Upcoming Changes to NY Home Care Services

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Personal Care Services (PCS) and Consumer Directed Personal Assistance Program (CDPAP) allow disabled New Yorkers to attain home care and the right to live in the community. Without these services, we would see an influx of our people forced into institutions or living in their homes without proper services. Our community has been fighting for years for the right to live in our own homes with the humanity we deserve.

Changes to Eligibility Criteria

This was supposed to go into effect on October 1st, 2020, but has been pushed back due to the extended federal emergency procedures. Set to resume tentatively on April 1st 2021.

Current rule for eligibility for services:

- You must have a physician diagnosed disability & need assistance with 1 or more ’personal care services’ which can include:
    - Level 1 (IADLs): social environmental support like laundry, cooking, shopping making beds, housekeeping, etc.
    - Level 2 (ADLs): medical needs like showering, dressing, etc.

What they are changing it to:

- Because of the recent Health Budget Law S. 7506-B; A. 9506-B passed through the State Legislature’s Health Committees, changes were made to other laws that modified the eligibility criteria for CDPA and PCS. Section 365-a and Section 365-f of social services law now dictate that:
    - You must have a physician diagnosed disability & need assistance with **‘physical maneuvering’** for **AT LEAST 3 ADLS (activities of daily living).**
    - Unless there is a dementia or Alzheimer's diagnosis, then you need **‘supervision’** with **AT LEAST 2 ADLs**
    - Recently, Assembly Bill A10486 was proposed by the state’s health committees. This bill advocates for people with traumatic brain injuries, developmental disabilities, cognitive disabilities, and blindness or visual impairment should also follow the **‘supervision’ with at least 2 ADLs rule.** This has not yet passed, and still violates CFCO.

How are they defining ADLs?

The Department of Health has the power **to define 'ADLs.'**

- Advocates across the state *highly* suspect that their ADLs will be defined by the Uniform Assessment System (info here), the assessment tool used for our yearly check-in with the nurse that does our evaluations. These ADLS are: Bathing, hygiene, dressing, walking/locomotion, transferring on/off toilet, toilet use, eating, bed moving (i.e. turning in bed).
- Specifying ADLs in the law means that Level 1 care or IADLs will no longer be used, even though they are critical. In the state register, the DOH even wrote that they want to reserve CDPA services "for those that need them the most," which implies they hope to exclude many.

How do they define 'supervision' or 'physical maneuvering?' Tiers of assistance on tasks in UAS-NY are:

- Independent
- Setup help only
- ***Supervision: oversight and/or cueing**
- ***Limited assistance: guided maneuvering of body without weight bearing**
- Extensive assistance: help from 1 person that involves weight bearing, consumer can complete 50% of task
- Maximal assistance: help from 2 people that involves weight bearing, consumer can complete 50% of task
- Total dependence: need assistance with 100% of task

Something for us to keep in mind …

Community First Choice (CFCO)

- CFCO is a state plan that allows people to access home and community-based services. It comes with a wide variety of rules and regulations that the state must follow for these services. Currently, 90% of NYS CDPA falls under CFCO, and thus, the state receives 6% funding for adhering to their guidelines. General information on it can be found here.
- … but their guidelines mandate that **IADLs (level 1 care) should be included** (reference here, starting at bottom of 'page 3') and that there should be **no discrimination/difference in services based on type of disability (**Reference**:** page 8 of the CFCO Technical guide by CMS),
- The proposed regulations in direct violation of CFCO, considering…
  - A) They don't include IADLs
  - B) People without dementia diagnosis have stricter criteria to meet for eligibility

Olmstead v. L.C.

- Olmstead was a ruling in 1999 that stated unjust segregation of disabled people in institutions is discrimination and in direct violation of the ADA. It mandates that public entities must provide community-based services to disabled people when they are appropriate, when the consumers want such services, and when it can be reasonably accommodated. You can find more information here.

