

# Employing Family Caregivers: An Innovative Health Care Model

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Providing high-quality care to children with medical complexity (CMC) requires more than a team of skilled physicians, nurses, and therapists. Family members also play a vital role in health care delivery. Through the considerable amount of complex health care that they provide in the home daily, family members are critical to the achievement of good health outcomes. Yet, family caregivers are not systematically valued in their role as providers of essential health care, which has significant consequences for families and society.

We describe an innovative health care model of paid family caregiving in Colorado and its effects on Ms Christy Blakely, a parent of a child with complex health needs. Ms Blakely is a professional advocate for CMC who partners on research grants with the remaining authors, all pediatric health care providers. Together, we work to evaluate how health care delivery models can achieve better patient health outcomes and support family wellness. Here, we aim to highlight Colorado's paid family caregiving model as one worthy of wider national consideration to improve the lives of children and their families.

## LIFE AS A PARENT OF A CHILD WITH MEDICAL COMPLEXITY

### Ms Blakely

Our daughter was born in 1982 at 36 weeks' gestation. She developed

what was then called hyaline membrane disease and suffered oxygen deprivation, which led to cerebral palsy. She was beautiful and demonstrated high cognitive intelligence early in life but met no physical developmental milestones throughout her childhood. She required full physical care, which meant that she needed assistance with all of the activities of daily living, including feeding, bathing, dressing, toileting, transferring, and mobility.

Doing my daughter's daily care was a struggle. Though I had a master's degree in special education, I often felt as though I was certified in everything but the care of my own daughter. Our days started at 4 AM, and nearly every minute was filled with medical tasks, phone calls, or appointments. I had no option but to stop working because I could no longer commit to the requirements of a classroom teacher. Our second daughter, born 1 year later, became independent faster than most because my attention was always focused on her sister. For example, she learned to French braid her own hair at a very young age, and I found myself embarrassed when others would comment on how beautifully I had done her hair.

At age 5 years, our oldest daughter began using a wheelchair and an augmentative communication device. When she entered elementary school, we received the Medicaid Home and Community-Based Services Waiver, which allowed access to home health

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Dr Carter and Ms Blakely conceptualized the work and drafted the initial manuscript; Drs Zuk, Brittan, and Foster conceptualized the work; and all authors reviewed and revised the manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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care that our private insurance did not cover. We were able to hire a certified nursing assistant (CNA) to come to our home in the morning to get my daughter up, showered, dressed, fed, and onto the bus. The idea was that I would then have time to prepare her sibling and myself for the day and that I could return to work. However, like other families relying on traditional, nonfamily caregiver CNAs, we struggled with frustrating gaps in services because of no-shows and overall staffing shortages that often left us without the help that we needed on short notice, such as a snow day that you don't expect.

### CHALLENGES FACING FAMILY CAREGIVERS OF CHILDREN WITH MEDICAL COMPLEXITY

#### Dr Carter

Though Ms Blakely's story is uniquely her own, it is representative of the stories of many other families who must care for their CMC while also earning a living. CMC are children with 1 or more complex chronic conditions that result in functional limitations and/or medical technology dependence.<sup>1</sup> CMC typically use large amounts of health resources through long hospitalizations, complex surgeries, and the need for multiple subspecialists. Although CMC comprise only 3 in 50 children with Medicaid, they account for 1 in 3 dollars of Medicaid spending for children nationally, a massive proportion that represented US \$1.6 billion in 2011.<sup>2</sup>

Despite this price tag, the current calculated spending on health care for CMC does not account for the substantial, daily, unpaid medical care provided by their family members, particularly for children with neurologic impairment and medical technology dependence. For

example, at least half of US family caregivers like Ms Blakely who have children with cerebral palsy spend  $\geq 21$  hours per week providing health care at home for their children.<sup>3</sup> Exacerbating this trend is a chronically understaffed, underfunded, and undertrained pediatric home health workforce, leading to haphazard and sometimes poor-quality home care for this underserved population.<sup>4</sup>

As Ms Blakely's story highlights, the need for family caregivers to provide such large amounts of complicated health care has significant consequences. Family caregivers often are not able to make time for their own health care needs and may face emotional stress and physical strain.<sup>5</sup> Many family caregivers must stop working outside of the home or decrease their employment hours to provide this sort of care for their children,<sup>6</sup> which frequently causes financial hardships for the families and detracts from the overall US workforce.

While the United States has some government policies related to unemployment, family and children, and disability and caregiver financial supports, many of those benefits are not available to parents of children with chronic conditions who are not currently employed or seeking employment.<sup>7</sup> Thus, there is a critical need for our health care system to:

1. value family caregivers for the crucial role they play in keeping their children well each day and achieving good patient outcomes; and
2. devise creative solutions to the simultaneous problems of family caregiver under- and unemployment and home health care workforce shortages.

### COLORADO'S PAID FAMILY CNA MODEL

#### Ms Blakely and Dr Carter

In 2001, families, community advocates, and Colorado lawmakers collaborated to establish a program within Medicaid that would allow family members, including parents, to be paid as CNAs for their own CMC.<sup>8</sup> Though the program requires additional commitment and effort from the family caregiver, it values families' work and has the potential to lessen their financial hardships and decrease the time their children are hospitalized.

