



THE SEVERELY HANDICAPPED COMMUNITY TRAINING PROJECT



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Issues Related

To

Community Integration

For

People With Severe Handicaps

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Issues Related To
Community Integration
For People
With
Severe Handicaps

Severely Handicapped Community Training Project

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AN ANALYSIS OF THE BENEFITS WHICH
RESULT FROM DEINSTITUTIONALIZATION OF
DEVELOPMENTALLY DISABLED INDIVIDUALS

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People with severe handicaps should live in their communities. Whether an analysis is made on a philosophical, political, economic, or programmatic basis, the conclusion is the same. Community integration is preferable in every respect. Philosophically, the only defensible theoretical position is that mentally retarded people should be prepared for and given access to culturally fulfilling lives in their local communities. Politically, it is clear that citizens with handicaps have the same rights as all other citizens in our society. These rights include access to educational programs in their home communities which prepare them for community living and access to supportive living environments which allow them to participate fully as citizens. Economically, community-based programs offer the most effective long-range alternative for providing cost-effective services needed by mentally retarded citizens. Programmatically, fully integrated community-based programs, when compared to segregated educational and residential settings, possess much greater potential for the total habilitation of severely handicapped individuals. Total habilitation includes maximum development of social and economic independence, social integration, and self-direction.

This paper describes the advantages of community-based programming for persons with severe handicaps. Evidence from four sources will be presented that makes it clear that community-based services are inherently superior to institutional models. The first section describes the philosophical imperative for deinstitutionalization. The second section describes attempts to guarantee severely handicapped individuals the right to habilitation and service in the least restrictive setting. The next

section describes the economic costs of community versus institutional services. The final section compares the two service delivery models in terms of their effectiveness in preparing persons with severe handicaps for comprehensive community integration.

The Necessity for Community Services

Community-based services for mentally retarded people have been proclaimed as morally and empirically superior to institutional services by numerous professionals (Baker, Seltzer, & Seltzer, 1977; Biklen, 1979; Blatt, Flynn, & Nitsch, 1980; Scheerenberger, 1976). Institution, as the term is used here, refers to facilities in which people with handicaps are congregated in environments larger than the normal family unit. Institutions limit the opportunity for residents to interact with all citizens within society, and conduct all activities of daily life under one roof, one campus, or one administrative entity (Wolfensberger, 1972). The destructive consequences of these facilities are widely known.

1. By definition, institutions segregate individuals from the rest of society (Biklen, 1979).
2. Institutions unconsciously promote human abuse and neglect (Blatt, 1973; Blatt & Kaplan, 1966).
3. Institutions foster routinization and regimentation (Blatt, Ozolins, & McNally, 1978).
4. Institutions are the most expensive form of service for mentally retarded individuals (Ferleger & Boyd, 1979).

5. Institutions deny autonomy to individuals, place unneeded restrictions on them, and contain a general lack of effective developmental service (Flynn & Nitsch, 1980; Wolfensberger, 1972).

This body of evidence on the negative effects of institutions is overwhelming. It is difficult to defend them on any ideological or moral basis. Recent legal decisions have begun to jeopardize their very existence.

Philosophical Justification

The vast majority of persons with severe handicaps currently living in Institutions are not there because of a programmatic need related to their disability (Menolascino & McGee, 1981). They are not there because they cannot walk. They are not there because they engage in self-injurious behavior. They are not there because they cannot talk. People with disabilities of equal severity as those found in all institutional populations are being served in communities throughout the country (Menolascino, McGee, & Casey, 1982). They live in institutions because of the way we as a society feel about people labeled severely handicapped.

The technical barriers to deinstitutionalization are large, but they **are** not insurmountable. Federal program incentives currently promote **continual** institutional services (Laski, 1980), but these incentives can be **redirected**. The phasing out of institutional programs is a monstrous administrative problem, but it can be resolved. Adequate community support **systems** can be established to eliminate the "dumping" of individuals into

local communities. Yet, to do all these things would not achieve community integration. The principal barrier to deinstitutionalization is philosophical. The real question to be resolved is: Should mentally retarded people be allowed to live with their fellow human beings?

Abundant evidence makes it clear that community-based services for mentally retarded people are preferable to institutional alternatives. Yet, professionals continue to debate whether or not deinstitutionalization will work. The real question is how can it work best. A social policy that segregates mentally retarded people for their protection, for our protection, or for supposed treatment should be immediately abandoned.

Political/Social Justification

The first court case that dealt with confinement of mentally retarded people in institutions, Wyatt vs. Stickney (1972), culminated in a decision declaring that mentally retarded individuals have a right to receive treatment in the least restrictive environment possible. No one could be admitted to the institution unless it was shown to be the least restrictive habilitation setting possible for that individual. The residents were also found to have a right to treatment within the institution. To deny these individuals adequate treatment was tantamount to incarcerating individuals who had committed no crime.

In New York Association for Retarded Citizens vs. Rockefeller (1975), the court found that Willowbrook had violated its residents' rights to treatment and freedom from harm. The court ordered that less restrictive alternatives should be made available to these individuals. Sufficient

community services were to be created so that Willowbrook's population would be significantly reduced over a six year period.

One of the most significant decisions rendered to date occurred in Halderman vs. Pennhurst (1977). Citing the 8th and 14th amendments to the Constitution, the 1978 Developmental Disabilities Assistance Act (DDAA), and Section 504 of the 1973 Rehabilitation Act, the court ruled that the very existence of Pennhurst, an institution, violated the Constitution and state and federal law. The court held that retarded people placed in state Institutions have a right to adequate care and freedom from discriminatory separation from nonretarded people, and further held that Pennhurst was Inherently incapable of providing that care. The court ordered that state and county governments must provide suitable community living arrangements and services to all residents within Pennhurst on a permanent basis. Admissions and commitments were ordered to cease, so that no person would ever again suffer from the institution's illegal practices. This conclusion was based upon the testimony of experts that none of the 1,200 people at Pennhurst needed to be there for reasons related to habilitation.

On December 13, 1979, the U.S. Third Circuit Court of Appeals upheld the substance of the original Pennhurst ruling and order. It stated that **the DDAA** established the right of all mentally retarded persons to receive habilitation they need in the least restrictive environment. The Third Circuit permitted the continued use of the institution during the phasing out **period**, but only if it was dramatically improved and only if a case-by-case **review** were to identify specific individuals for whom Pennhurst was

considered the only appropriate setting. Community living arrangements were ordered for all other residents.

However, on April 20, 1981, the U.S. Supreme Court ruled in the case of Pennhurst State School vs. Halderman that the DDAA is too vague to require states to provide services and habilitation in the least restrictive setting. It made its ruling on very narrow grounds: the intent of Congress when it wrote Section 6010 of the Act. Section 6010 states that mentally retarded persons "have a right to appropriate treatment, services, and habilitation" in "the setting that is least restrictive of ... personal liberty." The Court held that the intent of Congress in writing this section was too ambiguous to create substantive due process rights for retarded people and create affirmative obligations on the states. It concluded then that if Congress places conditions on states pertaining to the use of federal monies, Congress must express those conditions clearly so that states can decide whether or not to accept those funds. Justice Kohnquist wrote that Congress had only expressed a preference for habilitation in the least restrictive environment, and that Congress intended to encourage rather than mandate the provision of better services for disabled people.

The Supreme Court decision in Pennhurst was primarily a matter of statutory construction. It did not address constitutional claims to habilitation in the least restrictive environment or the intent of Section 504 to establish such a right. The Supreme Court recently began to address the habilitation issue in Youngblood vs. Romeo (1982). In Romeo, the

Court unanimously held that institutionalized retarded persons have "constitutionally protected liberty rights which require the state to provide minimally adequate training to insure their safety and freedom from restraint" (p. 4684). These rights are based upon the Due Process Clause of the Fourteenth Amendment (Turnbull, 1982). Although not specifying precise standards for adequate training, the Court clearly stated that residents have rights beyond those to food, clothing, shelter, or medical services. These rights include training related to personal safety and freedom from undue bodily restraints.

The Romeo decision did not specifically address the least restrictive environment issue or in any way overrule its decision in Pennhurst. Romeo may be most significant in its effect upon recent position statements which **advocate** providing only "enriched custodial care" to many institutionalized severely handicapped persons and denying them the training necessary **for** successful community integration (Ajello, McLeod, Coleman, Eikenberry, & Browning, 1981; Ellis, Balla, Estes, Hollis, Isaacson, Orlando, Polk, **Barren**, & Seigel, 1978). The Romeo decision rejects the notions of enriched environment or custodial care (Menolascino, McGee, & Casey, 1982) **and** affirms a right to habilitation, defined as "training and the development of needed skills" (p. 4681). Although additional litigation in this **area** is inevitable, it appears that institutions can no longer deny their **obligation** to provide habilitation and training designed to prepare persons **with** severe handicaps for less restrictive settings.

Before leaving this area, the concerns of two groups which have expressed opposition to deinstitutionalization should be considered. These

groups include the natural parents of institutionalized individuals and community members.

Natural parents. The perspectives of parents who voice support for institutions are understandable. It would appear that these feelings arise not from satisfaction with the institution (Gollay, Freedman, Wyngaarden, & Kurtz, 1978) but rather from legitimate anxiety about 1) the possibility of creating a secure and permanent community care system; 2) the need for advocacy, monitoring, and possible guardianship to protect their children's rights once the parents are gone; 3) distrust of state government services; and 4) hostility of communities to taking back their retarded citizens (Ferleger & Boyd, 1979). No parents want the incarceration of their child in a stunting institution. Most would prefer a full life in open communities. It is the task of professionals and advocates to make it work.

Community members. In order to judge the effectiveness of community residential programs, the issue of community acceptance must be carefully examined. "Acceptance" is a term that has application at several different levels. Certainly, opposition to mentally retarded people living in the community takes active, vocal, and, on rare occasions, violent forms. Neighbors complain and sometimes organize formal opposition. Zoning restrictions are erroneously enforced (i.e., equating group homes for the retarded with halfway houses for criminal offenders or drug addicts). Group home sites in several states have actually been destroyed by violent actions. All these acts *are* examples of formal community opposition. Unfortunately, community resistance is sometimes effective. Many proposed

group homes fail to open and many others are forced to close as a result of community opposition.

Baker et al. (1977) found that 35 per cent of the community residences they surveyed reported some form of opposition prior to opening. The frequency of the opposition did not correlate significantly with either the size of the proposed facility or the retardation level of the residents. However, this opposition seems to wane over time. This is not surprising. People with severe handicaps make good neighbors. They are an asset to the community in which they live. However, only exposure to severely handicapped people and interaction between them and community members can lead to acceptance and integration. Seventy-seven per cent of the community residences surveyed reported that some formal community preparation was undertaken. A surprising finding was that facilities that attempted formal community preparation were more likely to receive opposition than those that did not. This may indicate community preparation efforts could be counter-productive or that those facilities anticipated the opposition and worked to minimize it.

But community acceptance means more than the mere absence of formal opposition. Full community integration requires acceptance at a person-to-person level. Severely handicapped people need friends. Independence sometimes may mean loneliness and isolation. Integration into the community only to work in segregated settings, go to school in segregated facilities, or worship in segregated congregations is contrary to the goals of the communitization movement and should not be allowed to occur. The supposed desire of retarded people to "be with their own kind" is a myth

that should be destroyed. Normalization is only complete when retarded individuals participate in all aspects of our integrated society.

Economic Justification

Comparing the relative costs of institutions and community-based residential facilities is an extremely difficult task (Heal, Sigelman, & Switzky, 1978; Landesman-Dwyer, 1981). Costs vary considerably from state to state and among various types of community-based programs (natural homes, foster homes, group homes, etc.). There is also a considerable difference in the amount and type of service provided by institutional and community-based programs. Many older institutions function much like "miniature cities" (Bensberg & Smith, 1984). Some facilities operate hospitals, utility plants, fire departments, and security forces. Community-based programs, on the other hand, rely much more heavily on generic services to meet the medical, vocational, educational, and recreational needs of residents. Given the complexities of accurately comparing relative costs, available evidence appears to indicate that if there is a difference between the two service delivery models, institutions are a more expensive mode of services (Landesman-Dwyer, 1981; Scheerenberger, 1981).

Based upon 1981 data, Scheerenberger (1982) reported that our country currently spends over 3.5 billion dollars annually to serve approximately 125,000 people in public residential facilities. Average per diem costs for the 282 facilities surveyed was \$77.99, with a range from \$25.61 to \$213.00. These figures exclude the tremendous amounts of money being spent on institution construction and renovation. In contrast, although based upon earlier data, Intagliata, Wilier, and Cooley (1979) reported per

diem costs in the group homes they studied ranging from \$25.40 to \$30.14. Significantly lower costs were reported for other community-based alternatives, including natural families (\$5.78 per day) and foster homes (\$8.58 per day).

Numerous other surveys (Baker et al., 1977; Gage, Fredericks, Baldwin, Moore, & Grove, 1978; Tempieman, Gage, & Fredericks, 1982) have reported that costs for community-based services are lower than, or roughly equivalent to, expenditures in public residential facilities. To date no credible study has determined community-based services to be a more expensive option. Baker et al. (1977) summarize the situation:

(The significant) short term cost of community residences is not only justifiable on humanistic grounds by the improved quality of life in these facilities but on economic grounds as well. Community residences have much higher resident turnover than institutions, with many residents moving on to self-sufficiency or to less costly alternatives (p. 205).

Unfortunately, much of the fiscal incentive for maintaining state hospitals rather than providing community-based services lies in the federal budget process. Public mental retardation institutions are eligible for Medicaid reimbursement as intermediate care facilities. The Medicaid reimbursement policy leads to maintenance of institutions for State fiscal reasons alone. It is essential that these funds be converted for community use, or that a separate community funding mechanism be developed. Society cannot insure community integration to mentally retarded

individuals while spending billions of dollars to needlessly warehouse unfortunate individuals.

Taylor and his colleagues (Taylor., McCord, & Searle, 1981) shed further light on misdirected federal policies which perpetuate the existence of institutions. By requiring states to devote significant financial resources to bring institutions into compliance with federal standards, the Intermediate Care Facility/Mental Retardation program almost forces states to emphasize large state hospitals over community living arrangements. Every state in the nation is engaging in major institutional construction and renovation. However, recent changes in the Title XIX regulations now permit the use of Medicaid funds to support alternatives to public institutions. The Medicaid Home and Community-Based Care Waiver Authority allows states to fund non-institutional services for persons with disabilities through the federal-state Medicaid program. Although the use of the Medicaid waiver may increase the cost of community-based services (Bensberg & Smith, 1984), the program may provide a stable funding base to encourage the development of community residential alternatives (McGregor, 1982). Where state and regional officials are committed to normalization and the rights of severely handicapped people, Medicaid monies can and are being used to develop appropriate community residential programs.

Deinstitutionalization has other, less obvious, economic complications. For example, the American Federation of State, County, and Municipal Employees (AFSCME) has 250,000 members who work in mental health and retardation centers throughout the country. Over 5,000 employees have actually lost their jobs from closures and phase downs. If present trends

continue, or even accelerate, many more may lose their jobs in the future (AFSCME, 1980). Clearly the interests of these people must be taken into consideration in planning systems of community living arrangements. The Developmental Disabilities Assistance Act (1978) requires that states to protect employees adversely affected by deinstitutionalization. State officials cannot ignore their employees in planning deinstitutionalization and developing community-based jobs. To do so would result in groups such as AFSCME becoming bitter enemies of the community movement and attempting to sabotage efforts to move individuals into less restrictive settings.

The motivation and impetus for the community living movement is not economic. Community residential alternatives are superior to institutional placement in all respects. However, it is important to note that community placements are not only the best alternatives for persons with service handicaps, they are also the most cost-effective. Costs in community-based group homes have generally been shown to be equal to or less than institutional expenditures. In addition, community alternatives may potentially result in significant long-term financial savings, since per diem costs of natural family and foster care placements are substantially less than those of other alternatives. Rather than utilize cost-effectiveness information to debate the correctness of community versus institutional programs, researchers and service providers must focus their efforts toward identifying factors that promote the effectiveness and economy of community residential alternatives.

Programatic Justification

The essential issues in the deinstitutionalization are philosophical and legal. Society is richer when all its members are accorded respect and dignity. To deny liberty to any member of our society denies the liberty of us all. In addition to these arguments, appropriate community-based residential settings possess inherently greater potential to enable severely handicapped persons to grow, develop, learn new skills, and direct their own lives. A powerful and growing body of evidence clearly indicates that persons with severe handicaps who leave institutions to reside in community settings immediately increase their ability to live independently and socially interact with other members of their community.

Aanes and Moen (1976) reported significant improvement in independent functioning, socialization, and language development among individuals moving to community residential settings. Fiorelli and Thurman (1979) found increases in self-help and recreation skills, and Kleinberg and Galligan (1983) found positive changes in domestic and language skills and personal responsibility. Another study (Thompson & Carey, 1980) focused on a group of women moving from an institution to a community home and discovered significant increases in domestic activity, social skills, and language development. Similar results have also been reported in studies investigating learning and development in young children (Gage et al., 1978) who have left restrictive institutional settings for the opportunities of community living.

Other researchers have used matched control comparison designs, comparing individuals placed into community settings with similar individuals

remaining in institutions, to investigate the advantages of community-based programs. Close (1977) compared eight individuals moved to a community residence with seven similar individuals and found significant gains in the areas of self-help and socialization by community residents. Schroeder and Henes (1979) studied 19 matched pairs of individuals and reported that community residents acquired vastly improved social and communication skills compared to those who remained in the institution. In the largest single study, Conroy, Efthimiou, and Lemanowicz (1982) studied 140 individuals, 70 of whom left Pennhurst to reside in the community. Fifty-four of the 70 matched pairs were individuals with severe handicaps. People remaining at Pennhurst showed no growth after two years, while community residents, especially severely handicapped individuals, displayed significant increases in adaptive behavior.

The results of the studies described above *are* not surprising. The real goals of deinstitutionalization and normalization are increased independence and community participation for mentally retarded people. Realizing this, it becomes obvious that the best way to achieve these goals is through community-based training programs. A person learns to live at home by living in a home. An individual cannot effectively learn to move freely about a community, use recreational opportunities, communicate and socialize with other citizens or make decisions regarding their own lives when living in a facility which, by definition, restricts their access to other individuals and the community at large while sacrificing personal decision-making for routinization and regimentation. The obstacles to the development of effective training programs that face professionals in

segregated institutional facilities are simply too large to overcome. Attempting to develop individualized training programs based upon environments which severely handicapped individuals will potentially encounter is impossible when institutions are preparing individuals to live in communities that may be hundreds of miles away. Similarly, opportunities to employ community-based training strategies and to effectively generalize any skills required are minimal in segregated residential and educational settings.

Community residential programs can serve severely and profoundly retarded individuals. Programs in Nebraska (ENCOR) and Michigan (Macombe-Oakland) are frequently cited in this regard (Biklen, 1979; Menolascino & McGee, 1981). But isolated exemplary programs such as these do not mean that all institutionalized people can move immediately into community-based programs. Adequate programs simply do not exist in many communities. The simple "dumping" of individuals into unprepared communities cannot be justified in any way. A tremendous gap exists between normalization theory and community service practices. Kleinberg and Galligan (1983) observe that in many of the studies demonstrating increases in adaptive behavior after community placement, the improvement tends to occur immediately after initial placement. Immediate improvement is often followed by a stabilization of acquired skills rather than continuous, incremental improvement. Certainly some community programs do a much better job of maximizing the potential of severely handicapped individuals than others. While major improvement in community programs are urgently needed, these settings

clearly provide the best opportunity for persons with severe handicaps to acquire the skills necessary to live active, fulfilling lives.

Conclusion

The continuing efforts to debate the "correctness" of the deinstitutionalization movement is inactive which no longer serves a useful purpose. **Parents**, professionals, and individuals with handicaps will continue to **lead** the way toward local and national policies directed toward the development of community-based programs. This process is inevitable. **Community-based** programs are right and just, they affirm the basic rights **guaranteed** to all Americans, they are cost-effective and they provide **severely** handicapped individuals a chance to lead full and satisfying **lives**. Our task is no longer to argue their basic merits. Instead, the **time** has come to devote our energies toward establishing and developing community programs which guarantee severely handicapped persons their **ultimate** role as friends, neighbors, and citizens.

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Deinstitutionalization of the
Severely and Profoundly Retarded:
Facts, Figures, and Misconceptions

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Running Head: Deinstitutionalization

Deinstitutionalization of the
Severely and Profoundly Retarded:
Facts, Figures, and Misconceptions

The severely and profoundly mentally retarded (SPMR) comprise less than 5% of the mentally retarded population (Scheerenberger, 1979), but this population constitutes 75 to 85% of all persons living in large institutions for the mentally retarded (Bruininks, Xudla, Hauber, Hill, & Wieck, 1981). Over 100,000 SPMR persons live in large public residential facilities (PRF's) and many more are in private and smaller government-supported facilities. Of the approximately 5,200 new admissions to institutions in 1979, 61% were SPMR and over 35% of these were school-aged (Scheerenberger, 1981). Over 61% of the SPMR residents in PRF's have major multiple handicapping conditions of a physical nature.

It has been estimated (Scheerenberger, 1981) that over 15% of the total institutionalized population is ready for community placement, but that less than half of these (7,850 persons) will be placed. The rate of placement from PRF's in 1979 was 8% lower than in the ten previous years, and most experts believe that the decrease in community placements is due to the fact that the majority of persons remaining in institutions **are** severely handicapped. Because of the current nature of institutional populations, our approach to deinstitutionalization and community integration of more severely handicapped persons has to change from the procedures followed previously (Blatt, 1981; Landesman-Dwyer & Sulzbacher, 1981; Larsen, 1977).

The purpose of this paper is to review the literature pertaining to

the deinstitutionalization of SPMR persons in order to pinpoint factors that have particularly affected this process, and to provide some suggestions for future research and planning.

Defining Deinstitutionalization

The National Association of Superintendents of Public Residential Facilities set forth a three-process operational definition of deinstitutionalization in 1974. This three-stage process encompassed: (a) the prevention of admissions to institutions by finding appropriate community placement; (b) the return to the community of all residents who have been rehabilitated in institutional training programs; and (c) the maintenance of responsive residential environments that protect human rights and contribute to the expedient return of individuals to normal community living (Braddock, 1977; Larsen, 1977). Deinstitutionalization has also come to mean the "depopulation of institutions," or the simple movement of residents out of mental hospitals or institutions regardless of their placement (Scheerenberger, 1979). The term has been used to refer to care-giving systems that stress noninstitutional alternatives and the reduction of institutional dependence (Zachrach, 1976). For the purposes of this paper, the term will be used primarily to refer to the three-stage process of moving persons from institutions into appropriate community placements.

An Historical Perspective on the Depopulation of Institutions

For only a brief period in history prior to 1850, institutionalization was viewed as a wise solution to the problem of mental retardation, and at no time has more than 3% of the mentally retarded population resided in institutions (Gollay, Freedman, Wyngaarden, & Kurtz, 1973; Scheerenberger, 1981). As early as 1846, right after Gugenbuhl founded the first segregated

institution for the mentally retarded, Sequin wrote that placement of the mentally retarded in institutions was inappropriate (Heal, Sigelman, & Switzky, 1978). Though institutions were designed originally to facilitate a return to normal living situations, by the early 1900's they had become warehouses for any person deemed harmful to society. Even during this period around 6% of the institutionalized population was being discharged annually, which compares to the 102 discharged annually during the 1970's.

Care of the mentally retarded and mentally ill was custodial in nature from the 1800's to the 1960's, with the living alternatives including primarily the natural home or the institution (Braddock, 1977; Halpern, Sackett, Binner, & Mohr, 1980; Landesman-Dwyer & Sulzbacher, 1981). During the 1950's it was discovered that mildly and moderately retarded persons could learn to do much more than had been thought possible. Parent and professional groups were demanding more school and community services, while at the same time institutions began more intensive training and discharge efforts. Significant reductions in institutional populations began around 1955 with the widespread introduction of tranquilizing drugs (Halpern et al., 1980) and the advent of the "decentralization" concept in mental health care systems (Scheerenberger, 1979).

By the 1960's it was becoming apparent that the cost of maintaining large state institutions was enormous. At that time smaller institutions began to be built on a regional basis. From 1960 to 1970 state facilities doubled in number while the average number of residents per facility dropped from 1516 to 982 (Scheerenberger, 1981). Although there were approximately 23,000 more mentally retarded persons in institutions in 1970 than in 1960, many people were being discharged during the 1960's. In 1963 President Kennedy proposed to revamp the mental health care system

and several Congressional acts authorized federal funding of deinstitutionalization plans. It was in 1967 that the number of institutionalized persons actually declined. From that point on, tens of thousands of persons have been released from state-run facilities to a variety of living alternatives (Bruininks, et al., 1981). It was also during the late 1960's that researchers became interested in the adjustment to community life of deinstitutionalized retarded persons (Zigler & Zalla, 1977).

The decade of the 1970's truly marked the growth of community alternatives to deinstitutionalization, beginning with President Nixon's prediction of returning one-third of the population of retarded persons to community settings by 1981 (Bruininks et al., 1981). Not until this decade, with the landmark cases of P.A.R.C. v. Pennsylvania and Wyatt v. Stickney, and federal legislation such as P.L. 94-142, did our attention focus on the return of severely and profoundly retarded persons to community settings (Scheerenberger, 1981). By the early 1970's many of the mildly and moderately retarded residents had been placed, and the emphasis changed to improved programming and placement of the more severely retarded. The remainder of this paper will deal with the issues related to the movement of this population from institutions.

The Need for Continued Deinstitutionalization

Since institutionalization began there have been repeated accusations of the inhumane conditions that exist in most of the larger facilities (Heal, et al., 1978). The public became particularly aware of institutional conditions during the 1960's (Blatt, 1973; Gollay, et al., 1978); and it was during this decade that the philosophy of care and education of the mentally retarded changed dramatically. Most ideological changes and the

basis of deinstitutionalization can be attributed the principle of normalization (Nirje, 1970; Wofensberger, 1972). This concept refers to helping developmentally disabled persons obtain an existence as close to normal as possible, by making available to them conditions which approximate or equal the norms and patterns of society (Braddock, 1977). This principle implies that all persons live in the least restrictive environment possible, with institutions being the most restrictive of all environments. Many other later educational philosophies have been based on the principles of "normalization" and "least restrictive alternatives," such as age-appropriate, functional training of the severely handicapped according to the "criterion of ultimate functioning" (Brown, Branston, Hamre-Nietupski, Pumpian, Certo, & Gruenewald, 1976). Besides the popular ideology that institutionalization is not appropriate for any citizen, there is no research indicating that this kind of existence is optimal for anyone regardless of the degree of impairment (Blatt, 1981). In fact, there is a large body of evidence indicating the negative effects of institutionalization (Edgerton & Bercovici, 1976; Heal et al., 1978).

Secondly, there is a contingent of respected psychologists and special educators and related professionals who now espouse the idea that some SPMR persons are "ineducable" (Kauffman, 1981) and can be best served with custodial care (Ellis, Zalla, Estes, Warren Meyers, Hollis, Isaacson, Palk, & Siegel, 1981). However, not even these professionals have condoned the conditions that exist in today's institutions. While the opposition is also vocal and well respected (Zaer, 1981; Menolascino & McGee, 1981; Sontag, Certo, & Sutton, 1979), the current health of the economy has lent support to the debate.

There are also financial arguments for ridding society of our current

institutional system. It has been estimated that the annual cost of maintaining public institutions is over \$10 billion. Research on the economics of deinstitutionalization shows that in nearly all cases community living alternatives are equal to or less expensive than institutions (Braddock, 1981; Landesman-Dwyer, 1981; Templeton, Gage, & Fredericks, 1982). Other arguments for deinstitutionalization of the SPMR most commonly cited in the literature (Landesman-Dwyer & Sulzbacher, 1981) include: (a) the longer, healthier lifespans of retarded persons due to medical advances; (b) the active involvement of families and advocacy groups; and (c) the decreased bed capacities of old, dilapidated public residential facilities.

Review of the Literature

The importance of studying deinstitutionalization from many perspectives in order to formulate and execute effective policies and procedures has been emphasized by many experts in the field (Braddock, 1977). Hobbs (1975) nonetheless indicated that, although there is extensive research on single facets of this process, the general knowledge base for decision-making is inadequate to support current trends. Unfortunately, because few studies have involved many SPMR persons, it is unclear how this population is adjusting to the deinstitutionalization process (Landesman-Dwyer & Sulzbacher, 1981). This section of the paper takes a look at the research on deinstitutionalization of the SPMR and how this group has adjusted to other living arrangements.

Regardless of the population being examined, most deinstitutionalization research can be categorized into a few topical areas. Much of the literature has dealt with the qualitative and, more often, the quantitative study of community adjustment of mildly and moderately retarded individuals.

Even the first studies, conducted by Fernald in 1919 and Wallace in 1918, indicated that most deinstitutionalized persons could adjust to community living (Heal et al., 1978; Lakin, Bruininks, & Sigford, 1981). As early as 1924, in a massive study of 500 mentally retarded persons, Fernald found that only 8% of these persons could not adjust to community living (Heal et al., 1978). Other areas of study have included: (a) characteristics of community residential facilities (CRT's); (b) barriers to deinstitutionalization according to care-givers and families; and (c) the cost-effectiveness of the various living alternatives.

Characteristics of Community Residential Alternatives

Perhaps the most valuable investigations of CRT's in this country have been conducted by Baker, Seltzer, and Seltzer (1974), Bruininks, Hauber, and Kudla (1979), O'Connor (1976), Landesman-Dwyer, Berkson, and Romer (1979), and Landesman-Dwyer, Sackett, and Kleinman (1980). The types of CRT's surveyed in these studies included various sized group homes, small facilities serving under 30 people, nursing homes, foster families, sheltered villages, workshop dormitories, and semi-independent apartments. The kinds of facilities not included were unlicensed nursing, boarding, or foster homes, single-family homes providing services to a relative, and independent arrangements without supervisory personnel. Although natural families have not been included in most deinstitutionalization studies, it has been estimated that anywhere from 10 to 40% of persons discharged from institutions return to their families (Intagliata, Siller, & Wicks, 1981).

Scheerenberger's (1981) analysis indicated that by 1979 there were about 4,500 community residences other than natural or foster homes which

housed about 84,000 mentally retarded persons. There were close to 2,000 foster homes, in which over 5,000 retarded persons resided. Approximately 28% of mentally retarded persons lived in facilities of 10 or fewer persons, while over one-half lived in places serving 31 or more residents. Slightly more males than females had been placed in CRF's (55.3 v. 44.7%). About 62% of the residents were above 22 years of age, and 36% were between the ages of 5 and 21. In foster homes, 69% were over the age of 21. About 52% came from PRF's, 31% came from natural, and 17% moved from other CRF's. Of new admissions, 42% came from PRF's. Specific percentages of discharges to CRF's according to level of mental retardation were not indicated in any report. Nearly 65% of these residents were classified as mildly or moderately retarded, while 32% were classified as SPMR.

It is important to note that all studies cited the increasing numbers of SFMR and multihandicapped persons being referred to CRF's. As Mayeda and Sutter (1981) noted, PRF clients now considered prime candidates for community placement are significantly lower-functioning than those previously placed. Lack of skills in those still remaining in institutions has slowed down the rate of deinstitutionalization and certainly will influence future CRF placements.

The Economics of Deinstitutionalization

Comparative studies of residential services costs tend to be extremely difficult to conduct and analyze (Braddock, 1977; Heal & Laidlow, 1980; Heal et al., 1978; Landesman-Dwyer, 1981). It has been particularly tedious to compare PRF and CRF service costs because the entire array of services (or lack of services in many cases) has not been analyzed in any single comparative study. As well, differential costs of services

according to disability level or type of placement have not been reported. Considering all of the above, the reader should interpret the following data cautiously.

It has been estimated that the total yearly operating budget for PRF's in this country is well over \$1.9 billion. Other estimates show that the cost of serving the 2 million mentally retarded persons in institutions is over \$2.8 billion yearly (Blatt, 1981). Scheerenberger (1981) reported that the average per diem cost was \$60.10 per resident, with a range of \$23.51 to \$197.76. Baker et al., (1974) reported that in 1973 the average daily budget of their CRF respondents was approximately \$12.38 which compared to PRF costs of \$24.42 per day during that year. Heal et al., (1978) cited several other studies and concluded that the range of costs for total services in CRF's was probably somewhere between \$26 and \$40, which compared equally to the range of costs in PRF's. A cost comparison of CRF's and PRF's conducted by Gage, Fredericks, Baldwin, Moore, and Grove (1977) revealed that group home and institutional costs were very comparable, with homes with house parents costing \$998 per month per resident, and institutional costs running about \$918 per resident per month. Though based on a very small example, a more recent analysis (Templeman, Gage, & Fredericks, 1982) estimated group home cost to be \$355 /month, foster home care to be \$400/month and institutional care to be \$1,200/month. But when clients were deinstitutionalized and placed temporarily in a habilitative group home and then transferred to their own home or to a foster home a 57% savings in state payment "of institutional costs could be realized per child annually, even though the group home cost was higher than the institutional cost.

Intagliata, Wilder, and Cooley (1979) reported that group homes cost per resident ranged from \$9,255 to \$11,100 per year, family or foster care cost \$3,130, and natural home care cost \$2,108. All of these were cheaper than the annual cost of \$14,630 per resident of institutions.

