May 28, 2014

Sent via email to: dsrip@health.state.ny.us

The comments below are submitted in response to the NYS Department of Health’s request for comments on the DSRIP Project Toolkit by May 28, 2014. These comments pertain primarily to the three palliative care projects described on pages 57 – 59 of the Toolkit.

**Summary of Comments and Recommendations**

Not Dead Yet and the Center for Disability Rights, along with the undersigned organizations, recommend that the “Conversation Ready” Project be removed from the Toolkit due to the: a) transparent effort to steer safety net community members to sign advance directives that decline lifesaving healthcare and b) extreme bias against people living with disabilities.

We do, however, support the two projects involving the integration of palliative care services into PCMH models and nursing homes, and have three recommendations to strengthen those programs:

1. Ensure the provision of information and services relating to the Olmstead decision, Money Follows the Person, and the Community First Choice Option to patients and their families.
2. Ensure the provision of independent living information and services to patients and their families.
3. Require the proposed “quality committees” to include representatives from disability and aging advocacy organizations.

We also recommend that Project Advisory Committees include representatives from safety net consumer advocacy groups in at least equal proportion to the representation from provider, union, and worker groups.

**The “Conversation Ready” Project Should Be Removed From the Toolkit**

The “Conversation Ready” Project calls for advance care planning as a means of reducing hospitalizations. For this to be effective, people must be encouraged to refuse life-sustaining treatment as part of their advance care plan. A recent Pew Research study found that:

. . . [A]bout two-thirds of whites (65%) say they would want to be allowed to die if they had an incurable disease and were suffering a great deal of pain, compared with 26% who say they would ask their doctors to do everything possible to save their lives in such circumstances. By contrast, a majority of blacks (61%) and about half of Hispanics (55%) say they would tell their doctors to do everything possible to save their lives if they had an incurable disease and were suffering a great deal of pain. [Views on End-of-Life Medical Treatments, November 21, 2013, <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>]

The “Conversation Ready” project is focused on safety net providers. As such, the following Core Component is extremely deceptive and will incentivize “choosing” death over living with a disability.

Identify care coordinators to work with community based and faith based partners to facilitate End of Life planning in a socially/belief system compatible manner to increase patients (sic) acceptance of program. [Pg. 57, DSRIP Toolkit]

Giving provider networks financial rewards for being successful in this effort allows them to reduce hospitalizations and healthcare costs by encouraging individuals to “choose” death over treatment. The method by which the “Conversation Ready” Project proposes to influence people are set forth in The Conversation Project, a website listed on page 57 of the DSRIP Toolkit.

Though this site also refers to individuals coping with advanced and untreatable diseases, The Conversation Project makes it clear that the fear of living with a disability is what drives the seemingly innocuous decision-making process designed to steer people away from receiving care.

The website, found at www.theconversationproject.org, reads in part:

You’ll see that this isn’t really about dying—it’s about figuring out how you want to live, till the very end.

**“What matters to me is \_\_\_\_\_.”**

Think about the things that are most important to you. What do you value most? What can you not imagine living without?

Now finish this sentence: **“What matters to me at the end of my life is \_\_\_\_\_.”**

Sharing your “What matters to me” statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what’s worth pursuing treatment for, and what isn’t.

Here are a few statements to get you thinking:

“What matters to me is being able to recognize my kids.”

“What matters to me is being able to eat chocolate ice cream and watch football on TV.”

Understandably, individuals do not want to lose their abilities due to an accident, illness, or age. Yet disability is a natural part of the human experience and it is unacceptable that a government program will encourage people to choose death over disability.

A senior may lose their vision, but learn to enjoy audio books. A diabetic may miss chocolate ice cream, but learn to enjoy sugar-free alternatives and a healthier diet. A person with dementia may not recognize family, but still enjoy their company. There are a plethora of examples where people, happily and successfully, adapt with their disability.

The Conversation Project goes even further in specifically eliciting fears of long term disability and translating them into decisions to forego live-saving treatment:

What to talk about:

Are there circumstances that you would consider worse than death? *(Long-term need* *of a breathing machine or feeding tube, not being able to recognize your loved ones)*

What kinds of aggressive treatment would you want (or not want)? *(Resuscitation if your* *heart stops, breathing machine, feeding tube)*

When would it be okay to shift from a focus on curative care to a focus on comfort care alone?

The site does not reference any studies that prove that physicians often do not know what the duration of need might be. There is no indication that the need for such interventions could be either short term or permanent. There is no information on the tens of thousands of disabled individuals who are currently living a fulfilled life while permanently using these devices.

