

Adult Day Programs Versus Supported Employment (1988-2002): Spending and Service Practices of Mental Retardation and Developmental Disabilities State Agencies

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While supported employment has made significant gains since its formal introduction in 1984 (P.L. 98-527), segregated services continue to outpace the growth of supported employment. We discuss these and other important trends in this article, and conclude with recommendations that include (1) ensuring that all young adults leave high school competitively used or admitted to postsecondary education by age 18 and (2) that high schools coordinate post-placement follow-up for 3 years following employment or enrollment in postsecondary education. These recommendations are made because although current research suggests practices exist to employ persons with severe disabilities outside sheltered workshops and adult day care centers, these programs continue to grow at an alarming rate. In fact, the growth of supported employment has all but stalled since 2000. Diverting people and resources at the juncture between high school preparation and assuming adult roles such as employment appears to be a more realistic plan to promote integrated services over the foreseeable future.

As early as 1978, investigators began to evaluate the employability of persons with severe disabilities outside sheltered workshops (Rusch, Connis, & Sowers, 1978; Sowers, Rusch, Connis, & Cummings, 1980), primarily focusing upon competitive employment with the provision of long-term support after placement, often by a trained "job coach" (Rusch & Mithaug, 1980). Prior to 1980, the primary employment option for persons with

disabilities was the sheltered workshop, or remaining at home under the supervision of family. Today, however, there is little doubt that supported employment is a viable option for persons with severe disabilities, their families, and advocates.

In 1995, two articles were published that suggested that supported employment "had lost much of its momentum" (Wehman & Kregel, 1995, p. 286) and that "a dual system of integrated versus segregated services" (McGaughey, Kiernan, McNally, Gilmore, & Keith, 1995, p. 270) defined the future employment of persons with disabilities in the United States. As pointed out by Wehman and Kregel (1995), supported employment state systems change grants were awarded to all 50 states through Title III, Part C of the Rehabilitation Act Amendments of 1986, which resulted in model supported employment programs being established in virtually every state. McGaughey et al. (1995) reported that the number of local community rehabilitation agencies providing supported employment-related services grew from just over 300 in 1986 to approximately 5,000 in 1993. Clearly, new opportunities were established for supported employment as a result of this growth. However, as McGaughey et al. (1995) pointed out, expanded opportunities for segregated employment were also established.

In this article, we focus upon the spending and service practices of mental retardation and developmental disabilities state agencies (MR/DD) rather than those vocational rehabilitation agencies reported on by Wehman and Kregel (1995) in their article, "At the crossroads: Supported employment a decade later," published in *Journal of the Association for Persons with Severe Handicaps* and more recently in Kiernan et al.'s (1997) AAMR-sponsored monograph, "Integrated employment: Current status and future directions." We

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focus upon MR/DD agencies because we believe that the persons who are served by these agencies most likely represent persons with severe disabilities. Consequently, although our data may underrepresent the total number of supported employees receiving services, our results may be more representative of trends in alternative service provision for persons with severe disabilities in the United States. We attempt, however, to make comparisons between the data we collected and those collected and reported by Wehman and Kregel (1995) and Kiernan et al. (1997). In addition, we expand upon results recently reported by Braddock, Rizzolo, and Hemp (2004), which focused upon the growing role of Medicaid in employment expansion.

The results reported in this article are important because they provide readers with an important snapshot of how effective local service providers have been in providing past, current, and possibly future generations of adolescents and young adults with severe disabilities integrated versus segregated employment. As discussed in this article, segregated employment receives four times the financial resources that integrated employment services do today, and the trend is toward further growth in segregated adult services. Against this reality, this article makes two bold recommendations for practice that we believe are necessary to ensure that future generations of young people with severe disabilities find their roles in society apart from sheltered, segregated services.

Method

Our study used data collected by Rizzolo, Hemp, Braddock, and Pomeranz-Essley (2004). Readers are

referred to data collection, reliability, and analytic procedures described in detail by Rizzolo et al. (2004). Briefly, data collection instruments were mailed to the directors of the 50 MR/DD state agencies and the agency in the District of Columbia. Several hundred follow-up contacts were made across all MR/DD departments to ensure the reliability and validity of data acquired from published and unpublished state budget and program documents. For the purposes of this investigation, two broad categories of state spending and services were studied: funds supporting (1) persons in segregated facilities (e.g., adult day care, work activities, and sheltered workshops) and (2) persons in supported employment.

