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7-1-2001

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Recommended Citation

Dreilinger, Danielle; Gilmore, Dana Scott; and Butterworth, John, "Research to Practice: National Day and Employment Service Trends in MR/DD Agencies" (2001). *Research to Practice Series, Institute for Community Inclusion*. 25.

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National Day and Employment Service Trends in MR/DD Agencies

Danielle Dreilinger, Dana Scott Gilmore, & John Butterworth

Introduction

The past twenty years have seen an increasing emphasis on community-based services and equal access to employment for all individuals, including those with the most significant disabilities. The question is, to what extent have changes in philosophy translated into changes for state agencies and the people they serve? Since 1988, ICI has collected data on day and employment services for people with mental retardation and developmental disabilities through a national survey funded by the Administration on Developmental Disabilities. This brief highlights new findings, including a continuing increase in both integrated employment and community-based nonwork services. Comprehensive figures for all fifty states and D.C., as well as further analysis of historical context, trends, and implications for policy and practice, are forthcoming in *State Trends in Employment Services for People with Developmental Disabilities, Second Edition*.

Definitions

ICI's National Survey of Day and Employment Programs for People with Developmental Disabilities

has been used to collect data from state Departments of Mental Retardation/Developmental Disabilities (MR/DD agencies) for fiscal years 1988, 1990, 1993, 1996, and most recently 1999. The survey tracks services for individuals aged 16 to 64, excluding those who reside or receive services at large (16+ persons) congregate care facilities. The survey has maintained consistency over these years to ensure the ability to track key elements over time, including the number of individuals served, distribution of services, waiting list data, and funding for services. Figure 1 depicts the range of community and work services as defined in this brief.

Findings

All statements regarding changes in service patterns are based on repeated measures analysis of variance using data from years 1988, 1990, 1993, 1996, and 1999. The totals by service setting represent duplicated counts; some individuals are served in multiple settings. Therefore, these figures show agency service capacity, not a discrete number of individuals. (For the sake of readability, however, this brief will refer to "individuals.")

Figure 1

Community-Based

Community-Based Nonwork

A program where individuals engage in recreational, skill-training, or volunteer activities in settings where most people do not have disabilities (e.g., *Community Integration, Community Participation Services*)

Integrated Employment

A community-based job where most people do not have disabilities (e.g., *Supported or Competitive Employment*)

Nonwork

Work

Facility-Based Nonwork

A program whose primary focus is skill training, activities of daily living, recreation, and/or professional therapies (e.g., *O.T., P.T.*), in a setting where most people have disabilities (e.g., *Day Activity, Day Habilitation*)

Facility-Based Work

Employment that takes place in a facility where most people have disabilities, with continuous job-related supports and supervision (e.g., *Extended Employment, Sheltered Workshops, Work Activity*)

Facility-Based

There is a continued increase in the number of individuals served across all settings.

- The total number of people served increased, from 274,274 individuals in FY88 to 385,140 in FY96 and 469,842 in FY99.
- 107,820 individuals received integrated employment services in FY99, an increase from 86,252 in FY96 and 32,391 in FY88.
- The number of individuals served in facility-based and nonwork services increased from 298,888 in FY96 to 362,022 in FY99.

The percentage of individuals in integrated employment did not change significantly since FY96. These national percentages were obtained by summing the numbers from all states and dividing the total in each service category by the total served.

- Integrated employment increased from 12% of total services in FY88 to 22% in FY96.
- The percentage of integrated employment services delivered remained stable from FY96 to FY99 (23%).
- Facility-based and nonwork services comprised 77% of all services in FY99. This is a decrease from 88% in FY88.

The percentage spent on integrated employment increased.

These figures show the average distribution of expenditures across states.

- Expenditures for integrated employment increased to 26% of total expenditures, from 22% in FY96 and 12% in FY88.
- Expenditures for facility-based and nonwork services comprised 74% of total expenditures in FY99, a decrease from 78% in FY96 and 88% in FY88.

