Comparison of Training Center Expansion Options

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For the Parents & Associates of the Northern Virginia Training Center

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SB627 called for the creation of a work group of interested stakeholders to provide the Administration and the General Assembly with "options for expanding the number of Training Centers that remain open, in whole or in part, in the Commonwealth." The need for the group flowed from three facts: (1) the Settlement Agreement with the Department of Justice recognizes the legal rights of residents or their Authorized Representatives (ARs) under Virginia law to remain in a Training Center,[1] (2) the number of persons intending to exercise that option far exceeds the Training Center capacity set aside in the State plan to implement the Agreement,[2] and (3) there is insufficient community capacity to accommodate even those willing to consider community placements. After four sessions, the work group was unable to reach consensus, but it was able to identify six options for expanding Training Center capacity and six factors that are key to distinguishing among these options.

The composition of the work group and the lack of definitive data contributed to its inability to recommend one or more options. The wide range of viewpoints held by work group members both enriched the discussion and, at the same time, made agreement impossible. At the meetings, family members of Training Center residents reported their high level of satisfaction with the care their loved ones with Intellectual Disabilities (ID) have received and the importance of long-term staff and the wide variety of services that Centers provide to maximizing their quality of life. Advocates for community care for people with ID and DD (Developmental Disabilities) made compelling points about the need for more and better community services, particularly to reduce the long waiting lists. At the same time, the community representatives' opposition to the existence of Training Centers made it impossible for them to support the task of the work group – to "consider" options for expanding the number of Centers to remain open. We believe the solution to meeting the legitimate needs of people with ID and DD in the community lies not in overturning the legal rights and care needs of Training Center residents, but in expanding services for the community to bring the Commonwealth's spending on such services –

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[1] Section IV(B)(10) of the Agreement states that: "in accordance with Virginia Code 37.2-837(A)(3), for as long as it remains effective, no resident of a Training Center shall be discharged from a Training Center to a setting other than a Training Center if he or his Authorized Representative chooses to continue receiving services in a Training Center."

[2] The State Plan calls for Southeastern Virginia Training Center (SEVTC), with a capacity of 75 beds, to remain open for those who wish to remain in a Training Center. While it is not clear how many people will exercise the right to remain in a Center, there are strong reasons to believe SEVTC will not be large enough to accommodate them. SEVTC is already full to capacity and the most recent survey by DBHDS, conducted in the Fall of 2013, found that over 400 families were opposed to community placement. Furthermore, more than 100 families at Central Virginia Training Center (CVTC) have signed statements exercising their right to remain in a Center.

47th in the nation[3] – more in line with its per capita income – 8th in the nation.[4] That task, however, was not the charge of the work group and should be addressed separately in a different forum.

In addition, the work of the group was hampered by the lack of sufficient data to resolve many important factual issues. Therefore, this analysis focuses on the laws governing decisions as to the future of Training Centers and the logical processes that flow from those legal obligations, as well as broad principles we think should guide those making a final choice among the options. We also identify areas of uncertainty, some of which will remain for some time, and propose a strategy for adjusting plans as the facts emerge so as to balance resources and costs according to individual need.

Of the six factors, the group recognized that the first, and arguably the second as well, were important statements of law that should inform the decision makers but, as such, have little relevance to distinguishing among options. The other four factors distinguish among the options and are discussed here to clarify the meaning of the brief comments included in the comparison matrix.

Factor 1: The Commonwealth must provide comprehensive information to the Authorized Representatives of Training Center residents

The work group chose to give a weight of zero to this factor, recognizing that it is a legal requirement, hence should not distinguish among the options. At the same time, it raises important policy and practical considerations.

This factor identifies the requirement to provide current Training Center residents or their ARs with information about "**opportunities** to live in the most integrated setting appropriate to their needs,"[5] (emphasis added) while acknowledging their right to know that they can choose to continue a Center placement. It also implies that the Commonwealth provides adequate Center capacity to support all residents choosing to continue to live in a Center, although the number who will actually choose Center placement is not yet known.

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[3] University of Minnesota: Sheryl Larson, et al. *Residential Services for Persons with IDD: Status and Trends Through 2011*, University of Minnesota, 3013. The ranking is for utilization rates per 100,000 of state population, including Home and Community-Based Services (HCBS) and 4 – 15 bed Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID). Regardless of where people with IDD reside, whether in the community or in the state-run Training Centers, Virginia's commitment is not commensurate with its income level. Previously, data for 2009 showed that Virginia's expenditures per $1,000 of personal income ranked 43rd in community expenditure, 25th in institutional expenditures and, most importantly, 45th overall. David Braddock, et al., *The State of the States in DD 2011*, University of Colorado, 2011.