Results

Figure 1 shows the percentage of all persons with severe disabilities who were participants in states' MR/DD supported employment programs as a share of total day/work program participants. The percentage of supported employment participants more than doubled from 1988 to 2002, from 9% to 24%. However, upon further inspection it is evident that the growth of supported employment slowed considerably over the past 10 years (19% to 24%) versus the first 5 years (9% to 19%). Furthermore, growth in the number of supported employment participants dropped to 3% annually between 2000 and 2002, compared with 15% per year during 1988 to 2000. The initial growth in supported employment services was no doubt a result of states implementing model supported employment programs following the 1984 Developmental Disabilities Act amendments. Nevertheless, 76% of all day program

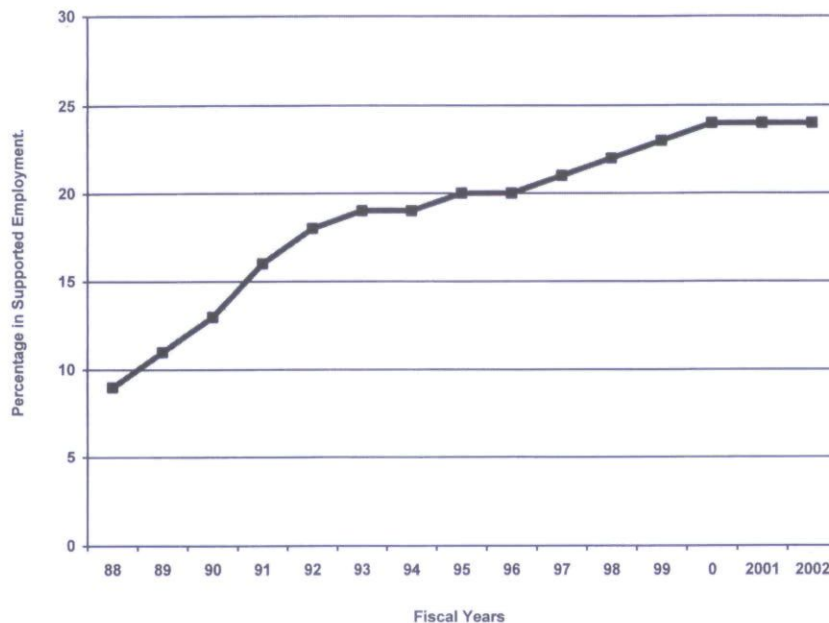


Figure 1. Percentage of adults participating in supported employment, 1988–2002. (Adapted from Braddock et al., 2004)

participants received services in adult day care, adult work activities, and extended sheltered employment programs. These estimates are similar to those reported by McGaughey et al. (1995), indicating that 70% of all participants in their study were in segregated programs.

Figure 2 displays the total number of individuals who participated across *all* day and work programs, and then specific data regarding day programs, sheltered workshops, and supported/competitive employment. We display these data across four approximately equal time periods (i.e., 1988, 1993, 1998, and 2002). These data are worthy of close examination. Note that about half of all participants (N = 239,000) were involved in day programs in 2002, with an additional 126,000 participating in sheltered workshop employment. Also note the steady increase in the number of day program participants across each of the four time periods, from a low of 106,000 in 1988 to 239,000 in 2002. Interestingly, there was a slight drop in the number of sheltered workshop employees between 1998 and 2002 (131,000 to 126,000). The larger increase in day program participants can be explained by noting that two optional Medicaid programs, Clinic and Rehabilitative Services, underwrite adult day programs. In 2002, federal Medicaid funding for adult day care programs totaled \$488 million (Fig. 3).

Supported employment has continued to grow over the 15-year period under examination here. In 1988 there were 23,000 supported employees; in 2002 states reported that 118,000 individuals with severe disabilities participated in supported employment. These numbers differ from those reported by McGaughey et al. (1995) and Wehman and Kregel (1995). Again, the primary reason for this discrepancy relates to our focus upon MR/DD state systems only versus these systems *and* the state vocational rehabilitation systems. Mc-

Gaughey et al.'s (1995) and Wehman and Kregel's (1995) estimates ranged from 100,000 to 300,000 individuals participating in supported employment. Although the total number of participants seems to differ, the percentages of adults with severe disabilities who participate seem to agree to a much greater extent, with approximately 25% to 30% participating in supported employment.

