

March 1, 2017

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Mother and Guardian of Taylor Andrew Bryant

Mother and Guardian of Tyler Jason Bryant, Deceased March 16, 2017

Mr. Chairman and members of the Committee:

I am the voice of twin sons, born as identical triplets at 29 weeks gestation, on Jan. 4, 1994. Two survived Neonatal ICU at University of Virginia hospital, discharged March 1994.. Extreme prematurity is the cause of their profound Intellectual disability, Spastic quadriplegia cerebral palsy, epilepsy, asthma and reactive airway difficulties.

We chose life instead of abortion on the day of delivery. Our family has never regretted Choosing life for our sons, despite its many challenges. Central VA Training Center In Amherst County, near Lynchburg VA was home by legal choice for 20 years.

Twins were forced out without consent by executive order of Acting Commissioner Jack Barber, DBHDS Virginia on January 17, 2017. Tyler Bryant would not Tolerate the abrupt changes and became ill the first night at Hiram Davis Medical Center, Petersburg, VA. He started IV antibiotics for Urinary Tract Infection the next Day. His asthma and airway problems increased, admitted to Southside Regional Hospital on Jan. 27, 2017, ICU on Jan. 30 until transfer without consent back to Hiram Davis Nursing facility for approximately 5 hours then back to the Southside Regional ER on Feb. 22, 2017. Preventable suffering included pressure ulcers, infections, inadequate pain control and lack of hypo allergenic care products.

Transfer to Chippenham Hospital, Richmond VA on Sat. night, Feb. 25 ICU.

Approximately 20 referrals and refusals to other care facilities in Virginia and North Carolina. Transfer to a step down Cardiac unit on March 12. Signed Hospice Care Agreement on March 13, Died at Chippenham on March 16, less than 60 days After forced from CVTC's Skilled Nursing Care close to home.

Tyler was denied right to transfer to hospital of choice on Jan. 27. I asked for VCU transfer, denied at the Southside Regional hospital ER by the admitting physician.

Tyler became homeless in the hospital as Hiram Davis stated he could not return. Citing his complexity, he had no where to go. I was called on March 10 to "pick him up". I had no waiver, staffing, oxygen, generator power, equipment. He was transferred from an ICU bed to a step down bed. Budget war at the individual level.

Hiram Davis is a nursing facility but not an ICF/ID. Also serves forensics, MH

And civilly committed sex offenders. On the Central State Campus, MH campus,
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Isolated and segregated in Petersburg. 139 miles from home one way.

Concerns: Disregard of Olmstead Choice, parent/guardian as primary decision maker.

Code of Virginia 37.2-837- Right to refuse discharge from a training center.

Sons health and lives adversely impacted by DOJ vs. Virginia Settlement Agreement of 2012. Plan to close 5 training centers for ID in an 8 year period. Sons forced out in 2017. Only 75 beds of ICF/ID in Chesapeake to remain open. 2 of over 1,000 lives impacted. Over 100+ currently at CVTC in 5 renovated ADA buildings. We were surprised to be forced out in 2017, prior to the projected 2020 date.

Re waiver vs. facility

Sons had waiting list status for over 1 year, then eligible for waiver for approximately 9 months at age 2 years after 24 hr care orders by Medical College of Virginia Pediatrics.

At the time of admissions, sons had had 26 hospital admissions and 8 surgeries.

Home care by family only for 2 years, then 3 day shifts per week of LPN or RN day. Rest of care by family. Also had home visits by physical therapist and case manager. Sons received DME support for wheelchairs, oxygen, pulse oximeter alarms, suctioning, Tube feeding pumps. I slept in 2 hour shifts. My mother and aunt were also nurse aides close by. Both had worked for years at CVTC and understood ID complex care well.

Continous private insurance through small business Anthem primary payor.

Father, now deceased in 2016, co-owner of Bowman's Locksmith, Lynchburg Virginia.

I was a public health RN, RN since 1981, also Pediatric RN experience.

I didn't work for 3 years when they were home. Older son was 8 year old when twins born. We live 45 miles from hospitals in Lynchburg. Beautiful mountain home area.

Emergency admission to CVTC when father had 2nd heart attack in 4 weeks in 1996.

Sons had most years of Pediatric care at VCU-Richmond PICU and specialists.

Also had emergency admission to St. Mary's Bon Secours, Richmond.

During flu emergency diversions, had 2 admission Roanoke, VA.

Tyler had not had an admission for over 1 year prior to Petersburg.

Taylor had been hospitalized in Dec. 2016 with pneumonia then diagnosed with acute mono. Twins move was postponed approximately 1 month due to his acute illnesses.

After age 18, both sons had ICU admissions and specialists in Lynchburg General Hospital including Pulmonary, Cardiology, Neurology, Neurosurgery and Endocrinology.