[4] Bureau of Business & Economic Research, UNM / http://bber.unm.edu/econ/us-pci.htm, Last Revised 4/2/13.

[5] The meaning of this phrase is an example of the disagreement among the work group participants. Community advocates believe the community is always the most integrated setting, while Training Center advocates, such as ourselves, believe that this is a factual matter for each person. While the *Olmstead* decision properly interpreted the Americans with Disabilities Act as encouraging community living, Justice Ginsburg qualified that broad statement with the need to examine each person individually: "Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution." 119 S. Ct. at 2189.

Thus, each option must be flexible enough to accommodate the number of current Center residents who will remain. This leads to the need to answer three key questions:

1. As a factual matter, are ARs being given adequate information to make informed, uncoerced choices as to residency? This is a matter of making sure DBHDS not only informs the ARs of the right to continued resident care in a Training Center (not necessarily the one in where the resident presently resides), but also of the differences between residential options, and does so in such a way as to afford a free choice. While this requirement appears obvious on its face, many ARs have reported feeling highly pressured to move residents into the community. Meeting this standard will enable DBHDS to get an accurate count of how many people wish to remain in the Centers.
2. How might the availability of a wide array of quality community options affect the number choosing to remain in Training Centers, recognizing that proximity to family is a major consideration for most families?
3. Can the option be scaled to provide comparable care and sufficient capacity to serve the as-yet-unknown final census of those choosing Center placements?

Factor 2: Maximize the individual's health, safety, and quality of life in the chosen setting

The work group applied a low weight (15%) to this factor because it believes that all options must satisfy this factor. SB627 memorializes this factor with respect to residents who are considering moving from their existing Training Center to either the community or another Training Center. It does so by requiring DBHDS to provide written certification that a resident will receive "comparable" care in the new setting. We believe that people with ID in community residences or on waiting lists should also be entitled to such quality care. This factor does come into play, however, when a particular option might face challenges in meeting this standard of care in a particular region of the State.

At the time of this writing, DBHDS has yet to define the standards for judging "comparable" care. Therefore, we set forth what we see as the key principles for determining comparable care that will serve as the basis for comments on the differences among the six options.

The Independent Reviewer and several quality providers in the community agree that the following are several of the key conditions for quality care:

1. *Having a stable, caring environment.* The first principle is that it is central to health, safety, and quality of life to have a stable, caring environment that values the individual and helps each individual engage in life's activities to the extent of their abilities. For those who are highly dependent upon others to accomplish these objectives, the organizational culture of the residential provider is often a matter of life-or-death.
2. *Staffing hours per individual per year*: Research findings reveal thresholds below which health outcomes deteriorate and above which more staffing yields no discernable benefit.[6] While we do not know what these thresholds are for

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[6] Feuerberg, Marvin. *Appropriateness of Minimum Staffing Ratios in Nursing Homes, Phase II Final Report*, CMS, December 2001.

individual Center residents with the complex needs, we can begin by asking whether the options offer similar staff hours per resident year as do the Centers.

3. *Cultivation and sustainment of staff skills and continuity of supports*: All quality providers recognize that continuity and skill of direct care staff are the foundation of health, safety and well-being of residents. Providers also recognize the need for I/DD specialists among doctors, therapists, and nurses. Some options face more challenges than others in providing this continuity and sustaining career paths for their valuable skills; for example, the community typically has twice the staff turnover rate as compared to the Centers.[7]
4. *Valid outcome measures*: Training Centers employ integrated treatment team approaches that examine all aspects of each resident's health, safety, and well-being. By contrast in the community, Medicaid does not reimburse providers for team meetings. Factor 2 also references "sentinel event monitoring." DBHDS is implementing such monitoring, but, for several years, DBHDS will lack the authority to collect all relevant information. More generally, DBHDS has yet to develop and implement effective risk indicators or outcome measures.
5. *Safety from emergency overload, error, abuse and neglect*: This consideration is especially important for individuals who are medically fragile or behaviorally challenged. They depend heavily upon having two awake staff on all shifts. While Training Centers meet this standard, even group homes with more than four residents cannot afford this coverage under the present Medicaid waiver (see Factor 4). Also, proximity to family and other advocates for the individual is a natural monitor of health and safety (See Factor 6).

