

Helping Kids Get At-Home Care

Story by Kate Marple & Erin Dexter

What would you do if your one-year old child depended on a ventilator to breathe, and the home nursing care needed to monitor it wasn't available? Would you keep your child in the hospital indefinitely? Would you quit your job to be home with your child, and stay up all night to make sure they didn't stop breathing? Would you put them in a long-term nursing facility 80 miles away where they'd have the care they needed, but where you wouldn't see them for days at a time? In 2015, for several parents in Washington State, the heartbreaking answer to all these questions was yes.



SEATTLE CHILDREN'S HOSPITAL

Seattle, Washington

<http://www.seattlechildrens.org/>

Seattle Children's is a pediatric hospital and research institute.

The hospital's **medical-legal partnership** with the Northwest Justice Project has provided legal services to patients and their families since 2008.



POLICY CHANGE SNAPSHOT

When children on ventilators were unable to leave the hospital due to a home-nursing shortage caused by low Medicaid reimbursement rates, the medical-legal partnership at Seattle Children's sued the state Medicaid Director and the Director of the Healthcare Authority to help kids return home. They then turned their attention to advocacy with the state agencies to fix the reimbursement rates.



The medical-legal partnership team gathered at Odessa Brown Children's Clinic — a community clinic of Seattle Children's Hospital and one of the MLP's partnering health sites — for their monthly staff meeting. **Photo credit** (above): Anya Morgan. **Photo credit** (to the right): Vorada Savengseuksa



The best option for these kids is to return home with nursing care where they can be with their families, grow developmentally, and avoid exposure to other diseases that could compromise their immune systems.

A variety of medical conditions — from birth defects to lung disease — can obstruct airways and require tracheostomy tubes to keep them open and clear. Those tubes have to be monitored twenty-four hours a day to make sure they don't become plugged; sometimes a ventilator is also needed. While some of these conditions will correct over time, these tubes are commonly needed for prolonged periods of time, even years.

When nothing else is wrong medically, the best option for these kids is to return home with nursing care where they can be with their families, grow developmentally, and avoid exposure to other diseases that could compromise their immune systems. But in 2015, many Washington families on Medicaid couldn't find nurses willing to take these jobs, in part because the Medicaid reimbursement rate for at-home nurses averaged almost \$10 per hour less than rates for other nursing positions, so kids were staying months longer than medically necessary at places like Seattle Children's Hospital.

AT THE TIME OF
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275
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Washington children were eligible to receive in-home care. Dozens of them were hospitalized unnecessarily, or were not receiving the amount of home care they were entitled to.



Providers began asking the medical-legal partnership attorneys questions about kids that the hospital was essentially boarding — young children on ventilators who didn't need to be at the hospital, but who couldn't be released without proper at-home care. Besides being unnecessary for the kids, the prolonged hospital stays were costly for Seattle Children's. Room and board alone totaled thousands of dollars a day; by comparison, the same amount could pay for round-the-clock care from a registered nurse for four days, at the private insurance pay rate. The questions providers asked attorneys were always the same: How do we get these kids in-home care? What is the state required to do?

The law was clear: The Americans with Disabilities Act says if Medicaid eligible individuals can be served in the community, they must be, and they must be given necessary supports to do so. And Medicaid laws state that with kids, care must be both paid for and arranged. In this case, Medicaid was willing to pay for the in-home care, but they weren't able to arrange for the nurses needed to carry it out.

The MLP attorneys asked social workers at Seattle Children's if they could identify specific patients who had been unable to find home nursing care. Six families with young children came forward. Some of their kids were still in the hospital, some were at home with insufficient care, and some had moved to long-term facilities two hours away where their parents could not see them every day. The MLP attorneys tried unsuccessfully to get the Healthcare Authority to make accommodations for these children. Then in October 2015, they filed a lawsuit, suing the state Medicaid Director, the Director of the Healthcare Authority, and the Healthcare Authority itself on behalf of the six families.

But these families weren't alone. At the time of the lawsuit, approximately 275 critically ill Washington children were eligible to receive in-home care. Dozens of them were hospitalized unnecessarily, or were not receiving the amount of home care they were entitled to.

The Medicaid reimbursement rate for at-home nurses averaged almost \$10 per hour less than rates for other nursing positions.



All policy work our MLP engages in is partially about solving a clinic problem identified by providers, in this case a serious and expensive discharge problem. But it was ultimately about giving kids a shot at their best life, and putting families back together. Every parent can understand the need to get their kid home.



Lindy MacMillan
MLP ATTORNEY

In January 2016, the judge ordered that under federal law, the state had the obligation to arrange for the skilled nursing care that had been authorized for the children who were named in the lawsuit, and that the state must fulfill its obligation to these children.

The successful lawsuit provided momentum for state legislation that passed in July 2016, raising the Medicaid reimbursement rate for home nursing care by \$10 per hour and making it more equitable with other nursing rates in the state. This change eliminated what was widely viewed as the biggest barrier to filling at-home care positions, not just for the six kids in the lawsuit, but for all Washington families eligible for these services.

Since these changes took effect, MLP attorneys have had fewer consults with Seattle Children's providers regarding authorization of home care for children dependent on ventilators. Cases do still come up where providers are struggling to discharge a kid and find home care, but when they do, there are now steps in place to better advocate for those patients.



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