

Community Participation Research Projects

Continuing Employability of Older Adults with Intellectual and Developmental Disabilities

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In 1991, approximately 756,000 adults with intellectual and developmental disabilities (I/DD) were involved in either employment or work alternative programming services in the United States (McGaughey, Kiernan, McNally, & Gilmore, 1995). Thirty percent of these adults worked in some type of supported employment situation, 45% worked in sheltered workshop environments, and 25% received non-work/alternative programming services. A variety of studies examining work experiences of individuals with I/DD documented a similar if not stronger importance attached to work for individuals with I/DD as is found in the general working population (Coker, 1997; Kregel & Wehman, 1996; Sinnott-Oswald, Gliner, & Spencer, 1990; Wadsworth, Harper, & McLeran, 1995). Research has indicated that maximizing employment experiences and opportunities among adult and older adult workers with I/DD results in individuals who are in greater control of and more satisfied with their own lives (Decker & Thornton, 1995; Kregel & Wehman, 1996).

The field of industrial gerontology has examined the optimization of work experiences and options and transitions to retirement for adult and older adult workers (Sterns & Camp, 1998; Sterns & Doverspike, 1989; Sterns & McDaniel, 1994). However, very little research has

been conducted regarding the work experiences of older adults with I/DD, in such areas as job satisfaction, employer/employee attitudes, skill assessment, goal setting, career development, or pre-work cessation education and planning. Information is needed in two areas. First, reliable descriptive data is needed regarding employability and employment barriers as experienced by adults with I/DD in both competitive and supportive employment. We are defining employability as the state of being employable - that is, having the skills and capacities to maintain employment. We are defining employment as the state of being employed. Second, we need to gather the day-to-day job placement and employment advocacy experiences of specialists in vocational centers that are attempting to outplace their workers. Such data will help us further identify barriers to employability. We've included this second area, because we recognize that a significant number of older adult workers with I/DD still work in a sheltered situation (Mank & Kiernan, 1994). Researchers have



noted that, despite the success of supported employment (Kregel & Wehman, 1996; Shuster, 1990; Wehman, Brooke, Inge, & Green, 1997), conversion from segregated workshops to integrated employment

services has been slow and difficult (Kregel & Wehman, 1996; Mank, 1994; Mank & Kiernan,



1994). This slow rate of conversion may be related to the employability issues.

Maintaining employability in older age for workers with I/DD has only recently been recognized as an important issue. Difficulties faced by older workers in maintaining employment and pension concerns have been well documented. Among workers with I/DD, age associated changes, such as premature aging or early physical decline are important concerns. In addition, most adults with ID do not have pension benefits or may be marginally eligible for Social Security. All of these issues pose formidable barriers to maintaining employment or being employable after a certain age.

Historically, concerns related to workers with I/DD have focused on the early part of the life-span (Shafer, Banks, & Kregel, 1991; Test, Hinson, Keul, & Solow, 1993). The opportunity for continued growth in employment, and the ability to maintain employment over long periods of time is an area of little or no research. Issues include making use of current skills and abilities, developing new ones, and obtaining needed assistive technology and accommodations help in maintaining employment. Some other issues relate to work cessation such as reducing one's hours to a part-time basis, and the possibility of retirement.

With the advent of on- the- job models of vocational training, such as supported employment, more adults than ever are involved in competitive employment. Such employment stems from skills learned in rigorous programs designed to assist persons with I/DD in job development, job placement, training, and extended periods of stabilization on the job. Many industries have found that such employment placement

programs produce dedicated and long-term workers. As noted by McNeil in Current Population Reports (Americans with Disabilities), some 40% of working age persons with I/DD are employed. However, as with any worker, age-related and age-associated changes may cause the individuals to lose productivity on the job, raise the risk of injury, or produce other impairments that lessen their value to their employer. Since employment among older adults with I/DD is a relatively new phenomenon, few resources or employment assistance services are readily available to

help solve the problems they may face. An additional concern is to how to ensure that earned assets are turned into pension rights and that Social Security benefits can be accrued in way that fairly reflects each individual's work history and contributions. These particular issues will take on even more importance in the years to

come as more adults enter and remain in the nation's workforce.