Figure 3 also suggests another interesting trend. The amount of federal money spent in support of day programs dropped, from a high of \$517 million in 1998 to \$488 million in 2002. At the same time, the amount of money that states spend on supported employment has grown appreciably since the Balanced Budget Act amendments of 1997 removed the requirement that home and community-based services waiver (HCBS) spending be limited to individuals who were previously institutionalized. This number grew from virtually zero spending in 1988 to \$108 million in 2002. However, regardless of this increasing trend, the amount spent for supported employment in 2004 (\$108 million) was less than one fourth that spent on adult day programs sponsoring segregated day care, work activities, and employment. This trend is also noteworthy as we recognize that the United States enjoyed the largest economic growth of any period in history beginning in 1992 and ending in about 2002.

Supported employment receives less than 20% of the total day program funding, which is not surprising when considering long-standing legacies of local support by politicians, community leaders, and parents for segregated employment patterns that predate supported employment by several decades. It can be assumed that these patterns of support are not easy to change, even if providers wanted to follow the recommendations made by Wehman and Kregel (1995), which included

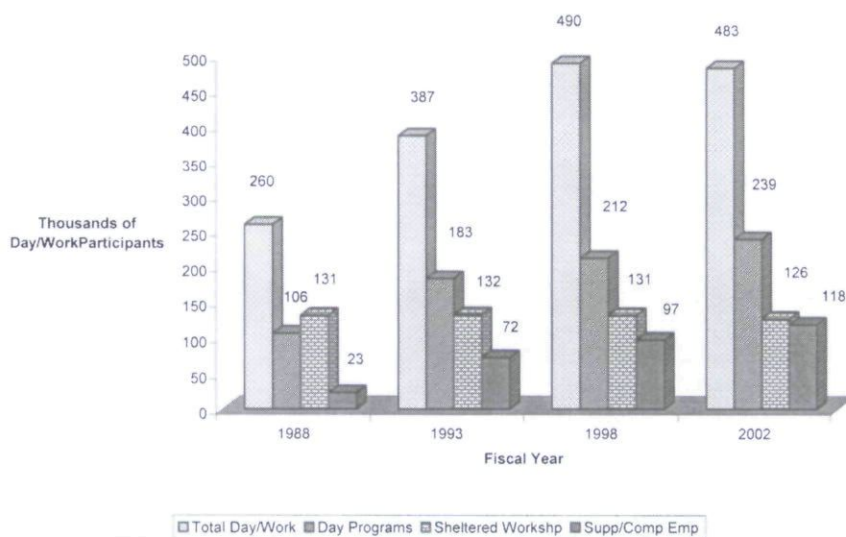


Figure 2. Total number of adults participating in adult day programs, sheltered workshops, and supported/competitive employment across four time periods (1988, 1993, 1998, and 2002). (Adapted from Braddock et al., 2004)

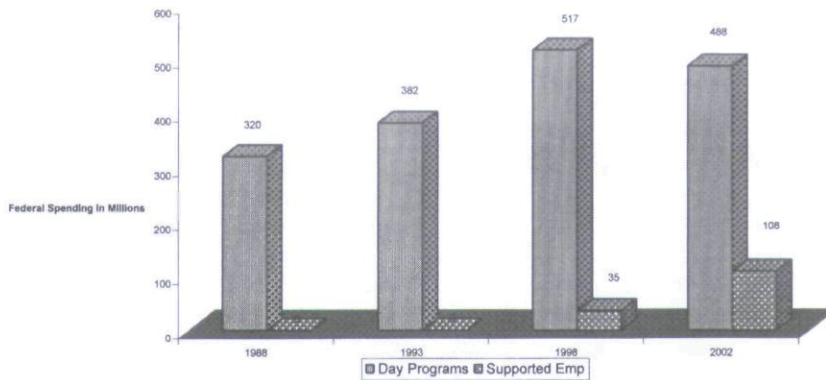


Figure 3. Federal support for segregated versus supported employment from 1988 to 2002. (Adapted from Braddock et al., 2004)

converting day programs to integrated employment and promoting meaningful outcomes.

