



MISSOURI HOUSE OF REPRESENTATIVES  
**WITNESS APPEARANCE FORM**

BILL NUMBER: <b>HB 1975</b>		DATE: <b>3/5/2024</b>
COMMITTEE: <b>Children and Families</b>		
<b>TESTIFYING:</b> <input checked="" type="checkbox"/> IN SUPPORT OF <input type="checkbox"/> IN OPPOSITION TO <input type="checkbox"/> FOR INFORMATIONAL PURPOSES		
<b>WITNESS NAME</b>		
<b>INDIVIDUAL:</b>		
WITNESS NAME: <b>ANNE DENMAN</b>		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE:                  ZIP:
EMAIL: <b>anneadenman@gmail.com</b>	ATTENDANCE: <b>Written</b>	SUBMIT DATE: <b>3/4/2024 1:41 PM</b>
<b>THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.</b>		

As a parent of a young adult son with developmental disabilities, and as a professional serving young children with developmental disabilities and their families, I believe it is imperative that children be able to receive nursing care in integrated educational settings. I work with several families of children with complex medical needs, and at least one of them has been unable to attend school for the past year because his medical needs were not adequately tended to by teachers and aides during the school day. Under federal legislation (IDEA) all public school children have a right to access the general education curriculum, and many children with complex medical needs and disabilities cannot safely do so because of a lack of nursing care at school. This barrier to a Free and Appropriate Public Education must end. Please pass HB 1975.



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<b>WITNESS NAME</b>		
<b>INDIVIDUAL:</b>		
WITNESS NAME: <b>ARNIE C. "HONEST-ABE" DIENOFF-STATE PUBLIC ADVOCAT</b>		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS:		
CITY:		STATE:      ZIP:
EMAIL: <b>arniedienoff@yahoo.com</b>	ATTENDANCE: <b>In-Person</b>	SUBMIT DATE: <b>3/5/2024 11:18 PM</b>
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**I am in Full Support of this Bill and the Requirement of obtaining and securing A Facility Operating License from the State Department of Public Health and Senior Services and the State Department of Mental Health. This a MUST!**



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<b>WITNESS NAME</b>		
<b>BUSINESS/ORGANIZATION:</b>		
WITNESS NAME: <b>BEN TERRELL</b>		PHONE NUMBER:
BUSINESS/ORGANIZATION NAME: <b>DEPT OF HEALTH &amp; SENIOR SERVICES</b>		TITLE: <b>LEGISLATIVE LIASON</b>
ADDRESS: <b>912 W WILDWOOD DR</b>		
CITY: <b>JEFFERSON CITY</b>		STATE: <b>MO</b>
EMAIL:		ZIP:
ATTENDANCE:	SUBMIT DATE: <b>3/5/2024 12:00 AM</b>	
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<b>WITNESS NAME</b>			
<b>REGISTERED LOBBYIST:</b>			
WITNESS NAME: <b>CONNOR STANGLER</b>		PHONE NUMBER: <b>573-673-7388</b>	
REPRESENTING: <b>CHILDREN'S MERCY KANSAS CITY</b>		TITLE: <b>MANAGER, GOVERNMENT RELATIONS</b>	
ADDRESS: <b>2401 GILLHAM RD</b>			
CITY: <b>KANSAS CITY</b>		STATE: <b>MO</b>	ZIP: <b>64108</b>
EMAIL: <b>cjstangler@cmh.edu</b>	ATTENDANCE: <b>Written</b>	SUBMIT DATE: <b>3/5/2024 8:55 PM</b>	

**THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.**

Dear Chair Kelly, Vice Chair Hausman, and Ranking Minority Member Proudie: Thank you for the opportunity to provide written testimony in support of HB 1975, which would create a prescribed pediatric extended care (PPEC) facility license in the state. Children’s Mercy is a leading independent children’s health organization dedicated to holistic care, translational research, breakthrough innovation, and educating the next generation of caregivers. For over 125 years, we have provided world-class pediatric care to the children of Kansas City and our region. About 3 million children in the United States are defined as ‘medically complex’ (“Children with Medical Complexity”, or “CMC”) because they have life-threatening conditions that affect two or more organ systems. The majority, about 2 million children, are covered by Medicaid, and that figure is expected to double over the next decade. The 2 million Pediatric members represent about 6 percent of children covered by Medicaid but generate more than 40 percent of the overall costs for Pediatric care. Spending is highly concentrated within a subset of children with medical complexity: five percent of these children account for 50% of total spending on children with medical complexity. Based on positive clinical developments for congenital and/or chronic conditions, survival rates for pediatric patients who would have otherwise passed away have significantly increased. As a result, the number of medically complex children, complications, childhood disabilities, and nursing care usage rates have increased in tandem. A large proportion of hospitalizations for medically fragile children are driven by a lack of appropriate, responsive, and accessible community-based services. Post-acute care continues to be inconsistent for children with medical complexity who might benefit from weeks to years of intensive, daily caregiving in a less restrictive and less costly environment. This is because access to home and community-based health is hard to find and driven by an inadequate supply of clinicians. Families struggle to secure nurses and many home health agencies simply don’t accept Medicaid referrals at this point. Unfortunately, this situation is very prevalent in Missouri. The realities of caring for a medically fragile child are felt by the entire family – families with children with special needs show inferior physical and mental health, increased stress, and experience significant financial burden. When surveyed, 68% of families of CMC reported financial hardship and 46% reported social hardship. The PPEC model is a Medicaid-funded fee-for-service model, approved in nearly 20 states, in which medically-complex children receive nursing services and care support at a community-based center. Each center has slightly different operating hours, but in general centers operate 5-7 days per week for about 12.5 hours per day. PPECs serve children ages 0 to 21, with some who come all-day 5 to 7 days a week, and some who come part-time as a complement to school and/or at-home care. PPECs are staffed with pediatric trained nurses (RN, LPN, CNA) that operate as a coordinated team to effectively care for children with shared learnings, better oversight, and “more eyes on the child.” PPECs have

better retention of nurses than home-based care delivery environments due to a team-orientated, collegial environment. This means that children receive continuous care from the same nurses for longer periods. For children with medical complexities, this continuity is paramount for the continuation of high-quality care. PPECs collaborate with the existing provider infrastructure to holistically care for a child's complex needs. PPECs can provide care coordination, transportation, important therapies, nutritional support, housing education, and family caregiver education among other services with a focus on child and family satisfaction. However, PPECs are not approved in some states, including Missouri! Therefore, CMCs are left to try to get skilled nursing care at home. Yet, the problem remains – there are not enough appropriate care options available for these children and their families. For families, the transition from the NICU, PICU, and other hospitalizations to an alternative setting can be overwhelming and often terrifying. For a children's hospital like Children's Mercy Kansas City, the transition from the NICU or PICU to the home setting can be stressful as the caregivers are challenged to manage the 24/7 care of the patient at home. The only option is home health, which has inadequate supply due to the nursing shortage and limited availability of home care for CMC. These challenges extend the length of stay in the hospital as we are forced to delay discharges to ensure a safe and effective discharge plan is in place. For providers and families alike, there are challenges with care coordination due to the many specialist needs required for the CMCs. Many of these families, as mentioned above, struggle with poverty, as many forego their job to take care of their medically complex child. PPECs help make all of this easier, more efficient, and more effective for the child and their caregivers. PPECs can and should be an important provider of services for medically complex children. We envision a world where all children, regardless of their medical condition, have access to the care and support they need to thrive in the environment that is most appropriate for their condition and needs. HB 1975 is an important first step to support our vision for Children with Medical Complexity. We appreciate your consideration. Thank you, Bob Finuf Senior Vice President, Value & Payor Relations, Executive Director, Integrated Care Services Children's Mercy Kansas City



