

Transitioning to Envable Lives for Adults with Autism

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As parents and professionals, it is unsettling and discouraging to embrace the outcomes for adults with autism are:

- In a study of 46 adults with autism born between 1974 and 1983, only 56% had ever been employed and their work experience averaged only 5 hours per week, mostly in volunteer or sheltered work settings. Only two individuals lived in a supported living situation in a home of their own (Eves & Ho, 2008).
- A study of 15 individuals found that most adults with autism were living at home, and only 41% were employed part-time (Ellison, Clark, & Langford, 2005).
- A more recent study reported that 20% of men with autism held jobs, with 10% working in sheltered employment and 10% in competitive employment (Cedurland, Hagberg, Billstedt, Gillberg, & Gillberg, 2008).

It is an understatement to say that such outcome data is far from enviable.

In describing enviable lives for adults with autism, my focus will be on my son, Jay. I will share the story of his life when it was *unenviable*; the process we used to attain an enviable quality of life and the incredible benefits that accrued to Jay and all of our family.

First, however, I must share the grievous fact that Jay died in January, 2009 at 41 years of age. He was truly at the top of his game: his life was as good or better than it had ever been. His story is a legacy to attest to the fact that, despite dismal research data on the uninspired lives of so many adults with autism, not only surviving but truly prevailing in adult quality of life is entirely within the realm of possibility for adults with very significant support needs. Jay experienced autism, a significant intellectual disability, and bipolar disorder. His legacy attests to what is possible when individualized, responsive, comprehensive, and especially dignified supports are put into place.

Before Jay Got an Envable Life

Jay was a product of the special education system, starting to public school just before the passage of the *Individuals with Disabilities Education Act*. His educational experience can be described as one that was “separate and unequal.” He was part of a special class, and that his special class was really never part of the life of the school where it was housed. He had an educational program, but he wasn’t a member of an educational community.

In the late 1980’s (and, unfortunately, still today in too many places), students with autism typically transitioned from segregated high school program to sheltered workshops and group homes. When Jay was 21, he followed the same trajectory. My husband and I knew that the program offered was not what we envisioned for Jay, but we thought we would be able to enhance the quality of the program through active participation on the agency’s board of directors. Shortly after Jay moved into the group home, his younger sister, Kate, visited him. She was dismayed to get a firsthand view of congregate and segregated living. She returned to our home from the visit and made her viewpoint clear in no uncertain terms by saying: “You wouldn’t want to live there. I wouldn’t want to live there. Why is it okay for Jay to live there?” Kate’s comments seared our souls, because we knew she had spoken bottom line truth. At that time, we reflected long and hard on Kate’s questions and wondered what it would take to put together the supports for Jay to have a life that he wanted to live, as well as a life at the same standard that we would want to live and a life that Kate would want to live. We started calling this kind of life “*an enviable life*” – a life that would have no double standard; a life that we, Kate, and others would want for ourselves; a life that would enable Jay to live his life to the fullest.

Although Jay was not able to express in words his dissatisfaction with the workshop, he clearly communicated through his aggressive behavior that having his life directed the adult system was simply not an option for him. He identified one individual in the workshop, who happened to be the son of a state legislator, to hit and choke every time he saw him which was on a daily basis. He spent a substantial portion of this day in a time-out booth and spiraled into a black hole of depression. We were receiving at least 3-4 calls per day reporting his transgressions in great detail.

We will never as long as we live forget the last experience of meeting with the agency's director just as they were expelling Jay. We told him that our vision was that Jay would be able to have a typical job with job coach support and live in a typical home having valued relationships with his family, housemates, and friends. The director was aghast at what he considered to be a ludicrous vision. Shaking his head, he asked us very pointedly: "What will you do when you fail?" The implication was obvious – he had every anticipation that Jay could not possibly "get a life" consistent with the visions we expressed, and he fully anticipated that someday we would come back begging to get on his waiting list and to work our way back up to the opportunity for Jay to try the sheltered workshop and group home once again. The good news is that Jay and our family did not fail at this vision; rather he and we succeeded beyond our wildest dreams. That's what I will share with you – the enviable life that Jay lived and the kinds of supports that enabled him to prevail. Given his untimely death in 2009, I am thankful beyond my words to express that he did not die when he was experiencing an *unenviable* life but rather when his quality of life was flourishing.

