

**Testimony before the General Assembly
Special Joint Subcommittee to Consult on the Plan to Close State Training Centers
Wednesday, September 2, 2015**

Community Services Board's Perspective of Community Transitions

Good Afternoon. My name is Jean Hartman. I am the Assistant Deputy Director for the Fairfax-Falls Church Community Services Board. The Fairfax-Falls Church CSB provides and coordinates a system of community-based supports for individuals and families of Fairfax County and the cities of Fairfax and Falls Church. Thank you for the opportunity to speak before the Special Joint Subcommittee today about the Community Services Board's perspective and experience with transitions from training center to community.

The Fairfax-Falls Church CSB has been the jurisdiction with the largest number of individuals for whom the Northern Virginia Training Center has been their home. In 2012 when the Department of Justice and the Commonwealth came to a Settlement Agreement, we had 89 individuals living at NVTC. Currently 34 of the 54 individuals remaining at NVTC are from Fairfax-Falls Church and another 14 live at CVTC.

On the one hand, we are fortunate that some 530 individuals with intellectual disability are already living in the Fairfax-Falls Church community with the assistance of a range of supports provided by experienced residential and employment and day providers. Individuals may have chosen to live in one of the 71 group homes, 7 intermediate care facilities, 37 supported residences, or 4 sponsored "host" homes; or they may be among the 100 individuals receiving supportive services in their private residences. At first blush we sound flush with an abundance of resources and options, but there is "another hand".

On the other hand, these dozen or so experienced residential providers were already fully subscribed when the decision was made to close NVTC. So, individuals in the community already awaiting residential services are now also in competition with those individuals currently residing in state training centers whose imminent service in the community is mandated by the Settlement Agreement. The reality of Northern Virginia's high property and operational costs combined with the uncertainty around Waiver reform funding, has made it difficult for providers to structure expansion plans. Thus we have been challenged to expand community capacity paced with the training center closures.

Nevertheless, (on the third hand) we *have* been able to expand community capacity with existing community partners and welcomed new partners. There will soon be 17 residential providers in Fairfax-Falls Church and providers have expanded services. Through Section 811 and Section 8 Housing Choice Vouchers, with Home Investment Partnership, in collaboration with other County agencies, and in joint projects with the City of Falls Church or housing partners like Marion Homes Knights of Columbus and others; providers have opened or are in the process of opening new homes, ICFs, and apartment options. The Department's Bridge funding has also been an important resource in this effort.

Of the 56 Fairfax-Falls Church individuals who have transitioned from NVTC to the community since late 2012: 42 individuals were served by nine different providers within Health Planning Region (HPR) II. 14 individuals or a quarter thus far, moved outside of Region II. Of the 34 NVTC individuals yet to move to the community, only 5 will be going outside of Region II. (4 to an ICF operated by RACSB and 1 to a group home in Fredericksburg.)

The numbers I've presented in today's testimony are important, but only to the extent they help portray the human experience of individuals' and families' lives that are significantly impacted, and forever changed by the transitions we are discussing. The word "transition" is intentional. It is meant to capture the thorough before, during, and after components of a successful and safe transition of the individual with all their supports into the community. It is not just a matter of moving, of relocating. It is not a simple flip of the switch where "now you live here" and "now you live there". The CSB's work very closely with the interdisciplinary staff at the training centers, individuals, families, and providers to thoroughly plan, implement, and carefully assess and follow up each transition. So, let me close with a few individuals' transition stories.

Mr. A. transitioned from NVTC to a group home in February of this year. The transition was not easy for Mr. A. and after the first month of decreased appetite and fluid intake, he was hospitalized. The hospital sought to start a feeding tube, but the family objected as they believe the problem was due to the individual's reaction to all the changes. The CSB Support Coordinator joined with NVTC staff to meet with the family, individual, and residential provider at the hospital and in the home. They provided doctor-to-doctor consultation to the hospital, reviewed the supports, and worked with the residential staff to model interactions and clarify preferences and choices. The family was exceptionally pleased with the rapid and comprehensive support and the turnaround they effected, such that Mr. A continues to do well in his new home.

