

Care Providers Take Responsibility To Heart

By Patrick J. Johnson Jr.

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In late February, Richard C. Brown, 81 - worried about his family being a burden - shot and killed his wife Martha, 80 and their children, Kenneth, 53, and Janice, 49, before committing suicide in his Enfield home.

A note Mr. Brown left behind explained that he and his wife had health problems and his children, both of whom had intellectual disabilities, were also dealing with illnesses. Although his children lived in group homes, he was worried about their care when he and his wife died.

Aftershocks from this tragic event are still being felt.

Mr. Brown spent his life devoted to his family and as an extraordinary advocate on behalf of people with disabilities. He helped found Friends of Retarded Citizens of Connecticut and was serving on its board when he died. He was affiliated with and served on the board of a number of similar groups. No one truly knows the answer to the question "why." Nor are we ever likely to.

What we can do is try to understand the desperation confronting parents with children who happen to have a disability. It can often appear that no one cares.

As one parent said to me at the Mental Retardation Council meeting a few weeks ago, "Unless you've walked in our shoes you have no right to judge!"

So the rest of us are left with the challenge of understanding a kind of existential reality where human beings are responsible for their actions, but sometimes those actions are guided by feelings of dread and anguish. Here are some thoughts to consider as we reflect on the lives and death of the Brown family:

Think about the courage it takes for parents to turn over most of the responsibility for their child to total strangers.

Think about the tremendous honor it is for those of us who provide residential care for children with disabilities to be asked by a parent or guardian to care for their loved one.

Think about the awesome responsibility that providers for people with disabilities individually and collectively assume when we accept the honor of caring for those we serve and support.

Imagine how easily a service provider can feel that the quality of life and, in many cases, the very lives of our program participants are in our hands.

At some point, the care providers can become the surrogate parents. When parents and guardians are still among us, they may sometimes wonder if their decision was right. In some cases they micromanage what we do. But even as they age, their presence assures some level of oversight regardless of whether they are still able to visit. But when they are gone, it is the care provider who often fills that role.

In many ways all of us who provide services today for the 19,498 people in our state with intellectual disabilities owe a tremendous debt of gratitude to Richard and Martha Brown and the parents of their generation who succeeded in getting people out of institutions and into community-based care.

Care providers for people with disabilities show parents and guardians by word and deed that their loved ones are safe and well cared for. We constantly reflect on what an honor it is to be chosen as caregivers by families who place the most profound trust of all, the care of their children, in our hands.

At the Browns' funeral, a nephew from Tennessee provided a poignant message to the day program and group home staff of the agencies that cared for Kenneth and Janice Brown. He thanked them for their extraordinary professional and loving care and reassured them that his uncle Richard's tragic decision had nothing to do with the quality of care they provided.

All of us who provide continuity of care for people with disabilities need to remember that parents of the children we care for can still influence what we cannot control - the future. In the final analysis, we create for those we serve the opportunity to experience faith, hope and love. Often what counts the most can't be counted.

Speaking not as president of Oak Hill, but as a member of a family with a loved one who is disabled and needs special care, I thank every service provider for the work you do so well and the role you play in providing for and creating a life of opportunity for people with disabilities.

May the Brown family rest in peace.

Patrick J. Johnson Jr. is president of Oak Hill in Hartford, a nonprofit provider of services for people with disabilities.