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<b>WITNESS NAME</b>			
<b>BUSINESS/ORGANIZATION:</b>			
WITNESS NAME: <b>JENNIFER WRIGHT</b>		PHONE NUMBER: <b>573-634-3070</b>	
BUSINESS/ORGANIZATION NAME: <b>SPECIAL LEARNING CENTER</b>		TITLE: <b>DIRECTOR OF THERAPY</b>	
ADDRESS: <b>1115 FAIRGROUNDS RD</b>			
CITY: <b>JEFFERSON CITY</b>		STATE: <b>MO</b>	ZIP: <b>65109</b>
EMAIL:	ATTENDANCE:	SUBMIT DATE: <b>3/5/2024 12:00 AM</b>	
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<b>WITNESS NAME</b>			
<b>INDIVIDUAL:</b>			
WITNESS NAME: <b>LESLIE DERRINGTON</b>		PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS:			
CITY:		STATE:	ZIP:
EMAIL: <b>lederrington@gmail.com</b>		ATTENDANCE: <b>Written</b>	SUBMIT DATE: <b>3/4/2024 1:51 PM</b>
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<b>BUSINESS/ORGANIZATION:</b>			
WITNESS NAME: <b>MELANIE HIGHLAND</b>		PHONE NUMBER: <b>573-526-3626</b>	
BUSINESS/ORGANIZATION NAME: <b>DEPT. OF HEALTH &amp; SENIOR SERVICES</b>		TITLE: <b>DIVISION DIRECTOR</b>	
ADDRESS: <b>912 WILDWOOD</b>			
CITY: <b>JEFFERSON CITY</b>		STATE: <b>MO</b>	ZIP: <b>65109</b>
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<b>WITNESS NAME</b>			
<b>REGISTERED LOBBYIST:</b>			
WITNESS NAME: <b>ROBYN SCHELP</b>		PHONE NUMBER: <b>660-441-3260</b>	
REPRESENTING: <b>KIDS WIN MISSOURI</b>		TITLE: <b>DIRECTOR OF POLICY AND ADVOCACY</b>	
ADDRESS: <b>3909 SHERMAN CT</b>			
CITY: <b>COLUMBIA</b>		STATE: <b>MO</b>	ZIP: <b>65203</b>
EMAIL: <b>rschelp@kidswinmissouri.org</b>	ATTENDANCE: <b>In-Person</b>	SUBMIT DATE: <b>3/4/2024 4:51 PM</b>	

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My name is Robyn Schelp and I am the Director of Policy and Advocacy for Kids Win Missouri. We advocate on issues of child well-being including child care and early education, child welfare, and health and mental health. Kids Win Missouri supports HB 1975 and appreciates Rep. Stinnett for sponsoring this bill. Kids Win Missouri supports the creation of prescribed pediatric extended care facilities which would allow certain licensed child care providers to care for children who receive nursing care. Finding child care is near impossible for parents of children with disabilities, including children who are medically fragile. This legislation would give parents of young children with daily medical needs the option to go back to work. It would give these children needing nursing care the opportunity to attend early care and education programs with their peers. While Kids Win Missouri has been very vocal in this committee about the importance of child care and early education, we also advocate for all children to have access to quality healthcare. Currently children who need nursing care covered by DHSS must receive this care at home. By allowing multiple children to receive nursing care by a nurse in a prescribed pediatric extended care facility, more children will be able to have appropriate nursing care. This is critical in areas of the state where there are shortages of nurses. I appreciate this legislature's commitment to improving access to quality child care. This bill extends access to quality care to children who have certain disabilities that require nursing services. I ask the committee to support HB 1975 so Missouri's children who are medically fragile can receive care at an appropriate child care facility.



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BUSINESS/ORGANIZATION NAME: <b>SPECIAL LEARNING CENTER</b>		TITLE: <b>EXECUTIVE DIRECTOR</b>	
ADDRESS: <b>1115 FAIRGROUNDS RD</b>			
CITY: <b>JC</b>		STATE: <b>MO</b>	ZIP: <b>65109</b>
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