Additional cost studies were reviewed by Braddock (1931) and others by Heal and Laidlow (1980) the noteworthy, but not always consistent, findings included: (a) a large annual cost savings (\$2,300 to 55,000) when clients returned to their natural homes; (b) a very small savings associated with community residence (\$400 per year) versus more favorable benefit-cost ratios for community placement (ranging between 1.52 to 1 and 11.86 to 1); (c) a shifting of responsibility for post-institutional services from the state to local and federal budgets making cost calculations difficult.

Operating institutions is "big business" in this country (Blatt, 1981; Braddock, 1977). Thousands of people benefit from the improvement and construction programs currently going in the larger, older state institutions. Many professionals with Ph.D.'s and M.D.'s vie for the \$40,000 to \$60,000 directorships. Hundreds of thousands of direct-care staff members and their unions support the maintenance of large, self-contained facilities so that the power of the working force can be centralized. Financial reports show that the operating costs of institutions go up as beds are emptied, and in many cases administrators actively seek to keep institutional capacity at maximum levels to defray expenses (Bachrach, 1976; Halpern et al., 1980; Heal et al., 1978). As Heal et al., (1978) reported, the movement from PRF's of higher functioning clients, who have always been a large "cheap labor pool," has caused a major

expenditure to institutions in that more expensive laborers (aides, janitors, cooks, etc.) have to be hired. Thus, it appears that much of the pressure to keep institutions intact comes from within, and as Burton Blatt (1981) so aptly stated, "Either we find a way to remove the overly attractive rewards that some people seek and find in this business . . . or otherwise little will change" (p. 236).

Professionals working in community service systems have reported most often that the main barrier to successful community placement is economics (Braddock, 1977; Gollay, 1981; Heal et al., 1978; McCarver & Craig, 1974). For example, the major source of income for most deinstitutionalized people is supplemental security income (SSI). Often there are stipulations or delays in receiving this money once a person leaves an institution (Halpern et al., 1980). Institutions suffer when a person is discharged because part of the SSI benefit, which went directly to the upkeep of the physical plant, is lost. Medicaid/Medicare funding has also been a source of frustration for retarded persons in the community. Usually clients have to meet certain multiple criteria other than mental disability to receive such funds (Bruininks, et al., 1981), and the more non-normalized and hospital-like a facility is, the greater the chance that funding will be provided. Unfortunately as revealed recently by Taylor, McCord & Searl (1981) Title XIX funds are used by some states to develop small institutions rather than normalized group homes because federal officials have failed to develop clear policies regarding the use of ICR/MR. funds for community settings.

In summary, there is probably less research concerning the economics of deinstitutionalization than any other area, but there is ample evidence

to indicate that economic issues are perhaps the most powerful controlling variables in this process. Although many experts have predicted that in the long run even community based settings meant for the most severely handicapped will be no more expensive than institutions, this factor continues to influence the deinstitutionalization process (Lafsen, 1977). Finally, although researchers have concluded that current funding patterns and federal policies within institutions and community facilities must be changed, concrete and specific alternative plans have not been formulated (Blatt, 1981; Braddock, 1977; Gollay, 1981; Heal et al., 1978, Landesman-Dwyer, 1981). All that we really know at this point is that CRF's seem to be no more expensive than PRF's.

Barriers to Deinstitutionalization

This area of research is practically inseparable from findings related to the community adjustment of deinstitutionalized persons, and in most cases similar methodologies have been used (Gollay, 1981; Heal et al., 1978; McCarver & Craig, 1974). For purposes of this paper, the distinguishing feature of this research was the fact that results were primarily obtained from surveys of parents and guardians, government personnel, and professionals from both CRF's and PRF's. An overriding concern in these studies is that rarely has information been obtained from the deinstitutionalized people themselves due to the problems associated with collecting this kind of qualitative data (Wynngaarden, 1981). This is particularly the case with SPMR persons who frequently experience communication difficulties.

Institutional administrators from across the country have identified several common barriers to community placement (Scheerenberger, 1979; 1981).

Alternative living situations for mildly and moderately retarded residents were noted as being adequate, while those for more severely retarded persons were rated as grossly inadequate. Educational programs and family support and medical services for less severely retarded persons were rated as fair, while such, services for severely retarded persons were judged inadequate. Behavior management services for all levels of retardation were considered inadequate. These administrators also reported that while severity of retardation affected placement, individual barriers to placement were equally problematic across levels. Behavior problems, lack of ambulation and self-care skills, ongoing medical problems, and lack of social skills were ranked in that order as the greatest client characteristics deterring placement. Physical aggression in all forms, which is most common in mildly retarded residents, was rated as the major cause of reinstitutionalization, while sexual misconduct, noisiness, and stereotypic behaviors were not seen as being particularly problematic. It is interesting that these latter problems are most often associated with more severely retarded persons.

Many studies of placement barriers involved the opinions of community personnel (Braddock, 1977; Gollay et al., 1978; Halpern et al., 1980; Zigler & Balla, 1977). As previously mentioned, funding is viewed as the most significant barrier to successful deinstitutionalization. Closely ranked as other barriers in all studies were lack of training in institutional rehabilitation programs, lack of community and family support services, negative attitudes toward the handicapped, lack of trained staff available for hiring in CRF's, and lack of vocational opportunities.

One of the most recent and thorough national surveys was conducted over a period of three years by Bruininks et al. (1981). Funding, lack of comprehensive community services such as respite care and transportation, and inability to recruit trained personnel were ranked as the greatest problems. This study also emphasized the concern over the misuse of nursing homes, and the growing need for new types of programs for more severely retarded persons. It is important to note that in almost all studies of variables affecting community adjustment, families of CRF clients and CRT professionals rank lack of services as more of a problem than behavior problems or any other client characteristics (Heal, et al., 1978). This finding has great implications for future research, which needs to focus more closely on setting characteristics, service provision, and the interaction of these variables with client characteristics.

One of the only studies to look systematically at barriers to the deinstitutionalization of SPMR persons was conducted by Gollary et al. (1978). In this study the families or primary care-givers of 440 deinstitutionalized persons across the country were interviewed (106 of whom were SPMR). It was found that the previous institutional experiences of the SPMR persons were much different from those of the mildly and moderately retarded, in that the SPMR were less likely to have received any structured habilitation programs geared toward deinstitutionalization. Families of SPMR persons indicated less satisfaction with the institutional programs than families of the mildly and moderately retarded deinstitutionalized persons indicated. Although the SPMR persons were in more restrictive community settings, the type of placement for these persons was quite similar to that for others.

The SPMR clients were also less likely to have paying jobs, and virtually all those receiving some income were in sheltered settings. Most, however, were in day activity centers. This problem has been discussed elsewhere (Bellamy, Sheehan, Horner, & Boles, 1980) in terms of the lack of vocational opportunity for deinstitutionalized SPMR persons despite the discrepant research results and accepted community service objectives. Care-givers also indicated the lack of participation of the more severely retarded in social and leisure activities requiring independence, such as going to movies, restaurants, and stores. However, the SPMR clients were perceived as having less difficulty than less retarded clients in personal relationships, including romantic involvements.

Finally, families of SPMR clients felt on the whole that their children were adapting well to community living. Perceptions of negative attitudes on the part of others in the community were not as great as among families of mildly and moderately retarded clients. Whether this is due to varying expectations for the SPMR population or to some behavioral tendencies that facilitate adjustment, the results of Gollay's work are still quite encouraging. In the least, this study provides evidence that while the problems of some deinstitutionalized SPMR clients may be different than those of the less handicapped, they are no greater.

Individual Characteristics Affecting Community Adjustments

Much of the deinstitutionalization research focuses upon the client variables influencing adjustment outside the institution (Heal et al., 1978). The methodology used in most of this research can be criticized on at least one account. The major criticism is the exclusion of severely and profoundly

retarded persons. Secondly, the primary criterion used to measure successful placement has been length of stay in the community before reinstitutionalization (Wilier & Intagliata, 1982). As Lakin, et al., (1981) emphasized, there really is little known about the quality of life experienced in CRF's. In one exception Schalock Harper, and Carver, (1981) examined the quality of life experienced in primarily mildly retarded persons five years after deinstitutionalization. Interviews with these clients revealed them to be characterized as low income and lonely, despite frequent use of the community. Thirdly, most studies have involved post hoc analysis of data, such as looking at adaptive behavior tests administered before release into the community. The interactional effects between client and setting characteristics cannot be analyzed with this approach (Heal et al., 1978). Finally, few studies are longitudinal in nature.

So single variable has been identified as a definite predictor of community adjustment among mildly and moderately retarded persons. Those factors most often cited in over 175 published studies reviewed by McCarver and Craig (1974) included personal appearance, psychomotor skills, social skills, and vocational skills. There have been findings in both positive and negative directions regarding age, IQ, and physical handicaps. In most cases, however, positive indicators of adjustment have not been a function of intellectual level (Balla, Butterfield, & Zigler, 1974; Nihira & Nihira, 1975). Other researchers (Gollay et al., 1978; Heal et al., 1978) have concluded that although IQ should not be a criterion for release, it should be considered in matching the client to a residential setting. Unfortunately, this process has only been utilized in a few cases (Schalock & Harper, 1973). Interesting but conflicting findings exist regarding institutional training programs and resultant success in the community. One of the other leading

predictors of success found in recent studies has been participation in active recreational activities, both as players and as spectators (Gollay, 1981; Landesman-Dwyer & Sulzbacher, 1981).

Although the literature contains several anecdotal reports of the community adjustment of deinstitutionalized SPMR persons, very few data-based studies have been conducted (Council for Exceptional Children, 1976; Heal et al., 1978; McCarver & Craig, 1974; Neufeld, 1977). A few early studies (Delp & Lorenz, 1953; Robinson & Robinson, 1976) conducted before communities began providing support services to deinstitutionalized SPMR persons showed that most of these persons adapted and remained in the community. There was some evidence collected during the 1960's (Kidd, 1979) that also showed that severely mentally retarded adults were capable of living on a long-term basis in community settings.

Schalock and his colleagues (Schalock & Harper, 1978; Schalock, Harper & Carver, 1981) have investigated longitudinally the factors influencing success in community placements. Although the majority of the clients **were** mildly to moderately retarded the most significant predictors of success **were** skills in personal maintenance, communication, community integration, clothing care and use, and food preparation. However when clients **demonstrated** bizarre behavior, nutritional problems or poor home up-keep, they **were** more likely to be returned to the institutional setting.

Iatagliata and Wilier (1982) examined a group of 301 deinstitutionalized clients, 38% of whom were SPMR. The intent of their investigation **was** to discover whether any differences existed in clients living continuously in the community versus those who had failed in previous community placements though were currently successfully placed in either

a group home or in family-care. Family-care was defined as a private home owned and operated by a family who provided a residence for an average of 3 retarded persons. The main predictor of those who returned to the institution versus those who did not was the level of maladaptive behavior; IQ or level of retardation was not a relevant characteristic.

What effects does community placement have upon the SPMR person?

As an attempt to evaluate the court-ordered deinstitutionalization of Pennhurst, Conroy, Efthimiou and Lemanowicz (Note 1) studied 140 clients, 70 of whom were deinstitutionalized and matched to 70, who remained at Pennhurst. Of the 70 pairs, 38 were severely retarded and 16 profoundly retarded, while only 2 pair were mildly retarded and 14 moderately retarded. Matching variables included sex, level of retardation, years spent at Pennhurst, self-care skills, age and IQ. Adaptive and maladaptive behavior were measured before placement and two years later, so that developmental growth between the two groups could be compared. Only the 70 clients who moved into the community displayed significant growth in adaptive behavior, while their matched clients demonstrated no progress. Changes in maladaptive behavior favored the "movers", though the change was nonsignificant. Level of retardation, sex and county in which the placement was made were all found to influence gains in adaptive behavior. First, the lowest functioning clients benefitted the most from relocation in terms of behavioral development. In addition day program hours received in the community was positively related to growth, while the PASS score (a measure of normalization) of a client's prior instructional ward was negatively correlated to progress made upon relocation. In other words, consistent with the work of Zalla and Zigler (1975), the "poorer" the ward a client is deinstitutionalized from the greater will be his or her

growth upon discharge to the community. Males made more gains than females, but they also tended to be lower functioning, thus confounding two factors. Finally though the number is too small to clearly analyze, gains were greater by clients placed in some counties than by clients placed in others. This later finding may be related to sex, level of functioning and varying patterns of services. The findings of Conroy et al., (1981) add more support to a growing body of literature finding significant gains in deinstitutionalized retarded persons regardless of their level of functioning (Aames & Moen, 1976; Close, 1977; Eyman, Demaine & Lei, 1979; Fiorelli & Thurman, 1979; Schroeder & Henes, 1978), thus lending more urgency to the mandate for community placement.

Landesman-Dwyer and Sulzbacher (1981) conducted one of the only systematic studies of the adjustment of SPMR persons to community living. However, this study must be interpreted cautiously because it dealt with a limited geographical area; it did not examine the characteristics of various settings **and** their relationships to individual characteristics and was not longitudinal **in** nature. The results, nonetheless, are important because they provided: (a) information on the characteristics of over 2,5000 SPMR persons remaining in the community, (b) some comparisons between persons remaining in CRF's **and** those reinstitutionalized; and (c) comparisons between SPMR persons and **more** mildly retarded clients in community settings. Results indicated that **SPMR** clients comprised 40% of Washington state's developmentally disabled **population**. Consistent with other reports about 70% of these persons **lived** in state institutions, 14% were in nursing homes, 9% were in group or boarding homes, and 7% were in private homes. Sixty-six percent of the SPMR persons in CRF's had been previously institutionalized, and only these **clients** were included in the comparison analyses of persons living in CRF's and PRF's.

The first phase of the study compared demographic and behavioral characteristics of SPMR persons in community and institutional settings. The institutional population on the average was 11 years younger and significantly more disabled in terms of level of retardation, motor functioning, hearing, self-help skills, and academic abilities. Although institutionalized residents showed significantly higher rates of behavior problems than those in the community, the magnitude of differences was small. Contrary to earlier studies there was no major difference between the groups in physical aggression behavior problems or in extreme withdrawal behaviors.

Another phase of the study examined traits of about 200 residents (56% of whom were SPMR) who had been reinstitutionalized. Nearly equal numbers of males and females were returned and the majority of returnees (51%) came from nursing homes. These settings reported essentially no prior experience with SPMR persons, a fact that is likely to influence their high return rate. About 21% returned from their own family homes, 19% returned from group homes, and 4% came from foster homes. The reasons most often cited for return of SPMR persons were physical harm to others, destruction of objects, and medical problems that could not be handled by a care-giver.

In two other related studies reported in Landesman-Dwyer and Saluzbacher (1981) 240 residents (13% SPMR) in 23 group homes across the state of Washington were observed and the behavioral differences according to level of retardation were analyzed. The primary differences were in social behaviors. For example, SPMR clients spent more idle time and interacted less with others than mildly and moderately retarded clients. Compared to mildly

retarded clients, the SPMR group spent only 7.9% of its observed time in social interactions. Other behavioral differences were noted in the lower **amount** of time the SPMR spent in household chores and away from the residence. While the extent to which idle time leads to inappropriate behavior **and** thus readmission to an institution for SPMR persons is unknown, it is likely to be a factor. Training in leisure activities and social interaction has had some success with SPMR persons and may serve to reduce the return rate as well as increase the client's quality of life.

Setting and Care-giver Characteristics

It has been written that the type of placement and the readiness of **the** community to adapt to the deinstitutionalized client may be more important than client characteristics (Heal et al., 1978; McCarver & Craig, 1974). This becomes particularly important when characteristics of the persons working in the settings are considered (Sutter & Mazedo, 1981). Some preliminary evidence seems to indicate that successful placement may be **enhanced** if placement settings are selected on the basis of a point-by-point **match** between the criteria of client acceptability of the personnel in the **setting** and behavioral characteristics of the client. The factual information available to date is that the most frequently used placements for clients are nursing homes and then group homes. We also know that nursing homes have the highest rate of reinstitutionalization, may lack **prior** successful experience with this group (Landesman-Dwyer & Sulzbacher, 1981, and that they have been condemned as institutional care-giving systems (Gollay et al., 1978).

There has been little emphasis on the placement of formerly institutionalized SPMR persons in foster or natural homes. These settings need **be** utilized more often in the future because: (a) this placement is

generally more normalizing than group homes, typically involving a "nuclear" family with a smaller number of people residing in the home; (b) foster home placements have been more successful for lower-functioning retarded persons than for mildly and moderately retarded clients (Intagliata, Crosby, & Neider, 1981; Sternlicht, 1978); and (c) cost analyses have shown this kind of placement to be cheaper than group homes (Intagliata et al., 1979).

Training for Deinstitutionalization

Bjaanes, Butler, and Keller (1981) wrote that the adjustment potential of the severely impaired is unknown because, regardless of where they reside, these persons do not receive the proper kind of training. In a large-scale study of over 2,000 mentally retarded clients from PRF's and CRF's in California, Bjaanes et al., (1981) found that the higher the level of functioning the greater the likelihood of structured training. This was found across all skill domains and settings. Moreover, it was discovered that regardless of functional level of the clients, more formal training occurred in institutional-settings than in CRF's. This is particularly discouraging in view of the fact that learning usually does not generalize across settings.

There is ample evidence showing which skills are most related to successful community living. These include: vocational skills, independent mobility, self-care skills including maintaining a neat personal appearance, and social skills, especially the ability to participate in active recreational activities (Heal et al., 1978; McCarver & Craig, 1974; Schalock & Harper, 1978; Schalock, Harper, & Carver, 1981). Because most recently recreational skills have been cited as particularly deficient in SPMR persons who have been reinstitutionalized (Gollay, 1981;

Landesman-Dwyer, & Sulzbacher, 1981), such skills deserve much more emphasis in future training and research programs. Studies have shown repeatedly that successful community adjustment is not necessarily related to IQ. With the teaching technology that now exists and the demonstrated behavioral potential of the severely handicapped, there appears to be little reason that SPMR clients cannot be taught the skills needed to live outside institutions.

Legal Issues

Turabull and Turabull (1977) reported several legal issues (or in some cases, matters that need to be legalized) which currently are deterring the deinstitutionalization process. First and foremost, residents of PRF's have no legal say-so in getting in or out of such places. This particularly affects the SPMR client, who is most often deemed legally incompetent due to his or her lack of communication or lack of training. The admissions and release process and the related legal assumption in favor of parental custody and parental veto of deinstitutionalization need to be critically examined. Other issues affecting community placement and discussed by Turnbull and Turnbull (1977) include: (a) professional accountability of decision-makers and trainers as being responsible for the successful placement of residents, (b) legal protection for the deinstitutionalized client in the form of monetary subsidies; and (c) the right to readmit voluntarily when placement is not successful.

Community Attitudes

Although research on community integrations has yielded contradictory results, generally it appears that liberals, younger couples, blacks, and frequent church-goers are most favorable toward movement of the mentally retarded into neighborhood settings (Heal et al., 1978). However there

is evidence that positive attitudes of the public and their actual behavior do not correlate. For example, as the location of a group home comes closer to a respondent's home, the attitude becomes more negative (Kastner, Repucci, & Pezzoli, 1979).

While some research has indicated that mildly retarded persons are perceived more favorably than the severely retarded (Siperstein & Gottlieb, 1976), the studies on community integration have not differentiated public attitude toward various levels of retardation (Gottlieb & Siperstein, 1975). Thus there is not evidence that the public is more opposed to the integration of the severely handicapped into their neighborhoods than to the mildly handicapped. It is particularly encouraging that families of severely retarded citizens residing in CRF's view the community at large as being friendly, accepting, and helpful (Gollay et al., 1978).

Conclusions and Recommendations

The literature reviewed indicated that the severely and profoundly retarded have similar success adjusting to community living after deinstitutionalization as do the mildly and moderately mentally retarded. In fact, the problems most often cited for returning mildly retarded to institutions, such as stealing, inappropriate sexual behavior, and physical violence, do not seem to be as prevalent in the more severely retarded. As well, families of severely retarded persons living in community settings appear to be more content with services and community acceptance than families of mildly and moderately retarded clients. Even the numbers of persons being reinsitutionalized do not appear to be significantly higher for the severely retarded than for those less handicapped. Finally, regardless of level of disability there is no report in the literature of a community

alternative being significantly more expensive than institutionalization. For these reasons, one can be encouraged about the prospects for future deinstitutionalization of the severely handicapped.

On the other hand, there are facts and figures which are rather disheartening. First, the SPMR client is not receiving the training necessary for successful community adjustment. This is the case across all skill areas and in all settings. Second, there is presently no rationale for placing SPMR clients in particular settings. Nursing homes, which in many cases have no better conditions: than institutions, are the most frequent placement site for SPMR persons. Nursing homes also have more returnees to institutions than any other sites. The most normalized and least expensive placement possibilities, foster and natural homes, are used very rarely for SPMR clients, although there is some evidence that these may be most appropriate for this population. Finally, there are thousands of SPMR persons institutionalized every year with very few coming back into the community. This population may not be adjusting to community life simply because it is not being discharged from institutions.

Consequently, the most effective means of deinstitutionalization of the SPMR population, as with any group, may be to block admission to the institution. This may be the only way to prevent the SPMR client from fighting a losing contest with many lesser handicapped institutionalized persons who vie for limited placements in the community. Secondly, nursing homes and other institution-like settings should be used with extreme caution if at all, since they may be just as non-normalized in every respect as the institution, and there is a high probability of reinstitutionalization. Finally, either communities must be equipped to take institutionalized persons of all disability levels regardless of entry-level abilities or

institutions must significantly strengthen their community training programs. Unfortunately history has shown that institutions are self-perpetuating systems that take in people and money but rarely return trained clients ready to face life in the "real world." It appears that there can be no meaningful deinstitutionalization until institutionalization is stopped. Proof of this lies in the current decreasing rate of discharges and the dramatic increase in readmissions since 1978 (Lakin, Krantz, Bruininks, Clumpner, & Hill, 1982).

On a more objective note, research on deinstitutionalization has almost totally excluded systematic observation of the SPMR population. Those studies examining this population have suffered from the same methodological problems as the research on the mildly and moderately handicapped. These problems revolve around (a) the lack of longitudinal, objective analyses of service, placement, and client attributes, (b) the relationships between these three variables; and (c) the lack of qualitative assessment of community adjustment with independent variables other than length of stay in a CRF.

Ultimately deinstitutionalization research must address the quality of life of SPMR persons both in community placements and institutions. Other specific recommendations for future study include:

1. The continued validation of procedures for determining and teaching the functional skills critical for survival in the specific community environments to which a SPMR client is discharged.
2. More attention given to the training of leisure/recreation skills in SPMR persons since the lack of these and other skills discriminates between those successfully placed in the 'community and those who are readmitted to the institution (Gollay, 1981; Landesman-Dwyer 5. Sulzacher, 1981);

3. The design of behavioral observation tools for measuring adjustment to community life to augment subjective reports of families and professionals **and** "length of stay" data (Lakin et al., 1981);

4. The establishment of training programs for school and community personnel and families to prevent institutionalization and reduce the failure of SPMR persons in community placement;

5. Longitudinal comparisons of community placements and services available to SPMR clients to determine factors responsible for successful functioning in the community other than client characteristics (Heal et al., 1978).

In summary, we do not yet know the potential of the severely and profoundly retarded for living in normalized integrated community settings. What we can assert, however, is that this population, when given the opportunity, has been about as successful as other deinstitutionalized groups. Thus it becomes difficult to justify detention of any person in an institution for the mentally retarded.

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COMMUNITY TRAINING:
A MODEL FOR PREVENTING INSTITUTIONALIZATION OF
SEVERELY HANDICAPPED CITIZENS

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Community Training: A Model for Preventing Institutionalization
of Severely Handicapped Citizens

During the past 10 years, there has been a serious move to help institutionalized mentally retarded and mentally ill people reenter the community, or in many cases, enter the community for the first time. This process has been called deinstitutionalization (Wolfensberger, 1972), and has been frequently controversial. There has not always been a consensus among professionals as to the merits of "deinstitutionalizing" mentally disabled individuals, especially those with more severe behavior and learning handicaps (e.g., Novak and Heal, 1981). A major argument advanced by those in favor of institutionalization has been that the community is not "ready" for severely handicapped people and that facilities, services and resources are not available. Opponents of deinstitutionalization suggest that members of the community and also parents/guardians of institutionalized severely handicapped citizens are more comfortable when the severely handicapped remain in residential facilities.

Although there have been substantial efforts at attempting to ascertain what the predictive variables are that lead to positive community adjustment by individuals who have been deinstitutionalized (McCarver and Craig, 1974; Sigelman, Novak, Heal and Switzky, 1981), somewhat surprisingly, few have systematically evaluated the components for preventing institutionalization for severely handicapped community members (Schutz, Vogelsberg, and Rusch, 1981). Indeed, it logically follows that if a community can be "prepared" to serve, relate to, and interact with its severely handicapped members who have never become institutionalized, then the community should be better suited to meet the needs of its newly deinstitutionalized severely

handicapped citizens. The emphasis for so long appears to have been almost exclusively on preparing the disabled individual to live in the community; there is an equally great need to train the community, especially significant forces in the community. It would be helpful to determine the major components and/or dimensions in a model for preventing institutionalization through community training.

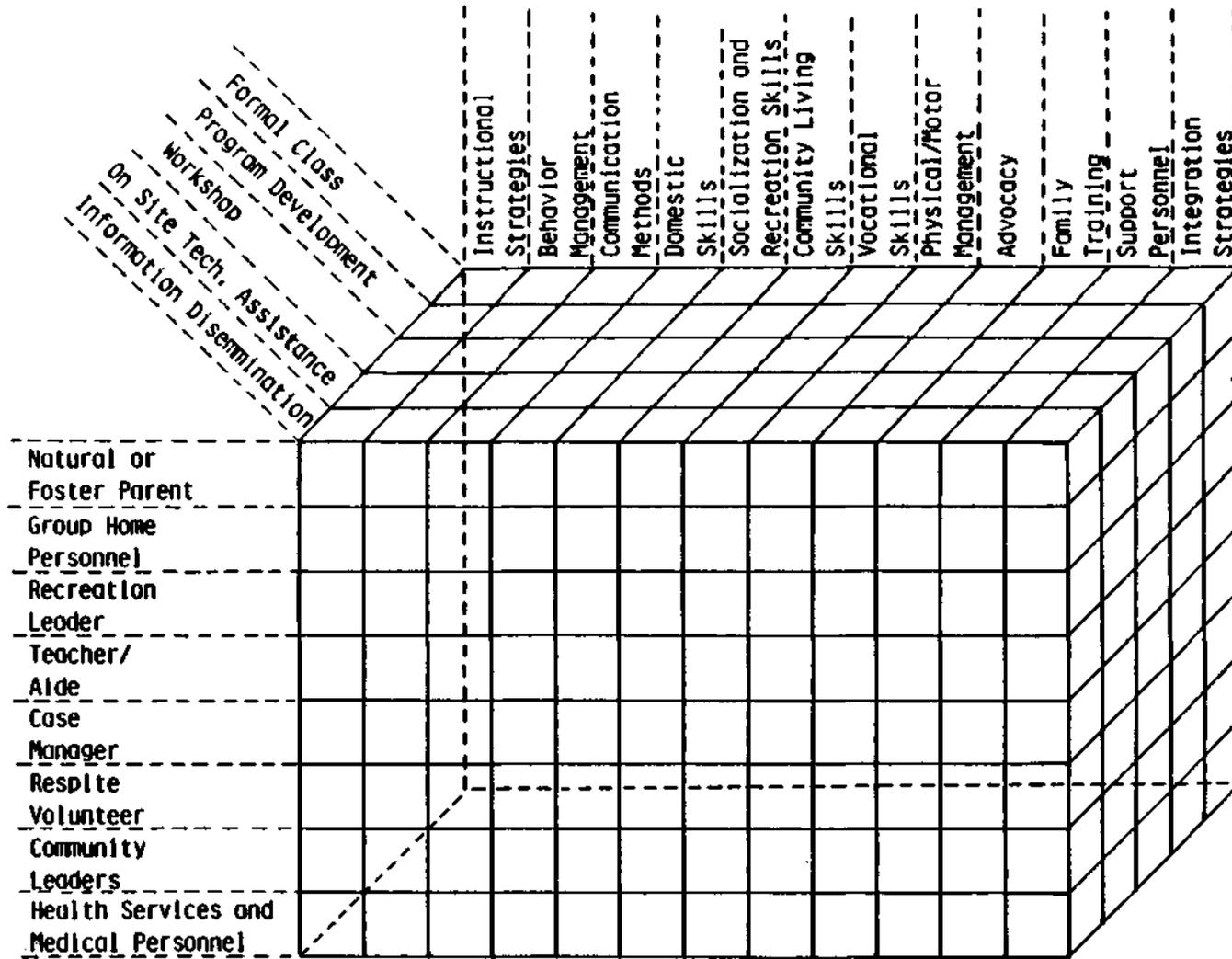
Therefore, the purpose of the present paper is to describe the development of a training system which facilitates community preparation and readiness for relating to an interacting with severely handicapped persons. In this paper we will delineate the major functions of a viable community training program. We make the assumption that local education agencies and community service boards can work cooperatively to fully utilize available resources and minimize duplicative effort. The final section of this paper will outline how this model could be organized and implemented utilizing the resources typically available in most communities. The specific model described herein is based on the efforts of The Severely Handicapped Community Training Project, a program funded through a contract from the U. S. Department of Education.

A Three Dimensional Model of Community Training

In reviewing the major aspects of how to prevent institutionalization through establishing a community training network, it becomes apparent that there are at least three different dimensions which must be considered.

- These are:
- (1) the target audience or group in the community to be addressed;
 - (2) the content or type of information which must be presented; and
 - (3) the format or manner in which the content is best presented.

FIGURE I



A MODEL FOR COMMUNITY TRAINING

The target audience, for example, might be one single parent struggling to maintain her 17-year old severely physically handicapped daughter at home. On the other hand, it might include a group of 12-15 city recreation workers who recently have been reassigned to work with handicapped children. Still another group might be 200 members of the local Kiwanis Club who are potential employers of severely handicapped young adults.

The second dimension of content represents our best efforts at establishing 12 strands of information which directly impinge upon and hopefully subsume all variables which affect retention of the individual in a community setting. These strands are described in more detail below and can be found in Figure 1, along with the other two dimensions of the model.

The format in which the content is delivered is the third important dimension of a community training model. Information can be imparted through workshops, individualized technical assistance, overall program development, formal classes, and material dissemination i.e., newsletters, brochures. What is required is the appropriate matching of content and format to the target audience.

Target Audience

The figure on the following page shows the groups of people in a given community which might receive training. Obviously, the range and number of people could be much larger than indicated in Figure 1. Briefly, we will review the implications of providing training services to the individuals listed in the figure.

Parents

Parents of severely handicapped individuals often seek training in ways to advocate for their son/daughter and also in ways to manage their behavior. Trained parents can help teachers and other direct service providers in

following through on instructional programs. Their expectations are usually more realistic, and often they are more likely to search for positive community alternatives rather than institutionalization. These factors hold true for both foster and natural parents.

Group Home and Supervised Apartment Personnel

Regretably there are still very few, in relation to the need, small community living arrangements for severely handicapped people in most parts of the country. The development of these arrangements and subsequent training of personnel to staff them will be one of the single biggest contributors to preventing institutionalization. The willingness on the part of group home staff to serve the severely handicapped as well as ability to train and manage behavior is crucial in community retention.

Recreation Leaders

The ability of parks and recreation staff to provide age-appropriate activities for severely handicapped individuals will play a key role in community integration. Recreational activities which take place in small groups, within neighborhood community settings, and with the opportunity for nonhandicapped to participate are important. Unfortunately, professionals in this are not trained to provide such experiences to the severely handicapped. A viable training system will meet this need.

Teacher and Aide

In order to provide the severely handicapped individual with the necessary life skills to function in the community, the teacher and aide must be extremely competent. It is essential that life skills including vocational, community, domestic, and recreation skills be taught. These should be functional, that is, of high utility and need to the individual.

Teachers must receive preservice and inservice training which provides the skills to devise age-appropriate, functional curricula that can be instructed in natural community environments. If a trained teacher cannot succeed, others in the community will lose confidence in severely handicapped citizens' potential for community living.

Case Manager

The case manager usually operates from a local community services board and helps coordinate services for clients. He or she also usually initially receives referrals and requests for assistance. This function is obviously critical to any viable training system since for client needs to be effectively met, the referrals to the case manager must be coordinated. Usually the case manager can provide insight as to the type of content as well as format of delivery.

Respite Care Personnel and Volunteers

When providing necessary support for parents and families of severely handicapped citizens, respite care programs will play a significant role. Volunteers can be trained to serve as emergency caretakers and help relieve strain on family members during periods of crisis or to provide respite on a routine basis. Respite care programs can be both center-based or home delivered. Either way, however, respite care professionals and volunteers require training in how to manage and treat severely handicapped individuals.

Community Leaders

- Community leaders are business people, service providers, church leaders, merchants, educators, and politicians. Such individuals tend to provide direction and support for community activities and must be

informed if we expect them to socially accept and include the severely handicapped. For too long these key individuals have been ignored or asked only to contribute money. Specific training efforts must be targeted toward this group if they are to develop positive attitudes and assert their influence in integrating the severely handicapped into normalized community activities.

