accommodated. However, we must also point out that the proposed regulations unfairly single out personal care. If the concept were applied fairly and uniformly, then cost-comparisons would be applied to all people in nursing facilities and would likely result in most of them being released to their own homes with homecare services, and if cost-comparisons were applied to people in so-called “traditional” homecare (typically a combination of Personal Care, Certified Home Health Care, and Private Duty Nursing), then many of those people would be required to use the Consumer Directed Personal Assistance (CDPA) program instead, since it is generally less expensive. The latter is, in fact, what many MCO utilization review processes do, and a desire to achieve such savings is what motivated the state to require that individuals seeking homecare services be told about the CDPA option for many years, before it counter-productively removed that requirement this year. We think this requirement should be reinstated, and if it is not, we request the information that led to the initial proposal to eliminate it in the options transmitted to the MRT. On its face, it appears to be a punitive measure aimed at CDPA providers who have organized to defend the program, rather than a fact-based effort to reduce overall Medicaid spending.

3. Absence of person-centered planning

Proposed new language in 505.14(b)(1) and 505.28(d) defines “development of the plan of care” as a part of the “assessment process”. Taken as a whole, the proposed regulations describe a care plan development process in which the service recipient’s participation is overshadowed by that of medical professionals and “others involved with the patient’s care if available to and determined necessary by the medical professional.”

The current regulations include a requirement that “The patient must use [other services, including segregated congregate living and/or day program services] rather than personal care services to achieve the maximum reduction in his or her need for home health services or other long-term care services.”

When Medicaid personal care services are delivered through managed care (and, as the NPRM notes, most such services are today), these requirements violate the federal 1915(c) person centered planning regulations (at 42 CFR 441.301(c)(1) and (2)), which are incorporated into the federal Medicaid managed care regulations at 42 CFR Section 438.208(c)(3)(ii) and apply to all long-term care services delivered through Medicaid managed care.

Those regulations prescribe a person centered planning process that is led by the individual receiving services to the maximum extent possible, and includes participation by anyone whom the individual chooses, and the resulting plan must reflect the individual’s preferences for service modalities and include an assurance that the individual was afforded the opportunity to choose the place where s/he will live. Requiring a person to accept placement in an assisted living facility when s/he does not wish to live there clearly violates these regulations. Further, development of a person centered plan of care must not be considered part of the “assessment process”. A proper assessment process develops information that becomes one point of consideration in the development of the plan of care. The results of an assessment process do not, in and of themselves, fully define a plan that must seriously take into account and, in the end, reflect, the desires, preferences, and aspirations of the person being served.

Also, 42 CFR 438.3(o) requires that all Medicaid managed community long term services and supports comply with the 1915(c) definition of “home and community based settings” (at 42 CFR 441.301(c)(4)). Many Medicaid-funded assisted living and social adult day programs do not

comply with that definition because they have institutional characteristics. We again point out that notwithstanding CMS's grant of an extension for full compliance with a formal "Most Integrated Settings Plan", the relevant federal person centered planning and home and community based settings regulations are currently in effect and must be followed. It should also be noted that when the new deadline for formal compliance is reached, some facilities which these regulations implicitly expect to be available may actually be closed.

4. Counter-productivity

The intent of the legislature and governor in passing the legislation that led to these proposed regulations, as stated in numerous public pronouncements, was to reduce the amount of money the state spends on personal care services, and, thereby, to reduce the state's total Medicaid spending. But the legislation, and these regulations, will have the opposite effect.

Fundamentally, if a person's ability to maintain his or her health and nutrition in his or her own home is significantly reduced, even if s/he does not meet the threshold of at least 3 ADL needs required by these regulations to obtain personal care services at the outset, his/her health will inevitably decline to the point where s/he does have those needs. In the meantime, having only one or two of the defined ADL needs is, for most people, enough to obtain a nursing facility level of care (LOC) if they do not have family or friends who can help them. Although the state's Assisted Living Program (ALP) is cited as a potential alternative, to be eligible for it, individuals must meet a nursing facility LOC, but must have very limited needs for support (most providers will reject people who need more than four hours of daily service), and the program itself is so small that new applicants are placed on waiting lists—it is not only not "the most integrated" option, it is not even actually an available alternative in many places. Therefore, many if not most of the people who will be denied a few hours a day of relatively inexpensive personal care services as a result of these regulations will instead be placed in much more expensive nursing facilities.

It is important to note that the 3-ADL minimum needs requirement, as stated in the regulations, is an entry-level requirement for eligibility for services. Individuals who do not meet it will not get to the later step of having a cost-effectiveness assessment of their plan of care. Instead, the state will be obligated by federal Medicaid law, which requires the provision of nursing facility services to all those who are eligible for them, to spend funds which a cost-effectiveness analysis undertaken prior to considering the person's ADL needs would have saved.

(Again, that is not to say that we believe simple cost comparisons on an individual basis to determine whether a person can get community-based or institutional long term services and supports are ever appropriate; clearly the DOJ guidance and *Olmstead* case law show that they are not. Rather, we are pointing out that the assumptions about actual costs on which these regulations are based are faulty and will lead to an overall increase in Medicaid spending that will exceed the rate of increase that could be naturally expected from an aging population for whom use of the least expensive types of long term services and supports is maximized.)

5. Disability discrimination

The new minimum needs requirements establish a rationale for illegal discrimination in the equal provision of services on the basis of disability by the state.

The need for personal care services to ensure the ability to live and work in the community cuts across a broad range of disabilities. As noted above, the new requirements impose a flat cut-off

of availability of *any* Medicaid personal care services to people who do not have an arbitrary number of “needs”, even though having even one such need, or indeed, having even an ongoing need solely for what are now termed “Level 1” services, can get a person admitted to a nursing facility. Perversely, the regulations establish a situation in which individuals with less severe types of disabilities may be more likely to be placed in segregated settings than those with more severe disabilities who will qualify for personal care.

This is a perfect example of what the US Fourth Circuit Court of Appeals meant when it said, in *Pashby v Delia*, “that a State may commit discrimination by treating one type of disabled person worse than another type of disabled person.”

Medicaid law permits states to use Medicaid waivers to provide specific types of services to specific disability groups, as long as the overall result is not discriminatory in the availability of services and supports in the most integrated settings to all groups, which would be illegal under the ADA. But a waiver is not what is being proposed. The proposal is simply to deny any form of homecare—an integrated community-based service—funded by any source, under any rules, to a group of people with disabilities who clearly need that service for their survival, while providing it to another group of people with disabilities who also need it to stay alive. Although it may be argued that in some sense the level of need differs between those two groups, members of both groups would qualify for nursing or assisted living facility placement—segregated options—and without a homecare option, members of both groups would be placed in those facilities as a matter of survival. That is simple disability discrimination on its face.

Conclusion

Enactment of these regulations will clearly put the State of New York in the position of fending off hundreds or thousands of federal human rights complaints and lawsuits that will surely be filed as soon as new personal care applicants begin to be turned away or are forced into nursing facilities or other segregated residential and day program settings.

Although the Department of Health (DOH) is in the position of having to respond to legislative action with regulations, it owes elected officials an honest appraisal of the situation. Such an honest appraisal must state that the regulations, and the law itself, will be overturned by federal courts within months of their enactment, and that a better approach to the problem of Medicaid spending growth is to recognize that an aging population makes such growth inevitable and the best that can be done to slow it is to reduce availability of the most expensive forms of long term care, and promote and maximize use of the least expensive forms of that care, including personal care and CDPA services.

We thank you for the opportunity to comment.