

THE EDUCATION AND COMMUNITY SUPPORT OF SEVERELY HANDICAPPED PEOPLE

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Dramatic changes have occurred over the last five years in the education of severely handicapped people. Educators who are working with them have developed a wide range of efficacious teaching procedures that have had a major impact on the performance of handicapped people. The increases in adaptive skills that have resulted from these instructional procedures have enabled severely handicapped individuals to perform at levels previously thought unattainable. Because of these increased levels of performance, it is now possible to argue that severely handicapped citizens should be helped to become active and accepted members of the community.

But the process of becoming active, useful citizens goes far beyond the traditional domain of the classroom educator. Therefore, the purpose of this paper is to develop the notion that the education of severely retarded or handicapped citizens is a joint venture. It is a joint venture that entails the close cooperation of

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a number of professionals, across a variety of disciplines, whose major work is concerned with both the individual and the social system within which the individual resides. If the integration of severely handicapped citizens into full community participation is to be achieved, it seems that professionals in a variety of positions should become active facilitators of this move. This paper is directed toward explicating these facilitating roles, within the context of a joint cooperative structure.

The Education of the Severely Handicapped

A number of the traditional assumptions underlying instructional programs for severely handicapped children have been challenged by those who believe that acquisition of skills may be more a function of instructional programming than a question of limited mental ability (Entrikin, York, & Brown, 1975). A crucial difference in the teaching procedures utilized with the severely handicapped, as differentiated from the normal or the mildly handicapped, is the degree of precision required in instructional programming (Brown & York, 1974). As a result, the disciplined precision required by a task-analysis approach to instructional programming has been relied upon in an increasing number of successful educational programs for the severely handicapped (Williams, Brown, & Certo, 1975).

In addition to advances in instructional technology with the severely handicapped, there have been a number of court decisions and, more recently, federal legislation that have provided additional impetus to community programming. Beginning with the landmark decision in Pennsylvania (Pennsylvania Association for Retarded Children v. Pennsylvania, 1972), a free public education was guaranteed for all retarded children, regardless of the degree of retardation or associated handicaps. This concept of zero-reject was extended to all handicapped children by Mills v. Board of Education of the District of Columbia (1972). The basic concepts of these court decisions have been combined into federal legislation as PL 93-380 and, as amended, PL 94-142. Although the initial thrust of the court decisions and early legislation supported the idea of zero-reject as it pertained to mildly or moderately handicapped students, the current emphasis is clearly on a zero-

exclusion model that applies also to the severely handicapped, who have traditionally been excluded from a public-school education.

Associated with this trend of allowing the severely handicapped into the mainstream of public education has been a growing disenchantment with institutionalization. The move toward a more normal educational experience, allied with the increase in the efficacy of educational technology, has produced a trend toward deinstitutionalization. This trend is an attempt to generalize the initial gains in skill development that have resulted from a more normal educational experience, through integration of the handicapped into the public school, to the more pervasive idea of the "normalizing" experience of community living.

The Need for Community Action Networks

Thanks to the advances in educational programming, the pressures exerted by "right to education" legislation, and the growing movement toward decentralization, increasing numbers of severely handicapped individuals are now remaining in their communities or returning to their communities from institutions. It is vital that we provide these community-based handicapped individuals with a range of educational and community services in order to assist them in learning to adjust to the demands of community living.

We know that, from an educational standpoint, severely handicapped children can learn the skills necessary for community living (Brown, Certo, Belmore, & Crowner, 1976; Brown, Crowner, Williams, & York, 1975). In addition, we have available a variety of effective and efficient methods and techniques for teaching the required living skills (see Fredericks et al., 1976; White & Haring, 1976; Williams, Brown, & Certo, 1975).