Ms. F is a 43 year old woman who had lived at NVTC from the age of *five* until last December when she moved to a group home in Culpepper nearer to her family. Ms. F's overall functioning is in the severe intellectual disability range. She has cerebral palsy, is non-ambulatory and nonverbal. After 38-years living in the training center, Ms. F's family was initially understandably reticent and concerned about whether her specialty medical care and equipment needs could be met in the community. But after a well-planned transition, Ms. F's family now observes that they "have never seen our daughter as sociable or animated" and that though they originally prayed NVTC wouldn't close, they now consider the "unanswered prayer a blessing".

We are fortunate to live in a community enriched by the lives of many individuals with intellectual disability who are supported to live rewarding and full lives in the community. Several of these individuals transitioned from training centers years ago, some are new neighbors. The CSB believes that a full life in the community is possible for all individuals with *careful* planning and *resourced* supports.

Thank you again for this opportunity and for your commitment to and investment in a life in the community for individuals with intellectual disability.

Testimony to the Joint Subcommittee on Training Centers

Alan Wooten, Executive Director, Prince William County CSB
Wednesday September 2, 2015

Good afternoon Members of the General Assembly and thank you for the opportunity to speak before you today. My name is Alan Wooten, and I am the Executive Director of the Prince William County Community Services Board, which serves residents of Prince William County and the Cities of Manassas and Manassas Park. I am here today to provide you a very brief summary of the transition of Prince William County residents from the Northern Virginia Training Center (NVTC) to community placements since 2012.

In 2012, there were 23 Prince William County residents residing at the NVTC. Since then, 16 have moved into community-based residences. Of the 16 that moved out, 11 moved to homes in the area and 5 moved to homes outside of the area at their families' requests. Today, there are 6 individuals remaining in residence at NVTC. Providers have been chosen for 3 individuals with move dates scheduled by the end of October. The provider selection process continues for the 3 remaining individuals. In addition to NVTC, there are 3 individuals from Prince William County who live at the Central Virginia Training Center. These individuals have significant physical and medical needs, and providers have not been identified for them at this point in time as we have been prioritizing NVTC residents given the shorter timeline for closure.

Prince William County's plentiful and more affordable housing market compared to other jurisdictions within northern Virginia has contributed to the increased number of service providers and increased service capacity in our County for over the past decade. As a result, our CSB has accepted responsibility for many persons with Medicaid waivers who have moved into Prince William County from our other CSB jurisdictions in northern Virginia. While this has added to the CSB's need for additional staffing to accommodate the high numbers of persons moving into our County for which we are responsible, we consider

ourselves fortunate to have a provider base that is well-aware of and experienced in meeting the unique needs of individuals with disabilities and that has demonstrated a willingness to explore every option possible to meet those needs. With that being said, sufficient funding to meet the needs of individuals and provide quality care is an essential ingredient in the recipe for successful community living.

Some of our providers have sought additional funding, such as community development block grant and private foundation funding to expand, adapt and enhance housing, to increase staff resources, to acquire needed specialized adaptive equipment, and to expand the array of services to meet individualized needs. Bridge funding has been essential to providers to afford necessary program enhancements and start-up costs to ensure smooth, safe and positive transitions from NVTC to the community.

I think it is accurate to say that the majority of the individuals our CSB has transitioned into the community from NVTC have high needs for personal assistance and supervision, and that many are physically and medically fragile. However, the transitions overall have been both positive and successful, which we attribute in large part to the extensive communication, collaboration and careful planning among CSB staff, NVTC staff, family members, and providers throughout the discharge planning process. Developing thorough and thoughtful plans of care, ensuring all resources are identified and in place prior to transitioning, and implementing strong systems of accountability are other key ingredients for success.

I want to leave you with two short success stories:

In April 2013 our CSB transitioned a person from NVTC who has a profound level of ID, autism, behavioral challenges (including PICA) and some medical issues. This person was transitioned into the community via Money Follows the Person (MFP) funding. The residential provider has nursing staff to monitor his health challenges and the day support provider has expertise in managing challenging behaviors. In addition, behavioral consultation was obtained from a third private provider. This individual is accessing his necessary medical care in

the community, including psychiatry and an ear, nose and throat specialist. He enjoys regular visits from his family, enjoys celebrating holidays and birthdays, swimming at the local recreational center, and became a member of a community church and was baptized several months after moving into his new home.

