March 24, 2020

Teresa Miller, Secretary
Department of Human Services
Commonwealth of Pennsylvania
333 Health & Welfare Building
Harrisburg, PA 17105

RE: COVID-19 and Children with Medical Complexity

Dear Secretary Miller:

The Imagine Different Coalition, formed in May of 2014, is a group of parents, advocates, professionals, and allies from across the state that has come together because of a common concern about the number of children with disabilities growing up in congregate care. As you know, the Coalition has focused its efforts to date on promoting well-supported and safe family life for Children with Medical Complexity. Given the public health crisis presented by COVID-19, we are compelled to write and urge that you take the measures outlined below so that our most vulnerable children are protected.

At the outset, please note that we emphatically agree with the recommendations of the Pennsylvania Health Law Project and others dated March 17, 2020 with respect to the Office of Medical Assistance Programs (excerpts attached), all of which are relevant to protecting children with medical complexity. We elaborate below on the subject of paying family members to provide extraordinary care for their children, and add the issue of environmental safety for in-home staff and the children they serve.

Payment to Family Members for Extraordinary Care

Parents have long been trusted to, indeed required to, provide skilled and unskilled extraordinary care to their children with medical complexity regardless of whether they have a nursing degree. Children are not discharged home from hospitals until their parents have been trained in their specific care needs. Parents routinely go without any level of respite, and often sacrifice the care needs of the rest of their family, to provide skilled, complex care to their medically fragile child. When authorized nurses or aides are not available, parents lose their jobs and go without sleep, all without pay. The COVID-19 crisis is exacerbating an already difficult situation. Parents should be permitted to be employed by home health agencies to provide extraordinary care for their children, and the process for doing this should be expedited during this pandemic.

There are compelling reasons to pay parents to provide care to their own children when nurses and aides are in short supply, and even more so at a time when many parents are required to be home, and when social distancing is
imperative for vulnerable children. First, children with medical complexity are at heightened risk of death from contracting the virus --thus a parent’s choice to expose their child to as few outsiders as possible should be honored and supported when possible. Second, parents willing and able to replace authorized nurses and aides to provide care for their own children would free up the limited supply of nurses and aides for other children at risk, especially those who need 24-hour awake supervision and care that cannot physically be provided by one parent, no matter how self-sacrificing. Finally, for children with medical complexity whose parents are suddenly out of work due to the crisis, replacement of some income may enable them to meet their family’s basic needs so they can provide critical care at home and reduce exposure. Otherwise, reduced income may put the child at risk of admission to an already over-taxed facility.

Our proposals must never be seen as an excuse to deny skilled nursing care to a child who has a skilled need. Rather, parents who choose to provide extraordinary care to their own children should be supported to do so, especially in this time of crisis.

1. A parent who is a nurse and who is willing to be employed by a nursing agency for the limited purpose of providing skilled care to their child should be permitted to do so, as long as their paid and unpaid hours are within safe limits as prescribed by state law.

2. A parent willing to be employed to provide non-skilled home health services to their child, should be permitted to do so, regardless of professional credentials.

Most children who are authorized for skilled nursing have both skilled and unskilled needs that are met by those nurses. For example, a child who needs 24-hour awake care by someone trained to handle their trach and ventilator will likely have a nurse authorized for 16-20 hours per day, with the parent expected to provide the remaining hours of care for free. In this situation, both nurses and parents provide assistance with feeding, bathing, transferring, and a myriad of other unskilled tasks, while also being prepared to intervene in medical emergencies, such as seizures or respiratory distress, as well as other skilled tasks specified in the plan of care such as medication administration. The Department should allow a parent to be employed by a home health agency to provide the unskilled care for 8-12 hours per day. The parent would still be available to provide the sporadic skilled care during those hours, just as the parent always does when a nurse is not there. This would provide families with much-needed revenue during this pandemic and would have the added benefit of freeing up a nurse for another child. In this scenario, a nurse or a second trained, willing and paid family member would need to relieve the parent for at least 8-12 hours per day for sleep and other tasks. For a child who sleeps through the night without oversight, or for a child with two willing parents, paying the parents might eliminate the need for an outsider to come into the home at all, thereby protecting the vulnerable child from possible exposure to COVID-19. (Note, whether parents should even be expected to provide free extraordinary care, and if so, how much, is a question for another post-crisis day.)

