

COMMENTARY

Better way is needed to help developmentally disabled

By Cindy Barkowski and Patrick J. Curran

As parents and families of developmentally disabled individuals, we are uniquely positioned to understand what it takes, mentally, physically and emotionally, to care for a disabled loved one, and no one is more concerned with their safety, health and well-being; they are our children, grandchildren and brothers and sisters.

In recent years, we've seen a number of troubling developments — a federally driven move toward “managed care”; a desperate need for residential options; the unwillingness of government to provide direct-care workers with a living wage, much less anything approaching what they actually deserve; and now the unforeseen impacts of the New York State Justice Center on the already difficult problem of attracting and retaining capable, compassionate direct care workers. All this has made it almost inevitable that families of the disabled would be galvanized into collective action.

The Eastern New York Developmental Disability Advocates, an independent, all-volunteer organization of hundreds of parents, families and friends of disabled individuals in the greater Capitol Region was created over 18 months ago to advocate for our family members and educate policymakers and the public on matters impacting the developmentally disabled, in order to enhance their lives and better protect their health, safety and well-being. ENYDDA takes no government or provider agency money.

• *Cindy Barkowski of Schenectady chairs Eastern New York Developmental Disability Advocates' Communications and Outreach Committee. Patrick J. Curran of Slingerlands is co-chair of the Government Relations Committee. Both are on its steering committee.* agency money.

In 2012, the NYS Justice Center was created and charged with protecting the health and safety of people with special needs and investigating all allegations of abuse and neglect. While the Justice Center has recently received a great deal of criticism, from ENYDDA's perspective much of it misses the mark and fails to grasp the most significant consequences of the center's actions. By contrast, we strongly support the Times Union's call to address the unintended, less publicized, but very real ways in which the Justice Center has negatively impacted the care and well-being of our disabled children (“Justice Demands Fairness,” Oct. 12).

We are deeply concerned about the Justice Center's broadly applied, heavy-handed criminal investigation-style practices. This punitive and relatively indiscriminate approach is driving away and discouraging many capable, compassionate caregivers from jobs that are already

among the most challenging, underappreciated and underpaid in society. It is exacerbating a staffing crisis, turning it into a pending disaster.

In a field where continuity of care is singularly connected to quality of care, we see increasing instances of understaffing and an extremely high rate of turnover. Among the shrinking number of direct-care workers who choose to remain, despite challenging conditions and being grossly underpaid, there is a growing atmosphere of fear, tension and over-caution.

The result is that the Justice Center has had a negative impact on the quality of care and well-being of a vastly greater number of disabled individuals than it has helped, far out of proportion to any good it may have done by pursuing actual cases of serious abuse beyond the extent to which they would have already been pursued prior the Justice Center's creation.

We understand, as few do, what the daily care of even one disabled person involves managing people who are often essentially small children in handicapped adult-sized bodies with all kinds of physical, emotional, behavioral and/or psychological issues. It's hard to imagine what it takes to care for several such people simultaneously, each with his or her own unique needs and challenges.

Accidents and incidents typical of those that occur with any child, and some not so typical, will occur in the normal course of care, and perhaps with even greater frequency.

But to make each of these incidents the basis of a criminal-style investigation, with suspensions, interrogations without benefit of counsel, and permanent notes on worker's records, while perhaps well-intentioned, has proven counterproductive, and is damaging the very workforce that is essential to providing this vital care.

Ironically, recent calls for the Justice Center to become even tougher and more prosecutorial in its investigation and handling of incidents are exactly the opposite of what is needed. It would only compound past tragedies to let our grief and anger over cases of abuse and even death so skew the way we oversee caregivers as to compromise that care altogether, and thus jeopardize the lives and well-being of so many others.

The stated mission of the Justice Center is fundamentally important, and we support it. The Justice Center may even be the right tool for achieving that mission. But the way in which it is going about its work is actually having the opposite net effect, and is diminishing the quality of care for a far greater number of disabled than it is helping.

It seems to us this can be fixed, and we stand ready, with thousands of other families around the state, to work together with the Executive Department, the Legislature and everyone involved, to find a better way.

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