Although we have made substantial progress in teaching severely handicapped people living skills and in helping them develop proficiency in these skills, one of our most pressing concerns is to find ways in which to maintain and generalize these learned skills to the handicapped person's natural environment. Even in this most difficult area, technological advances are beginning to surface. Instruction techniques that vary the physical setting, teacher,

language cues, and/or materials during initial skill acquisition have been demonstrated to facilitate generalization (Barrett & McCormack, 1973; Corte, Wolf, & Locke, 1971; Garcia, 1974; Johnson & Johnson, 1972; Kale, Kaye, Whelan, & Hopkins, 1968; Martin, 1975; Stokes, Baer, & Jackson, 1974).¹ It is our belief, however, that attainment of the total goal of both maintaining and generalizing classroom learning to the community will necessitate the involvement of professionals from areas other than education.

Successful adaption of severely handicapped children to a community living situation is a reciprocal process. It involves, on the one hand, the education of the handicapped individual to the point of maximum normalcy and, on the other hand, the adjustment of community service facilities to the needs of the handicapped individual and his family.

A variety of community living skills has been developed and taught to severely handicapped students. Aside from the more traditional programs emphasizing the self-care skills of dressing, toilet training, and eating, much more complex programs have been initiated. Certo, Schwartz, & Brown (1975) have taught severely handicapped children to ride a public bus system. Williams (1975) has taught severely handicapped students to respond differentially to individual components of language cues and has developed a mathematics skill sequence for the severely retarded.

Nietupski, Certo, Pumpian, & Belmore (1976) have taught severely handicapped students to draw up a shopping list and purchase groceries. Certo & Swetlik (1976) have taught severely handicapped students to make general purchases based on simple decisions of enough or not enough money. Williams, Pumpian, McDaniel, Hamre-Nietupski, & Wheeler (1975) have developed a procedure to teach social interaction skills to severely handicapped students.

It is, however, of little social value to the severely handicapped to possess skills that they cannot utilize and further expand. It is therefore necessary to develop a network of services that will allow for the maintenance and generalization of these learned skills within the community. Kenowitz, Gallaher, & Edgar (1977) have proposed such a system, which they term a community action network. The purpose of such a system would be to

sensitize community services to the needs of the severely handicapped and their families. According to these authors, such a network would serve in a linkage capacity to bring together families of the severely handicapped and all agencies that traditionally deliver a service these families could utilize.

Regardless of what term is used or how intensive a network is proposed, some attempt to develop a total service delivery system to families of the severely handicapped is necessary. If the initial promise of educational procedures is to be turned into the reality of community living, cooperation between educators and other professionals involved in community programming is essential. The remainder of this paper will outline a cooperative venture involving a variety of professionals in the areas of vocational training, social development, and recreational programming.

Vocational Opportunities

Now that it has been established that severely handicapped persons can acquire a wide variety of skills that were previously considered to be unattainable, it becomes important to attempt to apply these learned behaviors to areas other than the classroom. A prime target for this transfer process is the vocational area. Training of severely handicapped people in vocational skill acquisition and proficiency in highly complex tasks has already been demonstrated (Gold, 1972), but transfer of these work skills from structured, closed settings to the community has rarely been attempted.

Sheltered workshops and activity centers have been the most common response to the vocational needs of the severely handicapped. These alternatives to competitive, community employment have often been self-limiting, and certainly ineffective in providing the normalizing experiences necessary for employment in the community. Such alternatives may be, in part, the result of long-held beliefs concerning the limited capacity of severely handicapped people to function in a vocational setting. Even the most advanced programs of vocational training still involve some educational or sheltered workshop support.

Recently, Gold & Torner² have proposed an integrated plant employing both handicapped and nonhandicapped workers. DuRand³

has successfully piloted a project utilizing a work-station and a work-team concept to establish a degree of normalization for the handicapped. The work station consists of approximately eight severely handicapped people working under a separate supervisor in a small group, but placed in a regular, much larger, industrial setting. In this way they blend into the normal work environment. The work team consists of a small group of severely handicapped employees, together with a supervisor, who contracts for special jobs. This approach is most often used with such tasks as janitorial work or yard work.