For these proposals to work, the Department will need to ensure that home health agencies understand that hiring parents is fully supported and encouraged by the Department and the process should be expedited so as to minimize any unnecessary bureaucratic procedures.
Finally, some parents who are home during the pandemic might be willing to accept a trained home health aide who can call on the parent in an emergency, in lieu of a nurse, if no nurse is available or if an agency requests them to do so in order to help a child at greater risk. This must never be required. Furthermore, a parent’s decision to accept a lower level of care during this pandemic should never be considered a long-term substitute for necessary skilled nursing or used as a reason to reduce the child’s level of care – e.g. from nursing to home health aide generally – during later prior authorization review periods.

**Environmental Safety Measures**

During the COVID-19 pandemic, families attending to the needs of their child’s medical complexities require access to suddenly scarce resources to structure a safe and sanitary environment. Children with medical complexity, especially those with suppressed immune systems, are at increased risk of infection and other health complications during this unprecedented time. That risk is greatly exacerbated by lack of access to essential guidance and supplies in the home health care setting. OMAP should ensure that the needs of medically fragile children at home are prioritized given their high-risk status and set up an emergency funding pool to address environmental issues that impede the safe and sterile provision of in-home medical care during this crisis. Identified environmental needs for in-home care include the following:

1. Guidance for agencies and families regarding implementing isolation and droplet protocols in home settings.
2. Personal protective equipment and supplies (e.g. masks, gowns, gloves, and other necessary protective clothing) for all nurses, aides and family members who interact with the child.
3. Cleaning and personal care supplies (e.g. sanitizing wipes, hand sanitizer, cleaning solutions).
4. Access to private transportation for nursing staff (e.g. use of rideshare services like Lyft and Uber, which is especially critical for those staff who otherwise rely on public transportation to get to the family’s home.)

The very real and significant threat to life posed by COVID-19 demands that government officials act expeditiously to ensure that families who are caring for medically complex children can do so within a safe environment, with all necessary supplies, and with financial support of their extraordinary efforts. We thank you for your immediate consideration, and your continued commitment to safe and healthy family life for children with medical complexity.

Sincerely,

*Liz Healey*  
Liz Healey, Co-Chair

*Kate Maus*  
Kate Maus, Co-Chair

CC:  
Sally Kozak, Deputy Secretary, OMAP  
Nancy Thaler, Special Assistant, DHS
**Office of Medical Assistance Programs**

- **Moratorium on Pediatric Shift Nursing Reductions**
  
  o Medically complex children rely on shift nursing to remain healthy, infection-free, and safe at home with their families. Due to the high risk of institutionalization that many children would face if their shift nursing hours are reduced, we urge DHS to direct all PH-MCOs and the Fee-for-Service program to suspend all terminations and reductions of shift nursing services.

- **Ensuring Sufficient Staffing of Approved Shift Nursing and Home Health Aide Services**
  
  o Many children rely on the critical support of home health nurses and aides to keep them alive and well. When authorized nurses or aides are not available, parents lose their jobs and go without sleep. Shortages of nurses have existed for a long time, but there is reason to expect that home health nurses, as well as aides, will be in substantially shorter supply during the pandemic, putting children’s lives at risk. The following recommendations are, for the time being, limited to addressing this short-term crisis:
    - Ensure that all MCOs pay for overtime and provide adequate incentives, such as rate increases and bonuses when nurses or aides go the extra mile.
    - Allow parents, on a voluntary basis and with appropriate home health agency supervision, to be paid to provide care to their own children at home, to the extent that they have the credentials to do so, freeing up nurses and aides for children who would otherwise be at risk, and limiting outside contact for children who are particularly vulnerable to the virus. It would be necessary for the Department to ensure that the MCOs cannot require parents to stay home to care for their children.
    - Gear up to quickly recruit and train more home health aides who are also in short supply.
    - Triage may become necessary. One parent cannot safely provide more than 16 hours of paid or unpaid care per day, and so for children who need round-the-clock skilled awake supervision, at least one outside nursing shift per day must be an absolute priority for coverage.

- **Special Needs Unit (SNU) Targeted Outreach**
  
  o SNU case workers should make telephonic outreach to the parents/guardians of all children receiving shift care services, to ensure that approved hours are being staffed to the fullest extent possible and that children with medical complexity are receiving other medically necessary services like prescriptions, supplies, formula, etc. It should also be the responsibility of the SNU case manager to connect the family with social supports and agencies such as grocery delivery, Lyft/Uber, and other social services that allow families of medically complex children to engage in social distancing to protect their child from illness exposure.