In August 2014 another person with very high needs moved into a community group home in our County. He is diagnosed with a profound level of ID, spastic quadriplegia, dysphasia, epilepsy, and congenital heart disease. He must use a gastrointestinal tube for feeding and has a history of being prone to pneumonia. Both his residential provider and day support provider have nursing services on staff. He receives the following specialty medical services from community providers: endocrinology, gastroenterology, neurology, dermatology, pulmonary and nutrition. He enjoys taking walks in his neighborhood, movies and shopping. His grandparents visit him frequently and when they are away from the area, a family friend checks in to visit and to make sure he is okay.

Thank you again for this opportunity to speak today and thank you for your service to all the citizens of the Commonwealth.

September 2, 2015

Joint Statement of The Arc of Northern Virginia and
Parents and Associates of the Northern Virginia Training Center to
Members of the Special Joint Subcommittee to Consult on the
Plan to Close State Training Centers

September 2, 2015

Thank you for your service on this Subcommittee. My name is Rikki Epstein. I am Executive Director of The Arc of Northern Virginia. I am delighted to be joined today by Jane Anthony, Co-President of Parents and Associates of the Northern Virginia Training Center. We appear today on behalf of organizations in Northern Virginia that represent individuals with Intellectual and Developmental Disabilities (I/DD) and their families. Today, we share a common interest in seeing that both the Department of Behavioral Health and Developmental Services (DBHDS) plan to implement the Settlement Agreement and the quality assurance provisions of SB 627 are carried out in the best way to meet the needs of Northern Virginians.

Specifically, we believe success requires three things:

1. Revise the DBHDS Trust Fund provisions to assure that the revenues from the sale of the Northern Virginia Training Center (NVTC) property are used to serve the needs of people with I/DD who reside in this region, and assure that the proceeds from the sale of other Training Centers' property go to support people in their respective regions;
2. Make sure the outcome of Medicaid Waiver Reform is a system that provides funding that is appropriate to each region of the State. Equity requires that sufficient funds be made available so that people with I/DD, either moving from NVTC or from the waiting list, are able to find local placements in Region II to remain in contact with their families and communities of natural supports, just as people with I/DD from other regions of the Commonwealth have the resources to remain in their local regions; and
3. Assure that all people with I/DD who receive services from the state benefit from a robust quality management system based on scientifically sound methods and establishing performance baselines to ensure people's health, safety, and well-being.

The Trust Fund. As the planned closure deadline for NVTC fast approaches, we have some increasingly urgent concerns about the current Trust Fund that is slated to receive and distribute proceeds from the sale of the NVTC property. As the language for the Trust Fund is currently written, the funding from the NVTC sale could be used in areas of the state outside Northern Virginia or could be diverted for other purposes entirely.

The Trust Fund must assure regional equity. As you all know, Northern Virginia is a more expensive area to live in than many other parts of the State. The service providers and Community Services Boards in this area have consistently said that the very high cost of living in the Northern Virginia region is a substantial hurdle to

opening more residential settings, especially on tight timelines. Statewide, the waiting list for community Waiver slots is well over 10,000 people, almost exceeding those receiving waiver supports, and in Northern Virginia the waiting list for ID Waivers already exceeds the number receiving supports by 34%. Clearly, there is a need for start up money to serve people with disabilities within all regions and especially Region II and for revisions to protect the Trust Fund assuring that it serves its intended purposes.

NVTC families have researched the history of the creation of NVTC and affirmed that many of their families were involved in donating some of the land NVTC was built upon. Their very purpose was to enable the State to build a local facility so that they could spend more time with their loved ones with disabilities. Out of a basic sense of fairness for those families and the thousands of Northern Virginians with I/DD on waiting lists for services due to funding shortages, we ask you to ensure that the DBHDS Trust Fund is protected and used as intended.