To participate, the child must first qualify for CNA services through an agency-administered standardized assessment tool that identifies needs for activities of daily living assistance and medical tasks. Examples of medical needs relevant to eligibility include supplemental oxygen, secretion management, tube feedings, and repositioning to prevent skin breakdown.

The family caregiver must then become a licensed CNA in Colorado by completing an approved nurse assistant training program and must also pass a written and clinical exam. After achieving licensure, the family caregiver needs to be hired by a home health care agency that provides oversight and quality assurance. Many home health agencies seeking to hire the family caregiver will assist with the cost of training and testing. The pay for family members who serve as their child's CNA is no different from traditional CNAs, typically between \$13 and \$17 per hour. Currently, there is no maximum number of hours that a parent can serve in this role.

Despite the expressed popularity of the program among parent-led networks, little has been published about this model, and many health

care providers and eligible families are still unaware of its existence.

## EXPERIENCE AS A PARENT CNA

### Ms Blakely

When our daughter was born, I was taught how to place a nasogastric tube before she was discharged. Over the years, I acquired additional medical skills to meet her needs by piecing together knowledge from isolated, hospital-based skill trainings and conversations with medical equipment companies or other parents. However, I wished that I could have received more formal training to do all that I needed to do.

A friend of mine was one of the first advocates for Colorado's paid family caregiver model, and she introduced me to the program. I was amazed that I could be trained as a CNA and could then be paid to meet my daughter's health care needs, eliminating the unpredictability of traditional CNA services.

The 4-week class that I took through the home health care agency was geared toward parents becoming CNAs. It was scheduled at "family-friendly" hours, and the only costs were for the testing and licensure. The class included practical components, with several days of field experience. The field experience was somewhat scary because it mainly involved learning tasks by caring for adults, even though I really was learning so that I could care for my own child.

Despite the challenge, the CNA training was invaluable. It improved my ability to direct my daughter's care, eased the financial burden of both under- and unemployment, and decreased my overall stress. Additionally, the CNA skills were transferable to situations outside of our home. For example, I was able to share my knowledge with friends

who were caring for loved ones with complex medical conditions, and I felt more prepared to care for my mother when she entered hospice.

Through my work as a professional advocate, I have also witnessed the significant benefit of Colorado's paid family CNA program for many other participants, particularly for single parents who can then stay home and care for their children. The program gives families options and flexibility.

Those options and flexibility allowed our family to successfully care for our daughter. Today, she lives in a home of her own with a partner who also has cerebral palsy. She is thriving and manages most of her own scheduling and appointments. Her physical care has become more complex, but we all take pride in her achievements.

## PROGRAM CHALLENGES AND FUTURE NEEDS

### Ms Blakely and Drs Carter, Zuk, Brittan, and Foster

To date, very few states have implemented models of paid family caregiving, which greatly limits the potential impact that wider adoption could have on children and families. Many states have been slow to adopt similar models on the basis of the assumption that they require budgetary increases. In actuality, such programs represent budget-neutral options because the states' legal obligation to provide home health care benefits to eligible children does not change on the basis of whether family members or others are reimbursed for CNA services. Through the information described here and through our greater research efforts, we hope to contribute to a future in which every state has established a model of paid family caregiving.

However, parents without traditional CNA support may find themselves more isolated with little or no respite.<sup>9</sup> Thus, incorporating options for respite services into paid family caregiver models is essential. Furthermore, as families come to rely on the income, they may face financial insecurity with a loss of that income as the child ages or dies. Interested participating family members who acquire skills and licensure through the program should be proactively supported in leveraging future employment opportunities as CNAs elsewhere.

## ADDITIONAL WAYS TO SUPPORT FAMILY CAREGIVERS OF CMC

### Ms Blakely and Drs Carter, Zuk, Brittan, and Foster

We encourage all health care providers of CMC to dedicate time with their patients and families to ask about life at home. Too often, we do not step back to have the important, if difficult, conversation about what day-to-day life entails when caring for a child with high medical needs and how that might be impacting the family financially, emotionally, and physically. When those conversations do happen, we often learn that caregivers are suffering, and challenges that were already immense have only been further exacerbated by the coronavirus disease 2019 pandemic. Those conversations are the first steps in valuing family caregivers and assisting them in determining what programs might best support them.

Parent-led organizations and networks are also invaluable resources for helping families to find the combination of services that is right for them. Organizations such as Family Voices, Family-to-Family Health Information Centers, Parent-to-Parent, and Federation of Families can assist families and

providers in navigating complicated Medicaid waiver information and have extensive knowledge of health care service eligibility and coverage. They are also among the strongest advocates for health care system change for CMC, including the expansion of paid family caregiver programs. We encourage all providers and the families they care for to become connected to these organizations.

## CONCLUSIONS

There is a crucial need to address family caregiver under- and unemployment and home health care workforce shortages for CMC. Policy makers, advocates, providers, and health care systems should become familiar with Colorado's paid family CNA model for potential adoption locally and nationally as a budget-neutral way to address those critical issues.

To learn whether your state has or is creating a paid family caregiver program, contact your local family-driven organizations or your local American Academy of Pediatrics chapter. You also can visit the National Academy for State Health Policy for suggestions about how to develop programs and policies that

support family caregivers.<sup>10</sup> Together, we can work to keep children out of the hospital by supporting them and their families in the fullest ways possible.

## ABBREVIATIONS

CNA: certified nursing assistant  
CMC: children with medical complexity

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