The utilization of such approaches as work stations and work teams is an improvement over institutional settings, but there is potential for even more normal work environments for severely handicapped people. Schwartz,⁴ utilizing a work assessment model developed by Belmore & Brown (1976), has demonstrated the transfer of dishwashing skills acquired by severely handicapped individuals in a structured work environment to paid jobs under normal employment conditions.

Once again, the technology required to teach severely handicapped persons viable vocational skills seems to be available. But the maintenance of a severely handicapped worker on a non-sheltered job requires the cooperation of employer, employees, the training agent, and allied services. If extensive transfer of vocational skills acquired by severely handicapped workers is to be effected, a cooperative network of community-based professionals is obviously needed. Forming such a cooperative alliance on an individual basis for each worker does not seem to be the most efficient approach when one balances the time and effort expended against the number of positions required. Only through the joint efforts of a variety of knowledgeable professionals can we hope to capitalize on the results of the severely handicapped individual's rising potential and allow for the maintenance and generalization of his/her newly developed vocational skills.

Vocational competence is an important economic consideration in society. Productive work that contributes to the general well-being greatly affects people's attitude toward their peers. As severely handicapped workers demonstrate their vocational competence in the open job market, their perceived value to society will be enhanced.

Social Skills

Educational programs that enable the severely handicapped to acquire and become proficient in the skills necessary for social living have been demonstrated (Brown, Crowner, Williams, & York, 1975). Educational research has clearly established that severely handicapped people can develop competency in social skills that will enable them to blend successfully into the community (Neisworth & Smith, 1973). The implementation of programs emphasizing maintenance and generalization of social skills has, however, been less prevalent than programs for the acquisition of skills and the development of proficiency.

Social acceptance is a vital component in any attempt at community integration. It is often influenced by the number of problems the person presents to community members. To the extent that the presence of a handicapped person does not make others uncomfortable or compel them to perform activities they would not otherwise perform, the probability of community acceptance is enhanced.

The development of control over social behaviors has been a two-part process. First, a variety of procedures has been developed to modify or extinguish bizarre or inappropriate behaviors that interfere with social acceptance (Fox & Azrin, 1973; Koegel, Firestone, & Kramme, 1974; Weisberg, Passman, & Russell, 1973). Second, procedures have been utilized to develop more appropriate or nonexistent social behaviors in severely handicapped people (Morris & Dolker, 1974; Paloutzian, Hasizi, Streifel, & Edgar, 1971).⁵ Again, as in the area of vocational integration, the maintenance and application of these learned social skills in a community setting will involve cooperative effort from a community service network.

Community-based severely handicapped people and their families will need help with communication, housing, transportation, shopping, food preparation, economic transactions, selection and care of clothing, medical care, dental attention, babysitting needs, and a variety of other activities associated with community living. The provision of services to meet these needs will call for the active participation of mental health workers, medical workers, housing specialists, nutritionists, and family service pro-

professionals. These individual professionals, acting in concert, will be able to link individuals to services, modify existing services to meet pressing needs, and act to establish necessary services that do not exist.

Since social skills of either a verbal or nonverbal nature pervade most situations of human interaction, the development, maintenance, and generalization of these skills need to be incorporated as a subgoal in the services provided by all professional agencies that focus on the severely handicapped. As professionals we can be satisfied only when a severely handicapped person can, for example, go undetected into a store and buy some toothpaste without continual support.

Recreational Skills

Vocational skills and competency in social functioning are recognized as essential components of a normal lifestyle; but the handicapped also need recreational skills and interests (Brown, Bellamy, & Sontag, 1971), and this area has received little attention in the literature. There seems to be ample reason to conclude that the same basic methods and techniques used to teach other skills can be used to teach recreational skills as well.

