

Proposed Changes to NY Home Care Services & How We Can Fight Back

Version 1.4



Downstate New York ADAPT

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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.

Currently, the Department of Health (DOH) is proposing regulation changes that will make it increasingly difficult for many to access these services and be able to live in their homes. Long Island ADAPT hopes to team up with others willing fight these changes and provide feedback to the DOH on what this would do to our community... and we could use your help! This document may change & mold over time as we approach the deadline and gather more information.

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Where can I find the regulations?

I.D. No. HLT-28-20-00019-P

Proposed Action: Amendment of sections 505.14 and 505.28 of Title 18 NYCRR.

Statutory authority: Social Services Law, sections 363-a, 365-a(2)(e), 365-f(5)(b); Public Health Law, section 201(1)(v)

Short overview:

<https://www.dos.ny.gov/info/register/2020/071520.pdf> (page 16 of doc)

Full text:

https://health.ny.gov/health_care/medicaid/redesign/mrt2/docs/express_terms_summary.pdf

Overview of proposed changes:

Who is qualified for PCS or CDPA:

Current regulation:

- 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.

Proposed regulations:

- 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**
 - 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.
- But... DOH has the power to **define 'ADLs'**:
 - Advocates across the state *highly* suspect that their ADLs will be defined by the UAS: Bathing, hygiene, dressing, walking/locomotion, transferring on/off toilet, toilet use, eating, bed moving (i.e. turning in bed).
 - 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 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

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 Universal 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.

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),
- Are 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](#).
- The budget contains language that grants the DOH power to adopt standards and assessment methods to verify if an individual's need for Personal Care Services exceeds a specified level and "... **is capable of safely remaining in the community in accordance with the standards set forth in Olmstead v. LC by Zimring, 527 US 581 (1999)** and consider whether an individual is capable of safely remaining in the community."
- Olmstead is not about judging whether we are capable of ‘safely’ living in the community, it is about *our right to try*. Since DOH can interpret these regulations however they see fit, is there a chance Olmstead will be misconstrued? Will there be implications?

Other proposed changes:

- Adding a telehealth option. Although not fully explained in the regulations, they are proposing that some care can be provided over telehealth. Since home care cannot be completed over video chat, we were wondering if this would include nursing assessments where the consumer would take their temperature, oxygen level, etc. at home and report back. Again, this is speculation and we are waiting to hear clarification.
- Modification to the definition of ‘live-in’ caretaker: they need to have at least 5 hours of uninterrupted sleep out of 8-hour period.
- Definition of ‘self-directing consumer: a person who is capable of instructing, supervising, managing and directing consumer directed personal assistants.
- Mandate that we, the consumers:
 - Can only use one FI (CDPA agency)
 - No longer have the right to be informed of the option for CDPA if we are using other services
 - Are no longer required to be notified about our right to appeal the state’s decision
- Consumer-designated representatives must make themselves available for responsibilities, assessments, appointments, etc.
- No mention of a public hearing once commentary has been submitted. There is talk of a workgroup, but a public hearing seems extremely deserving with changes of this size. They will no longer respond to each comment but instead ‘summarize’ all comments.

Are people currently on CDPA/PCS grandfathered in?

Complicated question, because it was not something that was directly addressed in the regulations. Our understanding is that we are ‘grandfathered in’ in the sense that we will not have to adhere the ADL definitions of eligibility since we are already enrolled in the service. Although, having to switch our yearly assessment processes and no longer use our own doctors are very much in the realm of possibility.

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?

Much of the newly chosen language in the draft appears to be rather aggressive. Considering they increased eligibility criteria, removed our right to be notified of the option for CDPA or the appeal process, chose to make superfluous ‘safety checks’ by those unfamiliar with us more profound, and reframed Olmstead in a concerning way – our community is left wondering if this is just a new way for the state to control whether we can live freely in the community with access to care.

What can we do?

All of this feels simultaneously daunting and entirely unsurprising – our community has been fighting for decades for the right to live in the community with access to life-sustaining services. Luckily, the **DOH is open to hearing feedback for 60 days past the release of the draft of these regulations, which gives us until Sept 14th 2020 to voice our concerns.** They are required to read through all feedback.

Initially, they planned on moving forward with the regulations on Oct 1st. Yet, since the public health emergency was extended another 90 days due to Covid-19 on July 23rd, this date will likely be pushed back. We should still aim to have commentary submitted by Sept. 14th.