Discussion

Our findings suggest some positive and also some sobering news in terms of employment for persons with severe disabilities in the United States. For the first time in history, the number of adults who are participating in supported employment and sheltered workshops is about equal (118,000 vs. 126,000, respectively). Also, we have seen a drop in federal support of adult day programs (from \$517 million to \$488 million). On the negative side, our research found 365,000 persons with severe disabilities participating in adult day care and extended sheltered workshop programs in 2002, compared with 118,000 who are in supported or competitive employment positions. Furthermore, the number of individuals who participate in adult day programs appears to have increased at about the same rate as those who participated in supported employment (see Fig. 2). Both programs enrolled approximately 100,000 participants between 1988 and 2002 (133,000 in adult care programs vs. 95,000 in supported/competitive employment). Day programs and sheltered workshops grew from 236,000 participants in 1988 to 365,000 participants in 2002—a growth of about 129,000 new participants. Competitive and supported employment programs grew from 23,000 participants in 1988 to 118,000 participants in 2002—a growth of 95,000 new participants. Finally, funding for segregated adult day programs is over four times that for supported employment in 2002 (\$488 million vs. \$108 million).

These data suggest that supported employment is a viable program and is recognized as a fundable option between both state MR/DD and vocational rehabilitation programs. However, although a viable program, supported employment has not enjoyed the same financial support as alternative, segregated adult day programs over the past 15 years. In part, segregated options have been the expected outcomes for persons with severe disabilities since funding for sheltered work-

shops were introduced in the 1954 Vocational Rehabilitation Act Amendments (P.L. 83-565). Sheltered workshops, and the research and training-related programs that support them, have had an almost 25-year head start over those addressing supported employment.

It is safe to say that a dual system of service delivery for sheltered and integrated employment exists in the United States, and that, despite the growth of supported employment, we have underestimated the size and strength of sheltered workshops, adult work activities centers, and adult day care programs (cf. McGaughey et al., 1995). In 1997, Kiernan et al. estimated that there were 5,861 adult service providers, with 4,988 providers offering supported employment services. They suggested that the typical earnings of sheltered workshop employees are about \$400 per month. This meager monthly allocation represents less than one third of the total earned by adult service providers from all sources. For example, in 2002 Missouri sheltered workshop revenue exceeded \$100 million, with gross sales accounting for \$71,434,677 and state and county aid accounting for \$29,532,140; miscellaneous sources of income accounted for \$6,668,415 (Young, 2003). The approximately 7,000 adults with severe disabilities who worked in Missouri's community rehabilitation providers' sheltered workshops made approximately \$31 million in 2002, suggesting that their monthly earnings were equivalent to those estimated by Kiernan et al. (1997).

Unless we consider promoting new challenges that compete with funding for integrated employment, segregated employment will continue to thrive. Clearly, segregated employment is alive and well today, but so is the potential to promote segregated employment. Secondary special education, in particular, has experienced a renaissance in practices since the passage of the 1983 Individuals with Disabilities Education Act (P.L. 98-199), which introduced "transition services" (Rusch & Phelps, 1987), and the subsequent reauthorization of IDEA (P.L. 101-476) in 1990, which included a precise definition of transition services. The 1990 definition

named the types of outcomes that our schools should be attempting to achieve, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, and independent living or community participation (IDEA, P.L. 101-476, 34 CFR, Section 3000.18).

Unfortunately, even with legislation focused upon school practice and outcomes, there have not been any significant gains in the employment rates of young adults with severe disabilities since the early 1980s. On the one hand, our schools have never been as prepared as they are today to change the employment patterns of persons with severe disabilities. On the other hand, we continue to miss the mark in our quest to meet the expectations of the vast majority of young adults who want to work, and their families and friends who do not see segregated employment as the preferred employment option. In the concluding section of this article we make two recommendations that we believe are critical to our stemming the growth of segregated employment versus promoting the growth of integrated employment.

Recommendations for Preparation and Employment of Youths With Severe Disabilities

With our rising awareness of the rights of persons with severe disabilities, our better understanding and interest in their desires and goals, and our 25-year history of defining best practices to achieve these rights, desires, and goals, we make the following recommendations, directed toward our public schools' role in the preparation and employment of youths with severe disabilities.

Basic to these recommendations is the contention that schools must partner with federal, state, and local services to ensure that students find gainful employment and become contributing members of society, which has been a primary goal of our public education system since its formal creation over 100 years ago. The primary role of schools should be the coordination of the following two recommendations, not assuming the majority of costs and responsibilities.

