

REMARKABLY ABLE

Transition to Independent Assisted Living



After graduation, what's next? Persons with autism can live in community assisted living and reach higher levels of independence when their skills, interests, and gifts are magnified in a supported environment.

by Jackie M. Marquette and Stephen K. Miller

Too often society has accepted negative stereotypes about the limitations of autism. But researchers, advocates, and educators now recognize the untapped potential of persons with a developmental disability (DD) to become integrated into the community. We have coined the term, "remarkably able," to describe the functional level that a person with autism or other DD can achieve when offered appropriate assistance.

In essence, these individuals are not only capable—but remarkably so—if they have people to guide them. From work to community participation to leisure to housing, individuals with autism can live productive and rewarding lives through assisted independence.

Jackie's son, Trent, has autism, but has lived for four years in his own house with an assistant who has become his roommate and friend, guiding and supporting him. Trent has matured and grown, increasing his self-help skills through leisure activities and employ-

ment. He has a job at MEIJER INC in the lawn and garden area, 20 hours a week. Believing in this dream and creating a vision to fulfill it, Jackie wrote a book, *Independence Bound*, about how she and Trent worked through setting goals and taking steps to create an independent living arrangement. In this article, we examine the transition from high school to independent assisted living for individuals on the autism spectrum or with other DD. While this process may appear overwhelming, the benefits can far outweigh the difficulties—for the individual, the family, and society.

Throughout the school years, students with autism or DD prepare academically for adult life by developing and practicing life skills. Federal law protects educational services for these students. After graduation, however, those rights are gone forever. While it is true that several federal initiatives promote the inclusion of individuals with DD for living in the wider society,

the resources to support these policies are extremely scarce. There is currently a national crisis for those persons who are dependent on additional resources and assistance to participate in the community and enjoy life.

Parents of children with autism are frightened about life after graduation. Preparing the young adult with a DD for unknown challenges taxes both the individual and family. Unfortunately, the majority of these young adults still are relegated to living isolated lives at home or in sheltered environments.

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These options do not meet their needs and do not challenge their abilities. It took years before society accepted that special needs children deserved an education based on the "least restrictive environment." Likewise our country has been slow to recognize that the option of independent assisted living is necessary for these same children as they become adults. Ironically, the very success of these federal special education laws has created a crisis: an ever increasing pool of special education graduates unable to realize their own assisted independence due to the severe resource shortages.

The Path to Independence

How does a person with autism begin walking the path toward increased independence? What role does the family play on their child's behalf within a system of critical shortages? The research increasingly demonstrates that independent assisted living is facilitated through building an individual's self-determination skills. Acquiring those skills, however, may not be enough for some individuals. For many, the *family* must become involved in order to make the dream of independent living a reality.

Researchers have found that young adults with DD often look to their families for help in finding employment, housing, and comfort. Because of the lack of resources, families may need to search out and create options for friendships and community involvement. During this major life transition the family's role is not to control but to assist these young adults in expressing their individuality and choice.

The family is too often viewed by professionals as playing a passive role, a mere support behind the scenes. But parental bonds are exceptionally strong for the person with a DD. The family must first loosen those generational ties in order to take an active role in encouraging an independent life for their young adult (Marquette & Miller, 2002). Currently no guide exists that adequately addresses how a family can negotiate this psychological separation, an emotional process for both child and family. By facing this difficult juncture, families can move forward and experience the joy of helping their child participate in the community. The alternative may be paralysis, consumed by their overwhelming fears.

Likewise, how does a family create alternatives for assisted independence? Changes in routines, job, leisure, and community involvement—all follow immediately once high school ends. Graduation creates a void in scheduling, five days a week, 6 hours a day. Both emotional stress and daily activities must be faced if the young adult with autism is to find purpose and acceptance in the community.

One important aspect of transition for adults with DD that has not been addressed sufficiently is the outcome of independent assisted living. Prior to decisions about assisted-living options, however, families must examine their own beliefs and values regarding this monumental life change. This self-evaluation, while often frightening and wrenching, is necessary if the family is to participate effectively in the young adult's post high school transition.

Ten Steps to Creating Independent Living

Based on our own experience and the developing research in the field, we offer the following 10 steps as a guide to assist families, advocates, professionals, and service providers in the uncharted waters of transition, with independent assisted living as a goal.

1 Be aware that our relationship with our young adult must change in order to create new opportunities. It is normal for all graduates to desire life apart from their family. Persons with autism and DD are no different. They cannot mature when their relationship remains fully dependent. Changing how we relate to our young adults does not mean we love them less. Actually, we love them enough to let them grow.

