

**Employment Challenges, Opportunities, & Lessons Learned from Mark:
A Personal Story
by
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As a physician I was privileged to practice interventional cardiology for almost three decades. During my medical training I was drawn to this particular specialty because it provided excellent tools to not only to evaluate patients, but, more importantly, to quickly intervene in order to correct their problems with a high degree of success. The mindset of initially identifying a problem; evaluating it carefully; and trying to correct the problem as quickly as possible has become deeply ingrained in my professional and personal life. Recently, I have realized that unwittingly I've adopted this same approach since our son, Mark, was diagnosed at 18 months of age with a severe form of Autism Spectrum Disorder (ASD).

After Mark's diagnosis, like so many other families, we were frustrated by the lack of funding and coordinated scientific research and worked with other advocates to establish premier academic centers such as the UC Davis MIND Institute. During the past twenty-some years, there have been remarkable breakthroughs in our understanding of the science and causes of autism. The early detection, evaluation, treatment, and medical insurance coverage for this disorder have markedly improved. Despite these noteworthy and inspiring advances, employment opportunities for autistic remain woefully lacking. Arguably, transitional services, vocational training, and competitive integrated employment are significantly lacking (some would say virtually absent) for individuals such as our son who require intensive supports and accommodations.

During the past several years, my wife Wendy (Mark's mother) and I have focused on providing Mark with his own life that optimizes his potential for growth, independence, and self-satisfaction. A major emphasis of our endeavors has been related to finding jobs and employment for Mark. Even as I write the preceding sentence, part of my brain is saying, "Lou, shouldn't you be looking for jobs "with Mark; and NOT for Mark?" Nothing would give me great joy and pleasure, if indeed that could be the case. Regretfully, Mark would not be a candidate to work at Microsoft or SAP. For reasons that hopefully will become evident, working at an Amazon warehouse or Walgreen's facility are well beyond his capacities and capabilities.

Vocational training and opportunities for sustained, competitive integrated employment are (in my opinion) virtually absent for individuals such as Mark, who require intensive supports and accommodations. This problem is further intensified by recent federal and state rulings that many of the congregate settings and day programs are being phased out. Adhering to the old adage of "*every crisis presents a golden opportunity*," Wendy and I have been "*beating and*

bushes and leaving no stone unturned” in finding jobs for Mark (hopefully these are my final cliches).

As a prelude for discussing our hopes and aspirations for Mark’s future employment, I must provide an overview of the challenges and limitations that Mark seeks to overcome on a daily basis. The realization and acceptance of Mark’s severe limitations has been a difficult personal journey. For many years, I struggled with the misguided belief that we could either “cure” Mark of his autism or provide enough therapy and/or supports so that he could have “a normal life.” A few years ago, a friend gently informed me that my hopes were as ill-founded as my trying to dunk a basketball (I’m 5’9” and can’t jump). Furthermore, I’ve come to the realization that an honest and accurate assessment of Mark’s capabilities and limitations is a key and crucial element to find purposeful and meaningful activities in his life.

Mark, who is 27 years old, is our only son and the youngest of four children. His three sisters are all neurotypical; highly educated; and without any disabilities or special needs. Mark’s gestation; delivery and first year of life were all unremarkable. However, his subsequent lack of speech and language development resulted in the diagnosis of Autism Spectrum Disorder at the age of 18 months. Prompt intensive early intervention (ABA) therapy resulted in some developmental improvements and a modicum of functional language, but early attempts at “mainstream” educational classrooms were unsuccessful.

Individuals such as Mark with severe autism present a dizzying and frequently overwhelming array of symptoms, problems, and conundrums. An issue that has especially perplexing in our son’s case is the potential for an extreme variability in his moods, behaviors, and actions. At times, Mark will be engaged; behaving appropriately; and seemingly in good spirits. Suddenly, his good mood can evaporate in seconds. Aggressive or self-injurious behaviors have previously appeared in a flash. Fortunately, during the past several years these physical outbursts have become extremely infrequent and are currently nonexistent. Nevertheless, there are still times when Mark will become inexplicably agitated. These episodes are frequently accompanied by brief shouts and verbal outbursts; symptoms which have raised the possibility of Tourette’s Syndrome.

