

President's Message

Dear VOR Families and Friends,

Growing up I remember our family buying "Easter Seals". To show their support, donors placed the seals on envelopes and letters. The stamps we bought said, "Help Crippled Children", a cause that we could relate to, especially since part of our population still wore braces from Polio. Yet, when it comes to Intellectual and Developmental Disabilities (IDD), the Easter Seals organization advocates strictly for proposed legislation in the imminent Build Back Better Reconciliation package that would give Home and Community Based Services (HCBS) \$400 Billion, and **exclude** any funds for Intermediate (congregate) Care Facilities (ICFs). We thank you for your support in getting out our last "Action Alert" on Parity/Equity for Intermediate Care Facilities. We sent out a semi-automated VOR Action Alert on this on September 2nd. We also need you to *continue* talking with your friends and neighbors about this. To be clear, VOR supports freedom of **CHOICE** for **both** ICFs and HCBS/waiver settings.



The "ARC" (formerly, "Association for Retarded Citizens") has been **the** driving force to dismantle vital supports for the most disabled among us, those with significant IDD. VOR has been fighting a landslide of proposed policy that will hurt our loved ones. "Sheltered Workshops" are in imminent danger of being phased out. "Institutions", or what **we** call "*home for our loves ones*" (ICFs) only exists in 32 states now. And new legislation is aimed at weakening ICFs to the point of financial collapse.

Yet, despite almost 39 years of constant battles for equity as supported by the Supreme Court, VOR continues the good fight. Since June, we have contacted a considerable number of Congresspersons in an attempt to describe the existential harm that can be done by supporting anti-ICF and anti-Sheltered Workshop language. We need your support now more than ever before. We need your membership, and we need you to ask friends and relatives to become members. We ask for your donations in this time of extreme need. For the first time in our 38 years, we have hired a lobbyist to keep us on track with so much changing legislation. *Many ask what do we get for our donations and membership?* There are many of our standard and well-appreciated benefits like our various types of newsletters, our annual meetings, etc.; However, **the most important thing that you get are thousands of volunteer advocacy hours to do right by the most vulnerable people in our country...** like my dear son, Matthew.

A handwritten signature in cursive script that reads "Harris Capps".

Harris Capps

President, VOR Board of Directors

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THE VALUE OF A LIFE - BY JUDITH DYER

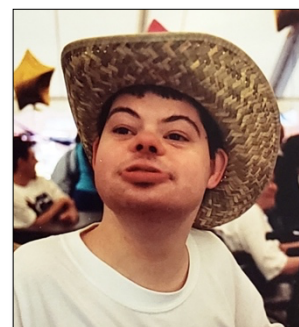
Danny was born and died on July 3rd with 51 years in between 1969 - 2020. Those years were given to him to complete his earthly mission. Very early on, a neurologist at Children's Hospital in Columbus, Ohio gave us the devastating diagnosis: Danny would not live to reach his second birthday. His brain stem and spinal cord were not fused correctly. The medical term was central nervous system dysfunction. There was no medical treatment available at that time. The doctor advised us to put Danny away and not get attached emotionally to him.

A pediatric specialist told us he wished he could give us a brighter prognosis. He compassionately said, "Take him home and love him as you would a normal child". Holding Danny close to me, the doctor's nurse put her arm around my shoulder, walked me to the door, and whispered to me, "God will provide". Danny was a sweet Down Syndrome three-month-old baby.

For nine years, my husband and I, along with our little daughter born before Danny and a baby born after Danny, experienced life in indescribable ways. We were always alert to Danny's seizures that would cause him to stop breathing. He was prescribed experimental drugs to save his brain while we tended to his needs of love, nutrition and medical requirements. What we didn't know - the damage done was irreversible. He would remain a three- to six-month-old child for the rest of his life.

In 1978, Dr. Chris Jackson, Director of Hazelwood ICF/MR in Louisville, Kentucky told us that they were very well equipped to care for severe and profound mentally retarded children because we could no longer protect Danny from the multiple problems he was developing as he grew. Local doctors where we lived told us they did not know how to treat children like Danny. How does one make a decision? July 10th that year was the most difficult, heart wrenching day of my life. We lived one hundred miles south of Louisville. My husband and I, our two daughters, and Danny made the drive there knowing just the four of us would return. Handing our precious little boy over to strangers with his clothes and a few toys was more than I could bear. I told my husband to drive around Louisville for a while. At 2 am he said we must go home.

As hard as that day was for us, it turned out to be the best thing we could have done for Danny, and for us too. For forty-two years, Danny lived a life with doctors and nurses around the clock, therapists in many departments, direct care personnel who kept him clean and comfortable, and nutrition specialists who prepared meals specifically suited to Danny's needs. There were many other people who were in charge of planning recreation and outings for clients geared to individual preferences, all under the guidance of compassionate facility directors. I did tell the case worker for Danny that he seemed to like music. Since he was non-verbal, it was his response to music by his body language that he was happy. It turned out that Dan really preferred country-western music the best. He would rock back and forth and voice his cute giggle.



Every year in the fall, Hazelwood held a Family Day Festival with colorful themes. It was pure fun for clients and families to enjoy a day together with outdoor games, rides, cook-outs, and live music. We never missed one.