For example, Jackie recalls how fearful and nervous she was when she moved out and Trent's assistant/roommate moved in. For Trent, this change was more traumatic. When Jackie would visit, he would follow her to the car saying "Go [with] Mom," very upset that he could not get in the car with her. Jackie remembers him standing in the yard staring after her as she drove away. Some time later Jackie heard from neighbors about how hard it was to watch these painful partings. Meanwhile, Trent's initial resistance faded as he understood that having his family close by was a new kind of security.

A related example of change can be seen in Trent's adjustment to life on his own. Caring for his personal needs and doing household chores had never been one of Trent's strengths. Jackie would end up "doing for" him. But with his roommate/assistant, Trent was forced to pick up after himself. New community routines, friendships, job, recreation (all guided by his new roommate or a community coach) led to improved confidence. Particularly noticeable was the decline in his obsessions. Trent's obsessiveness increased considerably after high school while he was living at

home, to the extent that he was not able to go out for eight months. Yet now, with assisted independence, his obsessive behaviors are far lower than at any time in his life, including his ability to self-monitor: "get stuck, no!" All of these are evidence of Trent's growth related to his independence. Painful at times for both, but important in the long run.

2 Be willing to loosen the emotional ties to our graduates, even if it means that they experience setbacks. Resilience comes through failure. We discover new information about what to try next time and to persevere when life becomes trying (which it inevitably will).

3 Recognize our own attitudes and beliefs as possible barriers to living independently. Quite often these negative messages represent biases from society. These myths hold us back. A couple of examples are useful.

"My son isn't ready to live apart from me. Who would understand his desires and needs? He can't be happy without his family." This represents the myth that only the family of the person with autism will love and protect the individual. In reality, there are both individuals and organizations that can help make independent assisted living a reality.

"My daughter will always live with me and when I get too old or sick, her brother will take care of her. She can go to the day program and sheltered workshop five days a week. This works well for us. The hours allow me to keep my job and she can make friends there." Here the myth is that the person with autism is not capable of anything more than subsisting in the "protected" but undemanding confines of a sheltered, segregated setting. Yet many of these same individuals are "remarkably able" to live and work in the community if given appropriate assistance.

We cannot emphasize enough the enormity of these personal attitudes as a barrier to assisted independence. Jackie heard "how could you let Trent live with a stranger?" repeatedly—from everyone in her family and from seven or eight close friends and associates. Yet one friend believed she was doing the right thing. Without this friend's encouragement and support, Jackie was ready to scuttle the arrangement at the last moment.

The best thing that ever happened for Trent was almost sabotaged by self-doubt and discouragement from family and friends. Trent's true potential would never have been known without the opportunity to live on his own with assistance. Growth is a part of the human condition; that is just as true for individuals with disabilities as for non-disabled people.

4 Upgrade our knowledge about transition. School districts and educators play a significant role in helping students and families by designing transition services for students. Jackie has delivered district-wide transition fairs and training for parents/advocates. Both families and professionals have reacted positively to a range of possibilities they had never considered. Although federal laws mandate that a transition plan be created by age 14, often 'real' thinking about

this doesn't happen until a person is closer to actual graduation. Action taken before graduation can ease the impending crisis generated by this milestone.

One mother found that the fair's information opened up ideas about community participation such as finding employment specifically tailored to interests and skills, finding a community coach, and living independently. "The prospect of independent living never occurred to me as I am unsure how I would know if my son would ever be able to live independently. We will begin incorporating 'daily living skills' into his daily routine."

Actions taken by school districts can also influence professionals and businesses. Hardin County Schools in Kentucky sponsored a series of transition fairs. The director of UPS Supply Chain Solutions (they handle shipping for online account purchases) in Elizabethtown, Kentucky saw the newspaper coverage. This eventuated a pilot job project for students with developmental disabilities. The pilot program—negotiated by the school district, UPS, and the Kentucky Department of Vocational Rehabilitation—is the first in the state to combine a private company with a school district and Voc Rehab to provide student paid employment.

5 Become knowledgeable about governmental services, resources, and programs that can help our young adults connect to the community. Some resources include supported living grants, Medicaid programs, state emergency funds, and vocational rehabilitation services. (These programs exist in Kentucky. Other states will have similar types of assistance, perhaps with different names.) Contact your community mental health and developmental regional program or nonprofit agency for information. School districts and universities may also be a good source of information.