An early indicator of whether the community is providing comparable care is the mortality rate among those transitioning to the community relative to that for those who remain in the Centers. At the work group meetings, DBHDS explained it did not have the analytic staff to perform a mortality analysis. Instead, it provided raw data and asked the group to draw their own conclusions. Dr. Robert Anthony, who holds a Ph.D. in physics and has years of experience in making such analyses, used the data to perform a preliminary analysis of mortality. While there are data and methodological limits, Dr. Anthony found *the data showed a mortality rate among those transitioning to the community to be double that among those remaining, and the odds of this being a random event are 1:40.* This result is deeply troubling and warrants an immediate effort by the State to secure all the data necessary to perform a comprehensive analysis to understand the reasons for this result.

Factor 3: Provide full and timely access to comparable and appropriate services and supports

Factor 3 emphasizes accessibility to comparable care. Again, this option was assigned a small weight (15%) since all options should offer timely access to appropriate services, although some options achieve this more easily than others.

Training Centers provide on-campus ready access to prescribed care, but smaller ICF/IID and waiver settings encounter several barriers to accessing services:

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[7] Hewitt, Lakin, and Larson. *The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities*, Report to Congress, January 2006.

1. *Limited on-site availability of health care professionals*: Typically, monitoring or treatment must be prescheduled visits and emergency responses consist of a phone call to a nurse and a 911 call for transport to a hospital emergency room.
2. *Travel time delays for professional services:* The dispersed locations of small ICFs/IID and waiver sites necessarily create a travel time overhead on professionals' valuable time for on-site visits and short but frequent treatments tie down the care giver to an isolated location.
3. *Lack of availability or caps on access to important health services for waiver placements:* Among such missing or capped services are dental care, skilled nursing facilities, observation care units, therapeutic equipment and facilities, complex assistive technology, and health professional time for team management of individual conditions.

The potential health consequences of providing supports to dispersed sites depend upon each individual's needs, vulnerabilities, and the predictability of acute events. While the work group did not have information about the distribution of such critical characteristics among the Training Center population, other sources reveal suggestive information. For example, all residents of NVTC have two or more diagnoses in addition to ID[8], while the local Northern Virginia Community Services Boards (CSBs) reported that 71 percent of NVTC residents had a diagnosis of profound ID, as compared to only 9 percent of those served in the community by the CSBs.[9] Thus, averages across these very dissimilar populations cannot be compared. Lack of information about the access to services for this population in community settings prevented accurate judgments on the adequacy of each option.

Factor 4: Minimize the cost of ongoing operational costs of serving individuals while providing comparable care. If Training Center care is more costly, would it have a negative impact on access to services for those being served in the community?

The work group recognized that operating costs represent a significant fiscal commitment, so this factor received the highest weight, 30 percent.

The group debated intensely whether the costs of Training Center care have a negative impact on access to services by those on community waiting lists. While everyone agreed that more resources are needed to serve those on the ID and DD waiting lists, a great deal of confusion remained over both the cost of eliminating the waiting lists and the relevance of the waiting lists to the choice among options. As we understand the situation, DBHDS will provide an updated assessment of the costs of eliminating the waiting lists, taking into account continued growth in demand for I/DD supports, direct Medicaid payments, and other costs. Here's what we do know: (1) the State budget to implement the Agreement provides funding only for the number of slots required by the Settlement Agreement, (2) which are fewer, on average per year, than the number funded

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[8] Diorio, Mark, *Northern Virginia Training Center: Presentation to Senate Finance Committee,* December 5, 2011, p. 7 (Demographics).

[9] Attachment C, Data Sources, Level of Intellectual Disability, developed by the local CSBs for the Northern Virginia Regional Plan (Recommendations for service delivery within Region Two to enhance services through collaboration for individuals with intellectual disabilities), May 6, 2010.

by the General Assembly between 2003 and 2010, (3) which were not nearly enough to keep up with the annual growth in the waiting lists, as estimated by DMAS in 2009, (4) which was lower than the actual growth since then. Thus, any forward looking analysis that takes into account the likely annual increases in the number of new people signing up for services will show that the waiting lists will be *substantially longer* by the end of the Agreement than they were at the beginning.

