

Employment for persons with disabilities: Where are we now and where do we need to go?

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1. Introduction

Nicki is a 21-year-old student with moderate intellectual disabilities who lives with her family. She has limited expressive language and communicates primarily through her body language and willingness to participate in activities. Nicki participated in a community-based vocational education program and then received supported employment services to assist her with gaining and maintaining a job. As a result, she has worked part-time at a small college dining center as a food preparation assistant for more than 1 year while still in school. Her job duties include making salads and preparing potatoes for baking. She also assists her co-workers with cleaning the work station by taking dirty pans to the sink area. Notably, her job was created by negotiating specific duties from a food preparation worker's job description. Nicki works approximately 25 hours a week and every other Saturday as part of her school curriculum and earns \$8.25 per hour. Transportation is provided to and from work by the school during the week and by her parents on the weekends.

Nicki is supported at work by her co-workers, managers, assistive technology (AT), and her job coach.

For example, her co-workers assist her with clocking in and out; putting on and taking off her hair net, apron, and gloves; setting up and replenishing her work supplies; and going on break. The assigned co-worker provides verbal and physical assistance throughout her work day as needed. Technological assistance has also been incorporated into the routine. For instance, the manager ordered a magnetic scanning card, which eliminated the need to manually enter her employee number into a computer in order to clock in and out. An audio prompting/praising system was also developed to provide her with consistent intervention and to decrease her dependence on co-worker prompts. The job coach provided upfront assistance with developing the job and then provided one to one jobsite training using systematic instruction, and helped identify and facilitate co-worker support. Now, the job coach is on site at most once or twice a week.

In this 20th anniversary edition of the *Journal of Vocational Rehabilitation*, we offer a special issue edited by Dr. Jeanne Novak on Supported Employment and Social Relationships in the Workplace. However, we also are providing provocative comments and perspectives from leading employment and transition specialists in the U.S. We must understand where we

have been, where we are, and where we need to go to improve employment outcomes for persons with disabilities.

There are thousands of people like Nicki in this country who are looking for a job that can lead to career. As most children leave middle school and enter high school, their thoughts turn to college, jobs, careers, and, essentially, what they are going to do with their lives. For young people with disabilities, the questions are as follows: Is there an internship that I can find that will help me? Can I get off a waiting list and into a vocational training program? Will VR find me eligible for services? Can I get a job that pays more than minimum wage? Will I be stuck in the same job for the rest of my life? Will I have to go to an adult activity center or a sheltered workshop? These questions take on even more meaning when one considers that increasing numbers of students have been educated with classmates without disabilities, thus heightening their mindset of working in real jobs or going to college.

The 2010 Harris Survey on disability trends, commissioned by the National Organization on Disability (NOD, 2010), surveyed people with disabilities and compared their attitudes and participation with other Americans. This marks the sixth effort over the past 24 years to assess the quality of life of people with disabilities on a wide range of critical dimensions, to measure the gaps between people with and without disabilities on these indicators, and to track them over time. The partners have established a series of 10 indicators of significant life activities of Americans with disabilities. These indicators, which have been tracked over the course of size surveys are: employment, income, education, health care, access to transportation, socializing, going to restaurants, attendance at religious services, political participation, and life satisfaction. In 2010, three new indicators were added, which included: technology, access to mental health services, and overall financial situation. While there has been modest improvement in a few areas, the general implication of the indicators is that now 20 years after the passage of the Americans with Disabilities Act (ADA), there has yet to be significant progress in most areas.

2. Among the findings

For example, employment success represents the largest gap between the two groups those with disabilities and those without. Of all working-age people with disabilities, not just young people, only 21% say

that they are employed, compared to 59% of people without disabilities – a gap of 38 percentage points. People with disabilities are still much more likely to be living in poverty. People with disabilities are less likely than those without disabilities to socialize with friends, relatives or neighbors, once again suggesting that there are significant barriers to participation in leisure activities for this population. The second-largest gap between people with and without disabilities is regarding Internet access. Eighty-five percent of adults without disabilities access the Internet, whereas only 54% of adults with disabilities report the same – a gap of 31 percentage points.

