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Research to Practice: Community-Based Non-Work Services: Findings from the National Survey of Day and Employment Programs for People with Developmental Disabilities

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Research to Practice

Community-Based Non-Work Services: Findings from the National Survey of Day and Employment Programs for People with Developmental Disabilities

Jennifer Sullivan Sulewski, John Butterworth, and Dana Scott Gilmore

Introduction

The past thirty years have seen considerable growth in community-based services and supports for adults with developmental disabilities. One category of community-based day supports, integrated employment, has been clearly defined and widely implemented for years. However, another emerging model, community-based non-work (CBNW), is used in a number of states but is less clearly defined and understood.

To learn more about this service category, the Institute for Community Inclusion (ICI) included questions about CBNW programs and policies in its 2001 national survey of state mental retardation/developmental disabilities (MR/DD) agencies. Findings show that while CBNW is a significant and growing part of the service mix, state definitions and requirements tend to be broad and unfocused.

Methodology

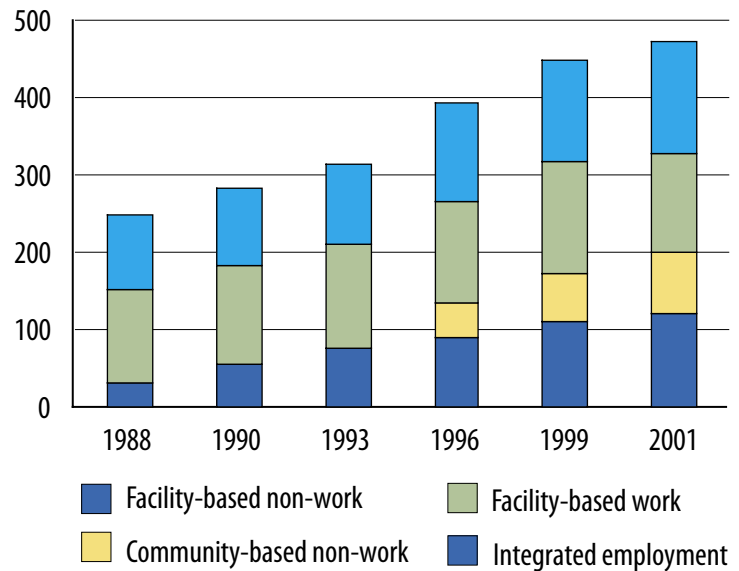
Since 1988, ICI has been collecting data on day and employment services for people with developmental disabilities through the National Survey of Day and Employment Programs for People with Developmental Disabilities. The survey is sent to the directors of state mental retardation/developmental disabilities (MR/DD) agencies in each of the fifty states plus the District of Columbia. Data collected include numbers served (overall and by setting) as well as the sources and distribution of day and employment services funding. The earlier surveys classified day services in three categories: integrated employment, facility-based employment, and facility-based non-work. Community-based non-work was added as a fourth category in 1996. The 2001 survey included additional questions addressing the role, guidelines, goals, and activities supported and populations served under CBNW.

Findings

CBNW services have grown steadily

Figure 1 illustrates the national trends in numbers served in day services over the 13 years of ICI's data collection. The data indicate that while the numbers served in facility-based services (work and non-work) have been fairly steady, the numbers served in community-based services (integrated employment and CBNW) have grown in both absolute terms and the percentage of individuals served. From its first appearance in the survey (1996), CBNW encompassed a considerable percentage (13%) of recipients. In 2001, responding states indicated that over 84,000 individuals (18%) received CBNW services.

Figure 1: Evolution of Day Services



How Did We Define CBNW?

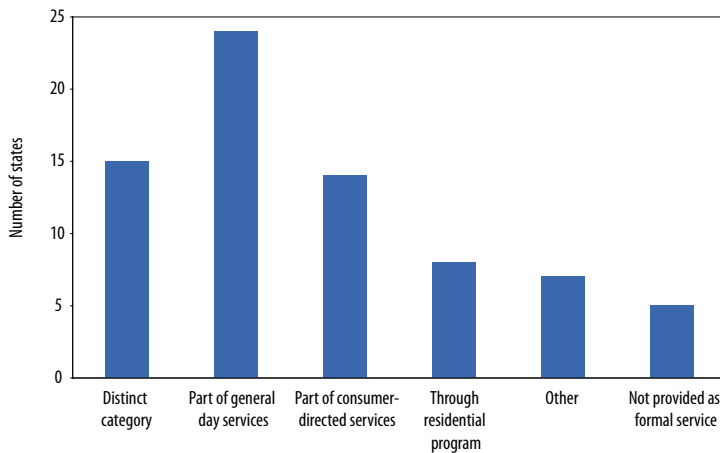
In this survey, community-based non-work was defined as "non-job-related supports focusing on community involvement such as access to public resources (recreational/educational) or volunteer activities; typically identified as Community Integration or Community Participation Services. Community-based non-work includes all services that are located in the community (rather than facility-based) and do not involve paid employment of the participant."



