

# Center for Disability Rights, Inc.

## Governor's Public Forum on the Establishment of a Health Insurance Exchange in New York State

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### Testimony of Diane Coleman, J.D.

My name is Diane Coleman and I'm the Director of Advocacy at the Center for Disability Rights. CDR is a non-profit service and advocacy organization devoted to the full integration, independence and civil rights of people of all ages with all types of disabilities. With services in 13 counties in New York State (NYS) and offices in Rochester, Corning, Geneva and Albany, CDR represents the concerns of thousands of people with disabilities.

I share the call of others testifying at this hearing that, first and foremost, we *must* pass legislation in the 2011 legislative session that takes significant steps towards the creation of a strong, consumer-friendly Health Insurance Exchange that meets the needs of all health care consumers, including people with disabilities.

Many people mistakenly believe that all people with disabilities have health insurance through Medicare or Medicaid, or both, but unfortunately, the proverbial safety net has many holes in it. For example, people who become disabled after developing a work history will have to wait two years after becoming disabled under Social Security rules before Medicare coverage begins. According to the Medicare Rights Center:

“An estimated 1.8 million people with disabilities are caught up in this waiting period for Medicare. Since SSDI recipients are unable to work, they cannot access the principal source of coverage for people under 65—employer-sponsored insurance. Instead, people in the Medicare waiting period generally obtain coverage if they qualify for Medicaid, or if they can pay the premium to continue under their former employer's plan under COBRA.

“According to a July 2003 Commonwealth Fund Report, nearly 39 percent of these individuals do not have health insurance coverage at some point during the waiting period and 24 percent have no health insurance during this entire period. (*Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs*, The Commonwealth Fund, July 2003).

“A study examining coverage during the waiting period for Americans aged 55-64 found that of those without coverage, about half were uninsured prior to the waiting

period. The loss of employer coverage accounted for 36 percent of the uninsured, and 4 percent had lost the Medicaid coverage they had prior to the waiting period due to their SSDI cash benefit. (*Transitioning to Medicare Before Sixty-Five*, Health Affairs, March 2008).

“For those with COBRA or other private coverage at some point during the waiting period (58 percent of individuals 55-64) the costs are very high:

- For the first 18 months, the premium for continuing health insurance coverage through COBRA costs up to 102 percent of the total cost of coverage (full premium plus a 2 percent administrative fee).
- For those receiving the 11-month disability extension, the premium for these additional months may go up to 150 percent of the total cost of coverage (*Transitioning to Medicare Before Sixty-Five*, Health Affairs, March 2008).
- It is common that during these 24 months, vulnerable individuals will lose their health insurance because they can no longer afford their COBRA or other private health insurance plans.

“Estimates for Medicaid coverage during the waiting period range widely (from 17 percent for individuals 55-64, to 40 percent in earlier research).”<sup>1</sup>

CDR agrees with the five basic standards for a New York State exchange developed by Health Care for All New York (HCFANY). These standards are as follows:

- **Standard 1: One statewide exchange for all.** One exchange will spread risk most effectively and maximize the buying power of consumers and small businesses. We must have one exchange that combines the small business or “SHOP” exchange outlined in the ACA and the individual exchange. This exchange should cover the entire state rather than be broken down into regions.
- **Standard 2: An exchange that offers quality and affordable benefit packages.**
- **Standard 3: An exchange that is easy to navigate and represents consumers.** Good consumer information, representation and enforcement will ensure maximum enrollment and improve health care outcomes.
- **Standard 4: An exchange that builds on the success of New York’s public programs.** There should be a seamless transition between public programs and the exchange.
- **Standard 5: An exchange that supports principles of health equity.** We believe that the exchange should promote equity based on race, ethnicity, gender, disability, language, sexual orientation and gender identity, and immigration status.

Of the issues I’ve just mentioned, I’d like to talk in somewhat more detail about how the Exchange can be developed to function effectively for people with disabilities.

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<sup>1</sup> Medicare Rights Center, End the Two-Year Wait for Medicare, FACT SHEET: Medicare Two-Year Waiting Period for People with Disabilities, [http://www.medicarerights.org/pdf/two\\_year\\_waiting\\_period\\_fact\\_sheet.pdf](http://www.medicarerights.org/pdf/two_year_waiting_period_fact_sheet.pdf).

