

HB 141 – Regards Prescribed Pediatric Extended Care Centers

Sponsor Testimony

Representative Rachel Baker and Representative Cindy Abrams

Thank you, Chair Huffman, Vice Chair Johnson, Ranking Member Liston, and members of the Senate Health Committee. It is a privilege to join Representative Abrams in offering sponsor testimony on House Bill 141, legislation that would establish Prescribed Pediatric Extended Care (PPEC) centers in Ohio.

PPEC programs are non-residential community-based daycare centers for children with complex medical needs. These centers offer a daycare and early childhood education experience for children, who because of complex medical needs, are often unable to attend typical daycare centers safely. These centers would offer daycare for infants and preschool aged children, and before and after school and summer services for school-aged children. The definition of children with medical complexity encompasses big range of diagnoses - which is why the bill doesn't list diagnoses but instead requires a provider to prescribe PPEC as a needed service - but to give you an idea, these are children who may have diagnoses like cerebral palsy, spina bifida, chronic lung disease, cardiac disease or defects, seizure disorders, or genetic disorders. They may have a trach and be dependent on a ventilator to breathe, they may have a feeding tube or require bladder catheterization.

Currently, there are a few care setting options for these children: They can live at home with direct care from their family, they can live at home with in-home nursing, or they can live in a residential setting like a skilled nursing facility. While all these options are needed and each child and family needs to be supported in what is best for them, providing supports to families to facilitate their child living at home is optimal when possible and PPEC centers would be one more option for families attempting to support their children in thriving at home.

In March 2023, a southwest Ohio taskforce surveyed Child Care Resource and Referral Agencies, representing all 88 counties regarding child care access for children with complex medical conditions, and 89% reported "poor access" to child care for children who require nursing staff services. Because of the scarcity of daycares equipped to serve these children, they often remain at home with 1:1 nursing care until they reach school-aged. However, as we all know, Ohio is facing a shortage of home health nurses and many families of children with complex medical needs find themselves without home health care services as needed. In learning about this need, we've also heard of children essentially living in a children's hospital inpatient room because their family was unable to secure nursing care to support them living safely at home. Even in the rare case when these families are able to find adequate home nursing, these children receive minimal socialization and inclusion in early childhood experiences spending the majority of their day at home with a home nurse or their family.

PPEC programs are a way to address the scarcity of home health nurses, while providing children with complex medical needs a safe early childhood education and socialization

experience in a classroom environment. Centers are staffed with a medical director, nurses providing routine and emergency care, and classroom teachers who build lesson plans and activities to meet each child's needs. Centers can even partner with local healthcare providers so that children can receive occupational therapy, speech therapy, and physical therapy while at the center, freeing families up from running to health appointments after work.

Many states currently license and fund PPEC centers, including Delaware, Florida, Kentucky, California, Colorado, Louisiana, Maryland, Minnesota, Mississippi, Nevada, New Jersey, New York, Pennsylvania, Texas, and South Carolina. There was a study conducted of medically complex children who received care in three types of settings: at home, in long-term care setting, or home with a PPEC. They found that children who attend a PPEC had the highest overall quality of life, and highest physical, emotional and social functioning.

Additionally, other states who already have PPECs have reported cost savings to introducing this model into the options for families. Children with medical complexities account for a very small percent of all children yet constitute between 30-40% of pediatric Medicaid spending. PPECs are one way to decrease the Medicaid expenditures. PPEC staff are able to deliver onsite interventions that result in decreased costly ED visits and admissions, reducing Medicaid costs. As a real-world example of the cost savings, we received data from a PPEC in Texas. Over a 34-month period, they documented 235 episodes of pediatric seizures, and their staff were able to manage the seizure without transferring to the ED in 227 of these instances. Additionally, over this time period, they documented 141 incidents of GI or tracheostomy dislodgement and in 121 of these dislodgements the incident was managed onsite without requiring transfer to an ED. They calculated cost if these incidents had required ambulance transfer and ED visit and estimate a \$1.9M savings to taxpayers over these 34 months - just from their center.

Ohio is home to the number 1 children's hospital in the country. Many families of children with complex medical needs move to our region to receive this care for their child. However, once here many families discover that while they are getting the top level of medical care, the community does not have the resources in place for these children to have a typical early childhood education experience. In Cincinnati, many of these families choose to live across the river in Kentucky to receive PPEC experience.

In talking with families who have children attending these centers in Kentucky, I learned another perspective. Centers are designed to be inclusive environments with a portion of the children having complex medical needs and the other portion being typically developing children. This allows families to send all of their children to the same early childhood center and allows typically developing children to have an experience in an inclusive learning environment where empathy and learning about children with different abilities can occur. Siblings of children with medical complexities can meet other families like theirs, normalizing their family experience.

While these centers are life-changing for children, they're also very important for their parents. Finding the right childcare, especially for a child with complex medical conditions, can be an obstacle for parents entering the workforce. Having reliable and consistent early childhood

education allows parents to remain in the workforce, reduces workplace absenteeism, and allows some respite during the day so that parents feel more equipped to provide care their children need after work.

HB141 would make PPEC centers a possibility in Ohio - this bill sets up a licensure process through the Department of Health through which centers would apply to become PPEC centers. Centers would achieve this licensure in addition to holding childcare center licensures. Additionally, the legislation sets up PPECs as a Medicaid service for children who qualify based on medical need. I hope through our testimony we've provided a basis for what this bill truly is - it is a win for children with medical complexity and their families, it's a win for their siblings who meet other families like theirs, it's a win for their parents allowing them to stay in or reenter the workforce, and it's a win for taxpayers. The most exciting part of this legislation to me is the basis it is founded in - that children with medical complexity are not just patients. They are CHILDREN first and they deserve to have the experiences of socialization, friendship, and play that will come with safe daycares.

Chair Huffman, Vice Chair Johnson, Ranking Member Liston, and members of the Senate Health Committee, thank you again for the opportunity to provide sponsor testimony. We would be happy to answer any questions.