

## Embracing a Working Life for All

Michael Callahan

**TASH** has advocated for inclusive lifestyles throughout its history. In our organization's earliest days, employment seemed to be the most straightforward avenue to achieve that goal. Following the emergence of inclusive education, community participation and home ownership, along with numerous other valued options, the role and importance of employment as a defining aspect of full community membership has lessened. To some extent, this is understandable. The venerable, good idea of supported employment has been with us for nearly twenty-five years. During that time the focus, status, and related discussions surrounding employment have dwindled among the 30 or so topic areas of TASH's annual conference .

To make matters even more confusing, employment has become a competitor not only for our organization's attention, it has become a choice on the menu of lifestyle options that implies one must decide whether or not to become employed. This makes no sense for an organization that advocates for all people to participate in the typical routines of life. As a parent of a teenaged daughter, my wife and I have recently experienced the confusing transition between school and adult life that all young people must go through. Not once did it occur to us to ask our daughter (who would experience a disability) if she wanted to work. In fact, it is clear that all of our community attitudes and many of its resources reflect the presumption that she will work. This experience leads one to

understand that it is typical within our society to presume that young people will work, that they are automatically "opted in" to that expected lifestyle. The only way we would expect them not to work would be for them to "opt out" of the role.

But this is not the case for far too many people with significant disabilities, the people for whom TASH advocates and seeks to empower. It seems that we have been so captivated by the concept of self-determination that we sit people at planning tables (or engage them in their living rooms) and ask them whether they would like to work. And too often the answer is "No, I would rather do something else." This has led to an alarming and costly increase in a plethora of "separate but equal" alternative lifestyles for persons with significant disabilities and an equally alarming decrease in the rate of employment among these same individuals as compared to the earlier days of supported employment. It must be clearly stated that people should have the right to opt out of a working lifestyle if that is truly their choice. However, the presumption that all persons with disabilities will go to work could profoundly affect the

manner in which funding, person-centered planning, and employment services are delivered. And, obviously, many more people would go to work

The first state to recognize and respond to this challenge is Washington. After noticing a dramatic rise in so-called community inclusion activities accompanied by a serious decline in supported employment outcomes, the state's developmental disabilities agency empanelled a task force of providers, advocates and bureaucrats to suggest alternatives. Starting in July of 2006, Washington embarked on the Working Age Adult Policy which directs state funding for persons between twenty-one and sixty-two to be used solely for employment in the community or, in limited situations, for a "pathway" to employment that clearly targets an outcome of work in the community.

But this isolated example represents a shaky step at best. It is incumbent on all of the stakeholders in the disability field, regardless of their specialty and focus to encourage employment for all people. This article speaks to the impor-

## Our values and our implementation strategies are not in sync

tance of employment as a defining aspect of citizenship and inclusion—one of but a handful of life outcomes that are enhanced by the myriad of other issues that we annually address. Employment should take its place next to school inclusion, homeownership, community living (membership, participation and contribution) and personal relationships as the essential defining ingredients of an inclusive lifestyle.

But in many ways, employment is the most complex outcome to achieve. Paid work, uniquely, involves a relationship that is almost impossible to guarantee solely through rights and resources. Employers are almost never obligated to hire a job seeker. And the complexities associated with the significant disabilities that define most of TASH's constituency have kept employment an unreachable goal for the vast majority of the people we are concerned about.

Beyond pay, there lies another aspect of employment that has created a barrier for many individuals with disabilities—competition. The disability field has used the term “competitive” as a modifier of employment for decades to distinguish employment in the community from sheltered segregated options. It seems that we did not give sufficient thought to the word we were using. *Competitive*—the term itself implies virtually everything that creates barriers for persons with significant disabilities—test scores, grades, rankings, evaluation results. It could be said that a functional definition of disability would reflect “a difficulty competing on arbitrarily defined dimensions.” But since competition for jobs is basic to our capitalistic economy, how do we address employment for individuals who experience a significant difficulty in competing without resorting to sheltered segregated options or endless preparation activities?

Job site supports, workplace accommodations, effective job matching and affirmative action policies have been used to assist job seekers with disabilities to compete more effectively. However, most in TASH would likely agree that these strategies have not opened the doors to employment for the vast majority of the individuals that we represent. In other words, our values and our implementation strategies are not in sync. We are in need of a new concept that addresses the fundamental relationship between employers and employees.

In 2001 the newly formed Office of Disability Employment Policy (ODEP) within the US Department of Labor followed a lead provided by Secretary Elaine Chao in a speech in which she stated, “As we invest in critical job training, we are giving workers the bargaining power they need to custom-design their jobs around their needs—instead of the other way around.” These comments opened the door to a reconceptualization of the competitive standard. Instead of solely responding to the needs of employers in a competitive,

demand-based manner, ODEP posed the following question, “Could we negotiate a customized job description for job seekers with disabilities by offering potential employers discrete contributions that relate to specific workplace needs?” This question has been resoundingly answered in the affirmative following five years of implementation of ODEP's Customized Employment initiative.

