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Employment: from Competitive to Customized

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In

TASH Connections Newsletter

Vol. 28, No. 9, Sept/Oct. 2002, pps. 16-19

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The Americans with Disabilities Act of 1990 (ADA) provides a strong mandate that describes the rights and responsibilities for employers and prospective applicants with disabilities regarding the hiring process and the employment relationship. However, after more than a decade of implementation, there continues to be unmet expectations - outright frustration, some would say — on both sides of this sensitive issue. Employers continue to be cautious about the narrow consideration the ADA requires concerning employee performance, essential job responsibilities and reasonable accommodation. They are not able to ask about issues relating to disability, other than the accommodations necessary to perform essential job responsibilities, during the interview and prior to a specific job offer. On the other hand, many applicants with disabilities are frustrated by their difficulty in meeting arbitrary job descriptions designed for non-disabled employees.

To further confuse the situation, the current ethic in within the disability community does not seem to encourage applicants to negotiate tailored job descriptions by presenting an employment proposal that identifies the specific skills that could match specific needs for the employer but, rather, for applicants to focus almost solely on a rights agenda. The bitter data from the decade of the post-ADA 1990's, a period of our country's strongest economic growth in history, indicates that the number of Americans with disabilities who were employed at the end of this robust decade was *fewer than* when the Act was signed in 1990 (Houtenville, 2000).

This confused situation seems to leave the people who are the interest of an organization such as TASH out of the employment picture altogether. If persons with disabilities who are fully able to compete are finding it difficult to become employed, how can we expect employment to become an expected outcome for people who experience significant disabilities? The answer can be found by examining the nature of the employment relationship between employers and applicants. When framing the ADA, Congress used the concept of "competitive employment". Within the ADA, applicants with disabilities must compete against two apparent issues: a) the essential responsibilities of the job, as described by the employer, and b) other applicants, disabled and non-disabled, who might also apply for the same job. Not only must an applicant be able to effectively perform the essential responsibilities of a job for which they are applying, they must also compete successfully against other qualified applicants.

Many applicants with disabilities indicate they are also competing against the fear of the unknown on behalf of many employers concerning issues relating to disability. While both sides - employers and applicants - have voiced their concerns, the structure of the ADA in its current form represents a compromise with a slant towards civil rights instead of the nature of the employment relationship.

This critical legislation walks a fine line providing "the art of the possible", the promise and usefulness of which will continue to unfold in the years to come. We are likely to find that the ADA is a better piece of civil right legislation than it is an effective tool to directly advance employment. It is time now to go beyond waiting on case law to decide specific issues. There are other ways for employers and applicants with disabilities to forge relationships, in addition to that of rights and responsibilities. The employment relationship can be voluntarily negotiated.

Within the disability field during the 1990's, practitioners revisited the challenge of the 1980's to work with applicants with significant barriers to employment, targeting those not likely to compete effectively even with reasonable accommodation provided by willing employers. It was discovered that if applicants with significant disabilities were represented by job developers who offered a specific employment proposal and, if employers were approached in an open manner using negotiation as opposed to legal entitlement, successful employment relationships could result (Examples: Callahan, 1990, Mast & West, 1995).

We found that persons with significant disabilities could become employed using tailored or personalized job descriptions and that employers, by and large, were willing to embrace this concept. However, many in the generic employment and traditional rehabilitation fields felt that this approach did not represent "true" employment. Critics seemed to feel that these individual strategies were a sort of aberration, only useful for persons with the most significant barriers to employment to function in a quasi-employment relationship in a grey area between "real" employment and charity-based volunteer work.

Indeed, the history of TASH has been marked by contentious debates regarding the nature of employment and the strategies necessary to assist people to work (Examples: the "Brown & Bellamy" debates of the mid-80's). Some felt that it was necessary to fundamentally alter the employment relationship, including payment for work performed, in order to assure full access for all persons who might want to work. Others felt that it was important to stay within

the traditional boundaries set by employer expectations, typical wages and competition. It is probably fair to say that these critically important debates fizzled as the tidal wave of supported employment shifted our focus from policy and theory to the tough reality of keeping persons in jobs defined by the Rehab Act of 1986 - mostly comprised of 20 hours of work per week at or around minimum wage. However, even as the debate waned, the issue of employment for persons with the most significant impact of disability did not go away. From the beginning of supported employment observers and researchers scolded practitioners for overlooking those applicants with the highest support needs and those with the most difficulty with competition.

Can the employment relationship be individualized?

