Rotary eClub
of the Southwest USA
A Rotary International eClub

To the members and guests of the Rotary eClub of the Southwest USA:

Thank you for giving me the chance to tell a story which I believe is one that allows us to see something important about ourselves and our society. I hope that what I tell you will help you to better understand some of the most vulnerable people in your own communities.

I am the mother of an autistic and mentally retarded son, Frank David Selman. At twenty-four, Frank David is one of the thousands of developmentally disabled adults living in this nation's Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). Although they make up only a small percentage of America's population, all their stories are important, but I can tell only one. Here is Frank David's.

Born three weeks early, Frank David came into the world with several noticeable handicaps, as well as others not immediately apparent. He showed little interest in food and gained no weight during the first month, prompting his doctors to label him a "failure to thrive" baby. Over the next year he would undergo surgery to correct a heart murmur and be fitted with braces for a clubfoot. He suffered frequent respiratory infections and intestinal problems, and he never slept for more than two hours straight. (He would be thirteen before he slept through the night.) A month rarely passed that we didn't make the two hundred-and-seventy-mile round trip to Arkansas Children's Hospital in Little Rock for treatment of his various problems. He was so tiny, so frail, so different from other babies.

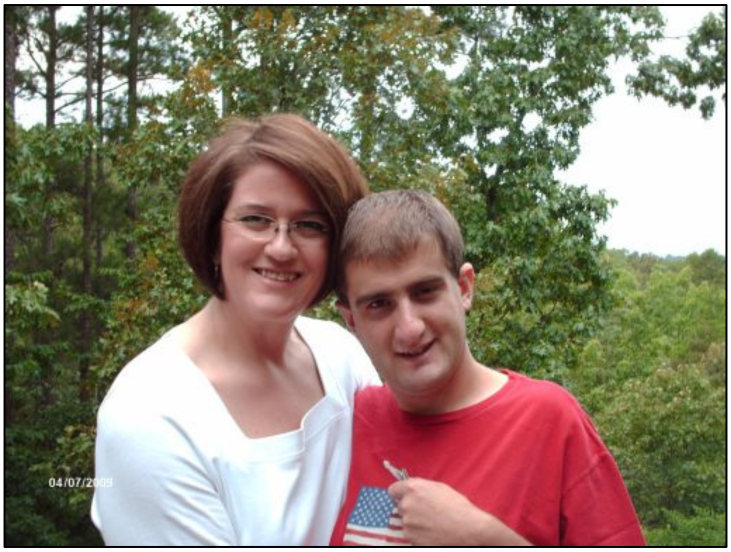
But oh how he was loved! His grandparents, his teenage brothers and sister, and my husband Frank and I kept trying to find new ways to engage his attention and to make him laugh. To his toys and other toddlers he was largely indifferent. He often shrieked in fear over an unfamiliar object or situation and could be calmed only by a car ride, lulled by its motion and comforted by its enclosed space. In fact, we learned early in his life that he was his happiest, most predictable self when strapped in his car seat, cruising down the road, and listening to country music. His odd speech (reversal of pronouns, echolalia, and difficulty in connecting words into even short sentences) and his compulsive behavior worried us; his illnesses left us drained and frightened. However, his good moments made all our efforts worth while. When he laughed, life was good.

The years passed. We all became adept at devising new strategies to manage him at every stage of childhood. With the loving help of many caregivers, childcare programs, family, and a supportive community, Frank was able to build a thriving optometric practice, and I continued as an English professor at Southern Arkansas University in our home town of Magnolia. At age six, Frank David's size and health had improved enough for him to enter kindergarten, where, after a few rough weeks of disruptive behavior, he was assigned the first of the succession of teaching aides who would be with him throughout his public school career. When he was eight, after many doctors, tests, and evaluations, we finally received the official diagnosis we long expected: moderate to severe autism and mental retardation, qualifying him for a full array of special education programs and therapists provided through the schools. Although more than a few times he became so uncontrollable that we would be called to take him home, his teachers' patience and the predictable structure of school life kept him happy. He believed the entire Magnolia school system had been set up just for him.

Numbers meant little to him, and he never learned to process whole sentences.  But he could easily read single words, familiar phrases, logos, and common signs.  Everyone celebrated the day in the fifth grade when he wrote his name all by himself.