Understandably, these highly variable and at times uncontrollable utterances and inappropriate behaviors pose severe complications to most, if not all, of integrated workplace environments. However, we have found that these challenges, although at times extremely difficult, are not insurmountable. Let me underscore that these insights and recommendations are strictly anecdotal; based only on our family’s personal experiences and must be tailored for each individual. Nevertheless, I would like to share some of the strategies and approaches that may be helpful in obtaining employment opportunities for autistic individuals who are overcoming significant behavioral-communication issues and require intensive supports.

Begin with The End in Mind:

It is absolutely imperative to seek and identify employment opportunities that are consistent with each autistic individual's strengths and abilities. In our son's case, having a specific "check-list" or SWOT (Strength, Weakness, Opportunities, Threats) was helpful. Examples of Mark's "Strengths" include: strong and very well coordinated; enjoys being active; no physical limitations; does well in a structured and consistent environment; visual learner; reasonable receptive language. His weaknesses include the following: essentially nonverbal; limited interests in social engagement; variable mood swings; occasional verbal outbursts; intermittent anxiety; tendency to perseveration. These (and other weaknesses) may lead to examples of the following "Threats": the most serious being that his disruptive behaviors could interfere with not only his productivity, but also have a major negative impact with his co-workers and his job environment. Examples, of other potential "threats" include: communication difficulties; lack of spontaneity, flexibility and problem-solving abilities. Which leads us to the issue of "opportunities": i.e. what type of job(s) could possibly lead to Mark's successful long-term employment. Based on multiple detailed discussions with Mark's behaviorists and support staff, Mark's support team proposed the following: that Mark's employment opportunities should ideally include as many as possible of the following possibilities:

Structured Environment:

Mark, like so many other individuals with ASD has always had difficulties coping with transitional situations and/or a changing environment. These challenges are especially heightened when exposed to new circumstances; increased demands; during concurrent periods of increased stress, anxiety or other emotional instability. Although these difficulties and challenges will be inevitably associated with any/all employment opportunities, in my opinion it is of paramount importance and absolutely crucial that we seek only those jobs that can be associated with a stable and highly structured work environment. In identifying a structured environment, I would consider the following factors:

1. Consistency: The tasks, activities, and job requirement are similar (if at all possible) on a daily or regular basis.
2. Predictable: That Mark will know ahead of time what jobs/activities are scheduled for that particular day or "timeframe." We have found that having a various visual schedule(s), timers, and other monitoring devices/prompts are all of utmost importance in having him understand and successfully cope with various employment activities.
3. Linear activities: Mark can become easily bored with pursuing the same type of work over prolonged periods of time. Therefore, we've tried to find occupations that enable him to establish a natural flow where various types of activities can be integrated in a natural and successful work environment. For example, prior to the Covid pandemic, Mark worked in the dining room of a large assisted living facilities that served over 100 seniors daily. His job required that he clear all of the tables; clean and vacuum the dining area; and prepare the tables and room for the evening meal. In essence he was able to

change activities in a way that were logical; predictable; and clearly had a beginning and an end to each of the various tasks. Furthermore, this schedule enabled him to change activities during his work period (ultimately 2-3 hours) that provided a significant degree to satisfaction and accomplishment.

Vocational training:

Regretfully, in my experience, this was regretfully limited throughout Mark's education. Although Mark was enrolled in various excellent special education classes with highly dedicated teachers, all too often the academic programs and curriculum did not apply to getting a job in the real world. Furthermore, his experiences with several [Workability II](#) experiences, also failed to impart any significant post-secondary job skills.

Therefore, we have sought employment opportunities whereupon vocational job skills can be:

1. Acquired initially outside of the workplace. For example, many of Mark's skills in learning how to work at the senior assisted living facility, were initially acquired by having him practice the same identical chores at various home settings.
2. Vocational organizations/programs. We have been very fortunate that Mark has been employed at Pride Industries, which is the nation's largest employer of individuals with disabilities. We found that his work experience at Pride provided an invaluable experience in working around other individuals and being part of productive goal-orient team.
3. Employer accommodations: We were extremely blessed that Eskaton Senior Care & Services was willing to provide a trial period during which Mark could learn and acquire the necessary skills to work at their assisted living facility dining room. What was also incredibly heartwarming, and uplifting was the manner in which the assisted living residents welcomed (and in some cases embraced) Mark and several other of his developmentally disabled coworkers. I am truly hopeful that post-Covid, Mark will not only resume working at Eskaton, but that we may find other employment opportunities related to services and supports for older adults.

