

SB 733

Testimony of Dr. Virginia Kean 33 Mt Washington Pediatric Hospital and Maryland chapter, American Academy of Pediatrics, Committee on Children with Disabilities.

Support

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Maryland is blessed with outstanding tertiary care for very premature infants and very sick children. This means more and more children who used to die in the hospital, re being sent home from the hospital to complete their recovery with dependence on technology. These include tracheostomies, ventilators, oxygen, gastrostomy tubes, dialysis, feeding intravenously, and other therapies that would not have been considered outside the hospital until recently.

While many of these issues can be cared for by the family, many need competent nurses to perform the care and all need licensed nurses to oversee the care. In Maryland we have a longstanding standard of care that children with tracheostomies should have an awake alert caretaker at all times, because should the trach plug or come out there is a high likelihood of death. Common sense demands that these caretakers be competent in the care of the children. To this end many home care nursing agencies have stepped into the market, providing home care nurses so that families can work days and sleep nights while having their child with complex medical needs home. The benefit to the child is improved developmental and social skills due to living in a home environment. The benefit to the state is millions of dollars in savings. It should be a win/ win for all.

And it is for children who have competent caring nurses. These nurses become trusted members of the family.

But unfortunately the home nursing workforce is not fully trained, nor is their competence evaluated before they are sent into the homes of unsuspecting families to care for their precious children.

At Mt Washington before a family can take home a child with complex needs they have extensive training in how to care for them. They are taught :

- 1.how to feed their children via gastrostomy tube, and program the feeding pump, and replace the feeding tube should it come out. .

- 2.To give a complex regimen of medications, and

- 3.most importantly for children with trachs the parents are taught how to suction and replace the tracheostomy. Two caretakers must perform three trach changes each on their child , supervised by a respiratory therapist( usually one week apart), then go through additional training and demonstration of competence in our Simulation Lab

Many families then go home and find that their nurse is either non- existent or not up to the job.

I am a primary care pediatrician for children with complex medical needs. . I have cared for many many children who are dependent on technology and home nursing. I think of them as being in home based intensive care. I have heard many many stories of the inadequacy of home nurses. Many families report that they can perform the cares better than the nurses. The nurses don't show up. They don't

know how to give the medications. They don't read the orders and make adjustments in medication doses and feedings. They don't know how to set up the feedings. They don't know how to suction the trach. They don't know how to change the trach, they don't use sterile technique. They come to work stoned. They sleep through the shift, they sleep through the alarms. They are rough with my child. They do not know as much as I do and they are supposed to be nurses! I'm more nervous when they are there than when they are not.

So frightening are the stories that some families refuse home nurses, preferring to give up an income so one parent can stay awake with the child all night. Some families fire the nurse, or change agencies hoping to find a better nurse with another company.

This is dangerous.

The home care nurses should be the most competent in health care. Sure, they only have one patient, but they lack the backup and support that hospital and facility based nurses rely on. Facility based nurses have to undergo training and competency assessment annually. They must have active Basic Life Support Certification, and those in critical care need to have Pediatric Advanced Life Support certification. Experience would suggest that this training and certification is not required of home nurses. The nurses must be terrified that something bad will happen and they will not be able to deal with it adequately.

Most children with home nursing are insured through the Maryland Medicaid Program. Surely the State of Maryland should be questioning whether we are getting what we are paying for.

In addition there is uncertainty about the credentials of the home care nursing force. Certainly there are some RNs and LPNs, well trained and highly competent, providing this care. However my personal observations in the office when some nurses attend visits give credence to parents' belief that their nurse is really a medical assistant, a nursing assistant, or even a completely non certified person. There are rumors of agencies falsifying credentials of uncertified people in order to fulfill contractual obligations.

Another point that is important to raise is that the people, mostly women, who do home care nursing are not well paid. Many of them work multiple jobs to support their families. They leave one patient to go to the home of another, often anticipating sleeping during their shift. It's essential that we undertake an effort to study the salary structure for these workers, and make efforts to pay them a living wage so they can fit sleep into their non-work hours. Children's lives depend on it.

Channing's law would establish systems to train and ascertain competence before a "nurse" could be assigned to care for a medically fragile child. There is no need for a new administrative structure because it would fall under the existing Maryland Board of Nursing structure. Mt Washington Pediatric Hospital has offered to be a site for training and assessment, and Maryland would need other sites throughout the state. There is cost associated with this, but the benefit is that fewer children would suffer the tragic events that Channing and her family have experienced.

I urge you to vote in favor of Channing's Law, SB 733. A child's life depends on it.