Figure 2

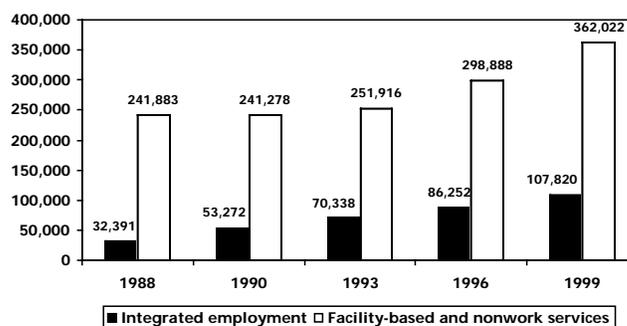


Figure 3

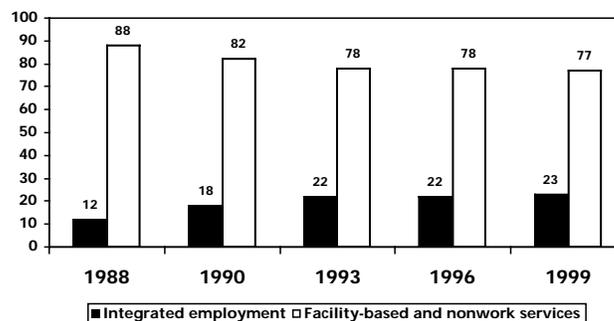
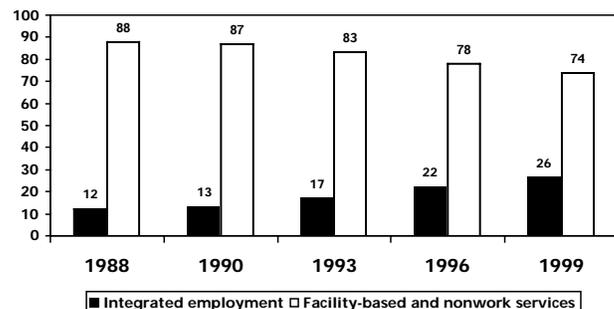


Figure 4



Discussion

State agencies continue to expand their capacity to provide day and employment services. Since 1996, there has been a large increase in the total number of individuals served, which corresponds to initiatives in many states to decrease waiting lists. Among the factors underlying this development are new monies targeted at unserved individuals, litigation, and demographic changes, including ongoing deinstitutionalization (particularly from nursing homes) and an aging population of caregivers seeking services for their adult children.

The number of individuals in integrated employment continues to grow steadily; however, the percentage of individuals in integrated employment across the country showed almost no change between FY96 (22% of services received) and FY99 (23%). This is due, in part, to large differences among states. The national distribution does not reflect the progress that some individual states have made. When viewed on a state-by-state basis, the percentage of integrated employment services delivered ranged from 11% to 61%, with states averaging

30%. This figure is higher than the overall national distribution because the contributions of states with smaller populations, many of whom have higher percentages of integrated employment, are outweighed by their larger counterparts.

Facility-based and nonwork services remain high, both as a percentage of services received and in the number of individuals receiving them. More individuals are currently in these services than are in integrated employment. Growth in facility-based and nonwork services has not levelled off. In fact, these data suggest that new investment has emphasized facility-based and nonwork services. Between FY96 and FY99, the number of individuals in facility-based and nonwork services grew by a little over 63,000, while participation in integrated employment grew by about 22,000.

As a primary service option, community-based nonwork was first noted in responses to the 1993 survey, and was added to the survey in 1996. With over 40,000 individuals in 1996 and 50,000 in 1999, community-based nonwork is an emerging service option that many states are investing in.

Expenditures on integrated employment, as a percentage of total expenditures, have also continued to increase over time. However, there has been a much greater absolute dollar increase in spending on facility-based and nonwork services. While current survey data show that most funds to support integrated employment come from state funding, there is also a growing reliance on Medicaid Waiver funds for supported employment.