One explanation for recreational skills' receiving less attention from educators may be related to the somewhat artificial distinction between academic concerns and play. It is likely that educators look upon recreation as more properly the function of the community and family. Although this may well be the case with the education of the less seriously handicapped, it cannot be justified with the severely handicapped.

The literature on the motor characteristics of the retarded points out that the retarded are markedly inferior to normal children on all motor tests (Francis & Rarick, 1959). Malpass (1960) has summarized the research on motor skills in retarded children and indicated that as a group they demonstrate less motor competence than normal children, and that the severely retarded are less physically capable than the moderately retarded.

But the problems in the area of motor skills of the severely handicapped cannot be explained simply as a lack of proficiency. Many older, severely handicapped people function physically at

very rudimentary developmental levels. For example, before a severely handicapped person might be able to participate in a game that required movement across a rough or uneven surface, he or she might need to learn to inhibit primitive reflex reactions to the tactile sensation of the uneven surface on the feet. By arranging for minor adaptations in a running game, such as running barefoot across a carefully designed surface, the benefits from a carefully planned recreation activity can be extended. Through the cooperative efforts of occupational therapists, physical therapists, and educators, recreational programs for the severely handicapped can become a very useful area of learning.

Aside from motor ability, three other considerations are relevant to the learning of recreational skills by the severely retarded. First, they do not usually spontaneously engage in play through association: they must be taught (Frye & Peters, 1972). Second, they must be taught any physical activity step by step, through a task-analysis procedure similar to academic programming. Finally, many recreational skills provide an excellent means of extending, maintaining, or generalizing social skills.

Fortunately, therapeutic and community recreation personnel have realized the extensive need for recreation for the retarded, and a variety of therapeutic programs has been developed for handicapped children (Frye & Peters, 1972). Unfortunately, little work has been carried out with the severely handicapped; but therapeutic and community recreation professionals have a strong background and commitment to the integration of the handicapped into more normal environments through the provision of recreational activities.

The Family as Catalyst

Educators now realize that the family is an important component in providing for the education of severely handicapped children. Home-school cooperation is a growing reality (Sontag, 1976), as both parents and educators recognize the child's need for a 24-hour environment conducive to learning. Educators have recognized that parents can learn to teach their children skills at home and to reinforce the skills taught at school through appropriate practice. This cooperative effort has led to increased ac-

quisition and proficiency of skills. In addition, this cooperative effort has had a pronounced impact on the maintenance and generalization of skills through the provision of opportunities to practice in situations offering a variety of persons, places, and language cues (Barrett & McCormack, 1973; Corte, Wolfe, & Lock, 1971; Garcia, 1974; Johnson & Johnson, 1972; Kale, Kaye, Whelan, & Hopkins, 1968; Martin, 1975; Stokes, Baer, & Jackson, 1974; Williams, 1975).⁶ If effective community services can be instituted so that they become an integral part of this home-based partnership, opportunities for appropriate practice will increase, which will, in turn, lead to even greater opportunities for the maintenance and generalization of academic, vocational, and social skills.

The positive benefits that accrue to severely handicapped people through the ability to utilize skills in a number of community settings is but one of the benefits of community programming. An equally important function of a community service network is to lend support when people are experiencing stress. It is generally agreed that the presence of a severely handicapped member within the family group produces stress. Not only are extensive adjustments demanded in family routines but family members must respond in unusual ways to even the most commonplace needs. Such services as babysitting, dental work, and transportation, which the nonhandicapped population may take for granted, are exceptionally difficult for families of the handicapped to obtain (Kerowitz, Gallagher, & Edgar, 1977).

The provision of services to help these families circumvent common areas of stress or to help them cope more effectively with unavoidable stress-producing situations would be an appropriate activity for a community service network. Mental health professionals have traditionally been involved in providing such supportive services to a variety of client populations, and their services would be a useful and effective addition to any community service system organized to work with the severely handicapped.

