**Best Professional Practices: Serving Persons With Severe Multiple Disabilities**

By: [Stuart J. Schleien](#), Cheryl L. Light, Leo H. McAvoy and Cheryl K. Baldwin


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**Abstract:**
Recreation/leisure programming for persons with severe multiple disabilities has been a neglected area due to the ambiguity of roles and responsibilities among the various servicing agencies and professional disciplines, and lack of instructional skills among recreation service providers. This article presents a process of networking among professionals, servicing agencies and families, and the use of state-of-the-art "best professional practices" in leisure skills programming for persons with severe multiple disabilities. The application of these techniques in other community facilities, such as in outdoor education environments, is also described. Problems associated with terminology and a possible transagency definition to better serve this low incidence population are examined.

**KEY WORDS:** Developmental Disabilities, Multiple Disabilities, Networking, Outdoor Education, Therapeutic Recreation

**Article:**
The therapeutic recreation specialist has commonly been given primary responsibility in the expansion of leisure repertoires of persons with severe multiple disabilities. Few community agencies have provided leisure services to this low incidence population. Community agencies are often unclear as to whose responsibility it is to provide leisure/recreation programs and services (Schleien & Ray, 1988; Schleien & Werder, 1985). Additionally, few therapeutic recreation specialists and generic community service providers have the necessary skills to adequately serve persons with multiple needs. This article synthesizes research literature to propose a model process to enhance community leisure participation by persons with severe multiple disabilities. The process proposed includes: 1) sharing the responsibility of leisure programming through networking, 2) using specific "best professional practices", and 3) identifying roles and responsibilities among the servicing agencies, professionals, and significant others.

**Networking**
Networking with other professionals is not always an easy task. It may involve developing a complex system of communication to actively promote the sharing of information, expertise, and "best professional practices." Many agencies are reluctant to duplicate services and/or expertise with other agencies. Areas such as recreation/leisure are typically given low priority and agencies often assume that some other agency is responsible for programming. As a result, leisure education becomes a neglected area. However, various disciplines are becoming increasingly aware of the advantages of consistent and collaborative programming. Not only have service providers become concerned with increased generalization and maintenance of academic, communication, and daily living skills, but also with the expansion and articulation of other skills (e.g., occupational and life-long leisure skills) that will transition people with severe disabilities into employment and independent living options (Everson & Moon, 1987, p. 87). Unfortunately, barriers exist that prevent consistent programming across environments and agencies. One major barrier is the ill-defined and broadly interpreted term "severe multiple disabilities".
Lack of Definition
Services are often provided to persons with severe multiple disabilities from a wide variety of agencies (e.g., residential/community living, vocational, recreational, educational). These agencies use various terms to categorize their clientele. With the abundance of terms being used, it has been difficult to specify and address persons within this low incidence population. Terms seem to fall within two categories; generic descriptions which refer to the population in a broad sense (e.g., dual sensory handicaps and profound handicaps) and disability-specific descriptions which refer to certain segments of the population (e.g., profoundly mentally retarded, cerebral palsied-deaf). These terms, however, are often either too encompassing or inadequately exclusive. For example, the assessment label "deaf-blind" refers not only to those individuals who are deaf and blind but also to those who are visually and auditorially impaired. This includes individuals categorized as blind/severely hearing impaired or severely hearing impaired/severely visually impaired. Consider, as well, that many individuals who are deaf-blind are either mentally retarded or functioning in the range of mental retardation. Should persons who are both mentally retarded and deaf-blind be categorized with persons who are deaf-blind but do not appear to have the same cognitive deficits? Through this example it becomes evident that the term deaf-blind may not accurately reflect the dynamics of this population (Barrett, 1987; Fredericks & Baldwin, 1987).

The following explanation attempts to satisfy the need for a more comprehensive definition: one that is general enough to include the variance of this population, yet specific enough to be viable for those servicing this population. The label, "severe multiple disability", refers to those individuals with a profound disability or with a combination of disabilities that so limits their daily activities that they require services and programming more innovative, extensive and intensive than common programming for individuals with disabilities provides. This population is characterized as, but not exclusive to being non-ambulatory, non-independently mobile, and in need of assistance in toileting, feeding, and other related services (e.g., occupational therapy, communication, therapeutic recreation (Covert, 1987; Fredericks, 1987).