6 Initiate tools such as the person-centered-planning process (PCP). This strategy can open doors and provide hope for building an individual's life in the community. PCP meetings can illuminate specific skills, interests, and gifts by drawing support and ideas from a team of people who know your son or daughter. Members may include educators, state agency personnel, service professionals (e.g., job coach or respite workers), or associates from church, friends, family, or neighbors. For more information, see *Life Building: Opening Windows to Change* by Dr. Beth Mount (2000) or visit www.inclusion.com

7 Network with professionals, friends, neighbors, and family to find persons who are interested in becoming a community/life coach for our young adults with autism. A community coach helps the person negotiate public settings and learn or maintain interactive skills. This is crucial in adapting to independent living within diverse settings. Jackie found persons who became a community coach for her son through colleges and universities, the school system, friends, and referrals by service providers. Always get recommendations and a police check.

8 Be creative in assessing our young adults' talents. When faced with a dead end, "think outside the box" about how strengths can be used in employment and leisure activities. Two examples show the link between strengths and possibility.

A recent high school graduate with Asperger's Syndrome loved surfing the internet and reading detailed characteristics about reptiles and snakes. He also enjoyed trips to the zoo. His job coach helped him explore a job opportunity as an assistant in a zoo.

Another young man with autism worked well at organizing flower pots for display at a large discount store. The steps in handling the pots, arranging them, and watering the flowers complemented his desire for task completion.

Embrace other people's suggestions. Understand that our young adults are on a journey to increased independence. Assess progress and then reevaluate. Take one step at a time, one day at a time, one area at a time. Success leads to the confidence to attempt new activities.

9 Get involved with support groups to advocate for increased community services at the local, state, and national level. As pioneer families in this field, we must work together to improve resources for adults with developmental disabilities. We, the families, are their most potent interest group.

10 Understand the importance of our needs as parents or advocates throughout this entire process. We need to develop activities that are separate from our young adult. This significant step helps loosen bonds to our children and is critical to our own well-being.

A New Beginning

When the prom and graduation party was over, Jackie felt Trent's life had come to a dead end. In reality it was a new beginning. All she could see at that time were scattered pieces of his life. How would Trent face the loss of his friends, familiar settings, and activities? For a time, both Jackie and Trent spiraled downward, in a state of withdrawal. Then she sought resources to facilitate his leisure activities and employment. As she pulled her own life together, the connecting thread was helping Trent live his new life as an adult. With a lot of effort and bolstered by the members of the person-centered-planning team, Jackie was able to create a new life for herself and her son.

Having independence is a fundamental right for all people. Finding a purpose in life includes experiencing freedom, work, challenges, growth, choices, and fun. Persons with disabilities have



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a right to these fundamental liberties. Because the family is the foundation of support, the action must begin there. The process must also involve other interested people, including the young adult, educators, human service professionals, and other family members and friends. We believe that persons with disabilities do not want to be dependent on someone else to take care of them. But they may be dependent on others to assist them in developing their gifts, exploring their interests, setting up options, and living safely. This requires collaborative effort and creativity on the part of families, professionals, and service providers.

Transition to independent assisted living for the individual with autism may appear impossibly difficult. *We don't have to achieve everything at once.* Jackie learned that her son's journey to independence was not linear. The path to increased independence may have twists, turns, ups, downs, and even bumps in the road. Trent lost two jobs and regressed socially before he began his transition to his own home. Accepting change in life and becoming open to new opportunities that increase independence can be painful. Yet independence can produce great joy, a life rewarding beyond all imagination for both the young adult and the entire family. We can achieve this. But love requires that we let our children take risks. What is the benefit? It's seeing our high school graduates reach for and achieve higher levels of independence and acceptance.

But My Child Can't Really Do This

"But Trent must be special. He must be high functioning. My child, and most individuals with autism or other DD, could never do what he has." We hear this all the time. Families are skeptical and believe their own child could never manage in an assisted-living arrangement.

This is a *very common reaction*. But it is *wrong!* We add this post-script to let families and professionals know the significant difference appropriate assistance can make for a person with autism. Trent was not high functioning. On a nine-point scale of handicapped status from 9 = non-disabled to 1 = profoundly disabled, Jackie estimates Trent would score 3, 5, and 3 in the areas of general functioning, cognitive ability, and social/emotional competence, respectively. This is without assistance. In contrast, she estimates his capabilities for those same factors, with assistance, would be 8, 7, and 7. This is clearly much higher than what he can do on his own. We have to understand that the potential of individuals with autism is fully captured only by what they can do with assistance. If we give our young adults a chance, they can truly become "remarkably able."

References

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