In protecting the Trust Fund, this Subcommittee and the General Assembly at large will be taking a big step towards fulfilling the promise of appropriate, quality care in the community and offering choice for people with intellectual and developmental disabilities. To secure these protections, we request that you take the following actions:

- Reestablish the Trust Fund through a constitutional amendment that requires funding derived from the sale of Training Center lands be used only for people with I/DD **in the region from which funding originated** for one-time needs such as start-ups and unforeseen emergencies; and
- Require that DBHDS submit a clearly detailed report annually to this Subcommittee and the General Assembly on all deposits into the Trust Fund and all expenditures.

Funding Medicaid Waiver Reform to Assure Local Placements. With the new reforms not scheduled to be implemented until after the March 2016 closure date for NVTC, local providers have been reluctant to assume the long-term obligations for the residents with the most significant disabilities leaving NVTC and those coming off of the waiting lists. To underscore this concern, there have been anecdotes of people opting for placements outside the region in order to get the services they need. According to the Department's data, only 24% of those discharged from NVTC in 2015 found local placements in contrast with 74% for the rest of the state. A recent DOJ letter supports this conclusion. Given the importance of keeping those with I/DD near their families and natural supports, we request that the Subcommittee:

- Secure from DBHDS the information necessary to understand the magnitude of this problem so that the General Assembly will be better able to understand how Medicaid Waiver Reform must be crafted to meet the needs of Northern Virginians.

Establish a Quality Management system that assures the safety, health and integration of people with I/DD. The settlement agreement contains detailed

requirements for Virginia to collect new data, to greatly expand its quality management for those in the community, and to report on instances of mortality and significant harm to those who transition from Training Centers into the community. In addition, SB 627 requires that DBHDS certify that the residents of Training Centers who move into the community receive supports and services that are “comparable” to the ones being received in the Training Center. These basic provisions of the settlement agreement and SB 627 are essential for the health, safety and well-being of those with I/DD receiving waiver supports in the community. They will benefit both those moving from the Training Centers and off the waiting lists. Unfortunately, the necessary quality management measures do not track the closure schedule for either SVTC or NVTC or with the schedule in the settlement agreement. It is vital that DBHDS expedite quality management employing scientifically valid data and methods.

To enhance quality management, we ask that the Subcommittee request DBHDS to take the following action:

- Describe and report to the Subcommittee and the public, within 3 months, the scientifically valid performance measures DBHDS plans to use to address each important aspect of health, safety, and well-being for people with intellectual and developmental disabilities currently served by DBHDS. This report should include an analysis of mortality data for individuals who have left Training Centers.

Thank you for your dedication to ensuring that all individuals with intellectual and developmental disabilities in Virginia receive the supports and services they need to live healthy, safe, and fulfilling lives in Virginia.

Testimony before the Special Joint Subcommittee to Consult on the Plan to Close State Training Centers

September 2, 2015

**Judith Korf, Co-President, Parents and Associates of the Northern Virginia
Training Center**

I am Judith Korf, Co-President of Parents and Associates of the Northern Virginia Training Center. My 44 year old son Adam has autism and severe behavioral issues including elopement, property destruction, and aggression toward others. He has resided at NVTC since he was admitted in November 1998 on an emergency basis after a group home placement failed.

In February 2012 I began searching for a home for Adam outside NVTC. I have met with providers including Community Residences, Good Neighbor, Chimes, Community Concepts, Total Quality Residential Services, AdvoServ, Insight, and most recently Community Systems. I toured two ICFs operated by Community Residences, and at least one waiver home operated by each of the other providers except Good Neighbor and AdvoServ. I found that most ICFs are geared for the medically fragile, while most of the waiver homes could not provide a sufficiently secure environment to keep Adam safe, or to prevent harm to persons and property around him. The first provider that seemed up to the challenge was Insight, which has a group home in Manassas especially designed for persons with challenging behaviors; however, after meeting and assessing Adam, Insight declined to offer him a place in that home. Two days ago I visited a Community Systems group home and had extensive discussion with management and staff. Community Systems is interested in establishing a new waiver home to support Adam and some of his NVTC roommates, tailoring the physical layout and the supports for a specific group and seeking extensive input from the families. I am somewhat optimistic that Adam may find a home with this provider, but it is too early to tell. If not, the clock continues to tick loudly, and it seems increasingly likely that Adam will move to the Central Virginia Training Center in Lynchburg, some 160 miles from here.

