

H.B. 64 Budget Testimony, FY 2016-2017

Charisse N. Montgomery, M.A., M.Ed.

Chairman Smith, Ranking Member Driehaus and Members of the House Finance Committee, my name is Charisse Montgomery. I am a mother, an author, an advocate, and a member of the Lucas County Board of Developmental Disabilities. *Thank you for allowing me to testify today in opposition of the proposed elimination of independent providers in H.B. 64.*

I am here to present the parent perspective on phasing out independent providers, but I also speak from the perspective gained through my academic credentials, which include master's degrees in English and Educational Psychology, with my research for the latter focused on empowering the parents of medically complex children. I am currently completing a graduate certificate in patient advocacy, and I have authored a book entitled *Home Care CEO: A Parent's Guide to Managing In-Home Pediatric Nursing*. Most importantly, however, I am Richie's mother. Richie is a precocious, charming three-year-old who was born with fiber-type disproportion myopathy, a debilitating muscle condition.

As the parent of a technology dependent child with significant disabilities, in-home nursing has been essential to my family. Having excellent caregivers in our home has allowed my husband and me to pursue our career goals, while knowing that our son is receiving quality care. Over the past three years, both agency nurses and independent providers have cared for our son.

When Richie first came home from the hospital with a tracheostomy, feeding tube, ventilator and other complex medical equipment, we used the two nursing agencies in our city that specialize in serving the pediatric population. While we had some success with these agencies, we quickly discovered the flaw in the agency model – quantity over quality. As a parent, my primary goal is ensuring excellent care for my son, and in our experience, the agencies have seemed primarily concerned about filling a time slot that allows them to bill for hours. The agencies sent some good nurses, but they often sent nurses who had the appropriate credentials but who were sorely lacking in professionalism, expertise and experience to manage our son's needs. Our frustration with these nurses led me to write *Home Care CEO* as a way to place the power of choice into the hands of the consumers who use nursing services.

We also began to find independent providers who could fill the gaps in our schedule with the skills and experience our son needed. We have found that independent providers, because they have to manage their own caseloads, are well organized and reliable. Because independent providers only work when a child is at home and not hospitalized, I have found that they are proactive about keeping our son healthy.

Currently, three agency nurses work in our home, along with three independent providers. Over the past three years, I have asked at least two dozen agency nurses not to return to our

home due to poor performance, ranging from not giving medications as prescribed to major unusual events like neglect and abuse. These cases, by the way, were not handled appropriately by the agencies for which the nurses worked. By contrast, our success with independent providers has been much greater, and I have only had to let go of two, one for inadequate experience and one for attendance.

The independent providers who work in our home have expressed frustration with the frequent and often unannounced changes in procedures for billing and documentation. When these changes occur without proper communication, the nurses are penalized for errors, which are now being called fraud. Independent providers continue to adapt to these changes in order to maintain their provider status, despite the flaws in the system.

The new plan for independent providers tells us, the consumers, that we will be able to keep our independent providers if we want to. However, the details of this part of the plan are unclear, leaving families skeptical that the state has the best interests of our children in mind. Taking away our ability to choose the care providers for our children ties our hands and leaves us at the mercy of agencies that may not manage quality effectively. The numbers show that parents do not support this change, and we fear that excellent independent nurses will leave the state or the profession before cutting their own pay in half to work for an agency.

I sincerely hope that in considering the finances involved in this issue, the committee also considers that expensive hospitalizations, as well as cases of abuse and neglect, are likely to increase when care is managed poorly. The social costs may also include increased institutionalization of children with more complex needs, which contradicts the goal of community-based care. I know that I speak for parents across Ohio when I say that disempowering us by phasing out independent providers does not meet the needs of our medically complex children. We are the voices of our children, the faces of self-determination, and we soundly oppose the elimination of independent providers.