Health Service and Medical Personnel

Certainly physicians, nurses, dentists, therapists, and other professionals representing the allied health fields are crucial in preventing institutionalization. The pediatrician, for example, will probably be the first person to communicate the presence of a handicapping condition to parents of a newborn or infant. This doctor's knowledge and influence can be tremendous. The acceptance and attitude of the family dentist will also affect the willingness of the family to retain the severely handicapped child in the community. The medical expertise which these professionals bring must be expanded to relate to other important educational and community factors which can prevent the child from leaving the community.

Training Content

The 12 training strands described here represent an effort on our part to identify major factors which are prevalent in preventing institutionalization. These are factors which have been identified with two points in mind. First, these strands are responsive to a training system within the **context** of inservice to parents and professionals. Other factors which go **beyond** the control of an inservice effort such as lack of space in a group home **may** at least temporarily precipitate institutionalization regardless of I training efforts. Second, these strands may be viewed primarily **as** long term preventative measures as opposed to crisis-intervention means. A brief description of each follows below.

Instructional Strategies

Instructional strategies pertain to how to teach severely handicapped individuals to be more competent. Strategies which have been most effective are based on applied behavior analysis and can be used in all community, school, and home settings. Most target audience groups in the community will need to have some degree of sophistication in instructional strategies.

Behavior Management Techniques

Unfortunately, a major defining characteristic of many severely handicapped individuals is inappropriate or excessive negative behaviors. Behavior management techniques can be used to prevent maladaptive behavior as well as solve inappropriate social behaviors. Normalizing and minimally intrusive child management techniques can be taught to community professionals and parents and will help reduce management problems.

Communication Methods

Another defining characteristic of many severely handicapped citizens is an inability to communicate effectively. Some individuals are totally noncommunicative while others have partial expressive and receptive communication problems. Hence in order to survive in an heterogeneous community environment, it is essential that severely handicapped citizens have a means for communicating, whether it be with pictures, gestures, signs, or a combination of verbalizations and one or more of the above.

Socialization and Recreation Skills

The ability to recreate independently and in an age-appropriate manner will also facilitate community retention. Since many severely handicapped citizens do not constructively utilize their leisure time, the likelihood of institutionalization is increased. Attaining community based recreation skills can be an ideal facilitator of friendships with nonhandicapped

people as well as a means of reducing inappropriate behavior. Parents, teachers, city recreation leaders, and adult service providers must be shown how to teach appropriate recreational skills to the severely handicapped.

Community Living Skills

If one is to actively participate in community activities then skills such as orientation and mobility (travel), shopping, doing one's laundry, and use of public facilities must be learned. These can be difficult skills to learn because they are not easily taught in a school classroom, but rather need to be trained in natural community environments. Yet, in order to truly improve the individual's quality of life, community living skills must be taught and it should be the responsibility of educators, parents, and the larger community to see that such skills are acquired.

Vocational Skills

Remunerative work is necessary for severely handicapped citizens to contribute as full citizens of a community. Although competitive employment is most desirable, sheltered enclaves or employment may be necessary for some individuals. Intensive skill training is essential along with advocacy on the part of staff to help the individual gain competence and acceptance in a job.

Physical/Motor Management

The ability to move independently or with as little assistance as **possible** becomes paramount in the community. Parents, teachers, and employers must **be** trained in ways to help many severely handicapped people become more **independently** mobile whether it be through motor skills training, the design and **use** of electro-mechanical devices, or architectural modifications. Occupational and physical therapists must share their knowledge in this area rather **than** place emphasis on isolated one to one therapy sessions.

Advocacy

Advocacy refers to how community members can help severely handicapped individuals and also how severely handicapped persons (and their families) can help themselves obtain all the rights and privileges they are due as citizens. The ability to know one's rights and to articulate a position on behalf of a client is an increasingly important skill to have as educational and social services are cut. It is also essential for professionals to know how to work with the media, politicians, and government and education administrators in such a way as to positively portray severely handicapped citizens and effectively communicate their needs.

Family Training

Parents and other family members must receive information on ways to manage and care for their severely handicapped son or daughter. In addition to specific management techniques, parental counseling and support groups should be provided in order to help the family maintain a high level of involvement. Without this form of service availability, family members may become frustrated, anxious, and resentful toward those professionals who are supposed to be helping the handicapped member of their family.

Support Personnel

Support personnel include professionals such as recreation leaders, language therapists, physical and occupational therapists, and nurses. Each of these disciplines view services to the severely handicapped from their own perspective. Therefore, training must be individualized and targeted to these professionals in language which they relate to and from trainers who have similar backgrounds and hence credibility. The issue here is that all persons recognize the importance of transdisciplinary programming for the severely handicapped.

Integration Strategies

In order to help severely handicapped citizens become integrated into regular schools and communities, it is wise not to leave this process to chance. Training of regular educators, groups of non-handicapped children and co-workers, and employers, or any other group which impacts the smooth integration and thus acceptance of severely handicapped individuals is necessary.

Format for Delivering Content

There are numerous ways to deliver the content to the target audiences described above. The forms of delivery we have chosen are described below.

Workshops

Workshops are formal presentations to groups of professionals and parents. This format primarily involves oral and audio-visual presentations supplemented by demonstrations, structural participation, and hand-outs (annotated bibliographies, instructional program ideas, material lists, etc). Workshops can be conducted on a short-term basis within a period of two hours, two days, or two weeks. Some involve follow-up in the form of on-site technical assistance. Workshops on any of the 12 training strands (integration strategies, behavior management, etc.) can, of course, be provided to all target audiences whenever there is sufficient demand.

Formal Classes

Formal classes may be arranged through local universities to meet the needs of a group of professionals or parents who want extensive information on curriculum and instruction on the severely handicapped. The classes may be offered for graduate credit and will normally meet at regularly scheduled periods. Most will involve practical work in a variety of settings. Lectures, discussion, many audio-visual presentations, and demonstrations will

be the format of the class.

Program Development

Program development involves one or more professionals consulting with an individual or agency in an effort to design, implement, and/or evaluate school, home, work, or community programs for the severely handicapped. This involves, typically, more of an overall program modification or systems change.

On-Site Technical Assistance

On-site technical assistance is an individualized form of inservice in which one or more staff members goes into the working environment of a service receiver (i.e., home, school, day treatment facility, group home) to provide assistance. This may involve solving a particular problem such as implementing a toilet training program. This type of "one-shot" effort is aimed at specific problem solving.

Resource Dissemination

Newsletters may be written, edited, and disseminated on a local, state, and/or regional basis at least three times yearly. Newsletters may deal with topical areas such as communication methods for the nonambulatory profoundly mentally retarded, integration strategies for public school programs or behavior management.

Other types of resources which may be disseminated include annotated bibliographies, material lists, and research and program information. Such resources can be compiled across the main program strands, and then distributed on a regular basis and upon request to any of the target audiences.

Local Level Implementation

It is appropriate to conclude by addressing how an inservice training model such as this could be implemented within any community given the

resources that typically exist. The community resources which exist in most localities are as follows:

1. Public School Special Education Services
2. Mental Retardation Services
3. Associations for Retarded Citizens
4. Parent Organizations
5. Rehabilitative Services
6. Public Residential Facilities
7. College of University (Special Education
or Psychology Department)
8. Cerebral Palsy Organizations
9. State Department of Education
10. State Department of Mental Health/Retardation
11. Welfare Department
12. Private Schools/Services
13. Interested Medical Specialists
14. Other funding agencies (e.g., United Giver's Fund, etc).
or Handicapped Advocacy Organizations

Cooperative Efforts

The quality or levels of service offered by each of these resources will, of course, vary greatly from community to community. However, each resource most likely has at least one paid staff member with the exception of parent organizations. Given this fact, one selected individual from each of these groups could serve on a volunteer board for a community training network. The major purpose of the board would be to provide training to the various community factions which come in contact with the handicapped and may directly or indirectly influence the acceptance and integration of these individuals in the community. With cooperative work **and** appropriate division of labor, there would certainly exist enough time **and** expertise from the board to provide low cost training to specific **target** audiences in the community. Currently, most community agencies or **resources** provide periodic training or public relations presentations. what we are suggesting here is simply to consolidate and fortify efforts in a **cooperative** manner.

Leadership

Forming a cooperative training network with agencies of diverse interests may be difficult to initiate. The success of such an endeavor will depend upon the commitment and organizing efforts of one or more persons in a leadership capacity. In a given community, this leadership may arise from one of the resource services which assumes primary responsibility for the severely handicapped. Examination of the listing above shows that the resources numbered 1 through 7 generally provide direct services on a daily basis to handicapped persons while the remaining services assume less responsibility for direct training and care-taking. Thus, the leadership for organizing and implementing a community training network as described herein should come from an individual(s) within one of the first seven groups listed above. These groups are primarily responsible for the successful integration of the handicapped in the community.

Communicating Information

The training network should meet regularly and develop a needs assessment survey to establish the most pressing needs of the various community factions who come into contact with the severely handicapped currently or in the future. A series of monthly workshops or training sessions should be established to approach these needs. All resources or individuals who volunteered for the training network should be utilized to maintain their participation and interest.

Referral forms should be developed and distributed to identify individual or group technical assistance needs. An elected chairperson of the training network should examine each referral and determine which resources within the network could best provide the requested technical assistance.

Improved Transitional Planning

The cooperative efforts of a variety of agencies bound together to provide community training will have far reaching impact on improving the understanding and acceptance of handicapped citizens but it may have added, unexpected impact on the agencies themselves. That is, the cooperative training efforts clearly may lead to improved transitional planning and communication among the agencies providing direct and indirect services to the handicapped.

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INTEGRATION OF HANDICAPPED STUDENTS
INTO SCHOOLS

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Description and Rationale of Integrative Experiences

The Education for All Handicapped Children Act (P.L. 94-142) requires that all children have access to a free appropriate public education in the least restrictive setting. The concept of least restrictive setting remains elusive for many students due to disagreements among professionals regarding the boundaries of such settings. From the perspective of normalization (Wolfensberger, 1972), the least restrictive setting would be one offering the "normal" range of opportunities and experiences to which children of a given age have access, providing the experiences do not impede the handicapped child's educational goals (Brinker & Thorpe, 1984). Unfortunately, confusion still remains on whether the least restrictive setting clause of P.L. 94-142 implies the integration of handicapped with non-handicapped children (Meyers, MacMillan, & Yoshida, 1975). This confusion has resulted in a large number of complaints to the U.S. Department of Education, Special Education Programs, concerning the least restrictive environment issue (U.S.O.E., 1982).

it has been noted that special educators and the public often consider **the** concept of least restrictive environment (LRE) for students with **severe** handicaps to deal with physical placement alone (Aloia, 1978; **Donder** & York, 1984; Kenowitz, Zwiebel, & Edgar, 1978). The more desirable **application** of the LRE concept includes social as well as physical integration opportunities (Bricker, 1978; Guralnick, 1976; Schutz, Williams, **Iverson**, & Duncan, 1984; Snyder, Apolloni, & Cooke, 1976). Brown, Nietup-**sfct**, and Hamre-Nietupski (1976) define the least restrictive environment

for students with severe handicaps to include both placement in age-appropriate public schools and a maximization of interactions between students with handicaps and their nonhandicapped peers.

An expanded definition of least restrictive environment has been referred to as mainstreaming (Kaufman, Gottlieb, Agard, & Kukic, 1975). Mainstreaming implies the physical, social, and educational integration of handicapped and nonhandicapped children (Brinker & Thorpe, 1984). Handicapped children are not only physically grouped with nonhandicapped peers, but have ample opportunities to interact with one another and to share the same educational context. Accommodations may be made within the educational goals and processes for the handicapped children, though instructional activities will be delivered in with those for nonhandicapped peers.

Whether referred to as integration (Bricker, Bruder, & Bailey, 1982; Brown, et al., 1976; Donder & York, 1984), or mainstreaming (Brinker & Thorpe, 1984; Kaufman, Gottlieb, Agard, & Kukic, 1975), the application of least restrictive environment, which provides opportunities for handicapped students to be educated with nonhandicapped peers, has additional appeal beyond P.L. 94-142 requirements. In-depth rationales for providing integrated educational services are discussed elsewhere (cf., Bricker, 1978; Brinker, 1984; Schutz, Williams, Iverson, & Duncan, 1984; Stainback & Stainback, in preparation). Briefly, the arguments for integration revolve around legal-legislative, social-ethical and psycho-educational considerations. The legal-legislative argument stresses the solid

statutory and judicial bases for the elimination of discriminatory treatment of disabled individuals (Gilhool & Stuttman, 1978). Besides P.L. 94-142, Section 504 of the Rehabilitation Act requires that services for handicapped persons be delivered in the least restrictive setting. Handicapped persons are now legally entitled to access to all aspects of the public domain. The social-ethical argument points to the deleterious effects on the individual, the family, and the community of isolating or segregating the handicapped person (Apolloni & Cooke, 1978; Brown, Branston, Hamre-Nietupski, Johnson, Wilcox, & Gruenewald, 1979; Gorham, Jardins, Page, Rettis & Scheiber, 1975; Stainback & Stainback, 1981). The practice of segregating handicapped individuals has fostered and maintained counter-productive attitudes toward those who do not fit the general expectations of normality (Bricker, Bruder, & Bailey, 1982). The final argument, psycho-educational, is by far the most complex and has its roots **in** a theoretical perspective of learning. The perspective was developed by Piaget (1952) and has been adopted by many early educators (e.g., Bricker & Bricker, 1976; Bricker & Dow, 1981; Weikart, 1972).

According to Piaget's perspective on learning, the interaction between **a** child's existing schemes or action patterns and environmental events **leads** to progressively more complex behavioral patterns, or the **construction** of more advanced levels of cognitive organization (Uzgiris, 1976). It would be reasonable to conclude that environments which **challenge** children by demanding adaptations and problem-solving will **produce more** learning than environments that do not challenge children to **assimilate or** accommodate new responses into his/her repertoire.

Combining children with behavioral diversity—strengths and disabilities that vary—would appear to provide an optimal environment to maximize learning and growth. The inclusion of nonhandicapped peers also offers the handicapped child a more balanced view of the world. Additionally, observation of nonhandicapped children provides teaching staff with a view of the typical child that can be easily distorted when interacting exclusively with a disabled population.

Another developmental concept that supports the educational benefits of integration is imitation. As a learning mechanism, imitation is not fully understood (Parton, 1976), but the imitation of human models, and, in particular, the effective modeling of peers has been observed in preschool children (Eckerman, Whatley, & Kutz, 1975). Peer modeling appears to be effective in promoting behavioral change in mildly handicapped children (O'Connor, 1969, 1972; Ross, 1970; Ross & Ross, 1972), as well as in moderately and severely handicapped children (Berkowitz, 1968; Talkington, Hall, & Altman, 1973; Whalen & Henker, 1969, 1971). Specifically, instructional strategies based on peer imitation can be a useful means of increasing language skills (Cooke, Cooke, & Apolloni, 1978; Guralnick, 1976), social behavior (Csapo, 1972; Devoney, Guralnick, & Rubin, 1974), material use skills (Apolloni, Cooke, & Cooke, 1977; Cooke et al., 1978) and instructional efficiency in group teaching situations (Biberdorf & Pear, 1977). In addition, behaviors acquired through peer imitation appear to generalize to settings in which there is little active instruction by adults (Guralnick, 1976; Nordquist, 1978; Strain, Cooke, & Apolloni, 1976).

However appealing the rationale for integration of the handicapped, the practice has not had widespread adoption by special educators in the field. Segregation still exists as special education classrooms continue to be housed in segregated facilities and segregated wings in public schools. Unfortunately, the labeling of special education students into categories such as severely, multiply, trainable and educationally handicapped seems to facilitate placement of students into segregated instructional units.

The educational integration of severely handicapped students transcends the issue of regular school versus special, segregated school placement (Schutz, Williams, Iverson, & Duncan, 1984). While physical integration should be present before other types of integration, both social integration and instructional education should be a goal for all students. Each will be discussed separately.

Physical Integration

Physical integration is the easiest to achieve. Thomason and Arkell (1980) have provided a model for educating severely handicapped students in **the** least restrictive environment. The model recommends that school districts disperse clusters of classes for severely handicapped students **throughout** the district's schools, and, to eliminate segregated wings **and/or** floors in these public schools, administrators should disperse **classrooms** throughout the school building next to classrooms of nonhandicapped **peers** of the same chronological age. The optimal application of **physical integration** would be situations in which a handicapped student is

placed with nonhandicapped peers. These situations can be orchestrated to include such opportunities as having lockers next to each other, using the cafeteria, halls, buses, and outdoor facilities together, and sharing instruction within art, music and gym classes, to name just a few examples.

The successful inclusion of severely handicapped students in educational environments with their nonhandicapped peers depends, to a considerable degree, upon the extent to which students and school personnel have been prepared for the experience (Stetson, 1984). While other factors such as the chronological age of the nonhandicapped students, building accessibility, and the number of classrooms within the school serving nonhandicapped students must be considered before implementing physical integration opportunities (Hamre-Nietupski, Nietupski, Stainback & Stainback, 1984), the receptability of school staff and nonhandicapped students is a factor which cannot be overlooked. Special educators need to be aware of the attitudes of those in general education and help facilitate the acceptance of the handicapped students accordingly.

It has been recommended that teachers and students alike should be prepared before being exposed to handicapped students on a daily basis (Donaldson, 1980, Hamre-Nietupski, Nietupski, Stainback & Stainback, 1984). While research has documented the improvement in attitudes of nonhandicapped students as a function of their exposure to the handicapped (Brinker & Thorpe, 1984; McHale & Simeonsson, 1980; Voeltz, 1980), information and sensitization sessions can be provided for nonhandicapped students and

staff as a means of influencing attitudes prior to instituting physical interactions. Both parents and school administrators should be included in these efforts.

One example of an Information/sensitization curriculum for educating nonhandicapped students about severely handicapped students has been developed by Stainback and Stainback (in preparation). These authors have organized their curriculum into two components: classroom instruction and guided experiences. The classroom instruction includes teaching students to recognize similarities between handicapped students and nonhandicapped students, helping students to understand differences between the handicapped and nonhandicapped, and, finally, how to deal with the differences. This component is designed to alleviate the fear students may have towards those who differ from them. This fear often interferes with the nonhandicapped students' ability to accept the handicapped (Cummings, 1974).

The second component of this curriculum encompasses guided experiences **with** the handicapped. The goal of this component is to allow the nonhandicapped students to use the information and knowledge they have gained about **the** handicapped. The experiences should be structured to reinforce positive attitudes towards the handicapped. There are a variety of ways this **can** be accomplished, including joining classrooms for the handicapped and **nonhandicapped** during special activities such as holidays and birthdays and **arranging** combined daily activities such as lunch, school assemblies, and **recess**.

Though this section focused on preparing nonhandicapped students for physical integration, two points should be noted. First, this type of

preparation should be implemented with other groups such as school administrators, teachers, and parents of both handicapped and nonhandicapped students. Secondly, we should keep in mind that physical integration is but the first step toward implementing a comprehensive program of social and instructional integration for all students. As such, we should recognize the need to incorporate information and experiences about handicapped individuals into all teacher training programs and all school curricula. If nonhandicapped students have the opportunity to be educated with handicapped students, they will be better prepared to interact with them in a variety of integrated community environments (Brown, et al., 1979).

Social Integration

Research suggests that physical integration alone will not guarantee social interaction between handicapped and nonhandicapped persons (Fredericks, Baldwin, Grove, Moore, Riggs, & Lyons, 1978; Goodman, Gottlieb, & Harison, 1972; Guralnick, 1980; Johnson & Johnson, 1980; Peck, Cooke, & Apolloni, 1981). However, it has been found that when interactions do occur they can benefit both groups (Schutz, et al., 1984; Stainback & Stainback, 1981). The implications suggest that handicapped students should be given the opportunity to interact in social situations with nonhandicapped peers (Brown, et al., 1979) and that most likely these interactions will initially be structured by teachers (Stainback, Stainback, & Jalen, 1981). These interactions can occur in a variety of settings throughout the educational context.

Four types of social interactions have been described by Hamre-Nietupski, Branston, Ford, Stoll, Sweet, Gruenewald, and Brown (1978). These are: 1) proximal interactions, which refer to examples of physical integration; 2) helping interactions, which occur when a nonhandicapped person provides assistance or instruction to a handicapped student; 3) service interactions, which refer to interactions initiated by nonhandicapped persons in employment capacities; and 4) reciprocal interactions, which results in mutual but not necessarily similar benefits (pp. 40-43). Two separate but related strategies can be undertaken to increase and improve the quality of social interactions.

The first of these strategies is aimed at training handicapped students how to participate effectively in social interactions. These efforts have been undertaken by those working with mildly handicapped students (Walker et al., in press) and severely handicapped students (Certo & Kohl, 1984; Gaylord-Ross & Pitts-Conway, 1984; Schutz, et al., 1984; Voeltz, 1984). Williams and his colleagues (Williams, Hamre-Nietupski, Pumpian, McDaniel-Marx, & Wheeler, 1978) have operationalized a continuum of social skills for use by severely handicapped persons during daily activities. These skills include: recognizing appropriate times and places for interactions; initiating social interactions; receiving or rejecting social interactions by others; sustaining social interactions; and terminating social interactions. Skills such as these may be trained through the use of behavioral techniques (Bates, 1980; Bornstein, Back, McFall, Miles, **Friman**, & Lyons, 1980; Renzaglia & Bates, 1983; Walker et al., in press). **Research** has demonstrated that severely handicapped students can be trained

to appropriately use interaction skills (Gable, Hendrickson, & Strain, 1978; Ragland, Kerr, & Strain, 1978; Wambold & Bailey, 1979; Whitman, Mercurio, & Caponigri, 1970) and that this is one **way** to accomplish social integration (Schutz, et al., 1984).

The second strategy for facilitating social integration is the training of nonhandicapped students. These students can be trained to prompt handicapped students to respond to social bids (Strain & Kerr, 1980). While this strategy has been used most extensively within preschools (Cooke, Cooke, & Apolloni, 1978; Guralnick, 1976; Peck, Apolloni, Cooke, & Raver, 1978), programs are beginning to utilize this strategy within elementary schools (Rynders, Johnson, Johnson, & Schmidt, 1980; Voeltz, 1984), high schools (Wilcox & Bellamy, 1982), and extracurricular activities (Wehman & Hill, 1982). The inclusion of nonhandicapped peers into social skills training with handicapped persons holds promise as a method that accomplishes social integration within an ongoing framework.

Instructional Integration

Instructional integration occurs the least frequently of all integration opportunities. This type of integration refers to the grouping of handicapped and nonhandicapped students for instructional purposes. Logistics, manpower, teacher skills (or lack thereof), and curricular restraints are a few of the problems encountered when trying to implement this types of instructional opportunity.

One strategy successfully used to group handicapped and nonhandicapped students for instructional purposes is peer tutoring (Almond, Rodgers, &

Krug, 1979; Donder & Nietupski, 1981; Kohl, Moses, & Stettner-Eaton, 1984; McCarthy & Stodden, 1979; Poorman, 1980). Peer tutoring has been defined as systematically training nonhandicapped students to serve as instructional trainers of handicapped schoolmates (Kohl, et al., 1984). Kohl and her colleagues outlined a systematic sequence to teach nonhandicapped students how to teach their nonhandicapped peers appropriate cafeteria behaviors. The sequence included formal information sessions, in which the nonhandicapped were instructed in: the responsibilities and roles of an instructional trainer; characteristics of the handicapped student; methods of communication and conversational topics; cues and correction procedures; reinforcement; effective use of voice and body; date cards; videotaped demonstrations; and role-playing. These sessions were followed by "in vivo" instruction and feedback sessions. Implementation of this strategy resulted in instructional integration within a variety of educational contexts.

An additional strategy to facilitate instructional integration is the heterogeneous grouping of nonhandicapped and handicapped children (including severely handicapped) across a variety of chronological ages and functioning levels within a single classroom (Bricker, et al., 1982). Current **administrative** policies prohibit this strategy from occurring in no more **than** a handful of elementary schools (Stainback & Stainback, 1981). Most **uses** of the strategy are currently occurring in preschool classrooms (Bricker & Bricker, 1971; Bricker & Sandall, 1979; Bricker, et al., 1982; Cooke, et al., 1978; Guralnick, 1976; Ispa & Matz, 1978). Allen (1981) has **cautioned** programs from attempting to blindly implement this type of **instructional** integration. She has listed a number of components that

should be in place prior to integration efforts. These include: parent involvement; skilled teachers able to work with and use other disciplines; structured learning environments; opportunities for interactions and imitation among both handicapped and nonhandicapped children; appropriate physical facilities; and interdisciplinary planning. An additional component that has been suggested is comprehensive evaluation procedures designed to measure the impact of an integrated program on the enrolled children and their families (Bricker, et al., 1982).

One technique suggested as both a planning and evaluation tool to aid in the implementation of instructional integration is a curriculum goal grid (Bricker, Bruder, White, Newman, & Carlson, 1980). This grid is an adaptation of the many skills - one task, one skill-- many task concept espoused by Williams and Gotts (1977). The grid may be used to list goals of each student across curriculum areas. In this way teachers are free to plan group activities in which individual skills are targeted. A sample grid for a group of toddler-age children appears in Table 1.

Conclusion

The techniques and strategies described in this paper are but a sample of those available to facilitate physical, social, and instructional integration. Our efforts to provide opportunities for handicapped students within the mainstream of education must continue. These efforts should expand and improve. For this to happen, all special educators must commit themselves to the goal of integration along physical, social and instructional dimensions. This goal must be undertaken systematically to insure its success.

INDIVIDUAL TARGETS FOR GROUP ACTIVITY:

DATE:

	NAME	GROSS MOTOR	FINE MOTOR	EXPRESSIVE LANGUAGE	RECEPTIVE LANGUAGE	SOCIAL Adult Object 3 Peer	SELF-HELP	SENSORIMOTOR OR PRE-ACADEMIC	
1.	David	Head control in indian sit Head control on holster	of arm-range of motion 6' up right; left arm movement; in sidelying; in upright	look and vocalize for event/action			oral norm in fading		
2.	Molly			label-vocab imitate 2 words	1 part command in context	Stay at activity 5 minutes with physical assess; stay at circle whole time;pa	pee 1X		
3.	Belinda	walks ind 2 steps	wrist rotation 2 turns	approximate 5 new words Imitate labels	vocals	Stay in group 5 minutes		Sort objectives by function	
4.	Kim	head control with support	sidelying move left arm	eye tracking to lights (Joyce)			oral stimulation		
5.	Misty	throw over-hand; catch ball in arms		Imitate 2-3 words utterances 1 word spontaneous	vocabulary	Stay in group 5 minutes	shoes off	Sort on 1 dimensions functions/ colors	
6.	Kevin	crawl 7 ft c stopping							0

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PARENT INVOLVEMENT IN SPECIAL EDUCATION

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Rationale and Prevalence of Parent Involvement in Special Education

There is little doubt that parents are important in the education of their handicapped children (Bronfenbrenner, 1974; Carney, 1983; Cartwright, 1981; Foster, Berger, & McLean, 1981; Strickland, 1983; Turnbull & Tumbull, 1982; Winton & Turnbull, 1981). The roots of this practice date to the days when parents often had the sole responsibility of educating their handicapped children. During the advent of public schooling for handicapped students, parents often worked together to locate an empty room and hire a teacher to enable their children to attend school. Once special education services became more available within the public sector, parent involvement became less a mandate and more a recommended practice. Indeed, within the educational area of early intervention, parent involvement was deemed a necessary component for programs' intending to maximize child progress (Bricker & Bricker, 1976; Bronfenbrenner, 1974; Shearer & Shearer, 1976).

Several reasons have been articulated to support the continued involvement of parents in their child's special education program. Some professionals feel the inclusion of parents will increase the likelihood of generalizing the child's educational programs across settings and people, thus making the training more effective (Bricker & Casuso, 1979; Filler, 1983). Others argue that the inclusion of parents in educational efforts will yield more knowledgeable child advocates (Biklen, 1974). Still another reason for involving parents in their child's education is cost (Bricker & Bricker, 1976; Lieberman, Banes, Ho, Cuellar, & Little, 1979;

Shearer & Shearer, 1976). Special education programs that deliver services in homes and use parents to teach their children are less costly than any other type of educational program (Garland, Swanson, Stones, & Woodruff, 1981; Macy Research Associates, 1978). An additional reason for involving parents in special education is that parents are the ultimate consumers of the intervention services, both in terms of input (fees, taxes, child) and output (child change), and should be intimately involved in the services (Lillie, 1975). Finally, some professionals believe that the probability of maintaining the child in the home and improving the family ambience is significantly enhanced if parents and family members feel they are effective caregivers to the handicapped child (Bromwich, 1981; Foster, Berger, & McLean, 1981; Lillie, 1976; Turnbull, 1983).

One additional dimension to the rationale for including parents in special education is that P.L. 94-142, The Education Of All Handicapped Children Act (Federal Register, 1977), mandates parent participation in the educational program designed for each handicapped child. This law gives parents the right to obtain and assimilate education information, agree or disagree with proposed educational evaluation and placements, participate in making instructional and other service-provision decisions, and contest educators' decisions (Turnbull & Turnbull, 1982). The multiple demands of this law presents the most persuasive argument for including parents involvement in special education.

These reasons have persuaded most special education programs to include parents as part of their service delivery system. An abundance of programs have reported the inclusion and involvement of parents. Parents

have been included in intervention programs that target children who are hearing impaired (Horton, 1976; Luterman, 1968), blind (Fraiberg, 1975; Fraiberg, Smith, & Adelson, 1969), behaviorally disordered (Wiegerink & Parrish, 1976), Down's syndrome (Hanson, 1977; Hayden & Haring, 1976; MacDonald, Blott, Gordon, Spiegel, & Hartman, 1975; Rynders & Horrobin, 1975), developmentally delayed (Barrera, Routh, Parr, Johnson, Arendshorts, Goosby, & Schroeder, 1976; Bricker & Bricker, 1976; Bricker, Bruder, & Bailey, 1981; Denhoff & Hyman, 1976; Filler & Kasari, 1981; Gordon & Schwarz, 1976; Hanson, 1981; Jenkins, Stephens & Sternberg, 1980; Nielson, Collins, Meisel, Lowry, Engh, & Johnson, 1975), and at-risk for developmental delays (Badger, 1977; Heber & Garber, 1975; Honig, 1977; Karnes, Teska, Hodgins, & Badger, 1970; Lambie, Bond & Weikart, 1975; Ramey, Holmberg, Sparling, & Collier, 1977).

Many special education programs offer to parents a variety of services **and** opportunities for becoming involved in their childrens' education. Cordon (1969) delineated six roles for parents in their childrens' educational program. These are: 1) parent as teacher; 2) parent as observer; 3) parent as learner; 4) parent as volunteer; 5) parent as decision-maker; and 6) parent as professional. Recently, these six basic roles have been **expnded** and further defined. Vincent, Dodd, and Henner (1978) delineated 3D potential roles for parents, and Wiegerink, Hocutt, Posante-Loro, and **Bristol** (1979) generated a total of 36 roles which could be adopted by parents participating in special education programs. Parents can **participate in** program planning, policy formulation, program and child progress

evaluation, and program dissemination, to name just a few of the available roles. It seems that the important question is not if parents should be included in special education, but how they can be most effectively included.

Two new directions of research have given insight into the role of parents within the special education process. The first has evolved out of the infant literature, where it has been demonstrated that the infant's early interactions with the environment, most notably the caregiver, have great influence on the infant's subsequent development (Bromwich, 1981; Goldberg, 1977; Klaus & Kennel, 1975; Massie, 1975; Sameroff & Chandler, 1976). This information has been instrumental in shaping intervention programs for handicapped young children. Rather than focusing solely on either the child or the parent, programs are now concentrating on improving the interactional aspects of the caregiver-child relationship. This is accomplished in a number of ways, most notably through building the parents self-esteem by teaching the parent to "read" the child's cues and respond appropriately to the child's social and communicative efforts (Bailey & Wollery, 1983).

Second, emphasis has been placed on the importance of the interactions that occur between the handicapped child and his family. Several special education programs have begun to focus on overall family functioning. These programs are designed to help the family address the long range needs of the handicapped child without sacrificing the integrity of their own family system (Foster & Berger, 1979; Fewell, 1978; Foster, Berger, & McLean, 1982; Turnbull, 1983). In particular, attention

has been given to various family structures and life cycles and how each relates to individual child and family needs. Figure 1 contains an overview of these variables as developed by Turnbull (1983).

These new directions have not eased the task of special educators intent on developing effective parent involvement programs. Indeed, the task becomes more challenging as programs try to incorporate both a content and context individualized to family needs. At this time, many special education programs have useful parent involvement programs. These programs range from once a year IEP meetings to extensive involvement by parents as classroom volunteers, teachers of their children, and program advocates. The effectiveness of these programs is determined by several variables, including the program philosophy, staffing pattern, and the evaluation strategies used to determine both family needs and satisfaction as well as programmatic impact. Each of these aspects will be briefly described.

Program Philosophy

A clear philosophy that dictates the programmatic goals and services is necessary to insure effective intervention, a sense of professionalism, and staff cohesiveness (McDaniels, 1977). Programs often neglect a philosophical perspective in their zeal to provide services to children and families (Sheehan & Gradel, 1983). Programs which do operate from a set of well defined philosophical assumptions (Bricker & Dow, 1980; Foster et al., 1981) seem to generate services that are effective for both children and families (Paine, Bellamy, & Wilcox, 1983).

