

Remarks of John Winske, Executive Director
Disability Policy Consortium
Marie Feltin Award Dinner
March 24, 2017

We thank BCIL and the Feltin Committee for honoring Disability Policy Consortium and our work.

I want to recognize our fellow awardees. To be mentioned in the same sentence as Robin Callahan and Jeff Keilson is humbling. Both are true leaders and consummate professionals.

I want to start by acknowledging May Lou Maloney and Bill Allan, they were the first two Executive Directors of the DPC and guided the organization for nearly two decades. They understood the twin pillars of cross-disability and self-advocacy which are the bedrock of the DPC.

It is such a privilege to work with people you adore and do the work you love. We have a team of brilliant leaders in Dennis Heaphy, Burt Pusch, Amy Kalogeropoulos. Liz Hardy and Charlie Carr. We also have such incredible emerging leaders like Maggie Sheets, Colin Killick, Kimberley Warsett, William Griffin. Scott McManus, Lenny Somervell, Amanda Shea and Colleen Flanagan.

We have a talented and seasoned board that allows our staff to take the difficult stances they sometimes must take.

We are in difficult times. Nationally, there are new leaders who see the world through a lens we do not understand, and speak of human beings in a language we cannot comprehend. We must remain positive. To not remain optimistic is accepting their narrative and thus their reality. That my colleagues, is something we must never do.

For the DPC to thrive, we need willing and committed partners. When the DPC was awarded the grant to serve as the One Care Ombudsman, we had only worked on

small single year contracts. Not only that, we were still in a lawsuit against the Executive Office of Health and Human Services around putting materials in an accessible format. Even today we remain the only consumer directed Dual Eligible Initiative Ombudsman Program in the United States.

We are reliant on funding partners like Blue Cross Blue Shield Foundation and Community Catalyst, not only for their dollars but their steadfast guidance.

We have a growing research division, nurtured by partners such as the Mongan Institute at MGH and their Director Lisa Iezzoni and Health Management Associates.

And last but not least we have incredible community partners such as BCIL, Metrowest Center for Independent Living, Recovery Learning Communities, Stavros, Bay State Council of the Blind, IL of the North Shore and Cape Ann, Mass. State Association of the Deaf, CCA, Tufts, BU and Disability Law Center.

For me personally this night is special. I knew Marie. She was my doctor. She along with Bob Master, Mary Glover and Dr. Peg McKenna restored my faith in medicine and health care. You see when you grew up with a disability, medicine meant being an oddity to be studied, being asked to demonstrate things you could not do, and being probed by 400 eyes as you sat in your underwear in the amphitheater of grand rounds. It was humiliating and degrading.

Marie was different on so many levels. She was the first doctor to ask "How are you doing?" and mean it. She cared about the whole you. She listened and inquired about you physically, emotionally, spiritually and yes sexually. She made tea. And her office was a black hole. A black hole of comforting warmth, a safe zone where you would not be harmed.

What Marie, Bob and Mary created is remarkable.

This model is based on independent living. The doctor is a trusted advisor who lets the consumer make informed decisions for themselves.

This is how the DPC approaches advocacy and research. Our philosophy is About Us By Us. We are carrying Marie's legacy to public policy by bringing consumers voice and lived experience to the table of policy development. We are employing people with disabilities as peer researchers and facilitators for focus groups. We are co-authoring the findings for journals. If it is about us, then we must also do the work, and yes share in the remuneration. I believe we are carrying Marie's legacy to a broader level

As I mentioned earlier these are tough times. Those of us steeped in Massachusetts liberalism and faith in social justice are dealing with a psychological "Ice Bucket Challenge." But maybe because I have seen a lot of change in 54 years that I remain optimistic.

Helen Keller once said, "Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence." To achieve the goals we envision, we must keep our faith, hope and confidence in all people with disabilities.

Again, we say thank you.