Helping the Developmentally Disabled Adult

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Interest in the adult with developmental disabilities and the incongruence that exists between services for the school-aged developmentally disabled individual and the adult developmentally disabled is increasing. Because of the deinstitutionalization that has occurred during the past 10 years, the developmentally disabled have moved from the large institutions to smaller groupings within the community. With this shift, there has also been an increased interest in moving individuals from activity centers and sheltered workshop experiences to gainful employment within the community. As has been reported, 90,000 students with developmental disabilities who need further services and/or employment leave the public school system each year (3, p. 8). Clearly, we need to focus on the adults with developmental disabilities in the 1980s, particularly with regard to community living environments and gainful employment.

Who They Are

The current legal definition of "developmentally disabled" is as follows:

The term 'developmental disability' means a severe, chronic disability of a person which—

A. is attributable to a mental or physical impairment or [a] combination of mental and physical impairments;

B. is manifested before the person attains age twenty-two;

C. is likely to continue indefinitely;

D. results in substantial functional limitation in three of more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, (vii) economic self-sufficiency, and

E. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are lifelong or of extended duration and are individually planned and coordinated (2, p. 2664).

Three to four million persons are estimated to have developmental disabilities. Prevalence rates estimated for the four major diagnostic groups of the U.S. population are as follows: mental retardation, 3%; cerebral palsy, 0.3%; epilepsy, 0.4%; and autism, 0.05%. The prevalence of developmental disabilities appears to be increasing because of medical advances, an overall increase in life expectancy, and improved health care and social service programs (4, p. 110).

The Issues They Face

Employment and housing are two major issues facing the adult developmentally disabled population. As these two areas are discussed, two issues identified by Will (5) must be kept in mind. The first is the need for well-coordinated services. On the federal level alone, there are at least 42 programs for the disabled. Coordination is becoming increasingly important, and more diffi-
cult, as individuals are located throughout communities rather than in large central locations. The second issue is the need to provide services within the community in settings with nonhandicapped peers.

Employment

A current priority of the Office of Special Education and Rehabilitation Services (OSERS) is “supported employment.” Supported employment assists the more severely physically and mentally handicapped individual who would not qualify for traditional vocational rehabilitation services. The overall intent is to move people out of activity programs to some type of gainful employment within their community. A concept within supported employment is that of a “job coach,” an individual who works with the developmentally disabled employee and their employer throughout the hiring, job training, and employment process. The supportive service is provided at the actual job site rather than in an activity center or preparation program.

State Developmental Disabilities Councils, as well as major consumer and service organizations, are being encouraged to promote the employment of the disabled. ADD set a goal of placing 25,000 individuals with developmental disabilities into competitive jobs throughout the United States in 1984. Early data suggest this goal was met (2, p. 9).

As more developmentally disabled individuals are becoming employed, related problems are being identified. Health care coverage is a significant problem. A person may have a sufficiently large income to become ineligible for Medicaid, yet not qualify for an adequate health care package, particularly one with rehabilitation components. This produces a disincentive for working.

Another problem is the timing of the introduction of employment. Work should not arise suddenly at age 22 when the individual leaves school but should be systematically addressed in the school program as a preparation for the adult world of work. The need for well-coordinated services is crucial during these transition years if we want the greatest possible number of developmentally disabled individuals to achieve gainful employment.

Housing and Community Services

Housing for developmentally disabled persons has changed markedly during the past 15 years because of the emphasis on deinstitutionalization and normalization. Many long-term institutionalized individuals have been relocated to community-based services, that is, group homes, foster care, personal care homes, supervised apartments, or nursing homes. The need for community accessibility, barrier-free environments, and appropriately trained direct care staff must be considered with any of these placements.

Deinstitutionalization has also resulted in a marked change in service delivery. Individuals who would have been served by a medical model within an institution are now in community-based programs that require the communities to be providers of needed services. Further complicating this shift in services is the fact that the developmentally disabled population, as a group, has more health care service needs than the nonhandicapped population. Their other health care needs may be in the areas of mental health, nutrition, and orthopedics. Additional support services that may also be needed are case management, transportation, and family counseling. Funding is critical to the availability of these services.