What continued to enthrall him were cars.  By the time he was in elementary school he could name every brand and model of vehicles, identify their keys, and tell us who drove what.  Getting rides in our friends' cars became his greatest treat.  He found rental cars especially absorbing.  We often drove to the Shreveport airport, ninety miles to the south, to rent cars for the long drive to the Florida Panhandle.  They kept him focused and content for the entire vacation.  When U-Save Car and Truck Rental opened an office in Magnolia in 2001, Frank David was overjoyed.  Visiting U-Save's cars and keys quickly developed into a daily ritual.  For the grand opening of a larger office near the college, the agency's founder sent him a company jacket and wanted a story about him for its newsletter.  It appeared in the fall issue of 2005 with the headline, "Our Greatest Fan of All."

His graduation in May crowned an exciting senior year of homecoming, senior pictures, the obligatory ring, and other 2005 paraphernalia, church recognition day, and a prom complete with a date, flowers, and tuxedo.  Proudly dressed in cap and gown, he played his part perfectly in the final ceremony.  It turned out to be the high point of his life at home with us.  Because of his special needs eligibility, we decided to keep him in high school for another year.



But we misjudged the effects his age and the absence of his former classmates would have. Throughout his life he had episodes of bizarre, uncontrollable behavior. We were familiar with these autistic explosions and knew how to survive them. In the autumn of 2005, however, they increased in number and intensity. His impulsivity put him in increasing danger, for he ran across the highway in front of our house frequently, walked into neighboring homes without knocking, and several times tried to jump out of my car when he saw a parked car that interested him. More and more, I was called by an exhausted teacher who couldn't manage him. No medication could calm him. My husband and I sadly realized that we could no longer control nor protect him and that we must find a suitable place for his long term care.

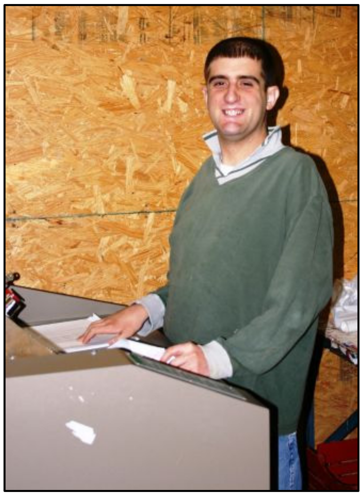
Thus began months of painstaking research, visits and interviews, medical evaluations, and endless forms. We finally decided to apply to the Arkadelphia Human Development Center (AHDC), closest of Arkansas's six large intermediate care facilities. These institutions provide 24-hour supervision, job training classes for residents who are physically able, medical monitoring by an on-campus staff of nurses, quick access to doctors and dentists, and a wide range of lively social activities. One tearful September morning when I had struggled to prevent him from entering a neighbor's house down the road, a providential call came from Arkadelphia. A young men's group home on its 330-acre campus had a place for him. We moved him into it that day and wept all eighty miles of the journey home, wondering how we could have done such a thing. Our answer came the next weekend, when we returned to Arkadelphia for the family day picnic and found Frank David too busy with his new friends to spend much time with us. We were thrilled.

Frank David has lived there for almost three years now and has settled in the comfortable routine of his life very well. He still has his odd moments, like the time he flushed all his housemates' toothbrushes down the toilet, but in general he behaves himself. As he did in the public schools, he has attached himself to the center's staff, who number over one hundred (roughly equal to the number of residents) and whose schedules, cars, and keys he quickly memorized. His favorite activity, of course, is getting to go anywhere in one of the official state cars or vans. He has participated in some great field trips—to Little Rock for the State Fair, the zoo, and the Harlem Globetrotters' exhibition; to Hot Springs to enjoy the crowd and eat the fifty-cent corned beef sandwiches that are sold the opening day of the horse races; to local movies; to nearby Lake DeGray for picnics and Independence Day fireworks; to football, basketball, and baseball games at Arkadelphia High School and at Henderson and Ouachita Baptist Universities; and to many Special Olympics events all over the state. The on-campus rewards for residents whose behavior has been exemplary are also considerable: cafeteria passes for lunch with the staff and vehicle passes for in-town forays to Sonic. Because AHDC is now in partnership with Clark County's recycling efforts, his work week duties have expanded from the wood working shop to include the recycling center, and he is enjoying the opportunities he has to be outside, tearing apart boxes and bundling cardboard. We see him often, at least twice every month, and still include him in most family vacations. He loves coming home, particularly for weddings and other special events, such as his favorite, the mid-May Magnolia Blossom Festival and World Championship Steak Cook-off, but after three or four days anywhere

he's always ready to go back to his life on the pine-covered campus of AHDC.

