

In Memory of Doran

Doran died at 18 in an institution because the Virginia Developmental Disability (DD) Waiver system failed him. He was non-verbal, non-mobile, and medically complex and vulnerable. Had he been home, he might still be alive. At home, he certainly would have cost Virginia taxpayers less for better care! He should have been home.

Doran Needed: Private Duty Nursing (PDN) 24 hours a day, 7 days a week.

Doran's Challenge: In 2 years of approved 24/7 PDN coverage, he only received full coverage 2 weeks! The lack of 24/7 coverage resulted in him being admitted to an Intermediate Care Facility (ICF), where his medical conditions worsened immediately and substantially.

Within a month, a chronic repeat wound was substantially worse than it had ever been. It took 1½ years to heal and required invasive surgery. The wound had never taken this long to heal before nor required surgery when he was home, where his care cost Virginia taxpayers less.

A year later, someone broke 3 of Doran's ribs. His injuries were not discovered until 3 months after this person had injured him. Since the broken ribs went untreated and healed on their own, the pain every time he was transferred to and from his bed or chair must have been excruciating. No one had ever broken any of his ribs when he was home, where his care cost Virginia taxpayers less.

After a year and half in the ICF, Doran had lost 25% of his body weight and was hospitalized as a result. He had never lost that much weight when he was home, where his care cost Virginia taxpayers less.

As a result, Doran was given Total Parenteral Nutrition (TPN) and had to be discharged to a transition hospital because now even the ICF could not care for him. When much younger, he had successfully been given TPN when he was home, where his care cost Virginia taxpayers less.

Doran died in the transition hospital after being administered a combination of medications with a known risk of stopping breathing because he had been agitated through the night. When he was found unresponsive, he could not be revived. Hundreds of Doran's agitated nights were successfully managed at home, where his care cost Virginia taxpayers less.

Why was a Private Duty Nurse not managing Doran that night at home, where his care cost Virginia taxpayers less?

First, nurses are not paid enough. The Independent Reviewer for the U.S. Department of Justice (DoJ) settlement reported this problem.

“...individuals with IDD, who live at home, were not able to hire or retain nurses...to provide essential supports...individuals with intense medical...needs, could not fill support hours that the Commonwealth had approved...**people who are qualified will not work for such low hourly**



Doran Did Not Have Adequate Private Duty Nursing Services to Live a Life Like Yours!

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pay...”¹

“In...2018, the Commonwealth’s rate for “skilled nursing” [was]...70% of the “market rate” for 2015... **There was no evidence...that the implementation of redesigned waivers [had] improved the availability of in-home nursing services...In fact, the demand increased for...institutional level of care.**”²

Second, if you were already being paid less than you were worth, would you choose to do more work for no additional compensation?

No, and neither do nurses.

In Doran’s experience, fewer than 5% of nurses would do the harder work at nights, on weekends, and care for someone with his complex medical needs. That is not enough nurses to fill 14 shifts per week.

Request In Memory of Doran: Customized rates for PDN.

At the Fairfax Regional Budget Hearing 2 years ago, the legislators present were told Doran would be admitted to an ICF if he did not successfully receive the PDN he was authorized. To avoid institutionalization, it was requested the Department of Behavioral Health and Developmental Services (DBHDS) be required to implement the customized rate for PDN to support people with complex needs so he could stay home with adequate supports.

A customized rate for PDN was not made available, and PDN did not improve, so Doran was admitted to the ICF at greater cost to Virginia taxpayers.

At the Fairfax Regional Budget Hearing the next year, the legislators present were told Doran had been admitted to the ICF because he did not receive the PDN he was authorized. It was again requested the DBHDS be required to implement the customized rate for PDN to support people with complex needs so he could come home with adequate supports.

A customized rate for PDN was still not made available, so Doran stayed at the ICF at greater cost to Virginia taxpayers. He did not survive 2 years of institutionalization. He should have been home, where his care cost Virginia taxpayers less.

Doran’s death was avoidable, and his institutionalized care was expensive for Virginia taxpayers and resulted in worse outcomes. The claim from the transition hospital to insurance for his final 35 days of life was \$44,850.92. That comes to \$53.93/hour for each hour of a 24-hour day. It is \$16.51/hour more than PDN companies were reimbursed for a Registered Nurse (RN) under a Medicaid Waiver in Northern Virginia on 31 May 2019. Based on Doran’s complex needs, if those companies could have recruited and hired RNs with a customized rate closer to \$53.93/hour than \$36.88/hour, he could have received the care he required at home, where his care cost Virginia taxpayers less.

And Doran would probably still be alive.

Doran did not need to be in an institution, but the Virginia DD Waiver system failed him, and

¹ Report of the Independent Reviewer on Compliance with the Settlement Agreement United States v. Commonwealth of Virginia, 2017, 5.
² Ibid., 37.

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Virginia taxpayers paid more for that failure. If you want to reduce the chance Doran's peers suffer the same fate, in addition to increasing Waiver reimbursement rates in general, please request the Department of Behavioral Health and Developmental Services be required to implement the customized rate for PDN.

Thank you! If you would like more information, please contact Doran's grieving father, Erin Coady, coadye@alum.mit.edu . Thank you for your time and reading Doran's story!