Although funding is now more readily available to community programs, problems still exist in obtaining reimbursement for medical services provided on an outpatient basis in the community.

A final issue related to both housing and employment is that of establishing a mechanism for effectively evaluating the appropriateness of these new programs. The following questions are of specific interest:

- What community-based programs are most effective in meeting the needs of the developmentally disabled population?
- Are services adequate?
- Is the programming provided during the transition years successful in enabling the greatest possible number of individuals to live independently and be gainfully employed?
- What follow-up/support services are necessary for ensuring that skills acquired by individuals with developmental disabilities are maintained and used?

We must begin to answer these questions to improve the quality of life of the individual with developmental disabilities.

Implications for Occupational Therapists

The number of occupational therapists working with the developmentally disabled and mentally retarded has risen dramatically from 13.3% in 1973 to 23% in 1982 (6, p. 56). The AOTA Standards of Practice for the Developmentally Disabled cite the reasons for referral, including dysfunction in self-care activities.
home-school-work activities, play/leisure activities, neuromuscular development, sensory integrative development, psychological development, social development, and cognitive development. With these identified problem areas as focal points, the occupational therapist clearly has a role with many adults with developmental disabilities, particularly in achieving placement in the least restrictive living environment and in obtaining gainful employment. Occupational therapy input may be particularly valuable during the transition years as the individual moves from the school system to the adult service system and is working to achieve independent living and obtain gainful employment.

The following are areas that occupational therapists must continue to emphasize when addressing the needs of the adult with a developmental disability.

- Increasing the visibility of occupational therapy through professional journals, newsletters, and conferences. This must include not only occupational therapy publications and journals, but also those of other professional groups. As services become more community based, the visibility of occupational therapy to groups such as case managers, group home staff, and job coaches must be increased.

- Developing and supporting legislation that will affect the financial coverage of occupational therapy services. Current activities of the American Occupational Therapy Association (AOTA) supporting this include the Occupational Therapy Medicare Amendments, which have been introduced in the Senate and House, as well as efforts to expand third-party reimbursement for outpatient occupational therapy services. As individual therapists, we must support AOTA's efforts on behalf of this legislation. State occupational therapy associations and local groups can also induce state agencies and private insurance companies to increase coverage for individuals with developmental disabilities.

- Developing outcome studies, particularly regarding the occupational therapist's role in increasing independence in activities of daily living and in obtaining gainful employment. With strong federal interest in community placement in the least restrictive environment and in supported employment, it is timely for occupational therapists to document their contributions in these areas, particularly with the physically handicapped developmentally disabled population.

- Clearly defining and communicating services that occupational therapists have to offer adult developmentally disabled persons. Because the functional abilities of individuals with developmental disabilities vary greatly, the role of the occupational therapist can vary greatly. The role assumed with a nonretarded, severely motor-handicapped individual may be very different from that assumed with an adult with Down's syndrome. However, occupational therapy's focus on purposeful activity, with an orientation toward self-maintenance, work, and play/leisure, must be more clearly communicated and documented with regard to this heterogeneous group.

- Increasing the interest and number of occupational therapists working with the adult developmentally disabled population. Based on the number and types of articles in the literature, occupational therapists seem to be more involved with the pediatric developmentally disabled age group than with the teenage and adult group. Yet a large need appears to exist for occupational therapists to work with adults with developmental disabilities. Treatment and services available for the adult developmentally disabled usually are indirect and consultative in nature. More direct intervention from occupational therapists is needed for this population to help maximize their functioning in activities of daily living.

Conclusion

The Decade of the Disabled as proclaimed by the United Nations and the House of Representatives is here. It has increased our nation's awareness that it is important to meet the needs of disabled persons throughout their life span and to help them achieve a quality of life that is as close to normal as possible. Occupational therapists, with their unique focus on purposeful activity, have a critical role in meeting these needs.

REFERENCES