



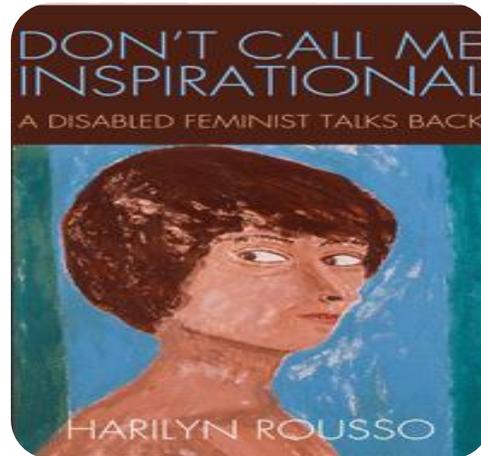
Disabled Feminist Speaker is NOT Inspirational

By Patty Black

(From NYSILC 20% Blog Post April 2013)

This past February, I had the pleasure of attending the first in a new series of programs at the recently established “Pat’s Place,” at the Independent Living Center of the Hudson Valley (ILCHV) in Troy dedicated to disability rights activist and leader Pat Figueroa, who passed away last April. The event was wonderful and well-attended as the room was quite crowded by the time I arrived in the brightly lit lecture hall a minute or so after the presentation had begun.

This arts event was a series lecture with readings from author and psychotherapist Harilyn Rousseau, who described herself as a “disabled feminist talking back” as she spoke of the new book she had written entitled “*Don’t call Me Inspirational.*” Actually, her lecture series was based on that very title and I became captivated with her the minute I sat down and began listening.



She read excerpts from her life growing up with Cerebral Palsy (CP) in a sassy, witty, and sometimes melancholy voice as she articulated the societal limitations she had endured. I could think of many adjectives to describe Ms. Rousseau...spunky, witty, bold, bright...yes, anything BUT inspiring!

Ms. Rousseau explained her qualms about the term “inspirational” and the inherent demeaning value it held for her. To illustrate verbally to us, she described an encounter she had at age 11 with a gym teacher when that word was first uttered to her.

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Gazing at her with amazement in her eyes, the teacher loudly exclaimed words to the following effect: "OH, you got yourself washed and dressed all by yourself this morning-what a wonder-you are *such* an INSPIRATION!" Well, the author could not help but think "For God's Sake lady, I have been washing and dressing myself since I was freakin' 4 years old!" Of course she did not express her exasperation out loud, but internalized her sense of indignation. She went on to explain that when people approached her with this "Inspirational" word later in life, it felt to her that this was their way of keeping her at a safe distance and not accepting her for what she was: an intelligent, capable peer who was just like them. For her, if they took her in as an equal (like them), it created too much fear in their own minds and opened up their own vulnerabilities. So calling her inspirational was more for the benefit of the speaker and not flattering for her in any way. Hence, the title of her book...I must say as someone who also grew up with a disability that I thoroughly enjoyed her richly detailed, heartfelt, wonderfully written memoir. Various themes from the book include struggling with an overly enmeshed but devoted mom who was disappointed in her daughter's inability to walk "normally," to a devious suitor who built up then simultaneously shattered her lifelong dream of becoming a Bride against the odds of her mom's and society's fears and prejudices. Actually, in the case of the ill-intended "fiancé" who broke his promise to her after making her feel like the most desirable princess ever, she learned she was quite fortunate to not end up with this cad. Actually, she came to find over time that he had betrayed her for reasons that had to do with his undesirable character rather than her disability, which had initially caused her much grief and pain. In hindsight, she was quite lucky to land on her feet without him beside her.

Ms. Rousseau closes her Vignettes by explaining in her very unique and bold voice how she continually comes to see and accept the image in the mirror, the same one she used to be ashamed and rejecting of. I found her tales entertaining and characterized by strength and endurance. I drew a lot of hope from her richly woven life journeys...and no, I won't call you inspirational Ms. Rousseau, but I will call you capable of provoking optimism and thought, and that is something we can all use, whether or not we have a disability!

For more information or to purchase book, click on the following link:

http://www.temple.edu/tempress/titles/2235_reg.html

Upcoming ILC Regional Forums in May

By Patty Black

Access VR will be holding four ILC Regional Forums across the State in May. The purpose of each of these forums is to better facilitate communication and provide updates about important issues and topics related to IL. A unique aspect of each meeting will be a Best Practice Exchange focusing on projects in each region. The first forum will be held at Capital District Center for Independence (CDCI) on May 1 from 1:00 – 4:00 PM. Best practice topics will include:

- ILC Hudson Valley Consortia
- Lower Hudson Valley Recovery Center
- Advocacy leading to revisions to special needs county registry
- Countywide gas station initiative
- Voter engagement program

The second forum will be held downstate at the CUNY Offices, 230 West 41 Street, New York City on the 10th Floor Conference Room from 1:00 – 4:00 on May 3. The best practice topics include:

- Lower Hudson Valley Recovery Center
- Advocacy leading to revision in county special need registry
- Countywide gas station initiative
- Voter engagement program
- Parent center overview
- Office of Victim Services Program

The third ILC Upstate Forum will be held at ARISE Inc., Syracuse, from 1:00 – 4:00 PM on May 7. Their best practice topics will be:

- Hospital residential aid program
- Fall prevention initiative
- ILC involvement with the new OPWDD DISCO model
- Peer Connection Program for improved outcomes

A fourth forum and agenda is being finalized. The final task for each forum will be a discussion of what participants will be able to take-away from each of these meetings.

