



STATE LEGISLATIVE AGENDA FOR 2012

HEALTH CARE PRIORITIES

HEALTH BENEFIT EXCHANGE

In 2014 everybody who does not get health coverage through an employer will be able to get coverage through a "Health Benefit Exchange", sometimes called an "Health Insurance Exchange". The Health Benefit Exchange will have a website, a call center and will have in-person assistance to help people get coverage through public programs, such as Medicaid and Family Health Plus (and possibly a Basic Health Plan that will cover people up to 200% of the poverty level), and private commercial health insurance with premium subsidies to help make the coverage affordable for people with incomes up to 400% of the Federal Poverty Level (\$44,680 for a single person, \$92,200 for a family of four). The Exchange will also be available to help small businesses obtain coverage for their employees.

New York must pass legislation to establish the Exchange this year because we must be able to show the U.S. Department of Health and Human Services on 01-01-13 that we are going to be able to operate the exchange on 01-01-14 or they will set up a federal exchange that might not be right for New York. The Executive budget has included Exchange language in it that is a good first step.

The Exchange should have a governing board that is free from conflicts of interest, has strong consumer representation and is subject to open meetings law.

No one serving on the Exchange Board should receive any financial remuneration from a health insurer, agent or broker, a healthcare provider, health facility, or clinic. There should be strong consumer representation, the meetings should be open to the public, and minutes of the meetings should be made public.

The Exchange should integrate private commercial coverage and public coverage and be capable of evaluating people for all possible Medicaid eligibility categories so that people with disabilities have equal access to the program.

For people with disabilities, who need comprehensive coverage that meets their needs, it will be particularly important that the Exchange be able to do a thorough evaluation of eligibility that takes into consideration disability or diagnosis related Medicaid such as Medicaid Buy-in and Medicaid Spenddown, and the Medicaid Cancer Treatment Program. Under current law, the Medicaid agency must not deny or terminate Medicaid based on income without exploring all possible avenues of eligibility. HRA has not been adept at complying with this. CIDNY sees many people who have an increase in earned income who are told they are ineligible for Medicaid when, in reality, they have a disability and are eligible for Medicaid Buy-in. In establishing an Exchange, we have an opportunity to correct this problem. We would not want an Exchange to enroll a person with a disability in private commercial coverage with a premium subsidy when that coverage is underinsurance, given the person's disability, and they are eligible for Medicaid

Buy-in. We also wouldn't want a person to be enrolled in Family Health Plus, which does not cover their Methadone program, when they are eligible for Medicaid with a \$46 spenddown which provides this coverage. The Exchange must be capable of recognizing the need for coverage that will adequately serve people with disabilities. The website and call center must ask applicants if they might have a disability, a cancer diagnosis, or a pre-cancerous condition being treated. The in-person assistance available through the Exchange must be familiar with disability related and cancer diagnosis Medicaid eligibility and any navigators or consumer assistance available through the exchange must be disability competent.

Merge the individual direct pay and small group health insurance pools.

The Exchange legislation proposed by Governor Cuomo in the 2012 budget includes a study of the effect of merging the individual direct pay and small group health insurance pools for risk sharing purposes. NYFAHC strongly urges that market merger be adopted. High premiums and shrinking enrollment have created a vicious feedback loop in the individual market with Direct Pay HMO/POS enrollment plummeting from over 100,000 in 2000 to less than 25,000 today, and the market is in a state of collapse. While an individual mandate will bring new purchasers into the market and will lower prices to a degree, both affordability and choice for individuals would be even more enhanced by a market merger. Urban Institute's modeling of an Exchange with a merged market found that the average single premium would be 70% lower than the average annual single premium in the current direct pay market (\$4,540 v. \$15,273). With a non-merged group and non-group market, non-group premium would increase by 14%. Employer sponsored premiums would only decrease by 1% and 53,000 more people would be uninsured. But the benefits of a merged market go beyond just affordability. In a world in which there is great fluidity between employment by employers, self-employment and unemployment, there is no reason why the same set of insurance options should not be continuously available to all people regardless of the category they may find themselves in at a given time. Loss of a job should not mean having to switch to an entirely different insurance product. In addition, the transition to a single market could be accomplished with the least disruption if done simultaneously with setting up the new Exchange.

To minimize adverse selection, New York should require insurers participating in the Exchange to offer standardized health plans sold in the Exchange to individuals and small groups outside the Exchange.