In DSRIP, the role of the professional should be to provide thorough information and support that assists people to adapt to disability. The medical community should never leverage common societal prejudices against disability to persuade people to forego healthcare in order to save money.

The DOH-referenced Conversation Project website even includes a Likert scale regarding various issues. The phrase associated with declining care is rated the highest, which steers responses towards “choosing” death.

“I want to live as long as possible, no matter what” vs. “Quality of life is more important to me than quantity.”

“I’m worried that I won’t get enough care” vs. “I’m worried that I’ll get overly aggressive care.”

“I wouldn’t mind being cared for in a nursing facility” vs. “Living independently, no matter what.”

“No matter what” clearly does not mean “get the services and supports I need to live independently.” It obviously refers to the fact that the person would rather decline healthcare and die than live in the community with a disability. This is a false choice which blatantly omits key information about people’s right to home and community based services, and prioritizes saving money over saving people. The state should never promote death through refusal of healthcare as the alternative to institutional placement.

The Cuomo administration must promote the Community First Choice Option and Olmstead. The suggestion that seniors and people with disabilities cannot get the right to live independently with services and supports, but will instead be given information about how to die and save Medicaid funds, is the ultimate form of discrimination and completely deplorable.

The “Conversation Ready” Project must be deleted from the DSRIP Toolkit.

**Enhance the Two Remaining Palliative Care Services Projects with Disability and Independent Living Expertise**

The two remaining palliative care projects are entitled “Integration of Palliative Care Services into the PCMH model” and “Integration of Palliative Care Services into Nursing Homes.” Good quality palliative care can be of great benefit in meeting individual needs, both in relieving pain and approaching people holistically to respond to their specific circumstances. This could certainly reduce unnecessary hospitalizations.

Both of these projects require performing provider systems to:

* Develop partnerships with community and provider resources including Hospice to bring the palliative care supports and services into the practice/nursing home.
* Develop a quality committee to monitor and address quality.

Individuals who need palliative care are, almost by definition, people with disabilities. A holistic approach to serving this population requires a partnership with the disability-led independent living centers, and information about the full range of independent living services, especially on how to access home and community based services.

Based on these considerations, we recommend that the following core components be added to the two palliative care projects:

1. Ensure the provision of information and services relating to the Olmstead decision, Money Follows the Person, and the Community First Choice Option to patients and their families.
2. Ensure the provision of independent living information and services to patients and their families.
3. Require the proposed “quality committees” to include representatives from disability and aging advocacy organizations.

In addition, according to the DSRIP FAQs:

Each emerging Performing Provider System (PPS) is required to form a Project Advisory Committee (PAC). The PAC will advise emerging Performing Provider Systems on all elements of their DSRIP Project Plans and should include representation from each of the emerging PPS partners as well as workers and/or relevant unions.

It is unclear how providers can expect to optimize their success in reducing unnecessary hospitalization without getting the advice of “patient” advocacy groups along with the advice of provider partners. Project Advisory Committees should therefore include representatives of safety net consumer advocacy groups in at least equal proportion to the representation from provider, union, and worker groups.

The disability rights community believes that these changes will enhance the DSRIP Toolkit. Eliminating the “Conversation Ready” project and adding advocate and community-based organizations to the palliative care conversation will keep this initiative in line with Olmstead while reducing unnecessary hospitalizations.

We welcome the opportunity to discuss these comments with you.

Sincerely,

Diane Coleman, President and CEO

Not Dead Yet

dcoleman@notdeadyet.org

Bruce Darling, President and CEO

Center for Disability Rights

bdarling@cdrnys.org

On behalf of:

Lindsay Miller, Executive Director

New York Association on Independent Living

Susan Dooha, Executive Director

Center for Independence of the Disabled, New York

Melvyn R. Tanzman, Executive Director

Westchester Disabled On the Move Inc.

Maria Dibble, Executive Director

Southern Tier Independence Center

Denise A. Figueroa, Executive Director

Independent Living Center of the Hudson Valley

Doug Hovey, Executive Director

Independent Living, Inc.

George Hoehmann, Executive Director

Rockland Independent Living Center

René Snyder, Executive Director

AIM Independent Living Center

Margaret Mikol, Executive Director
SKIP of New York, Inc.

Christina Curry, Executive Director

Harlem Independent Living Center

Hindy Kohn, Executive Director

Community Service Center of Greater Williamsburg

Chad Underwood, Chief Operating Officer

Access to Independence of Cortland County, Inc.