Independent of that analysis, as indicated, the Settlement Agreement establishes a minimum number of waiver slots the Commonwealth must fund, and DBHDS has submitted budgets to fund those slots. However, those budgets do not provide for additional slots to serve others on the waiting lists, *regardless of how many choose to continue Training Center care*. Thus, there is no connection, legal or otherwise, between how many people choose Center care and the reduction in the size of the waiting lists. Virginia is obligated both to respect AR choices of Training Center care and to fund the number of waiting list slots included in the Agreement. Should fewer ARs choose community care, it might reduce somewhat the cost to the Commonwealth, but, based on the DBHDS budget, it would not fund one additional waiting list slot. The only way to reduce the waiting list is to provide additional funding beyond that required by the Settlement Agreement and included in the DBHDS budget to fund it.

That said, it is important to analyze the different cost options to meet the important goal of this factor to maximize efficiency and, thereby, reduce the cost to the State of whatever option is pursued. Here, too, there was much debate in the work group over costs. Because DBHDS has yet to define comparable care, the Department analysts had to make many assumptions as to cost. As they said during the last work group session, the lack of a definition of comparable care and the shortness of time to prepare the analysis may have led to some assumptions that warrant modification or qualification.

Training Center costs, at least with respect to existing costs, are fairly easy to estimate. DBHDS simply determines the per-resident cost by dividing the total cost of all contributions to supports by the number of Center residents. With a decline in census, Centers must still maintain a variety of types of staff along with the overhead of a fixed plant and grounds. Thus, without other assumed adjustments per-resident, costs rise. If, on the other hand, the DBHDS analysis had assumed savings by sharing some of the property or staff skills, for example, with a Veterans' health center, then Center costs might decline more in proportion to census. Also, were DBHDS to assume that medical and therapy services were provided by contract relationships with the DDHSN or local ICFs (as DBHDS proposed for the options with smaller ICFs/IID), this too might enable per-resident costs to remain nearly constant as Center census varied.

The far more difficult task was estimating the cost of comparable care in the community. Beyond the central question of what constitutes comparable care lies the tricky exercise of compiling cost data for the waiver placements that appear in a plethora of distinct budget categories and are generally reported as averages that include many who have much less severe conditions than do Center residents. To illustrate the confusion this creates, consider that DBHDS offered the work group transition waiver cost estimates based on the average for the residential waiver, $68,000. This figure is clearly far too low, as one can determine by just a few facts: (1) as discussed above with regard to Factor 3, the average Training Center resident is far more disabled than the average person in the community (although there are people with similar disabilities living in the community); (2) the January 2012 HHR budget for the Settlement Agreement was based on an assumption that all Training Center residents would move into waiver homes and at an average cost of $105,860 per resident; (3) the DBHDS sample of 57 people who transitioned from Training Centers to waiver homes in FY 2012 found an average waiver cost of $140,611 per resident; (4) the $68,000 assumption does not include the cost of the new waiver, which will provide more supports for people with greater disabilities; (5) the figure does not include the costs of all services paid for by Virginia taxpayers through other State budgets; and (6) the estimated cost of providing care in the community did not include the cost of those who transitioned into more expensive community ICF/IID or Nursing Facility placements.

Amid all this confusion, the following facts and principles offer some guidance for comparing options. Staffing accounts for 80 percent of operating costs at both Training Centers and waiver group homes. The remaining 20 percent goes toward maintenance and transportation. The following principles should apply to staff expenditures:

1. If the hours of staff time per individual were approximately the same for Training Center and waiver placements, and those staff had comparable wages and skills, then the full cost of comparable care in either setting should be quite similar.
2. Conversely, if the community could implement a more cost-efficient system of supports, so should the Training Centers be able to adopt similar cost-saving measures.
3. If in some situations CMS rules for ICF/IID operations require higher standards or additional types of services than do waiver settings, then how can a community placement that doesn't meet those standards provide comparable care?

While there are some fixed administrative costs at a Training Center, they should not be so large as to yield a cost significantly greater than the cost of comparable care in the community. Furthermore, the DBHDS did not estimate all of the costs of administration for comparable care in waiver placements.

Factor 5: Maximize efficiency and overall affordability of the care system with regard to financial impact, system capitalization, and redirecting savings to improve the system

These one-time costs were weighted 15 percent. They arise from the occasional costs of the transition process, of buying land and properties, of upgrading properties, and of any future transition as the system of supports for those with I/DD continue to evolve. It also includes siting, permits, and licensing that often pose long delays.