New York should structure risk adjustment to protect the integrity of policies that provide high actuarial value products to people with serious illness and disability.

Currently proposed Exchange legislation also provides for the study of risk adjustment mechanisms. Any risk adjustment mechanism should be carefully structured to ensure that insurers are required to use funds generated through risk adjustment to support those products subsidize not only insurers that suffer disproportionate claims experience, but the particular products sold by those insurers where the high cost individuals tend to enroll.

Current required benefits under the insurance law should be maintained in policies sold inside and outside the Exchange.

The Exchange proposal in the budget requires study of whether the state should maintain all its current health mandates and, if so, how it will finance the mandatory provision of any benefits that exceed the essential health benefits defined under the ACA. The individuals with serious or chronic illness or disability whom NYFAHC serves are often dependent on state mandated benefits for effective and truly comprehensive health care. NYFAHC urges the state to ensure that any study of current mandates consult with the populations currently using the benefits in assessing their need; and to adopt and defend a method of assessing the cost of such benefits which takes into account other costs avoided as a result of the

improvements in health associated with the mandates. To avoid adverse selection, the same mandated benefits should be required in products both inside and outside the Exchange.

New York should continue to require all benefits currently required under the public health law and social services law to newly Medicaid eligible individuals regardless of whether they are identified as “benchmark benefits” by the Secretary of Health and Human Services.

Some of the newly eligible individuals will have serious illnesses and disabilities that require access to comprehensive benefits and treatments. In fact the Secretary has indicated that some of the previously “optional groups” that included people with disabilities will in the new “mandatory adult group” that could receive benchmark benefits which would constitute underinsurance, given their medical condition. This could include people in the two year waiting period for Medicare. We should not have similarly situated individuals receiving different Medicaid coverage in New York.

Apply the Managed Care Bill of Rights/Appeals processes to cover all products in the insurance market (EPOs, PPOs).

New York’s Managed Care Consumer Bill of Rights contains strong protections for consumers in managed care plans that were further enhanced during last year’s legislative session. The Bill of Rights was enacted in an era in which only managed care plans operated through contracted networks of physicians. Their restrictions on access to care contrasted with indemnity insurers that reimbursed consumers for covered care by any licensed medical provider. In recent years, however, indemnity insurers have adopted the network model as well, and they have as a result created obstacles to access to appropriate specialty care similar to those facing managed care enrollees in the early 1990s. Conforming legislation is required to subject EPO, PPO and similar plans to the same network adequacy requirements as managed care plans and to require them to cover services outside the network when in-network services are not adequate. Further, the Department of Financial Services should ensure that New York’s recently enacted provisions extending external review of health plan decisions to disputes over the setting of care are interpreted to give consumers a right to external appeal when they are denied access to out of network specialists or specialists with particular expertise, whether in managed care or other plans.

REVISIT LIMITS ON MEDICAID BENEFITS AND SERVICES

Last year’s budget implemented a number of limits on Medicaid benefits and services primarily for the expected cost savings. Since the passage of last year’s budget the Medicaid Redesign Team adopted the recommendations of its Basic Benefit Review Workgroup that included the principle that these sorts of decision would be based on evidence and effectiveness derived from an assessment of effectiveness, benefits, harms, and costs.

20 visit limit on Physical Therapy, Occupational Therapy, and Speech Therapy should be subject to an override.

Arbitrary hard caps like these may not make sense in all situations. People who have a stroke may need more than 20 physical therapy visits to regain the function of walking. People subject to these limits may require surgery as a result or experience depression that may require therapy or prescription drug treatment. Medicaid Utilization Thresholds which have been used in New York have provided a procedure for a physician override. Such a procedure should be implemented with these limits.

Enteral Formula should be permitted for people who have wasting and should be subject to an override.

Last year's budget limited enteral formula (like Ensure) to people who have tube feeding or people with inborn metabolic disorders. This year's budget expands it to people with HIV-related wasting. Coverage should be expanded to people who have wasting related to any diagnosis and should be subject to an override.

Limits on orthopedic shoes, orthotics, and compression stocking should be subject to an override.

Last year's budget limited orthopedic shoes and orthotics to children with growth and development problems, diabetics, and situations in which a shoe was attached to a lower limb orthotic or brace. Compression stockings are covered only for treatment of open wounds and during pregnancy. We have encountered a consumer who did not have the exact permitted conditions who was at risk of falling and was likely to need surgery if custom made shoes were denied. A procedure for a physician override should be implemented for these limits as well.

