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Community Adjustment of Young Adults with Mental Retardation: Overcoming Barriers to Inclusion

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Movement of persons with mental retardation out of institutions and into community settings is occurring at an ever-increasing pace (Amado, Lakin, & Menke, 1990). State and federal laws have legitimized the basic rights of persons with mental retardation to live, work, and participate in typical community settings. Yet, physical integration is not synonymous with full community inclusion. Numerous barriers remain that serve as obstacles to successful assimilation into community life. For instance, successful social integration depends on attitudinal changes of persons without mental retardation—families, friends, service-delivery professionals, and the general public—toward persons with mental retardation. The way young adults with mental retardation are perceived by others often restricts their opportunities for participation in activities that allow for development of social relationships, enhancement of self-esteem, and enjoyment of life. Removal of such barriers requires that they first be identified. Action plans and strategies can then be developed to remove, or at the least minimize, effects upon the quality-of-life experienced by this segment of the population.

Barriers to Full Inclusion

Young adults with mental retardation are confronted with numerous barriers to community integration as they move from the dependence of childhood and early adolescence to the autonomy and independence of adulthood. The most obvious of all barriers is lack of access to community living environments. Deinstitutionalization has resulted in a large increase in the number of persons with mental retardation living in community settings. However, an estimated 90,000 people with mental retardation remained in large, state-

operated institutions as recently as 1989 (White, Lakin, Bruininks, & Li, 1991). For young adults with mental retardation to experience the many benefits of community inclusion, they must first live in settings that provide access to a wide range of employment, recreational, and self-enrichment activities.

A second obstacle to full inclusion within the community stems from the rather restrictive attitudes of parents and family members. Many parents express concern about impending moves from institutions to small community facilities. Reasons for apprehension include fears about the appropriateness of available community settings, anxiety that the move will have a negative impact on the family, and concerns that the young adult does not possess necessary skills to function adequately within the community. Discussions with parents following moves of their young adults to community settings revealed more positive feelings about these placements, as 80% of the parents reported satisfaction with the deinstitutionalization process (Larson & Lakin, 1991).

A third major barrier to community inclusion results from opposition on the part of community members. Some community members resist development of group homes in their neighborhoods (Bates, 1986; Gale, Ng, & Rosenblood, 1988; Lubin, Schwartz, Zigmond, & Janicki, 1982). Reasons for such opposition include concerns about negative influences on property values, neighborhood character, and neighborhood children (Lubin et al., 1982). However, follow-up studies have demonstrated indifferent or accepting attitudes by community members (Conroy & Bradley, 1985; Gale et al., 1988) and no decreases in property values (Ryan & Coyne, 1985; Weiner, Anderson, Nietupski, 1982) following the opening of small community residences.

A fourth and equally critical barrier to community inclusion has resulted from lack of funding necessary to provide quality services in small community-based settings (Jaskulski & Metzler, 1990). While the majority of young adults without mental retardation are typically able to find enough resources to move from parental homes within a year or two of leaving school, general lack of financial resources prevents many young adults with mental retardation from moving into supported community residential settings during the same developmental period.

Full access to all aspects of community living is the principle goal of most inclusion programs. The general barriers discussed here significantly limit such access. However, more specific obstacles to integration within the community also exist. These barriers limit access of young adults with mental retardation to programs, environments, and services that have the potential to substantially enhance the quality of living. Specific barriers of special relevance to the therapeutic recreation specialist include those limiting access to recreational leisure programs, hindering development of social networks, impeding economic self-reliance, and obstructing the young adult from obtaining needed support services.

Barriers to Recreational/Leisure Integration

One-third of all persons with mental retardation in the United States have a reported need for recreational/leisure services but are unable to obtain them (National Consumer Survey;

Temple University Developmental Disabilities Center, 1990). This staggering figure indicates that numerous barriers to participation in recreational/leisure activities need to be addressed. Barriers to the integration of young adults with mental retardation within recreational/leisure settings have been identified in several different reports in recent years (e.g., Temple University Developmental Disabilities Center, 1990; Thurlow, Bruininks, Wolman, & Steffens, 1989; Thurlow, Bruininks, & Lange, 1989). The major barriers identified by these research groups are summarized in table 1. The most frequently reported barrier to participation in social and leisure activities was the lack of a companion, friend, or advocate with whom to share the experience. Other barriers included lack of finances and lack of transportation to leisure activities. It is clear from these studies that more work is needed to facilitate development of social relationships that enable young adults with mental retardation to experience full inclusion within recreational/leisure settings.