Now, sadly, the very existence of this nation's remaining ICFs/MR as well as the happiness and well-being of Frank David, his friends, and the thousands of other severely mentally retarded citizens dependent on these institutions, is severely threatened by the groups within the Department of Developmental Disabilities, operating within the Department of Health and Human Services in Washington. Led by ideologues who argue that these people's civil rights were abused because they had no say in deciding their placement and by other groups who lobby to dismantle the whole system of institutional care, this movement has successfully closed down most large centers for the mentally ill and many ICFs/MR throughout the nation. They bring class action suits against the ICFs/MR using our loved ones' names as plaintiffs, with neither the consent nor even the notification of their legal guardians! They argue that these people, among the most vulnerable in America, would be better served in small community-based housing or at home. They are wrong. Citizens with less severe retardation can certainly live more independently, but I assure that you Frank David, his fellow residents, and those all over this nation with similarly severe mental disability cannot. Imagine your toddler playing freely in the street whenever he or she pleases. Yes, your child would be exercising his or her civil right to, as one zealot has said, "the dignity of risk these people deserve." However, such "dignity of risk" might well cost your child, your loved one, my Frank David, and many others who are severely mentally retarded their lives.

Last year the DHHS Administration on Developmental Disability proposed new regulations for the DD Act, which will come up for renewal sometime in 2009. The new regulations extend the already hostile power of tax-funded groups in alarming ways put forth in often



Orwellian language. For instance, the term "mentally retarded" has disappeared altogether in favor of the less specific term "intellectually challenged." As a professor, I hope my students are intellectually challenged; my son and his friends at AHDC are mentally retarded. Such language is the strategy of those who want to "mainstream" and "normalize" the mentally disabled and thereby deny their medical diagnosis in order to dilute and eventually to eliminate the services they desperately need which are currently being provided by our nation's surviving large institutions.

A recent closure serves as a warning to us all. After a congregate care institution in Nebraska was ordered to "downsize" earlier this year, sixteen of its residents were moved to smaller facilities and nursing homes. Within a few months, eight of those who had been moved from where they had lived so many years had died. I believe that while their physical needs were being met in the new places, their emotional needs and the jarring disruption of the change had robbed them of their will to live.

I began this article by saying that all these mentally retarded residents have their own stories. Because they cannot articulate them on their own, it should be the mission of all of us who care for them to raise our voices to protest the dismantling of the very homes that protect them and provide for their wide range of mental and physical disabilities. Although they are fine for the mild to moderately retarded person, the small community-based homes into which the DDS wants to crowd our severely mentally retarded cannot adequately protect them and serve their needs.

It is said that every nation will be judged by the way it treats its most vulnerable citizens. Many of America's large population of homeless people are those who lost the institutions that housed and treated them. Do we also want to put our severely mentally retarded on the streets?

Thank you again for the chance to tell my son's story.

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Those interested in learning more about the work of the AHDC may contact it at:

Arkadelphia Human Development Center
Margo Green
P.O. Box 70
Slot 5540
Arkadelphia, AR 71923
870-246-8011

Those interested in the challenges faced by America's mentally retarded, please see the next page for further resources.

## Recommended Reading:

Kepfner, Fern — Before and After Zachariah, Academy Chicago Publishers; 1988

"A defense of institutional care as a positive alternative, and, in [the author's] case, a necessity for self-survival."

Torrey, E. Fuller — The Insanity Offense – How America's Failure to Treat The Seriously Mentally Ill Endangers Its Citizens, W. W. Norton & Co.; 2008

Torrey's book about the failed public policy of deinstitutionalization for persons with severe mental illness is chilling. We believe the same forces ("civil rights") are at work to destroy the service system for persons with severe and profound mental retardation. Dr. Torrey concluded that policies for persons with mental illness including deinstitutionalization was a major calamity of the 20th century.

VOR — "Call to Action to State & Federal Policy Makers: Media Coverage highlighting the increasing need for more effective federal and state protection in the ever-expanding community system of care for people with mental retardation" VOR@compuserve.com; Rev. September 2002; http://vor.net/abuse_neglect.htm

VOR is the only national advocacy organization for persons with mental retardation and developmental disabilities which supports an array of quality service options, including home, community AND licensed facility-based care. (1-877-399-4VOR, http://vor.net)