

Mary Ohl

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Thank you so much, and it is a really great pleasure to be here today and I want to of course, thank our host Vision for Equality and Sheila Stasko from the Waiting List Campaign, for bringing us all together for this hearing.

I am certainly delighted to be here with all of you today. So good morning, (good afternoon), Chairman DiGirolamo, Chairman Cruz, Committee Members and Staff.

I thought it would be interesting for people to listen to the story of a young man with significant challenges strive to be part of his community and the creative ways he finds in order to do that.

Covering his lifespan from birth to now almost 5 decades later and facing a whole new challenge of having aging parents s trying to support him.

You will see some innovative ways he and his family have strived for Dennis to have an Everyday Life like you and me.

In the interest of time if you go to the website: [Odpconsulting.net](http://Odpconsulting.net) you will see a very short documentary that ODP made about Dennis's life several year ago. I promise you will not be disappointed.

Also there is a transript before you of my Testimony todayl.

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My name is Mary Ohl. I am 67 years old, and a retired ICU Nurse. My husband, Walter, is a retired shop steward and 75 years old. We live in Milford which is in North Eastern Pa., in Pike County.

I will be giving you testimony today from the perspective of aging caregivers who has raised a son, Dennis with significant disabilities.

Dennis sends his best wishes to you all and has given me permission to share his story with you today. He had to work and sends his apologies.

Here is some History and background about our family:

Dennis was born 47 years ago and diagnosed with Noonan's Syndrome. This syndrome effects cognitive and physical areas, he is legally blind and partially deaf and has multiple cardiac defects. He was diagnosed with an Intellectual Disabilities and Autism.

The first 5 years of his life were mostly spent in the hospital. If he got the slightest cold he would end up in the ICU on the critical care list for weeks.

He received last rights at least 6 or 7 times and was virtually given up by his doctors and medical team.

I just kept praying for a miracle for the Lord to keep him alive and finally after about 5 years the critical visits to the hospital ended. Till this day I know it was a miracle!

Dennis had survived and now it was the early 70's. The decade of our countries most enormous unrest and division.

Between the War in Vietnam, the Watergate Hearings, and the eventual resignation of President Nixon, America's core sense of peace

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and unity and for a better future was deeply shaken.

About the same time, around 1972 and especially poignant and unforgettable TV documentary by Geraldo Rivera was released that exposed the atrocities of the Willow brook State School for the Mentally Retarded in Staten Island, New York.

It was called, "The Last Great Disgrace".

Willow brook was the largest institution in the United States and housed almost 6000 developmentally disabled people during the 1950's and 60's.

In 1972 Geraldo Rivera, a reporter took his hidden camera into the facility.

It exposed the horrible living conditions of 1000's of residents and graphically displayed the filth, odors, overcrowding and inadequate care of thousands of the residents.

I was 24 years old and had my baby Dennis sleeping peacefully in his crib in the next room .I became overwhelmed with tremendous sadness, disbelief and horror.

How could this be happening? How could this be happening a few miles away from my home? And how could this be happening in the United States of America?

This exposure prompted enormous public outrage and finally in 1987 Willow brook was finally closed.

Subsequently new laws and regulations were passed to protect people who lived in institutions.

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Finally, when Dennis was around 7 or 8 years old Dennis was able to go to a school for the developmentally disabled in Manhattan.

It was around 1975 when the Education for All Handicapped Children's Act was enacted. Up until then children with disabilities were unable to attend school.

Of course this came about because of the tireless efforts of Parents and advocacy groups like the ones sitting before you in this room, namely The Association for Retarded Citizens formed around 1950. They fought for the right for children with disabilities to have the right to an education.

After several years when Dennis was 18 years old we moved to Milford, Pennsylvania.

The first thing we did was sign him up in the local Public High School.

This was such an exciting time for Dennis because it was the

First time he would be in an Inclusive School with kids his own age.

Things were fine for a couple of years but in the back of my mind

Was the impending question of what happens to him when he becomes 21?

For most people this is a time of celebration and eagerness to realize all your goals you have worked for.

It usually means going on to college or starting a new job that you have been working towards through High School.

But unfortunately the future options for Dennis was not as bright and

hopeful.

We were advised that a Sheltered Workshop would at least keep Him safe, occupied and not sitting in front of a TV all day.

