

Testimony before the House Human Services Committee
Open the Doors to Dignity for individuals with Intellectual Disability and Severe Autism
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First there was Pennhurst and the news anchor and the revelations and Lt Governor Raymond Boderick then District Justice Boderick and the rebuilding money turned over to ARC and the first public private partnership in the state began. It was I think 20,000. Now there is 2.12 billion budgeted for the IID/ Autism services partnership so yes there are market forces.

There was Pennhurst and sadness at the way systems failed but lessons were learned and children were saved. It was a poignant time infused with great awareness and full confidence that we could do better and we did. Remember Tom Gilhool and the beginning of school inclusion and leading the nation and knowing for sure how to do the right thing. **A major reason for institutionalization was the *lack of access to a public education and the support that provided to parents . . . PARC v Commonwealth of Pennsylvania* was the first right to education case. It led to a consent decree that Congress ultimately codified as the Education for All Handicapped Children Act of 1975. Thomas K. Gilhool of the Public Interest Law Center of Philadelphia was lead counsel in the case. He recalls that in 1970, 15,000 school aged children were going into institutions. By 1978 (the effective year of the 1975 legislation), that dropped to 1,500.”**

It was invigorating but it was a judgment moment and not a sanctifying event and it did not carry a guarantee that one would be right always from that time forward. Falling for the right once/ always right ploy leads to a brittle leadership style and management prerogatives that punish innovation and do not allow for the onward march of institutional awareness. Trouble starts when time moves on but the satisfied stay wed to singular value system that is not shared.

And then too there is always mission creep. I would like say here that the mission of the ODP is not our mission. We have no seat at that table.

Then there were the Olmstead Supreme Court Decision and a new energy to move another class, the disabled, into the mainstream so new freedoms were mandated and implementing strategies were devised but at the same time also both Justices Ginsberg and Kennedy warned against bureaucratic overreach at the hands of the federally funded protection on and advocacy agencies. They knew. In Pennsylvania I was witness to a 5 year court case costing upwards of 100,000 for us the family members to keep our loved ones settled in the Centers that were their homes. It was the Benjamin Decision, still in play. We had the choice and we exercised our choice to stay put ~~ a choice and a right that never squared with OPD policy and practices

I became my sister Sharon's guardian about 10 years ago in time to see ARC and Disability Rights Pennsylvania and Temple University's Institute of Disabilities and PAR (Pennsylvania Advocacy and Resources for Autism and Intellectual Disability) and others choose as their second goal the destruction of my sister's safe home. I was and remain incredulous. The market force folks and the mission creep devotees seemed to have settled on the strange tactic of home wrecking (HB 1650) in such a show of might is right that they did not even bother to articulate a reasoned principle cause. It was Through the Looking Glass for sure.



Thank you Polk Center. You have been my home for 67 years and I am still smiling. Love Sharon Rose

So here we are today. One of you will have to ask ODP why did you close the doors on a sure and steady haven. Why? Why didn't you have the foresight and courage to repurpose to an emerging population rather than disrupt and shortchange. How is it you could not see to be a vital force for partnership and consensus building rather than to dismiss and disregard?

ANCOR is a trade association of providers, they do a yearly report [The Case for Inclusion](#) and in 2108 they ranked Pennsylvania at 19 and the main reason for the poor rating was the relatively high number disabled individuals still living in state run institutions ~~~ more than 900 which I think is the highest number of any state/or second I take that as an enormous source of pride for common sense compassionate care giving, a belief held from the time of our Quaker beginning as a Commonwealth.

It would be hard to find a more committed group of people than we are, more solution driven, and more in awe of the institutional memory of Polk and White Haven and Selinsgrove and Ebensburg. Their combined knowing is worth millions and millions of dollars. It is in a word priceless; you cannot buy that kind of certainty and solidarity. It took 300 years. Not understanding the value of that workforce it to miss seeing the forest for the trees. They are a resource.

And now here comes the family of a new generation of lambs saying we sure do need a safe place to live together in congregate housing, with an institutional structure. So we more or less invited ourselves here to invite you to action. It is an invitation for you to better understand. So thank you. We meet here because you have the duty and the charge and the wisdom and the reach to see the big picture. That is why we are so happy to be here and again we thank you.