About Jay's Envable Life

A Week in Jay's Life

Jay had an incredibly satisfying life. It was totally customized to his preferences, strengths, needs, and opportunities to make contributions. Figure 1 includes a snapshot of a typical week in Jay's life. This schedule combined regular activities, variety, and formal behavioral supports. In terms of regular activities, Jay was a creature of habit in many ways and thrived on the regularity of most of his schedule. Each week approximately 22-25 individuals were involved in providing support to him, and each one had a regular niche in his weekly schedule. Such regularity provided a sense of connection, anticipation, and comfort in knowing the rhythm of each day.

Jay also enjoyed some variety within the larger predictable frame. The variety came from different co-workers with whom he had lunch on a daily basis, three different music therapists rather than just one, and weekend activities that varied according to what was happening in his community.

Medicaid Funding Through the Participant-Direction Option

Starting in 2000, Jay qualified for the participant-direction option of Medicaid. Participant-direction redirects Medicaid from agencies to individuals in order to promote opportunities for individuals with disabilities and their support teams to "call the shots." Participant direction in our state routed the Medicaid funding as follows:

- From the federal Medicaid agency to the state developmental disabilities (DD) agency
- From the state DD agency to the local DD agency
- From the local DD agency to a fiscal intermediary (in our case, an accountant in our community)
- From the fiscal intermediary to the payment of individualized supports and services for Jay.

The amount of funding for individuals with disabilities depends upon their support needs. Because Jay required 24/7 support and had intensive needs across all settings, the amount of his support was substantial.

In addition to Medicaid funding, Jay received Section 8 housing (rental assistance), Social Security Disability Income (SSDI), and Medicare. As I will describe later, Jay worked 20 hours a week at the University of Kansas and thus had his salary and the University's benefit package. By pooling these resources, Jay could clearly afford an enviable life.

In terms of his own skills, Jay did not count money or have the capacity to manage his own fiscal affairs. Through the collaboration of the fiscal intermediary, his housemates, and family, Jay received the benefits of this funding without needing to have the competence to manage the funds himself.

A Home of His Own

Jay lived in his own home for about 20 years. Jay's home was one block from his job. This is a major advantage for an individual who was unable to drive a car. Based on what we learned about physical lay-out, privacy, and togetherness from his first home, we particularly looked for a home that would have two living areas in it. Jay's home was two-story. His bedroom was on the first floor, along with an additional bedroom, a living room, a dining room, a kitchen, and a family room. His housemates lived on the second floor and had their own bedroom, family room, and office. This means that they had their own privacy, as did Jay; but they also enjoyed the shared spaces of the home on the first floor.

His last housemates were Tom and Laura Riffel. Tom and Laura are middle-aged and have three children who are adults. During the early years of having housemates, Jay typically had university undergraduate or graduate students. We found students were terrific in many way

– all of his housemates have had particular strengths and gifts that have exceeded our expectations. When Jay became middle-aged, we found that having more stable, seasoned housemates who have “been around the corner” a number of times and who know what it means to truly create a home and not just a house was especially important to him. His housemates were paid by Medicaid, and they provided core support to Jay in activities of daily living, coordinated his very busy weekly schedule (see Figure 1), and facilitated the “comings and goings” of the many friends and support people who were part of his life.

Laura and Tom did not perceive of themselves as Jay’s “staff”, and neither Jay nor we had that perception. They were housemates, and, yes, they provided far more support than housemates typically provided when people do not have disabilities. They developed a relationship that was not hierarchical or controlling. Unlike group homes, they did not provide support on a shift basis. It was their home, too; and they enjoyed the daily/weekly rhythms of living there along with Jay.

Work

Jay was employed at the Beach Center, the research center that my husband and I co-direct at the University of Kansas. He worked at the Beach Center for 21 years and was getting ready for work the morning that he died. He worked 20 hours a week on clerical tasks, including carrying the mail to a couple of buildings, copying, collating, stuffing envelopes, shredding paper, and recycling. He had a job coach who provided him with support, and he received responsive assistance, encouragement, and friendship from the Beach Center employees – about 45 individuals.