Table 1. Barriers to Social and Recreational Integration: Percentage of People with Disabilities Reporting Each Type of Barrier

Type of Barrier	National Con- sumer Survey ^{a,e}	Foster/ Group Home Survey ^b	Post School Outcomes ^c		Post School Outcomes ^d Cross-sectional Analysis		
			Moderate	Severe	7-10 yrs	3-5 yrs	1-2 yrs
No companion/ friend/advocate	31%	21%	36%	33%	38%	44%	57%
Lack of money		27%	18%	10%	14%	25%	29%
Lack of transportation (leisure, shopping, appointments)	23%	17%	27%	3%	25%	3%	7%
Activity not available		25%	18%	20%	24%	10%	14%
Need recreational/ leisure services	34%						
Lack of time		20%	15%	30%	0%	13%	0%
Lack of specific skills		15%	21%	10%	10%	9%	7%
Interfering/ challenging behaviors		17%	12%	13%	14%	9%	21%
Need self-help/ support group	20%						

Note: a. $N = 13,075$; Temple University Developmental Disabilities Center, 1990; b. $N = 336$; Hill, Lakin, Bruininks, Amado, Anderson, & Copher, 1989; c. $N_1 = 33$, $N_2 = 30$; Thurlow, Bruininks, Wolman, & Steffens, 1989; d. $N_1 = 21$, $N_2 = 32$, $N_3 = 14$; Thurlow, Bruininks & Lange, 1989; e. This study reported the percentage of people needing but not receiving a particular type of service or support. All the other studies reported percentages of people who mentioned each barrier among those people who experienced barriers to integrated activities.

A second major barrier to full integration within recreational/leisure settings is the lack of practical, widely available guidelines for planning and implementation of integrated programs. While a few excellent guides in this area exist (e.g., Rynders & Schleien, 1991; Schleien & Ray, 1988), this type of information is either not generally available or frequently used by professionals in the field. However, one such program, Unified Sports of

Special Olympics, has set forth published guidelines to assist program leaders with provision of opportunities for shared participation in sports for persons with and without mental retardation. Guidelines of this formally integrated, national program, have explicitly stated goals that have enabled both participants and the Unified Sports program itself to overcome barriers of recognition and acceptance and, thereby gain increased support and popularity among the sporting public. Figure 1 illustrates growth in participation since the Unified Sports program's inception in 1986.

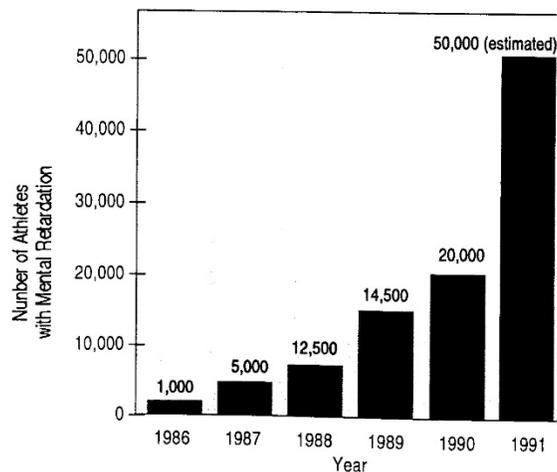


Figure 1. Number of participants in Special Olympics Unified Sports, 1986 through 1991.

A third barrier to integration within recreation/leisure settings stems from lack of skills young adults with mental retardation have available to take advantage of these programs. Unless participation is initiated by a family member or professional support is available for program participation, many young adults with mental retardation are not able to take part in these activities. Failure of families and service providers to provide sufficient opportunities for young adults with mental retardation to develop physical and self-determination skills necessary for independent access to programs greatly restricts opportunities for participation.

