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PRACTICE FOCUS: DISABILITY RIGHTS



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We can only hope that state leaders learn that cutting budgets at the expense of at-risk children rarely delivers the result one expects – and it could lead to a class action that is certified and a federal court injunction, writes Howard M. Talenfeld of Colodny, Fass, Talenfeld, Karlinsky, Abate & Webb.

More must be done for at-risk children and their parents

By Howard M. Talenfeld

To any Florida attorney who fights to protect the rights of and prevent damages to severely disabled children, the past several years have been tough to watch.

Children with highly complex medical conditions and who had been cared for by their parents or guardians have been wrongly denied skilled, private duty nursing hours to assist in the care. Left little choice, some parents were forced to send the children to institutions, including nursing homes.

Many children suffered. A few died.

Most galling was the rationale. The move was an attempt by Florida's Agency for Health Care Administration to balance its budget on the backs of Florida's medically fragile children and their parents who want to care for them at home.

AHCA's rules of Parental Responsibility for Home Health Services, as implemented through its contracted agent, eQHealth Solutions, severely reduced the number of hours that they are willing to reimburse parents for medically necessary private duty nurses. The reductions were not only an abomination, but they were a violation of federal law, charged a federal class action lawsuit and a U.S. Justice Department investigation.

AHCA and eQHealth Solutions ignored the medical histories and the number of hours these parents have historically received and were entitled to in an attempt to force the parents, many of whom have full-time jobs, to care for these children instead of paying for private duty nurses. Many of these children are on ventilators or have tracheotomy tubes to breathe and gastrostomy tubes to feed. The lawsuit charged that the reductions in hours forced parents to give up their children to pediatric nursing homes.

AHCA and eQHealth Solutions have also ignored the capacities, or lack thereof, for many of the parents to assess emergencies and intervene with life-saving procedures. If you elect to care for your child at home, the thinking went, then you must be prepared to perform complex medical tasks beyond the scope of almost any parent.

For too long, this was a heart-wrenching, frustrating, even enraging episode in the state's pursuit of privatized management of key social services. Some called it unjust.

This month it might change.

Quietly and with little fanfare, AHCA has recently revised its rules. It amended language in the Florida Medicaid Home Health Coverage and Limitations Handbook and the Florida Medicaid Prescribed Pediatric Extended Care Coverage and Limitations Handbook "to more accurately describe the process for evaluating parental responsibility when reviewing requests for both private duty nursing and PPEC services for children under the age of 21."

Among the changes, along with assigning care coordinators for those receiving private-duty nursing services via Medicaid, teams of healthcare professionals and doctors, as well as parents, will confer on care. This may be a significant change, given how parental scheduling, work burdens and their lack of nursing skills often were not considered material in determining when or whether to provide nursing care.

Children may also have the chance to be enrolled in medical day care centers. Medically needy kids will receive care, and possibly an education, regardless of whether the parents work. It previously required that the parents work to receive such services.

In short, AHCA wrote that when determining the need for private duty nursing services, the agency will not require that parents participate to the fullest extent possible in performing skilled interventions that normally could only be provided by a licensed nurse. Instead, "If the parents or legal guardians are willing and capable of providing more than activities of daily living and instrumental activities of daily living care, private duty nursing services can be authorized to supplement the care provided by those parents or legal guardians."

The changes, which must be approved as part of a rule-making process, could, if fully implemented, affect some 1,600 kids statewide. And AHCA may now pay for these services.

Why did AHCA implement the changes? Maybe it was the deaths of several juveniles — and the class action lawsuit that was filed. Maybe it was the ongoing negotiations with civil rights attorneys from the U.S. Justice Department. Maybe it was the widespread press coverage concerning the apparently arbitrary nature of eQHealth Solutions definition of "medical necessity."

According to some reports, eQHealth saved almost \$45 million over one year by limiting private-duty nurses and other caregivers. But at what ultimate price?

Life-saving medical procedures should not be performed by parents, albeit those committed to providing the best possible care to their children, yet not trained professionally to do so. That's why AHCA is supposed to budget for such care.

This sad episode in Florida's care for its severely disabled and medically needy children may not yet fully come to a close. Though AHCA's change could be an improvement, work still needs to be done to help kids — and their parents.

In the end, though, we can only hope that state leaders learn that cutting budgets at the expense of at-risk children rarely delivers the results one expects — and it could lead to a class action that is certified and a federal court injunction.

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