Jay’s job provided benefits on multiple levels. Most importantly, it provided a positive anticipation of each day in terms of looking forward to being there, structure and routine, an

opportunity to do meaningful tasks that others appreciated, a broad network of friends and opportunities for social interaction, as well as the usual rewards of a paycheck and health benefits. Jay's bipolar cycle was a major consideration in how job support was provided. It was necessary to calibrate the intensity and nature of his job coaching according to his mood cycle.

Cheers Connections

There has been a favorite U.S. television program called "Cheers." On the television program, Cheers was a bar, the kind of bar where people could go and everyone knew their name. I do not use "Cheers Connections" to refer only to bars, but to all places where Jay went regularly where everyone knew his name (and provides him with unconditional acceptance).

Several of Jay's particular "Cheers Connections" music venues, church, concerts in the park, bakeries, and countless restaurants. It was especially important for Jay to have "Cheers Connections" because given the nature of his behavioral challenges, we were never sure what might happen at any particular time and in any particular environment. At the Cheers Connections, Jay sometimes got into challenging situations; and because he was a "regular," the other regular patrons knew exactly what he needed and when he needed it. Consistently, they stepped forward to provide support without being asked.

We embraced the fact that Jay, his housemates, all of his support people, and his family had responsibilities in establishing the kind of comfortable, connected, and camaraderie relationships with people throughout all of Jay's favorite places in the community so that he was welcomed, supported, and safe. Remembering always that "what goes around, comes around," Jay's team sought to extend support to these same individuals so that they would be the recipients of support as well as providers.

Friends

Friends are one of the major missing elements in the lives of many people with autism. We placed major emphasis on supporting Jay to be a friend and then to experience the joys of friendship. We learned that Jay and his support team had to extend themselves to others in reciprocal ways.

Jay has had many natural networks for developing friendships – co-workers, neighbors, members of our church, the regular patrons of all of his “Cheers Connections” and the people who provided support to him. In extending himself to them, we emphasized that Jay should:

- Be an interesting conversation partner by asking his friends questions about things that are important to them such as their children, pets, and hobbies.
- Do kind gestures for others at times of special celebration or special sadness in their lives.
- Give others holiday cards or gifts.
- Host parties and invite people to his home for fun and frivolity.
- Do favors for people and help them, especially in times of need.

Promoting Wellness

As Jay continued to experience intense anxiety and significant mood swings throughout adulthood, we realized that even comprehensive, multi-component positive behavior support and the most fine-tuned medication we were able to figure out were still not enough to regulate fully his mood cycles and keep his stress level under control. We concluded that we needed to explore holistic health. Jay found comfort, relief, and anxiety/depression reduction from his weekly experiences with yoga and massage. He had a yoga class on a weekly basis from a teacher who helped him relieve stress through stretching, strengthening, and breathing. He had a weekly massage with an emphasis on relaxation and stress relief. Holistic health provides opportunities

for people with autism to move beyond what traditional psychological and medical research has offered within a sole Western health paradigm.

The Ultimate Dimension of Envable Life

Michael Wehmeyer cut to the very jugular of what it means to live an enviable life in his eulogy at Jay's memorial service:

The lessons Jay imparted were simple, but important in the context of our too often hectic lives. He reminded us to remember the holidays; to revel in family and loved ones; to live life with gusto; and to have favorite foods that excite you. But Jay's ultimate lesson to me came this week. When the press release announcing Jay's death was posted Wednesday night, I paused after I read the link from the KU home page to the news release. That link read: University mourns longtime employee Jay Turnbull.

Think about that for a moment. The headline could just as easily have read "University Mourns son of Distinguished Professors" or "University Mourns Special Worker." Instead the headline points out a simple fact; that Jay was a person in and of himself, independent of who his parents were or whether he had a disability. He was a person who worked for 20 years and who contributed to the mission of the Beach Center, the Life Span Institute, the School of Education, and the university.

And in reflecting on that headline, and thinking about Jay and his impact on my life and the lives of others, I realized that the most important lesson Jay taught me was not really about the possible lives people with severe disabilities can lead, that people with severe disabilities could live in their own homes or perform meaningful work or lead a full social life. Those are important lessons, I know, but these lessons are really about the business of education or the

rehabilitation business or the business of the myriad of professions that provided the supports that sustained Jay.