Barriers to Social Integration

Young adults with mental retardation face numerous barriers to developing integrated social networks. One barrier faced by young adults stems from difficulty in asserting control and choice over important aspects of daily living. In recent years, several researchers emphasized developmental transition from dependence to self-determination as an important outcome of early adulthood for persons with mental retardation (Abery & Bruininks, 1990; Karan, Lambour, & Greenspan, 1990; Halloran & Henderson, 1990). Barriers to self-determination may be raised when parents ignore preparation for independent liv-

ing, resist or prevent their young adults from participating in normal developmental activities (e.g., spending the night with a friend, or participating in adult-oriented recreational/leisure activities), or advocate for maintaining solely asexual relationships (Daniels, 1982).

Ward (1988) identified rights of making choices and risk-taking as fundamental prerogatives of adolescent and early adult development. Interference with these rights constitutes a barrier to development of a supportive social network of friends and significant others. For example, if young adults with mental retardation are not allowed to choose age-appropriate recreational/leisure activities, it significantly decreases the likelihood they will meet same-aged peers with similar interests. One major factor that influences formation of social relationships is similarity of interests (Hartup, 1983). Attitudes and expectations of parents, residential staff, and other professionals often result in young adults with mental retardation having little input into leisure and recreational activities in which they participate. This places such individuals at risk for having social networks that neither meet basic support needs nor enhance quality of life.

Numerous specific barriers also limit development of rich social networks for young adults with mental retardation. The first of these entails lack of access to reliable transportation (Mangen & Abery, 1990; Ittenbach, Larson, Spiegel, Abery, & Prouty, 1991). Individuals with mental retardation living in rural settings typically have limited options as to how they can get together with friends and acquaintances. Young adults in urban areas also find access to transportation services difficult. Identified transportation barriers include prohibitive costs, complicated routes and procedures, stringent eligibility requirements, lack of reliability, and physical and psychological vulnerability of using such services.

Another specific barrier to development of social relationships is lack of safe, accessible, age-appropriate situations within which to meet others (Mangen & Abery, 1990). In many areas, young adult hangouts are unsafe for persons with disabilities. Park and recreation professionals often concentrate efforts on providing programming opportunities to children with few noncompetitive programs for young adults. Without support, many young adults with mental retardation are unable or unwelcome to participate in any leisure-time activities (e.g., health clubs, concerts, theater). Hesitancy on the part of recreational staff is one of the major reasons such activities are often inaccessible. Recreational/leisure professionals will likely remain anxious about integrating persons with disabilities into programs until their knowledge about disabilities and disability-related issues is increased.

Additional barriers to social integration include insufficient support provided to general recreational/leisure professionals once persons with mental retardation are integrated into existing activities, and general lack of knowledge of existing programs. Many recreational professionals report receiving inadequate support when persons with disabilities are integrated into their programs or activities. This includes lack of time to prepare necessary adaptations, as well as difficulty accessing and efficiently using the time of therapeutic recreation specialists (Mangen & Abery, 1990). In addition, many parents, professionals, and young adults with mental retardation are completely unaware of recreational/leisure programs that exist within their communities. Inadequate outreach by

sponsoring organizations and poor interagency communication are two factors that contribute to this state of affairs.

Barriers to Economic Integration

When compared with individuals without disabilities, types and levels of employment available to young adults with mental retardation are restricted. These differences are symptomatic of barriers affecting economic integration of all young adults with disabilities. While nearly two-thirds of young adults without mental retardation are competitively employed 30 months after high school graduation, less than half (47%) of young adults with mild mental retardation are so employed (Affleck, Edgar, Levine, & Kortering, 1990). The picture is more dismal for persons with moderate or severe mental retardation, as only a small percentage of the total population is competitively or supportively employed, 29% and 6%, respectively (Bruininks, Lewis, & Thurlow, 1990). This often results in young adults with mental retardation not possessing necessary funds to engage in age-appropriate recreational/leisure activities.

