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Center for Independence of the Disabled, NY

Testimony to the New York State Assembly Committee on Health and Senate Committee on Health

On The New York Health Act.

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This testimony is submitted on behalf of Center for Independence of the Disabled, New York (CIDNY), a non-profit organization founded in 1978. CIDNY's goal is to ensure full integration, independence and equal opportunity for all people with disabilities by removing barriers to full participation in the community. CIDNY helps consumers understand, enroll in and use private and public health programs and access the care they need. We appreciate the opportunity to share with you our thoughts about the New York Health Act and some of our recommendations.

According to the American Community Survey 11.6% of New Yorkers have a disability with 2.1% having a visual disability, 2.8% having a hearing disability, 6.6% having an ambulatory disability, 4.5% having a cognitive disability, 2.8% having a self-care disability, and 5.5% having an independent living disability.

New Yorkers with disabilities are more likely to have health coverage than people without disabilities (95.2 % compared to 91.6%). They are more likely to use public coverage – Medicare and Medicaid – than people without disabilities (23.4 % and 53.9% compared to 1.7% and 19.1%).

People with disabilities have a right to a transparent, accountable health care system that provides accessible coverage including comprehensive benefits and services based on medical necessity. The current disjointed system of Medicare, Medicaid, private commercial coverage and other specialized programs is fragmented and confusing, difficult to navigate, and often fails people with disabilities.

Because of the many struggles that people with disabilities face when using the current health system, CIDNY strongly supports passage of the New York Health Act.

The New York Health Act would cover *all* New Yorkers, regardless of disability status in *one* program.

It would be administered by one publicly accountable health plan instead of a federal program, a state program, and 58 county programs with confusing eligibility rules that constantly change depending on your income, your age, or your disability status. People we help who have Medicare could have Medicare Advantage with Part D or Original Medicare, a Medigap Plan, with stand-alone Part D Plan. On top of these things you could have non-MAGI Medicaid and a Medicare Savings Program to pay your Part B premiums and cost sharing or EPIC.

The people we help enroll in plans have the task of comparing a large number of plans. Among the most important things a consumer checks in determining what health plan he or she will enroll in is whether the providers they see are in the Plan's network and whether the prescription drugs on which that individual depends are covered in the plan's formulary. For consumers with serious or chronic illnesses, they may need home care and have long relationships with a variety of specialists who understand their disability and know how to treat their conditions. All of the specialists they see are unlikely to be in one network, so they have to make trade-offs.

The New York Health Act would dispense with all of this. A system in which health care consumers have the free choice of any participating provider with a separate care coordination service to assist members in managing, referring to, locating, coordinating and monitoring health care services to assure that all medically necessary health care services are made available and effectively used in a timely manner could go a long way to improving this situation.

People with disabilities have difficulty finding providers with offices and facilities that are accessible and that have accessible diagnostic and medical equipment. They also have difficulty finding providers that understand their responsibilities under the Americans with Disabilities Act to accommodate any disabilities they might have. Program Standards and Requirements for health care provider accessibility for people with disabilities and people with limited ability to speak or understand English and for cultural competence should be robust and should require training for providers. The Commissioner should adopt the United States Access Board standards for medical diagnostic equipment.

Of particular interest to people with disabilities are the following:

Long Term Care

CIDNY appreciates the groundbreaking inclusion of long term services and supports in the New York Health Act including sufficiently funded home care that enables people to maintain their independence in the community. The present system for providing long term care using Medicaid Managed Long Term Care Plans has broken down as most plans have cut back on hours they offer enrollees. Plans that do offer adequate hours to enrollees are going out of business because the capitated rate provided to them does not cover the cost of the level of care their consumers require.
Under the current system there is a substantial financial incentive for MLTC plans to unload costly high service need members by moving them from the community to nursing facilities. CIDNY appreciates the Program standards that call for the maximization and prioritization of the most integrated community based supports and services in this legislation.

A New York Health Act that allows free choice of care coordination as a separate service, eliminates the managed care capitated rate structure, and is adequately funded will help people with disabilities avoid unnecessary institutionalization.

Durable Medical Equipment

People with disabilities will be looking for a benefit package that includes durable medical equipment that meets their needs. Guidelines and practices that were carefully developed for fee-for-service Medicaid to enable access to complex rehabilitation equipment for those who need it are not available to people getting care through a Medicaid Managed Care Plan. Individuals with complex needs and chronic disabling conditions cannot remain mobile, safe and healthy without equipment that addresses their specific disability. They need access to suppliers who have at least one storefront in New York State, have certified technicians on staff and that are able to service and repair the complex rehabilitation equipment.

When CIDNY's benefit counselors help people enroll in an MLTC, they have a difficult time getting the information they need from the Plan about how complex rehabilitation equipment is secured. We ask what the procedures are for getting complex rehabilitation equipment assessed and fitted. We ask if they work with a specific wheelchair seating clinic. If not, do they have their own pt/ot team who will work with their vendor to evaluate and fit the consumer? Plans are unable to answer these questions.

Patients with complex medical conditions and with disabilities rely upon mobility devices not only to stay in the community, but also to prevent pressure sores, facilitate breathing, and relieve joint pain. A CIDNY Consumer, who has traveled to Albany twice to visit legislators, requires a wheelchair with a tilt feature that she must use every hour to avoid skin breakdown. When her chair was being repaired, she could not get it back for 9 months, her condition deteriorated, and a wound care nurse had to be sent to her home.

CIDNY recommends that durable medical equipment provided under the New York Health program include complex rehabilitation equipment that is secured through suppliers with at least one storefront in New York State, have certified technicians on staff and that are able to service and repair the complex rehabilitation equipment.

Physical Therapy, Occupational Therapy, and Speech Therapy

People with disabilities who require physical therapy, occupational therapy, or speech therapy encounter visit limits in Medicaid and commercial plans. Medicare has a dollar threshold.

CIDNY's consumers were dismayed to learn of the adoption of a Medicaid Design Team proposal to place an arbitrary limit on Physical Therapy, Occupational Therapy, and Speech Therapy in Medicaid. For more than five years our consumers have traveled to Albany to tell legislators that arbitrary visit limits do not make sense and discriminate against people with disabilities. One of our consumers decided not to even begin physical therapy for a hand condition because she knew that 20 visits would not begin to treat it. Another consumer had her neck lock shortly after her PT visits were discontinued. A consumer with osteoarthritis of the spine back and knees told us that her physical therapy is often over in March or April and that she then has to try to manage for 8 months or so with massage or whatever she can put together.

Any misguided attempt to seek savings at the expense of individuals' ability to avoid pain, recover from surgery, and prevent physical decline will harm enrollees. It can result in the need for more expensive treatments like surgery and prescription medications that do not have arbitrary limits. CIDNY appreciates that the New York Health program will base all services on medical necessity so that health care consumers can participate fully in daily life, maintain their health and independence.

New York Health Board members

To ensure that the needs of people with disabilities and other health care consumers are adequately met, CIDNY suggests that the 40 member New York Health Board should have more than six that are designated representatives of consumer advocacy organizations. The consumer advocacy organizations should be representative of the various health care constituencies and should specifically include representatives of health disparities populations.

Thank you for consideration of our comments and recommendations. For further information, please contact Heidi Siegfried, CIDNY's Health Policy Director, at 646.442.4147 or hsiegfried@cidny.org.