SPIL Reviewed and Approved by Full Council

By Brad Williams

At the March 15, 2013 NYSILC Full Council Meeting, the State Plan for Independent Living (SPIL) 2014-16 was officially reviewed and approved by the council members after voting on each section of the SPIL and the overall plan. Overall, the plan includes five new objectives related to SILC operations, a Statewide Systems Advocacy network, self-sustaining capacity building grant opportunities for outreach to underserved populations, CBVH IL FFS for legally blind individuals not served by other programs, and support for a Statewide IL conference.

Five additional objectives were carried over from the currently amended SPIL (2011-2013) with unspent, Title VII, Part B funds: a Disability Voting Rights Network, CIL coaching, first cycle of the capacity building grant opportunities, database, and deaf-blind SSP demonstration project. Each one of these objectives has a very specific end date that is identified and needed to be extended into the new SPIL. One objective, related to the NFTD waiver, was discontinued because nobody applied to the re-issued RFP.

In anticipation of the Federal government providing instructions on the exact impact of Sequestration, the council also approved a 5.1% reduction plan for the five new objectives and will utilize it to make final adjustments to the plan.

During the next two months, the SPIL will go through the State “technical review” process before receiving approvals from SED (the Regents) and CBVH/OCFS (the Governor’s Office), and the three signatures from the State Plan Partners. The SPIL has to be submitted to RSA by July 1st, 2013 on the RSA MIS. RSA then reviews the plan during the summer months and negotiates any outstanding issues before approving the plan (hopefully) by October 1, 2013.

New NCD Chair Sends Letter to President about FY14 Budget

Nat'l Council on Disability Statement on the President's FY14 Budget

April 17, 2013

The President
The White House
1600 Pennsylvania Ave., NW
Washington, DC 20500

Dear Mr. President:

I am writing on behalf of the National Council on Disability, an independent federal agency that advises Congress and the Administration regarding laws, policies, practices, and procedures that impact people with disabilities.

Last week, you released your FY14 budget proposal outlining your vision for federal spending in the next fiscal year as well as your most recent offer to Speaker Boehner to achieve additional deficit reduction in a balanced fashion. NCD appreciates the need for deficit reduction efforts and looks forward to providing assistance to help ensure that such efforts do not further harm low-income populations and people with disabilities, who have already borne the brunt of past reductions in federal spending.

It is because of this commitment that I communicate the importance of including in any further deficit reduction conversation, measures to advance the economic well-being of Supplemental Security Income (SSI) beneficiaries. SSI beneficiaries face the most severe levels of poverty of any group of Social Security beneficiaries. In addition, due to the asset limits as part of the program, SSI beneficiaries are prohibited from saving more than \$2,000 in total, thus denying them the opportunity to take steps to move out of poverty and prepare to enter the workforce.

While we were pleased to see that SSI beneficiaries were exempted from the proposed "Chained CPI" index, we believe additional measures are needed to protect this population, particularly as cuts to federal spending in current law pose grave threats to low-income Americans with disabilities. We urge you to incorporate common-sense program reforms to SSI designed to improve beneficiary well-being and enhance the ability of SSI beneficiaries to participate in the workforce.

We encourage consideration of the policy issues below for inclusion in any future deficit reduction effort:

- Raise the SSI asset limit, currently set at \$2,000 since 1989, to \$10,000 and index it to inflation going forward;
- Raise the income offsets for SSI beneficiaries and index them to inflation going forward;
- Eliminate asset limits for participants in work incentive programs, such as 1619b and the Medicaid Buy-In, who are accessing SSI primarily for the purposes of receiving Medicaid benefits rather than utilizing the program for income support;
- Establish a National Medicaid Buy-In program to allow for greater workforce mobility for working people with disabilities who may wish to change jobs across state lines;

NCD previously communicated with you on this issue in our letter of December 20th, 2012 http://www.ncd.gov/publications/2012/Dec202012_2/, and wrote more extensively on the topic of asset limitations in SSI in our 2005 report, *The Social Security Administration's Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems*: <http://www.ncd.gov/publications/2005/11302005>

We believe that action on this issue is long overdue and strongly urge you to ensure the inclusion of these common-sense program reforms to SSI within any further deficit reduction arrangement. People with disabilities are disproportionately harmed by the sequester and other cuts to federal spending. Within that context, it is vital that current law be altered to allow SSI beneficiaries to save in order to blunt the impact of current and future cuts.

Sincerely,

Jeff Rosen
Chairperson

This statement is available on NCD's website at:
<http://www.ncd.gov/publications/2013/04182013/>