Employment Supports:

I believe that many of the most important factors related to employment opportunities for individuals like Mark are dependent on activities that start long before job placement is contemplated. Our family's experiences include the following observations and conclusions:

1. Soft-skills training: Soft skills are non-technical skills that relate to how you work. They include how you interact with colleagues, how you solve problems, and how you manage your work. Soft skills are the skills that enable you to fit in at a workplace. They include your personality, attitude, flexibility, motivation, and manners. It's especially important to identify and address these issues for ASD individuals, such as Mark, who require intensive accommodations and supports. For Mark, some examples of these soft skills included: being comfortable in a strange environment; adjusting to ambient background

noises and other distractions; being around strangers; acquiring anxiety-coping mechanisms other than verbal outbursts, to mention only a few. In summary, soft-skills are extremely important but should be focused on strategies and outcomes that enable the autistic individual to feel comfortable, relax, and focus on the job at hand.

2. Job Coach: Mark is currently enrolled in California's Supported Living Services (SLS) Program. This program consists of a broad range of services to adults with developmental disabilities who live apart from their families and are supported by an array of staff and services to secure the maximum possible level of personal independence. We are blessed to have an amazing group of individuals who have not only supported him at his home and in the community but have also performed admirably and have been incredibly effective as his job coaches in various endeavors. Their high degree of success has been directly linked to the following:

- a. Knowing & communicating with Mark. They all have an incredible awareness of Mark's moods, anxieties, and stress levels such that they are able to either redirect him in a positive or productive manner, and/or provide prompt interventions to deescalate any untoward situation before it arises.
- b. A trusting relationship. It is equally important that Mark knows and trusts the staff. Therefore, his levels of anxiety and stress during the initial period(s) of employment accommodation are naturally going to be much lower and amenable to effective vocational training.
- c. Incremental approach. Since the staff are part of Mark's regular daily activities and routines, his staff can adjust his preemployment vocational training in a flexible and incremental manner. With this approach, Mark's time on the job can be gradually increased without disrupting the rest of his other activities and routines.
- d. Promoting independence. Since Mark's staff are with him during 8-hour shifts, it's much easier for them to actually fade their activities as "job coaches" providing actual employment supports. They can still be on site and standby should Mark encounter any unexpected problems.

Engagement & Assessment:

When we first met with disability employment specialists, invariably they first asked, "What does Mark like to do and what kind of jobs or activities is he interested in doing?" Unfortunately, our persistent (and only) response that he loves to watch TV, especially train videos, was not helpful and often led to abbreviated interviews.

Since Mark has extremely limited inherent interests, we have taken a different approach. Specifically, we first find a job situation that is highly structured; consistent; and provides the appropriate vocational training and supports. Subsequently we then implement a gradual and incremental approach to each job and/or activity. Multiple steps, usually concurrent, are involved. Factors that we have found helpful include the following:

1. Time limits: Starting with a shorter period of time for each activity tends to avoid anxiety, frustrations, behaviors and promotes a feeling of accomplishments. Often have a timer or other form(s) of visual reference may also be helpful. These prompts are also useful in gradually increasing the duration for the job in question.
2. Reward & Compensation: Motivation to work are invariably related to “getting something out of it.” Therefore, we have always tried to link new challenges for Mark with some sort of reward or activity that he enjoys and associates with the task. Although we try to avoid food-related rewards as much as possible, an occasional trip to the ice cream store may be desirable. Other rewards have included small stipends that enable him to purchase favorite DVDs; trips to our favorite balloon store; visits to the Railroad Museum; or simply downtime that enable him to watch his favorite TV program or video. However, it’s important that we use a visual schedule or other forms or communication such that Mark associates the “reward” with and as the direct consequence of “doing and completing his job.”
1. Backward Chaining: When teaching life skills to individuals with special needs, this term refers to breaking down the steps of a task and teaching them in reverse order. For example, setting a dinner table at Eskaton, began with our job coach doing all of the initial work (i.e. getting all of the utensils, placing the tablecloth; etc) and then having Mark complete the setting by just placing all of the dishes in their appropriate places. After mastering that task, Mark then required to place the glassware; then the silverware; and so on until he could do everything by himself. In other words, during the vocational training process, the job coach does less and less which Mark did more and more, and always ended with him performing the final step. We have found that this is an important technique that is applicable to teaching a variety of jobs and other complex behaviors.

