MaineHealth

MaineHealth
Local Health Systems
Franklin Community Health Network
LincolnHealth
MaineHealth Care At Home
Maine Behavioral Healthcare
Memorial Hospital
Maine Medical Center
Mid Coast-Parkview Health
NorDx
Pen Bay Medical Center
Southern Maine Health Care
Synernet
Waldo County General Hospital
Western Maine Health

Part of the
MaineHealth Family
MaineHealth Accountable Care Organization

MaineHealth Affiliates
MaineGeneral Health
New England Rehabilitation Hospital of Portland
St. Mary's Health System

Testimony of Dr. Colby Wyatt, MaineHealth
In Opposition to LD 1292
"An Act Regarding the Parental Right to Direct the Health Care of Children"
May 6, 2021

Senator Carney, Representative Harnett and Members of the Judiciary Committee, I am Dr. Colby Wyatt, Pediatric Pulmonologist at the Barbara Bush Children's Hospital at Maine Medical Center, and I am here to testify in opposition to LD 1292, "An Act Regarding the Parental Right to Direct the Health Care of Children."

While I currently live and work in southern Maine, I grew up in Burnham, Maine and have many family in the central part of the state. I have a deep appreciation for the diversity of experiences and beliefs that exist throughout our state and bring this understanding to my practice. Every day, my colleagues and I at the Barbara Bush Children's Hospital are committed to providing compassionate, high quality, and medically appropriate care to some of our state's most vulnerable residents, our sick children.

I would like to address our significant concerns with the legislation before you today in three parts: 1) advanced directives and medically ineffective care; 2) minor consent, and; 3) infection control.

Advanced Directives and Medically Ineffective Care

Initially on reading this legislation, I was puzzled as I am actively involved in end-of-life discussions as part of my practice. I was unaware of any instance where there was care that was withheld without the knowledge or consent of a parent. However, I don't see every pediatric patient at the end of their life, so I discussed this with our hospital administration and many of my fellow pediatricians, and I feel this is important to emphasize: MaineHealth is unaware of any issues that have arisen at any MaineHealth hospital or other care setting involving the withholding of treatment for minors without the knowledge and consent of a parent or guardian.

I believe that is simply because this it is not how health care is delivered. Providers are already held to ethical and professional practices around these discussions and decisions. As part of my practice I have a special interest in the care of children with respiratory failure from neurologic disease and those who are technology dependent, living on ventilators at home. Some of these children have diagnoses that will shorten their lives significantly, including dying in childhood. When children have these diagnoses it is the standard of care to have regular end-of-life discussions with the parents of these children. It is my job, and the job of my colleagues, to understand what the parents' values are and what their wishes are for their child and their child's health care. I have spent

countless hours advocating for the parents' wishes regarding the life of their child and helping to provide the resources and interventions needed to help them obtain, what they consider to be, the best quality of life for their child. This is the current standard of care, and the legislation before you today is unnecessary and attempts to legislate the provider-patient relationship.

When a child is nearing the end of their life, the typical conversation with a parent begins with a recognition of the child's current health status and a review of our prior discussions on the parent's wishes and a discussion of whether they continue to feel the way they did during our prior conversations. We then talk about interventions, medications, and the impact of these interventions on the child and the family and the likely outcome of these interventions. The steps in care are presented as options that range from minimally to maximally invasive with the potential benefit and harm of each intervention described. However, these choices are not presented like menu items at a restaurant. While parents are told about all of the options, there is a component of advocacy for the well-being of the child that is central to the conversation. Sometimes an intervention that is maximally invasive has no real clinical benefit for a child other than prolonging pain and suffering. An example would be providing a tracheostomy tube for mechanical ventilation in a patient in constant seizure with no medical chance of the seizure resolving. Like most of my health care colleagues, I took an oath to "First, do no harm", and I take this oath very seriously. It is ethically important to prevent the suffering of a child due to ineffective medical interventions. This value is already expressed in Maine Statute (Title 18-A, Article 5) which states - clinicians cannot be forced to provide medically ineffective or medically inappropriate care contrary to generally accepted health care standards.

I have never personally reached a point in the care of a child where there was such a disagreement in the desired intervention for a child that a treatment would be withheld or not offered against parental wishes. If this were to happen, then there is an option that the care of the child is transferred to another provider or institution willing to provide the level of care desired. However, when I checked with my colleagues and our administration, they were unaware of this ever occurring at a MaineHealth hospital.

Finally, there are several areas where this legislation could create additional complications. Currently, there are methods for addressing the difficult scenarios where two parents disagree with the appropriate course of action and treatment for their child, or instances of suspected child abuse when parents refuse admission or assessment of their child. Lastly, and arguably the most tragic, instances in the worst cases of child abuse where burdensome and ineffective care may be requested to prolong the life and suffering of a child in order to make the difference between an abuse charge and a homicide charge. This legislation would undermine the processes already in place.

Minor Consent

As the sponsor addressed in her testimony, enacting a law that gives parents total control over their child's health care runs contrary to current Maine Statute (various statutes, including Title 22, Chapter 260) defining when a minor can consent to treatment, including the prevention and treatment of a sexually transmitted infection, substance use disorder treatment, and the collection of sexual assault evidence. We appreciate her willingness to address this through an amendment, as data shows that minors are more likely to be forthcoming about their health care needs and also seek health care when confidentiality is afforded by a provider. Stripping a minor's ability to consent to care does not change their behavior, though it can change their willingness to seek care. We are opposed to any policy change that could potentially deter access to care.

Infection Control

The current COVID-19 pandemic has made much more public many of the infection control measures that have already existed in hospitals to protect patients, health care providers, and the general public from highly infectious diseases. During the pandemic, hospitals have been required to meet U.S. Centers for Disease Control and Prevention (CDC) guidelines related to patient and care team member safety. COVID-19 positive patients and patients under investigation are placed in isolation to prevent the spread of the disease, but we have worked diligently to facilitate visitors for minors since the start of the pandemic. In fact, I am unaware of any instance in which a parent or guardian did not have physical access to their minor child who was COVID-19 positive or presumed positive while being treated at a MaineHealth hospital. The legislation before you today, however, will strip clinical and administrative teams of the latitude to make this decision in which we balance patient benefit and risk to the patient, visitor, care team, and community. It would also place us in a most difficult position in which we are stuck between adhering to U.S. CDC guidelines and licensing regulations and State law. I would also note that today we are considering this legislation with COVID-19 in mind, but we must also consider that hospitals may treat other highly contagious diseases in the future, including, for example, Ebola.

Thank you for the opportunity to testify in opposition to this legislation, and I would be happy to answer questions.