RESPONSE TO EXECUTIVE BUDGET PROPOSAL

Support streamlined and increased funding for Consumer Assistance

Because of the rapid and enormous changes in the way that people with serious illnesses and disabilities will be getting their care, it is important that additional resources be dedicated to ensuring that people with serious illnesses and disabilities get the services and supports that are right for them. This year's proposed Executive Budget contains language authorizing contracts with one of more entities to engage in education, outreach services, and facilitated enrollment activities for aged, blind, and disabled persons who may be eligible for Medicaid and appropriates \$1.5 m. in state funds for such assistance. It also contains a dry appropriation for Community Health Advocates (CHA) New York's Statewide Consumer Assistance Program established under the Affordable Care Act which provides individual counseling and education to New Yorkers who need it about all types of coverage. Last year CHA helped 28,589 New Yorkers who needed help finding or using their health insurance. CIDNY supports a funded initiative to ensure more education, outreach and enrollment assistance for people with disabilities and older New Yorkers in need of long term services. We also support appropriations for Community Health Advocates. Ideally this consumer assistance and assistance provided through the Exchange would be arranged in such a way that it would be integrated. so that there would be no wrong door for someone seeking assistance.

Support increased funding for Office of Administrative Hearings. The state hopes to embark on a fairly radical transition to mandatory enrollment in managed long term care and other care coordination models. Concerns about capitation arrangements that offer incentives to reduce services and different assessments of need for those services make it necessary that the Office of Fair Hearings have adequate resources and training so that consumers have full access to the existing fair hearing process to protect their full due process rights and ensure adequate care. The Executive Budget appropriates \$.5 m. for this purpose. CIDNY supports this as a good first step.

Reject the Elimination of Spousal/Parental refusal.

This proposal will harm low income couples where the spouse in need of care will be forced into an institution or divorce in order to prevent impoverishment. Rather than eliminate the spousal refusal provision outright, CIDNY would like to see this provision modified to limit its availability to only those spouses or parents whose income and assets fall within the spousal impoverishment limits for nursing home care (\$2739 in monthly income, \$109,560 in resources).

These individuals would be fully eligible for Medicaid without a spousal contribution if admitted to a nursing home, so there would be no real cost continuing the spousal refusal provision for people who wish to remain in the community. This change would respond to the federal concern by making spousal refusal unavailable to those who have substantial assets and income. In addition, New York City and several other counties use this standard informally when determining which cases to pursue with legal action. A hardship exception should continue to apply to cases in which the spouse truly refuses to contribute or document his or her assets to protect inform spouses in domestic violence or abuse and neglect situations where, though a couple may live together, only one controls the money or finances.

Support the requirement that managed care plans and managed long term care plans offer the consumer directed personal assistance care program to their enrollees.

All consumers should have the option to independently recruit, hire, train, and supervise their own personal assistants. As this requirement is implemented, we expect that the existing Consumer Directed Personal Assistance Program (CDPAP) model, affirmed by the regulations 18 NYCRR 505.28, be preserved and that the Fiscal Intermediaries (FI) remain separate and distinct from assessment and authorizing functions. In addition, the current fair hearing process must be preserved throughout implementation of all aspects of Medicaid managed care and managed long term care.

Improve New York's Hospital Financial Assistance Program.

Each year, New York's hospitals receive over \$ 1 billion in funding from New York's Indigent Care pool to help pay for the cost of providing care for uninsured and underinsured New Yorkers. As a requirement for these payments, hospitals must comply with the Hospital Financial Assistance Law. The Budget proposes an adjustment to the distribution formula for part of Medicaid's Disproportionate Share Hospital (DSH) funding, funding intended to compensate hospitals that provide high volumes of Medicaid and uncompensated care and care. The adjustment would eliminate bad debt from the formula used for funds distributed through the Office of Mental Health, but it does not go far enough. As recommended by the Governor's Medicaid Redesign Team, CIDNY urges the state to enforce HFAL compliance to ensure that all patients who qualify for financial assistance receive it and take the necessary steps to make the Indigent Care Pool payments 100% accountable.

Support State implementation of the Community First Choice Option in federal health reform, to which the State has committed. Adoption of CFC will ensure the State draws down an additional 6% FMAP for services provided under the Option, estimated to be an additional \$90 m. annually for New York. CFC should serve as the centerpiece in an aggressive *Olmstead* implementation strategy to ensure the right of individuals with disabilities to be served in the most integrated setting appropriate to their needs. CFC will change lives and save the State Medicaid dollars.