No, what Jay taught me, and what I believe he taught so many around the world who join us today to mourn his passing and celebrate his life, was that we are not in the education business or the rehabilitation business, or any other business; we are, each of us, in the dignity business. By the quality of his character and the example of his life, Jay reminds us of the dignity of living full lives; lives rich with friends and family and the dignity of work and the security of home and the joy and gift that is each day.

Given the adult outcomes data cited at the beginning of this article, it is clearly imperative that we create visions of what it truly means to “be in the dignity business” and then to implement systems of support characterized by dignity that ultimately lead to enviable lives.

References

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- Ellison, D., Clark, C., & Langford, B. (2005). Where are they now? Adult functioning in autism spectrum disorders. Presented at IMFAR, Boston, May.
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Weekly Schedule

Activities

Time	Mon	Tues	Wed	Thur	Fri	Sat	Sun
12-8:30 AM	1-F	1-H	1-H	1-H	1-H	1-H	1-H
8-8:30	2-F	2-H	2-C1	2-C4	2-C1	2-C1	2-H
8:30-9 AM	5-C1	5-H	5-C1	5-C4	5-C1	5-C1	5-F
9-9:30 AM	6-ST	5-H	5-C1	5-C4	5-C1	5-C1	5-F
9:30-10 AM	6-ST	4-H	4-C1	4-C4	4-C1	4-C1	10-F
10-10:30 AM	8-MS	4-H	4-C1	4-C4	4-C1	4-C1	10-F
10:30-11 AM	8-MS	9-YT	4-C1	4-C5	4-C1	4-C6	10-F
11-11:30 AM	4-H	4-H	4-C1	4-C5	4-C1	4-C6	10-F
11:30-12 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C6	5-F
12-12:30 PM	3-JC	3-JC	3-JC	3-JC	3-JC	5-C6	5-F
12:30-1 PM	5-JC/CW	5-JC/CW	5-JC/CW	5-JC/CW	5-JC/CW	5-C6	4-F
1:30-2 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C6	4-F
2-2:30 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C4	4-F
2:30-3 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C4	4-F
3-3:30 PM	3-JC	3-JC	3-JC	3-JC	3-JC	4-C4	4-F
3:30-4 PM	4-H	4-C2	4-H	4-C5	4-H	4-C?	4-F
4-4:30 PM	4-H	4-C3	4-H	4-C6	4-H	4-C?	4-F
4:30-5 PM	4-H	4-C4	4-H	4-C7	4-H	4-C?	4-F
5-5:30 PM	4-H	4-C5	4-FR	4-C8	4-H	4-C?	4-F
5:30-6 PM	4-H	4-C6	4-FR	4-C3	5-C5	4-C?	4-F
6-6:30 PM	5-GF	5-C2	5-FR	5-C3	5-C5	4-C?	4-F
6:30-7 PM	5-GF	5-C2	5-FR	5-C3	5-C5	4-C?	4-F
7-7:30 PM	7-MT1/GF	7-MT2	7-MT3	7-MT3	4-H	4-C?	5-F
7:30-8 PM	7-MT1/GF	7-MT2	7-MT3	7-MT3	4-H	4-C?	5-F
8-8:30 PM	5-H	5-H	5-H	7-C3	4-H	4-C?	4-F
8:30-9 PM	5-H	5-H	5-H	5-H	4-H	4-C?	4-F
9-11 PM	1-H	1-H	1-H	1-H	1-H	H/C?	1-F

? means that specific companion varied.

1 Sleep
2 Personal Care
3 Work
4 Leisure/Comm. Part.
5 Bkt/Lunch/Dinner
6 Speech Therapy
7 Music Therapy
8 Massage
9 Yoga
10 Church

People Providing Support	
H – Housemates	
F – Family	JC – Job Coach
ST – Speech Therapist	C1-C6 – Companions (6 people)
MT1-MT3 – Music Therapists	FR – Fraternity (2-4 guys)
M – Masseuse	GF – Girlfriend
Y – Yoga Teacher	CW – Co-Workers (5-7 people)