Specific barriers to employment of young adults with mental retardation include limited employment options, a shortage of support services to enhance productivity, low pay, lack of integrated opportunities for work, exclusion from vocational services due to eligibility requirements, insufficient staff, and lack of funding resources (Jaskulski & Metzler, 1990). Although barriers to employment have been well studied in recent years, less well studied is the level of control young adults with mental retardation have over expenditure of personal income. In an economy in which spending patterns influence fashions as much as social norms, young adulthood is a time in which individuality is asserted through dress, hobbies, friends, gifts, and even diet. These activities and material goods are obtainable only through disbursement of income.

As suggested by Ittenbach et al. (1991), young adults with mental retardation often do not have control over how their funds are spent. This often results in an inability to purchase desired goods and services. Participation in recreational/leisure programs is often overlooked by professionals and families when decisions are made regarding disbursement of income earned by young adults with mental retardation. Whether decisions made by others prevent these young adults from taking part in integrated recreational/leisure programs altogether, or channel them into participation in programs not of their own choosing, basic rights of the individual are often ignored.

Barriers to Obtaining Needed Support Services

To participate fully in community life, many young adults with mental retardation require support services. This includes assistance in the form of recreational/leisure services, friend-advocate programs, transportation, in-home respite care, self-help/support groups, vocational training, and case management. While a wide variety of support services is needed by young adults with mental retardation, many of these types of assistance are not

available to individuals (Temple University Developmental Disabilities Center, 1990). Unavailability of and lack of access to these services constitute barriers to full inclusion within the community.

A second barrier limiting access to integrated community living is shortage of financial resources to support specific needs of young adults with mental retardation. This includes general lack of resources to deal with specific needs such as challenging behaviors; physical and/or sensory impairments; extensive care needs in eating, dressing, or toileting; and exceptional medical needs. Persons with severe mental retardation, extensive medical needs, or challenging behaviors are less likely to move from institutions to integrated community settings and are more likely to be admitted or readmitted to institutions than counterparts who do not possess these characteristics (Borthwick-Duffy, Eyman, & White, 1987; Lakin, Hill, & Bruininks, 1988; Vitello, Atthowe, & Cadwell, 1983; White et al., 1991). These individuals participate less frequently in typical community activities whether they live in urban or rural settings or in large or small residences (Bell, Schoenrock, & Bensberg, 1981; Dalgleish, 1983; Hill, Rotegard, & Bruininks, 1983). In addition, young adults with exceptional needs rarely work within integrated community settings (Wehman, 1991). Despite these barriers, however, young adults with mental retardation, including those with challenging medical needs, challenging behaviors, or severe mental retardation can and do live successfully in community settings (Hayden & DePaepe, 1990; Larson & Lakin, 1989; McDonald, 1985). The challenge for all service providers is to identify resources and supports that enable all such persons to be fully included in community settings.

Overcoming Barriers to Community Inclusion

Young adults with and without disabilities report learning a great deal from each other when given opportunities to interact through inclusive education, supportive employment, and recreational/leisure programs. While such programming is unlikely to lead to full inclusion within the neighborhood and community, it nonetheless creates potential for longstanding social relationships. Unless collaborative affiliations are developed between community service organizations (e.g., schools, park and recreational programs, the YMCA/YWCA) and direct service providers who nurture relationships outside of educational and employment settings, it is unrealistic to expect that full community inclusion will ever occur.

Knoll (1990) identified 11 characteristics of environments that support a high quality of life for persons with disabilities. These include real choices in all aspects of daily life, instruction to develop functional skills, opportunities for interaction with a variety of people, use of generic services, access to community resources, age-appropriate settings and materials, entrance to a wide range of community environments, living in a typical neighborhood, meaningful daily activities, use of nonaversive interventions, and opportunities to develop friendships. The therapeutic recreation specialist is in an excellent position to insure that environments of young adults with mental retardation are characterized by most, if not all, of these qualities.

Enhancing quality of life for young adults with mental retardation is a difficult and complex task. One must not only facilitate development of social ties between young

adults with disabilities and the rest of the community but also create and strengthen relationships among organizations that serve such individuals. In designing and overseeing implementation and evaluation of inclusive recreational/leisure programs, the therapeutic recreation specialist is in a position to promote development of lasting social relationships among persons with and without disabilities, change societal attitudes and expectations about young adults with mental retardation, and provide young adults with mental retardation access to a wide range of environments in which they can choose and initiate social relationships. If the therapeutic recreation specialist is to be successful in fostering greater community inclusion of young adults with mental retardation, the design and implementation of recreational/leisure programs must be undertaken in a planned manner. Program design must not only draw upon content of therapeutic recreation and a knowledge base of developmental, social, and economic characteristics of young adults with mental retardation, but on support systems available and necessary to meet specific needs. Based upon this assumption, several recommendations are in order, recommendations that must be kept in mind when designing and implementing recreational/leisure programs.