REDUCING HEALTH DISPARITIES

People experience different access to care and different health outcomes based on their race and ethnicity, gender identity, disability and housing status. The Medicaid Redesign Team's Health Disparities Workgroup came up with 14 recommendations to address these health disparities which were adopted by the Medicaid Redesign Team.

Data collection to Measure Health Disparities.

The Executive Budget implements and expands on the data collection standards required by the Affordable Care Act by including detailed reporting on race and ethnicity, gender identity, the six disability questions used in the American Community Survey, and housing status. In addition it provides funding to support data analyses and research to promote programs and

policies that will better identify, understand, and address disparities. \$1 m in state fund and \$2m in all funds is included for this. CIDNY urges the legislature to support this provision in the budget and to require uniform collection and reporting of data stratified by race, ethnicity, disability status, gender, and language spoken throughout the state by all public and private health plans, hospitals and other health care institutions.

Improve Language Access to Address Disparities.

The Executive Budget amends Medicaid rates for hospitals, diagnostic and treatment centers, and health centers to provide reimbursement for the costs of interpretation services for patients with limited English proficiency and communication services for people who are deaf or hard of hearing and provides \$1.35 m. in state funds for it. CIDNY supports this proposal and recommends a statewide policy that requires all state agencies to provide language assistance services, including necessary interpreter services and communication services and the translation of frequently used forms and documents

Promote Language Accessible Prescriptions.

In 2009, the NY Attorney General announced a landmark settlement with New York's largest pharmacy chains requiring them to provide free translation of medicine labels. The Executive budget contains language that would require a prescriber to indicate the primary language of someone who is limited English proficient on the prescription form and require pharmacists to provide for translation or other language services if they have reason to know that the person is limited English proficient. Translation and interpretation services for limited English proficient patients and standardized prescription labels should be required to ensure understanding and comprehension. CIDNY strongly supports this proposal.

Permit Pre-qualification for Emergency Medicaid.

Emergency Medicaid is available to allow income New Yorkers, regardless of immigration status. To get coverage, an attending physician must certify that the person has a medical condition that meets the definition of an "emergency." If so, the person fills out a full Medicaid application which, depending on their eligibility, may or may not be approved. The Governor's MRT recently recommended that New Yorkers be allowed to pre-qualify for Emergency Medicaid in advance of any need for medical care. This would raise the awareness of Emergency Medicaid and give providers assurance of payment for services provided. Many states already do this: California, Michigan, Oregon, Massachusetts, South Carolina, Texas, Maine, Nevada, Arizona, Virginia, Maryland, Louisiana, Delaware and New Hampshire. CIDNY asks the State to pass legislation to support this important safety-net measure.

INCOME PRIORITIES

REJECT PROPOSAL TO DELAY PUBLIC ASSISTANCE GRANT INCREASE

Many people with disabilities In 2009 and 2010, the first two phases of a scheduled 3-step increase in the public assistance grant took effect, representing the first increases in the basic allowance in 19 years. In 2011, the legislature failed to implement the final stage of this modest grant increase and now the Governor's budget proposes to further delay the implementation of the third and final installment. If this proposal is adopted, an extremely modest increase in the already drastically inadequate welfare grant will – in July 2013 – have taken **five years**, instead of the intended three. The grant increase (from \$750 to \$780/ month) is the equivalent of only about \$1/day for a family of three, and is intended to help families meet **all essential needs** including such basics as rent, utilities, laundry, diapers, and school supplies. In the 22 years since 1990, the cost of living in New York has risen by more than 70%; during that period, the welfare grant in New York has increased by 20%. The grant has thus, for many years, left poor

New York families continually less able to meet their most basic needs, forcing them to focus more on survival than on doing what needs to be done to improve their lives. At a bare minimum, the insufficient but essential increase pledged by the legislature and the governor must be implemented in the 2012 session.

HOUSING PRIORITIES

Set Aside Housing Units For People With Disabilities

Create incentives for affordable housing projects that set aside 10% of its units for people with disabilities living below the 30% Area Median Income (AMI) or \$26,000 per year for an individual.

Market and Reserve Accessible Units for People with Disabilities

Developers should be required to properly market to and reserve accessible units for people with disabilities. Developers are required to document how they reserve and market accessible units, but the State needs to disclose how it verifies or enforces these requirements.