Having a universal definition can promote greater continuity, understanding and cooperation between servicing agencies, interdisciplinary team members and other concerned individuals. This definition can give professionals a better idea of what needs exist for their clients and the types of programs that individuals within this low incidence group may enjoy and access successfully.

Rationale for Recreation/Leisure Participation
It is crucial for networking agencies, interdisciplinary team members and other individuals to understand the significance of recreation/leisure for everyone. This includes persons with and without severe multiple disabilities. Recreation activities can help promote physical health and conditioning, provide opportunities to develop social relations, and lead to the development of new skills.

The neglect of adequate networking, interdisciplinary support and relevant programming and services for persons with severe multiple disabilities is unfortunate because appropriate participation in recreation activities is an important aspect of successful community adjustment (Cheseldine & Jeffree, 1981). Also, appropriate participation is associated with the development of collateral skills (Schleien, Kiernan, & Wehman, 1981), and with the reduction of maladaptive behaviors (Adkins & Matson, 1980; Flavell, 1973; Voeltz & Wuerch, 1981). Typical deficits that persons with severe multiple disabilities experience include: (1) leisure skill repertoires; (2) choice-making and self-initiated behavior; (3) social skills and other leisure-related support skills; (4) maintenance and generalization of skills; and (5) community integration. Because these individuals differ markedly from one another in their abilities, it is necessary to approach service delivery in an individualized manner in an attempt to satisfy personal needs and preferences. The therapeutic recreation specialist works toward such goals as: increasing environmental exploration and manipulation; broadening the range of life-long leisure skills; expanding independent leisure behavior, socialization and cooperation skills; developing collateral or support skills; improving self-concept and self-esteem; and providing opportunities to perform acquired skills.
It is necessary to understand that the capabilities and learning potential of children and adults with severe multiple disabilities far surpass the traditional levels of competencies that have been reached in the past. Leisure skill programs must be designed and implemented carefully, incorporate sound behavioral principles, occur throughout the individual's lifespan, and be effectively and consistently supported within a network system or interdisciplinary team. Consequently, these persons will demonstrate that they too can participate successfully, if only at least partially, in many leisure environments and activities. Fortunately, specific leisure skill instructional techniques and curricula which incorporate behavioral training procedures in conjunction with purposeful environmental arrangements and other "best professional practices" have been developed. Additionally, they can be learned and implemented by willing servicing agencies and professionals.

### Table 1.

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"Best Professional Practices" in Leisure Skill Programming

**Needs/Preference Assessment**

As can be seen in Table 1, a vital first step in the process of leisure programming, the needs/preference assessment, provides important information in identifying activities and materials that will best meet the participants' life-long leisure needs. This assessment addresses several key areas including general background information (e.g., age, abilities, physical characteristics) about the individual, and appropriateness and functionality of the targeted activities.

Information for a needs assessment can be gathered from a variety of sources (e.g., family members, careproviders, teachers, related services personnel and other support staff). This information gathering process can strengthen the networking process by allowing all parties to contribute pertinent information concerning: (1) the participant's family background, physical, and medical needs, (2) educational needs (3) social/emotional needs (e.g., types of reinforcers that are effective, preferences, means of selecting items), (4) family and individual leisure preferences and activities in which family members commonly engage during their discretionary time, and (5) information regarding client and community resources. Specific needs assessment inventories available include those by Wehman & Schleien (1981) and Wuerch & Voeltz (1982).

A second area of a needs assessment should address the appropriateness and functionality of activities relative to the normalization principle. Functional skills are those that an individual frequently demonstrates in daily life whether at home, on the job, or in the community. A nonfunctional skill is one that has a "low probability of being required by daily activities" (Brown et al., 1979). When developing a leisure skills curriculum, one may assess its worth or validity by determining the functionality of the curricular activities. For example, a nonfunctional activity frequently incorporated into a prevocational or recreational curriculum would be placing pegs into pegboards to increase a child's pincer grasp and voluntary release skills. A functional alternative could be teaching the child to play with a Lite-Brite (by Hasbro) game. Both activities have identical topography, but the Lite-Brite game provides additional sensory stimulation and reinforcement and is an age-appropriate activity
that could be enjoyed and practiced at home. (See Voeltz and Wuerch (1981) for a checklist that can be used to evaluate activities for appropriateness).