Acknowledge Uniqueness of the Individual

Young adults with mental retardation are as heterogeneous as persons without disabilities. They have unique personalities, interests, abilities, and aspirations. Some young adults with mental retardation prefer to spend time with large groups of people, others with a few persons with whom they are intimately acquainted; some prefer active, team-oriented sports, others passive, individually-oriented activities. The assumption that all young adults with mental retardation are alike infringes on their integrity, identity, and sense of personal worth, an assumption that is still widely held by many professionals who work with persons with mental retardation. The therapeutic recreation specialist must maximize goodness-of-fit between recreational/leisure programming and interests, skills, and needs of the person served. This assumes a knowledge not only of programs available within a community but of the individual for whom the program is to be developed. One avenue through which such information can be obtained is through participation in personal futures planning sessions with collaboration between the young adult and significant others (Mount & Zwernik, 1988). These sessions have the potential to provide a wealth of knowledge regarding the individual's aspirations, dreams, and desires, as well as specific information about activities they might enjoy.

Respect Independence and Self-determination of Persons with Mental Retardation

Far too often professionals working to enhance the lives of persons with mental retardation assume the care-provider knows best. Persons with disabilities are placed into programs without ever inquiring as to their levels of interest or providing them opportunities to make informed choices about participation. All young adults, including those with mental retardation, are entitled to exercise control over basic aspects of their lives as part of the developmental process (Havinghurst, 1972). Therapeutic recreation specialists can ensure that young adults with mental retardation have opportunities to exercise self-determination

by making them integral parts of the planning team, encouraging their participation in program design and content, and valuing their contributions. Allowing a young person with a disability to shape at least some activities that compose daily life also provides a powerful message to parents and other professionals as to age-appropriate expectations in this area.

Emphasize Strengths and Contributions of the Individual

All individuals have strengths and weaknesses. However, for far too long service providers have used a deficit-based model to design programs for young adults with mental retardation. That is, emphasis has traditionally been on what one could not do rather than what one could do. While it would be inappropriate to ignore limitations of a disability, programming is likely to be significantly more effective if based upon skills an individual possesses rather than on skills he/she lacks. As young adults with mental retardation move into more normative settings, the heterogeneity of skills and abilities will evolve, just as they do for young adults without mental retardation. Allowing the young adult, rather than others, to identify well-developed skills and abilities is a second strategy that has proven to be of value. Focused programming on selection and planning of social activities rather than task accomplishments is one way to accomplish this.

Acknowledge Developmental Status of Young Adults with Mental Retardation

If community inclusion is to become a reality, young adults with mental retardation need to have access to the same age-appropriate community experiences as peers without mental retardation. Opportunities to access the same community experiences as individuals without disabilities play a crucial role in friendship development. Without such access, it is unlikely that young adults with mental retardation will share common interests with peers, develop similar belief systems, or be perceived by peers as similar in other respects. In developing inclusive recreation and leisure programs, the developmental status of the young adult with mental retardation must be acknowledged. This means focusing inclusion efforts on programs or activities socially valued by other young adults. Integrating a young adult with mental retardation into a volleyball or softball league, for example, would be more appropriate than facilitating inclusion in a shuffle-board or croquet association.

Identify Barriers to Inclusion

Young adults with mental retardation are confronted with numerous barriers to full inclusion within society. Awareness of specific barriers faced by young adults within the local community is the first step in the process of creating action plans with the goal of removing these obstacles. By gaining a thorough knowledge of the community and resources that persons with disabilities have available, service providers increase chances that all programs with which they are affiliated are truly accessible to members of the entire community.

