

Q&A: The Next Steps to Improving Home Health Care for Children with Medical Complexity

Below are responses to questions the panel was unable to answer during the webinar.

Respondents

- **Molly Hofmann, MSN, PCNS-BC, AFN-BC**, Associate Director of Care Coordination, University of Illinois at Chicago-Specialized Care for Children
- **Roy Maynard, MD**, Medical Director, Pediatric Home Service
- **Carolyn C. Foster, MD, MSHS**, Assistant Professor, Division of Academic General Pediatrics and Primary Care, Department of Pediatrics, Feinberg School of Medicine, Northwestern University, and Attending Physician, Ann & Robert H. Lurie Children's Hospital of Chicago

Q&A

Payment:

What is the role of private payors in improving home health care?

Roy: Recognizing the cost associated with prolonged hospitalization in lieu of home nursing should encourage private payors to pursue the less costly alternative. In the future, this may involve greater payment reform and collaboration between payors and health care systems. Options could include bundling payments rather than fee-for-service. Cost sharing to pursue alternatives to decrease cost of care and improve the quality of care may also be of benefit.

Molly: Private payors usually have higher reimbursement rates that may lead to a more skilled labor force and improved access to home health services. Privately paid agencies may also have the ability to recruit and train staff with more experience and higher skills. They may also be more likely to use telemedicine and other technology to improve care.

What are your thoughts on paying family members to provide home health care?

Molly: Currently in Illinois, the Medicaid program allows payment for a parent to provide skilled nursing care for their adult child (18 years and older). The parent must meet all provider qualifications and be employed by an approved Home Health agency. There are limitations on hours—40 per week is the maximum and there are additional monitoring requirements by the nursing agency. Historically the state has taken the stance that being a parent brings caregiving responsibilities, regardless of the health status of your child. As we are learning more about how to improve support for families of children with special needs (particularly the medically complex child), more needs to be explored about what the states should expect from parents – along with what the states should provide. This is especially the case as we are learning more from families about how their caregiving responsibilities create barriers to them finding and maintaining work outside of the home.

What is the best way to pursue additional funding for home health care at the state level?

Roy: Lobbying at the state level may have the most impact. Advocating for expanding waiver programs that patients may qualify for is also needed. These vary from state to state and county to county and often a waiting list is in place due to limited funds available for these programs. In Minnesota there is now a small cottage industry to help families move into other counties where their likelihood of getting a waiver is increased.

Molly: The pursuit of additional funding at the state level can typically take legislation or litigation. States are challenged with improving services and supports without increases in funding. It challenges us to try to find creative ways to save money so that those resources can be used elsewhere.

Is there any lobbying going on to encourage private insurance companies to pay for skilled private duty nursing in the home? Is this work being done at the state level or nationally?

Roy: I am not aware of any lobbying efforts to encourage private payers to pay for skilled private duty nursing in the home. I am aware of individual cases where families have challenged coverage for homecare nursing.

There are attempts to increase coverage by class-action lawsuits:

<https://healthlaw.org/resource/groups-file-class-action-against-calif-over-care-of-children-with-disabilities/>

Disability Rights Centers in each state may be able to provide some guidance. The National Health Law Program is also a resource:

<https://healthlaw.org/resource/o-b-v-norwood-united-states-district-court-northern-district-of-illinois-and-united-states-court-of-appeals-for-the-seventh-circuit/>

What can be done to help home nurses retain steady income when children with medical complexity may be in and out of the hospital?

Roy: Some home health agencies provide “assurance pay” for nurses displaced from their regular patient when hospitalized. This takes effect only if there are no other available assignments and comes with certain stipulations. For instance, a nurse relieved of duties by a family may not be eligible for this. Nurses may also use paid time off to collect for scheduled hours that were missed due to a patient’s hospitalization.

Training:

Can you share information on the Nitty Gritty Nursing training?

