

APSE Notes

Defying the odds: You can't put a square peg in a round hole no matter how hard you try

Joe and Marilyn Henn

In the real world of employment for individuals with disabilities, the outcomes are very poor. This is especially true of individuals with more significant disabilities. In the face of this, we want to tell you a remarkable story about a young lady with significant autism. Nancy is 31-years old, non-verbal, and is considered by tests to be in the bottom 10% of all those with autism. She uses sign language, gestures, and a few words to communicate. She has severe behavior problems and has exhibited kicking, screaming, biting, tantruming, and other dangerous behaviors.

In spite of all of this, today she works 40 hours a week at union scale and receives full benefits. She does this with the support of a full time behavior support specialist/job coach, who she pays from her work earnings. Her many job duties include: microfilming, catching metered mail, delivering inter- and intra-departmental mail, and making notepads. She has now worked full time for over nine years. She also has lived for 10 years in her own home in a "Family Consortium" model of supervised group living. She lives with 3 roommates of different abilities.

In 1999, Nancy received APSE's National Personal Achievement Award. In 2003, she won the national Outstanding Individual with Autism award from the Autism Society of America.

For job success, Nancy needed a lengthy transition from school to work, which occurred with help through the Kent State University Cooperative Transition Service Program. Nancy was first placed in the Kent State library picking up books left on tables and in cubicles. She started one hour a day for 1–2 days a week, and quickly increased her work time, surprising her IEP by

learning to control her disruptive behavior at work. She added a second job delivering interoffice mail in the Department of Education building. After 4 years, she developed good work habits, was more independent, and learned to manage her behavior at low levels. With 1 to 1 supervision, staff learned to intervene before the behaviors became severe.

Statistics show a 20% chance of employment for young people with disabilities who do not have work before they leave school. As Nancy's parents this worried us. So we began to help Nancy with the hunt for a paid job in the community a year before she graduated (when she would no longer have access to mandated supports through IDEA). We went through the Rehabilitation Services Commission/Bureau of VR, but subcontracted for job development work with Rachael McMahan, a Kent State graduate student in the Center for Innovation in Transition and Employment.

Rachael contacted us weekly and followed up on our suggestions as to where to look and how to present Nancy. She used a resume, a videotape of Nancy working at KSU, letters of recommendation and references. We developed a close working relationship as Rachael pursued job possibilities for Nancy. She did not contact people from human resources, but started at the top of potential work sites. When she could not get an appointment with the Mayor of our city, she was able to contact and meet with the Deputy Mayor. He put her in contact with the County Department of Human Services, where Nancy was placed in a job as a mail clerk/messenger. It took 9 months of very hard work to find the job, and Nancy began to work while still in school. She used a PASS plan to set aside earnings

to pay for a 1-1 job coach. This allowed her to work and still keep her SSI, food stamps, and Medicaid eligibility. The PASS plan continued for 4 years, during which time we learned that even though Nancy knew her job, she needed someone to constantly monitor her behavior. Natural supports would have been a good option for Nancy. However, because people bid in and out of jobs in her office each year, it was difficult to find a stable source of work peers to help out.

Nancy has since moved from a PASS to an IRWE (Impairment Related Work Expense), another Social Security work incentive. Although her SSI payment has been reduced somewhat, she still maintains her food stamps and Medicaid eligibility.

We have provided Nancy a car that her staff uses to drive her to/from work. Having a car removes any geographical constraints to employment. Nancy has help from one adult service provider, who provides Behavior Support at work and residential support at

home. They will eventually provide fiscal supports as well.

Nancy is considered to be the most productive microfilmer in her department, since she microfilms at two and one half times faster than her nearest non-disabled co-worker. She is well liked and known all over the downtown area where she works. Her quality of life is excellent as she lives, works and recreates in the community. Her future is bright and we couldn't be more proud of who she is and what she has accomplished. We don't know what the future will bring, but we do know that Nancy is up to life's challenges as she continues to "defy the odds".

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