Study Purpose/Objectives

This project searched to understand the current employability and employment experiences of adults and older adults with I/DD. Research issues incorporated into this study included:

1. Determination of employability and employment practices nationally.
2. Identification of barriers to continued employability and employment.
3. Identification of occupational situation patterns.
4. Development of best practices employability guidelines for employment service personnel.

Researchers have noted that, despite the success of supported employment, conversion from segregated workshops to integrated employment services has been slow and difficult.

5. Development of a consumer-oriented employability and employment training pack which addresses workplace and personal accommodations (including employment rights, responsibilities, and options).
6. Identification of pensioning systems and practices and recommendations for a transportable pension rights system.

Sample Population and Methodology

The target population addressed in the interviews, surveys, and focus groups were workers with I/DD at least 35 years of age or older and who are either a) employed, b) involved in a supported employment program, or c) are seeking employment, but are currently working in a sheltered workshop setting. The project included three data gathering efforts: interviews with service providers, national survey, and focus groups.

The agencies included in this research study appear to be representative of activities going on during the time period of 2001-2003 in these states. There was an approximately equal representation of rural and urban agency locations. Most individuals were referred to a specific agency either by the state department of vocational rehabilitation, or by the state department of MR/DD. In addition, in many states, individuals were referred from special education schools to the employment programs.

Data Collection and Measures

The 5-year research plan in this area has had to be revised several times to reflect the increased understanding of issues that have emerged in this important area. We began with an extensive literature review in the area of work and aging for individuals with ID/DD. The next step was to carry out in-depth interviews with key personnel in Ohio regarding how



sheltered, supported and community employment was presently being implemented in their Board of Mental Retardation.

At the end of July 2000, 20 people from 10 different sites (workshops, supported, or community employment) were interviewed. The issues and content of these in-depth interviews were used to determine key issues that were used to develop the national survey. The final version of the national survey focused on three areas. The first section consisted of general information questions about the agency including employment services offered, numbers served, patterns of referrals, assessment of skills, abilities and interests, older worker programs and retirement services. The second part of the questionnaire concerns practices regarding supported employment (i.e., community employment of persons with MR/DD with assistance from a job coach or other professional). The third section concerns practices regarding sheltered workshops or segregated work centers (i.e., a designated place of employment for adults with MR/DD only).

A total of twenty states using funding for supported employment based on the latest data available FY 1998 were surveyed. These states included the top ten states (Washington, Oklahoma, Connecticut, Utah, South Dakota, Louisiana, Michigan, Arizona, Maryland, and Colorado) and the bottom 10 states (Missouri, Alaska, Alabama, Idaho, Arkansas, Washington, D.C., Hawaii, Illinois, Tennessee and New York).

Phone interviews with multiple state agencies serving individuals adults and older adults with MR/DD made it clear that each state had different organizational approaches to supported, segregated and sheltered employment. Ohio, which was the basis of our initial research, was highly organized with 88 county boards. Many states do not have this level of organization and in many states there is extensive contracting of services to multiple agencies. It became apparent that in order



to conduct the research as planned, we had to contact each state agency on MR/DD, determine an appropriate contact and then asked for nominations for representative agencies for supported, sheltered workshops, and/or segregated employment.

Previous studies of services had used a national ARC list. However, a rather small sample size of 17 completed surveys was definitely not a good representation of MR/DD agencies in the United States, and we wanted to get a more complete picture of what is going on around the country. At this point, we augmented our survey sample with the national ARC list for the same 20 states that we had used previously.

In the Summer 2003, the names and the addresses of the agencies on the ARC list were obtained, and 303 surveys (165 to top ten states, and 138 to bottom ten states) were mailed to those agencies along with cover letter and self-addressed postage paid return envelope. Out of 165 surveys mailed to top ten states, 32 were returned. Out of 138 surveys sent to bottom ten states, only 22 were returned.