Less than half the state agencies considered CBNW a distinct funding category

Agency representatives were asked to indicate all the ways CBNW fit into the agency’s funding structure. The most common response was “part of general day services” (Figure 2). The next most frequent response was “a distinct funding category.”

Figure 2: How CBNW Fits into State Agencies’ Funding Structures



States had few specific guidelines for CBNW

Over one-third of the respondents (12/32) did not identify any specific guidelines or requirements for CBNW. Ten respondents said their agency had a minimum staff-to-individual ratio. The same number said that the agency specified a maximum group size. Only four states specified a minimum number of hours in the community. The low use of specific requirements reflects the general flexibility around CBNW and a lack of clear consensus regarding what factors make a day program “community-based.”

Most states included a wide variety of activities in the CBNW category

All but one respondent (31/32) checked six or more of the ten possible responses to a question about activities included in CBNW, indicating that individual state agencies support a wide range of activities under this service category. (See Table 1.) The only service types included by fewer than 29 of the 32 responding states were community education programs (25 states), recreation programs for people with disabilities (24), and unstructured recreation time (21).

The wide range of activities is also apparent in the written definitions of CBNW provided by respondents. Definitions either did not specify activities at all or included broad categories of activities such as “typical activities of community life,” “socialization activities,” and “recreation.”

Both group-based and disability-specific activities were part of most CBNW programs

Group activities were common, with more agencies considering community exploration in a group part of CBNW than community exploration for individuals. In addition, educational and recreation programs for individuals with disabilities (activities such as therapeutic horseback riding) were frequently part of CBNW. More agencies included participation in disability-specific educational programs than participation in community educational programs. The majority of agencies (24) also included participation in recreation programs for people with disabilities.

Table 1: Specific Activities Included in CBNW

Activity	Number of agencies (N=32)
Transportation to community activities	30
Volunteer opportunities	30
Community exploration in a group	29
Participation in educational programs for individuals with disabilities	29
Guided community exploration for individuals	29
Participation in community recreation programs	29
Participation in community educational programs	25
Participation in recreation programs for individuals with disabilities	24
Unstructured recreation times	21

Note: Activities listed come from the survey questionnaire.

States identified multiple populations as targets for CBNW

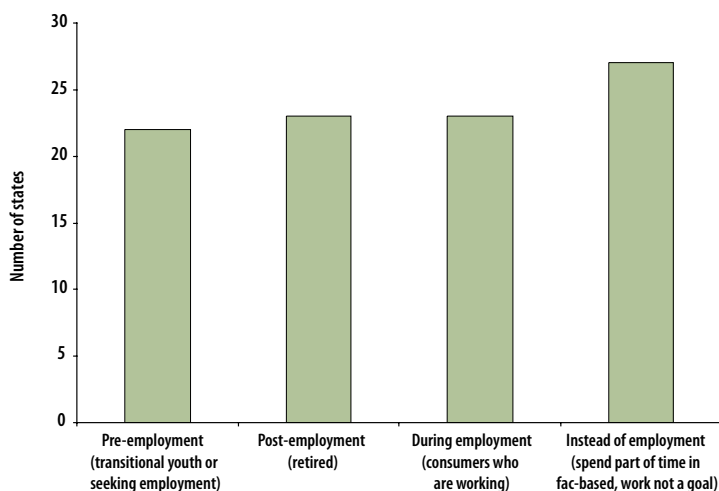
Most respondents indicated that CBNW was targeted at multiple population groups. Almost one-third of respondents (10/32) said that CBNW was targeted at all six population categories presented in the survey: transitional youth, people who are retired, people who are working, people in facility-based programs, people seeking employment, and people for whom work is not a goal. Each population group was chosen by at least two-thirds of respondents with the exception of transitional youth, whom only 13 states targeted.