Submitting Commentary to DOH:

From their [website](#): “Questions or comments on the material posted should be directed to:

New York State Department of Health
Bureau of Program Counsel, Regulatory Affairs Unit
Corning Tower, Empire State Plaza, Rm. 2438
Albany, New York 12237-0031
Phone: (518) 473-7488
Fax: (518) 473-2019
regsqa@health.ny.gov
Attention: Katherine Ceroalo”

Example talking points for submissions:

- *Asking the DOH to share the evidence-based tool that will aid in determining our hours.*
How can we provide commentary and feedback on a regulation that will release the tools they want to use AFTER it gets instated? The idea of having our hours of home care determined by an algorithm is unsettling, and will miss many nuances of the disabled experience.
- *How do they imagine tele-health fitting into CDPA/PCS?* Home care is about getting help with showering, dressing, and living in the community – they should tell us what they think tele-health can do for us! Will it be used in a way that gives us access to more services, or as a way to take away or replace pre-existing services?
- *About the ‘physical maneuvering’ for 3 ADL eligibility rule:* Of course this is too narrow! Sadly, it has already passed through state legislature... but the DOH has the power to decide how they interpret it. Tell them that:
 - **Level 1 (IADLs) SHOULD BE** included in eligibility for personal care service. They should EXPAND their criteria. How are disabled people that only need assistance with laundry, cooking, shopping, or housekeeping supposed to survive without it?

- Alaska tried this and it didn't go well for the state... Check that out [here](#).
- If IADLs aren't included... **our state violates CFCO**. Are they really interested in losing 6% federal funding?
- **Personal assistance is SO MUCH more than just 'physical maneuvering'** of our bodies, and it is NOT the only valid form of assistance. Luckily, DOH has the power to clarify how they interpret this law, so let's point them in the right direction. Physical maneuvering can be broadened to the physical maneuvering of the environment, our adaptive equipment, etc.
- Overall, tightening eligibility restrictions only makes it harder to for people to access CDPA and a good quality of life, which inevitably will decrease the health/well-being of our community and increase medical costs long-term. How many injuries will be sustained during a time where disabled people are denied home care, and how many of us will experience a decrease in our health?
- Determining eligibility shouldn't be about judging how 'self-sufficient' we are by checking off a list of arbitrary ADLs. It is about *meeting us where our needs are*.
- *We deserve to be assessed by our own doctors that we not only feel comfortable with, but understand the gamut of how disability manifests in our lives.* Disability varies day to day, and ONE day of an assessment by a medical professional that does not know us is NOT indicative of the reality of our condition.
 - Not only that – but won't having 2 doctors cost significantly more? What resources are we wasting by making us have a separate medical evaluation outside of our yearly physicals?
- *Disabled people have lives and things to do – we don't deserve to have this process even more complicated!* Changing the yearly process to something even more arduous and lengthy is hurting our time, our doctor's time, and the states' time.
- *Language in the regulation implies that they want to give the state much more room to assess the 'safety' of us living in the community and whether this is 'the best option.'* It should be our civil right to live in our homes, and **SHOULD NOT** be up to the state to make that decision for us. Olmstead is about our right to live in the community, not the state's duty to judge the safety risks of us doing so.
- *How appropriate is it to pass these regulations during an international pandemic?* Covid-19 cases are rising in nearly every state, and it is just a matter of time before it begins again in NY as well. Does the DOH want to be responsible for leaving those with underlying conditions with *no home care* so they can't isolate? Or putting them in a nursing home, where numbers skyrocket and so many have died?
- *Tell them briefly about how CDPA or PCS helps you, and what these changes would do to your life and our community!* The more we are viewed as real, whole people – the more they will take us seriously and the harder we will be to dismiss.

What if you're our ally? Maybe you don't use home care currently, but you're a concerned citizen. In addition to above...

- *Use the angle of your personal experience.* How does CDPA/PCS help your loved ones?
- *Use your professional background.* Do you work in law or healthcare? Angle your letter using your professional knowledge!
- Remind them you're a concerned citizen because ...

- It's not a functioning society if disabled people (who make up 20% of the population) have to fight for their basic needs to be met. When an entire subset of the population is kept out of healthcare, employment, etc., there are larger societal ramifications for the economy and public health.
- Able bodiedness is temporary! Eventually these policies will impact most of us, and we should all be concerned. In a functioning society, we should all be able to age with the comfort of knowing we can still live a decent quality of life when we become disabled.

Feedback Letter Template:

July , 2020

Katherine Ceroalo,
New York State Department of Health
Bureau of Program Counsel
Regulatory Affairs Unit
Corning Tower Building, Rm. 2438
Empire State Plaza
Albany, New York 12237

Proposed Amendment to 18 NYCRR § 505.14 and 18 NYCRR § 505.28

Dear Ms. Ceroalo:

I, (NAME HERE), submit this comment in opposition to the proposed amendments to 18 NYCRR § 505.14, related to personal care services (“PCS”), and 18 NYCRR § 505.28, related to consumer directed personal assistance program services (“CDPAS”), which would implement recent statutory changes resulting from recommendations of the Medicaid Redesign Team II as adopted in the State Fiscal Year 2020-21 Enacted Budget and to make other conforming changes.

Specifically, ... (Voice your concerns!)

Very truly yours,
(NAME)
(EMAIL)

Alternatively, you could visit www.STOPLTCCUTS.com by CDPAANYS. You will find more tips on submitting feedback, and an easy to access online portal where submissions go directly to the DOH!