Program Staff

An additional programmatic determiner is the staffing pattern and job descriptions of staff within the program. For example, is there a social worker or parent educator on staff responsible for working with parents? If not, do the teachers have time written into their schedule for parent needs? This aspect of release time for staff seems an important component of any program committed to meeting parent and family needs. On the other hand, there are programs that allot time for parents (most often early intervention programs), yet this time is not systematically scheduled or monitored.

Program Evaluation

The most important consideration for programs is the systematic evaluation of parent needs and satisfaction and programmatic impact. Parent involvement programs have recently come under attack for the lack of data documenting successful or unsuccessful outcomes (Clarke-Stewart, 1981; Grey & Wandersman, 1980). This status must change if special education is to be effective both for and with families. Evaluations should be undertaken to address the question: What types of parents, with what types of children, benefit from particular types of parent involvement activities (Turnbull & Turnbull, 1982)?

A first step programs must take to insure valid parental involvement is to assess individual family needs (Mori, 1980; Snell & Dunkle, 1979; Turnbull, 1978). This can be done through a formal assessment (as depicted in Table 1) or through an informal interview. Either strategy should only

be used after rapport and trust is developed with the family. Likewise, additional formal and informal strategies may be developed to evaluate entry level needs of families in more specific areas. Programs should use these evaluations to monitor and assess their impact on parents in the individual areas after the involvement activities are completed. For example, if a parent-program goal was to obtain respite services for a parent, did the parent actually use the service? If a goal was to teach a parent behavior management skills, did the parent actually use the skills when dealing with her child? Finally, consumer satisfaction questionnaires should be given to parents as both summative program evaluations (see Table 2) and formative evaluations (see Table 3) (Vincent, Laten, Salisbury, Brown, & Baumgart, 1980).

The area of evaluation is by far the most complex. One strategy that has been developed to help articulate and evaluate parent involvement goals is a parent plan similar to a child's IEP. These plans have been used by a number of programs serving parents (Bricker & Casuso, 1977; Filler & Kasari, 1981). Table 4 contains a form used to develop parent involvement plans. Sample goals and activities will be discussed further in this paper.

Once programmatic decisions have been made, a program can begin to formulate options for parent involvement. Since families are diverse and may have different value systems, it is important to reiterate the individualized nature of the involvement options. However, family activities do not have to always be implemented within individual sessions. Sometimes it may be helpful to implement activities in small or large groups. For

purposes of program management, it is recommended that goals be chosen within the larger programmatic areas of support needs, informational needs, and educational and advocacy needs. Additional information on each area follows.

Support Needs

It has been found that families with handicapped children are more likely to have additional financial costs, stigma, considerable amounts of time given to personal care of the child, interruptions of family sleep, social isolation, limitations in recreational activities, difficulties in handling behavioral problems, difficulty in handling shopping and other normal household routines, and pessimistic feelings about the future (Moroney, 1981). It is no surprise that few areas are as crucial to both a family and child's well being as a supportive environment.

The absence of a support system has been related to greater degrees of stress experienced by families having a handicapped member. Stress has been defined as a set of circumstances that require change in the individual's life pattern (Holmes & Rahe, 1967). For families of handicapped children, stress has also been viewed as the result of an ongoing process of interaction between constitutional and environmental influences (Beckman-Bell, 1981).

Four major stress periods have been identified for families with a handicapped child. The first is when the parents become aware that their child is handicapped. The next period is when the child becomes eligible for educational services and the parents must face the level of disability.

Another period is when the child leaves school; and the last is when the aging parents can no longer assume responsibility for the child's well-being. Of course there may be many additional times of stress for families **depending** on their individual circumstances.

Of the many variables related to stress within families having a handicapped child, two seem to be most prevalent. These are caretaking demands and a low level of social responsiveness within the child (Battle, 1974; Beckman-Bell, 1981; Robson & Moss, 1970; Schaeffer & Emerson, 1964). **Caretaking** demands seem an obvious stressor since the more time that is **needed** to feed, bathe, position, handle, and attend to the medical needs (eg., administer medication) of the child, the less time there is for **parents** to attend to individual and family needs.

Social responsiveness is a less obvious stressor for families. Social **responsiveness** may include a variety of early communicative behaviors such as **smiling**, laughing, eye contact, gestures and vocalization, which occur **la response** to the behavior of others. It has been found that the lack of **facial** responsiveness demonstrated by brain damaged and autistic children **disrupts** the relationship between the child and his/her parents (Fraiberg, 1975; Marcus, 1977; Robson & Moss, 1970). Likewise, behavior problems in **children** that preclude social responsiveness (for example, self-stimulatory **behaviors**) are also often reported to be a source of great stress for **parents** (Kozloff, 1979; Marcus, 1977; Richman, 1977).

The implications for programs serving severely handicapped persons seem **apparent**. Support must be offered to parents not as an optional **activity**. such as participating in a support group, but as an ongoing

policy implemented by all service providers. First and foremost, school personnel must demonstrate that they are an ally of parents. The school program and the parents should agree that the primary goal for both is the most effective educational program for the child. Too often parents and schools have preconceived notions which tend to set the tone of the parent school relationship as adversarial (Vincent, et al., 1980).

A second area for school improvement is in the IEP meeting. Often, parents receive no information prior to the IEP meeting and no preparation in regard to its format, participants, and outcome (Carney, 1984; Goldstein & Goldstein, 1979; Goldstein, Strickland, Turnbull, & Curry, 1980). Very rarely are parents viewed as IEP team members (Vincent & Broome, 1982) and for most IEP's represent a major source of stress. A change in policy seems warranted as most parents attend IEP meetings yearly (Strickland, 1982; Turnbull & Turnbull, 1982).

Lastly, programs should emphasize the individuality of family needs and should not attempt to have parent involvement goals that supersede that individuality. Supportive activities should be as individual as each family. For some families an activity may be to locate respite care to provide relief from overwhelming caretaking responsibilities. For another family, it may be joining a support group or attending individual counseling sessions. These activities do not have to always be implemented by the school program, but the school or individual service provider should be prepared to help parents gain access to the activities as needed. Table 5 presents sample support activities for parents.

One final note: parents should be made to feel comfortable not participating in school programs. In an effort to sponsor a highly visible program of parent involvement, some special educational programs have demanded a high percentage of parental time and energy. Parents, likewise, have felt a need to provide the best education for their children by complying to the program demands. This has been reported as causing greater stress for families (Bailey & Wollery, 1983). Indeed, one study demonstrated that parents wanted effective school programs for their children in order to reduce the time demands of implementing educational activities in the home (Winton & Turnbull, 1982).

Information

School programs need information from parents and parents need appropriate information from programs. The type and level of information wanted by parents is often determined by the status of their child. Some information needs are static (e.g., What is an O.T.? What are the benefits of competitive employment?). Others are dynamic (e.g., How did my child do today in the kindergarten with nonhandicapped peers? Did my child take his medication?). In both cases, parents initiate the request for information.

Webster (1977) has identified four types of informational requests from parents. These are requests for facts, opinions, clarification, and discussion. Requests for facts sometimes present a dilemma to service providers, because some professionals fear that if parents know all the facts they may be more, rather than less, anxious. It has been pointed

out, however, that if parents want descriptions and facts, their anxiety will not be alleviated by further delay or distortion (Webster, 1977). In fact, they may feel even more threatened and distrusting of the service system if information is withheld.

A second category of questions includes requests for opinions. Opinions should be given cautiously and the service provider should emphasize and separate the opinions from facts. It is also important that opinions be given to parents only when asked (Murphy, 1979; Stewart, 1974). Further, service providers should be prepared for parents to reject their opinions.

The last two types of questions are requests for clarification and requests for discussion. These two requests may be construed as indications that the parent may need some more time and assistance to assimilate the initial information that was given to them. This should not be unexpected in that parents arrive at understanding and accepting information at their own pace and the process should not be hurried for fear of creating more anxiety.

Many times programs present information to parents in a uniform manner and assume understanding. Yet, data have suggested that parents can absorb and use only a certain amount of information at any one time (McDonald, 1962). Service providers must be sensitive to the information needs of their families and be prepared to assess parental understanding and needs as an ongoing mechanism for program effectiveness.

Nowhere is parental information needed more than in the search for appropriate services for their handicapped child. Families of handicapped children usually have to interact with many different service agencies, such as medical, educational, and social agencies (Vincent, et al., 1980). In trying to gain access to these resources, parents may be confronted with services differing in priorities and mandates, overlapping geographic boundaries, contrasting administrative structures, or even incomprehensible acronyms (Rubin & Quinn-Curran, 1983). This situation is most devastating for parents new to service delivery system.

According to Rubin and Quinn-Curran (1983), a parent must take three steps to gain access to service systems. First, parents need to identify what their needs are. Second, they need to translate their needs into the proper service label. Third, they need to contact the appropriate agency that delivers that service. The first two steps, in particular, rely on the quality and degree of information given to parents.

The informational needs of each family should be addressed by all special education programs. Policies should be adopted by programs to insure that parents are given the information they require. Further, formal and informal assessments should be conducted with parents to help them identify any additional informational needs.

Various modes can be implemented to present specific information to parents. These include one-on-one sessions, workshops, parent groups, and written correspondence such as newsletters, brochures, resource manuals and the often used notebook between home and school. Winton and Turnbull (1983) have documented that parents of preschool-aged children favor

frequent informal informational contacts with their children's teachers. **Whatever** the mode, service providers should insure that their communications **with** parents are: clear; in response to identified needs; free of jargon; and monitored for effectiveness. Table 6 presents sample informational activities.

Educational Needs

Education can be differentiated from information, in that education results in a predetermined change of behavior. Parent education programs have traditionally focused on teaching parents how to teach their children new behaviors. Over the years, much data have supported the success of this practice.

It has been demonstrated that most parent education is delivered by a professional performing a service to the parent. This has been done in large groups (Hall, Grinstead, Collier, & Hall, 1980), small groups (Wiegerink & Parrish, 1976), or individually (Adubato, Adams, & Budd, 1981; Filler & Kasari, 1981). The service setting has varied from the parent's home to a structured service setting (e.g., school). A variety of techniques have also proven successful in implementing training. These include lectures, films, discussions, videos, audiotapes, programmed texts, modeling, immediate and delayed feedback, verbal and written feedback observations, and charting skill acquisition (Baker & Heifetz, 1976; Berkowitz & Graziano, 1972; Bricker & Bricker, 1976; Clements, 1975;

Graziano, 1977; Hayden, 1976; Johnson & Katz, 1973; Kroth, 1975; O'Dell, 1974). The general agreement seems to be that concrete training methods that employ demonstration and practice are most effective.

The content of parent training programs seems to correspond directly to the skills needed by the targeted child. By far the most successful application of this has been with behavioral technology. The basic content revolves around a paradigm of antecedent-behavior-consequence. The parents are taught how to arrange antecedent stimuli in a way to evoke target behaviors from their child and how to deliver consequences that will strengthen or weaken the behaviors. Observation skills and data collection procedures are usually included, as well. O'Dell (1974) lists several reasons why this paradigm should be used in parent training: 1) unskilled people can learn to apply the techniques; 2) the techniques are based on an empirically derived theory; 3) the techniques can be taught in a group; 4) the acquisition of the methodology takes a short training time; and 5) the methodology can be applied in the natural setting.

Behavioral technology has proven effective in teaching parents basic behavior management skills (Patterson & Reid, 1973), language development (Garcia & Batista-Wallace, 1977; Jones, 1977; MacDonald, Blott, Gordon, Spiegel, & Hartmann, 1975), feeding (Thompson, Palmer, & Linsheid, 1977), discrimination training (Bricker & Filler, 1976), sensorimotor skills (Brassell & Dunst, 1978), social skills (Koegel, et al., 1983), play skills (Mash & Terdal, 1973), self care skills (Aduvato, et al., 1981; Heifetz, 1977), motor skills (Filler & Kasari, 1981), and skills covering all

domains of behavior (Brackman, Fundakowski, Filler, & Peterson, 1977; Bruder, 1983; Hanson, 1977, 1981; Hayden & McGinness, 1977; Shearer & Shearer, 1976).

Given the abundance of parent training data, the limited number of adequately controlled studies on the effects of training on parents and the subsequent effect to the child is startling. As noted by Clarke-Stewart (1981), most special education programs tend to report child performance measures as the only outcome measure when using parents as teachers. Measures that assess change in parents, as well as measures that document programmatic variables such as the instructional methods used with parents, the length and intensity of service to parents, and parent characteristics have often been neglected (Clarke-Stewart, 1981; Gray & Wandersman, 1980; Molloy, 1980; O'Dell, 1974). Recent reviews of programs using parents as teachers have articulated the need for closer examination of the variables affecting this service delivery strategy (Cataldo, 1980; Clarke-Stewart, 1981; Gray & Wandersman, 1980; Levitt & Cohen, 1975; Molloy, 1979; Stevens, 1978).

As behavioral technology has developed, parent training programs have broadened the scope of their interventions. Recently, investigations have focused on training generalized behavioral skills, which may be used across behaviors, tasks, and cues (Bruder, 1983; Koegel, Glahn, & Niemenen, 1978; Petrie, Kratochwill, Bergan, & Nicholson, 1981). Besides continuing this line of inquiry, future needs in the area of parent training seem to be the identification of training content which trains parents to be successful, independent interventionists for their children (Bromwich, 1981).

Educational needs can be expanded beyond teaching parents to teach their children and encompass other needs of parents and families. For example, many parents may want to learn advocacy skills. An advocate is one who stands and speaks on behalf of another person or group of persons in order to bring about change. Throughout their children's lives parents will fill the role of an advocate. Every time an IEP is designed, parents may have to advocate for the type and frequency of both educational and related services to be delivered to their child. Usually the success of the parent is directly related to the way in which they advocate. Parents usually do not automatically know the most effective ways to advocate. Special education programs can offer specific activities to parents to teach them how to identify needs, how to use appropriate strategies to meet the needs, and how to monitor their efforts to insure the specific needs are being addressed.

Specific educational activities, as support and informational activities, should be individualized to parent requests and parent preferences. Again, ongoing evaluation must be emphasized. As with the other needs, educational needs may be met through a variety of modes providing they include demonstration, practice, and feedback to the parent. However, large group sessions are usually least effective when teaching new behaviors to families. Table 7 contains sample activities for educating families.

Parent-to-Parent Involvement

An added dimension that special education programs are incorporating into their service delivery systems is the use of parents to deliver services to other parents. The benefits of this strategy include cost (Bruder, 1983; Hoffman, 1982; Reschly, 1979), maintenance of learned skills within the teaching parents (Bruder, 1983; Sanders & James, 1983), and the support which the model facilitates (Eheart & Accone, 1982; Jenkins, Stephens, & Sternberg, 1980). Most programs using this model focus on the educational needs of the parents.

Special education programs that use the parent-to-parent model include a preschool for behavior disordered children (Strain, Steele, Ellis, & Timm, 1982; Wiegerink & Parrish, 1976), a toddler program for behavior disordered children (Hoffman, 1982), an infant stimulation program (Reschly, 1979), and a program serving at-risk infants (Bruder, 1983). Two other intervention programs using this model serve both school age children and preschoolers (Hall, Grinstead, Collier, & Hall, 1980; Jenkins, Stephens, & Sternberg, 1980).

Unfortunately, the intervention programs that use parents to teach other parents lack substantial evaluation procedures. The same criticisms that have been aimed at early intervention programs using parents as their children's teachers (Cataldo, 1980; Clarke-Stewart, 1981; Gray & Wandersman, 1980; Levitt & Cohen, 1975; Molloy, 1980; Stevens, 1978) also apply to programs using parents as teachers of other parents. There are little data to date on the parent-child teaching process, the parent-to-parent teaching process, and outcome variables affected by the teaching.

Research studies recently have supplied outcome data on the feasibility of a parent-to-parent teaching model (Adubato, et al., 1981; Bruder, 1983; Takemoto, 1982). All of these studies used single subject designs to evaluate the effectiveness of this strategy. Two studies examined spouse-to-spouse training with parents of young children (Adubato, et al., 1981; Takemoto, 1982), while the third included nine parents of at-risk infants, six of whom participated as teachers of other parents (Bruder, 1983). The last study also provided information on: 1) parent acquisition of new behaviors; 2) child acquisition of new behaviors; 3) parent acquisition of teaching principles; and 4) the fidelity with which parents taught other parents new behaviors.

Two additional research studies examined a parent-to-parent model in conjunction with a professional. Minde and his colleagues (Minde, Shosenberg, Marton, Thompson, Ripley, & Burns, 1980) used a parent to assist a professional during support groups for parents of infants who were receiving services in a Neonatal Intensive Care Unit. Parents who participated in the group demonstrated more positive interactions with their infants than parents who did not participate in the group experience. Likewise, Ball and his colleagues (Ball, Coyne, Jarvis, & Pease, 1984) implemented a behavioral training program for parents of developmentally disabled youngsters. Parents who participated in this program were able to effectively use behavior management techniques with their children.

The effectiveness of these studies suggests the utility of a parent-to-parent model, provided that evaluation of parents' needs and skills occurs both before and after their involvement as teachers. Caution should

be noted: Not all parents may want to be teachers of their children (Turnbull & Turnbull, 1982); so too, not all parents may want to teach other parents.

Conclusion

Parents are often an underserved component of the service delivery for handicapped students. Special education programs should address the needs of parents systematically to maximize student progress and family functioning. This paper has attempted to outline a framework for encompassing parent support, informational and educational needs.

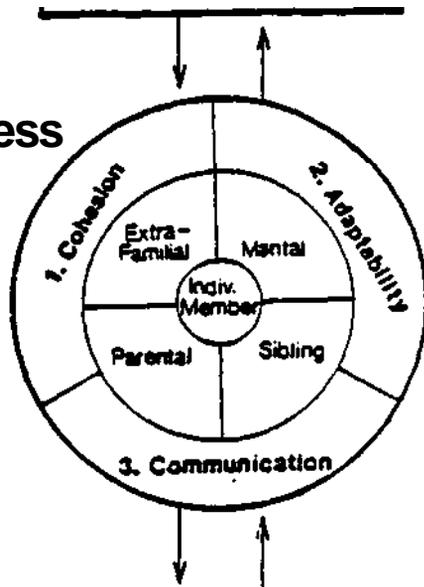
Family Structure

1. Membership Size and Type
2. Cultural Style
3. Ideological Style

Inputs

Family Systems Framework

Process



Family Life Cycle

1. Developmental Stage and Transitions
2. Structural Change
3. Functional Change
4. Socio-historical Change

Change/ Stress

Family Functions

1. Economic
2. Physical
3. Rest and Recuperation
4. Socialization
5. Self-definition
6. Affection
7. Guidance
8. Education
9. Vocational

Outputs

* Table 1
Family Needs Checklist

Name: _____

MO DAY YR

Instructions: Check Yes or No for each item.

SECTION 1: KNOWLEDGE

Community Resources	YES	J	MO		COMMENTS
Do you have questions about:					
1. Physician					
2. Physical Therapist					
3. Occupational Therapist					
4. Speech/Hearing Therapist					
5. Counseling					
6. Vision Testing					
7. Orthopedics					
8. Public Health Care					
9. Genetic Counseling					
10. Dental Health					
11. Advocacy Groups					
12. First Aid Procedures					

Support Services

Do you have questions about:	
13. Respite Care	
14. Transportation	
15. Supplemental Security Income	
16. Recreation	
17. Aid to Dependent Children	
18. Day Care	
19. Babysitting	
20. Food Stamps	
21. Housing	
22. Legal Aid	
23. Health Insurance	
24. Financial information	
25. Support Groups (e.g., Association for Retarded Citizens, United Cerebral Palsy, etc.)	
26. Availability of Preschool Programs for Your Child	

Table 2
Early Intervention Program (IEP) Parent Questionnaire

	Activity 1		Activity 2		Activity 3	
	Yes	No	Yes	No	Yes	No
I. Organization						
4. I was made familiar with the objective and purpose of the activity.	---	---	---	---	---	---
5. I clearly understood what I would be doing during the activity.	---	---	---	---	---	---
6. I clearly understood what my responsibilities were during the activity.	---	---	---	---	---	---
II. Value						
7. The activity was beneficial for my child and I.	---	---	---	---	---	---
8. I learned at least one new piece of information from this activity.	---	---	---	---	---	---
9. I plan to use information from this activity at home.	---	---	---	---	---	---
10. I think other mothers could benefit from this activity.	---	---	---	---	---	---
III. Involvement						
11. Would you like more opportunity to ask questions during the activity?	---	---	---	---	---	---
	H	L	S	H	L	S
12. How much active participation would you like in this activity if presented again?	---	---	---	---	---	---
13. How much input would you like to have in planning activities?	---	---	---	---	---	---
IV. Comments:						
14. What did you like best about the activity?	_____					

Table 3
Individual Group Home

Child's Teacher: _____ Month Child Started in Program: _____

1. My child is: (check one)

- handicapped or has developmental delays
 nonhandicapped, does not have developmental delays

2. The types of parent involvement activities I have participated in include: (check all that apply)

- observing classrooms
 jointly planning my child's educational programming with teacher
 working with my own child in the classroom
 working with other children in the classroom
 working on one or more of my child's goals at home (no data)
 running home programs on one or more of my child's goals (taking some data)
 group parent meetings

Please underline the two parent involvement activities you feel have been most useful to you in helping your child learn

Please rate each of the choices below on the 5-point scale by circling the appropriate number.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
3. As a result of participation in the Early Intervention Program (EIP) my child has shown improvement in the following areas:					
a. receptive language (how well child understands communication)		2	3	4	5
b. expressive language (how child communicates to others)		2	3	4	5
c. social development (how well child gets along with adults and other children)		2	3	4	5
d. gross motor skills (skills using large muscles; i.e., walking)		2	3	4	5
e. fine motor skills (skills involving small muscle control; coordination at manipulating objects)		2	3	4	5
f. cognitive skills (problem solving and "thinking" skills)		2	3	4	5
g. self-help skills (i.e., eating and drinking, toileting, grooming, dressing, and undressing)		2	3	4	5

Table 4
Parent Involvement Objectives

Parents Name:

Interventionist:

Date Started	[Objective	Activities	Resources Method	Evaluation Method	Evaluation Results	Date Ended
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Table 5

SAMPLE SUPPORT GOALS AND ACTIVITIES

Parent Goals	Activities	Evaluation	<u>Final Report</u>
1. Locate respite services	<ul style="list-style-type: none"> a. Call community mental health agency b. Call Associated for Retarded Citizens c. Call relatives, friends d. Call religious affiliation 	<ul style="list-style-type: none"> a. log of telephone calls b. log of telephone calls c. verbal report d. log of telephone calls 	<ul style="list-style-type: none"> a. list of possible respite b. use of respite service
2. Join a parent group	<ul style="list-style-type: none"> a. Call community mental health agency b. Call Association for Retarded Citizens c. Call other parents d. Call each parent group contact 	<ul style="list-style-type: none"> a. log of telephone calls b. log of telephone calls c. log of telephone calls 	<ul style="list-style-type: none"> a. list of possible parent group b. description of parent group c. joining a parent group
3. Explore the possibility of family counseling	<ul style="list-style-type: none"> a. Discuss with family b. Call community mental health agency for list of counselors c. Determine cost of counseling d. Determine financial feasibility for counseling 	<ul style="list-style-type: none"> a. verbal report b. log of telephone calls c. list cost 	<ul style="list-style-type: none"> a. decision yes/no/not at this time for counseling

Table 6

SAMPLE INFORMATION GOALS AND ACTIVITIES

Parent Goals	Activities	Evaluation	<u>Final Report</u>
1. Learn more about child's handicap	a. Meet with teachers b. Locate materials (articles, books on subject) through library or University c. Formulate questions for doctor	a. meeting minutes b. list of available reading materials c. questions for doctor	a. record of material read b. record of answered and unanswered questions

Table 7

SAMPLE EDUCATIONAL GOALS AND ACTIVITIES

Parent Goals	Activities	Evaluation	<u>Final Report</u>
1. Learn specific teaching techniques to use with child	a. Meet with teacher b. Practice techniques with teacher with feedback in classroom and at home	a. meeting minutes b. teacher's evaluation of parent's skills	a. record of parents' ability to teach, maintain, or reduce specific behavior in child
2. Learn legal rights and responsibilities for child's educational and civil tell being	a. Meet with teacher b. Locate material (articles, books) through library or university c. Contact advocacy organizations d. Attend workshops	a. meeting minutes b. list of available reading materials c. list of resources from advocacy organizations d. verbal report e. behavior in an IEP meeting	a. record of materials read b. record of any unanswered questions c. joining a parent group d. record of IEP meeting

Table 8
Stressors Arising from
Socio-historical Change

<u>Cultural Trends</u>	<u>Economy</u>	<u>Political Trends</u>	<u>Formative Events</u>
Women's movement	Unemployment	War	Natural catastrophies
Independence movement	Inflation	Political climate denying or reducing services to handicapped populations	Guidance from mentor
Emphasis on self-fulfillment during post-parental and retirement years			
Normalization			

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A Supported Work Approach to Competitive Employment of Individuals
With Moderate and Severe Handicaps

Severely handicapped individuals do not participate in the workforce to the same extent as nonhandicapped citizens. Today, despite improved public awareness of the rights of severely handicapped persons and significant increases in the number of day programs for adults (Bellamy, Sheehan, Horner, and Boles, 1980), hundreds of thousands of potentially employable individuals remain idle. Unemployment rates of 50 percent to 75 percent (U. S. Commission of Civil Rights, 1983) and average annual wages of \$414 for retarded workshop clients (Whitehead, 1979) provide a dramatic description of the current deplorable state of affairs. Failure to incorporate persons with moderate and severe handicaps into the labor force wastes a valuable human resource. The cost of dependency in terms of public income maintenance and other forms of assistance places a tremendous strain on our nation's economy. Even greater are the human costs of idleness and dependency on the lives of severely handicapped people.

Research and demonstration activities during the past 10 years have resulted in significant improvements in the vocational training and placement of persons with severe handicaps. Early emphasis was placed almost exclusively on training severely retarded and multiply handicapped individuals to perform sheltered work tasks (Bates, Renzaglia, & Clees, 1982; Bellamy, Peterson, & Close, 1975; Gold, 1972; Hunter & Bellamy, 1977; O'Neill & Bellamy, 1978; Wehman, Renzaglia, Bates, & Schutz, 1977). Recently, additional efforts have been directed toward training and placing severely handicapped workers into less sheltered or nonsheltered settings which focus more on competitive employment.

For example, several investigators have reported success with job placement, job site training, and follow-up of moderately and some severely retarded clients. Sowers, Connis, and Thompson (1979) described the placement results of the

University of Washington Food Service Training Program which has clearly been one of the forerunners in this area. This program continues in a successful manner. In a similar vein, Kraus and MacEachron (1982) published the results of the Transitional Employment program for mentally retarded persons. In this report, it was found that participants' work behavior, ability to meet job requirements, and wages were predictors of competitive placement. Brickey and his colleagues (Brickey & Campbell, 1981; Brickey, Browning, & Campbell, 1982; Brickey, Campbell, & Browning, 1983) have also done an excellent job of placing, training, and tracking mentally retarded graduates of sheltered workshop programs. Brickey's work, in particular, highlights the cost-effective features of sheltered workshop programs that provide regular and systematic follow-up of placed clients. In Vermont, Williams and Vogelsburg (1980), have been active in demonstrating the competitive employment capabilities of moderately and severely handicapped workers in nonsheltered settings. Over 40 clients, primarily from adult day programs, have been successfully placed in the last two years.

In our own work over the past five years we began with simple case study demonstrations (e.g., Wehman, Hill, & Koehler, 1979) and have since moved to benefit cost analyses of our placed clients (Kill & Wehman, 1983) as well as an on-going follow-up of client progress (Wehman, Hill, Goodall, Cleveland, Pentecost, & Brooke, 1982; Wehman, M. Hill, J. Kill, Brooke, Ponder, Pentecost, Pendleton, & Britt, 1984). To date, over 150 clients have been placed into competitive employment and approximately 55 percent are still working. The median measured intelligence quotient of those clients was 47 with the majority being labeled moderately mentally retarded. Kochany and Keller (1981) have described some of the reasons our clients fail to maintain employment. Major reasons include parental dissatisfaction, transportation breakdowns, client maladaptive behavior, and changes in employer policies. In addition, some clients move away

or simply wish to change jobs after a period of time.

Competitive employment is usually superior to placement in any type of sheltered work environment. It offers the possibility of dramatically improving an individual's lifestyle while resulting in tremendous financial savings for social service agencies. Competitive employment allows persons with moderate or severe handicaps to earn significant wages and receive fringe benefits not available to workers in sheltered settings. The work performed in competitive environments is often more meaningful and challenging to the individual. It also offers the greatest opportunity for long-term job retention and advancement.

- Competitive jobs are usually not affected by lack of available work or the seasonal variability that often plague sheltered work programs. Perhaps most important is the ability of competitive employment to facilitate the integration of severely handicapped individuals into all facets of community life. Opportunities to travel more independently, utilize retail environments, and develop friendships with nonhandicapped coworkers are greatly enhanced for individuals working in the competitive sector.

Competitive employment also possesses a number of other significant advantages. It can lead to improved perceptions of handicapped workers by parents and policymakers. If parents become convinced that their child can succeed in competitive employment and make a meaningful wage, they may be more likely to take the major risks involved in working out transportation problems, overcoming Supplemental Security Income (SSI) disincentives, and providing support to their son or daughter. Policy makers are more likely to be impressed by vocational training efforts which result in placement in competitive employment. It is unreasonable to expect legislators to continue to provide millions of dollars annually to support programs which result in workers making a few dollars a week. Competitive employment placements are most persuasive in seeking greater funds for

continued job placement efforts. The benefit cost analysis data of Hill and **Wehman** (1983) strongly suggest that competitive placement programs can actually result in long term savings to taxpayers.

What we need to know, however, is the best way to place and retain moderately and severely handicapped individuals into competitive employment. It is evident that the traditional model of placement with no intensive job site training and follow-along does not work for most moderately and severely handicapped people. Our experiences as well as those of many other investigators referenced earlier document this fact along with the reality of thousands of severely handicapped people not receiving access to rehabilitative services because they are not deemed to be "employable".

In this paper we will present a model which has worked effectively for almost six years. We call it supported work because clients receive staff support in differing degrees of intensity and depending on their unique needs. A detailed description is provided of how supported work can be applied to improving competitive employment opportunities for moderately and severely handicapped people who typically have been unemployed in society. It is important to note that supported employment can refer to other approaches to facilitating paid work for severely handicapped persons. For example, a recent U.S. Dept. of Education, Office of Special Education and Rehabilitative Services initiative (1984) characterizes supported employment as paid work which usually occurs in regular work settings. It may involve competitive employment but might also involve sheltered enclaves, mobile work crews, sheltered industries or other creative approaches to improving employment opportunities. The critical aspect of this U. S. Dept. of Education initiative is the focus upon the historically or chronically unemployed severely handicapped population.

The Supported Work Model

A supported work approach to competitive employment involves highly structured job placement, individualized training, and job retention of clients with moderate and severe handicaps. It is characterized by intensive job-site training in integrated, community-based employment settings. The model is applicable for use with large numbers of individuals who have had limited previous exposure to competitive work environments. It can be successfully implemented by public school and community service programs in both urban and rural areas. The supported work model contains four major program components: 1) a comprehensive approach to job placement; 2) intensive job site training and advocacy; 3) ongoing assessment of client performance; and 4) a systematic approach to long term job retention and follow-up. Table 1 summarizes the principle components and associated characteristics of the supported work model.

Although it is probably not necessary for all handicapped persons, the supported work model is suitable for use with large numbers of handicapped individuals in both public school and community service programs. The model is generally intended as an alternative vocational outcome for persons unable to succeed or gain entrance to traditional public school work-study programs or monitored employment programs operated by rehabilitation facilities. Within public school settings, these individuals are usually served in programs for students labeled moderately mentally retarded or, in a few instances, mildly mentally retarded. Individuals labeled severely mentally retarded or multiply handicapped will also be prime beneficiaries of this approach although we have less data focusing exclusively on this population. Within community service programs, the model may be applicable to persons who are usually labeled by rehabilitation facilities as possessing severe disabilities and who are most frequently served in sheltered workshops or activity centers.

The supported work model possesses several key features that distinguish it from other approaches to job placement. In contrast to less intensive job placement approaches such as the "job club" (Azrin & Besalel, 1980) or selective placement (Rubin & Roessler, 1978), the supported work model relies on a comprehensive approach to job placement that actively deals with the non-work related factors which often stand as barriers to employment i.e. parental concerns. Another key difference between a supported work approach and other approaches is its extensive application of job site training and advocacy procedures. This emphasis allows clients to be placed who do not possess all the necessary work or social skills required for immediate job success. This represents a significant departure from traditional placement approaches that require the client to be "job ready" before placement can occur and alternative approaches that train a client to a specific level of mastery within a training environment prior to a final placement.

Other distinguishing features of the supported work model are its commitment to long term assessment of client performance and delivery of job retention and follow-up services. In sharp contrast to rehabilitation programs that typically provide follow-up services for several months, clients within the supported work model may receive systematically planned job retention and follow-up services for many years after initial placement. Finally, the supported work model is perhaps unique in its identification of a single "job coordinator" who is responsible for all facets of the placement, training, advocacy, assessment, and follow-up process. Rather than utilizing professional staff who specialize in a single aspect of the placement process, reliance upon a job coordinator greatly enhances continuity across all phases of the placement and follow-up process.

