A Remembrance with Gratitude Don Putnam

Ten years ago this summer, I was fortunate to begin a rich friendship with Don Putnam. I met Don briefly in Washington, D.C. at the 2007 annual meeting of the national organization VOR where we connected quickly, employing the shortcut language which "survivor - warrior -families" - those of us whose loved ones have lifelong disabilities - use. That summer, I was beginning a project to summarize in one document the many examples I and others had collected and which families could use to show how federal funds had been used and were being used to undermine and eliminate congregate care facilities for people unable to care for themselves. Over a period of months, until February, 2008, Don and a small group of advocates and I worked over the phone and through e-mail messages to produce a document which grew to 50 pages. During the project, I communicated almost daily with Don and others in the shared belief that we were speaking out for our family members and also for their peers, present and future, those with slight or no awareness of danger, those unable to voice their hurts and needs, individuals with profound cognitive deficits. We acted with a sense of urgency and we felt engaged in a noble undertaking, a project with the potential to right a great public wrong. We hoped the document would be used in support of at-risk-persons, giving voice to them and to their care needs while also acting to protect the option of congregate care settings, where we knew from personal experiences that trained staff were successful in assisting grown men and women unable to care for themselves to be healthy, safe and clean in settings where they could move freely and with safety, and where routine medical, dental, skillbuilding-training and other support services were located on-site. We were driven by the love and concern we shared for our family members with disabilities, and more: for persons, present and future, who had no one to speak for them and who all their lives would need the protection of others for their very survival.

By the time the project was submitted to VOR, I had come to rely on Don for his detailed fact-checking editing work and I had also become acquainted with his commitment and work to strengthen Oakwood Center. Don's exceptional military experiences, his successful careers and organizational talents were evident when he participated in advocacy work in behalf of at-risk citizens on both state and national

initiatives. He worked tirelessly to build up the organizations in which he was involved and he was selfless in his quest to empower fellow advocates. He reviewed information and activities of many groups and agencies which he summarized and passed on to those of us without the talent for research. Our mutual advocacy projects – large and small – followed through the years. When he fell ill, I joined others in praying for him and for Nora. We continued to correspond and he continued to send messages of support and information. My last message from Don – his wise voice – came three weeks before he died.

The oldest of our three children, John, whose severe brain injuries were evidenced from birth, will turn 49 this year. Forty-nine! The wonder that he – and we – have survived the terrifying, grievous and incomprehensible realities of our son's lifelong disabilities is humbling. Don and Nora's son David is our son's peer. We share a bond with the Putnam family. We have been strengthened and we have endured because of the warrior – like efforts of fathers, mothers, sisters, brothers and other family members and friends working to achieve good human services policies for those unable to care for themselves. Don Putnam was a father, advocate and friend writ large. I will forever be grateful for his tenacity, leadership and humanity, and for his friendship. I miss him sorely.

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