Not knowing anything at the time I followed what learned people had told me, so in 1989 after Dennis graduated we enrolled him in a Sheltered workshop.

Remember, this was a long time ago and programs like supported employment, integrated and competitive employment in the community was rare to none.

My husband and I knew instinctively that Dennis didn't belong there...so quite by accident we found a Day Program that provided socialization for Dennis. Life skill training and last but not least transportation.

As time went by, I began searching for answers to questions about Dennis's life...his future and how I could make his life better and fulfilling.

I knew there had to be a better way to value and respect myson for who he was and what he wanted to be.

My search led me to Harrisburg.

In Harrisburg I found groups of parents that met to talk about How their sons and daughters could have better lives.

Lives in their communities, not institutions, even maybe living in their own homes, working at real jobs in their very own

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communities. And, yes becoming valued members in their communities and societies.

The next couple of years were spent educating myself about

Attaining a quality life for my son Dennis.

I joined many work groups, committees and family support groups.

This search for answers did not happen overnight it was the

Beginning of Mine and Dennis's journey for several years and still to this day to search for these elusive answers to having a life like everyone else.

A big conference was held in Hershey, Pa. around 2001. It was called "Everyday Lives, Making it happen".

Nancy Thaler, was Deputy Secretary of MR (it wasn't ODP yet).

She had already served in that capacity for over 8 years and under 2 administrations I might add.

Well there was no turning back for me and Dennis after that Conference!

After that I had to learn about Person Centered Planning, Essential Lifestyle Planning, Self Determination and many, many more methods and ideas.

I became a Person Centered Thinking, Everyday Living, Self Determined Junky!.....I couldn't get enough.

All of a sudden the light bulb went off and all the parents, Self Advocates, families, providers, agencies, state and counties were all on

the same page.

Finally, the professionals weren't talking a foreign language to me.

Dennis would hopefully have a healthy, happy, inclusive, and God willing an Everyday Life....

Least I forget one of the most important reasons I am sitting here today in front of this distinguished body is because of the people who are sitting in front of you in this room.

Except of course for the younger ones who are now carrying on the torch for all of us.

I do wish to take the time and to note a few of the pioneers who are sitting in this room before you such as

Nancy Thaler, Celia Feinstein, Sheila Stasko, Maureen Devaney, Dee Cocchia, Nancy Murray, Maureen Cronin, Graynel Edwards, Lisa Tesler, Bonnie Miller, Mel Knowton, Shirley Walker and so many, many more of devoted soldiers .....CONTINUE LATER....

They have mentored me, encouraged me, cried with me, struggled with me and have shared an unbreakable bond.... the struggle to make sure our children's future are safe, healthy and happy and afforded the same opportunities as your sons and daughters are.

I could sit here and tell you all the road blocks, deaf ears, locked doors, and stop signs we have met but I would rather tell you about a life of someone who was NOT on the Waiting List In Pa.

This is Dennis's Circle of Support or as I like to call it his Social

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Capitol or Relationships.

As you can see it is a rich, full, all encompassing, ever changing fluid picture of a real person's life full of dreams, friends, family, supports and fulfillments that strive to respect and value Dennis as a human being worthy of all the good things that life has to offer.

As aging caregivers there is one more thing we had to do to ensure that Dennis would be as independent as possible and have a good Quality life.

That was to plan for the Final Chapter.

What if one or both of us die?

What I am about to say is very shameful, shocking and sad but at Night before going to sleep I would pray to God that if He took me would he please take Dennis too.

I'm told that a lot of elderly parents with adult children with disabilities have felt the same way.

What we decided to do was while we both were alive to make sure Dennis was in his own home with a team of loving care takers.

We gave Dennis our home and moved out and around the corner from Him, We had to take another mortgage out and help him with all his expenses.

This was all done under Person Directed Services under the employ of

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A Support Broker who is paid for under the waiver.

To say this was the hardest thing we ever had to do for Dennis is a Tremendous understatement...but we knew for us to be able finally be Comfortable about leaving him it was our only alternative.

So now we are at the end of our lives but at the beginning of Dennis's new life... a young man who is living in his own home, working, volunteering right in his own community developing friends and relationships who will sustain him along with all the love and support of

All the wonderful people in this room who have come together as a team to help Dennis and all the Dennis's out there who desperately need our friendship, advocacy and support.

My husband, I and Dennis thank you all.

Mary Ohl

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