In the remainder of this section, we will discuss the four major program

components of the supported work model in greater detail. Each component (placement, job site training and advocacy, ongoing client assessment, and job retention and follow-up) will be defined and illustrations will be provided to demonstrate the applicability of the model to public school and community service programs.

Program Component I; Job Placement

The placement of the client into a job appropriate to his or her abilities is the first major component of the supported work model. A great deal has been written about job placement (e.g. Goodall, Wehman & Cleveland, 1983; Vandergoot & Worrall, 1979). However, we believe that the process of job placement involves more than simply finding a job for a client. Major aspects of the job placement process include:

1. A comprehensive assessment of job requirements and client abilities which results in an appropriate job match;
2. An active approach to handling non-work related factors such as travel, social security, and caretaker support.

The placement process begins by surveying the community labor market to identify the types of jobs that appear likely to have vacancies or high turnover rates and which appear to be within the capacity of potential clients. After specific jobs have been identified, an accurate analysis of work environment requirements must be completed. This process has been variously referred to as ecological analysis (Wehman, 1981), top-down curriculum (Brown, Branston-KcClean, Baumgart, Vincent, Falvey, & Shroeder, 1979), or job analysis (Vandergoot & Worrall, 1979). It is critical that adequate detail be provided in terms of job requirements, characteristics of the work environment, and other features which may influence job retention.

Initial client assessment is conducted concurrently with the job development

and analysis activities. A multifaceted approach to client assessment is employed. Information is obtained concerning client adaptive behaviors, parent/caretaker attitudes, transportation possibilities, the client's expressed willingness to work, and other relevant factors. In addition, the assessment will determine the client's current ability to perform some of the vocational skills that may be required in the targeted job areas. An inability to perform a large number of these skills does not preclude a client from placement, since a major strength of the supported work model is its ability to place individuals who do not possess all the work skills needed for immediate job success. However, if the client has not received at least a minimal amount of training through a pre-employment vocational program, the placement and retention process will take a great deal more time and, in the long run, will be more costly to the agency providing the service.

The results of work environment analysis and initial client assessment can be used to determine an appropriate job match. For example, how many of the skills required by a particular job is the client currently able to perform? This information can be used to project the amount of staff time that may be required during the early stages of employment. If a client is being considered for a position on an evening or weekend shift, how will the client get to and from the job? Public transportation may be limited at these times, and alternative transportation arrangements may be required before placement can occur. It is also important to consider whether the client has expressed interest in the type of job under consideration. Our experience has shown that handicapped workers often have strong job interests and preferences. Placements made without regard for a client's expressed interests will frequently fail after a short period of time. These examples illustrate the necessity of matching both job requirements and client characteristics to ensure successful placements.

The second major aspect of the job placement process in the supported work model involves an active approach to handling non-work related factors such as travel, social security, and caretaker support. Within a more traditional placement framework, it is often accepted that the client or caretaker will handle most of these concerns if a job is made available. For persons with moderate or severe mental handicaps, job placement would be impossible or highly unlikely without this type of support. Arranging for alternative forms of transportation to and from work, assisting the client in dealing with changes in social security status, and addressing the natural fears of concerned parents requires the active involvement of a trained professional. In many instances, effectively handling of non-work related factors will make the difference between a successful and an unsuccessful placement.

Program Component II: Job Site Training and Advocacy

As noted earlier, on-the-job training is certainly not a new concept. However, in most employment models, a trained professional is not available early in the placement to actively intervene on behalf of the client. Employers are often viewed as solely responsible for training the client. Frequently, no specific training is provided. Instead, brief and infrequent follow-up checks or visits are made for a short time after the initial placement. In short, two major steps in the placement process are omitted, namely, specific skill training and adjustment to the work environment.

Our experience in placement and our communication with others using a supported work model strongly indicate that job site training and advocacy are essential features of the model. Job site training refers to direct instruction provided by a trained professional enabling the client to perform all skills required by the job. Advocacy involves noninstructional intervention on behalf of the client. Both job site training and advocacy are necessary to promote the

client's initial adjustment to the work environment and long-term job retention.

Application of behavioral training strategies to vocational skills in nonsheltered or competitive work environments has received relatively little attention by researchers. Rusch has clearly been the leader in this regard with studies related to acquisition of selected work skills (Schutz, Joste, Rusch, & Lamson, 1980), time-telling (Sowers, Rusch, Connis, St Cummings, 1980), time on-task on the job (Rusch, Connis, & Sowers, 1980), reducing inappropriate self-stimulating behaviors (Rusch, Weithers, Menchetti, & Schutz, 1980), and selected communication training (Karlan & Rusch, 1982). It is apparent to us that the technology of behavioral training needs to be extended into nonsheltered work environments with individuals who heretofore have been considered poor candidates for competitive employment. We have barely begun to scratch the surface in this area. Applications of reinforcement principles, manipulation of antecedent stimulus conditions, and use of coworkers as peer trainers are all areas which require closer investigation.

Advocacy, or noninstructional intervention on behalf of the client, is the other principle feature of this component. In many cases, handicapped workers will need less time spent on training and more time spent on orientation to the new work environment. Advocacy may involve a variety of different activities on the part of the job coordinator, such as: responding to a supervisor's concerns about the implications of the client's disability (likelihood of seizures, use of medication, necessity of adaptive equipment or augmentative communication systems); working out communication problems and assisting the client in developing social relationships with coworkers; or communicating with parents/caretakers about how the job is going. Although the impact of planned advocacy has not been evaluated in the published literature, our previous experiences have taught us that this is an essential aspect of job retention.

The following example serves to illustrate the potential impact of planned advocacy efforts. If a job coordinator notices that a client is having a difficult time locating the employee cafeteria or vending machines, interacting with coworkers during breaks, and failing to return from breaks at the appropriate time, systematic advocacy efforts should be initiated. A supervisor or coworker may be identified who will agree to assist the client during these periods. The job coordinator may provide this "on-site advocate" with information about the client's interests and abilities, allowing the individual to more effectively communicate and interact with the client during breaks. The individual may agree to help the client obtain lunches or snacks in the employee cafeteria and may remind the client when it is time to return to the work station. The job coordinator must make certain to reward the individual for his or her efforts on behalf of the client, monitor the situation to ensure that the client continues to receive assistance as needed, and see that these activities do not place too great a burden on the supervisor or coworkers. Eliciting the aid of a supervisor or coworker is an effective method of fading the involvement of the job coordinator at the work-site and, at the same time, significantly improves the client's chances for long-term job retention.

Program Component III; Ongoing Assessment

A distinctive feature of a supported work approach involves ongoing assessment or monitoring of client performance. Typically, within more traditional job placement approaches, a rehabilitation counselor will place a client and then, at some point in the future, possibly check with employers to determine the adequacy of the client's job performance. When placing clients with severe handicaps, this type of "assessment" is often insufficient, because the worker may be terminated or quit the job before the counselor is even aware that any problem exists.

Ongoing assessment activities include the collection and analysis of subjective information obtained from employers, clients, and parents/caretakers, and the direct measurement of client behavior. Once a placement is made, there is an immediate need to gauge the employer's perceptions of the worker's performance. Initially, supervisors' evaluations should be obtained approximately every two weeks to identify any potential problems or employer dissatisfaction. When a problem is identified, this subjective information should be followed by direct measurement of the client's behavior to determine the scope of the problem and to identify potential intervention strategies. After the job coordinator has intervened to correct any problems in client performance, the results of the intervention program should be validated by again asking the supervisor to evaluate the worker. This process will ensure that improvement in the client's work performance, documented through direct measurement of behavior, is adequate from the employer's point of view.

In the same manner, the client and his or her parents/caretakers should be assessed on a regular basis to determine their satisfaction with the job placement. Identifying any concerns may allow the job coordinator to intervene before the client leaves the job. Although quantifiable data are the most desirable, in some instances verbal feedback to a job coordinator may be sufficient. In all cases, the amount of assessment data collected is clearly related to variables such as the ability level of the client, the amount of staff available for data collection, and, above all, the specific need for data to evaluate a certain problem.

Program Component IV: Job Retention and Follow-up

Follow-up, the fourth component of the model, is an activity or service consistently referred to in the rehabilitation system. However, the amount and nature of follow-up services actually provided to clients remain unclear. In a

recent analysis of the Projects With Industry Program (Reismer, Haywood, & Hastings, 1983), follow-up was found to be a frequent activity of those projects. Yet, the type and quality of follow-up services and their impact on job retention were not assessed.

Systematic follow-up services are critical for a number of reasons. The client may lose enthusiasm and display a reduction in productivity after the initial excitement about the new job has subsided. A change in work schedule may require the job coordinator to retrain the client on his or her new bus schedule. Modifications in work assignment or a new supervisor may necessitate additional training on new job tasks. Similarly, a change in the home situation may adversely affect job performance and require follow-up services which involve the client's parents/caretakers. Maintaining contact with the client, employer, and parents after the initial training period will allow the job coordinator to foresee potential problems and prevent their occurrence, rather than delaying intervention until the problem has escalated into a crisis.

A supported work approach to competitive employment views follow-up services as long-term activities that are provided over a period of years. As indicated above, changes in supervisor, work assignment, or home situation may endanger a client's job retention years after initial placement. Traditional placement approaches that terminate follow-up services within a period of months appear unable to meet the job retention needs of severely handicapped clients, who are often adversely affected by changes in their home or work environments. Hill, Cleveland, Pendleton, and Wehman (1982) list regular on-site visits to employers, phone calls, review of supervisor evaluations, client progress reports, and parent evaluations as effective follow-up strategies which promote job retention. Ultimately, job retention and follow-up may be the most crucial component of the supported work model, since moderately and severely handicapped workers are often

immediately at risk of losing their jobs in competitive environments unless some type of retention plan is devised. Although this strategy has been viewed by skeptics as being too expensive, the benefit cost analysis of Hill and Wehman (1983) seems to refute this notion.

Implications for the Supported Work Model in Different Service Delivery Settings

Although the previous section provides important information regarding the supported work model, the model is of little value if it cannot be applied by the principle service delivery systems serving moderately and severely handicapped persons. These service delivery settings include both public schools and community service programs such as sheltered workshops and adult day programs. The section which follows specifically addresses the problems encountered in these settings and recommends changes in current policies that may help to solve these problems.

Typical Problems Encountered in Service Delivery Settings

Public schools and community service programs each present their own unique set of problems for implementation of the supported work model. For example, relatively few university training programs equip special education or vocational education teachers with the specific competencies needed to train and place students into competitive employment, work with employers, and develop linkages with adult service systems. These difficulties have led to a minimal amount of job placement by school system personnel of handicapped students into jobs which pay unsubsidized wages.

Community service programs also possess many inherent problems that inhibit attempts to implement the supported work model. Funding limitations make it extremely difficult for these programs to recruit and retain qualified staff. Significant staff turnover is not uncommon. As the Bellamy, Sheenan, Horner, and

Boles (1980) study noted, relatively few of the adult day programs surveyed focus extensively on vocational training and/or placement. Often community service programs are heavily influenced by volunteer groups or associations which may seek to protect handicapped adults and maintain nonvocational, developmentally-based programs.

The obstacles facing service providers attempting to implement the supported work model in public schools and community service programs are numerous and complex. Rather than dwell on these obstacles, however, it will be much more constructive to focus our attention upon ways to overcome these problems. The policy recommendations listed below begin to address some of the ways in which the supported work model can be integrated into existing service systems.

Strategies and Policies for Overcoming Public School Problems

Based upon the success of the supported work model with moderately and severely handicapped adults (Wehman, et al., 1984) it appears that this approach to job placement must be utilized fully for students who are still in public school. Such an undertaking will require extensive changes in the curriculum used with severely handicapped students, the organization of secondary programs, and the content and nature of university training programs (Brown, Shiraga, Ford, VanDeventer, Nisbet, Loomis, & Sweet, in press). We have outlined below several specific policy changes which must occur to allow the application of the supported work model to the training and placement of severely handicapped students in secondary programs.

1. Public school special education programs must make a clear philosophical commitment to place and maintain students with moderate and severe handicaps into competitive employment. Current vocational training efforts frequently emphasize the acquisition of "prevocational" skills, evaluation activities, or training on isolated vocational tasks that bear little similarity to the skills

needed for success in competitive settings. Relatively little attention is often paid to the placement of students in jobs which pay unsubsidized wages. Follow along of the students' progress is not provided. Policies must be developed at both the state and federal level that will facilitate the implementation of the supported work model. New roles must be created for vocational placement specialists to function as job placement coordinators within secondary programs for severely handicapped students. Local school systems should be encouraged to develop systematic transition programs as well as support part-time employment for severely handicapped students (Clarke, Gruenwald, Abramovitz, & Bellamy, 1980). Transition programs will enable systems to coordinate their job placement efforts with those of other agencies in their community. State education agencies can play a leadership role in developing and conducting follow-up surveys that will serve as a measure of program effectiveness.

2. State and federal agencies must carefully monitor service delivery models, curricula, and instructional practices to facilitate implementation of all components of the supported work model. Students confined to segregated educational facilities cannot acquire all the social and interpersonal skills required for success in competitive employment settings. Monitoring activities must guarantee students access to integrated educational environments. In addition, significant changes must occur in curriculum development activities for severely handicapped students at the intermediate as well as secondary levels. No longer can special educators be satisfied to move students through non-functional developmental sequences. Functional curricula derived through ecological inventory approaches (Wilcox & Bellamy, 1982) must be incorporated through each student's intermediate and secondary programs (Wehman, 1983). The supported work model also implies a reliance upon a community-based approach to instruction. Strategies must be devised to overcome the transportation problems, liability

concerns, and administrative constraints which currently hinder efforts at community-based programming (Wehman & Hill, 1982).

3. Special education personnel preparation funds should be used to stimulate the development of university training programs that prepare specialists in the vocational training and job placement of students with moderate and severe handicaps.

Very few teachers are currently prepared at either the undergraduate or graduate levels to perform the job development, job analysis, job placement, job-site training, and follow-up activities required by the supported work model. New training programs must produce vocational placement specialists who possess the ability to work effectively with employers and personnel managers, coordinate their efforts with community service agencies, and provide quality on-site training and follow-up services.

Strategies and Policies for Overcoming Problems in Community Services

Several major policy changes and subsequent strategies need to be considered if community service programs such as sheltered workshops and adult day programs are to substantially improve their rate of job placement and retention. The suggestions which are made here are derived from policy reports, personal observations, and frequent interactions with community service personnel in many states.

1. Public policy commitments and clear financial inducements must be established to encourage placement of people with severe handicaps into competitive employment. Most community service programs do not have a specific mission which emphasizes the competitive employment outcomes and service provisions which purportedly lead to paid employment. Policies should be generated at both the local and State levels that prioritize client employment as a critical aspect of any program. The policies should include a clear financial inducement for

competitive employment placement. As noted earlier, community service personnel receive no positive financial consequence for job placement and retention. For example, substantial cash installment payments for placement and, eight months to 10 months later, retention, would put contingencies on job placement and also job maintenance. This form of monetary contingency would greatly facilitate the use of supported work model or a very similar system. In addition, a much longer follow-up period of 8-10 months must be used rather than the normal 60 days which many rehabilitation facilities follow. Workers with moderate and severe handicaps require much longer periods of work adjustment.

2. Rehabilitation agency officials who designate programs as vocational training and placement vendors for services should encourage or stimulate use of a supported work model. In order for sheltered workshops or other community service programs to receive rehabilitation funds for client services, they must be approved as a vendor (Revell, Wehman, & Arnold, in press). During this approval process, officials should encourage the payment of monies for application of a supported work model of job placement. Similarly, rehabilitation counselors and other referring sources who are paying for workshop services must demand more in the way of competitive employment placement. When counselors become knowledgeable about the work potential of clients of severe handicaps, they may be more motivated to require specific supported work services from community service programs.

3. More funds need to be directed to sheltered workshops and other community service programs to develop pre-employment programs closely linked to jobs in competitive employment. A widely held assumption has been that learning general work habits and acquiring bench work skills will prepare individuals to perform competitive employment tasks in regular work settings. Our placement experiences with severely disabled clients do not support this notion. Most of these indi-

viduals need training in specific vocational skills and opportunities to learn how to interact with nonhandicapped people in community settings. The development of more work crews or sheltered enclaves in the community, as well as in-house training programs, would broaden the continuum of locally available vocational options and greatly facilitate entry into unsubsidized employment. Developmental Disabilities monies, the Joint Training Partnership Act, and local mental retardation funds may all be used to support pre-employment programs. Recently, the Social Security Act (Title XIX) Medicaid Waiver has been used in some states to successfully implement vocational training activities.

4. Personnel in community service programs, including sheltered workshop and other rehabilitation staff, must receive extensive training in job placement, job site behavioral training, and follow-up strategies. Federal policymakers need to consider expending developmental disabilities, special education, and rehabilitation training funds to train community service providers. Specifically, a critical need exists for adult day program supervisors, instructors, residential counselors, case managers, respite care providers, and administrative staff who understand the importance of employment and the potential of the supported work model. In addition, significant changes should be made in university rehabilitation programs. Preservice programs, in particular, do not sufficiently prepare personnel to effectively implement the supported work model. Much more attention must be given to active job placement, training as opposed to counseling techniques, and follow-up strategies. As clients with more severe handicaps are referred for services, counseling skills will wane in importance and behavioral training skills will become imperative.

5. Demonstration programs need to be established for innovative community service day programs which focus on employment. In recent years substantial numbers of special education and rehabilitation demonstration projects have

validated the usefulness of the supported work model. However, few demonstration activities have been implemented in community mental retardation programs. Many more programs are needed that incorporate the most effective methods currently available for training and placing individuals with severe handicaps into jobs.

Concluding Remarks

There is a very limited likelihood that persons with moderate and severe handicaps will earn meaningful wages in real work without some approach like the one described in this paper. It is apparent to us that the type of structure and long term commitment which is described in the supported work approach is necessary to facilitate greater opportunity for competitive employment. This paper has addressed the employment needs of the severely handicapped persons and the high rate of unemployment among disabled people in the United States today. We have recommended an approach which has worked with many moderately mentally retarded persons in the past (Wehman et al, 1982; 1984.) and which requires consideration for greater accomodation into local service delivery systems. To this end, numerous public policy recommendations were made, both for public schools and also community service adult day programs and sheltered workshops. Only when more attention is paid to significantly modifying these service delivery systems to reflect employment-oriented outcomes will moderately and severely handicapped persons gain entry to the nation's labor force in large numbers.

Table 1

Checklist of Activities in Supported Work Approach to Competitive Employment

<u>Program Component I;</u>	Job Placement	<ul style="list-style-type: none"> .structured efforts at finding jobs for client and matching client strengths to job needs .planning of transportation arrangements and/or travel training .active involvement with parents on identifying appropriate job for client .communication with social security administration
<u>Program Component II;</u>	<u>Job Site Training and Advocacy</u>	<ul style="list-style-type: none"> .trained staff provides behavior skill training aimed at improving client work performance improving client work .trained staff provide necessary social skill training at job site •staff works with employers/coworkers in helping client .staff helps client and coworkers adjust to each other
<u>Program Component III;</u>	<u>On-going-Assessment</u>	<ul style="list-style-type: none"> .provides for regular written feedback from employer on client progress .utilizes behavioral data related to client work speed, proficiency, need for staff assistance, etc. .implements periodic client and/or parent satisfaction questionnaires
<u>Program Component IV;</u>	<u>Follow-up and Retention</u>	<ul style="list-style-type: none"> .implements planned effort at reducing staff intervention from job site •provides follow-up to employer in form of phone calls and/or visits to job sites as needed .communicates to employer of staff accessibility as needed •helps client relocate or find new job if necessary

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TRAINING FOR COMMUNITY INTEGRATION

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Efforts by parents, professionals, advocacy groups, and disabled citizens themselves have resulted in the movement of adults with severe handicaps from institutions to family-like dwellings and in the maintenance of school-aged persons in local communities. As a result, personnel in public schools, community residential facilities, and state hospitals face the task of preparing individuals with severe handicaps to live independently and to participate in all facets of community life. Some of their efforts are successful. Many people with severe handicaps lead fulfilling lives in settings that allow them to participate as family members, citizens, and workers. However, not all training programs succeed. Serious problems persist.

Many more individuals with severe handicaps still enter institutions every year than return to their local communities. A large number of individuals who do leave institutions are forced to return, victims of failed community placements. Those persons who remain in the community often lead lives of loneliness and isolation, unable to participate significantly in community activities. Many of these problems are directly related to the fact that individuals with severe handicaps, in most instances, do not have access to adequate training programs that effectively prepare them for community integration.

Secondary special education programs for students with severe handicaps frequently rely on curricula based upon developmental sequences. Such an approach results in instruction that is neither functional nor age-appropriate, and that will in no way equip individuals with the skills needed in post-school environments. Severely handicapped individuals

residing in institutions in many instances receive substandard programming in segregated settings that cannot prepare them to live in our complex society. Many people currently living in community residential facilities are not prepared for optimal independence, do not significantly utilize community services, and have little voice in planning and directing their own lives.

This paper describes critical characteristics of effective training programs designed to prepare people with severe handicaps for successful community integration. Five basic principles will be delineated which address shortcomings found in many current training efforts. The principles are applicable to training programs currently being conducted in public schools, community residential facilities, and institutional prerelease programs. Training programs in all these settings must improve if persons with severe handicaps are to be adequately prepared for community living.

Any attempt to design effective training programs must take into account the problems faced by severely handicapped people currently living in local communities. Therefore, before discussing critical program characteristics, recent efforts attempting to describe the community adjustment of handicapped persons and the effectiveness of current training programs will be briefly reviewed.

Co-unity Adjustment of Persons with Severe Handicaps

Assessing the adjustment of severely handicapped persons living in local communities is a complex and difficult task (Lakin, Bruininks, &

Sigford, 1981). Many studies simply have not included persons with severe handicaps. Others have taken a limited view of successful adjustment, focusing only on the length of time an individual remains in the community and not addressing other factors which indicate the quality of a person's life. Despite a lack of accurate information, it is obvious that residing in a community residential facility or with relatives does not guarantee a severely handicapped person a normal lifestyle (Bercovici, 1981; Gardner *is* Cole, 1981; Laski & Spitalnik, 1980; Menolascino, 1983). An evaluation of successful community integration should consider at least three factors: independent living, social integration, and individual self-direction. Each of these factors is discussed below.

Independent living. Independent living skills refer to those activities that decrease an individual's dependence upon other people (e.g., grooming, cooking, and home management skills) as well as activities that allow the individual to use generic community services (e.g., mobility, shopping, employment skills) (Vogelsberg, Williams, & Bellamy, 1982). Independent living skills such as basic self-care and personal maintenance, food preparation, clothing care, independent mobility, and vocational skills have been identified as critical for successful community living (Schalock, Harper, & Carver, 1981; Heal, Sigelman, & Switzky, 1978). Despite the unquestioned importance of these skills, persons with severe handicaps rarely receive adequate training to enable them to lead optimally independent lives.

Though most individuals are able to care for their basic personal needs, severely handicapped persons spend less time engaged in home

maintenance activities than other residents of community living arrangements (Landesman-Dwyer & Sulzbacher, 1981). They frequently participate to a small degree in cooking activities designed for large numbers of individuals (.8-12), but fail to learn to cook for themselves independently. While they move about the community and visit grocery stores and other retail environments, they rarely do so unaccompanied, infrequently go to restaurants, and usually have no major role in shopping for the family or the group home. Severely handicapped persons also are frequently excluded from any type of employment opportunity (Wehman, Kregel, & Zoller, 1984). Failure to develop adequate independent living skills may severely restrict an individual's lifestyle. For other individuals, the consequences may be more severe. A lack of independent living skill training may lead to an individual being institutionalized or excluded from a less restrictive residential setting.

Social integration. The previous section addressed the importance of independent living skills in the lives of severely handicapped persons. As more people with handicaps remain in their local communities, it becomes increasingly clear that there is a significant difference between living in the community and being integrated into the community. In too many cases, persons with severe handicaps are living with their families or in community residential facilities, yet are still isolated within their homes and excluded from participation in many facets of community life. Social behaviors, interaction with other members of the community, and participation in active recreational pursuits must all be examined to determine social integration.

The importance of social behaviors and interpersonal relationships in the community adjustment of persons with severe handicaps has been widely documented (Reiter & Levi, 1980; Schalock, Harper, & Genung, 1981). In a comparison with mildly and moderately mentally retarded individuals, Landesman-Dwyer and Sulzbacher (1981) found that persons with severe handicaps spent more idle time within their residence, interacted less with others, and spent much less time outside the residence. When individuals leave the residence, they rarely do so unaccompanied (Scheerenberger & Felsenthal, 1977). A recent study (Wehman, Kregel, and Zoller, 1984) examined the community adjustment of 300 mentally retarded graduates of special education programs. A very large number of individuals (60%) reported spending free time socializing primarily with other members of their family. Few individuals (24%) spent any significant time interacting with members of the opposite sex. These findings corroborate the results of earlier studies (Baker, Seltzer, & Seltzer, 1977; Gollay, Freedman, Wyngaarden, & Kurtz, 1978), which found that individuals living in community residential facilities generally did not develop friendships outside the facility, did not visit others in the community, and rarely dated. Clearly, severely handicapped individuals do not interact to any degree with other members of the community.

Engaging in active, community-based recreation activities is another powerful indicator of social integration. Current evidence (Salzberg & Langford, 1981; Wehman, Schleien, & Kiernan, 1980) indicates that many individuals spend leisure time inside their homes rather than participating in community-oriented recreation/leisure activities. Gollay and her

colleagues (1978) found that individuals engaged primarily in passive recreation activities and that group activities (clubs or organizations) were selected least often. Community recreation activities almost always occurred in programs designed exclusively for disabled individuals. The absence of appropriate recreation activities in the lives of severely handicapped individuals is significant for two reasons. First, community-oriented recreation activities are an important tool in achieving social integration; that is, they increase the interaction between persons with severe handicaps and other community members, and enable them to use generic community services. Second, a lack of recreational skills may result in an abundance of idle time, which may in turn result in increases in inappropriate behaviors. Such behaviors may ultimately lead to the removal of a severely handicapped person from a community setting (Gollay, 1981; Landesman-Dwyer & Sulzbacher, 1981).

Self-direction. Severely handicapped persons living with their families or in community residential facilities often have little voice in planning and directing their own lives (Baker et al, 1977; Scheerenberger & Felsenthal, 1977). Resident self-direction appears limited to minor types of decisions. They decorate their own rooms, control a limited amount of spending money, move freely about their neighborhood. However, most individuals have little control over their lifestyle or even minor daily activities.

Individuals with severe handicaps are told where to live. Few have any role in selecting their own jobs. They have little control over where they will go and when they will leave their homes. Other people decide what they will eat and wear. Some have no personal allowance. Often

restrictions are placed upon an individual's daily behaviors, including curfews and prescribed bedtimes. Interaction with members of the opposite sex is closely supervised and highly restricted. Some community residential facilities do not allow entertainment of members of the opposite sex or the consumption of alcohol on the premises. Sadly, many severely handicapped individuals do not lead lives that reflect their individual goals, desires, aspirations, and preferences.

Effectiveness of Current Training Efforts

Researchers have devoted a tremendous amount of time and effort investigating many factors such as age and IQ of the individual and size and location of living environment in terms of their relationship to successful community integration (Heal, Sigelman, & Switzky, 1978; Sigelman, Novak, heal, & Switzky, 1980). But surprisingly, few investigations have addressed the effects of training programs designed to enhance the independent living and social integration of persons with severe handicaps. The quality of a person's individualized training program, the competence of the staff working with each person, and the sophistication and usefulness of the training techniques employed - these are the factors that will truly determine whether or not someone is adequately prepared to live in our society. Effective training programs enable people to reside in optimally independent, least restrictive living situations. They minimize the chances that someone might be institutionalized. Also, they improve

the quality of life of these individuals and allow them to be fully participating, self-directed citizens.

Unfortunately, many community residential facilities have poor training programs or a total absence of training programs (Schalock & harper, 1981). Many of the 160 residential programs studied by Butler and Bjaanes (1975) had few training programs or no programs at all. The burden to provide training to clients within community living arrangements generally falls upon residential staff who are also responsible for providing recreational opportunities, counseling individuals and maintaining the home. These staff members are frequently underpaid, poorly trained, and afforded little respect by social service agencies.

Institutional prerelease training programs also appear to be failing to meet the needs of persons with severe handicaps. Despite what might be expected, there is surprisingly little evidence that institutional pre-release training facilitates community adjustment (Sigelman, Novak, heal, & Switzky, 1980). Given the fact that follow-up programs are generally poor, it is quite understandable that individuals may fail to generalize skills supposedly acquired in the prerelease program. It is also difficult for program staff to anticipate all the potential problems an individual will encounter in the community. Significantly, when prerelease training is provided in the institution, persons with severe handicaps are far less likely to participate in the program than other individuals (Bjaanes, Butler, & Keller, 1981).

These problems do not exist only in training programs conducted in community residential facilities and institutions. Preparing individuals

for community integration is also the responsibility of public school special education programs. To date most attempts to accomplish this task have been largely ineffective. Secondary special education programs often rely too heavily upon curricula based on a model of normal human development. The use of these models as the basis for curriculum development results in programs that are neither functional nor age appropriate (Wilcox & Bellamy, 1982), and that fail to meet the needs of severely handicapped individuals.

Critical Characteristics of Community Integration Training Programs

The identified lack of independence, social integration, and self-direction in the lives severely handicapped individuals and the inadequacies of current training efforts described in the preceding sections define a powerful and urgent need for effective, comprehensive community integration training programs. This section outlines important principles that address shortcomings found in most current training efforts. Five basic principles will be identified and discussed.

1. Training programs should recognize that persons with severe handicaps have the same needs as all people. These needs include the development of independence within their homes and communities, in the management of their own affairs, and contributing to their economic self-sufficiency; social integration into all facets of community life, developing friendships and family relationships, interacting with other members of the community, and pursuing active recreational interests; and

self-direction to plan their lives on a day-to-day basis, selecting their own activities, and setting long range personal goals.

The concept of community integration implies the right of persons with severe handicaps to conduct their own affairs within the limits of their abilities. For professionals, the concept implies the responsibility to prepare individuals to move about the community, use community services (hospitals, churches, restaurants, theatres, retail stores, etc.), communicate and interact with other people, and engage in self-chosen recreational pursuits. Therefore, training programs should incorporate and address the following three goals:

- Enable severely handicapped people to achieve maximal independence within their homes and communities
- Ensure the full participation and social integration of severely handicapped people in all aspects of community life
- Guarantee severely handicapped persons maximal freedom of choice in directing their own lives.

2. The content of training programs should be comprehensive in scope.

Living in the community requires many different skills. Repeated demonstrations have shown that people labeled severely handicapped can acquire adequate self-care skills to allow them to become partially or fully independent in their own homes. Sophisticated training technologies have been devised in areas such as toileting, eating, and grooming. These successes have led many to believe that these individuals can function effectively in environments much more sophisticated and demanding than those typically identified for them, and provide an empirical basis for

raising the goals and expectations for persons with severe handicaps in a number of adult life roles. It is now plausible to assume severely handicapped individuals will be able to function in a range of community settings without total dependence upon family members or professional staff.

At the same time, few training programs prepare individuals for all aspects of community integration (Schutz, Vogelsberg, & Rusch, 1980). An effective training program must address all facets of community integration, including independent living, social integration, and self-direction. Demonstration activities have primarily been concerned with teaching specific, isolated skills, such as bus riding (Sowers, Rusch, & Hudson, 1979) or ordering in fast food restaurants (Christoph, Nietupski, & Pumpian, 1979). Other efforts at advanced community integration programming have dealt with teaching several skills appropriate to a single environment, such as grocery shopping (Nietupski, Certo, Pumpian, & Belmore, 1976) or teaching a generalized skill to be used across a variety of settings, such as purchasing (Marholin, Touchette, Berger, & Doyle, 1979) or emergency skills (Matson, 1980).

A lack of comprehensive training programs may result in a "postage stamp approach" to community integration. Individuals may acquire isolated skills in specific areas, but fail to learn a wide enough range of skills to improve their actual independence, social integration, and self-direction. Training programs must address the skills necessary to enable individuals to care for their personal needs, manage their residential environment, and use a wide range of community settings. In addition,

training programs must provide persons with severe handicaps appropriate social skills. This training should deal directly with any behavioral difficulties that may result in the exclusion of severely handicapped individuals from integrated community settings. Individuals also need instruction in communication skills, interpersonal skills, and active, community-orientated recreational activities that will help them interact with other members of the community and avoid social isolation. Table 1 lists all the competency areas that must be addressed for a community integration training program to be truly comprehensive.

3. Training programs must be based upon an analysis of the specific home, neighborhood, and community in which the person will live. The use of developmental sequences as the basis of training programs for adolescents and adults has been widely criticized (Wehman & Hill, 1980; Wilcox & Bellamy, 1982). Persons with severe handicaps must be taught to perform skills required for success in complex, integrated environments. Rather than a developmental approach, the appropriate method for devising the content of a comprehensive program relies upon an empirical analysis of the residential and community environments in which the severely handicapped person will function. This process has been referred to as ecological, or "top-down" curriculum analysis.