When my husband's job gave him an opportunity to work out of the Louisville District office in 1983, we moved across the river to Indiana as our older daughter decided on Indiana university after high school graduation. Our younger daughter chose Purdue University when it was her time to choose a school. Living close to Danny for many years from the 1980s until my husband and I moved to Arizona in 2012, we were involved with all aspects of Danny's life. There was a period when federal and state legislation attempted to close large facilities for mentally retarded persons and placed them in group homes and private homes in communities. For more than a decade, theories under the names of normalization, least restrictive environment, and mainstreaming have been tools used to deinstitutionalize America's vulnerable intellectually disabled persons. Across the country many of our loved ones died from neglect and abuse. The Concerned Families of Hazelwood was a strong group that actively fought to keep our children's home open. It was extremely stressful. I was one of a number of guardians who addressed the Kentucky legislators in Frankfort. Our younger daughter presented a paper in a college communications class about protecting the voiceless, powerless segment of society that people don't hear about. It raised a lot of questions and interest and recognition from the professor about a subject most people don't know about. I have a folder full of letters I've written to those in power explaining the need for the protection large facilities can afford those who need total care, the protection only multiple layers of staff can address the fragile medical and mental emergencies that can arise anytime.

One of the most rewarding programs in Hazelwood was the Foster Granny Program. It matched retired women from all walks of life to share their love on a "one on one" basis with a client who need that love connection along with all the clinical provisions. When I was with Dan and his granny walked in saying hello, Dan would look around to see her.

There were monthly meetings with guardians and case workers along with staff members who work with each client and annual meetings with directors and state representatives to look at the progress each client was making within their ability range. Over the years, there were four governors who came to see for themselves the work being done at Hazelwood. They were all impressed, some with tears in their eyes and a resolve to maintain the building with needed renovations. One governor agreed to have a chapel attached to the main building if it was totally funded by private donations. My husband was retired, so he volunteered to secure a design/build company since he spent many years in the construction business. It became a reality and was dedicated in December 2007. It has served as a place for celebration and song for holidays, a quiet refuge for prayer, for chaplains to conduct services and for memorials and funerals for clients.

Over the years, aging took its toll on Danny's health. Down Syndrome individuals age faster than the average person. He was having aspirated pneumonia more often He needed surgery to remove his gall bladder that was full of stones. The seizures that plagued him required a VNS implant in 2013 and a G-tube in 2016. The doctors and nurses at Hazelwood are my heroes. They never give up. They have always looked for ways to make life as pain free as possible for their patients. When I called one retired doctor to tell him that Danny had died, I thanked him for everything he did for Dan. There was a pause and then he said, "Danny did more for me than I ever did for him."



There were many good times over his fifty-one years. I have photo albums with many pictures of Dan with his family on all his birthdays and just visits, activities at Hazelwood: relaxing on a float in the therapeutic pool, on the special swing designed to hold wheelchairs, outings to ballgames, and having lunch at restaurants, Derby Day bed races, Halloween costumes and haunted rooms, music therapy with tambourines and bells, sitting with his grannies soaking up their warm, loving attention and physical therapy walks with a personally designed walker. Dany's two sisters regularly brought their families to visit him. His nieces and nephews grew up taking turns pushing Uncle Danny in his wheelchair around the paths outside or in the multipurpose room. Our grandchildren came to understand that Danny was a special member of our family. As they got older, they developed a sense of compassion for people with disabilities

Danny's life mission was to open the human heart to love and become a productive force for good in the world. His influence on those around him is echoed in the line from the movie "Dead Poets Society" - "The powerful poem of life goes on and you can contribute a verse."

JENNY'S BIKE - BY PEGGY CONNOLLY

Jenny was adamant that she would have a three-wheel adult bike a few years ago when we attended a fund-raising auction. She's not ridden that bike very much since she bought it several years ago. Actually, Jim and I even thought about selling it because it takes up so much room in our shed due to the wheelbase. We never acted on that inclination, and it has remained in our shed ignored and forgotten.

Jenny walks in the neighborhood about a half mile every day. Last spring, she indicated she wanted to walk by herself instead of with me. I have to tell you that was a hard decision for Jim and me to make. Her difficulty with language is a real disadvantage for her and makes her vulnerable to harm from others. To this day I am nervous about her being snatched from us and harmed in some way. In today's climate it is a real fear for us parents who have lower functioning I/DD sons and daughters. As you know there is a fine line between warning your kids of the bad things out there but not making them too timid to be adventurous. Triple that fine line for parents of I/DD kids.

Jenny came to me a couple of weeks ago and indicated she wanted to ride her bike instead of walking. And she indicated she wanted to ride it by herself! I don't have to tell you that threw us for a loop. Jenny has a habit of holding her head down and looking only at the space in front of her feet. So, we warned her about cars backing out of driveways, of others walking or riding bikes on the sidewalk etc. etc. She had to hold her head up or risk getting hurt or hurting others. Of course, she said she would. She doesn't do it well, but she attempts to remember to watch for cars and people.

So, I laid out a half mile route for her. I couldn't keep up with her on foot, so I drove the car slowly with her as she rode her bike on the designated route just to see how she did with safety and awareness. She had to learn to use hand brakes as that's the only break for this bike. And I have to tell you she did pretty well....not great but good enough that I felt the need to drive with her only a couple of times before I turned her loose to be on her own.

Jim was really uneasy about all this as was I. We talked about it and I ended up reminding him and myself that we had to honor her request to be autonomous from us. I told him it was a milestone for her, and we needed to allow her to grow.

I'm glad to see this growth in Jenny...this wanting to be separate from us in some ways. She needs that independence since we are aging parents and will someday not be with her. But I have to say these past weeks have been some anxious ones. Since I'm able to relate to you what has happened to the bike, I guess I'm in a better place now.



There was a reason why Jenny wanted that bike at that auction though none of us, including her, knew what it was at that time. This girl has accomplished a milestone in emotional growth, and I am so happy for her.



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**VOR is a national, non-profit organization
Speaking out for people with
Intellectual and Developmental Disabilities**



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