Policy Changes and Future Implications

Several recent changes in policy are likely to influence future services and figures.

Supreme Court rulings

In July 1999, the U.S. Supreme Court ruled in the *Olmstead* case that the cost of services cannot be used as a factor in determining what service is most appropriate for an individual, i.e., people cannot be denied community residential services even if there is a cheaper alternative. While the scope of this ruling has not yet been tested for day and employment services, people who want integrated employment services but are not receiving them may now have some legal recourse. However, this advance may be negatively impacted by the February 2001 *Garrett* ruling, which

limits the reach of the employment protections in the Americans with Disabilities Act (ADA) into state and local government jobs. Bearing in mind that some states have more stringent civil rights protections than those found in the ADA, less federal protection for workers with disabilities may reduce employment opportunities in state governments in some states. With the federal courts taking a hands-off approach to employment discrimination suits, the experiences of individuals with disabilities across the country may become less uniform.

Workforce Investment Act

One intention of the Workforce Investment Act (WIA) is to increase access for people with disabilities to generic employment and training services via local One-Stop Centers. While WIA may be less significant for this population than for others, more accessible generic employment services can only improve integrated outcomes for consumers. Although MR/DD agencies are not mandated partners in WIA, they should have as much involvement as possible with Workforce Investment Boards to ensure that One-Stop Centers become useful job-seeking resources for people with developmental disabilities.

Rehabilitation Services Administration extended employment decision

In January 2001, the Rehabilitation Services Administration changed its regulations to remove extended employment (sheltered workshops) as a successful outcome measure for state Vocational Rehabilitation (VR) agencies. At press time, implementation was pending. The elimination of extended employment would be both a strong philosophical statement and a powerful practical strategy to increase integrated employment among VR consumers.

Waiting list lawsuits

Several states have recently been faced with lawsuits and, in response, must reduce waiting lists rapidly. On the one hand, this development will benefit individuals who have been waiting for services. However, these mandates are likely to increase facility-based services, because integrated employment services take more time to develop, and the system will be under pressure to expand capacity rapidly.

Challenges

The effects of community-based nonwork on systems and individuals.

The increase in community-based nonwork indicates a growing trend in the importance of community integration. However, there is currently limited data on the structure and activities included in this service category. Agencies, researchers, and policymakers need to better understand the impact of community-based nonwork on quality of life, service system priorities, and access to integrated employment. It is difficult to determine whether these services are being used to promote employment or as a service alternative. There is some evidence that states that invest heavily in community-based nonwork have better employment outcomes. However, anecdotal evidence from community rehabilitation providers indicates that a focus on community-based nonwork can detract from finding people jobs in the community. ICI will begin studying these services in the fall of 2001.

Reduce investment in facility-based and nonwork services.

Despite changes in philosophy in the disability field, state MR/DD agencies continue to maintain dual systems. Investment in facility-based and nonwork services shows no evidence of levelling off or decreasing. This causes difficulty for those attempting to explain the increase in integrated employment in terms of philosophy change, because agencies are not decreasing services that are incongruent with the community/supported employment models. Integrated employment appears to be an add-on to, rather than a replacement for, traditional services. However, these data may show incremental change: a service continuum in transition. This is indicated especially by the increase in community-based nonwork, which may represent a deinstitutionalization of facility-based nonwork.

Maintain growth in funding for integrated employment.

Anecdotal evidence from states suggests that attention to integrated employment has waned as Supported Employment and Transition Systems Change grants have ended. Funding streams with more flexibility, e.g., more flexible Medicaid funds (such as those created by the 1998 policy shift), are crucial in supporting states to expand opportunities for integrated employment.

Acknowledgements

This brief reflects the contributions of Sheila Fesko, Robert Schalock, Susan Foley, Robert Gettings and NASDDDS.

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This document was supported in part by cooperative agreement No. 90DN0032 from the Administration on Developmental Disabilities, Administration for Children and Families, U.S. Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Developmental Disabilities policy.



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