Appropriate residential and day supports have not grown in this region at a rate that can accommodate those expected to leave NVTC by the end of this year. The new waiver is still undefined, discouraging providers from expanding in this most expensive part of the state. Some families have accepted placements on the fringes of Region II, and others have gone outside it. The promise that each family will have three viable options to choose from appears to have gone by the wayside; these days many of us are desperate to find just one. With CVTC being the last resort, it seems that the DOJ objective of greater community integration and proximity to families has been abandoned. For some of us the result may well be the exact opposite.

Special Joint Subcommittee to Consult on the Plan to Close State Training Centers

I do not want to take up too much of your time because I know you had a long day. I am very aware that NVTC is closing, although I strongly feel that the “settlement” agreement does not say that ANY training center needs to be closed and that the DBHDS (central office) has not even considered any other options or compromises and that this land provides the Commonwealth “solutions” to many of its problem areas. However, my family, on behalf of my brother, as well as many other families are being strongly encouraged into accepting a placement that we can only HOPE will meet the needs of our loved ones today and in the future. However, as indicated by the appointed “independent reviewer” as well as the Department of Justice there are significant issues with the lack of resources in Northern VA and a lot of families have had to place their ones more than 50 miles away from them. We feel incredibly fortunate that my brother is going to hopefully be placed in Arlington. BUT we have not seen the “brick and mortar” yet and don’t know if this will be a “comparable, appropriate and good” fit for him. However we are optimistic and willing to work with ALL the concerned parties to make this work for my brother because the other option is CVTC which is 160 miles away and closing in 2020.

Therefore, I am asking for following:

1. Documentation that ALL the proceeds from the sale of the land will go onto a “trust fund” to be used exclusively for the improvement & development of resources & services in Northern Virginia? And, not what happened to the 5.4 Million Dollars from the sale of the Chesapeake Training Center which went almost directly into a "one-time only" budget shortfall.
2. Documentation that the “new revised” waiver, that has NOT been completed and won’t be available until 2017, will be funded completely for a minimum of ten years which hopefully will provide my brother and his colleagues from NVTC stability as well as their providers?
3. How can over 80 acres of land off Braddock Road only be worth 24 million dollars? We need an OPEN, TRANSPARENT and TRUE accounting. Please remove the vagueness and mystery surrounding the future of this exceptional resource, the NVTC land and facilities. Maybe, there should be examination as to whether the sale should be converted to portions and leases and have all the “buyers” being named clearly showing no conflict of interest? Furthermore, couldn't we solve a multitude of needs by holding onto a portion of this property for some unique resources like a perfectly usable Gym, a Therapeutic pool, only one in Northern Virginia, and Dental facilities to name a few?
4. What are the real "choices" and flexibility of movement between "Placements" as we move

into the future? Will we simply NOT have ICFs available in the very expensive NOVA area? How does banishing our family members to distant facilities protect their civil liberties and improve their actual quality of life choices and safeguards? What is the detailed “PLAN B” if these placements don’t work for my brother or other “transitioned” residents from NVTC.

Thank you for your time. I hope as legislators you remember the “stress” and “heartache” that this process has caused. And, remember that you may have to “place” a loved one into a system that, although trying, is FAR from ready or prepared. The central office has appeared to have its own agenda from day one and has NOT taken into consideration what ALL of the EXPERTS are telling them. This mad dash to evict, close and sell the Northern Virginia Training Center is a tragic, desperate budget move that deserves careful and sincere public scrutiny. Obviously common sense is not that common---hopefully you can restore some of that.

Respectfully Submitted,
Donna McHugh

Statement of Peter Kinzler

Father of NVTC Resident Jason Kinzler

Before the Special Joint Subcommittee to Consult on the Plan

to Close State Training Centers

September 2, 2015

Members of the Subcommittee, I appear today as the father of Jason Kinzler, who has resided at NVTC for over 35 years and will soon be moving to a Waiver group home. I am also speaking as a person who served on the SB 627 work group and a participant in the meetings with The Arc of Northern Virginia to assure quality community options in the region.

My plea is simple – please assure that the combination of bridge funding and the new Waiver are sufficient to assure that people leaving NVTC can remain in their communities of “natural supports,” as intended by the Settlement Agreement. For most NVTC residents, that community consisted of family members, the hundreds of people who volunteered at NVTC and others in the surrounding area who befriended the residents during their trips into the community.