The concern that individualized, negotiated employment does not reach the level of "real employment" began to be allayed early in 2001 when, within a week of her confirmation by Congress in January of 2001 as the Secretary of the U.S. Department of Labor (DOL), Elaine Chao suggested in a speech that, *"In one sense, the new economy is deconstructing work, with jobs that can't be pigeonholed into a traditional workday or workweek, and corporate structures that, in some cases, are eliminating the need for a workplace altogether. Workers themselves are demanding more autonomy, more freedom, more **customization** (emphasis added) of the terms and conditions of their employment. As we invest in critical job training, we are giving workers the bargaining power they need to **custom-design** (emphasis added) their jobs around their lives - - instead of the other way around. "*

While skeptics might reasonably argue that her true intent was to weaken the power of labor unions to arbitrarily represent groups of workers, Secretary Chao's remarks, taken at face value, indicate that the strategy that had been working for persons with significant disabilities for over a decade has relevance for the broader population. In other words, customized employment is real employment.

During the decade following the passage of the ADA, Congress passed sweeping reform of U.S. Labor law in the Workforce Investment Act of 1998. Within this legislation, persons with disabilities are welcomed into generic employment services, along with a host of other categorical groups that were consolidated within this sweeping Act. This generic system shares similar issues with employers in addressing the needs of users with disabilities. One solution identified by USDOL was to use the concept of ***Customized Employment***.

Even though, conceptually, customized employment represents a relevant approach for both persons with disabilities *and* the general population, it is fair to say that little has been written or discussed about the strategy on a nationwide basis until the summer of 2001. On July 20, 2001, the Federal Register published a solicitation for projects to implement *customized employment* options within DOL-mandated local workforce boards for persons with disabilities who might need such approaches to become successfully employed (Federal Register, 2001). Again this year DOL has issued a solicitation containing the following definition of customized employment that will be used in the proposal for federal funds:

"Customized employment means individualizing the employment relationship between employees and employers in ways that meet the needs of both. It is based on an individualized determination of the strengths, needs, and interests of the person with a disability, and is also designed to meet the specific needs of the employer.

It may include employment developed through job carving, self-employment or entrepreneurial initiatives, or other job development or restructuring strategies that result in job responsibilities being customized and individually negotiated to fit the needs of individuals with a disability.

Customized employment assumes the provision of reasonable accommodations and supports necessary for the individual to perform the functions of a job that is individually negotiated and developed (Federal Register, June 26, 2002, Vol. 67. No. 123 pp 43154 - 43149).

Characteristics of Customized Employment

Possibly the most defining characteristic of Customized Employment is that it is "real employment" - real employment performed in typical community work settings for typical wages by *one* person. Customized Employment is different from other forms of employment mainly in terms of the unique manner in which the *essential responsibilities* (ADA, 1990) of the job are negotiated by or on behalf of an applicant and the suggestion that applicants and family

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members consider allowing job developers to disclose aspects of the person's disability for purposes of negotiation. Other characteristics of customized employment include:

The job description of an applicant with a disability is customized through ***voluntary negotiation with an employer.***

Applicants with disabilities often, though not always, use job developers to assist in the ***negotiation of customized job descriptions.***

The primary focus of the customized job description is on ***contribution*** instead of ***competition.***

Job developers and applicants with disabilities ***present employers with a proposal*** to be considered by the employer in a voluntary manner.

Applicants ***voluntarily disclose issues concerning their disabilities*** as a good faith strategy to resolve support and accommodation issues that may be needed.

Negotiation is based on a ***"template strategy"*** in which an applicant's potential contributions are placed as a template over potential employer needs. Any matches between applicant contribution and employer need might become the component responsibilities of a customized job description.

Funding for additional applicant support needs, beyond those provided by employers through reasonable accommodations and supports offered to typical employees, might be available through funding sources such as vocational rehabilitation, the workforce system, social and adult services, schools and community organizations.

While job responsibilities and the conditions of employment that surround the job are negotiated, ***pay is determined by the commensurate wage paid*** for the traditional job description most similar to the customized job.

The implications for persons who are the focus of TASH seem clear. Customized employment offers a strategy from which *all* persons who wish to become employed can become employed. It is our responsibility within TASH to recommit to assuring the provision of the supports, representation, resources and, most importantly, the values necessary to make employment a part of life for all.

Customized Employment for Marci Garvin

Marci is a woman from Ft. Worth, Texas, who experiences the most significant impact of disability in her life. Marci represents almost perfectly an entire group of people in our society for whom the idea of a meaningful life evokes feelings of confusion, complexity and doubt. Even if society were to embrace the notion that Marci should have a life of participation and passion, membership, relevance and the opportunity for contribution, figuring out how to assist her to accomplish all that would still be difficult.

As a child of the "94-142" generation, she had access to educational services in a manner that earlier members of her group never dreamed of. However, the role of schooling in the lives of persons with the most significant disabilities is often as unclear as role of adult services in assisting people with such labels to be active participants in our culture. The implied promise of an effective and inclusive education is that if one goes through it, there should be some clear benefit in relation to adult life as a result. When Marci reached twenty-one, the path ahead seemed to lead only to an adult day center or to her family's living room. To her parents thinking, this kind of life seemed unfair, boring and unsatisfactory.

