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OUR STORY

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It wasn't until our son, Mark, was three months old that we learned he had Down Syndrome. On that fateful day my first question to our pediatrician was: What happens forty years from now?

In the meantime, she encouraged us to have another child and after genetic testing, we looked forward to the birth of our fourth child, Andrew, to join Eugenie, Carol and Mark.

My husband, Gene, was always optimistic and encouraging. Working through the acceptance and trauma of mental retardation and developmental disabilities took me five years, but life went on just the same and I returned to teaching, putting aside the question: What will happen forty years from now?

We were incredibly blessed with services for Mark while living in N.Y. Mark had daily bus service to the Shield Institute and to the Occupational Day Training Center (public high school) and was always involved in a program.

When we moved to Florida in 1995, Mark was twenty-eight and we still had not faced the old inevitable question: What happens forty years from now? "Forty" was a lot closer.

That question was never resolved until March of 2009 when Mark was accepted into Bishop Grady Villas in St. Cloud to start in September. While we are overjoyed that Mark will be part of a beautiful and caring community, it is bittersweet for us. The separation won't be easy.

While Mark was still a teen-ager, I had visited Camphill Communities at Copake, N.Y. I was awed at the arrangement of beautiful family homes in a country setting where "companions" lived with house parents, their children and co-workers on a large tract of land originally donated back in the 40's. Daily activities included organic and dairy farming, a coffee shop, country store, bakery, woodshop and studios for crafts such as weaving, bookbinding, candle making and horticulture. Studios were designed with soaring windows overlooking lush forested areas. Recreational and educational areas as well as individual homes were beautiful and inviting. There was no question in my mind that this was where I wanted Mark to live. We were told, however, that the waiting list was enormous, so we let it go, but never totally forgetting.

When we moved to Florida in 1995, we learned of a group that had been in contact with Camphill in 1992, urging them to open up a community in Melbourne. It was not actively pursued because there was some question of a hot button issue at the time, where this type of community carried the connotation of a "commune."

I was determined to bring them back and in 1999 organized a meeting at the Hilton in Melbourne, where I had invited the Pietzner's of Camphill to give a presentation. While it stirred up some interest, my passion was not contagious, and so, the initiative died.

However, another initiative had evolved in the late 90's by the group originally interested in Camphill -- the Society for Exceptional Adults (SEA). It designed a planned residential community called "Cobblestones," consisting of a subdivision in Viera to be developed by Mercedes Homes, offering a host of services and recreational amenities. The response initially was enthusiastic, but the plan did not satisfy many questions regarding ownership. The real killer was that it lost its main focus of serving people with developmental disabilities because of the restrictions imposed by the Thousand Foot Rule in Florida Statute 419.001 and also the 10% Density rule, contained in the Administrative Code of the Agency for Persons with Disabilities (APD).

I had resolved not to let this issue die and started a non-profit organization, Parents Planning Programs (PPP) for the Developmentally Disabled of Florida. Through this organization, I became an advocate for planned residential communities and began a series of meetings to stir up interest. It was then, that one of the administrators of APD, who had been invited to speak, claimed that this type of community was an "institution" and that they would not support it!

We learned that this administrator was shortly thereafter replaced by a new administrator who was more amenable to our position. This gave us some hope.

Meanwhile, PPP started a program called Sunday Safaris where we arranged outings to special community events -- soft ball games, beach parties, river cruises, boat rides, musical events and trips to places like Blue Springs and Forever Florida. Problem was, although the group homes signed up, adults in their own supported living apartments did not have the transportation to attend, nor were their companions willing to work on Sunday. So they remained at home unless I personally picked them up.

Loneliness is a major issue in the lives of our more dependent people, as well as the fundamental issue of safety where they are often victims of molestation and abuse. In our case, Mark, who is incapable of communicating would be overwhelmingly "segregated" if forced to live in a community which shuns him. Case in point, he was once dropped off in error at our house instead of his brother's while we were away. Not a single one of our neighbors, with whom I have friendly relations, made the slightest effort to contact anyone in the family to find out what he was doing there. One family, in fact, turned him out when he stepped into their house. He was unable to voice his plight. I think many people would exert a greater effort over a lost dog, at least call Animal Control. Where was the safety net in this case? He needed, above all, a safe place to live in a community of his peers. An isolated apartment or group home just wouldn't do! To this day we still do not know how he managed to get to our local Fire Station where Gene is a volunteer.

As I was becoming more connected to the world of developmental disabilities, I joined Arlene Lakin's FVMR (now FVDD) as a board member as well as the Family Care Council (FCC) of Area 7.

A major event occurred around 2000 with the announcement of the Catholic Diocese of Orlando's planned residential community, Bishop Grady Villas (BGV) in the heart of St. Cloud. After visiting their eleven acre campus with six beautiful homes, a community center, garden and

wood shop work sites, I had no doubt that this would become a showcase in Florida for the concept of planned residential communities.

Of course, we made an application for Mark, but he was not accepted because they said they did not have sufficient support staff to address his needs. Additionally, the entrance fee was \$50,000 and would require a monthly fee of \$1,500. We knew that BGV would have enormous difficulty surviving because there were not enough people who could afford it.

My work was cut out for me: to connect BGV with the Agency for Persons with Disabilities and bring about a partnership. The resistance was strong initially, since our area 7 FCC administrator said that BGV violated the Thousand Foot Rule and the 10% Density Rule.

However, through many meetings with local legislators and stakeholders, he said that APD could partner with an Assisted Living Facility such as BGV. From there, it was a matter of getting BGV to apply for licensing as providers of Med Waiver services. I worked along with them and it finally happened in December 2007.