Publicly available data and anecdotal information indicate this is frequently not the case. DBHDS data show that those discharged from NVTC during FY 2015 were only about *one-third* as likely to obtain a local placement as those discharged from Virginia’s other Training Centers. Northern Virginians should not – in fact, cannot legally – be deprived of the same rights as others just because we live in a more expensive area.

The main problem stems from the fact that the necessary funds for ongoing services are supposed to come from the new Waiver and it won’t be in place until after NVTC is scheduled to close. Thus, providers are being asked to extend services for seriously disabled persons without knowing if the follow up to bridge funding will be sufficient to cover their costs. This is why the Northern Virginia CSBs and private providers for years urged DBHDS not to close NVTC until the funding was in place.

NVTC families also shared their difficulties with DBHDS, citing examples of recommended placements that were either entirely inappropriate or at a considerable distance away.

Placing my son Jason has been a challenge. For a long time, no provider in Fairfax County was willing to take him because the funding was not sufficient to cover the high cost of meeting his needs. Finally, Insight of Prince William County agreed to accept Jason. We are grateful to Insight and confident they will provide excellent care. But why were we forced to move Jason about twice as far away to find a good placement?

If there is a serious problem finding local placements, why are some families accepting ones that are out of the local counties? The answer is simple. Families, most of whom are quite old,

preferred a community placement at some greater distance to the only other option offered by DBHDS, a move to CVTC. That would have meant rarely being able to see our loved ones. Families would not have faced this dilemma had DBHDS simply tied the closure schedule to the standing up of local community services.

To provide the best outcome going forward, I endorse the joint statement read earlier calling for DBHDS to provide this Subcommittee with the information necessary to understand the magnitude of this problem so the new Waiver can be crafted to assure sufficient funds for people moving from NVTC and the waiting lists to find placements in Region II so they can remain in contact with their families and communities of natural supports.

Testimony before the Special Joint Subcommittee to Consult on the Plan to Close State Training Centers

September 2, 2015

Robert Anthony, Ph.D.,

Board Member, Parents and Associates of the Northern Virginia Training Center

Good afternoon, I am Robert Anthony, and my concern is no longer about keeping NVTC open, that issue has been decided. Rather, my concern is with the delayed application of systemic-level analysis of trends and patterns as called out in the Settlement Agreement's quality management provisions, overdue since June of 2014. The story of applying comparative analysis to mortality data illustrates this concern.

In support of the Senate Bill 627 Work Group, the DBHDS did tabulate deaths and resident populations and an analysis claiming that these data showed safer outcomes in the community. However, my correct analysis of those initial data revealed the opposite: the mortality rate among those who left the centers was double that of those who remained. The Commissioner doubts this result, and it is possible that some miscategorization among these initial data could have led to this result. Yet at minimum, we families had hoped the Department would have taken this warning seriously enough to perform the appropriate follow up analysis, but after more than a year's time it has not.

Virginia has the raw data to perform the simplest of all systemic-level analyses, a comparison of the mortality rate among those who have left Training Centers over the last 4 years with those who have remained. Such an analysis would give substantial scientific evidence for whether those who have been discharged are receiving "comparable care" according to the spirit of the SB 627. It would also provide an important baseline expectation for mortality rates among our most vulnerable citizens with Intellectual and Developmental Disabilities who live in the community.

We recognize that scientific analysis of systemic-level trends or patterns poses a dilemma for DBHDS. A negative result from such an analysis typically does not diagnose the underlying causes of any problem that might be detected. Hence any negative result puts the Department in the awkward position of declaring 'there is a problem' but not knowing what it is, or what to do about it. Systemic-level analysis is intended to raise the alarm and to focus follow on analytical effort to look for the root causes. This dilemma is built into any effective Quality Management process.

Please resolve this dilemma by requesting independent systemic-level analyses of quality management data. In particular, we ask for an immediate comparative analysis of mortality. In addition to verifying safety or leading to a reduction of needless deaths, such an analysis would benefit everyone in the community by establishing a performance baseline of expected mortality going forward.