

National Council on Independent Living Award Remarks – Dr. Penny Shaw, PhD. July 22, 2020

Thank you for having selected me for this year's Corey Rowley National Advocacy Award.

I have been living in a Nursing Home in Massachusetts since 2002, due to multiple functional limitations resulting from an acute episode of Guillain Barre syndrome. I am unable to live in the community because MassHealth policies are inadequate to provide the level of care I need.

I have experienced the well-known problematic conditions of living in nursing facilities - paternalism not self-determination, lack of privacy/shared rooms and dignity, neglect, disorganization - clothes lost, mail lost, food ordered not received, challenges of living with behavioral residents and more.

At my facility- level I am the chief complainer about serious unmet needs. Our owner has repeatedly put profit over care and safety. For residents this resulted in short-staffing and verbal abuse from understaffed overworked staff.

My filing complaints has been successful.

The Coronavirus pandemic has highlighted what those of us with disabilities already knew - that we do not want to live in nursing facilities. The danger of institutional bias - death from the coronavirus - is now evident to everyone.

This spring I was appointed a member of the White House Coronavirus Task Force's Coronavirus Commission on Safety and Quality in Nursing Homes. I am interested in long-term permanent changes.

I suggest because the general public is now aware of the dangerous conditions in nursing homes we should capitalize on this to accomplish our goal of altering the system.

We need to be outspoken about what is right and just - the human and civil right we aspire to - to have equal opportunities to live in the least restrictive environment.

We need to challenge the unjust status quo by imagining a better way - by fighting to change laws, policies - to move our agenda of independent living forward. Change cannot wait.

We should organize to achieve the following -

- Defund nursing homes as they currently exist, especially those with a history of excessive profits made by owners resulting in substandard care and services - like the one I live in.**
- Seek out policy makers, legislators use our voting power, contact public press, and funders like IHI to move public Medicare and Medicaid - monies to individual PWDs to give them choices.**
- Pay family caregivers and their helpers to keep family members out of institutions.**
- Develop models of disability-run co-op independent living housing, and disability-run PCA service and support agencies.**
- For those requiring supervised congregate living...redesign using better models**

I am optimistic that we can prevail and liberate people like me.