Require Inclusive Home Design

New York should require basic accessibility features to be incorporated in all publicly-funded housing construction. Having accessibility features at the time of construction is less costly than renovating new homes. This would meet the needs of people throughout their lifespan and allow homes to be more visitable to friends and family members who are disabled.

New York should pass the Inclusive Home Design bill. This bill would include all new construction and substantial rehabilitation of residential housing that receive financial assistance for construction from federal, state, county or local governments. This would cover detached or semi-detached single family homes, town houses or any individual unit in a duplex or triplex.

Expand Source of Income Non-discrimination Statewide

New York should make discrimination by landlords based on a tenant's source of income illegal under State Human Rights Law. This non-discriminatory provision already exists in New York City. The bills we are urging passage on are A. 1121/S.83, sponsored by Assembly member Bing and Senator Squadron.

Increase Transition Community-Based Services with Housing Subsidies

Increase the use of cost-effective community-based services to people who are making the transition out of nursing facilities. Programs such as Consumer Directed Personal Assistance and the Nursing Home Transition and Diversion Waiver – that include housing subsidies – need adequate funding to provide cost-effective services to people with disabilities making the transition from nursing homes and other institutions. The dollars saved by assuring successful transitions to the community could be used to increase community-based services and affordable, accessible housing.

SPECIAL EDUCATION PRIORITIES

Ensure Participation of Psychologists in the Committee of Special Education

CIDNY opposes the amendment of Section 4402 of the Education Law School would mandate that psychologists participate in a Committee of Special Education (CSE) meeting only if the

meeting is for the purpose of determining a student's initial eligibility for special education. The amendment would allow any person other than a psychologist to attend the CSE meetings and interpret the evaluations.

Psychologists are trained to evaluate assessment instruments, and therefore their removal from the CSE will reduce the reliability and validity of assessment data and may increase classification rates.

It is less likely that psychologists will be invited to CSE meetings if psychological evaluations are not required.

Low income families who may not understand the psychologist's role and cannot afford private evaluations could be impacted by the proposal.

Keep Psychologists in the Evaluation Process

CIDNY opposes the repeal of Section 200.4(b)(2). This Section mandates that school psychologists determine the need for an individual psychological evaluation and provide a written report prior to every reevaluation of a student with a disability.

A school psychologist is uniquely qualified to determine when a psychological evaluation is necessary.

The current provision was originally implemented to provide fiscal relief during the 1990s budget crisis and provides flexibility to districts.

When providing a psychological evaluation, psychologists also identify the need for other evaluations. The current requirement ensures that students are evaluated appropriately.

Written reports provide formal accountability, reduce the possibility that evaluations will be inappropriately omitted, and allows school districts to better determine students' individual needs.

Parity for Private Schools Supplying Special Education Services

CIDNY opposes amendment of Senate bill S5816 subdivision 2 Section 3602-c.

If the parents of a child who already receives special education services in a public school want to transfer that child to a private school, they are required to notify the district of the transfer, prior to April 1st. However, if the student is assessed as needing special education services after April 1st or before June 1st then notice to seek special education services in a private school is 30 days before next school year begins.

This different treatment serves no purpose except to punish parents and the children who have been receiving special education services in the public school system. It is illogical that some parents can give a thirty day notice (which can be in August) and still receive the necessary special education services for their child, while other parents must give 120 days' notice in order to request special education services in a private school setting.

This bill would also limit the services that students with disabilities are offered if they attend private schools – students would not be entitled to special education classes or integrated co-teaching services.

Private schools are under the same mandate under IDEA and the ADA to offer the same services to students with disabilities as the services that are available in public school system. The State

would be in shaky legal territory if it seeks to limit services to children with disabilities that are mandated by federal law.

New York State Board of Regents' Meetings

CIDNY supports Senate Bill 6322 and Assembly Bill 9127. These bills would require that the Board of Regents hold at least two meetings a year in New York City. Currently all meetings are held in Albany, where the public in the Albany area has the ability to attend meetings and comment on proposed policy initiatives and changes and to hear the deliberations of the Board.

The Board of Regents makes determinations on education that affect the entire State. If meetings are held at least twice a year in New York City, then New York City-area parents, students and teachers will have the same ability as their upstate counterparts to witness Board deliberations and to comment in person on proposed policy initiatives and changes.