The population group patterns provide an indicator of the relationship between CBNW and integrated employment, the other major non-facility category. The population groups listed above can be grouped into four categories according to their relationship to employment:

- Pre-employment (transitional youth or individuals seeking employment)
- Post-employment (retired individuals)
- During employment (supplemental service for individuals who are working)
- Instead of employment (individuals who spend part of the day in facility-based programs or for whom employment is not a goal)

Grouping responses in this manner makes it apparent that CBNW is most frequently provided instead of employment (see Figure 3). The other three relationships were also common, however, indicating that CBNW does not have one clear role relative to employment.

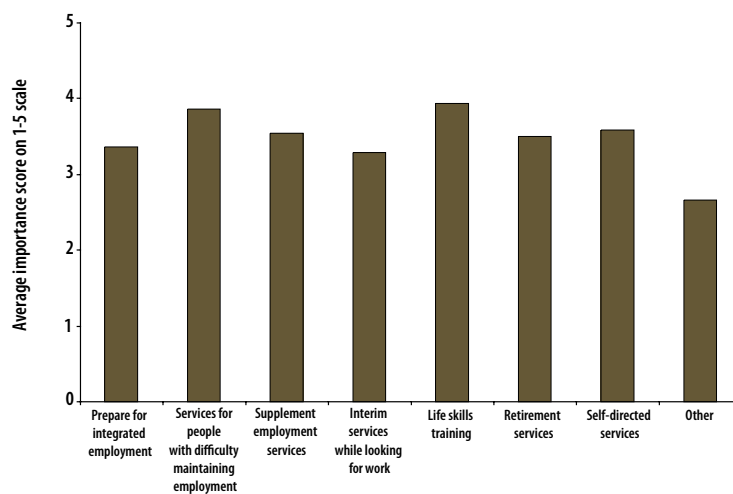
Figure 3: Relationship of CBNW to Employment



State agencies identified multiple goals for CBNW

Similarly, no one particular goal prevailed for state CBNW programs. There was little variation in average ratings across goals on a 1:5 scale (from not at all important to very important; see Figure 4). The highest-rated goals were providing services to people who have difficulty maintaining employment and providing life skills or independent living training. Skill development and training were also frequently mentioned in states’ written definitions of CBNW.

Figure 4: Goals of CBNW



Conclusions

Community-based non-work is an increasingly significant part of the day services mix for adults with developmental disabilities. Since 1996, both the number and percentage of individuals participating in CBNW has grown nationally.

CBNW can be a useful way to supplement employment supports for people who work part-time, enabling them to spend more of their non-work hours engaging in community-based activities rather than being at home or at a facility. It can also be used to support retirement activities for people who are over 65 and no longer want to work, to enable transition-age youth to gain work skills through higher education or volunteer work, and to provide meaningful day activities for people who are between jobs or have not yet found a job.

The findings from this survey suggest, however, that CBNW may not be fulfilling its promise. Several concerns arise from the data.

First, CBNW is not a clearly defined or delineated service type. In terms of funding, CBNW is often part of a broader service type (such as general day services) rather than a separate category. There are usually few specific requirements, and CBNW generally encompasses a variety of activities, population groups, and goals. The lack of clear goals and standards brings into question how states can effectively manage program quality.

Second, the expected role of CBNW is also unclear, particularly regarding its relationship to employment. The growth of CBNW services may represent a shift of emphasis from employment to a broader and less well-defined goal of “community inclusion.” Such a shift is also suggested by the finding that state agencies often consider CBNW an alternative—rather than a supplement—to employment. While further research is indicated, states need to be careful that CBNW services do not replace continued growth in access to high-quality employment opportunities.

Third, the inclusion of group and disability-specific activities in CBNW (such as therapeutic horseback riding) may limit its potential for community integration. In these activities and programs, the primary social interaction is likely to be with other individuals with disabilities and with staff. Although such activities are physically located in the community, they do not necessarily contribute to community membership because opportunities to meet and interact with community members not involved in disability services are limited.

Note that while these survey findings provide some insights into how CBNW is defined and managed by state MR/DD agencies, the actual implementation of these services takes place largely at the local service provider level. It is impossible to tell from this survey whether CBNW as currently implemented contributes to the broader goals of disability services and supports—goals such as choice, community integration, individualized services, and independence. Qualitative research is under way at ICI to determine the extent to which CBNW achieves those goals at the local and individual levels.



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