Top down curriculum analysis is generally conceived as a multi-step process (Snell, 1983; Wilcox & Bellamy, 1982). The first step consists of a cataloguing or listing of the residential and community environments which an individual currently uses as well as the environments that will be used in the future. Next, the environments are analyzed into specific sub-

environments, and the major activities performed in each sub-environment are identified. This process ensures that the training program will reflect the demands of the specific settings which the individual is likely to frequent. For example, in the competency area of fast food environments, numerous settings may be relevant. The sequence of behaviors necessary to obtain a meal at a Wendy's is quite different from the sequence required at a Baskin-Robbins ice cream store. Similarly, residing in one's natural home, group home, or supervised apartment may each require a severely handicapped individual to perform different activities. Table 2, adapted from Schalock (1983), illustrates a hypothetical breakdown of the activities related to previously identified competency areas that may be required of an individual in different residential settings.

Finally, the identified activities are task analyzed into component skills and training programs devised. All programs should be designed to enable the individual to perform activities in the natural environments in which they will occur. More than simple performance behaviors must be taught. Community activities such as buying a hamburger, going to a movie, or attending a social activity all require specific communication abilities and social skills. These must be identified and incorporated into the training program.

A major component of community integration training must center around the language skills necessary for success in the verbal interactions which occur in the community. An analysis of the language required to perform specific community tasks will result in the development of training programs that are based upon empirically determined environmental demands.

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This approach is distinguished from current attempts to derive the content of language training programs from a developmental analysis (Bricker, Dennison, & Bricker, 1976), operant analysis (Guess, Sailor, & Baer, 1976) or a combination of methods (McLean & Snyder-McLean, 1978). There are certain tasks that recur in the environment and cannot be successfully accomplished without some type of communicative behavior; for example, ordering food or merchandise or responding to questions posed by a community agent. No attempt to teach community integration skills would be complete without systematic instruction in the communication behaviors required to perform those tasks. An analysis of what language is required by specific environments is essential, as well as the development of valid procedures to effectively teach these skills to severely handicapped individuals.

4. Training programs must contain provisions which guarantee that skills acquired during training will generalize to new environments. It is very important that severely handicapped individuals generalize the skills they learn in instructional settings to actual home and community environments. Although some evidence exists to show that community integration skills can be taught and do generalize to a person's new environment (Crnic & Pym, 1979; Schalock, Harper, & Carver, 1981), it cannot be assumed that skills taught in isolated or simulated settings will transfer to natural surroundings. Generalization can take several forms. Home maintenance skills acquired at school may be used at home. Skills acquired in one community setting, such as street crossing or utilizing retail environments, may be used in many situations. Self-monitoring

systems useful in one type of situation (weekly household cleaning tasks) can be transferred to other behaviors. A number of strategies have been found successful in facilitating the generalization of newly acquired skills. These strategies have focused primarily on the settings in which training is provided (Vogelsberg, Williams, & Bellamy, 1982) and on the instructional methods employed during training (Horner, Sprague, & Wilcox, 1982).

Community integration training can be provided to severely handicapped individuals through simulated or community-based instruction. Simulation training, which refers to instruction provided in an environment other than that in which the behavior will ultimately occur, has been used to teach many skills such as making purchases and grocery shopping (Nietupski, Certo, Pumpian, & Belmore, 1976) and use of public transportation (Coon, Vogelsberg, & Williams, 1981). Community integration training using simulation strategies has the advantages of being less costly, enabling learners to receive repeated practice on difficult-to-learn tasks, and enabling learners to receive immediate feedback if errors are made. However, Vogelsberg and his colleagues (1982) point out that skills acquired in simulated environments will not automatically generalize to natural settings. At a minimum, after an individual has acquired a skill in a simulated setting, the skill should be evaluated in the natural environment, and additional training should be provided if the learner has not adequately generalized the skill.

Community-based instruction refers to training that is conducted in the setting in which the skill being taught is ultimately designed to occur.

A variety of activities, such as bus riding (Sowers, et al., 1979) and time management (Sowers, Rusch, Connis, & Cummings, 1980) have been successfully taught in community settings. Community-based instruction has several distinct advantages. It enables learners to practice skills under the conditions and criteria demanded by natural settings. In addition, a community-based instructional model allows learners to practice all important components of an activity, such as crossing streets and interacting with others, while moving to and from the training site.

Reliance upon a community-based instructional approach, however, does not guarantee that an individual will be able to generalize all acquired skills. If a skill is acquired in a single natural setting, it cannot be assumed that the learner will be able to perform the skill in other, untrained settings. For example, a learner taught to purchase food independently in one fast food restaurant may not be able to use other fast food settings without additional training. This generalization problem is referred to as teaching the general case, that is, teaching general skills that enable learners to be competent in both trained and untrained settings (Becker & Engelman, 1978). General case programming forces professionals to decide what community settings should be used for training, how many cases must be trained before a person acquires a general skill, and in what sequence or order training should proceed. Horner, Sprague, and Wilcox (1982) have developed a six step approach for providing general case programming. In view of the cost and time involved in implementing community-based instruction, professionals should incorporate the principles of general case programming into their

activities. This will ensure that severely handicapped persons will derive maximum benefit from instruction and be able to use acquired skills in all facets of community integration.

5. Training programs Must be based not only on an assessment of a person's abilities, but also on the person's likes and dislikes, interests and desires. An effective community integration training program should insure that a severely handicapped person is able to select his or her own lifestyle, make choices, and plan daily activities. Included in this area would be such activities as managing one's own spending money, developing interpersonal relationships, selecting one's own role as a family member, advocating for oneself, planning daily routines, and choosing one's own lifestyle. It also involves learning to cook what you like to eat, selecting clothes that you like to wear, and engaging in recreational activities which are enjoyable for you.

Identifying the interests and preferences of persons with severe handicaps, many of whom are unable to express their desires verbally, is a difficult task. If possible, the person should be interviewed directly. If this is not possible, perhaps the individual could indicate their preferences through a modified forced-choice picture pointing system. In response to questions such as "Which of these activities would you like to do?", the person may be able to point to photographs of different recreation activities which could be learned, different foods which could be prepared, or different community environments which could be frequented. Another alternative is to observe the individual, making use of reinforcement sampling techniques, to identify materials and activities the person

engages in most frequently or indicates a preference for in another way. All of these approaches assume that the individual has had some previous exposure to, or experience with, the activities she/he is selecting. Without prior exposure, the person has no basis for making an informed decision. Therefore, it is very important for professionals to provide adequate time for persons with severe handicaps to explore a wide range of residential settings, community environments, and recreational alternatives, prior to asking them to make choices and selections.

Conclusion

The development of community integration training programs for persons with severe handicaps presents a challenge to professionals in public schools, community residential facilities, and institutions. Successful community integration implies that individuals are prepared: 1) to be optimally independent in their home and community; 2) to be socially integrated into all facets of community life; and 3) to exert significant influence in making decisions regarding their daily activities and overall lifestyle. Five specific principles have been described which may guide professionals as they attempt to develop effective programs. The principles address the goals of training programs, procedures for generating the content of training programs that are comprehensive in nature and incorporate the desires and preferences of severely handicapped individuals, and procedures for implementing instruction within a training program.

Table 1

COMPETENCY AREAS FOR COMMUNITY INTEGRATION

<u>In the home:</u>	<u>In the community;</u>
Caring for personal needs	1. Community mobility
Housekeeping and hose management	2. Fast food environments
Clothing care	3. Restaurants and cafeterias
Food preparation and Management	4. Retail store environments
Managing finances	5. Service environments
Communication skills in the home	6. Leisure and recreation activities
First aid and safety skills	7. Social clubs and organizations
Sex education	8. Civic activities and responsibilities
Time awareness and utilization	9. Interpersonal relationships
Appropriate social behaviors	

Table 2

ACTIVITIES REQUIRED IN DIFFERENT RESIDENTIAL SETTINGS

COMPETENCY AREA	NATURAL HOME	GROUP HOME	SUPERVISED APARTMENT
Caring for personal needs	Grooming skills	Health care	Handles medication
Housekeeping and home management	Clean up after recreation activity	Cleans bedroom	Makes minor repairs
Clothing care	Dressing skills	Laundry skills	Clothing repair
Food preparation and management	Independent eating	Meal preparation	Meal planning and shopping
Managing finances	Purchases items	Uses checking account	Budgets money
Communication skills in the home	Expresses needs	Utilizes expressive system	Utilizes telephone
First aid and safety skills	Follows proper nutrition	Responds to emergencies	Secures home from intruders
Sex education	Awareness of bodily functions	Respect for privacy of others	Knowledge of contraceptive devices
Time awareness and utilization	Prompted daily routine	Unprompted daily routine	Independent scheduling
Appropriate social behavior	Safety in unsupervised situations	Self-referenced behaviors	Interpersonal relations

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Developing a Volunteer Respite Care
Training Program

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Developing a Volunteer Respite Care Training Program

Many communities are beginning respite care programs to provide services for families of individuals who are severely handicapped (Upshur, 1982; Brickey, 1983; Hagan, 1980; Paige, 1977). Respite care has been defined as the provision of temporary daytime or overnight relief to families who are caring for disabled individuals at home (Upshur, 1982). This type of community service has become increasingly necessary as more families choose to keep their severely involved children at home rather than in institutions.

Stress and emotional distress often result when a family attempts to provide the many daily needs of a severely involved relative. Brickey (1982) identified nine indicators of high stress for families. These include: 1.) lack of day programs; 2.) lack of support (i.e., single parent households); 3.) lack of assistance (i.e., a few people handling all personal hygiene tasks); and 4.) the presence of children with severe or profound mental retardation. Pagel and Whitling (1978) found that 45% of the families who readmitted their son or daughter to Pacific State Hospital in California did so because of lack of respite care services. Obviously, home care may prove to be a burden unless the family receives relief services from the community.

This paper describes the development of a volunteer in-home respite care program by the Severely Handicapped Community Training Project and St. Joseph's Villa in Richmond, Virginia. St. Joseph's is a non-profit, non-sectarian child care facility funded by private contributions and endorsement funds. The organization had been operating a center-based weekend respite program to serve individuals under 21 years who were mentally, physically, or emotionally disabled. (The staff consisted of two full time employees; one had an undergraduate degree in special education, and the other had an undergraduate

degree in speech therapy and a Master's degree in pre-school handicaps.) The center-based program had received numerous requests for in-home respite care services but had been unable to provide staff to meet the demand. The staff asked the Severely Handicapped Community Training Project (S.H.C.T.P.) for assistance in developing a training course that could be used with volunteers. The S.H.C.T.P. was a three-year federally funded contract from the U. S. Department of Education designed to provide training to individuals in the community who worked with severely handicapped persons. The staff consisted of three full-time staff members who had advanced degrees in education of persons with severe handicaps, and one who had an additional degree in occupational therapy. Services from the project were provided at no cost.

Parent Survey

An initial component of the development of the training program included the development of a survey related to in-home respite care services, which was mailed to 120 families who already used the center-based program. Thirty-four percent of these families responded to assist in determining parental needs. The mean age of the respondent was 41 years, but the sample included individuals in an age range from 27 to 69 years. Ninety-three percent of the respondents were mothers, with the remaining respondents represented by one father, one grandfather, and one step-mother. Ages of the handicapped individuals being cared for ranged from 2 to 22 years with a mean age of 12 years. The primary disability noted was mental retardation (66%); other categories included cerebral palsy (10%); multi-handicaps (12%); and autism (7%).

The first portion of the survey was designed to determine the need for in-home respite services and to define parental expectations for the proposed volunteer care providers. Results showed that 44% of the respondents said they needed a sitter once or twice per month and 56% said three times or less. The

majority of the respondents (90%) preferred that the sitters be over 16 years of age, with 26% requesting 16-18 years, 33% selecting 19-21, and 31% choosing 21 years or older. Sixty-five percent indicated that they would use a sitter for long periods of time, i.e., all day or all week-end versus only for several hours. They also preferred to have a sitter available in their own home rather than use the sitter's home or the center-based program. Many respondents (4.5%) also expected the sitter to care for other children in the family.

The second part of the survey asked the parents to comment on the content of the training program. They were asked to score each of nine topics indicating whether it was not important for training, minimally important, important, or very important. Table 1 indicates the percentage of each rating for every topic.

Table 1
Respite Care Training Topics

Topic	Not Important	Minimally Important	Important	Very Important
1, Behavior Management	0%	19%	22%	59%
2. Care of Wheelchairs	0%	24%	52%	24%
3, Characteristics of Mental Retardation and Physical Handicaps	0%	3%	60%	37%
Communicating with Parents i.e. how to ask questions; provide information about their child	0%	3%	58%	39%
5. Dressing	0%	43%	45%	12%
6. Feeding Handicapped Children	0%	12%	50%	38%
7. First Aid	0%	13%	56%	31%
8. Leisure/Play Skills	0%	18%	51%	31%
9. Lifting and Positioning Skills	0%	6%	55%	39%

In reviewing Table 1, behavior management was noted as the most important training component with 59% of the respondents selecting "very important". This was not surprising, and behavior management traditionally has been included in training packages. Another area of concern was the ability of the sitter to communicate with the parent regarding the handicapped individual. Respite care trainers might consider adding a session using role play activities to train care providers in talking with parents. Also of interest is parents' desire that respite care providers understand characteristics of handicapping conditions. Sixty percent replied that this was an important concern, and 37% stated it was very important. An almost equal number responded that it was important to train in the areas of personal care for the handicapped, first-aid, and leisure skills.

Program Development

Staff from the two agencies recruited volunteers interested in becoming volunteer caregivers by posting flyers at local churches, universities, and high schools, broadcasting public service announcements on the radio, placing notices in the newspapers, and sending letters to local service organizations. Within a month, 25 individuals had expressed interest in completing a training program to become respite care providers. The volunteers ranged in age from 16-58 years, with only three having any previous training working with persons with severe handicaps.

The Severely Handicapped Community Training Project staff was responsible for developing the training materials for the participants. The major focus was to develop a training package that could be implemented by the two staff members of St. Joseph's Villa respite program on a repeated basis with a minimal amount of outside assistance. Therefore, the manual was developed in a "script" format that anyone could implement, rather than requiring specialists who might be

difficult to locate. The only section for which the staff did not assume responsibility was first aid. It was discovered that rescue squad volunteers or the Red Cross could easily provide this assistance.

The second area of concern was to develop a training program that would be informative, but not presented in a predominantly lecture format. Therefore, most of the information that has often been delivered in a classroom atmosphere was incorporated into skits, role play activities, group discussions, slide-tape shows, and practical application situations. The focus was to encourage the participants to have fun while learning valuable information related to becoming trained care providers.

The topics selected to be covered included characteristics of persons with severe handicaps, communicating with parents, first aid, behavior management, leisure-recreation activities, and physical management of handicapped individuals. These topics were presented in four two-and-one-half hour sessions over a one-month period. One practical session was required for the physical management information, and each volunteer spent one Saturday at the center-based respite care program. These two sessions provided all trainees with "hands-on" experience with children who were severely handicapped. The Severely Handicapped Community Training Project assisted with the first class, but all subsequent groups have been trained by the two St. Joseph's staff.

Class sizes have ranged from 8 to 14 volunteer members. Sample training sections follow this article in the monograph.

Care Provider Utilization

After the volunteers completed the training program, their names were placed on a list of trained care providers maintained by the St. Joseph's staff. The in-home respite care service was then advertised to parents who were on the

mailing list for the center-based program. Forty-five families used the list during the first year of the program. The utilization procedure for families included the following steps:

- 1.) Pay \$10 annual fee to cover center expenses of maintaining baby-sitter list.
- 2.) Call center-based program to request sitter.
- 3.) Talk to program supervisor (either staff member).
- 4.) Receive name of trained sitter that is available (program supervisor finds an available care provider.)
- 5.) Call sitter and arrange time and fee. (St. Joseph's recommends a fee of \$2.00 - \$4.00 per hour.)

The attached appendix includes the forms that the St. Joseph's staff uses for keeping updated information on families who use the service.

Discussion

All of the families who have used the service have requested sitters 18 years or older. This is consistent with the parent survey results. St. Joseph's staff reports that parent evaluations of the care providers have been consistently positive. Sample comments include:

."[The care provider] takes a personal interest in [our child] and he responds to her beautifully. We feel very confident with his time spent with [our child]."

."We were pleased [with the care provider]. She made an initial visit to meet the children and talk about routines we had. The evening she sat seemed to go well. The children were happy"

."The arrangements were very prompt!"

The training program proved successful in providing in-home care provider an extension of services to an existing center-based respite care service. It is felt that any agency that currently serves families of individuals who are

severely handicapped could implement a similar volunteer service with minimal expense. The greatest expenditure of time is involved in recruiting and training the volunteers. An estimate of the time required for training one group of 8 to 14 volunteers using the existing materials (see Appendix), including preparation time, would be 25-30 hours. After the initial class preparation and training sessions, responsibilities are reduced to phone calls for matching care providers and baby-sitters and to evaluating service provision. In some cases, agencies may be able to recruit outside professionals to voluntarily teach the course. This would even further reduce time commitments from the sponsoring agency.

Another positive aspect of this training program was the delivery format. Volunteers clearly preferred the informal atmosphere rather than formal lecture sessions. This appeared to be a reinforcing variable which kept the volunteers returning for training sessions. Future programs may be interested in determining if this makes a significant difference in recruiting and maintaining care providers and if the format affects the eventual quality of care provided.

Appendix A
Parent Survey

Severely Handicapped Community Training Project
In-home Baby-sitting Questionnaire

Relationship to child: (mother, father, etc.) _____

Age of person completing this form: _____

Age of handicapped family member: _____

Average number of times a sitter is used per month: _____
(excluding day care, St. Joseph's center program, school)

Disability of child (i.e. mental retardation, CP, etc.) _____

Circle ONLY ONE

1. I would use a trained baby-sitter recommended by St. Joseph's who knows how to work with physically handicapped children and who is at least
 - a. 12 years old
 - b. 13-15 years old
 - c. 16-18 years old
 - d. 19 - 21 years old
 - e. older than 21

2. I would consider using an untrained baby-sitter (please fill in age if you select B)
 - a. Never
 - b. if over the age of _____
 - c. if recommended by another parent or friend
 - d. if I knew the person
 - e. b, c, and d

3. I prefer that my child be taken care of by a baby-sitter
 - a. in my own home
 - b. in the baby-sitter's home
 - c. at St. Joseph's center based respite program
 - d. no preference

4. I would use a trained baby-sitter in my home
 - a. for short periods of time (2 hrs. or less)
 - b. for an evening out
 - c. all day
 - d. over-night
 - e. all week-end
 - f. other (specify) _____

5. If you have other children in the family would you
 - a. expect the trained baby-sitter to sit for them
 - b. make other arrangements for their care

For each of the following items, rank them in relationship to their importance for training baby-sitters. Circle the number using the following scale:

	not important 0	minimally important 1	important	very important	
		not important	minimally important	important	very important
1. Characteristics of physical handicaps and mental retardation	0		1	2	3
2. Behavior management i.e. how to cope with aggression, self-abuse, inappropriate behaviors, etc.	0		1	2	3
3. First Aid	0		1	2	3
4. Talking with parents i.e. how to ask questions, provide information about their child.	0		1	2	3
5. Feeding physically handicapped children who have problems.	0		1	2	3
6. Dressing handicapped children.	0		1	2	3
7. Care of wheelchairs, braces, appliances for the handicapped.	0		1	2	3
8. Lifting and carrying techniques (How to move the child who can't walk).	0		1	2	3
9. Leisure-play activities for handicapped and retarded individuals.	0		1	2	3

Please feel free to comment on the idea of having trained baby-sitters available.

Appendix B

St. Joseph's Forms

SAINT JOSEPH'S VILLA
IN-HOME RESPITE
REGISTRATION FORM

Name of Client: _____
Last First Ni ckname

Name of Parents: _____

Address : _____

Home Phone: _____ Business Phone: _____ Mother: _____
 Father: _____

Client's Birthdate: _____

Emergency Contact: _____
Name Relationship
Address Phone: _____

Names, birthdates of other children at home: _____

P e d i a t r i c i a n : _____ Phone: _____

Neurologist: _____ Phone: _____

Hospital Preferred: _____ Phone: _____

Dentist: _____ Phone: _____

School (if any): _____

Type of Handicap: _____

Height 6 Weight: _____

Communication Skills: _____

Self Help Skills: (Toileting, Dressing, Feeding, etc.) _____

Ambulation: (Does client walk? Use wheelchair?) _____

Degree of Retardation (if applicable): mild ___ moderate _____ severe

Any emotional problems? _____

Brief description of condition, special problems, etc.

Immunizations (give exact dates):
 Polio _____ Rubella (German Measles) _____
 Smallpox _____ TB Tine Test _____
 DPT _____ Mumps, Other _____

CLIENT INFORMATION SUMMARY:
CONTINUED

Toilet Habits

- a) Is he/she toilet trained? _____
- b) How does he/she indicate need to use bathroom?
- c) Can she/he use standard toilet fixtures? _____ If not, explain?

other _____

d) Does he/she use any special equipment (Wheelchair, braces, helmet?) If so, then is this equipment used? _____

e) Can he/she: sit up alone _____ Stand _____ and _____ Walk _____ Run _____
Climb stairs _____ Other. _____

f) Does he/she have speech _____ if not, describe how child/adult makes
wants understood: _____

Does _____ he/she understand language ?

Emotional Characteristics

a) Does he/she like to be cuddled and/or _____ hugged? _____

b) Has he/she ever been away from home _____ Ever been cared for by someone other
than family? _____

c) If he/she is hyperactive and/or has any emotional problems, describe any behavior
that care provider should know about and what should be done.

d) What kind of discipline is most effective with this person?

e) Describe in detail any special behavior program that should be followed;

f) How much supervision does he/she require? _____

Describe a typical day's schedule for the child/adult:

Recreation

1. List this person's favorite activities.

2. Where are this person's toy/recreation equipment located.

3. What areas of your home (if any) are "off limits" to this person.

4. Does this person have any medical problems affecting recreational activities.

CAREGIVER EVALUATION FORM

ST. JOSEPH'S VILLA RESPITE CARE PROGRAM

In Home Services
8000 Washington Hwy
Richmond, Va 23227

We are constantly trying to upgrade the program to meet the needs of the families and care providers involved. Therefore, we would appreciate your prompt response to the following questions. Please complete the form and return it to Saint Joseph's Villa after each respite service.

YOUR NAME:

NAME OF CLIENT:

HOURS AND DATES OF SERVICE:

CARE PROVIDER USED:

Were you satisfied with the care your child/adult received from the care provider?
Please Comment.

Would you like this care provider referred to you again?

Were you satisfied with the Saint Joseph's Villa referral procedure? Please explain.

Any other comments about this referral or program in general.

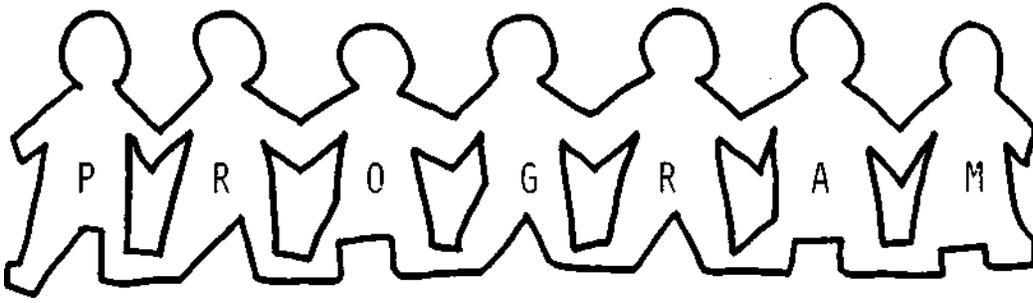
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Respite Care
Training Manual

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CHARACTERISTICS

- I. FIND YOUR OTHER HALF
- II. COMMON MISCONCEPTIONS
- III. CHARACTERISTICS OF VARIOUS DISABILITIES

Materials Needed for Characteristics Presentation

Cards for Introductory Activity - "Find your other half"

Extension Cord

Masking Tape

Name Tags

Paper Cutouts of the Various Disabilities

Pencils

"Points to Remember" Handout

Slide Projector and Slides

Tape Recorder and Tape

Characteristics of the Handicapped/Disabled Person

I. Introduction: Opening Activity/"Find Your Other Half"

We are here today (tonight) to learn more about various handicapping conditions that the children you will be working with have. Often we all have common misconceptions about what people can do who are different from us. In talking about the characteristics of handicaps and in participating in various activities, I hope we will gain a better understanding of what our special children are like.

In order for us to get to know, each other a little better, I have written the names of the disabilities we will be learning more about on cards. I've taken each and divided it into two parts, writing one half on one card and the other half on another.

Hold up the two cards
with MENTAL RETARDATION
on it for an example.

I'm going to pass out these randomly, and when I say "go," I want you to find your other half. After you have found your partner, write down two things that come to mind when you think of that handicap.

Pass out the cards.
Say "Go."
Wait until everyone is finished.

I'd like for us to share some of the thoughts you had about each handicap.

Go around the room encouraging
groups to share their opinions.

Words to be printed on cards

1. Mental Retardation
2. Cerebral Palsy
3. Seizure Disorders
4. Multiple Handicaps
5. Emotional Disturbance
6. Orthopedic and other health impairments
7. Down Syndrome

II. Common Misconceptions: "Fact or Myth"

Leader: We have just taken a few minutes to talk about what you think handicapped and mentally retarded people are like. Now let's look closer at some common misconceptions many "normal" people have regarding handicapped persons.

I am going to pass out a "True/False" survey. We will answer each question one at a time after everyone has a chance to mark his/her answers.

Pass out the "Fact or Myth"
Survey Form

Leader: Let's talk about our answers together. Everyone should feel free to speak out! No one will be teased for giving the wrong answers. Remember these are common misconceptions.

Go over the items in the survey. The following statements are offered as suggestions for discussing each point you want to cover.

Note: You may want to use a slide show that uses various pictures of retarded/handicapped people to emphasize your opinion of each true/false question.

Fact or Myth Survey on Handicapped Persons

Item 1: All retarded people should generally be treated like children because that is their cognitive functioning level.

1 False

Answer: As long as we treat a retarded person as a child, s/he will act like a child. Everyone is capable of learning and growing. By allowing the individual to participate in adult activities with adult responsibilities, s/he will be better accepted and integrated into the community. We want retarded individuals to be as independent as possible. Thinking of them as children regardless of age never allows them to reach their greatest potential.

Item 2: When retarded people grow up, most really can't hold down productive jobs, but they can make intricate craft items.

False

Answer: The old philosophy in working with retarded people was that they could not be productive. Most professionals felt that they could be kept busy making craft items.

The current trend, however, indicates that most retarded persons can hold jobs and be very productive. There are many workshops especially designed for handicapped/retarded people. Also there are many competitive jobs available, such as janitorial services, food services, and clerical work. If a person can learn a craft (some of which are complicated), s/he

can learn to work.

Item 3: Anytime you see a disabled person having difficulty doing something, jump right in and help him/her.

False

Answer: Many disabled people will have difficulty completing tasks that are normally very easy, such as putting on a coat or eating a meal. We need to let them be as independent as possible. Jumping in to provide help could make them feel helpless or useless. Always ask before giving assistance if the person can communicate. If s/he can't talk, ask the parents what help is needed.

Item 4: Luckily, almost all retarded people are happy.

1 False

Answer: Retarded people have the same "ups and downs" that everyone else has. This means they are equally happy, sad, worried, satisfied, etc. as "normal" people are. Some people think they are happy all the time because they don't have the same kinds of problems/worries. This is a misconception since everyone has difficulties relative to his/her own life situation.

Item 5: Most retarded people are only mildly retarded and generally live normal lives when they grow up.

True

Answer: Many people are mildly retarded and have difficulty learning in school. However, they become adults who commonly lead productive lives working and participating in the community.

Item 6: Handicapped people really feel more comfortable around other handicapped people.

False

Answer: The old assumption was that handicapped people were better off "with their own kind." This rationalization was often used when people were institutionalized. We know that most people are happier when placed in as normal an environment as possible.

Often severely handicapped people can't talk and don't socialize with each other. When placed together, they have little opportunity to interact. These same individuals, however can become a more integrated part of their environment when we interact with them and help them get out into the community.

Item 7: Almost all blind people have some residual sight.

True

Answer: Many blind people can often see lights, shadows, and shapes. Few are totally blind with no visual awareness.

Item 8: The best way to guide a blind person around is to hold his/her hand or take him/her by the arm.

False

Answer: You should allow the blind person to hold onto your arm at the elbow. He/she should then follow a pace or two slightly behind you in order to anticipate your actions. Be sure to tell him/her when you are turning, stepping off curbs, going up steps, etc..

Item 9: A person may have physical problems caused by cerebral palsy and still have normal intellectual processes.

Answer: A person who is physically handicapped is not necessarily retarded. Some people with cerebral palsy who can't do anything for themselves have normal intelligence.

Item 10: People with epilepsy are usually also mentally ill.

Answer: Epilepsy is a disorder in the neurological functioning of the brain. It has nothing to do with the person's sanity or insanity.

Item 11: People with a hearing loss can speak normally.

True [

Answer: A person with some hearing can generally learn to speak normally.

Item 12: You should really not make retarded people do anything, because they tend to get angry or aggressive.

False

Answer: Everyone should have expectations to complete. Retardation should never be used as an excuse. Allowing someone to get away with doing nothing is really a dis-service. Often, allowing a retarded child to do nothing causes more problems when the child becomes an adult and is expected to complete certain responsibilities. Teach them early, as any normal child should be taught, that there are things expected of them.

Item 13: Retarded men are often sexually aggressive.

False

Answer: This is a myth that people used to believe. There is no truth to it.

Item 14: If a disabled person has trouble saying something or just takes too long, say it for him/her.

False

Answer: Think about it. Would you want someone talking for you? How did you feel when you were younger and one of your parents would "talk" for you?

Item 15: All of us have some kind of impairment.

True

Answer: Many of us wear glasses, have a slight hearing loss, can't complete tasks others find easy, etc. No one is

perfect!

After completing the survey,
pass out the "Points to
Remember: sheet. Briefly
outline the points listed on it
in closing this topic.

11. People with a hearing loss can usually speak normally.

True

False

12. You should really not make retarded people do anything because they tend to get angry or aggressive.

True

False

13. Retarded men are often sexually aggressive.

True

False

14. If a disabled person has trouble saying something or just takes too much time, say it for him/her.

True

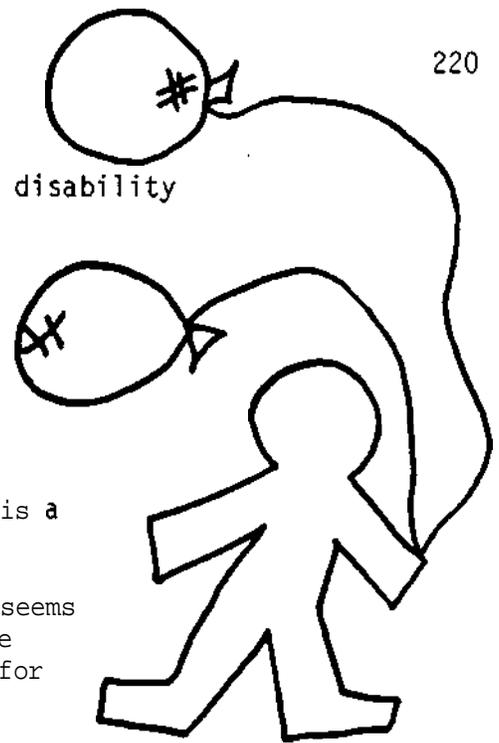
False

15. All of us have some kind of impairment.

True

False

Points to Remember
when you meet a person with a disability



Remember that a person with a disability is a person—like anyone else.

Offer assistance if asked or if the need seems obvious, but don't overdo it. Respect the person's right to do as much as possible for him/herself.

Appreciate what the person can do. Remember that difficulties the person may be facing may come from society's attitudes and barriers rather than from the disability itself.

Remember that we all have handicaps; on some of us they show.

Speak directly to the person with a disability. Don't ever talk "about" them when they are present even if you think that they don't understand.

Don't move wheelchairs or crutches out of reach of a person who uses them.

Give whole, unhurried attention to the person who has difficult speaking.

Don't talk for the person, but give help when needed. Keep your manner encouraging rather than correcting. When necessary, ask questions that require short answers or a nod or shake of the head.

Don't talk "baby-talk" to a person who is physically and/or mentally handicapped. It is often easy to treat these individuals like infants even though their age indicates that they are not.

Characteristics of Various Disabilities

Trainer: We are going to be discussing the various characteristics of six different disabilities. First of all you must remember that we work with children and adolescents, not handicaps. Try not to concentrate on the problems they have. For example, you should never refer to a "Down syndrome boy," but instead say, "a little boy named Johnny who has Down syndrome." We all have problems, some of which we might not want to be known by!

These are the disabilities we will be defining:

1. Behavior Disorders
2. Cerebral Palsy
3. Down syndrome
4. Epilepsy
5. Mental Retardation
6. Multiple Handicaps

You may want to put up a poster that has these six disabilities listed on it.

Behavior Disorders

You may baby-sit for children with severe behavior problems. These children have inappropriate behaviors, such as self-abuse (e.g., banging their heads), aggression, self-stimulation (e.g., rocking excessively), hyperactivity, destructiveness, etc.. Some children will not interact with the environment and don't seem to enjoy playing with things or other people. Many times no one knows what causes the problem. Sometimes children learn to act bad in order to cause problems, or get out of doing things. We can control children with behavior management techniques, which you will learn about in another training session.

As you are talking you can I
pin up a giant cut-out with
these characteristics listed
on it. See "cut-out"
characteristics for ideas.