Another hurdle had been eliminated. But there were still other matters that had to be settled. In March of 2008, Parents Planning Programs (PPP) and Noah's Ark launched a campaign to eliminate the 10% Density Rule in the Supported Living program, which APD refused to delete from their Developmental Disabilities Med Waiver Services Handbook, although it had been gone from the Administrative Code for three years. They were overruled as a quota system, and with the support of AHCA, we finally saw its demise.

Now we are faced with another quota system – the Thousand Foot Rule contained in Florida Statute 419.001, which says that group homes must be distanced from each other by 1,000 feet. This would defeat any attempt to initiate a planned residential community. I appealed to our local legislators in Brevard to introduce a bill to amend Ch. 419, which would exempt group homes of six or fewer residents from this 1,000 ft. distancing requirement if they were contained in a planned residential community to provide supports and amenities for people with developmental disabilities. It would be designed as a planned unit development to be approved by local zoning. Sen. Thad Altman agreed to introduce the bill and was joined in the House by Rep. Kelli Stargel.

My efforts to accomplish such a vision were encouraged by Jack Kosik's plans for Noah's Ark in Lakeland on 56 acres awarded by former Gov. Jeb Bush. With much help from Arlene Lakin of FVDD, Jack and I worked together to get the language of the bill as simple and direct as possible. Thus S.B. 1124 and H.B. 371 were born in 2008.

Amazingly, beyond my wildest dreams, the Senate passed the bill unanimously at its final hearing and the House Committees voted 80% in its favor.* At this point, we were optimistic.

While the bill was still in House committee hearings, the federally funded Florida Developmental Disabilities Council (FDDC), the Advocacy and Protection Center and the Mailman Institute for Higher Education learned of the proposed legislation and sent out alarms. FDDC issued an "Alert" that claimed Med Waiver funding would be used to create "institutions" and segregation. I Petitions were sent out claiming the same misuse of funds and segregation. The FDDC and Advocacy Center presented these "concerns" to the House Committees and elicited statements from Rep. Maria Sachs and Rep. Hazelle Rogers that our proposed legislation would revert to lock down facilities and ghettos.

FDDC tried to amend the bill by substituting Supported Living for group homes. Other amendments were added to define a planned residential community to require at least 10 acres and a minimum population of 1.5 million in any county. A final amendment by Rep. Sachs concerned satisfying federal guidelines by the Federal Centers for Medicare and Medicaid Services (CMS). This raised the question as to what these guidelines are and what "community based" services meant. At the final hearing on the House floor, Rep. Sachs grilled Rep. Stargel with questions that paralleled the FDDC's Alert with allegations of institutionalization and segregation. The final coup was delivered by a lengthy attachment to H.B. 371 by Rep. Ford. The result was a "postponement" which spelled the defeat of our legislation.

We have not given up and are encouraged by Sen. Altman and Rep. Stargel who will reintroduce the legislation. Meanwhile, the FDDC has responded to our complaints to the federal Association for Developmental Disabilities of lobbying and misrepresentation of the proposed legislation. Shortly after, the FDDC organized a "Work Group" to study residential alternatives in a series of four meetings from July through November. I was invited to participate and was able to argue for fair representation from administrators of planned residential communities nationwide such as Camphill, Lambs Farm and Bishop Grady Villas. Jack Kosik arranged presentations from Carl Penax of the Loveland Center and Jim Whittaker of The Arc Jacksonville at the second meeting, both strong supporters of planned residential communities.

However, the FDDC will continue to set the agenda in the remaining meetings and to reach "consensus" for proposed legislation. We question what their idea of "consensus" means.

Our message to those who fear institutionalization and congregate living is that what we are proposing is CHOICE, the same choice afforded to all other citizens to live in a community of their choice, next to their friends if they wish. We feel that the 1,000 ft. rule is basically discriminatory, but are trying to offer another solution to the segregation and isolation of residents in group homes. We have no intention of robbing the Supported Living program to pay for planned residential communities. We encourage creativity and private initiatives to determine whether they are serving people with developmental disabilities exclusively, or whether they are open to a more eclectic arrangement of group homes, private family homes and supported living dwellings. We want to encourage grass roots organizations to forge ahead with whatever theme or focus will drive their planned residential community. We want to insure that Med Waiver recipients will not be denied Residential Habilitation services to which they are entitled because of the location of their group home. We defend the rights of individuals and families to decide where and with whom the person lives as specified in the ADA. We think of "community" as a state of mind and shared interests rather than a location.

We are not asking for a government owned and operated facility. We only ask that our privately owned creative initiatives be allowed to contain group homes providing Med Waiver Residential Habilitation without the restriction of the 1,000 ft. rule, a form of de facto segregation.

We do not believe that it is the function of the FDDC or any federally funded agency to dictate what is best for individuals with developmental disabilities, to set quotas or to require its stamp of approval on residential design. Choice of individuals and their families is the ultimate determiner.

We reject the paternalistic idea that federally funded agencies know best what lifestyle is best for people with developmental disabilities.

We recommend that they consider a more thoughtful definition of "integration," "inclusion" and true "community living." From our perspective, we see our people shunned, isolated, and frequently abused or neglected.

We urge them to join the ranks of more enlightened advocates who encourage and are developing innovative, humane and supportive living arrangements in the interests of "true community living."

To this end, I will devote my efforts in my remaining years. I ask for your support and effort to achieve our dreams for our family members.

Lila Klausman, Pres.

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*(24 in favor and 6 opposed – five opposed in the Economic Development and Community Affairs Policy Council: Braynan, Gibson, Long, Sachs and Thompson. One opposed in the Health Care Services Policy Committees: Rogers).