Molly: The Nitty Gritty Nurse Training was developed in collaboration between the University of Illinois at Chicago Division of Specialized Care for Children (UIC-DSCC), IL Title V program for CYSHCN, and a team from the Ann and Robert Lurie Children’s Hospital in Chicago. Both teams work with medically complex children receiving in-home shift-based nursing care. Through collaborative discussions the teams were noting concern about the quality of nursing care provided in the home setting. It was recognized that skills for many of the technology related aspects of these patient’s care was not part of basic nursing training and not enough training was available from the home nursing agencies, so the teams created a skills-based training. The clinical aspects of the training materials were created by Lurie’s team with the intellectual property belonging to UIC-DSCC with the intent that this would enable UIC-DSCC to share the training with other children’s hospital providers in Illinois who may be interested in replicating the training in their region. Topics included care of the tracheostomy, home-ventilator management, airway clearance, and care of the g-tubes/j-tubes/central lines in the home. The intended audience was nurses working in the home setting and continuing education credits are available.

What are the panelists’ thoughts on creating a nurse residency program for recent graduates within home health agencies?

Roy: In order to promote home nursing, our organization offers clinical rotations in home care. Nursing students, with the permission of families, may shadow a homecare nurse in the home. Other opportunities for nursing students include hi-fi simulation in our facility. This latter opportunity has been taken and continues to be taken advantage of by many nursing students and currently we have about 150 students signed up for future simulation lab experiences. Our homecare nursing organization participates as

panelists in career fairs to promote partnership with the local nursing schools. This has also included sponsoring conferences as well as offering breakout sessions to provide exposure to homecare nursing as a career opportunity.

Molly: A nurse residency program for home health agencies is an interesting idea. Nurses working in the home setting are often providing complex care (skills above what is taught in school) and are practicing in an environment where they are often alone (no peer available to seek assistance or guidance from). A nurse residency program is designed to increase the training provided to nursing students. Improving the foundational training provided to a nurse before they are working in the home could lead to significant improvements in quality and likely, job satisfaction. The concern about nurse residency programs getting implemented though is the cost.

Our program has identified the need to provide advanced training to home health care nurses and families in our community. One challenge we encounter is funding the training. What was the process you used to access Title V funds and are there other viable options for supporting training initiatives?

Molly: Illinois' Title V agency for CYSHCN also works with our Medically Fragile Technology Dependent Waiver so it helped that we are part of the same organization. All states have dedicated money from Title V that is dedicated to CYSHCN with the primary intent that this money be used to improve the systems caring for these children. A training that is geared towards a group, such as the Nitty Gritty Nursing seminar, meets the criteria of a systems-based project. Each state has a little bit of a different structure for how their Title V dollars are used, so I would suggest reaching out to your state's Title V program for CYSHCN to discuss the opportunity.

When thinking about how we recruit and train more nurses and clinicians into the pediatric home health care sphere, what do you think are aspects of the work that may appeal to young practitioners?

Molly: This is a great question. In Illinois, one of the things we are in the beginning stages of working more with families on pertains to understanding more what are things that some families do that help them maintain the nurses who work for them so this information can be shared with other families. The continuity of care offered to nurses working in the home setting may be of appeal. Opposite of the hospital environment where you only work with a patient and family for a brief time, the home environment allows you the opportunity to understand more about a family unit and how that impacts the health of the child (especially over time). It can be very rewarding to see a patient and their family achieving their goals. For nurses who are going back to school, working in the home setting could allow opportunity to earn extra income while having time to complete coursework, particularly if working overnight.

Roy: The role of a homecare nurse is different from a hospital-based nurse. Here is a list of some of the aspects that help define a homecare nurse:

1. Autonomy and independence.
2. Long-term relationship with a family and their child.
3. Working in the community. Some nursing shifts may take place at school, the mall, an amusement park, appointments, and on occasion family trips.
4. Hands on experience. For example, in a hospital a respiratory therapist manages the ventilator but that domain falls under the auspices of the nurse in homecare.
5. The rewards of working in homecare include watching their patient thrive and witness growth, development, and milestones.
6. For nurses with aspirations beyond homecare, acquiring experience as a homecare nurse may help when seeking other employment opportunities

Is anyone aware of a state or region that is successfully implementing a trach/vent training/certification program for skilled home nurses that can lead to a higher reimbursement rate for those nurses?