The DBHDS is responsible for these costs at Training Centers and can explain them in detail, although the initial cost analysis included some inconsistencies concerning which buildings remain open and how future maintenance is reported. By contrast, the per-resident costs for acquiring ICF/IID homes comes out to be less than that for renovations at the Centers without an explanation why this should be so. Although the cost of acquiring waiver homes was not reported, the local CSBs in Northern Virginia estimated their costs at about only 20 percent lower than that for an ICF/IID home of comparable capacity. Finally, we have been told that even with the funding, permits and licensing can take two or more years to acquire.

The NVTC campus offers many services that are either unique to its region, difficult to find in the community, or not covered by Medicaid. Whether to preserve these facilities for the community is an important policy decision. Here are a few examples of the unique features at NVTC: the dental clinic, the Observation Care Unit, the only heated therapeutic pool in Fairfax County, an all-weather outdoor court, a gymnasium for events and client recreation, a rehab shop to build or modify equipment tailored to individual needs, skills training for those who cannot find employment, a safe and restful nature walk area, a sensory stimulation room, and examination and therapeutic equipment.

If the I/DD census were to continue to drop, these and all the other NVTC campus facilities and capabilities might remain useful to serve a multitude of other disability communities. For example, everyone anticipates an increase in demand for the most intense supports as residents with I/DD in the community age, as the DD epidemic continues, and as more people with other forms of mental incapacity need services.

Factor 6: Value geographic proximity to families, services and supports, and greater access for individuals to their local community

The work group assigned this factor the second highest weight, 25 percent, as being close to family and other “natural supports” is so important. Over 40 years ago, Virginia established regional Training Centers so that residents could be closer to their families and community ties. More recently, the Settlement Agreement requires Virginia to provide opportunities for Center residents to find placements in the community, the local community near family and friends. To meet these concerns, and to be acceptable to us, an option must assure that NVTC residents receive comparable care in the local region, whether the care is provided at NVTC, a local ICF/IID, or a local waiver home. Northern Virginians should not be deprived of the ability to see their loved ones regularly just because we live in a more expensive area of the Commonwealth.

Conclusion: Implement a step-by-step adaptive strategy to cope with the present uncertainties

The “risks” line of the associated matrix of comments that assess the six options according to the six factors illustrates the many unknowns related to one or more of the options. We don’t have enough information to evaluate whether they will work.

The “opportunities” line raises even more unknowns. For example, there are opportunities to use the unique staff skills and facilities of today’s Centers to serve other populations with ID, but these possibilities have not been aggressively pursued to determine whether they could succeed. Also, smaller Centers or constellations of smaller ICFs/IID might be acceptable to all or most of those choosing to remain in Centers, and smaller ICFs/IID or more robust group homes might be able to provide comparable care. These ideas should be tested.

What we do know is that closing Training Centers will eliminate some valuable, proven unique capabilities for people with ID, such as the Skilled Nursing Facility at CVTC, access to of a wide range of medical professionals at SWVTC otherwise not available in other areas of the region, and the unique services discussed above and the flexible capacity at NVTC that acts as a safety net for the underserved community in Northern Virginia. What we don’t know is whether these highly valuable capabilities can be preserved or replaced with comparable options if the Centers close.

These and other uncertainties cloud any definitive choice of an option at this time. Yet a systematic and adaptive step-by-step strategy should lead the Commonwealth to an evolved system of supports for those with I/DD that balances access to essential protections and services, community integration, and costs according to individual need. We recommend the following approach to achieve these values:

1. Immediately perform a comparative mortality analysis to determine whether the current transition processes are or are not generating excessive mortality.
2. Explore all of the uses for existing Training Center staff skills and facilities for use now or in the future in serving various populations with disabilities. Determine whether there are promising prospects for effective and economical joint arrangements with other disability groups.
3. Explore the capabilities of smaller, more dispersed ICFs/IID. Can they serve those with the most challenging needs, and do they offer a means of stabilizing professional career paths for I/DD specialists? If promising, implement a spectrum of appropriate types and sizes of ICFs/IID.
4. Continue to implement and refine the Quality Management tools, the REACH and DDHSN programs, and the new waiver and its associated eligibility process until these form a robust system of supports proven by evidence-based methods.
5. Implement a separate initiative to reduce the ID and DD waiting lists.

Each of these steps should be accompanied by a forecast of potential future needs and a thorough accounting of all costs to the taxpayers, and pursued with scheduling paced by meeting maturity milestones.