The concept of customized employment has provided one of the critical missing ingredients in the mix of achieving successful employment for all who wish to work. It stands on the shoulders of all the previous strategies and indeed contains all of their essence. DNA Customized employment allows each individual to define the conditions necessary for success, the specific contributions to be offered and the areas of work interest to be pursued as employment personnel negotiate for a one-of-a-kind job. Since the job seeker instead of the system or the employer, sets the dimensions of the customized job, it is now theoretically possible to extend employment to all who wish to work. Of course it is important to state that employers must voluntarily agree to the negotiation of any customized job, but employers have not proved to be the barrier at this point. After five years of implementation across more than 30 sites across the entire country, it is solving to realize that employment providers, systems and funds have proven to be more of a challenge than employers. In other words, we are the problem.

But the necessary examples of individuals with the most significant disabilities continuing to work over long periods of time are scant. For this reason a new commitment must be made to employment. We must crack the code for achieving access to paid community employment for all who want to work. And we must embrace the positive presumption of a working life for all people. Efforts have begun to accomplish these tasks. We are beginning to develop examples of the strategies necessary for employment to become possible for everyone, but much work remains to be done.

What is required next is going to take considerable effort. In some ways the issue of employment is more complex than ever with the continuing shifts within our economy—outsourcing, financial and labor concerns and over-tightening margins. Solutions will be found on a person-by-person basis rather than in large labor focused initiatives. And the role of the generic workforce system presents many of the same complexities and opportunities that were faced when TASH suggested that regular schools were the best place for students with disabilities to be educated. Most of the resources and service capacity dedicated to employment for the people we represent are bound up in entities dedicated solely to disability. Finally, it is incumbent on each of us to examine our feelings regarding the importance of work within one's life. To paraphrase Marc Gold, “How much less of ourselves would we be if we did not go to work?”

In order to succeed, we will need to proceed on several fronts, simultaneously.

**Adopt** a clear presumption of employment for all persons with disabilities as well as the importance of employment as a defining aspect of full citizenship and community inclusion.

**Avoid** strict competitive employment by embracing customized strategies that allow the employment relationship to be negotiated in ways that meet both the needs of job seekers and employers.

**Distinguish** personal assistance from the typical supports of "job coaching" so that if an individual needs ongoing assistance to perform job tasks it will be available.

**Engage** and assist the generic workforce to effectively serve job seekers with disabilities and encourage disability-specific employment services to work within the generic system to the greatest extent possible.

**Find** a workable balance between hard-nosed competition and charity that allows employers a valued means to extend consideration to job seekers with the most significant impact of disability.

**Enhance** innovative and accessible technology that allows persons with the most limited movement to perform tasks that meet discrete workplace needs.

**Assure** that all funding sources including Medicaid embrace customized employment outcomes, services and supports.

Allow an individualized balance to be struck between earning wages and receiving necessary cash and medical benefits.

Encourage a pathway to economic sufficiency through asset development and ownership of tangible property, including one's own business.

**Explore** new avenues to encourage and develop entrepreneurial efforts by persons with disabilities.

Beyond these suggestions I feel that it is time to revisit our roots within TASH. Thirty years ago this organization, through the leadership of Briton Bhatt, put forth a radical manifesto called the Community Imperative. This document addressed two powerful goals a) the articulation of a clear position of the value of the community for all persons and b) a refutation of all arguments as to why some individuals should not be in the community. I submit the time has come for TASH Employment Imperative. I recommend the following as a working draft and would be pleased to join other members who may be interested in framing the statement and developing a refutation of all arguments against people with disabilities working in the community.

I  
N  
C  
L  
U  
S  
I  
O  
N

**The Employment Imperative**

*A refutation of the belief that people cannot or need not work because of disability Extending the Community Imperative of 1979*

**In the domain of Human Rights:**

All people have fundamental moral and constitutional rights. These rights must not be abrogated merely because a person has a significant disability. Among these fundamental rights is the right to earn a living in the community.

**In the domain of employment and business ownership:**

- All people benefit from the relationships available in the workplace.
- All people benefit from self-sufficiency.
- All people have strengths to contribute.
- All people need meaningful life routines.
- All people need to control the resources necessary for life.
- All people have unique needs that can be supported in the community.
- All people have interests that provide motivation for employment.
- Fully participating citizens benefit from being employed.
- Such conditions are optimally provided through employment in the community.

**Therefore:**

In fulfillment of fundamental human rights and in securing optimal self-sufficiency, personal satisfaction and means of making a contribution, all people regardless of the significance of their disability should be employed in the community.

*Michael Callahan is with Marc Gold Associates/Employment for All. For more information about this article, contact Michael at magold.com or www.employmentforall.org.*