Roy: As addressed in Dr. Foster's article there are specific programs in Seattle and Chicago for trach/vent training. Whether that translates into higher reimbursement is less clear. There are 2 different levels of reimbursement based on the complexity of the patient. Nurses employed in our agency may have different hourly rates of pay based on whether their degree is LPN or RN.
(<https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2018.05531>)

What are the key elements of training for home health care nurses that should be considered (e.g. format, location, topics)?

Roy: I would think most would agree standardizing home healthcare is paramount to improve the quality of home care services. There is a paucity of information on this topic. That was one of the key reasons our organization wrote 2 articles on pediatric home care nursing. Our articles are titled "The Ventilator-Dependent Child: What Every Home Health Nurse Needs to Know" and "The Ventilator-Dependent Child: Best Practices for Educating Home Care Nurses." These articles are published in *Home Healthcare Now*.

Research and Quality Measurement:

Please provide a link for the article that Dr. Maynard referenced

Roy: <https://pediatrics.aappublications.org/content/143/1/e20181951>

Do you know of any studies examining how money dedicated to home health care might decrease the need (and cost) associated with other placement options for children with complex medical conditions?

Roy: We have data comparing hospital costs to extended hours of home care nursing, (<https://pediatrics.aappublications.org/content/143/1/e20181951>), but I am not aware of any data comparing costs of extended hours of homecare nursing to transitional or long-term facility-based care.

Carolyn: Other publications to consider: <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2018.05531> and <https://www.ncbi.nlm.nih.gov/pubmed/31153586>

Coverage and Benefits:

How would you address public/private insurance use of "custodial care" to deny nursing and other home care? Do you have recommendations on points to use in an appeal?

Roy: The following links are from the section of home care AAP site. The first link addresses the AAP policy on financing home healthcare and provides additional resources for perusal. The second link provides templates of letters that may be helpful in addressing payment and financial issues. These examples are not endorsed by the AAP but families, possibly in conjunction with an attorney/ombudsman, may find this information helpful in addressing issues. The medical necessity letter/template may be most helpful for addressing an appeal for home care nursing. This template mentions the role of EPSDT in mandating home health services:

<https://www.healthychildren.org/English/family-life/health-management/health-insurance/Pages/Paying-for-Your-Childs-Home-Health-Care.aspx>

<https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/template-letters-sample-policies.aspx>

Molly: Many times private insurance denies services as custodial care knowing the state will most likely cover them instead. Federal CMS defines custodial and skilled care as follows:

Custodial:

- Consists of any non-medical care that can reasonably and safely be provided by non-licensed caregivers.
- Can take place at home or in a nursing facility.
- Involves help with daily activities like bathing and dressing. In some cases where care is received at home, care can also include help with household duties such as cooking and laundry.
- May be covered by Medicaid if care is provided in a nursing home setting and not at home.

Skilled:

- Is medically necessary care that can only be provided by or under the supervision of skilled or licensed medical personnel.
- Can be more costly than custodial care and can take place at home or in a skilled nursing facility.
- Examples include physical therapy, wound care, intravenous injections, catheter care, and more.
- May be covered by Medicaid.
- State Medicaid programs have different rules that determine when skilled care is medically necessary and payable by Medicaid.

Medicaid is required to cover skilled care under EPSDT for children under 21 and typically will cover under HCBS waivers for over 21. States individually define criteria to determine medical necessity, so that might be where things get complicated.

As far as points to use in an appeal, I think that the appellant must understand how medical necessity is being defined and then work with their primary or specialty care physician to demonstrate the care needs. If skilled care is already occurring in the home or other setting, nursing notes can be used as well. With any insurance appeal, good documentation from medical providers is extremely valuable.