Specific Jobs & Employment Opportunities:

1. Services for Older Adults: Prior to the onset of the Covid pandemic, Mark had been working for several years at an Eskaton assisted facility dining area, which served about 110 residents daily. His job consisted of clearing cafeteria area after lunch; vacuuming and thoroughly cleaning the area and preparing the dining room for the evening meal. Mark enjoyed and was quite capable in this endeavor, since it provided a quiet, consistent, repetitive and highly structured environment. We anticipate that he will resume this activity after the pandemic crisis has been resolved.

Mark’s employment at Eskaton was also noteworthy by the rapport and empathy that was evident between Mark and the residents. Although essentially nonverbal, Mark is quite attuned and sensitive to ambiances and general vibes. Being in a welcoming and warm environment was an important factor in Mark’s successful employment. We’ve noticed a similar type of rapport in other facilities and circumstances between seniors and autistic adults. In some situations, older adults just enjoyed being in the same room and “hanging out” with some of our autistic employees. Therefore, we’re hopeful that post-Covid,

Mark may expand his employment at Eskaton to other activities such as housekeeping, transportation, culinary, and other support services.

2. Vending Machines: The “microenterprise concept” is another opportunity that merits consideration. Several autistic individuals have been successful in starting their own food trucks, bakeries, coffee shops, or delicatessen, or other independent endeavors. Since the complexities of running a business exceed Mark’s potential and capabilities, we’ve just started another project: Mark’s vending machine business. Specifically, we’ve purchased two vending machines that are located in the lobby of a large (70,000 square foot) commercial office building.

This venture has required Mark (with staff support) to do the following on a weekly basis: a) Take inventory of both machines; b) Purchase bulk quantities of 30-40 different types of products; c) Restock both machines. These activities have resulted in the following outcomes and benefits: 1) Mark is much better at learning to count and understand numeric concepts; 2) He is more comfortable in large shopping (i.e. “big-box”) environment; 3) He has improved organizational skills. 4) The venture is economically viable and we are currently in the process placing vending machines in several other sites.

3. Dog-Walking Service: For the past several years Mark and his staff have been providing dog-walking services for three families, all of whom live in Mark’s neighborhood. These activities, which are scheduled on a regular and consistent basis, average in total about six hours per week. We have found that Mark not only enjoys the regular exercise, but that consistent physical activity has a pronounced calming effect that significantly reduces his levels of anxiety and stress. In view of his active and consistent appetite, his regular walking schedule also keeps him fit and trim.

Furthermore, Mark’s dog-walking service has provided a nice conduit and potential for social interactions. Not only does he interact with the dog-owners families, but his consistent jaunts throughout his community have enabled him, and his staff, to meet and interact with many of his neighbors and even make some friends. Learning to bake is another unanticipated benefit of this activity. Since we recently realized that Mark enjoys feeding snacks to the animals, Wendy has been teaching Mark to bake his own dog biscuits. This process has also been helpful in promoting Mark’s organizational skills, learning to initiate and complete sequential tasks, and, most importantly, the satisfaction of a personal accomplishment: i.e. feeding his biscuits to the dogs.

I was told many years ago that as we go through life, all of us need, “*A job, a home, and a friend.*” For autistic individuals such as Mark, a job is especially important since it can serve as a conduit to friendships, social interactions, and as the gateway to a greater sense of freedom,

independence, and self-worth. I am hopeful that our families efforts in exploring and promoting our son's employment opportunities will not only improve the quality of Mark's life, but may also provide a modicum of benefit to other families and individuals who are overcoming similar challenges.