- There will be **MANY Olmstead law suits** when people start being DENIED home care because of this change but APPROVED for nursing home care because they meet the "nursing facility level of care" score of a 5 on the UAS.

The **Department of Health** takes these laws and writes regulations for Centers for Medicaid and Medicare Services (CMS) to follow. Their most recent proposed regulation can be found here: https://health.ny.gov/health_care/medicaid/redesign/mrt2/docs/express_terms_summary.pdf

Some concerning aspects of their regulations include changes to our yearly assessment processes.

Current regulations:

1. After your yearly physical, your physician has 30 days to fill out paperwork (ex: M11Q form) stating your medical needs.
2. Nurse from the state visits to complete Uniform Assessment System (UAS). This 2-hour interview involves the nurse picking from a drop down menu of our 'level of need' for clearly defined tasks, which computes our 'UAS score.' You can access more information on UAS here.
3. Case manager from HRA/LDSS does in-home assessment, determines hours of care that we deserve, and then the plan of care reaches consumer.

Proposed regulations:

They are proposing that we take an already lengthy process and make it even more arduous. Assessments will **NO LONGER be provided by our own doctors** but instead a 'independent' Maximus contracted provider. The proposed changes would include the following yearly assessments, where it is emphasized that they do 'safety checks' at every level to determine whether we truly are fit to live in the community.

1. *Independent Social and Environmental Assessment:* a Maximus provider will complete the UAS assessment.
2. *Independent Medical Assessment:* Maximus provider will review our UAS. They are allowed to read our previous medical records and contact our doctor. From here, plan of care is developed.
    a. If 12+ hours of care, Independent Assessors of medical professionals will hold a "panel" to see if the current plan is "appropriate."
3. *HRA/LDSS* case managers will…
    a. Receive Independent Assessors plan of care and modify if needed
    b. Determine our hours of care*
    c. Do safety assessment to see if "we are safe in the community" or if we can "be more appropriately served with other services."

*How will they determine hours?

- There is talk of creating an 'uniform tasking tool' for HRA/LDSS to use in determining our hours of care. (See page 24 of this State Plan Amendment and Section 4403-f of the public 17 health law).

- There is speculation that the DOH may use a modified version of the UAS for this matter. That the 'score' produced will be what determines the number of hours we will receive, but the DOH *has not yet released* what the tool used will be.

DOH also added a new lookback period for those applying to home care. This means that they will comb through 2.5 years of peoples finances to ensure that they never went over the "allowable" amount. If they had, they will be denied.

What does all this realistically mean for our futures?

These regulations set up an environment where those that are "not disabled enough" do not get services, and those that are "too disabled" have to endure lengthy assessments where it becomes easier for the state to judge them as 'more fit' for an institution.

By making eligibility based on this list of ADLs that don't include transferring into wheelchairs, transferring in and out of bed, and many other important tasks of daily living (like cooking, shopping, laundry, etc.) they are making it impossible for many disabled people to access home care. If someone doesn't meet their requirement for the 3 pre-approved ADLs because they need assistance with other necessary tasks for survival that they don't take into account, they will be living in the community without access.

Those that *do* meet their stricter requirements for CDPA will be forced to endure an even more arduous yearly assessment process that is designed to discourage people. We will no longer have the right to our own doctors, and be forced into getting assessed by medical professionals that do not have the same knowledge of our lives.

It is very clear how reductive disability becomes in the eye of the law. The idea that we need 'Independent Assessors" because those that know us are "biased" is deeply flawed. To understand the breadth of how disability manifests in our lives or the gamut of how it differs day to day, you have to have a relationship with the disabled person— it is not something that will be understood by a panel of random medical professionals in a single meeting, or with an algorithm that decides how many hours of care we receive. How much more humanity will be removed from these processes and our basic rights?

Some helpful resources:

- NY Health Access' summary on the issues: http://www.wnylc.com/health/news/85/#home%20care
- A presentation on these matters: https://www.youtube.com/watch?v=qoUB1xlJVds&t=2019s