A third area to be addressed in a needs assessment concerns an individual's level of proficiency when engaged in a particular activity. An ecological assessment or an environmental analysis inventory (Belmore & Brown, 1976; Certo, Schleien, & Hunter, 1983; Schleien & Ray, 1988) could be conducted to determine the specific components of the activity that the individual has already mastered and those requiring additional training. The environmental analysis inventory is helpful in developing instructional sequences, identifying their component tasks, and identifying appropriate teaching strategies as well as adaptations/ modifications that may enhance participation.

**Skill Selection Guidelines/ Functional Curriculum**
Following the initial needs assessment the therapeutic recreation specialist selects the most important and relevant skills to be targeted for instruction as part of the leisure/recreation program. Most professionals agree that the skills selected must be functional and chronologically age-appropriate (Certo, Schleien, & Hunter, 1983; Fardig, 1986; Wuerch & Voeltz, 1982).

**Collateral Skills Development/ Infusion Chart**
In addition to providing pleasure and entertainment, participation in recreational activities enhances development in social, emotional, psychological, communication, problem solving, motor, and other collateral skills since it allows for continued practice of newly acquired skills in positive and naturally occurring contexts. Vander-cook (1987) reported that as persons with severe handicaps became more proficient in two recreational activities (i.e., pinball, bowling), their social repertoires became more sophisticated. A likely explanation for this phenomenon is that greater skill with the mechanics of an activity allows individuals more freedom to expend greater efforts monitoring their social behavior. If social competencies can be improved, "incidentally," within the context of age-appropriate activities, valuable intervention time could be saved and social competencies could accrue within the context in which they are expected to be expressed. Research has also shown that play experiences enable the child to perceive a more positive body image and self-image (Wehman & Schleien, 1981). As self-image is cultivated, social and personal security increases. This type of environment could provide a setting for accomplishment to counteract the feelings of learned helplessness or inferiority, which many persons with severe disabilities experience through repeated failure (Dattilo & Rusch, 1985; Seligman, 1975).

Other collateral skills that could be acquired within the context of a leisure program include increased communication and language skills (Rogow, 1981; Bates & Renzaglia, 1982), various social skills such as cooperation, relationship building (e.g., making friends), taking turns and sharing materials (Kibler, 1986; Schleien & Wehman, 1986), and appropriate manipulation of materials and motor skills (Orelove & Sobsey, 1987; Sherrill, 1986). Other life domains could also be addressed during leisure/recreation activities. For example, if an individual with severe multiple disabilities was to participate in a horseshoe activity, he/she could learn about appropriate clothing (i.e., activity of daily living), necessary motor skills involved in grasping and pitching horseshoes (i.e., gross and fine motor skills), and possibly an adapted method of scoring and measuring (i.e., functional academics/math). Undesirable behaviors have been known to decrease following an individual's acquisition of appropriate object manipulation skills or functional leisure skills (Alajajian, 1981; Flavell, 1973). As an example, Alajajian (1981) discovered that an additional outcome of a jogging program focusing on physical fitness in students with severe sensory impairments and cognitive deficits was a noticeable decrease in their self-abusive and self-stimulatory behaviors.

**Instructional Programming**
Following the critical processes of assessment and skill selection, the therapeutic recreation specialist must decide on a systematic method of instructing the targeted leisure skills.
**Task Analysis**
Numerous authors (Schleien, Ash, Kiernan, & Wehman, 1981; Schleien & Ray, 1988; Storey, Bates, & Hanson, 1984; Wehman & Schleien, 1981; and Wuerch & Voeltz, 1982) have supported the use of a task analysis when teaching leisure skills to persons with severe multiple disabilities. By depicting the component steps of an activity that are easily teachable and observable, task analysis instruction has several advantages. First, it serves as an assessment tool that provides skill proficiency information. Secondly, a task analysis individualizes a program, allowing for adaptations to be made based on the learner's needs and abilities. Thirdly, it provides a teaching sequence that can be used consistently by multiple trainers.