Good jobs in America are not easy to come by. As this is written, the U.S. is struggling to emerge from the greatest financial crisis in 70 years with unemployment rates exceeding 9% and underemployment over 18% [21]. This is a country that wants people to work, expects people to work, and even defines who they are by their type and amount of work.

So, what lies ahead for Nicki and what possibilities are there, especially in these difficult times? What jobs will be available for her? In education, rehabilitation and other postsecondary agencies, there is an increasingly strong feeling that vocational services should make transition-age students a priority – a feeling that has been intensified by the large investment in resources for special education entitlement programs. Certo, Luecking and their colleagues [6] have called for a national model of “seamless transition” for students from school to work. They observe:

“Despite the various mandates and funding mechanisms, the low employment rate of people with severe intellectual disabilities and the consequent social and economic marginalization are significant social problems [16]. Securing and maintaining employment continue to be the areas that result in the largest negative discrepancy between those with severe intellectual disabilities and those without. Eight percent of those with several intellectual disabilities were employed, in comparison with 81% of those without disabilities. More recent data show these figures are essentially unchanged (National Organization on Disability, 2010).”

Transitioning from school into segregated day program centers and sheltered workshops cannot be an acceptable end point for young people with disabilities ([2, 10, 19; U.S. Senate, October 20, 2005). While segregated day programs may be the only placement option for some, most students with disabilities aspire to

competitive employment as their first career option and work to achieve that [12, 23]. Teachers must help these aspirations become realities. If people with disabilities do not view themselves positively and have high vocational aspirations, then the expectations of advocates, family members, friends, and others working on their behalf will reflect that position.

Despite national and state policies promoting integrated employment, the majority of adults with intellectual or developmental disabilities (71%) are served in facility-based programs or non facility community programs [3]. Migliore, Mank, Grossi, and Rogan [15] focused on whether or not this gap between policy and practice is in part due to the lack of interest of adults with intellectual disabilities and their families for employment outside facility-based programs. The overwhelming response of workshop clients was clear: we want competitive employment. Results were based on the answers given by 210 adults with intellectual disabilities in 19 sheltered workshops, their respective families or caregivers ($N=185$), and staff members in these workshops ($N=224$).

Migliore et al. [15] reported that the majority of respondents would either like employment outside sheltered workshops or at least consider it an option. Moreover, the majority of respondents believed that adults with intellectual disabilities can perform outside workshops, if support is made available if needed. It is noteworthy that the preference for employment outside of workshops is not associated with the severity of the disability.

3. Why do we work?

What are the reasons for work and promoting meaningful career development and career advancement for individuals with disabilities? Why should the large number of adult day programs reevaluate their mission and move to supporting competitive employment outcomes as their predominant service? First, work is a way of human life in the United States. Work enhances other skills such as communication, socialization, academics, physical health, and community skills. Most importantly, work is good because it is a normal feature of what people in our society do and how they are perceived.

Second, many of the laws (e.g., Americans with Disabilities Act of 1990 [PL 101–336]) that have been passed by Congress related to disability services promote meaningful. These are not laws that promote protracted day program services and protracted day

program institutionalization, and there are no laws that promote not having a defined opportunity to be able to work, even for those individuals with the most severe disabilities.

Third, work is a vehicle to promote the greatest amount of economic well-being. For some individuals with disabilities, going to work may require carefully planned benefits counseling and arrangement of state and federal income programs to go along with Social Security incentives and Medicare/Medicaid rules; however, it is more likely that people who are employed in a competitive job, as compared with sitting in a day program day after day, will have the better opportunity to improve their economic situation.

Fourth, regular inclusive employment leads to a greater opportunity for upward mobility and career advancement. Very few people start with high-paying jobs and the best benefits. It is essential to have the “first job”. It is essential to have paid work experience in a real work setting to learn how to perform under pressure. Only with paid employment or the establishment of a personally owned small business can an individual hope to expand the business or increase the amount of hours or pay rate received.

Consider another extremely important reason for promoting employment – that of greater self-esteem, perceived self-competence, and ultimately greater skill development in areas such as socialization, communication, and financial literacy. Knowing that one has a regular job in which work performance is valued and needed has a tremendous influence on one’s dignity and on the perception that one has about personal capabilities and capacity. The inability to work regularly contributes to “learned helplessness,” or a self-fulfilling prophesy of incompetence. The longer this self-perception occurs, the less likely that one will be able to successfully work. An additional reason for work is the greater likelihood of establishing new social networks and community participation [4]. It is increasingly well known that social networks are some of the best ways to open up possible jobs.