Cerebral Palsy

Children with cerebral palsy had damage to the brain sometime during the first year of life or while in the mother's womb. This problem does not get worse. Most people will have difficulty moving and not be able to walk. Some will have problem using their hands. Others may have difficulty eating and doing many of the things you and I take for granted. This cannot be cured, but children can learn to move better and take care of themselves to the best of their ability.

Down Syndrome

Individuals with Down syndrome have one more chromosome in their body than normal. You might notice that their eyes appear slanted due to an extra fold of skin on the eyelids. Many are short in stature, with short fingers and toes. Often they will have hearing problems as well as heart defects and mental retardation. These children can learn to do a lot for themselves and can become productive community members if given the proper training.

Epilepsy

Anyone can be affected by epilepsy. This is not a disease but a symptom of a brain disorder which can be caused by birth trauma, brain tumors, head trauma, or car accidents. The most severe seizure type is called grand mal. This type results in loss of consciousness with muscle

jerking and thrashing and a possible temporary loss in bladder control. Petit mal seizures are less severe with only a momentary loss of consciousness. The eyes may roll upwards and flicker, and the head may nod or jerk. Seizures usually can be controlled if the person is taking his/her medication properly. It is very important that you give any medicine the parent asks you to at the proper time and in the right amount. Missed medication can result in seizures!

Mental Retardation

People with mental retardation have below average intellectual functioning, with problems learning basic everyday tasks. These could be such things as learning to dress, feed, and toilet. With proper training, mentally retarded people can develop basic skills and work and live in the community.

Multiple Handicaps

These individuals have two or more handicaps that usually result in severe problems. They could have a combination of any of the following disabilities:

- mental retardation
- blindness
- deafness
- cerebral palsy
- spina bifida
- epilepsy
- behavior disorders
- etc.

After you have finished the talk on characteristics, show the slide show. There should be a slide for each child that represents the different disabilities. See Script for characteristics, "Hello my name is. . ."

"Cut-Out" Characteristics

You may use brown butcher paper to make six giant five-foot paper doll cutouts. This serves as a visual aid to the audience while you are talking. Put up one at a time so that at the end of the presentation all six cut-outs will be side by side on a wall.

Doll #1: Severe Behavior Disorders

Inappropriate behaviors

- self-stimulation
- self-abuse
- echolalia
- autism
- hyperactivity
- may be
 agressive
- tantrums

Doll #2: Cerebral Palsy

Non-progressive disorder of movement occurring by the first year of life.

Characteristics

- abnormal muscle tone
 spasticity/athetosis
- sometimes mental retardation
- speech deficits
- oral problems

Causes

- birth trauma
- infections
- anoxia
- unknown

Doll #3: Down syndrome

Chromosome defect

Characteristics

- sometimes mental retardation
- physical characteristics
 - short fingers and toes
 - slanted eyes-extra fold on eyelids
 - large tongue
 - fine hair
- heart defects/circulatory problems
- decreased muscle tone

Doll #4: Epilepsy

1. Anyone can be affected
2. Not a disease but a symptom of
 disturbance in a group of brain cells

Types

- Grand mal
- Petit mal

Causes

- birth trauma
- brain tumors
- head trauma
- car accidents

Treatment

medication (very important)

Doll #5: Mental Retardation

Decreased intellectual functioning

Characteristics

- often can't talk
- decreased ability to learn
- decreased attention span
- difficulty learning simple daily tasks

Causes

- birth injury
- prematurity
- genetic
- maternal illness
- often unknown

Doll #6: Multiply handicapped

Individual has two or more disabilities such as:

1. mental retardation
2. deaf
3. blind
4. spina bifida
5. behavior disorders
6. cerebral palsy
7. epilepsy
8. speech impairment
9. orthopedically impaired

Script for Characteristics Slides
"Hello, my name is"

MENTAL RETARDATION

Hi, my name is Melanie, and I'm mentally retarded. Sometimes I don't understand when people tell me things but if you'll tell me in plain talk I will understand. I get mad when I can't do things like tie my shoes and button my shirt. My teacher is helping me to learn to do these things. She's nice, she says, "You've done a good job!" Since I'm just learning things you may have to help me. But give me a chance to do it myself. See, I'm really like any other kid, I like to play, I like to learn to do new things, I like school. You'll have fun babysitting me! We have good food!

DOWN SYNDROME

My name is Danny, I have Down syndrome. I was born looking this way. My eyes are kind of slanty and sometimes I talk funny. I have short fingers and short toes. Hey, guess what, if you'll come baby-sit me, we'll arm wrestle. Oh, yes one more thing--I have trouble learning. When I was born the doctor told my mom I was mentally retarded, but my teacher is teaching me to be a busboy at McDonald's. If you'll baby-sit for me we can have a Big Mac and a Coke. It's only across the street.

MULTIPLE HANDICAPS

Hi, I'm Mrs. Johnson. My son, Jimmy, has quite a few problems. He's blind, he's mentally retarded, and he is physically handicapped. In other words, he has three big problems, but he's a good little boy. Jimmy loves to talk to people even though he can't talk very well. He really likes to listen to stories and records. He can't get around by himself. If

you babysit you'll have to move him from place to place in his wheelchair, but that's really no trouble. Everyone who meets Jimmy likes him. In spite of all his problems he's a delightful child. I do hope you'll come meet him.

CEREBRAL PALSY

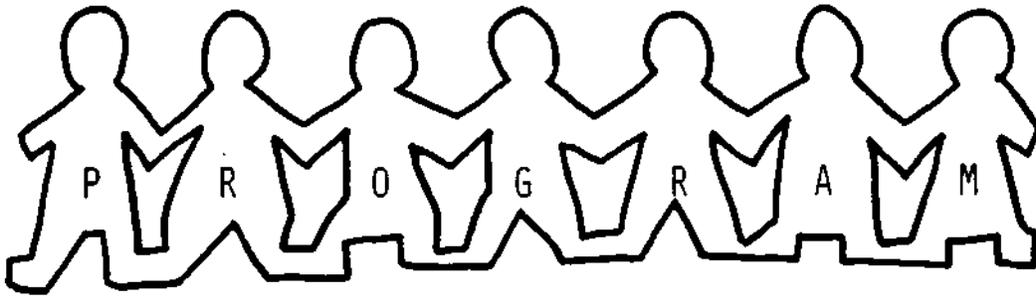
My name is Craig. I have cerebral palsy. Don't let my looks fool you, I'm a straight "B" student. My problem is my muscles don't work right. I can't feed myself. I've tried, but it's a mess. You'll have to feed me. Oh, I better tell you something I do. You might think it looks icky. It's called drooling. Don't be scared. I'm working on stopping it. My therapist is teaching me to swallow. Soon this won't be a problem. Don't be afraid of the way I look. I think, I feel, I cry, I love people. We'll have fun if you'll come babysit for me. Bet I can beat you at a game of checkers.

SEIZURE DISORDERS

My name is Susie. I'm a very normal kid with one big problem. It's called grand mal seizures. Boy, will it scare you the first time you see me have one. Let me tell you what happens to me. My body gets stiff, and I mean stiff. My arms and legs thrash and jerk like crazy. I hate to tell you this but sometimes I wet my pants and drool. This really embarrasses me. I'm lucky though. If I take my medicine I usually don't have seizures. My parents worry a lot when they go out, so sometimes they won't go. If you'll come babysit me it'll be nice cause my parents can have a good time and we can play house. I have lots of neat dress up clothes you'll like.

SEVERE BEHAVIOR PROBLEMS

My name is Louise. I'm talking for my sister, Elsie, who has severe behavior problems. She doesn't talk very much. Hope this doesn't scare you off. My parents and I really need a break. We never get to go anywhere cause people think Elsie is crazy. She's not. Let me tell you about her. She doesn't like anyone touching her. No big deal. Find other ways to play with her. She loves to rock and flap her hands. School is helping her with this. If you babysit, and I really hope you will, we'll tell you what to do when she rocks and flaps. Sometimes you'll see her sitting and doing nothing. You'll have to help her enjoy playing. Hope to see you at our house. Hey, we have cable T.V..



BEHAVIOR MANAGEMENT

SKIT

MANAGING CHILD BEHAVIOR

RELATING TO PARENTS

BEHAVIOR BINGO

CLOSING ACTIVITY

Materials Needed for Behavior Management Presentation

Baby-sitter kit to include:

- (1) soap
- (2) rope
- (3) aluminum foil badge
- (4) masking tape
- (5) key
- (6) candy
- (7) telephone
- (8) baby-sitter outfit

Behavior Management hand-out

Behavior Management program

Magic Markers

Masking Tape

Newsprint pad or blackboard

Role play cards for communication activity

SKIT - BEHAVIOR MANAGEMENT

(Do not tell the audience that they are going to see a skit.)

Straight man: "Ladies and gentlemen, today we are going to be talking about managing inappropriate behaviors. We are privileged to have a guest from VCU who will be part of our program today."

PAUSE - Look slowly around the room and say:

"Excuse me a minute while I check to see if she has arrived."

LEAVE THE ROOM

Miss Ima Crazy enters the room very erratically and says:

"Lordy, I've struck it rich. A whole room of babysitters. How long is that leader gonna be out of here? Well I've got to be quick, but I have a surprise for you. First of all, let me give you my credentials."

REACH INTO POCKET AND PULL OUT LONG LIST.

"Well, I've been baby-sitting for over 25 years. Let me tell you, I know how to keep all those little brats in line! I'm willing to sell you my fool-proof baby-sitter's kit real cheap. Then you won't have to sit around and listen to a boring lecture!"

HOLD UP KIT AND SAY. . .

"This is it. Guaranteed to make kids mind everytime! Let me give you a free sample of what's inside."

PULL OUT ONE ITEM AT A TIME AND SAY:

SOAP: Now most Mom's might ask you to give their little kid a bath. This is the perfect thing to do when he's being bad. Why, you can wash that little monster's mouth out with soap! It works every time.

PLAY BADGE & ROPE: *This is a great little trick. When the brat has run around the house just one too many times, just tie him in a chair! * If mom and dad comes in all you have to say is that you were playing cops and robbers. Everyone knows that the bad guys get tied up when they're caught.*

*Tie one of the participants in the chair and then pin on the badge as you say this.

MASKING TAPE: Pull a piece off; walk up to someone in the audience and say:

"This keeps 'em quiet. Nothing drives me battier than a bunch of yakking kids."

KEY: *"This is wonderful! It's the key to the bedroom. Why you can just lock those kids away while you enjoy watching your favorite T.V. show or talk on the telephone."*

BIG BAG OF CANDY:

"These work wonders. Everytime those little monsters are bad or get in your way, just give them some of these. They'll be quiet for at least a few minutes. If it's a long night, be sure to take along a large bag!"

TELEPHONE:

"This is a babysitter's best friend. Just call up everyone you can think of and let the kid do anything he wants to."

"Well ladies and gentlemen, you have just witnessed some of the best tricks of the trade. This fantastic kit is only 50 bucks!"

STRAIGHT MAN ENTERS THE ROOM AND SAYS:

"What in the world is going on here? We don't have any maid's positions here."

MISS CRAZY PUTS HER HAND ON HER HIP AND SAYS:

"Who you talking to joker? I may be an old maid, but it ain't because I applied for the position. I was just leaving."

LOOK BACK AT AUDIENCE AND SAY:

"I'll set up my stand by the front door. Bring your money out at your break!"

At the end of the skit the trainer should enter and say the following:

TRAINER: Of course "Harriet" has just told us all the wrong ways to cope with children when they misbehave. Today (tonight) we are going to talk about what you can and should do when you baby-sit to prevent and control bad behavior.

"How to Make it Through the Night!"

Preventing and Managing Child Behavior

Before we can talk about how to manage child behavior, we need to talk about why children do the things they do.

Ask audience to give reasons
why children misbehave.

Reasons for misbehavior:

1. For attention. . . .Children will act "bad" if you are not paying any attention to them. We often make the mistake of leaving kids alone when they are being good and paying attention to them (even if it is negative attention) only when they are doing something we don't like.

2. When they are bored. . . .Children seem to get into more trouble when there is nothing else to do.

3. To make you angry. . . . Kids will act "bad" just to see you get angry. They will often laugh and think it's funny when someone gets excited over something they have done.

There are many things you as babysitters can do to control what happens during the time you sit with a child. The first one that we are going to talk about is positive reinforcement.

What is Positive Reinforcement?

Positive reinforcement can also be called positive rewards. For example, when you clean your room and your mother tells you what a good job you have done, she has rewarded/reinforced you for good behavior. You most likely will repeat cleaning your room again and again in order to receive your mother's praise. Offering your dog a bone for doing a trick is also an example of reinforcement/reward. The pet will do what you ask in order to get the treat.

We all work for rewards

For example:

1. We all work to earn money.
2. We often do what our parents/friends ask of us to receive their approval.
3. John may cut the grass when his dad says that he can use the car after he is finished.

ACTIVITY

When I say "go" list as many activities or items as you can that you like.

Allow one minute. Then ask the group to share their work.

The activities, items that you have listed can be called positive reinforcers. You all will "work" to be able to have or do the things on your lists.

Pick someone's example in the audience and demonstrate how you could use this as a positive reinforcer.

Many times you as babysitters can prevent or stop bad behaviors by knowing how to use positive reinforcement. First you need to become familiar with what is rewarding to each child you babysit for. All children do not like the same things. _____

Point out that everyone's lists are different. One person might not like what someone else does. Ask the group to pair off in two's and swap lists. Each person should pick an item off their partner's list that they do not find reinforcing.

How can you find out what rewards kids like?

Pause and go over to large pad of paper. Use this to write down their ideas as well as to include other points.

1. Ask parents what is rewarding to their child. Also find out if it is all right to use these items or activities as rewards.
2. If parents don't know,ask about the following. . .
 1. favorite toy/game
 2. favorite thing to do
 3. favorite snack
 4. responds to praise?
3. Watch the child while you are babysitting. You can often learn what things s/he prefers when s/he is playing or eating dinner. For example, he/she may always play with one particular toy which may be used as a reward for good behavior.

Now that we know what positive reinforcement is, let's talk about how you go about using it when you babysit. We said that kids often misbehave to get our attention. Therefore we need to provide attention/reinforcement when our kids are being good.

LET'S SET UP A GAME PLAN

Play 1: Find out what bad behaviors/negative things the child might do during the time you are babysitting. Ask parents what you might expect (e.g., tantrums, aggressive behaviors, running away, hurting self or others). Then find out what behaviors are not serious to the parents, like rocking or thumbsucking. You may not want to try to prevent these behaviors, since the parents do not see them as important. Also, trying to prevent some things may result in worse behavior.

Play 2: Find out what the parents do when the child misbehaves. Ask if you can do the same thing. For example, there may be a specific program that should be followed as soon as the child does something. Be sure you understand before they leave, and you're on your own.

Play 3: Find out what things the child should do, such as go to bed at a specific time, undress himself, put his toys away, etc.

Play 3: Go over what is rewarding to the child.

Play 4: Briefly figure out the natural breaks or changes in the time that you will be babysitting. For example, a typical evening might be:

1. play-time
2. preparation for dinner
3. eat dinner
4. clean up
5. more play
6. prepare for bed
7. bedtime

Play 5: Concentrate on each period separately. If the child understands, explain to him/her what is expected. Give the child positive attention when he/she is being good. Remember, children act out to get our attention!

Role play: Example
Have child playing
quietly. Second
person demonstrates
positive reinforcement.

Play 5: Try to involve the child in some activity during each time frame. Children with nothing to do "act out." Again, reinforce the child while you are doing things together!

Play 6: Arrange the environment so that bad behaviors can't happen. Ask Mom and Dad what things upset their child. Maybe forcing him/her to do something results in bad behavior. For this time frame try to avoid what upsets the child.

Example: The mother tells you that John screams everytime you try to take his toy away from him. You may not want to insist that he give it up as long as it doesn't interfere with some special request the parents have made.

Grandma's Rule of Positive Reinforcement:

Many of us will do something we don't particularly want to do if it allows us to get or do something we want. For example, I might work at night so I could leave early from the office to go to the beach. I

don't really want to work at night but I will in order to get to go to the beach.

Get the participants to make a list of things they don't like to do and a list of what they do. Use several people's lists as examples of this principle.

You can explain to some kids that they can have a certain thing if they are good for a period of time. Let them know that they can have the reward if they are good.

Let's look again at the time slots that we divided our evening into. Also we will talk about what types of reinforcement you could use if the child is good for the specified time period.

<u>Activity Period</u>	<u>Rewards at</u>
<u>Throughout the Evening</u>	<u>End of Activity</u>
Play time	Help with making something for dinner
Good behavior while you are preparing dinner	Extra serving of food
Good behavior at dinner eating appropriately	Dessert
Clean-up after dinner	Play a game after clean-up
Play time	Snack
Prepare for bed	Story or radio

Some points to remember when giving positive reinforcement:

If you have told a child that s/he can have a certain reward if s/he is good, you must follow these rules.

1. Make sure the child understands exactly what is expected.

Don't change your mind. BE CONSISTENT!

2. Don't make threats you can't live up to.

(for example. "You won't get your dinner if you do that.")

3. Leave room for some mistakes. Give one warning and remind him of the reward. Don't give repeated warnings. Follow through with the loss of the reward after one warning.
4. Be neutral. If a child does something wrong, try not to get emotional. Remember, she may be misbehaving to see our reaction. Just say "Because you did that, you missed your chance for the reward." Immediately set up a new time period to gain the next possible reward. Don't dwell on bad behavior.

Punishment

What are we to do if the child is bad?

Often most people's reaction to bad behavior is to punish the child.

What are some things you don't like?

Pause. Let the audience have
time to list things they do
not like.

If you did something bad and I immediately followed it with some act or thing you really didn't like, this would be called punishment. For example, if everytime I smiled you all shouted "NO" at me and I stopped smiling, the loud "NO" would be punishment.

Talk about the lists the
students have made. Punish-
ment can be physical, verbal, etc..

There are several reasons you, as babysitters should not use punishment.

Pause. Ask the audience to
help you come up with reasons,

1. People in general behave better under good, positive situations than under the threat of punishment.
2. Mentally retarded people often do not understand the threat of punishment.
3. Some handicapped people like what you or I might consider punishment. For example a child who is being aggressive may find physical punishment pleasurable.
4. ETHICAL REASONS! You, as babysitters, need to be aware of the rights of the child. Physical and verbal abuse is considered against the law. It is very easy to really hurt a handicapped child with only a slight smack. These children often have brittle bones that are easily broken. You don't want to be responsible for serious injuries!

So what are we going to do when the child is bad?

First we need to remember what behaviors Mom and Dad said were O.K. and which ones were not. Then we can use a technique called EXTINCTION or simply ignoring.

We said that children often exhibit behavior to draw attention to themselves or to bother others. The babysitter should ignore bad behavior and look for good behavior to reward.

Role play...babysitter with a child who is being really bad. Sitter should ignore the child until good behavior occurs. Reward should then be given.

You must ignore the bad behavior completely. The least bit of attention could result in the child continuing to do what you don't like.

Sometimes we should not ignore behaviors. When should we not interfere and when should we?

Encourage the group to come up with a list of when to interfere and when not to.

1. Dangerous situations.
2. Protection of property.
1. If you decide that you must interfere, you should begin by firmly telling the child to stop what he/she is doing. Do not get excited. Calm control will always work better. Say it with authority but don't say it loudly.
2. If saying NO_ does not work, do not repeat yourself or make threats. Many times we cannot carry out threats we make.
3. Often moving the child to another room or taking him/her out of the situation will help. Re-direct their attention to some other activity, if possible. For example, if the child is in the kitchen screaming for food he can't have, get him out of the kitchen doing something else. If she is throwing things at the T.V. set that might break it, move her to another room or activity.
4. If a child is hurting himself physically, you may need to stop him. Be careful...do not use excessive force. You could hurt a child if you roughly grab him to stop self-abuse. Just firmly try to physically control him so that he stopshurting himself. Do this for as brief a period as possible. Always say "no hitting," etc. in a firm voice. Be calm. Act with authority. Try to redirect the child's attention elsewhere. Reinforce good behavior.

Role play a child who is hitting his face. Babysitter enters and says "NO". Take the child's wrists and hold them down for 10 seconds. Say "good" and direct hands to a toy.

5. Another thing you could try is called time-out. This simply means that the child is taken out of the situation where he is being bad, and you do not pay attention to him for a brief period of time.

Role play two examples of time-out.

1. Minor time-out. Babysitter says to the child who is being bad... "I am not going to play with you when you do that." Babysitter moves away and starts reading the paper. This should be for a brief period of time.

2. Major time-out. Child is sent to another room until he/she calms down.

CAUTION: This only works if the child wants your attention. You must be reinforcing him/her throughout the evening so he/she will want to be good to get your company.

Communicating with Parents

An important part of your baby-sitting job will be relating and communicating with parents. They know their child better than anyone and can provide you with information that can help you be successful. Often, however, this task of talking with someone you don't know very well isn't easy. You might find yourself being very shy or maybe even feeling superior. These attitudes can often be seen in the way we move our bodies ("body language") or in our tone of voice. For example, what do the following examples of "body language" say to you?

Demonstrate several of the following body language suggestions. Have the audience tell you how they feel about each one.

Body language examples:

1. Chin tilted down, eyes looking at floor.
2. Arms folded tightly across chest, legs crossed.
3. Hands in front of mouth while speaking.

Now let's role play several situations that could happen when a baby-sitter and parent try to communicate.

Randomly select members of the audience to role play. Pass out index cards with the different situations on them. Complete each role play and talk about how they would be perceived by the parent.

Parent Perceptions:

Role Play Situation 1:

This example should show how a baby-sitter could make a parent feel guilty about leaving the child with a sitter. Discuss how you want to relay

important events of the evening to the parents, but don't dramatize to the point of upsetting them. By meeting them, smiling, and relating the events calmly, you can tell them what they need to know without upsetting them.

Role Play Situations #1:

Demonstrate how "exhausted" body language can upset a parent.

Babysitter: You had a terrible evening. Johnny has run around and just went to bed fifteen minutes before the parents got home. You are sitting slumped in a chair with your head against the back. You do not get up when the parent comes in.

Parent: You have just had a wonderful evening with a good friend. You come home to find the babysitter exhausted. Suddenly you feel very guilty about leaving your child with a stranger.

Role Play Situations #2:

Explain how parents can be offended by "know-it-all" attitudes. Get the participants to talk about how they could give parents new ideas without making them defensive.

Babysitter: Mom told you that Susan never eats her vegetables. You decided to try using positive reinforcement with her and are successful. When the parents get home you are intent on demonstrating how successful you are as a babysitter.
Body Language: As you tell about your success you have your chin "in the air".

Parent: You get very offended when the babysitter talks to you in a superior attitude. Who is she anyway? You've taken care of this child for ten years and can't get her to eat. Respond by saying, "You must have just had a lucky day. She will occasionally eat a little bit."

This role play situation demonstrates how you can turn a parent off to new ideas by making them feel defensive. They won't be inclined to try what you have suggested.

Role Play Situation #3:

This role play situation should demonstrate how a shy, reserved attitude

might be interpreted as incompetence.

Babysitter: You had a good day with your physically handicapped "charge." In general, you are a very shy person. Mom comes home and you begin to tell her about the fun you had; some activities include finger-painting, making cookies and playing dolls with Joan (5 years old). As you talk you do not look the Mom in the eye and you have your chin tilted down while you are speaking.

Parent: You aren't too sure of this one. She never looks you in the eye or holds her head up. She seems nice but you thank her, thinking you won't call her again.

Role Play Situation #4:

The example given here should demonstrate how to positively interact with a parent.

Babysitter: A mother has arranged to talk to you about babysitting her child. You are feeling good about what you learned and you want to tell her about it.
Body Language: You should be relaxed, smile, look parent in the eye and talk about the program.

Parent: You are very impressed with this open, honest teen-ager. You certainly will call her to baby-sit.

Activity: "Behavior Bingo"

To review all the material on behavior management techniques, play a game, "Behavior Bingo."

1. Pass out the score card to all members of the training class. Give them something to mark their answers (gold stars).
2. Play the game until three people have bingo. Have a first, second, and third prize for the winners.

Making the cards

1. Draw a bingo form on typing paper.
2. Randomly place the correct answers on the card.
3. Each card should have one free space. (No one person should have all the answers).

Punishment	Ask the parents	Grandma's rule of positive reinforcement
Time Out	FREE SPACE	Ignore
Positive reinforcement	Dangerous situations	For attention

4. Try to make all of the cards different so that no two people reach bingo at the same time.

Answers

1. For attention
2. Positive reinforcement
3. Grandma's rule of positive reinforcement

Answers Cont.

4. Punishment
5. Ethical reasons
6. Ignore
7. Dangerous situations
8. Time out
9. Ask the parents

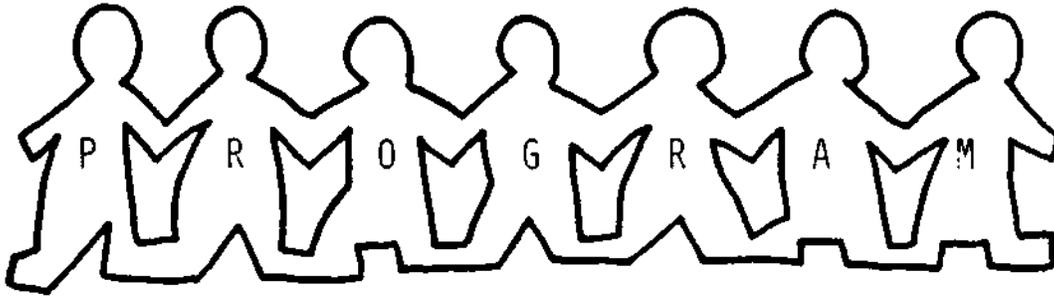
Questions for Bingo Game

1. Why do children misbehave?
2. Your mother gives you a piece of cake as a reward for doing the laundry. This is an example of _____.
3. Johnny hates to eat green beans. You tell him he can have his favorite toy to play with after dinner if he eats them. What principle of behavior management have you used?
4. When Sam throws his toys, mom hits his hand. This is an example of _____.
5. We do not use physical punishment because of _____.
6. If Sally is throwing her rag doll and not hurting anyone, we might choose to _____ that behavior.
7. Under what conditions should you stop bad behavior rather than ignore it?
8. You may choose this technique to stop a bad behavior when it occurs.
9. How can you find out what is reinforcing to a child when you babysit?

Closing Activity - "Car Wash"

This activity should demonstrate that we all like and need positive attention and praise.

1. At the close of the program ask the participants to form two equal lines approximately three feet apart.
2. Explain that we often forget to praise each other or give positive feedback when someone has done a good job.
3. Then say that everyone will take a turn walking down the center of the lines.
4. Each group member will say something nice or positive about that person as s/he passes by.
5. To give everyone an idea of how to participate, provide examples of positive statements. For example, look at various participants and say such things as:
 - a. You really gave some good examples tonight when we talked about positive reinforcement.
 - b. It's nice having you with us since you participate in the group discussions.
 - c. I appreciate the help you gave tonight when we put out the refreshments etc...
6. After someone passes through the group, s/he takes a place at the end of the line. Then the next person at the head of the group moves down until everyone has had a turn.



PHYSICAL MANAGEMENT

SKIT "HARRIET, THE HELPFUL BABYSITTER"

LIFTING THE HANDICAPPED CHILD

FEEDING TECHNIQUES

(SLIDE SHOW AND PRACTICE)

Materials Needed for Physical Management Sessions

Feeding demonstration supplies

- a.) bowls
- b.) crackers
- c.) cups
- d.) drinks
- e.) soft food (e.g..applesauce)

Feeding slides

Posters of wheelchairs and lifting techniques

- Skit props
- a.) chair
 - b.) table
 - c.) telephone
 - d.) padded tongue blade
 - e.) pudding

Slide projector

Video equipment

Video-tape of lifting and feeding techniques

Wheelchair

SKIT: "Harriet, The Helpful Babysitter"

Two areas should be set up close together. One represents Harriet's apartment and should have a small table, a telephone and a chair. The second area is for the home in which Harriet is to babysit.

Scene 1:

Harriet enters and sits
at the table looking at
the phone. Mother and child
enters and mother dials phone. Ring.

MOTHER: *Hi, can you come baby-sit my blind child? My name is
Mrs. Johnson and we live at 619 Iron Gate Road.*

HARRIET: *Oh, I'd love to babysit your blind child. I'll be right over.*

Harriet goes over to the
next area where the mother
is waiting for her.

HARRIET: *Hi, I'm Harriet.*

Mother and Harriet shake hands.

MOTHER: *I'm so glad you're here! I'll be gone just a little
while to the grocery store.*

Mother exits. Harriet begins
to tug on the kid to take her
for a walk.

HARRIET: *Come on Susie, let's go outside to play.*

As Harriet attempts to help,
she bumps into things and in
general does not know what she
is doing. Mother enters with
groceries.

MOTHER: *What are you doing?*

HARRIET: *Oh, I'm so glad you're home!*

Harriet exits to her house
while mother and child go
off stage.

ACT II:

Harriet sits by phone
drumming her fingers,
sighs and says:

HARRIET: *Wonder why Mrs. Johnson hasn't called me back to babysit.*

Enter next mother and child.
Mom dials phone - phone rings,

MOTHER: *Hello, Harriet, this is Mrs. Mills. I live at
615 Franklin Avenue. Could you babysit my little girl
who is physically handicapped?*

HARRIET: *Hello, yes, I'd love to babysit your handicapped child.
I'll be right over.*

Harriet goes to house.

MOM: *Harriet, be sure to feed Sarah at 6:00.*

Mother leaves. A few seconds
later Harriet looks at her
watch and says.

HARRIET: *Oh, it's 6:00...feeding time, Mary!*

Harriet begins to feed child.
Generally she should do this
incorrectly and make a mess.
Mother enters and says.

MOM: *Oh no, what have you done?*

HARRIET: *I know, it's time for me to leave.*

Harriet exits to her area where
she sits down and looks at the
phone.

HARRIET *Well, I bombed out with the blind kid and I blew it with the physically handicapped boy, but I know I'll be great with behavior problems.*

Next Mom and child enter the set.
Mom dials the phone and says.

MOM: *This is Mrs. Martin. I have a child with severe behavior problems and need a babysitter tonight. The address is 23 Parklane.*

HARRIET: *Hi. Behavior problems? Hey, I can handle that babysitting job. I'll be right over.*

Harriet goes to house.

MOTHER *You'll really have to watch Lulu carefully because she runs all over the house.*

Mother Leaves.

Harriet ties the child to a chair and sits watching her intently.

HARRIET *Now, I'm watching you like your mother said!*

Mother enters.

MOTHER *What's going on here?!*

HARRIET *I know, I know. It's time for me to leave.*

Harriet leaves and sits by the phone,
Mother and child enter other set.

HARRIET *I'm running out of handicaps. There aren't too many kids left for me to babysit.*

Mother dials phone. Ring!

MOTHER: *Hello. My name is Mrs. Smith. I have a child who has grand mal seizures and I'm looking for a baby-sitter this afternoon.*

HARRIET *Oh, I can handle seizures. I'm on my way!*

MOTHER: *Thank you so much. The address is 106 New Kent Place.*

Harriet rushes off to
the babysitting area.

MOTHER: *Are you sure you can handle seizures?*

HARRIET *Yes, I'm great!*

Mother leaves and child begins
to have a seizure. Harriet
tells the child to stop jumping
around and tries to put a tongue
blade in her mouth.

HARRIET *Oh dear, oh my. This just isn't working right. Was it that
you're supposed to stick something in their mouth or not?*

Mother enters and says

MOTHER: *What's happening?*

HARRIET *I know, don't call you. You'll call me.*

Harriet goes back to her area
and picks up the phone.
Dials number.

HARRIET *Hello, St. Joseph's? Can I come to your next training sessions?*

LEADERENTERS ROOM AND SAYS: *We have just seen Harriet fail as a babysitter
because she did not know what to do. Today/Tonight we are going to
learn how to work with physically handicapped people.*

Moving, Lifting, and Positioning
Handicapped Children and Adolescents

TRAINER: You may baby-sit for physically handicapped individuals who cannot stand or walk and will need your assistance for moving from place to place. They also need wheelchairs for transportation and positioning since many can't sit without support. It is important for you to know how to correctly provide assistance for several reasons:

1. If you move or lift a physically handicapped person and don't know how, you could hurt yourself as well as the person.

2. Often by lifting and positioning a disabled individual correctly, you can help him/her be more independent. For example, sitting correctly in a wheelchair might mean that the child can feed himself. Done incorrectly, he may lose this independent skill because he can't control his body.

Show slides that would illustrate how improper positioning can limit a child's ability.

Since so many children use adaptive equipment, let's look first at some of the wheelchairs they might have.

There are several ways to demonstrate wheelchairs.
1.) Ask a medical supply house to loan you chairs.

- 2.) Ask for sales catalogues so that you could pass around various pictures.
- 3.) Make charts demonstrating wheelchair types.

Activity NOTE: Regardless of the manner of presentation, specific wheelchair parts should be discussed. Participants should be able to practice moving the chairs, locking the brakes, removing arm rests/footrests, etc. Divide the participants into smaller groups and let them take turns examining various chair types. See the wheelchair diagrams for specific parts to be discussed.

LEADER: Now that we have had an opportunity to look at different types of wheelchairs, let's talk about how we go about moving individuals into and out of them. There are some rules of good lifting and body mechanics that you will want to remember.