**Shaping and Chaining**
A task analysis approach is usually implemented through a variety of behavior shaping and chaining procedures. Shaping consists of the instructor reinforcing approximations toward the desired or final behavior rather than reinforcing the final response itself. For example, the learner could purchase a snack from a vending machine by using extensions on the push-buttons. This adaptation could gradually be reduced as the response becomes more accurate until the participant is manipulating standard size buttons on the vending machine. At this time, previously reinforced approximations are ignored. Chaining, on the other hand, involves the sequencing of the responses within the task. In a forward chain, the learner is initially instructed on the first step of the task analysis (i.e., locate vending machine) and then guided through the remainder of the steps. In a backward chain, instruction is initially provided on the final step in a response sequence (i.e., consume snack item) until that step is mastered. The remaining steps are then taught in reverse order, one at a time, always including the previously instructed step in the teaching sequence. In this manner, the student immediately enjoys the naturally reinforcing consequences of the activity which enhances the learning process.

**Cue Hierarchy and Prompting System**
Cues and prompts are intricate parts of instructional programs that attempt to elicit behaviors before they are mastered. Prompts (usually arranged in a hierarchy of least-to-most intrusive) are used to develop new behaviors or correct undesirable ones and may include physical guidance, modeling appropriate behaviors, gestures, and verbal direction. A desirable outcome of instruction is to have the play materials become the natural or environmental cues that elicit appropriate and independent leisure behavior.

When comparing two different prompting procedures (i.e., antecedent and correction procedures), Day (1987) and McDonnell (1987) found that prompting strategies were more effective when delivered prior, versus subsequent, to an erroneous response. Prompting strategies have been major components of effective behavioral packages teaching persons with severe multiple disabilities a variety of skills (James & Egel, 1986; Meehan, Mineo, & Lyon, 1985; Powell & Ogle, 1985; and Storey, Bates, & Hanson, 1984).

**Reinforcement**
Because individuals with severe multiple disabilities do not find many activities enjoyable early on in training, a reinforcement component is usually included in leisure skill instructional procedures. The reinforcement procedure consists of delivering desirable events, consequences, or objects to an individual immediately following the occurrence of an appropriate response. The strength of a reinforcement procedure lies in the immediacy of delivery. Effective reinforcers, often highly individualized, will increase the likelihood that the desired response will occur again. Common and effective reinforcers are individual-specific and may include food, praise, attention, switch-activated buzzers, vestibular-related materials and activities, and access to favorite recreational materials (Sandler & McClain, 1987; Sobsey & Reichle, 1986). Reactive recreational materials such as Simon, cameras, remote control vehicles, and vending machines that result in sensory feedback provide natural reinforcers. Wehman (1977) suggests that the use of effective reinforcers, frequently and contingently, may be necessary to promote learning.

**Choice Training**
Traditionally, individuals with severe disabilities have not been given the freedom or opportunity to make leisure choices (Dattilo & Barnett, 1985; Guess, Benson & Siegel-Causey, 1985; Shevin & Klein, 1984;...
Even when given opportunities to make these choices, they frequently exhibit skill deficits in communication, facial expression, gross and fine motor movement, attention span and other behaviors commensurate to activity selection (Dattilo, 1986; Guess, Benson, & Siegel-Causey, 1985; Shevin & Klein, 1984). If acquired, these skills become helpful in indicating a preference to participate in or terminate an activity, as well as indicating with whom he or she wishes to participate.

Although not a simple process, specific techniques to facilitate independent choice-making and self-initiated leisure behavior are available (Shevin & Klein, 1984; Wuerch & Voeltz, 1982). The first step in the process involves identifying an individual's avenue of preferential expression or communication such as smiling, head nods, positive vocalizations, attempted object possession, specific eye movements, and the length of time that an individual attends to or manipulates an object.

A second step in the process involves teaching the skills necessary for accessing or participating in an activity, while appropriately manipulating objects and materials. Several researchers (Dattilo & Mirenda, 1987; Guess, Benson, & Siegel-Causey, 1985; Shevin & Klein, 1984) have found that teaching individuals with severe disabilities how to operate microswitches was helpful in enabling independent access to a variety of activities (e.g., listening to music, watching action videos, activating a blender, viewing a slide show).