4. Business: The social engine of america

Business is the social engine in America. Everyone needs to work. Everyone needs a paycheck and benefits. We are so often defined by whether we have a job, what it is, how long we have worked there and what is it we do. Americans strongly focus upon this aspect of their lives.

Young people with disabilities need to be a part of the work community. This job can be private sector employment, public sector employment, self-employment or other opportunities but the only way for the country to significantly turn around these protracted dismal employment outcomes is going to be partnering with business, getting business at the table with schools and community programs to understand the vocational capacity of young people with disabilities.

Why should business be interested in hiring young people with disabilities? There are numerous reasons. First, and perhaps most obvious when placed into a proper job with the supports and plans like we saw with Nicki, young people with disabilities become not good workers, but outstanding workers. Outstanding is defined as working every day, producing at high level of reliability and being highly productive. Productivity, which is basic business language means how much work is produced with the lowest amount of labor expense.

Secondly, the public, i.e., potential customers, prefer companies that hire workers with disabilities [5, 20] The public and coworkers have consistently demonstrated giving business to companies with strong hiring practices of individuals with disabilities.

There is a third reason businesses are open to hiring. People who work in companies and their suppliers and their customers often have children youth and adults with disabilities in their families. The sensitivity which many employers and supervisors feel toward including young people with disabilities is very high but schools and rehabilitation programs have not figured out the best ways to maximize the possible long term relations that can exist here. Businesses will increase their likelihood of hiring when they have more exposure to workers with disabilities.

Finally, most businesses are good stewards in the community. They sponsor little league basketball teams, church functions, health functions, and often engage in significant philanthropy. The prospect of hiring young people with disabilities and helping to give them a start in the world of work is highly consistent with this social responsibility philosophy that so many companies, private and public sectors both believe in and practice.

So we know that young people like Nicki have the work capacity and interest to work. We know that business is the primary partner that can be the solution for jobs. We know that work is highly valuable. Hence, what needs to be done in the next 5 years to make all of this happen on a large national scale?

5. Five guiding elements for employment systems change

We believe business is willing and we believe young people like Nicki are willing and able, yet we are still showing limited success. Why is this? Why is it that we have models based on research that show persons with disabilities can work but the outcomes are inconsistent with individual's capacity? The answers lie in our ability to change local and state systems of service delivery.

There are now some states and communities who effectively incorporate these new opportunities and challenges into their ongoing systems development while others continue to struggle with systems that maintain non-integrated day and work related programs as a predominant service option for persons with the most significant disabilities. States whose systems change efforts are consistently most effective frequently appear to be using most of the five elements listed below.

5.1. *Support self-determination and person centered planning for people with disabilities*

State and community systems that support the interests and service needs of people with a disability have a number of characteristics. The first is emphasizing access to services. For example, an individual who is currently receiving a center-based day service wants to move to a job in competitive employment. This individual needs supported employment to be successful. However, the public funds that are supporting the day service cannot be used for supported employment, and there are not alternative funds available. Access to the desired service is blocked because programs are funded, not people. Responsive systems fund people, not programs, by removing funding barriers such as mismatched rates that create financial incentives for one service over another. Delvin [7] has demonstrated the impact of self-determination on career choices and selection with 4 persons with intellectual disabilities.

Profiling of provider agencies is another characteristic of systems that proactively support self-determination and informed choice for people with disabilities. Funding agencies make information available on the participant profiles and outcomes achieved by service providers. This information tells a potential consumer, for example, the type of jobs found for individuals utilizing a particular provider, wages and

benefits earned, and employment longevity. Consumer responsive systems also build satisfaction measures into their performance standards, allowing the actual users of services to note the extent to which jobs found and services provided match the states goals and evolving interests of the individuals in supported employment.

The presence of measurable and mission-driven change is the predominant characteristic of states where effective systems change is taking place. In comparison, states resistant to real change attempt to add-on new initiatives while maintaining traditional programs and funding alliances. The first step in a systems change effort is to articulate a consumer driven purpose and goal, followed by a consensus building effort that recognizes and attempts to balance the interests of key stakeholders in the change effort. Once consensus around a common goal is achieved, a secure foundation is now in place that is not dependent on the leadership of a particular program.