Using social media as a tool for advocacy:

A large portion of changes to home and community-based services rests in the hands of the Department of Health, and their interpretations of laws do not have to run through the Assembly or Senate. This leaves advocates in a complicated position, because the DOH not only has ultimate power, but also carries a rather nebulous and faceless name. Cuomo appoints people to work in the unit that writes these regulations, and the identities of these people remain relatively anonymous. Even more so unknown is their familiarity with and education on the reality of living with a disability.

Although, we can reach out to Assembly people and Congress members on social media, who are responsible for signing laws that the DOH must follow.

So who can we speak out to on Twitter?

Gov. Cuomo: @NYGovCuomo

DOH: @HealthNYGov

Gottfried, Chairman of NYS Assembly Health Committee: @DickGottfried

Rivera, Chairman of Congress' Health Committee: @NYSenatorRivera

Twitter Tips:

- Using **#hashtags** will group tweets together that are writing about similar things, so that when someone searches that specific hashtag, they'll see your tweet.
- Using the **@ symbol** followed by a person's username allows you to write specifically to an account, and they will be notified.
- Each time someone **likes** or **retweets** a tweet, the people tagged in it will get notified, so more likely they'll see it.
- **Character limit of 280** – be concise!
 - If you have more to say, **create a thread** and **# them** so people can follow your line of thought.

Accounts to follow that are contributing to these conversations:

@LI_ADAPT

@cdpaanys

@DRNY_org

@CDPAPWatch

@Nylag

@despinabakos

@MedicaidMtrsNY

@BrooklynBCID

@DisVisibility

Sample tweets:

(character limit of 280)

Proposed changes to #CDPA and #PCS services released by @HealthNYGov will give the state more power to judge whether we should be sent to institutions, and we will not stay silent about it #SaveCDPA @NYGovCuomo

Dear @HealthNYGov, how deliberate is it that your proposed #CDPA regulations make it easier for the disabled to get shoved into institutions at the same time @NYGovCuomo's sending COVID patients there? #SaveCDPA #DisabilityRights

Disabled NYers deserve the right to be assessed by our OWN doctors and to make the decision on our OWN to live in the community. @HealthNYGov's proposed changes may send us back decades.

Just checkin in @HealthNYGov & @NYGovCuomo, whats the plan for when thousands of disabled NYers cant access home care bc of the eligibility changes? When it becomes easier for the state to say we are 'unsafe' living in the community or deny us... Open a new Willowbrook? #SaveCDPA

#NothingAboutUsWithoutUs - @NYGovCuomo @HealthNYGov, please consult disabled people when you create regulations that drastically alter our lives. We deserve to be in the conversation #SaveCDPA #SavePCS. REFORM 18 NYCRR § 505.14

Hey @HealthNYGov, who was consulted when it was proposed that home care eligibility should be based solely on a short, arbitrary list of ADLs? Any actual disabled people that rely on these services to survive? #NothingAboutUsWithoutUs

Alaska tried to remove 'level 1' care (IADLs) out of eligibility for home care & a lawsuit made them realize it's a violation of rights. @NYGovCuomo and @HealthNYGov- do you want to realize restricting eligibility is WRONG before or after the legal action?

http://dhss.alaska.gov/dsds/Documents/pca/IADL_Shared_Living_Explanation.pdf

NYS Health Committees signing legislation that said needing help w/ THREE ADLS = eligibility for #CDPA is dangerous for our community. @DickGottfried @NYSenatorRivera, did you know it used to be 'assistance w/ 1 task of daily living'? Make laws that give us access #SaveCDPA

Or send a longer message by creating a thread (2+ tweets that are connected):

“NYS Health Committees @DickGottfried @NYSenatorRivera, you recently signed legislation changing eligibility for CDPA to needing help with ‘physical maneuvering’ for 3ADLs. This drastically changes criteria + will exclude many disabled people from home care. (1/2)

Please help advocate for legislature that mandates the DOH include Level 1 Care like cooking, shopping, housekeeping, etc. IN THEIR ADL LIST and REMOVE the mandate that ‘physical maneuvering’ of our bodies are the only valid form of assistance #SaveCDPA (2/2)”

... Get creative & make your own!

Conclusions

If you decide to submit feedback to the DOH and would feel comfortable **sharing your submission** with us, send us a copy of it: DNYADAPT@gmail.com

With your consent, we would love to keep track of submissions to be able to hold DOH accountable, and share/reuse some feedback that was submitted! Your name/any identifying information **will not** be shared.

A big thank you to ...

CDPAP Watch, CDPAANYS, LeadingAge, NYLAG for your wisdom and resources!

Some helpful links:

- <https://www.leadingageny.org/providers/managed-long-term-care/mrt-news/doh-releases-preview-of-proposed-independent-assessor-regulations-for-personal-care-and-cdpas/>
- <https://cdpapwatch.org/news-and-policy>
- <https://www.dos.ny.gov/info/rulediagram.html?fbclid=IwAR1js3zqqiqTAMlyYFxskjhKHpbVTYI2mvtHO5vQK994RCXfB182ypw8-3A>
- <http://www.leadingageny.org/?LinkServID=03D38A24-E841-FA5B-A9047B24118A88FD>