The third step in the process involves teaching the individual to discriminate between objects or activities by presenting him or her a known preferred object (e.g., microswitch which provides access to music on the radio) and a known non-preferred or neutral object (e.g., wooden puzzle). This affords an opportunity to choose the preferred item. As the individual develops consistency in selecting various preferred items, further desirable items can be presented. A fourth and equally important step in the process entails the provision of frequent opportunities in varying environments for the individual to exercise the choice-making skills that he or she has acquired.

**Adaptations/Modifications**

Individuals with severe multiple disabilities often have difficulty exploring and manipulating their environments due to physical, cognitive, and/or sensory limitations. Identifying and developing adaptations for activities and materials could provide individuals with increased opportunities for participation. Wehman and Schleien (1981) developed three guidelines which should be considered when adapting programs:

1. Adapt enough to increase participation, success and enjoyment, but only adapt when necessary.

2. View any changes or adaptations to the activity or materials as temporary; work toward engagement in the original, unmodified activity.

3. Make adaptations on an individual basis, meeting individual needs. Do not adapt an activity for an entire group if only one participant requires a change.

There are five alternatives to consider when adapting programs and environments for participants. These include:

1. Material adaptations (e.g., using a tubular steel bowling ramp to bowl)

2. Procedural/rule adaptations (e.g., stand closer to the dowel when pitching horseshoes)

3. Skill sequence adaptations (e.g., changing into swimming attire before arriving at public swimming pool)

4. Facility or environmental modifications (e.g., make walking path hard surfaced versus graveled)

5. Lead-up activities (e.g., learning to play kickball leads to playing softball) Partial participation is a proposed
strategy to ensure that persons with severe multiple disabilities will partake in activities that require skills beyond their abilities (Baumgart et al., 1982). Partial participation is enhanced via assistance from non-disabled peers including volunteer advocates (Ray, Schleien, Larson, Rutten, & Slick, 1986) and "Special Friends" (Voeltz, Wuerch, & Wilcox, 1982), and implementation of cooperative grouping arrangements and cooperative learning activities (Rynders, Johnson, Johnson, & Schmidt, 1980).

**Maintenance and Generalization**

In order for newly acquired leisure skills to be retained, it is important that the learner have the ability to transfer these skills across several environments, people, and materials. Numerous researchers (Banks & Aveno, 1986; Horner, Dunlap, & Koegel, 1988; Schleien, Certo, & Muccino, 1984; Storey, Bates, & Hanson, 1984) have demonstrated that even though persons with severe multiple disabilities have difficulty maintaining and transferring skills, it is possible to successfully promote the retention and generalization of skills by implementing particular instructional methods. Horner, Williams, and Knobbe (1985) discovered that maintenance of an acquired skill necessitated at least two performance repetition opportunities per month following acquisition training. Skills can be sustained when networking transpires with families/careproviders, professionals, and key servicing agencies. As a result, there is a greater likelihood that individuals will experience additional opportunities to practice and perform these skills in nontrained and integrated community settings.

Another method of promoting skill generalization and maintenance is to use naturally occurring reinforcers during instruction. Reactive recreational materials (e.g., Lite-Brite, Simon, remote control vehicles, video games) and activities (e.g., bowling and purchasing a snack from a vending machine, jumping on a mini-trampoline, activating a switch to turn on a cassette recorder) contain naturally occurring reinforcers that promote and maintain independent leisure behavior.

A third method to enhance skill generalization and maintenance is to vary the conditions of skill performance (Horner, Dunlap, & Koegel, 1988). Coffee purchasing (Storey, Bates, & Hanson, 1984), bowling (Schleien, Certo, & Muccino, 1984), and cooking skills (Schleien, Ash, Kiernan, & Wehman, 1981) were instructed using task analyses and graduated prompting. The participants were then offered opportunities to perform the acquired skills in multiple environments with subsequently less intrusive prompts resulting in successful generalization across environments.

"**Best Professional Practices" in Outdoor Education**

These "best practices" are not only useful for therapeutic recreation specialists, related disciplines and traditional servicing agencies, but have recently, for example, been found by the authors to be effective in outdoor education facilities. Persons with severe multiple disabilities have interests in the same general outdoor activities as non-disabled peers. West (1981) found activities such as hiking, camping, and other outdoor education pursuits to be preferred over the typical indoor activity offerings. Not only do outdoor education methods and activities include a wide array of approaches that range from the study of the composition of a snowflake to the acquisition of snowshoeing skills, but they also include a focus on experiencing, understanding, appreciating, and enjoying the outdoors to enhance an individual's quality of life.

