

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

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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.