

Moving From Pennhurst's Dark Control Into A Brightness Called "Speaking For Ourselves"

By Robert Perske

Today, *The Encyclopedia of American Law* lists *Halderman v. Pennhurst State School and Hospital* as one of their "Great American Court Cases." The case began with 32 court days in Philadelphia, followed by a hearing in the United States Supreme Court. After an additional series of zigzagging legal skirmishes, a final order for the institution's closure was handed down on July 1, 1986.

As an observer during the trial and Supreme Court hearing, I watched Pennhurst's total control system die while numerous community-based efforts came alive. One of these budding organizations, a group of self-advocates, really grabbed my attention.

After being muted by others for so long, they gave themselves a cocky action title, "Speaking For Ourselves." Songwriter Karl Wil-

liams even wrote a song that reflected their deepest longing. They sang it like one would sing The National Anthem during many of their early meetings. Two of four stanzas:

Once I was afraid to speak
I was lonely I was weak
With a voice so very small
That I had no voice at all

We are speaking for ourselves
Speaking for ourselves
No one else can do as well
Speaking for ourselves.
(Williams, 1998)

In the 1990s, I watched this organization grow and thrive. Then, during the late 1990s, I voiced some of my early reflections at their state convention. A few excerpts from my speech notes:



Debbie Robinson opening the rally in the State Capitol

I got to know some of you during the court cases that argued for the closing of Pennhurst State School. I remember when you first started to speak for yourselves.

It was rough.
It was hard.
It was scary.

But do you know what?
The more you spoke for yourselves
It got easier.
You did better.

But do you remember what it was like before you started speaking for yourselves? I remember. I worked in an institution. We institutional workers were in control. Here's how we did it:

We believed that you couldn't speak for yourselves. "Only we can speak for you," we said.

We failed to see you as individuals. "John, I know you'd love walking into town, but if we let you go, we would have to let everyone go," we said.

We herded you like sheep. We said things like, "Okay, folks. Head 'em up. Let's move out. It is time to go to the dining hall... Or it is time to go to the showers



Carolyn Morgan speaking at the mike

... Or it is time for you to go to bed."

So we worked hard to control you. We thought we were doing it for your own good. We didn't know any better.

Now that you dare to speak out, look at a few of the many things you are doing:

Jerome Ianuzzi and Carol Talley got married, and so did Frank Wetmore and Mary Ella White.

Do you think you could have gotten married before you joined Speaking for Ourselves? Now all we can say is "Congratulations" to all four of you.

Richard Hamer chose to move into a home with two close friends. You made that choice on your own.

Roland Johnson made a formal presentation to President George Herbert Walker Bush. It was even shown on national television.

Jerry Ellis and Lester Noch, you have been friends together at Pennhurst. Now you live in your own house – and you picked that house.

George Ware went out and got his own job.

Many of you worked on a project with the National Park Services at Independence Hall. You taught the rangers about solving "barrier" problems and how to treat persons with disabilities as valued human beings.

Debbie Robinson, you became



Roland Johnson, Mark Friedman and Jerome Ianuzzi



Marchers in the street

a leader of others who now testify before legislators, governors, and town councils. Quite often these officials paid more attention to you than to the rest of us because you know what it was like to live in unfair and tough times.

Good for you. Keep going!

* * *

They did keep going. For example, on April 26, 2001, Speaking For Ourselves inspired more than 200 persons to march through the streets of Harrisburg and into the Pennsylvania State Capitol. Once inside, founding member, Debbie Robinson, wearing her baseball cap, spoke about the organization's deep longing for "the closing of institutions and the creation of community services for all." She was followed by Carolyn Morgan, then president of Speaking for Ourselves – and more than 30 other members moved to the microphone and added their voices to this unified plaintive call.

A Final Observation

After observing the members of Speaking for Ourselves, I learned how the members loved and respected the organization's first state coor-

ordinator, Mark Friedman. Never to my knowledge did he ever speak out at rallies and convocations. Never did he take leadership by delivering direct orders in public. After rummaging through photographs of the organization, never was there a snapshot of Friedman in them. And yet the love and respect from the members for this coordinator was palpable.

Friedman remained present in the background. He listened to the dreams the self-advocates voiced. He helped them to organize themselves accordingly. He reinforced their efforts. He cheered them on. He knew how make them feel proud of their own successful achievements. He often showed love to the members like a father or a brother would.

I finally found a photograph of Friedman taken by an outsider showing him standing between founding members Roland Johnson and Jerome Ianuzzi. His face belongs in this story.

Reference

Williams, Karl (1998). RE-SPECT: Songs of the Self-Advocacy Movement. Cannylark@aol.com. ■