

Amanda's Story

Our Family

Many people believe it takes a village to nurture and support an individual. Some will say, for example, that a child cannot have too many adults who care about her. And research shows that social engagement plays a contributing role in an adult's physical and emotional well being.

The village has always been part of our daughter's world from her earliest days. This was especially important to us because she is our only child – and because our daughter was diagnosed in her third year as mentally retarded and then several years later as being on the autistic spectrum. She also is blessed with good health, a sense of curiosity and an engaging smile.

We always arranged for opportunities with groups of normally developing youngsters -- a toddler playgroup, a nursery school, a multi-generational family setting after school, a small alternative cooperative elementary school, a regular after-school program, and the first fully-integrated camper at Girl Scout camp. Each of these programs was active and experience based with a strong social focus. Our daughter usually was actively engaged and an enthusiastic participant in these settings unlike formal school settings in which she was generally compliant and very passive. As she grew into her teens, she participated in the Best Buddy program. We recruited college students from the arts, social work and education for after-school activities out in the community.

The decisions our family has made for our 30-year-old daughter have been a natural progression from her earliest days.

Our Daughter's Needs Today

While Amanda has learned and accomplished many things, she needs daily guidance and assistance with tooth brushing, showering thoroughly, trimming nails, rinsing hair, attending to menstrual needs and other personal hygiene issues. While she can dress herself, things may be inside out or backwards and they may not be appropriate for the weather or the occasion. She can be oblivious to her body or physical surroundings. She does not operate in the conceptual world (read, write, calculate, tell time, know the days of the week). Her language may seem very scattered and she is continuing to learn the social rituals of language. She does not always report accurately or clearly.

She does not have the judgment to determine if something needs serious attention. It has been challenging for Amanda to find a meaningful relationship with work. She can become very passive. The social component in a calm but rich environment appears to be the key to meaningful engagement.

Her Life

We have long observed that our lives are not defined solely by a place to live and a place to work – but also by the richness and vitality of the other people and experiences in between. We wanted nothing less for our daughter. In her teen years, we had already begun thinking about and exploring what an adult life might be for our daughter. Engagement in the larger world and a strong social environment continued to be our focus. We also hoped to find a setting where the arts, the outdoors, healthy food and a

physically active life were important. We were committed to helping Amanda build a life beyond our family home – and we wanted the peace of mind of seeing her thrive in her new life well before our death.

After she completed high school and attended several adult day programs, our family chose a path not available in or near our community in Florida. Now that we are in our mid-60's and our daughter has just turned 30 with no extended family, we have both perspective and a sense of urgency for Florida families

As many 21-year-olds do, Amanda left home to live and learn on a campus with a diverse group of peers and others. The transition was not easy – for any of us. However, we watched her blossom with a vibrant life outside that of her family. At Camphill Soltane www.camphillsoltane.org, she lived in one of eight houses in a family setting with a roommate and other housemates. She had chores in her house and responsibilities outside her house. She attended classes and had freedom of movement and independence throughout the 50-acre campus. She performed in plays, made music with her housemates, helped to steward the land, hiked the Appalachian Trail and giggled with friends. Her graduation was a joyous but bittersweet day.

After briefly returning home to her former day programs, it was apparent that she wanted and needed more. She is fortunate to now live in Camphill Village www.camphillvillage.org, a similar community of individuals, some disabled, who live and work on a 600-acre farm. She is settling into two meaningful work settings. To our amazement, she finds her way around this large community independently. When she returns to the Village, she flings open the door to her home and shouts “It’s me – I’m here”!

Amanda has thrived in these community settings in part because they have been a good match for her temperament and sociability – and they have daily rhythms and a safe, accessible environment with supports for personal care and daily living. Equally important is their vibrant cultural and social life. A final important component is the stability of the community's existence. Despite the expected changes in roommate or house parent or work assignment, Amanda remains well grounded in her community with other caring adults and peers who contribute to her well being. We, as her parents, want nothing less for ourselves.

Not only do residents in Camphill programs engage in activities outside their village, but members in the larger community often are part of village life as acknowledged by recent recognition. Camphill Village was honored as the 2006 Small Company of the Year by Columbia County Chamber of Commerce. Kimberton Hills www.camphillkimberton.org, a sister community in Pennsylvania, was voted The Best Place to Hear Live Music in Chester County in 2008.

While we are supportive personally of Camphill communities, there are many other ways to form intentional communities that share some of these same characteristics. We are heartbroken that Amanda does not live geographically close to us. This has resulted in a considerable financial burden for us as well as missed opportunities to support her community through our on-site engagement and volunteering.

We are dismayed that other Florida families like ours do not have such choices and that, in fact, these initiatives are viewed as undesirable or offering less than a full life.