Recommendation 1

Our first recommendation is that all students must leave high school competitively employed or admitted to a university, college, trade school, or certification program in their 18th year, and that high schools assume the leadership role in this effort.

No student should leave high school with an uncertain future. Employment and postsecondary education must become a reality for all students with severe disabilities. We recommend that high schools assume the leadership role in guaranteeing that all youths are competitively employed or enrolled in postsecondary education on or before their 18th year. It is important that

we recognize that the dual system of adult service provision in the United States is complicated and resistant to change and represents over 50 years of tradition. At best, we can expect only continued incremental change if we are to follow recommendations that point to community rehabilitation providers taking the lead in converting their resources to support services that challenge their very existence.

We propose that all students with a disability must have an Individualized Program of Employment (IPE) or an Individualized Program of Postsecondary Education (IPPE) completed in their 18th year. A nationwide Web-based system that promotes the coordination of integrated employment at the local level must be established. Virtually every community in America has access to vocational rehabilitation, and all students with disabilities are eligible for Social Security benefits. It is time to move forward with efforts that coordinate these programs and the myriad adolescent- and adult-related social services that exist to support housing, income support, and workforce investments. High schools cannot be expected to provide the entire financial support needed to meet this first recommendation; partnerships with the Social Security Administration, state vocational rehabilitation, and state MR/DD programs must be made.

Virtually every high school in America provides counseling to students without disabilities who are enrolling in universities and colleges after graduation. These students have access to a well-defined system of qualifying for entrance and receiving gift aid such as grants and scholarships and/or self-help aid such as Federal Work-Study, campus jobs, and loans. Students can apply for federal financial aid by completing the Free Application for Federal Student Aid (FAFSA). This system can and should also benefit students with severe disabilities wishing to enroll in postsecondary education.

Recommendation 2

All students must have access to long-term follow-up services to ensure their successful transition to integrated employment and/or postsecondary education.

All youth with severe disabilities must have access to coordinated, long-term, follow-up support services that focus upon (1) placing students in jobs that provide better wages, (2) developing workplace supports, (3) retraining in the event of losing one's job, and (4) working with the complex network of adult services agencies to provide coordinated housing, income, and medical supports. Such coordination must continue for at least 3 years after a student leaves high school.

Since the passage of legislation that has targeted transition from school to work, we have not affected the numbers of youth with disabilities who are competitively employed, with or without support. Proportionately, our track record today is worse than it was 20

years ago. This record is in stark contrast to our potential; we have never been better prepared to offer tried and tested "best practices" that could change these outcomes (Rusch & Chadsey-Rusch, 1998; Rusch, in preparation). We must focus upon these outcomes now. High schools must assume the leadership role in ensuring that current and future generations of students with severe disabilities are diverted away from segregated services and included in the mainstream of society.

Further, universities, colleges, trade schools, and certification programs must be expected to place their students in competitive employment after they have completed their postsecondary education. A nationwide effort involving high schools, postsecondary education institutions, and all social services agencies must coordinate the employment of students with severe disabilities after they complete postsecondary instruction.

Conclusions

Much progress has been made over the past 25 years in terms of identifying best practices that promote the integrated employment of persons with severe disabilities. However, our research suggests that persons with severe disabilities are just as likely to wind up in segregated work as they are integrated work, despite overwhelming evidence that persons with severe disabilities can meet their lifelong goals of being competitively employed and earning wages that they can rely upon to meet their personal needs and desires. There is also overwhelming research that points to savings to society that are three- to four-fold in support of integrated employment, not segregated employment (Rusch, Conley, & McCaughrin, 1993).

Schools and all professionals, parents, and consumers must work toward building new bridges between the high school programs that are preparing our youth and the myriad adult services agencies that are designed to provide income support, training, housing and more (e.g., social security programs, state vocational rehabilitation programs, state MR/DD program). In the next 25 years we should see new and impressive trends in our efforts to provide a certain and desired future for all persons with severe disabilities, including the conversion of scarce resources toward the support of these services versus adult day programs that promote the segregation and marginalization of an entire population (Devlieger, Rusch, & Pfeiffer, 2003), programs that clearly are alive and well today. We must focus our resources upon integrated employment for all students in their 18th year, including providing additional opportunities for an education, and we must recognize the need to coordinate services to support these young adults as they become valued members of our society.

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