House Health Care Testimony: Children and Mental Health Crisis in waiting for ED's for psychiatric beds
9am-12noon April 22, 2021
Kathleen Kourebanas, parent

Systematic Issues: VT AHS out of compliance with Olmstead Integration Mandate
ada.gov/olmstead/q&a_olmstead.pdf
ADA_Olmstead_and_Medicaid.pdf

I'm told that only a Federal Judge can enforce Olmstead in VT's Agency of Human Service policies. Until then, lack of compliance is contributing to the use of Emergency Rooms as holding rooms for 'next steps' in a state that lacks infrastructure to meet the need.

VT receives Federal Medicaid to support disabled Vermonters.
Title II in Americans with Disabilities Act states "Governments must make Public policies funded by Federal funds equal opportunity accessible"…
"Olmstead Integration Mandate applies to everything a state or local government does, including how it plans, designs, and funds its service systems."
For children, their most integrated setting is home. Clare McFadden, the state's autism specialist wrote the White Paper on Autism, a Report for the Act 264 board. Yet, best evidence-based practice of supporting and training families to best support children was never written into any policies.

Act 264 is a big meeting which coordinates services between school-agency-families if a child is having a crisis. The state has authority to amend policies to meet the human service needs of a child's plan, *if they choose to. But the school *HAS to, they must provide FAPE. The state is never held accountable. The school pays the bill and sends the child away from home, rather than "creating the supports and training the family to build a continuum of support that could and should last through a lifetime." -best practice McFadden White Paper to Act 264 Committee. The school and state do not work together to build infrastructure at home, as they should, as agencies will say they "don't have the ability to staff children on nights and weekends, lack the funds to do so, and lack the ability to have oversight..." Why? Because VT is out of compliance with the 1999 Supreme Courts Olmstead Decision. The Agency of Human Services has not adapted to change, has not been held accountable to fully integrate disabled Vermonters into our communities, and in turn, this keeps Emergency Departments over run.

Without accountability, the infrastructure needed in a child's Coordinated Service Plan to meet their needs at home and in their community will stay stagnant, which we know, perpetuates over run Emergency Departments. Clare McFadden created a hamster wheel. In our case, 3 Emergency Room visits, and 3 failed Act 264 meetings.

At age 16, I brought Martha to the emergency room, in hopes for help, as she was unsafe at home. Brattleboro said she was too acute for their milieu. We waited 6 weeks for an open bed at Spring Harbor Hospital in Maine. *Dr. Greenblatt gave us permission to go home and wait,

over-riding the rule from Clare McFadden of DAIL, who said “that there is only funding available if you are in ‘crisis’ and if you go home, you are not in crisis.” This ‘rule’ is keeping children in the emergency department when they don’t need to be.

Within a year, we were back in the Emergency Room. Our home staff had quit and Howard Center said they “did not have the ability to staff and create infrastructure that Martha needed” and our only choice was an out of state placement. But Vermont receives Federal funds to create services NOT to send Martha away? We went back to the hospital in Maine, as out of state placements only accept patients directly from the hospital.

Martha had one option, a residential school in NH, chosen because VT had a Medicaid contract with them, not because it fit her profile. I was told if I didn’t accept this choice, I would have to pay the hospital bill in Maine, as VT wouldn’t pay to keep her there until we found a more appropriate placement. She quickly deteriorated there. Clare McFadden authorized her placement, even though Martha scored a 0 on her Vineland Adaptive Rating scale, a test that an autism specialist should be very familiar with.

Martha deteriorated, and I suspected physical abuse. I’ll never know for sure, as she could not answer questions to be interviewed by NH Children and Families. ER Doctors should know that VT has no jurisdiction over state lines, and we cannot protect our most vulnerable out of state. ER Doctors should also understand what a Vineland Adaptive Rating Scale is. If you score low, you don’t have the skills to adapt away from your natural supports.

Martha has never been the same. Dr. Rettew was her psychiatrist as she returned to Vermont. Martha cried for 3 straight months, we put her on lithium. Currently, we are attempting to titrate her off, as we don’t know if she needs it, it’s difficult to differentiate between ptsd and depression.

My questions are: Can a Dr authorize a child to return home and wait for a placement, as Dr. Greenblatt did for my daughter? Or is it true that the system will only fund a child in crisis if they remain in the hospital, as Clare McFadden says? Is everyone going to wait until a Federal Judge enforces Olmstead or can we hold the system accountable now, as we know its perpetuating crisis?

Short Term Fix:
Create a wing in all Emergency Departments: 3 beds, sensory room with dark, quiet space, room to walk, take bath or shower, structured day for those waiting for weeks, school work, schedule to follow, use Spring Harbor Hospital model, staff with behavior techs with safety sleeves etc., not security guards in uniform, crisis plan describing likes/dislikes, comforts, skills in each child’s file so intake staff can already have that info, help them regulate in a quiet space in hopes after fight flight subsides, they may return home with a continuum of care plan (goods budget-make home safer), contact local EMTs, police to have your child’s photo and crisis plan in case you need help, as VT’s First Call is not always funded or available. Put Coordinated Service Plan in place, hold DAIL accountable