While Marci's parents were confused as to what a meaningful life should look like, they felt she needed to make a contribution to her community and be appreciated for that contribution. Some would say that Marci and persons like her should simply be appreciated, honored and included in society "for whom they are", without arbitrary or typical expectations. While Marci's parents certainly agreed with the idea of acceptance for their daughter, they wanted far more. They wanted Marci to experience the daily routines, the variety, the ebb and flow of a typical life. Most particularly they wanted Marci to have a job.

But who was this young woman on the cusp of adulthood? In an effort to have that question answered for purposes of receiving adult services, her family had Marci "evaluated" by a well-known vocational evaluator. The results were devastating. Marci was described as functioning as a seven-month-old infant. If this assessment was accurate and meaningful, it was obviously a stretch to imagine that Marci might work for pay in the community. But her parents felt that this view of Marci — this comparative, competitive view ~ did not have any practical relevance. Instead, with assistance of a handful of supporters who were willing to take a risk, they embraced the idea of *discovery*.

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Discovery allowed Marci's complex life to be explored rather than to be compared to others. And it provided a new way of looking at her disability. And it set the foundation for customization of employment. Instead of seeing Marci's life in relation to traditional indicators of success such as skill levels, productivity, independent performance and the like, she could be viewed from the perspective of what works in her life, what moves her to be present, and what kinds of supports might she need to make a contribution. We found that instead of capturing Marci in a two-page assessment report of comparative performance that her complex life could be described in a document the size of a book. Of course, no one wanted to write a book before Marci became employed so a ten page descriptive profile was used to capture all the information found in discovery.

Marci doesn't speak and the communication she uses is the most subtle imaginable. Since birth, her mother says that Marci has never shown emotion though facial expression. Her body is often in a state of movement and, occasionally, what appears to be agitation. Her mom says that when the external situation is pleasing and meaningful to Marci, she becomes still, attentive, and present. It provides the clearest way for Marci to express choice and preference. Marci rarely interacts in a physical manner with objects and people, but we learned that she does have some control over her right arm that is less rigid from spasticity than her left. She often moves that arm across the front of her body in a gentle rocking motion from right to left.

The process of discovery was essential to uncover the subtle manner in which Marci expresses her feelings and reacts to the world around her. We were able to determine the environmental conditions that seemed to fit best with Marci as well as those situations and people she seemed to prefer over others. What was missing from the equation was a way for Marci to contribute in a work place.

In reviewing her school records, it was discovered that teachers had attempted to introduce a saucier-shaped electrical switch to Marci for purposes of turning on a tape recorder for playing music. Marci seems to enjoy the effect of music and this was thought to be a functional task that might lead to other ways for her to control her environment. Hand-over-hand assistance was offered to Marci to first turn on, and then turn off, the tape player. However, that task was quickly discontinued due to what was perceived as resistance on Marci's part. After careful consideration and analysis of this activity by a dedicated support person a flaw was

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discovered. While turning on tape player is undoubtedly a functional task for those of us who love music, turning it off not as functionally motivating. The proposed solution involved using a 20 second telephone answering tape with music that Marci seemed to like. She would be assisted to turn the music on and after twenty seconds the tape would stop and rewind automatically. The next assist would be to turn the music back on.

This single idea, derived through discovery, was the basis for Marci's job using Customized Employment as a *specialty stapler* in the personnel office at the Fort Worth Star Telegram, the daily newspaper for that city. She has been working for over three years in a job in which the hours are set to meet Marci's needs. The switch that Marci turned on, initially, to hear the music she liked, operates the stapler. Within a couple of months, the music was no longer needed. She receives commensurate pay for her work and assistance from a job trainer funded by the Medicaid Waiver program in her state. Since starting work, Marci has routinely made more per hour than her support personnel. During the past year, shredding of personnel documents has been added to her responsibilities. This task utilizes a sheet feeder, which Marci operates with her switch, comprised of an old ink-jet printer Velcro taped to the top of the office's auto-feed shredder.

Marci has been employed for six year at the Star Telegraph. But this job only cracks open the door to the possibility of Marci having a life that approximates the rhythms of those led in her community. Beyond the work place, she needs assistance to, first, identify and, later, participate in activities that connect her to her community. In the summer of 2001, Marci and her family agreed to participate in a self-determination pilot in her county. Through this project Marci has begun to participate in community activities outside of work that include receiving personal shopping assistance from the manager of a Bath and Body Works store, picking up her medication at her local pharmacy and having her Ensure blended in a Starbucks *Frappiccino* machine. She also has recently gotten a debit card in her name to make purchases as she shops in her community.

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