1. The most important thing to do is to ask the parent to demonstrate how to lift their child. **PRACTICE** before you are left alone.
2. Never pick up someone by yourself who is half your body weight or over.
3. Bend your knees to lift. Your leg muscles are much stronger, and you will be able to lift the maximum amount of weight. **NEVER** lift using your back by bending forward at the waist. This will result in injury.
4. Never twist or rotate at your waist when lifting. Move your body as one unit.
5. Keep the weight you are lifting as close to your body as possible. The further away it is, the "heavier" it will be.

6. Have the surface you are moving to as close to you as possible. For example, when putting the child in his wheelchair, move it as close to the child as you can. Don't pick him up on one side of the room and move to the other. The further the distance you move someone, the greater the chance of injury.

7. If you do injure your back, be sure to have it checked by a physician.

As you talk about these points, try to demonstrate each. Show how you can use the principles of lifting when you move anything heavy such as a large bag of groceries.

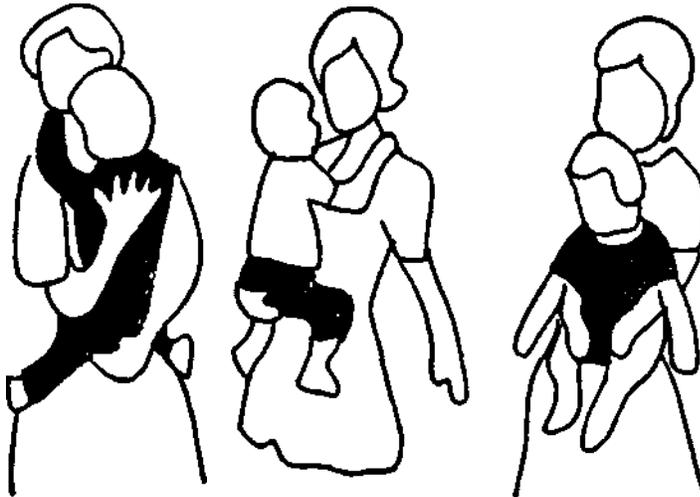
Lifting Demonstrations

Have a small child available to demonstrate lifting techniques. If not, a lifesize rag doll maybe an alternative. Slides, video tapes, or drawings/posters could also be of benefit. The trainer should demonstrate and then have the participants practice.

One-person lift - small child - chair to mat

1. Position the chair parallel and as close to the mat as possible.
2. Lock the brakes.
3. Position yourself to the side of the chair.
4. Unfasten all straps. (Do not leave the child after unfastening the straps.)

5. Bend at the knees.
6. Place one arm under both of the student's thighs.
7. Lift the child up and out of the chair, bringing him/her as close to your body as possible.
8. Move the child so that he is in a modified seated position. Hips should be flexed to 90 degrees (right angle) with one of the lifter's arms under both thighs and the other around his back.



These pictures may make a good poster/visual aid. It would be beneficial to also show slides of children held these ways.

9. Turn body away from the chair as a total unit. Do not twist or rotate at the waist.
10. Move to the mat.

11. Kneel onto the surface you are lowering the child onto, keeping a straight back.
12. Lower child onto the mat in a seated position.
13. Assist him/her to supine, supporting the head if needed.

NOTE: This technique can be used for moving any small child to lying down (i.e., bed). Instead of kneeling onto the bed, bend at your knees and lower the child with as straight a back as possible.

One person lift - mat to chair

1. Position the chair parallel to the mat.
2. Lock the brakes.
3. Kneel next to the child on the mat (Half-kneeling position).
4. If the child is on his stomach, roll him to his back. Assist him to sitting. (Be careful not to let his head fall backwards.)
5. Place one arm under his thighs flexing his hips to right angles. Knees should also be bent.
6. Other arm should be around the child's back under each of his arms.
7. Move the child until he is as close to your body as possible.
8. Lift the child up off the mat onto your knee. (This will help you prepare to stand while getting the child's weight close to your body.)
9. Come up from half kneeling to standing.
10. Move towards the chair so that your body faces the chair and is parallel .
11. Bend at the knees while lowering the child into the chair.
12. Make sure that his hips are to the back of the chair and that his body does not lean to either side.

Fasten all straps securely, making sure that the seat belt rests snugly across the student's hip bone approximately where the legs flex.

For this lifting technique divide the participants into pairs. Have them practice transferring each other to the toilet, bed, etc. and back again.

One person assisted transfer: If the person you are lifting can assist by standing momentarily, follow this procedure.

1. Position the wheelchair at a 45 angle to the surface that you are moving the person to.
2. Lock the wheelchair brakes and remove the armrests or footrests if possible. Unfasten seat belts.
3. If the person has more motor involvement on one side than the other, make the transfer in the direction of the stronger side. For example, if the person has left sided hemiplegia (involvement), transfer him to the right whenever possible.
4. Stand in front of the person and bend your knees so that you will be lifting with your legs and not your back.
5. Have the person come to the edge of the chair.
6. Grasp the person firmly by the belt. If this is not possible, you should put your hands under each hip.
7. Guard the person's feet by positioning yours together so that he cannot slip through your legs.
8. Have the person place his arms around your neck.
9. Prepare to lift by rocking back and forth and counting to 3.
10. Lift on the count of 3 and place the person into the next chair.
11. Make sure the person is secure in the seat and cannot fall.

This same procedure can be used to transfer a person to almost any other surface

e.g., toilet, bed, sofa.,;

Points to remember when moving and positioning handicapped individuals

1. Try to provide only as much support as you have to. Don't treat the children like infants.
2. Try to carry children so they have to hold up their heads and control as much of their own bodies as possible.
3. Provide good slow, steady movement when moving the individual. Let them know what you are doing at all times. Quick rapid movements can cause loss of muscle control and startle reactions. You could drop a person if this happens.
4. Try to position the children securely. Fasten all seat belts.
5. Never leave a physically handicapped child unattended. The child could fall and hurt himself.
6. ALWAYS ask the parents to show you how they move and position their child!

Show slides to demonstrate good vs. bad positioning, lifting, and handling techniques as a closing to this topic. Get the participants to tell you what is incorrect about the procedures being used.

Suggestions for incorrect vs. correct positioning and handling a slide show:

1. Person attempting to lift a person that is more than half his body weight.
2. Person lifting without bending at the knees.
3. Person twisting at his waist while lifting a child.
4. Person lifting a child when the wheelchair is far away from the surface he is moving towards.

Child sitting in his wheelchair unattended with seatbelts unfastened.

Child sitting in his wheelchair leaning excessively to one side.

Person transferring a large child who can assist without bending at the knees.

Person transferring a large child who can assist without guarding his feet.

Person carrying a child like an infant.

Follow each incorrect
slide with one that
shows the correct tech-
nique.

Feeding Handicapped Children

Trainer: Many physically handicapped children and adolescents cannot feed themselves due to severe motor limitations. This includes the inability to use their arms and hands as well as decreased ability to control the muscles of the face and mouth. As a sitter for these individuals, you will need to know how to properly provide assistance.

The first thing to remember is to always ask the parents what you should know about a child's mealtime. There are many different reasons for getting this information.

1. All children cannot eat regular table food. Many who need to be fed choke easily. You do not want to give a cookie to a child who cannot chew.
2. Many handicapped children are allergic to various foods. Be sure you know what he/she can and cannot eat. Allergic reactions are dangerous.
3. Mom and Dad may use special techniques to feed their child. If not used, you may find mealtime impossible.

In order to fully understand some of the difficulties these individuals might have, we are going to see slides and practice feeding each other.

Have the group pair up
for the feeding experience.
Pass out for each person
a towel, cup of water,
spoon, and bowl of soft
food, (e.g., yogurt, apple-
sauce, pudding.)

Note: The feeding examples should be distributed throughout the slide show. As a specific point is made, the participants can experience the difficulties associated with feeding problems.

SAMPLE SLIDE SHOW

1. Positioning . Trainer says: The first step to successful mealtimes is to have the person in a good position. The child with physical handicaps often cannot control many movements in his body. Due to brain damage, abnormal reflexes may influence how he moves his mouth, arms, trunk, etc. By trying to place the child properly in his wheelchair you can often keep these reflexes from interfering with mealtime. Let's look at some examples.

A. Problem-Spasticity-Show a slide of a child on the mat who has severe spasticity resulting in total body extension. His mouth should be open wide and head extended to point out that excessive hip extension influences other parts of the body.

B. Solution: Show the same child sitting in his wheelchair. Hips should be flexed to the back of the chair and secured with a seat-belt. His knees should be bent and feet supported. Slide is intended to demonstrate that the child is more relaxed and muscle tone decreased due to proper body support. Mouth should be closed and the face should look more relaxed than in the previous picture.

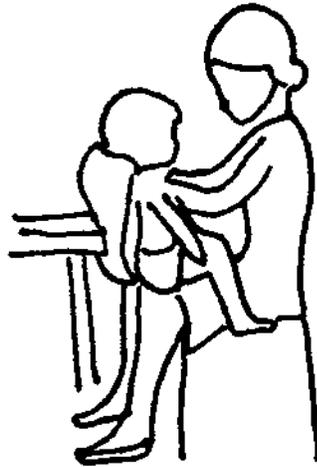
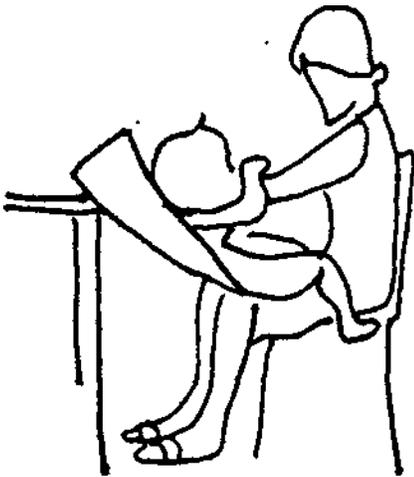
C. Problem: Slide of a spastic diplegic child who is seated in a chair without foot support. This should show how the child loses body control and must concentrate on maintaining a seated position.

Feeding Activity: Have the participants sit on the edge of their chairs and pick their feet off the ground. Ask them if they feel the muscle tone increasing in their bodies.

D. Solution: Slide of the child after he is provided with adequate foot support.

E. Problem: Child with her head not in midline. Talk about the influence of the asymmetrical tonic neck reflex.

F. Solution: Show same small child positioned on a wedge in the feeders lap. Adult should be demonstrating the importance of keeping the child's head in midline.



G. Problem: Head in hyper-extension. Explain that many of the children will have poor head control resulting in head hyper-extension. Show a slide of a child whose head is thrown back with exaggerated mouth opening. Tell the participants that this position opens the airway and the child could inhale food.

Feeding Activity: Have the participants try to swallow with their heads in hyper-extension.

H. Solution: Slide should demonstrate the use of Jaw control to

keep the head in a neutral position. You could also have slides showing how the feeder may inadvertently hyper-extend the head even when using jaw control.

I. Solution: Slide showing application of firm, deep pressure with the palm of the feeder's hand to the child's chest will cause head flexion.

J. Solution: Slide showing the feeder placing hands on either side of the child's face to flex the head forward. (Do not put hand on the back of the person's head to push out of hyper-extension).

Feeding Activity: Have the participants try to swallow with their heads in hyper-extension.

K. Problem: Head in Flexion

Feeding Activity: Have the participants attempt to swallow with their heads in flexion.

L. Solution: Slide should demonstrate the use of jaw control

SPECIFIC ORAL MOTOR PROBLEMS

A. Problem: Lip Retraction

Feeding Activity: Have the participants try to swallow with upper lip retraction. You may want them to hold their upper lips away from the bottom lips.

after they feed each other, point out that many people scraped the

spoon on their partner's teeth. This should never be done since it might elicit a bite reflex or chip a tooth. Explain that good lip closure is important for adequate swallowing patterns.

B. Solution: Slide should show the feeder using her own index finger to apply firm pressure to the upper lip to assist with lip closure.

C. Problem: Tongue thrusts (Reverse swallows)

Feeding Activity: Have the participants try to swallow by moving their tongues forward instead of back in their mouth.

D. Solution: Slides should demonstrate the following: 1) Jaw control with pressure to the base of the tongue. Tell the sitters that they need to apply firm consistent control. Lightly placing the hand on the face will not provide any assistance. 2.) Head position influences tongue thrust, especially when hyper-extended. Aim for the head in midline and neutral.

E. Problem: Bite reflex. Many children have an involuntary bite reflex. Stimulation to the teeth or lips will cause them to clamp down on a spoon or any object placed in the mouth (even a finger). Release of this reflex often does not occur until the child relaxes.

F. Solution: Never try to pull the spoon out of the person's mouth. This results in a stronger clamping of the teeth on the spoon. Speak in a quiet voice and gently but firmly provide deep pressure to the person's chest with a slow rocking motion. Remove the spoon when he relaxes his hold. (Slide showing deep pressure to chest.)

G. Problem: Facial sensitivity. Many severely handicapped children and adolescents are sensitive to touch around the face. Mealtime may be unpleasant to them if the feeder provides too much stimulation.

(Slide showing child reacting negatively to touch,)

H. Solution: Do not constantly wipe the child's mouth as you are feeding. Control of some food loss from the mouth can be achieved by giving only small bites of food. When wiping the mouth, start at the angle of the jaw and wipe in one firm stroke towards midline. Repeat for both right and left sides of the face.

I. Problem: Decreased muscle tone, Many individuals have a decreased ability to use the tongue, lips, facial muscles, because they have low muscle tone. Movement may be very slow when it occurs.

Feeding Activity: Ask the participants to swallow without moving their tongues.

J. Solution: Always give individuals with low muscle tone adequate time to swallow. Never put large spoonfuls of food in their mouths. Small bites should be placed on the end of the spoon and the person should always swallow before another bite is given.

Feeding Activity: Have the participants rapidly feed each other. Point out how uncomfortable this feels even to a nonhandicapped person.

K. Problem: Difficulty drinking from a cup. Show a slide with the feeder trying to give a child a drink. The head should be slightly hyper-extended and the child's bib/towel wet indicating that too much liquid is given per sip.

Feeding Activity: Have partners to each other give a sip of liquid when their heads are hyper-extended.

L. Solution: Have a slide showing the feeder using a cut-away cup and jaw control. Emphasize the importance of giving small sips one at a time.

Trainer: Now that we have seen some of the problems you might need to deal with, let's close with a few major points to remember.

1. Always get the child in a good position with all adaptive straps fastened.

2. Try to feed the child directly in front. Head and trunk should be in the midline.

3. Never allow the head to tip extremely back or forward.

4. Make the child use his lips to remove the food from the spoon.

5. Place small bites on the spoon. Wait for the person to swallow before giving more food.

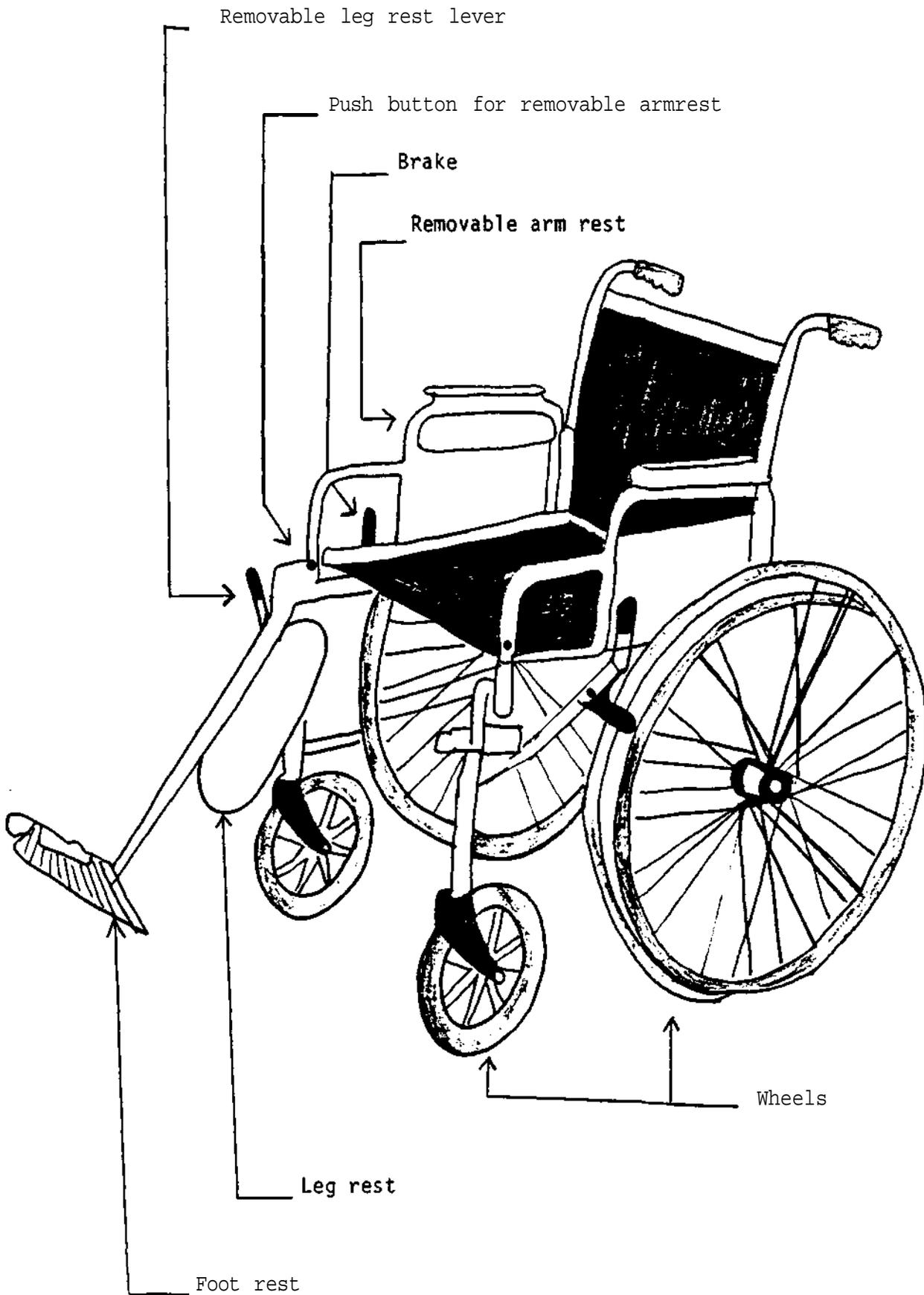
6. Make mealtime pleasant! Direct the conversation to the child.

7. Always ask the parents to tell you if there are special tips relating to mealtime.

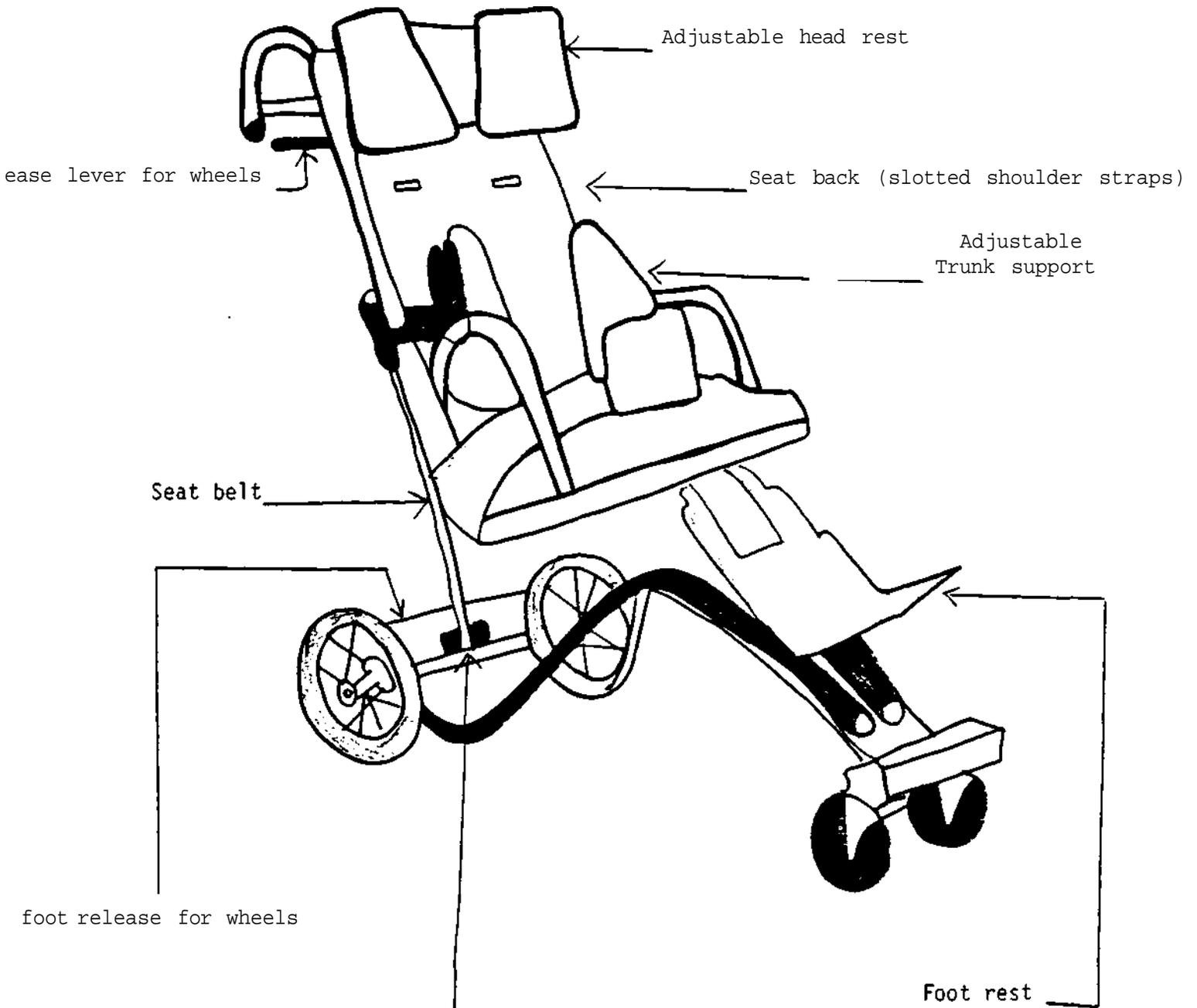
Feeding Activity: If at all possible, try to give the participants a chance to feed a handicapped child with supervision. This should relieve any fears they might have.

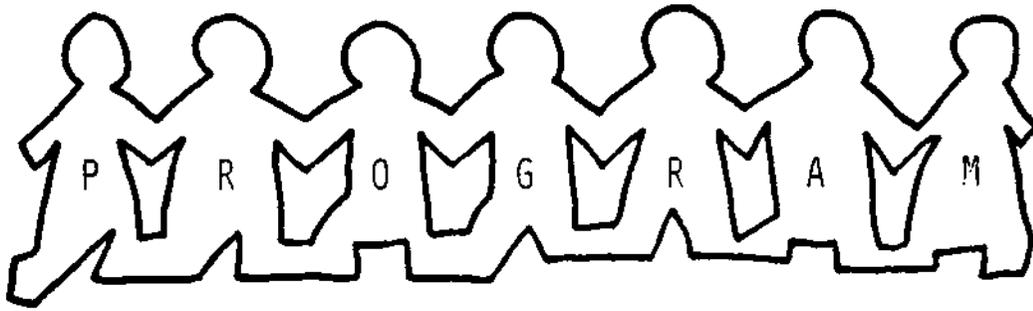
Closing Activity: "Wheelchair Hunt"

1. Use the picture of "Important Parts of a Wheelchair" for this activity.
2. Leave the spaces blank for labeling.
3. Have enough pictures for groups of four participants. Each picture should be a different color.
4. Cut all of them into several large pieces.
5. Hide them around **the room** in accessible/visible places.
6. At the time of the **presentation**, divide the participants into groups of four people.
7. Tell them that pictures of the parts of a wheelchair have been hidden in the room.
8. Assign a color to each group.
9. Give them ten minutes to find the picture, assemble it, and label the parts.
10. Have a small prize or reward for the group who completes the most of the task. Give a lesser prize for the remainder of the groups.



TRAVEL CHAIR





LEISURE/RECREATION

LEISURE/RECREATION SLIDE PRESENTATION

ADAPTATIONS FOR THE PHYSICALLY HANDICAPPED

LEISURE ACTIVITY

Materials Needed for Leisure-Recreation Session

Activity description sheets

Audience handouts for session

Extension cord

Paper for participants

Pencils

Slide Projector

Slide show

Leisure/Recreation Slide Presentation

Trainer: We have discussed that children often misbehave, "act-out" when they are bored or have nothing to do. It's important for you to remember this and try to provide leisure/recreation activities for a child when you baby-sit. Additionally the time will go by quicker for you and the child if there are things to do rather than sitting and watching the clock!

Let's look at some slides to learn how you can best interact with handicapped and mentally retarded children and adolescents.

Slide 1: Respite provider talking to a parent about toys/activities.

Slide 2: Parent showing play items to care provider.-

Slide 3: Respite provider making a list of preferred toys and activities.

Narrative: A respite care provider should always ask the parents or guardian what things the child enjoys most and when it is best to try them.

Slide 4: Respite provider holding a large bag with toys and materials he/she has brought along.

Slide 5: Frisbee, nerf ball, deck of cards, crayons, watercolors, puzzles, etch-a-sketch, transistor radio, scissors, glue, construction paper, comic books, etc.

Narrative: Take along any toys or materials that you have used successfully with other children and adolescents.

Slide 6: Young child watching respite provider manipulate hand puppet.

Slide 7: Young child playing with pull apart toy.

Narrative: Passive activities are usually better play alternatives before bedtime. These activities are appropriate for young children.

Slide 8: Teen-ager listening to mini-cassette with headphones.

Slide 9: Teen-ager and respite provider baking cookies.

Narrative: Passive activities such as listening to music, watching TV, cooking, playing board games, and needlework are good for teen-agers. Do not play baby-like games with older children. You might be tempted to, especially if the person were severely retarded. We want to use toys/games that closely match the person's chronological age to provide a normalized leisure skill.

Slide 10: Child in a wheelchair with respite provider window shopping in a mall.

Slide 11 Teen-agers at baseball game (One should be handicapped.)

Slide 12 Handicapped adolescent playing pinball in video arcade.

Slide 13 Young handicapped child with adult on playground equipment in the city park.

Narrative: If you are planning to take the person for whom you are providing respite care into a community setting, make sure that you are familiar with the situation and can handle behavior problems, physical barriers, and possible negative attitudes from other people. Get written permission to visit community facilities from parents or guardians.

Slide 14: Child crying and looking away from the care provider who is holding a book.

Slide 15: Respite provider showing a child two or three toys such as crayons, coloring book, miniature cars, and a board game.

Narrative: If the handicapped child is not enjoying a particular leisure activity, do not insist that he/she continue. Try to provide options for what can be done at anytime.

Slide 16: Adult helping a young handicapped child get on a tricycle.

Slide 17: Adult and handicapped teen-ager making a magazine cutout collage.

Slide 18: Adult and handicapped child playing cards.

Slide 19: Adult playing with pull apart toy as handicapped child watches intently.

Narrative: Participate in activities with the child and make them seem really enjoyable. The children will learn by observing you and modeling your behavior. Do not assume that the child does not want to participate because he/she does not initiate activities. You may always have to be the initiator.

Slides 20-25: A variety of slides showing older handicapped children and adolescents playing with age-inappropriate toys such as pre-school puzzles, dolls, rattles, etc.. One slide should show a very young child looking at a complicated board game such as Monopoly.

Narrative: Try as much as possible to provide age-appropriate activities. For example, adolescents should not be encouraged to play with dolls or pre-school toys. Younger children, on the other hand, should not be expected to play complicated board or card games with complex rules.

Slide 26: Handicapped child eating dinner.

Slide 27: Same child watching T.V..

Slide 28: Handicapped child taking medicine.

Slide 29: Same child looking at a picture book.

Narrative Recreational activities make good reinforcers. Use the "Grandma's rule" or Premack principle and have the child complete a non-preferred but essential activity such as feeding, medicine taking, or bathing before he/she can participate in a leisure activity such as watching TV or looking at a book.

Slide 30: Any slide showing a handicapped child or adolescent participating in an age-appropriate leisure activity with an adult.

Narrative: Providing leisure activities to the child for whom you are caring will probably be the most enjoyable aspect of respite care for you. Have Fun!

Adaptations for Physically Handicapped
Children and Adolescents

Trainer: Many physically handicapped children and adolescents have difficulty using their arms, hands, and legs. This could limit their ability to engage in leisure activities since most leisure pasttimes require gross and fine motor movements. There are several things you can do as a respite care provider to assure that the physically handicapped person doesn't sit and do nothing while you are babysitting. Let's take a look at some slides of children who are severely handicapped.

Slide 1: A child sitting in a travel chair that he/she cannot wheel. Shows toys placed across the room.

Narrative: You may have to make toys accessible to the child. For example, a physically handicapped person may be confined to a wheelchair and not be able to seek out things to do. Don't assume he/she does not want to play because he/she stays in one place.

Slide 2: Same child playing with a variety of toys that have been placed on the lapboard of the wheelchair,

Slide 3: Adolescent sitting in wheelchair trying to watch T.V.. He is poorly positioned(i.e.,his hips are not to the back of the chair, resulting in poor trunk and head positioning.)

Narrative: Poor positioning in a wheelchair often severely limits the individual's ability to sit up and hold his head erect. It may appear that this boy isn't interested in watching T.V. when ,in actuality,he is having an extremely difficult time controlling his head.

Slide 4: Same boy positioned properly and enjoying watching T.V. (head should be erect and in midline.)

Slide 5: Girl lying flat on her back in an "extensor" pattern. Try to demonstrate her inability to lift her head or use her hands while lying supine. Toy could be placed to one side on the floor.

Narrative: This child would find it almost impossible to engage in a leisure time activity. Due to severe motor involvement she would even have trouble rolling to her side to get the toy.

Slide 6: Same little girl should be positioned on side lying with a wedge for support under her head. Toys are in easy reach for playing.

Slide 7: Adolescent boy lying flat on his stomach in a "flexor pattern" with arms flexed under his body.

Narrative: In this position the boy can't raise his head or reach out with his hands. You might think, he was tired or uninterested in looking at anything.

Slide 8: Boy now positioned over a wedge/roll with arms forward, head up looking at a magazine.

Slide 9: Small child sitting on the floor in a slumped position...demonstrate how the child must use his/her arms to sit up. Toys should be on the floor within reach.

Narrative: This child must support himself in sitting due to poor balance with his arms and hands. Obviously, leisure time activities would be difficult to engage in if not impossible.

Slide 10: Show child sitting in a small chair with table for a play surface. Arms and hands should be touching toys.

Slide 11: Individual sitting in a wheelchair arms should be abducted and externally rotated with hands fistled. Baby-sitter is holding out a bean-bag.

Narrative: This person is severely limited in her arms and hands. She finds it extremely difficult to bring her arms forward and together to reach for the bean-bag.

Slide 12: Respite care provider assisting the person to bring her arms to midline and helping aim the bean-bag at a target.

Slide 13: Small child with flat puzzle pieces trying to pick them up, but obviously having difficulty grasping.

Narrative: Some children have problems grasping objects. You may have to provide built-up handles for easier manipulation.

Slide 14: Same child picking up puzzle pieces that have attached handles.

Slides 14, 15, 16, 17, 18, 19: See attached drawings

Narrative: You may find the following positions good for playing with physically handicapped children. Each provides control and assistance so that the individual can concentrate on the activity rather than having to concentrate on positioning of his/her body.

Leisure Activity

1. Divide the participants into small groups of no more than five members.
2. Give them descriptions of two children and a corresponding list of recreational activities for each child.
3. Explain that each group should select the activities that are appropriate and those that are inappropriate.
4. The inappropriate activities should be adapted (e.g., change the materials, rules, or add devices) so that the child could participate and so they would be age-appropriate.
5. Pass out the hand-out on Adaptations of Common Leisure Time Activities to provide assistance.

Description of Child #1:

The boy you are baby-sitting is 14 years old and has Down . syndrome. The parents told you before they left that he doesn't enjoy anything particular other than eating and watching TV. They don't mind what you do for leisure activities. Specific characteristics include: 1.) respiratory problems, 2.) very large, short fingers, 3.) overweight, and 4.) hard of hearing/speech problems. However, he does understand what you tell him and doesn't have any major behavior problems.

Possible Activities:

1. Riding younger brother's big-wheel (inappropriate)
2. Finger painting (inappropriate) -
3. Comic books/magazines (appropriate)
4. Record player/radio (appropriate)
5. TV (inappropriate unless nothing else works)

7. Frisbee (appropriate)
8. Five piece puzzle belonging to 5 yr. old sister, (inappropriate)
9. Alphabet blocks (inappropriate)
10. Playing "old maid" cards (inappropriate)

Description of Child #2:

The little girl you are babysitting is 8 years old and multihandicapped. She is severely retarded with cerebral palsy and seizures. Due to physical limitations, she is confined to a wheelchair. However, the little girl can use one arm and hand, speak one word or two word phrases, and hear and see. The parents have told you that she gets very frustrated when she can't successfully complete motor tasks such as holding a pencil or small toy.

Possible Activities:

1. Pick up sticks (inappropriate)
2. Throw/catch bean bags (appropriate)
3. Radio/record player (appropriate)
4. Viewmaster (appropriate)
5. Crayons/watercolors (inappropriate)
6. Cutting/pasting/collage making (inappropriate unless adapted)
7. Swimming (appropriate)
8. Window shopping (appropriate)
9. Kickball (inappropriate)