

Life & Arts

ANNE LANG RAISING AUSTIN ESSAY



Anne Lang (right) and her daughter, Megan, have gone through a huge milestone. Megan has moved into a group home. She has autism. CONTRIBUTED BY ANNE LANG

Preparing autistic daughter to leave nest

Developing trust builds independence and makes next steps easier.

Recently, we moved our 21-year-old daughter into a state-supported group home for adults with special needs. While she was quite excited to embark on this huge chapter in her life, my husband and I were left to sort through a roller-coaster of emotions.

"We raise our children to leave us," or so the saying goes. And in most families, the going-away stage for neurotypical children usually begins around age 18 — whether it's for college, a first apartment and job, far-flung travels, or an early marriage. But what if a child has autism? Do we raise that child to leave or to stay?

In our family, we raised our daughter Megan to someday leave us, just as we did her older sister — a recent college graduate who lives and works out of state. In the years following Megan's autism diagnosis at age 3, we gradually came to accept she simply couldn't (and arguably shouldn't) live with us forever.

When she reached her 20s, we reasoned because Megan presumably will outlive us by

several decades, it would be best to make a residential separation sooner rather than later. Much as we might have wanted her to remain within the loving cocoon of our family home, we believed she could far better expand her social development and community integration in a group setting.

Actually, we had started early in preparing Megan for a future apart from us, though we didn't always consciously think of it in those terms. Instead, as we would with any child, we wanted Megan to have fun and variety in her life.

So for one week each summer, starting at age 7, she attended a special needs camp near San Antonio. The camp had swimming, horseback riding, crafts, boating, campfires, dances and more.

When Megan was 14, we began looking for special-needs camps with extended sessions. The

camp that most closely met our admittedly rigid standards was painfully far from home, in Connecticut, but it offered sessions ranging from two to eight weeks.

The first summer, Megan went for four weeks and thrived on the program, which included all the activities she'd enjoyed at her previous camp.

So the following year, we sent her for the full eight weeks. Although we sorely missed her, she happily repeated that pattern for the next six summers.

In one particular way, Megan is unlike most individuals on the autism spectrum. While many kids with autism and related disorders spiral into sensory overload in situations involving large crowds, loud music or other chaotic activity, Megan has always been drawn to such extreme forms of stimulation. The livelier the scene, the more she liked it.

Given Megan's perpetual thirst for adventure and her extensive sleep-away experience, it wasn't difficult to introduce her to the notion of living in a group home. We decided to initiate the process during the middle of her final year in public school, feeling that the transition to a group home might be smoother if her weekday agenda continued to include the district's daily life-skills classes (for special-needs students ages 18-22) that she attends on a separate campus.

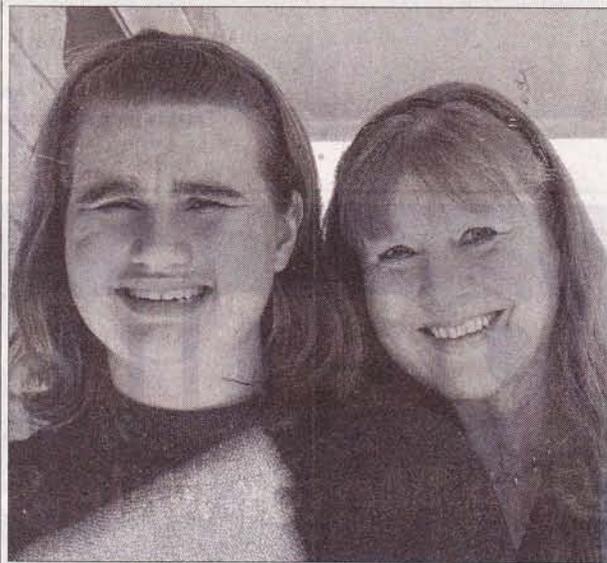
Our search for exactly the right group-home agency and residence took about a month. Naturally, we were seeking a safe, clean, cheerful, active, respectful environment where Megan

would have opportunities for personal growth, additional training in life skills, avenues for supervised employment, and enough on-site and off-site activities to satisfy her desire for all kinds of fun.

We finally found just the right home, with an opening at just the right time: An all-female, six-bed residence that happened to be less than five miles from our house. Megan's required trial run – a four-day visit during which staff and social workers observed her to see if she would fit in with the other residents and the general routine – was deemed a success, all around. Megan was bouncing exuberantly when I picked her up, and some of the more verbal residents even pleaded with me to let her permanently join their family.

One week after that visit, we'd finally cleared all the administrative hurdles required for move-in. My husband had to be out of town for work, so I was the one who took Megan shopping for necessities, frequently chatting with her about the ways in which her life was going to change – as well as the comforting ways in which it would stay the same, since she could come home for one overnight stay each week, periodic 72-hour "passes," a few mini-vacations, and major holidays.

However, it was daunting to realize that as part of the deal, we were totally relinquishing our roles as Megan's caregivers. We would no longer be the ones choosing her schedule, her doctors, her meals, her brand of toothpaste, or even which coat she might wear to school each day. Essentially, we were turning her over to the state's mental health care system – although we're still her legal guardians, an important fact.



Anne Lang (right) has been preparing her autistic daughter Megan for the day when she should leave home since Megan was a child. CONTRIBUTED BY ANNE LANG

Megan, who has low speech capabilities but fairly high cognitive skills, appeared to be elated about the move. She was singing as we loaded the car with items such as her favorite stuffed animals, assorted electronics and family photos. Her excitement tugged at my heart: While I was glad she was looking forward to this enormous life change, I also was sad to realize how obviously ready she was to leave home.

Leaving is poignant for family

We had indeed raised her to leave us, right? Yet the sudden reality of Megan's leaving seemed to represent a more poignant milestone than when her sister had left for college. Our older daughter, being neurotypical, had reached the phase of maturity where she had trusted her own self enough to fly from the nest. Megan, on the other hand, could only

operate at the level of trust that she'd invested in my husband and me, dating back to her infancy.

It dawned on us that during all the trials and errors of raising a special-needs child, evidently we had done at least one thing right: We'd instilled in Megan such a deep level of trust that somehow, beneath the impenetrable cloak of autism, she knew that we would never put her in a bad or scary situation. She knew it long ago when we put her on the school bus for the first time. She knew it when we sent her to camp all those summers. And she knew it when we sent her off to live in this entirely new home.

With Megan, only time will tell if this move was the wisest path we could have chosen at this juncture. So far, the arrangement certainly seems to be working out. But those of us she's left behind are struggling to fill the holes her absence has made in our house and in our hearts.