

\$30,000.00

By Tom Kashatus That's the title of my testimony. Why \$30,000.00? Because if most people had to spend \$30,000.00 – give or take a few bucks - within a short period of time on behalf of a “loved one” for disability services they would probably be wiped out of their long term and short term savings – maybe even go into debt and be saddled with a payment for the rest of their lives. My wife and I are retired in our 70's. We've had a good life – me a retired prison guard, she a homemaker – no regrets – never took a two week vacation – but we raised five kids, and we love every one of them. Maria was our first – she is special and she is my hero. Her story is attached to this testimony.



However, I am here today to talk about a friend and her name is Celine Nauman of White Haven, PA. To really appreciate this story, put yourself in the place of Mrs. Nauman. To the left is a photo of Mrs. Nauman, 77 years old, with her seven children. Jimmy is on her right and Danny is on her left. Standing from the left are Lisa, Marie, Billy, Beth, and Elsie. Jimmy, a resident of White Haven Center (WHC), an ICF/IDD, recently passed away at age 54 from complications and so did Lisa, tragically from cancer. Danny, age 56 and now a resident of Allied Services in Scranton, also suffers from IDD and was being taken care of by Mrs. Nauman – until that became impossible due to her health and physical limitations. Mrs. Nauman needs a wheel chair for mobility.

In January 2016 it became necessary that she needed help with Danny and she began to pursue long term care for him. From hers and Jimmy's experience with White Haven Center - 47 years - she felt that WHC would be the most appropriate placement for Danny. Her two boys would be close and she could "visit regularly and keep an eye on them." Mrs. Nauman also had experience with IDD self advocates who lived in community based living arrangements and worked at REDCO Day Program in Hazleton. She was employed as a Therapeutic Service Aide for 15 years there. She felt that their living standards, personal hygiene, diet, etc., was substandard and wanted better for Danny.

Unfortunately upon onset of her new journey, Mrs. Nauman was pressured into accepting a group home, "Keystone," in West Hazleton. There she witnessed verbal abuse, diet abuse, lack of active treatment, etc. Subsequently, she hired an attorney. It was a difficult task to find an attorney to handle the case. Eventually a 406 petition was filed in Luzerne County Court, that being Danny's home of record, to start the process for court placement of her own choice at WHC.

A judge was appointed, counsels were set, etc. In the meantime, Danny fell and broke an arm at Keystone and ended up in a hospital. For recovery, Danny was sent to Weatherwood Nursing Home in Weatherly – a place not appropriate for one with IDD. This became a nightmare for Danny as he deteriorated physically and emotionally. *If a resident at WHC, recovery could have taken place there with full time staff close by, 24/7 close nursing care, one on one staffing if necessary, and a full time doctor on duty five days a week.*

In the meantime, continued negotiations were pursued by the State to have Mrs. Nauman select a group home for Danny. One thing for

sure – the State of Pennsylvania has smart lawyers who “know every trick in the book” to prolong a court case. This became a long drawn out process as the State and County caseworkers continued to insist that there were group homes available and they were appropriate for the services that Danny needed. After visual inspections, Mrs. Nauman saw none that suited her satisfaction for Danny. For a number of reasons, postponements continued to surface, bills kept piling up, and finally Mrs. Nauman had to make a choice on whether to continue the WHC journey for Danny. In the end due to financial restraints Mrs. Nauman had to make a “forced choice” to have Danny placed at Allied Services in Scranton. Now, regular face to face visits with Danny are unfortunately and tragically limited for a mother who was always there and close to her son since he was born – limited to telephone conversations – while 157 certified empty beds for services, give or take, at WHC remain empty.

Because of a slanted policy of bureaucrats in the ODP (Office of Developmental Programs) influenced by the Pennsylvania ARC and DRP (Disability Rights of Pennsylvania), advocacy organizations who received tax dollars from all Pennsylvanians, IDD citizens who are in need of services are told that ICF’s are available for their benefit; but they are private ICF’s such as Saint Joseph’s and Allied Services of Scranton. If someone knows that state centers exist and asks if they are available, they are strongly urged to look to a private facility. Even the chance for a tour of a state center is frowned upon and very unlikely about to take place.