Include Systematic Programming to Stimulate Social Interaction

One benefit of participation in recreational/leisure programs is that an individual has opportunities to interact socially with others with similar interests. Taking part in joint activities can lead to the development of friendships. However, physical integration is not synonymous with social inclusion. Because of limited opportunities for integrated social interactions, many young adults with mental retardation may remain anxious or reluctant to engage in such activities. Incorporating systematic programming to stimulate social interactions (e.g., cooperative learning) into recreational/leisure activities is one avenue through which to make participation a more effective learning and social experience.

Use Creative Problem-Solving Techniques

Development of inclusive recreation and leisure programs for young adults with mental retardation is a challenging task. Direct service providers may not always be able to arrive at the most effective solutions to problems faced on their own. An innovative problem-solving approach that has been successfully used in inclusive education programs with promising results is an approach based upon the Osborn-Parnes Creative Problem-Solving Process (CPS; Parnes, 1988). The approach encourages all participants to act as problem-solvers and provides a structured way to deal with barriers to inclusion as they are encountered. The CPS process enhances group cohesiveness, taps problem-solving abilities of multiple individuals, and fosters greater investment in making inclusion work among group members.

Encourage Staff Development and Capacity Building

Education and dissemination of inclusion resources to recreation personnel are important roles of the therapeutic recreation specialist. Staff development and capacity building are necessary skills for developing attitudes and skills of all service providers. Providing staff with information on best practices within the field and other information about how to make programs accessible contribute to sense of ownership for such activities rather than looking for other professionals to problem-solve for them.

Facilitate Development of Linkages between Available Resources

Few young adults with or without disabilities can live high-quality lives without the aid of community resources. Fewer still take full advantage of available resources. Much of this is due to lack of communication and coordination between existing programs and agencies. Many young adults with mental retardation and their families are unaware of existing resources within communities. This state of affairs is also often true for professionals within disability-related fields. Therapeutic recreation specialists are in excellent positions to facilitate this information exchange and create more effective linkages among organizations that serve young adults with mental retardation and between these young

adults and organizations themselves. Effective coordination of services and programs offered by the YMCA, local park and recreation departments, community education programs, can do much to remove barriers effectively limiting inclusion of persons with mental retardation in recreational/leisure activities.

Develop New Resources

Due to support needs of young adults with mental retardation, therapeutic recreation specialists need to develop resources beyond those currently available to insure that full inclusion becomes a reality. These resources can be obtained if community and service organizations, corporations, small businesses, and public and private schools are recruited to join in the pursuit of full community inclusion. The most valuable resource that can be obtained from such organizations is not money, but, rather, involvement of members of the community. Use of such individuals as volunteer support staff, integration facilitators, and mentors will increase accessibility of programs to young adults with mental retardation while also serving as vehicles through which to change community attitudes toward persons with mental retardation.

Conclusion

This article compliments the expanding literature base on community inclusion of young adults with mental retardation. It is based on the assumption that persons with disabilities of all types, levels of severity, and ages can benefit from greater inclusion within community settings. Attempting to integrate children, youth, and young adults with mental retardation into the community is a complex task. It will not be successful without taking into consideration all aspects of the individual and the community in which the person lives. Practitioners within the field of therapeutic recreation possess unique skills and opportunities to facilitate integration into recreational/leisure programs and to promote greater inclusion within society.

In general, barriers to integration highlighted in this article are those that have been consistently identified as major impediments to enhanced community inclusion of young adults with mental retardation. This does not mean to imply, however, that they are the only barriers people with mental retardation face in their attempts to gain rights and responsibilities of full citizenship. Characteristics of the individual, family, and community must be considered in designing and implementing programs that enhance community adjustment. Similarly, recommendations offered to readers do not supply specific information necessary to design and implement inclusive recreational/leisure programs. Specific ideas for inclusive program planning and implementation are provided in several resource guides available elsewhere (e.g., Rynders & Schleien, 1991; Ray, Schleien, Larson, Rutten, & Slick, 1986; Schleien & Ray, 1988; Wilhite, Reilly, & Teaf, 1989). The reader is provided with a series of ten recommendations that, if tailored to needs of specific individuals and communities, will very likely enhance the potential for success as young adults with mental retardation move toward full community inclusion.

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