Outdoor education facilities have a potentially strong networking system because they are sponsored by a wide variety of agencies, including schools, cities, state parks, regional parks, and non-profit organizations such as foundations, camps, and social service agencies. Integrated outdoor education programs ideally offer participants opportunities to interact with nondisabled peers in educational and community settings, learn an appreciation of the outdoors through participation in activities that teach basic outdoor education concepts, and become acquainted with and access community-based educational and leisure resources. Preliminary findings of a study that the authors are conducting (McAvoy & Schleien, 1988) indicate that persons with severe multiple disabilities can successfully participate in integrated outdoor education programs if facilities are physically accessible and if the instructors are trained in the integration "best professional practice" strategies discussed in this article.
Roles and Responsibilities of TR Specialists and Other Key Players

While it is expected that therapeutic recreation specialists possess the knowledge to plan and implement appropriate recreation programs and services for clients with severe multiple disabilities, seldom do they operate alone in this process. Successful leisure skill acquisition and participation depends greatly on the amount and quality of networking that transpires. Networking implies a process of cooperation among all persons who share common interests and concerns. As such, it involves the establishment of ongoing and productive working relationships between therapeutic recreation specialists and others who are striving to meet similar ends. Networking can begin with a telephone conversation, a personal or interdisciplinary team meeting, or a workshop that one attends. The astute therapeutic recreation specialist will determine the strengths of these social contacts and will solicit the assistance of others in planning and delivering community leisure services (Schleien & Ray, 1988).

Table 2.

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<tr>
<th>Networking</th>
<th>Leisure Service Process</th>
<th>Key Players</th>
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<tbody>
<tr>
<td></td>
<td>Therapeutic Recreation Specialist</td>
<td>Parents, Siblings &amp; Careproviders</td>
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<tr>
<td>1. General Information</td>
<td>X</td>
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<tr>
<td>2. Identifying Needs</td>
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<td>X</td>
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<tr>
<td>3. Identifying Preferences</td>
<td>X</td>
<td>X</td>
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<tr>
<td>4. Selecting programs/skills to teach</td>
<td>X</td>
<td>X</td>
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<tr>
<td>5. Implementing programs/instruction</td>
<td>X</td>
<td>X</td>
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<tr>
<td>6. Providing ample opportunity to practice skill</td>
<td>X</td>
<td>X</td>
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<tr>
<td>7. Evaluate program/instruction</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>8. Summarizing findings and reporting</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>9. Providing approp. feedback</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>10. Determining future program/instructional efforts</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>11. Maintenance of skills learned/application of skills learned to other environments and activities/tasks</td>
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An effective way to identify meaningful contacts is by developing a "Networking Matrix" as described by Schleien and Ray (1988). This matrix (See Table 2) lists key players who can aid in the implementation and delivery of community leisure services. It identifies their roles and responsibilities within this process but may vary from community to community. Professionals are encouraged to use the matrix as an adaptable guide for meeting their agency’s and community’s needs. One may find that certain players are more significant in the community leisure service process than is noted in this matrix. The therapeutic recreation specialist may wish to further personalize each category by identifying individuals and agencies by contact person, agency or category.
affiliation, address, and telephone number. The therapeutic recreational specialist can use the matrix to identify people presently connected with the individual and decide who can provide essential information and assistance. Other agencies could use the matrix for similar purposes.

**Summary and Conclusions**

It is necessary for strong support systems in communities and residential facilities to exist if people with severe multiple disabilities are to learn and maintain leisure skills throughout their lifetimes. The interdisciplinary approach to programming has been successfully used in our educational system (Rainforth & York, 1987). We cannot afford to provide exemplary services to individuals solely in school settings or in segregated after-school programs. The instructional procedures that have been discussed in this article should be woven into the leisure/recreation support system network. Only when we collaborate and use these system-wide practices in home, school and community settings will it be possible for persons with severe multiple disabilities to experience meaningful, exciting, and successful lives through expanded leisure and social repertoires.

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