Having a medical home with electronic records is important for continuity of care and medications history. Both CVTC and Hiram Davis use paper records.

Areas of Concern:

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1. Abrupt termination of FDA- Individual Use drug at day 10, used successfully for 13 years. The medication was hand delivered by the CVTC physician, Dr. Kenneth Slater,
To the Hiram Davis MD, Dr. K. Tran on the day of admission. There was no Policy or procedure to have this sole source drug made available to the admitting hospital.
Support Right to Try Drug legislation- already passed in Virginia in 2015.
2. Lack of electronic records. Paper records, delays and confusion of months to have medical problems known and identified at CVTC to be recognized
By Hiram Davis. Difficult to transfer essential information to ER's, specialists, And hospitals. Hiram Davis continues use of hand written medication orders.
3. Near misses for Taylor Bryant with ongoing medication errors and omissions. On March 3, 2017, Taylor had temperature low in 94 range, pulse in 40's Related to low potassium level. This medication had been terminated and levels fell to significant low before emergency replacement.
4. In April 2017, Taylor was given an antipsychotic medication instead of Blood Pressure because 2 drugs sound alike. Evening dispensing error after ER visit.
5. In September 2017, Taylor had no seizure drug available on a weekend morning so none was given. Paper charting, paper orders, lack of weekend pharmacy delay.
6. In January 2018, Taylor was moved for the 5th time due to bed bugs extermination.
Bed bugs found in his nursing facility bedroom. He had previously been moved For life safety renovations summer of 2017. He is aware of different room.
7. Overdose of an antibiotic in 2018, given every 4 hours instead of every 12 hours.
8. Taylor has moved again March 1, 2018 for the 6th time to the 3rd floor for Life Safety Code renovations.
He is aware of familiar and unfamiliar places. Lack of coordination, planning. He was already moved for 6 weeks last summer for renovations.
Going higher in a non- ADA, locked elevator building increases his fire egress risk.
Going into mixed populations increases his risk of injury from others.

Hiram Davis has locked doors, elevators and ward style rooms without sinks. It is 43 years old, non- ADA compliant with a 2.8 star rating on Medicare.gov Nursing Home compare. The closest hospital is 12 miles away using 2 interstate highways. MH individuals scream, hit and threaten on the same floor as sons. We see people in chains and with police or security escorts. I have been hit and threatened.

CVTC in 2016 was a 5 star facility with 1 deficiency. Fully ADA, renovated in 2011. Sons shared a room with individual control air flow and a private bathroom. First floor fire egress. No MH, forensics or sex offenders. 4 miles from ER.

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Hiram Davis has been under CMS penalty for 3 years for poor infection control rates. Hiram Davis units on second and third floors. Life Safety Renovations in progress third floor ceilings. Son has a slide mat under his bed for use to slide down stairs if fire.

Clinics and offices are on the first floor.

Chairman Bob Goodlatte has been a faithful friend and supporter of CVTC and families for decades. I appreciate his leadership in advocating for training center care and Parents/ guardians as decision makers. I'm thankful 9 Virginia Representatives wrote a cautionary letter to then Governor McAuliffe cautioning closing TC.

My Worst nightmare came true. Tyler died far from home and I wasn't there.

I was in my kitchen when the phone rang. I had seen him the afternoon before. 49

hospital days. 4 days of hospice care in the hospital unit. Funeral and burial in Amherst

At age 23 years. My mother, oldest son and wife, sister and others supported me for 40 + days Living in hotels or living in the hospital or ER's with Tyler. Many friends and churches donated gas cards and gifts to keep us going. Outrage continues over forcing people out of CVTC.

I continue to worry about Taylor's care and the lack of safety culture at Hiram Davis. I see custodial care at its worst there... people not getting out of bed, living in hospital Gowns in wards. I arrive after hours of driving to be locked out waiting to be escorted Upstairs. I see safety issues every visit- communication failures, lack of care.

Sons needs included tracheotomy, oxygen, tube feedings for 14 or more hours per day, Multiple medications, wheelchairs, braces for hands and feet to prevent contractures.

Infant range of cognitive level, non-verbal ranging 9-15 months. Unable to do any ADL self care, cannot use call bell or ask for help.

Both love music and affection. Family involvement changes from multiple times per

week and same county response time to emergencies far away. I saw Taylor on Sat. Feb. 24. He was awake for about 2 hours. He has had 6 physician changes in past year at Hiram Davis. Tyler had no specialist appointments prior to hospitalization. Started all over with new specialists. Taylor has had Care at Southside ER and outpatient at John Randolph. Fragmented Care with some specialists in Henrico, VCU and others
Not affiliated with the same hospital network system.

