

February 26, 2024

NYAIL urges the State to preserve the role of Independent Living Centers in the future of the Consumer Directed Personal Assistance Program and reject proposals that infringe on consumers rights

The New York Association on Independent Living (NYAIL) represents Independent Living Centers (ILCs) and the people with disabilities they serve. ILCs founded the Consumer Directed Personal Assistance Program (CDPAP) in New York State and are critical to the effective utilization and administration of the program. ILCs were instrumental in piloting CDPAP through a Developmental Disability Planning Council (DDPC) implementation grant before the enabling legislation was enacted in 1995. ILCs helped to create and chose to administer CDPAP through Fiscal Intermediary (FI) functions to support program participants to exercise control and independence over their services.

As consumer directed, grass roots organizations, ILCs are uniquely positioned to be FIs for CDPAP as this program embodies the mission and philosophy of an ILC. ILCs were created by and for people with disabilities to enhance and protect the rights of all individuals with a disability. The ability for individuals to direct their own services and support, determine who will provide that care and remain in their home and community is the basis of the program and aligns with our collective mission. In addition, the wrap around services provided through an ILC by peers are critical to the effective utilization of the program, and result in better outcomes for the participants.

There are currently 11 ILC FIs, and a number of these also provide FI services to ILCs with no FI to benefit their members. After almost 30 years of operation for many of them, the combined enrollment in ILC FIs is approximately 5,600. ILCs have never put numbers over service and are not in any way contributing to publicly expressed complaints which resulted in the proposed Budget changes about aggressive enrollment, questionable advertising, conflicts in interest or fraudulent operating practices.

The ILCs unique role in administering this program was acknowledged by the State. Existing State Social Services law Section 365-f (4-a)(i)(A) specifically lists independent living centers as programs eligible to be fiscal intermediaries.

The original 2019-20 Executive budget proposal intended for ILCs to continue operating the program, permitting the Department of Health to contract with ILCs and entities that had been providing FI services since 2012. However, in the final Budget agreement, the Legislature authorized DOH to use a Request for Offers (RFO) contract award process to authorize Fiscal Intermediaries' continued operation, and ILCs were included only as entities eligible to apply. The RFO process was flawed and as a result has been renegotiated by the

Legislature in recent state budgets; however, the result still does not address the ‘bad actors’ nor did it ensure a continued role for all ILCs despite their longevity of service, strong fiscal accountability, and experience serving people with disabilities. The 2024-25 Executive Budget now proposes sweeping changes to the program, including repeal of the RFO process with broad DOH authority to initiate a new authorization process.

NYAIL urges the State to preserve the role of Independent Living Centers in the future of CDPAP. This has always been the State’s intent and the legislative language exists to accomplish this. Irrespective of the process to identify providers moving forward, RFO or designation by DOH, ILCs should be ensured a contract to continue delivering FI services if they elect to.

The ILCs have a long history in offering FI services, and all have been subject to OMIG review and audit with no findings of fraud. ILC FIs ensure a local community presence with physical offices in their regions served and staff available to provide in-person peer support to participants. This is necessary to ensure the success of program participants in managing their own services. In addition to having a physical presence in the communities they serve, ILCs are locally operated organizations and understand the available resources and needs of their respective communities. ILCs are multi-cultural and disability competent and do not have a cookie-cutter approach for service delivery, but rather adjust services based on the stated needs of the individual. Given its geographical distribution of centers, the ILC network can effectively serve the entire State. There are 41-state funded ILCs in NYS with over 50 offices, serving all areas of the State. Several of the 11 ILC FIs currently work in collaboration with other ILCs to offer the program.

NYAIL shares the State’s concerns regarding the increased number of FIs and the desire to restore integrity in the program. We are in favor of eliminating all conflicts of interest in the CDPAP program. In addition to preserving the role of Independent Living, as NY considers how to scale back the number of FIs we urge you to prioritize providers who have:

- Mission focus
- Local presence
- Experience providing FI services prior to 2012
- Cultural competence and demonstrated experience serving the population(s); and
- No financial incentive or disincentive to limit the supports needed by persons with disabilities to live independently in the community.

While NYAIL supports the desire to restore CDPAP to its original intent, the proposed 30-day amendments do not do this. We urge the Executive to reconsider and the Legislature to reject Budget proposals that restrict access to the program and infringe on consumer rights.

Specifically:

NYAIL opposes the ban on allowing a Designated Representative (DR) to direct care of a CDPAP participant. Designated representatives have been part of CDPAP since the program was created. DRs play a critical role in CDPAP, allowing those whose disabilities prevent them from self-directing their own services to have someone perform that role

instead. This particularly impacts children, people with developmental disabilities, those with cognitive disabilities, and those who are non-verbal or face a language barrier. An average of 36% of the consumers in the ILC FI programs utilize a DR. This change would leave tens of thousands of people suddenly ineligible for CDPAP. With the severe home care workforce shortage, especially Upstate, Managed Long Term Care plans push members into CDPAP because they simply cannot staff the cases with traditional personal care. It is nearly impossible to staff 24-hour live-in care – and low hour cases as well -- without using CDPAP. If a family member cannot serve as DR for a person with dementia or other disabilities, these consumers will be left with no care. Many will be forced to utilize Private Duty Nursing or into nursing homes; both far more costly to the State and quality of life for the consumer if they can find that service at all.

In addition, denying participation in CDPAP for individuals who lack the mental capacity to "direct" their own care is illegal. As a service provided under NYS' State Medicaid plan approved by CMS, CDPAP must be offered Statewide to any Medicaid recipient who meets the eligibility criteria. Under the Americans with Disabilities Act, eligibility criteria may not be used that screen out people based on their disability. Prohibiting an individual with dementia or an Intellectual/Developmental Disability (IDD) from having a DR would deny them CDPAP based on their disability. Allowing a DR is required as a "reasonable accommodation" of their disability.

NYAIL opposes state-mandated training for CDPAP aides. This is a direct contradiction to the intent of the program, which is to give the consumer or their DR full responsibility for recruiting, hiring, training, supervising, and terminating their own staff. This proposal would prevent an aide from working until they have completed a state-mandated training course, the details of which are not provided, removing a core pillar of consumer responsibility and likely making it harder to recruit aides or cause a delay in services. Many CDPAP aides perform skilled nursing tasks for which no aide training program exists.

NYAIL opposes setting maximum daily and weekly limits on the hours PAs can work. The federal and state overtime requirement already impose a practical limit on hours, as many FI's do not allow overtime. Some consumers want or need aides to work overtime, and if the CDPAP FI approves it this should be left to the consumer and the PA. The proposal would authorize DOH to issue emergency regulations – with no public comment – to limit how many hours the aide can work each day and each week, reducing needed services and taking control away from the consumer – and threatening an even more dire workforce shortage.

NYAIL is concerned regarding the intended changes to administration reimbursement (PMPM) indicated on the revised Medicaid scorecard. New York's shift to PMPM reimbursement in 2021 was already a significant cut to the administrative reimbursement associated with operating an FI and the rates have not increased since, despite ever-increasing requirements and costs. Any further cuts would impact an FI's ability to keep up with necessary corporate compliance, state requirements (e.g., labor law, sexual harassment training), billing, auditing, human resources and other requirements. This change disproportionately impacts the smaller and long-term providers, such as

Independent Living Centers who also have contracts with local Social Service Departments. This would have little impact on the newer and larger FIs that mostly only contract with MLTCs or are operated by MLTCs.

For more information, please contact:

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