

2017 VOR State Report for Virginia

The Department of Behavioral Health and Developmental Services continues to press ahead with their plan to close two of the three remaining Training Centers in Virginia. These closures were not required by the Settlement Agreement with the Department of Justice, but both DOJ and the court's Independent Reviewer are cheerleaders for closure. The DBHDS claimed that closures would free up resources to support more of those on our waiting list, but this has not happened as it continues to grow as before.

Meanwhile, there is considerable fallout from the closure process:

- Mortality had risen by 88 percent but recently surged even more, consequently DOJ is taking another look at this.
- The Supports Intensity Scale (SIS) is being used to assign each individual on waiver to a level of support, but this is a deeply flawed process and is being reviewed by another state agency.
- The dental services that were promised those leaving a Training Center are not yet adequate or stable.
- Regional Community Support Center (RCSC) services previously offered at each Training Center have reverted to whatever the community can provide, leading to important gaps. For example, try to get the services of an endocrinologist who takes Medicaid.
- After the closure of Northern Virginia Training Center in March of 2016, the parents and associates organization could not find enough traction for advocacy to keep meeting and subsequently disbanded.

On the positive side, the DBHDS implemented a Quality Management program although it currently lacks adequate analytical support and does not report either their data or conclusions publicly. We hope that with the support of VOR and DOJ we can convince the Commonwealth to hold itself accountable, especially to protect those who are most vulnerable as a result of their IDD and accompanying medical and behavioral complications. By having a credible independent analysis of needs and performance, the DBHDS should be more effective in focusing resources where needed and in its requests for funding from the legislature.

Mortality: According to the Settlement Agreement in effect thru 2021, the DBHDS must review and report all major harm and deaths of former Center residents to the court. However, these reviews are protected by HIPPA, and the Department does not publicly release summary statistics or analyses of consequences of closure. Nonetheless, a tragic surge in mortality among the

most vulnerable has caused DOJ to re-engage to take another look at mortality. Of the 28 individuals who left a Skilled Nursing Facility in our Central Virginia Training Center, 9 have died within about 15 months. Capitalizing on this opportunity, we updated our mortality analyses and sent them to DOJ. These gave even more arguments in support of our prior finding that among all the original five Centers CVTC residents had a uniquely high mortality rate. Furthermore, one of the two Centers already closed had had a surge in mortality rate of 2.9 times and the other had a brief surge of 3.8 times.

The SIS: By using the SIS as the principal guide to determining each individual's level of service, DBHDS has been "rebalancing" the system of supports – a process they believe will shave costs from the more expensive people on waiver to be able to fund additional waivers. But our analysis shows how misguided this is since the SIS scoring algorithm is mathematically inconsistent and miscategorizes about 20 percent of those with extraordinary needs. The legislature must also have been concerned since a budget amendment passed this year requires Department of Medical Assistance Services to review the use of the SIS. We are trying to get a representative on the Working Group advising this review.

Dental: Those who were being forced to leave their Training Center as a result of its pending closure were promised dental services if they chose a waiver placement instead of another Center. The DBHDS has been trying to replace the Center-based dental suites staffed by visiting dentists with contracts to fund local private dentists to also treat the former residents. Many of the former residents require full anesthesia for routine dental procedures, and few in private practice can accommodate this. To date there have been delays of 9 months before getting a tooth cleaning as well as the failure of a pilot project for cost reasons. Currently, new dentists are under contract, but the arrangements have yet to prove themselves.

Advocacy: Following the disbanding of the Parents and Associates of NVTC, those from Training Centers and others with comparable needs in the community have essentially lost their voice with the legislature. Some of the money the parents association left to Service Source, a day program and employment provider with a network of service advisors, will go to sponsor an annual report that focuses on the challenges and conditions of those who have the most intense needs and are most vulnerable to harm. We hope that these reports being produced annually will empower legislators familiar with our cause to implement meaningful and lasting oversight to track those who are most vulnerable, including our NVTC "Exiters." Otherwise, we fear there will be a slow erosion of funding and quality supports.