DOJ brought in experts from University of Massachusetts in May, 2017 after 10 deaths Of individuals transferred from TC to Hiram Davis. U. Mass issued approx. 15 pages
Recommendations of how to improve care. Cited multiple errors, lack of safety culture.

Federal Court Involvement- 2012- present. Oversight by Richmond Federal Court Judge John Gibney. 5 CVTC family members and 3 experts testified on Nov. 6, 2017.

The first open court hearing since 2012's Fairness Hearing.

Judge Gibney denied the families Motion to Grant Injunctive Relief based on lack of jurisdiction.

The Independent Reviewer Donald Fletcher reports status to the court every 6 months. These are closed to the public. Reports are linked detailing areas of compliance and noncompliance. 5 years later, still multiple areas of noncompliance.

Ongoing Virginia General Assembly Legislative efforts to keep CVTC open. Leadership by State Senator Steve Newman, State Senator Mark Peake, Dr. Scott Garrett, Delegate from Lynchburg and Delegate Ben Cline from Amherst. Legislature is still in session with budget amendment language still pending.

VOR- National Level Advocacy. I've been a member at least 20 years.

Caution re Protection and Advocacy- federal funds used against institutional care settings.

File Amicus briefs and oppose facility level care. I served on the board of VOPA 2 terms, last ending in 2013. I was appointed by the Senate of Virginia as ID family member. Protection and Advocacy is now a non-profit called DisAbility Law Center.

Medicaid appeals and problem solving.

6 appeals for our sons in 3 years. Problems with PASSR scoring, inaccurate, and delays to get Tyler a larger wheelchair- 9 months waiting for approval.

Recent issues with establishing ABLE account funds transfer for Taylor such as photo ID. Account was frozen until bundled submission of data from single source.

Taylor could not be expected to get a DMV or passport ID. He required a facility photo ID. This required over 2 weeks of administrative delays as the first case of its type there. Banking routinely requires more than one type of ID such as social security, date

of birth and photo ID to prevent fraud. Health Care also often requires photo ID.

Conflicting information from different agencies such as the billing comes through Central State in Petersburg. My assigned Medicaid worker is at Marion. Different \$\$ instructions. Months to resolve appeals.

Please advocate for the full continuum of care including skilled nursing facility for ID care. I am thankful for your dedicated work and appreciate your care and prayers for Taylor and others forced out. Our friend, Peggy Wood, lived for 50 years at CVTC. She was forced from CVTC without consent in Jan. 2017. Multiple hospitalizations. Her CVTC roommate, age 93, also forced out, died within weeks of transfer.

I advocate that families be able to opt out of class action Settlement Agreements. Pg. 5

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Some states have had state operated facilities stay open such as Pennsylvania, Arkansas, NJ and Illinois. Virginia picking 75 beds was not based on Choice or medical status.

I oppose per capita spending limits as there is a wide range of ability/ disability.

Bundled hospital payments for ER, acute care pressure complex people to have Limited lengths of stay. Also hard to transfer to another accepting hospital.

Martha Stinnett Bryant
Nurse Educator with Amherst County Public Schools. I teach class and clinical high school. I teach Introduction to Medical Sciences and Nurse Assistants with clinical. 14 years in Education 2004-present

University of Virginia, School of Nursing, BSN 1981

Pediatrics, Acute Care
Virginia Baptist Hospital 13 year experience
Lynchburg VA 24503

Public Health Nursing 3 years experience

Central Va Training Center 3 years, Charge Nurse

Full Time Mother and Home Care Nursing of twin sons- 2 years, 9 months

Past President and Past Vice President, Central VA Families and Friends, Inc. 20 years

VOR member, 20 years

VOPA Board Member, 2 terms of 2 years per term ending in 2013

Resident of Amherst County, Virginia

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OSIG case #15554- July- October 2016 Investigation from phone hotline complaint.
Found that the CVTC nurse manager was hostile impacting care. She is still manager. Currently the Director of Clinical Services. Considered expert on care.

Founded Adult Protective Services abuse cases Taylor Bryant, December 2016
Incident- founded in June 2017. Case closed because he was then in Petersburg.

Founded Adult Protective Services case, Taylor Bryant, September 2017. Dinwiddie.

Supporting documentation and findings: Pg.
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University of Massachusetts Expert Findings, On site visit and chart reviews May 2017.

Nursing Home Compare, Hiram Davis, Petersburg
Nursing Home Compare, Central Virginia Training Center

Why Did Tyler Bryant Die, the State Must Answer, news advance.com editorial

Senator Newman Calls for Investigation, "horrific outcome", WSET- TV

Family and Friends Mourn long-time CVTC resident- Newsadvance, WDBJ7- TV,
WSLS- TV

OSIG Case findings - Virginia hotline report Case #15554

VOR.net Legal Resources, Abuse and Neglect, State Reports