Data Analysis and Findings

Descriptive analyses were conducted to examine the employment opportunities and services provided to individuals with MR/DD. Surveys were returned from 61 agencies representing 20 states.

Most agencies (n = 50) reported that they offered sheltered/segregated employment. However, forty-nine agencies offered transitional and competitive employment opportunities as well, and sixty five percent of agencies reported providing opportunities to visit actual job sites. These individuals enter from both school programs and the general community.

The assessment of skills related to work and training provided varied considerably. Some agencies used standard assessment tools, but the majority used agency-developed instruments,

which makes it difficult to get a clear picture of the assessment approach. In terms of training, most agencies relied on their local special education schools that provided on-site vocational training, and those consumers who did not have any training received similar on-site job training.

When agencies responded to the question “when is a worker considered old?” the ages ranged from 40 to 70 years (average age was 57). A small number of agencies indicated that individuals were eligible for retirement and indicated that retirement eligibility ranged from 55 to 60 years. Only nine out of 50 agencies have case managers assigned specifically to serve older consumers, and worse yet, only six (about 12%) agencies offered any pre-retirement and life-planning services.

Only 28 out of 45 agencies (total N = 61) that answered this item indicated that they provided training for their professionals on the issues related to aging. The content of training includes job development, physical and emotional needs, behavioral management, the aging process, and better understanding of Alzheimer’s and other dementias. In addition, even less, twenty-four of 35 agencies reported having an alternative-to-work/recreational programs.

Thirty-four out of 61 agencies surveyed reported that they had a substantial number of individuals employed both full- and part-time in sheltered/ segregated settings; the age ranged from 18 to 60 years old. In addition, twenty-six agencies reported

When is a worker considered old?

Respondents in agencies reported ages ranging from 40 to 70 in response to the question “when is a worker considered old” (average age was 57).

that they provided other types of transitional employment.

Twenty-three agencies offered vocational training, 21 agencies offered rehabilitation classes, 24 offered alternative-to-work/recreational programming, and 29 agencies provide transportation services to and from the work site. Unfortunately, those 12 agencies that relied on public transportation did not provide transportation training to their consumers. In addition, between 4% to 36% of consumers received assistive technologies from the agencies, while between 1% and 95% of consumers provided their own assistive technologies.

Furthermore, a large number of agencies, 31 out of 33, routinely referred consumers to supported employment programs, and the reasons for referral include assessment results, consumer's wish to participate in supported employment, consumer's current job/work progress, and/or health conditions. If a consumer loses a supported employment position, they might be placed on a waiting list, immediately returned to the segregated/sheltered employment site, placed on a list for a new employment assessment, or given a referral for a new supported employment position.

Finally, as reported earlier, the pay rate for the consumers in these settings is very low, ranging from \$0 to \$5.15 for minimum wage category and \$0 to \$47.50 for maximum range category. Worse yet, there were no additional benefits, such as health care and pension. However, the majority of agencies (27 out of 33) provided flexible schedules for their consumers.



Implications for Research and Practice

During the course of this project, a manuals and training curricula were developed. These can be used on a national and international level to maximize and enhance the employment opportunities and experiences for adults and older adults with intellectual disabilities.

Publications and Products

Sterns, H.L., Kennedy, E.A., Cohen, P.R., & Begovic, A. (2004). *Person-centered planning for later life: Work, aging, and retirement. A curriculum for mature adults with mental retardation and developmental disabilities.*

Sutton, E., Heller, T., Sterns, H.L., Factor, A., & Miklos, S. (2004, Revised edition). *Person-centered planning for later life: A curriculum for mature adults with developmental disabilities.*

Sterns, H.L., Kennedy, E.A., Begovic, A., Miller, J., & Sotnak, D. (2004). *Research report: Employment practices for adults and older adults with mental retardation and/or developmental disabilities.*