Policy can be changed at the top, but that is unlikely if the bureaucrats could not see the light. It may have to take legislation to

insure that our most fragile citizens in Pennsylvania, whether in community based living situations or institutions – to include state centers - are entitled to the “Cadillac of services” to have a quality of life that they deserve. Individuals and those who have guardians should be given the opportunity to select a venue of their choice after a complete review of providers of services is experienced – to include that of state centers.

Certified Beds in PA State Centers

WHC	275	118 filled	157 available
Selinsgrove	564	290 filled	274 available
Ebensburg	402	208 filled	194 available
Polk	521	200 filled	<u>321 available</u>
	Total available beds		946

What happens to my child after I am gone?

Letter to the Editor / Published: July 23, 2017



Editor:

The imminent closing of Hamburg Center, a state facility for the intellectual and developmental disabled (IDD), has prompted State Rep. Kerry Benninghoff, R-171, Centre County to submit House Bill 1650 to the State House Committee on Health. He had taken this action with a number of co-sponsors recently on July 8 to basically close all four remaining state facilities — White Haven State Center, Luzerne County; Selinsgrove State Center, Snyder County; Ebensburg State Center, Cambria County; and Polk State Center, Venango County — as a cost savings measure to assist in balancing the fiscal year budget 2017-2018 and somewhat thereafter.

For quite a few years now, the closure of these state facilities has been the target of major advocacy organizations — The ARC of Pennsylvania, The Disability Rights of Pennsylvania, The Waiting List Campaign, Vision for Equality (Temple University), Self-Advocates United as 1(SAU1), etc. — as they stress in their dissertations when making public comment. They also stress that all intellectually disabled individuals would be better served in the community (group homes) and that there would be a cost savings which would enable more services available for people on the “waiting list” for services.

Over the past 25 years there has been a tremendous exodus of “self-advocates,” residents of state centers, of which many successes have been revealed - and many failures which have been kept from being transparent. The successes have developed into a philosophy that all intellectually disabled will thrive better in the community, and that is just the way it is. County caseworkers have been instructed — only by state policy and not law — not to even offer state facilities as a provider of services for even the most fragile IDD individuals — taking away their right of choice even though the court system allows for a process to do so.

Our daughter, Maria, was born in 1968; and by the time that she was 12 she became a resident of White Haven Center after it was determined that she suffered from profound intellectual and developmental disabilities. A number of attempts at residing in group homes and receiving services in the community failed to give Maria a quality of life comparable to her peers. With a recommendation from the Children’s Service Center of Wilkes-Barre and her primary caseworker, a process took place whereby she was admitted to White Haven Center. Today, after 37 years, she spends her time with friends who she

has been with since day one and staff who have known her for years. Twenty four hour nursing care is available for all residents and other services are second to none. Mom and Dad visit Maria at least once each week and continue to wash her clothes and linen. Her family will always be supporters of those less fortunate. Today, Maria is still unable to walk or stand by herself, cannot talk or express pain and very seldom cries, but she smiles when she sees a familiar face and our heart tells us that she knows her family. White Haven Center, an “institution,” is responsible for that.

Keep in mind that there are always two sides to a story and the old adage “not one size fits all” comes into play here. My personal belief is that there are certain IDD individuals with severe and profound disabilities who can do better and will have a better quality of life, long term and with familiar staff, under the care and services provided by a state facility such as White Haven Center. Rather than close our state facilities, the excellent services which they provide should be considered to be used as part of a wide range of attainable services for those on the emergency “waiting list” resulting in the depletion of that unfortunate list. A facility and campus such as White Have Center is void of the racial epithets expressed openly in the community, the drug deals and usage of drugs experienced on our streets, and acts of violence which have now become the norm and an everyday occurrence in our homes and outside environments.

There is certainly a lot more to this issue than what is stated here and an open debate is deemed necessary and asked for. In the end, this bill must be defeated as it will only be a “pile driver” into the lives and hearts of many of our most fragile Pennsylvanians while taking away their right or legal guardian’s right of choice as documented by a 1999 Supreme Court decision referred to as “Olmstead.”

Thomas Kashatus

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