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VOR calls for compassionate advocacy and politics.

Caregivers of people with profound intellectual disabilities need options, not abandonment

It's hard for average families to fathom what would drive a mother to abandon her disabled daughter, as reported by the *Daily Herald*, a Suburban Chicago newspaper ("[Algonquin mom: Leaving disabled woman in Tennessee was best](#)," July 7). Yet, this story is repeated across the country, often with "murder-suicide" being the escape for those involved.

Advocacy and politics have reduced and, in some areas, eliminated specialized care options for people with intellectual and developmental disabilities (ID/DD), resulting predictable tragedies.

Elderly parents are forced to care for middle-aged disabled children long beyond humane standards. In other situations, individuals with profound ID/DD with complex, 24/7 needs are cared for by underpaid, untrained staff. Tragedies are predictable.

"I feel for the mom in Illinois who left her disabled daughter in Tennessee for better care and for the families in California, Connecticut and elsewhere who felt their only escape was death," remarked Sybil Finken, VOR's immediate past president. "Imagine the desperation they must have felt."

Finken and her peers across the country know first-hand the challenges of caring for disabled children. Like many VOR members, Finken found solace in a quality out-of-home residential placement for her son, Seth, who has profound ID/DD, is deaf, blind, has a significant seizure disorder, is non-ambulatory and non-communicative.

"He's totally dependent on the compassion of skilled caregivers. My husband and I just could not do it, though it broke our hearts to admit that in 1984," said Finken. "Fortunately, Glenwood Resource Center (GRC) is practically in our backyard and they accepted him. Today, families are not so fortunate. So-called advocates and government lawyers have targeted good places like GRC, resulting in closures all across the country. It's shameful. Families are left totally stranded and without any good options."

Some families are driven to the breaking point. Hundreds of thousands of other individuals with ID/DD languish and they and their families wait years, sometimes decades, for adequate services.

VOR calls on advocates, elected officials, policymakers and citizens to come together and commit the resources necessary to providing our needy citizens the services they require in care settings best able to accommodate their needs. Very often, that is not the family home or even a small group home. Families need our collective compassion, not our abandonment.

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VOR (www.vor.net) is a national, non-profit organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities.



Seth Finken with his mother, Sybil, at Seth's home at Glenwood Resource Center, licensed residential facility for persons with profound intellectual disabilities.