5.2. Focus on community integrated job outcomes

A second feature of systems change is the need for emphasis on outcomes and the use of data that measures progress. Some states, as well as local communities and providers of service, have created data systems that show the outcomes for all people served, as well as the growth of supported employment. Such states have the means to directly measure the implementation of processes aimed at the mission. Without data, progress or lack of progress becomes an argument rather than a review of the evidence that can be made available.

5.3. Expand relationships with business

As noted earlier, business is the critical source of employment in America [20]. This means that the more employers are willing to hire persons with significant disabilities such as Walgreens who has been a real leader, the more other employers will follow. There are numerous ways relationships with business can be expanded and improved [12, 13]. The first is focusing more attention on the interests and needs of potential employers to meet production demands with employees who can work effectively. A positive job match works to the benefit of all involved. However, the willingness of an employer to be responsive to hiring persons with a disability is harmed by a hasty job match that does not

truly recognize the needs of the employer in relation to the abilities and interests of the individual seeking employment.

Many employers are uninformed about disability and are puzzled by the requirements of legislation such as the Americans with Disabilities Act. However, employers are the source of employment so long denied to most persons with significant disabilities. Multiple strategies exist with demonstrated effectiveness in helping employers realize and experience the abilities of many individuals with a disability to work productively. Without strong alliances and connections with the business community, systemic change will not occur for integrated employment outcomes. The jobs rest with private and public sector employers.

5.4. Systems change is mission driven

The clarity and singular focus of the mission of supported employment has contributed greatly to its success to date. This mission involves real jobs of choice in integrated work places with individualized long term supports [14, 23]. This mission stands in clear contrast to traditional services that resulted in the segregation and unemployment of the past. This clarity of mission provides states and local programs direction that makes progress toward implementing the mission measurable.

States and local programs incorporating this mission into their policies governing employment services create an environment that moves systems away from non-integrated day and work approaches. In business and in government, as well as in supported employment, clarity of mission has proven repeatedly to be one critical element in success (i.e., [17]). While supported employment has evolved in the last fifteen years and incorporated innovations and improvements over time, the basic goal of community integrated employment for persons with the most significant disability remains the same. As systems change efforts are implemented for the future, this clarity of mission should be reaffirmed and articulated in new ways.

5.5. Align dollars with mission

The fifth theme of systems change is insuring that resources, i.e., dollars, support the mission [9]. This is an enormous point. Once the person's plan for work is in place, and the community and local program have their mission clear, the dollars MUST follow

this mission. In some states, sheltered work remains a successful closure option for State Vocational Rehabilitation agencies, even though the Rehabilitation Act places a primary emphasis on community integrated outcomes. Other states have discontinued funding for sheltered employment (such as the States of Washington and Vermont) and have established clear policies where only community-integrated services are supported financially. In this manner, the mission becomes on operational reality and foundation for addressing new challenges and opportunities.

As Hall et al. [9] note:

“Funding is a central tool for improving the quality and range of employment service options. While outcome-based funding models are more common in the Vocational Rehabilitation system, there is a need for funding structures in intellectual and developmental disabilities (IDD) service systems that signal a clear preference for high-quality, cost-effective integrated employment outcomes. In an environment of increasing fiscal demands and limitations, and expansion of self-directed services and individualized budgeting, state IDD systems must engage in rate-setting and funding discussions that are rooted in their priorities and long-term goals.”

In this paper they provide detailed analyses of Connecticut, Florida, North Carolina, Oklahoma, and Tennessee in terms of how they provide employment funding for persons with developmental disabilities.

If financial resources are used to support outcomes that are not in line with the mission of community integrated employment services, then the mission is merely a dream with little chance of becoming a reality. Some states have created differential funding rates, providing greater funding for integrated outcomes. For example, Iowa Vocational Rehabilitation pays an incentive payment to SE providers based on the degree to which persons funded for supported employment work in community integrated jobs on a full time basis at least minimum wage [18]. Offering financial incentives to support community integrated employment rewards local programs and encourages real work opportunities for persons with the most significant disabilities.

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