## **The Exchange Must Be a Governmental Entity/ Need for Strong Consumer Representation on the Exchange Board**

As a disability rights advocate, I believe that disability representation on the Exchange Board is essential. I have seen millions of dollars spent on construction of facilities that claimed to be accessible but, in fact, did not meet minimum written standards for disability access. I have seen long standing government laws and regulations requiring access to people with visual or hearing disabilities ignored for decades by governmental entities themselves. We are among the most frequent users of health care services, and it makes no sense to ask or expect other consumer groups to represent our needs. When others try to speak for us, they usually get it wrong.

I agree with HCFANY that the board should ideally have roughly 7 members of which three to four would represent consumers. Consumer representatives are most likely to have the interests of consumers – the intended beneficiaries of the ACA – at heart. These members should have demonstrated expertise in health care coverage as well, reflect the gender, racial, ethnic and geographical diversity of the state, and include at least one person with a disability with direct involvement in disability policy work or advocacy. Health insurers, hospitals and health care institutions can provide valuable information to the exchange, so they should be on a state-created advisory committee; however, these entities should not serve on the exchange board due to their conflict of interest.

Moreover, the exchange must be a governmental entity. A non-profit is not appropriate for an entity that will be performing governmental functions like determining whether individuals are eligible to receive premium credits. A non-profit will not be as accountable to state residents and consumers as a governmental entity would be. Finally, consumers may be concerned about providing private data, like Social Security Numbers, and income information, to a non-profit entity. Whichever form (state agency or public authority) is chosen, the new entity must have strict conflict of interest rules, like not having any affiliation with an insurance carrier or other entity contracting with the exchange.

## **Need for Strong Consumer Assistance and Navigator Programs**

Prior to moving to New York in 2008, I served as Executive Director of a disability rights organization in Chicago that collaborated with an area agency on aging to assist Medicare beneficiaries when prescription coverage began under Part D. Even with the federal government's major public education campaign and heavy private sector marketing, many consumers needed direct one-to-one assistance to select and enroll in the coverage plan that would work best for them, and trouble-shoot problems that inevitably arose. People with disabilities and serious illnesses need comprehensive coverage that may require putting together a package of benefits. Their eligibility for public coverage is often complicated. They may need advocacy to get their plan to cover care or services they require.

Therefore, we must ensure that there are strong consumer assistance and navigator programs to help enroll New Yorkers, help New Yorkers to select health plans that meet their needs, and assist them with disputes with health plans and providers. The exchange legislation must ensure that the state consumer assistance program (CAP) that is in place today (known as "Community Health Advocates") continues, and that this existing program is effectively coordinated with the ACA-created navigator program (which under the ACA, starts in 2014) and other entities that already exist in the state that provide assistance to consumers (like state agencies and state-funded "enrollment facilitators"). Centers for independent living that are run by people with disabilities should be encouraged to become enrollment facilitators. The state should ensure that

CAPs and navigators receive adequate funds, which we anticipate primarily will be come from the federal government (including funding from the exchange in the case of navigators).

While the exchange should have a well-functioning web page and toll free number as required by the ACA, that is not enough. The website must be accessible to screen readers that turn text into compute speech for people with visual disabilities. Materials must be simple, easy to understand, available in multiple languages and accessible to people with disabilities, including large print and Braille.

Rochester is also reputed to have the largest per capita deaf population in the country, so we are perhaps more aware than many of the needs of the deaf community. Informational materials should all have the option to be viewed in American Sign Language on the web site, and DVDs that include a sign language option should be made available upon request.

The design of the Exchange should be used to reduce disparities in health access and health outcomes based on disability status, race, ethnicity, gender, sexual orientation, language and age. Health care reform efforts must strive to eliminate gaps in coverage, remove physical barriers, eradicate attitudinal barriers, and integrate the sick and disabled into larger risk pools and community based care.

I urge Governor Cuomo and the State Legislature to create New York's Health Insurance Exchange in a way where it is really simple and accessible to New York's people with disabilities of all ages. Health insurance and health coverage is complicated. We need a system that can help us find good quality, affordable health care. We also need an Exchange that will stand up to insurance companies that continue attempting to deny people the care they need at the time when they need it most. Thank you for the opportunity to testify today.