A common source of stress in families with a severely handicapped member is change. Community service personnel, mainly mental health workers and medical personnel, have typically provided either services of an informational nature, relating to placement possibilities for a severely handicapped person, or services

of a supportive nature, relating to the adjustments necessary to maintain the person in the home. The focus on placement or adjustment has usually been based on the assumption that the handicapping condition would persist in its present form over time. This assumption of stability has proved to be erroneous, for it fails to take into account the impact of educational programs that have produced levels of functioning that were previously thought unattainable.

Learning to cope with changes in performance will have a major impact on the families of the severely handicapped. In some ways, acceptance of and adjustment to the handicapping conditions may be easier than dealing with the stress generated by uneven and sporadic change. The demands of a rigorous home learning program, coupled with the unknowns associated with individually specific anticipated performance estimates, are bound to produce conditions of stress and uncertainty within the family.

In summarizing this section on the family, we might well look at the family group as a central agent that mediates the provision of services to the severely handicapped. These services can be looked upon as a combination of direct services to meet immediate needs and social action to influence future interactions. Community service professionals must constantly remind themselves of the reciprocal nature of social change. Community programming must attend not only to the adjustment needs of the handicapped vis-a-vis the larger society but also to the corresponding need to influence the larger society to adjust to the handicapped.

Conclusion

Increasing numbers of severely handicapped people are becoming members of our communities. They have the legal and the moral right to an appropriate education and to adjunct community services to prepare them for independent functioning as participating members in the daily activities of their communities. Educators have made a solid beginning in showing the way to teach skills that were previously thought to be unattainable. Now, through the cooperative efforts of a larger community service network, educators and other community service professionals can work together on maintaining and generalizing these essential

skills. Community service professionals have the opportunity and the responsibility to adapt their traditional expertise to ways of providing for the needs of the severely handicapped. These needs are urgent, and the potential for meeting them through cooperative effort is but a handshake away.

NOTES

¹ N. Certo (1976) A systematic comparison of the relative effectiveness of inducing generalization through the utilization of a concurrent versus successive procedure during initial skill acquisition with handicapped students. Unpublished doctoral dissertation, University of Wisconsin, Madison.

² M. Gold & R. Torner (1974) A request for a program-related investment. Unpublished report, Macron, Inc., Champaign, HI.

³ J. DuRand (1976) Year-end report. Unpublished report, Minnesota Diversified Industries Plant #1, Minneapolis, Minn., May 6, 1976.

⁴ R. Schwartz (1976) Teaching severely handicapped workers to function as dishwashers in simulated and natural settings. Unpublished Master's thesis, University of Wisconsin, Madison.

⁵ A. Kazdin & B. Erickson (1974) Development of play responses in the severely and profoundly retarded. Paper read at Association for Advancement of Behavior Therapy Convention, Chicago.

⁶ Certo, op. cit.

REFERENCES

- Barrett, B., & McCormack, J. (1973) Varied teacher tutorials: A tactic for generating credible skills in severely retarded people. Ment. Retard., 11, 14-19.
- Belmore, K., & Brown, L. (1976) A job skill inventory strategy for use in a public school vocational training program for severely handicapped potential workers. In L. Brown, N. Certo, K. Belmore, & T. Crowner (Eds.). Secondary programs for severely handicapped students. Vol. 6. Madison, Wis.: Madison Public Schools.
- Brown, L., Bellamy, T., & Sontag, E. (Eds.) (1971) The development and implementation of a public school prevocational training program for trainable retarded and severely emotionally dis-

- turbed children. Vol. 1. Madison, Wis.: Madison Public Schools.
- Brown, L., Certo, N., Belmore, K., & Crouner, T. (Eds.) (1976) *op. cit.*
- Brown, L., Crouner, T., Williams, W., & York, R. (Eds.) (1975) Madison's alternative for zero exclusion: A book of readings. Vol. 5. Madison, Wis.: Madison Public Schools.
- Brown, L., & York, R. (1974) Developing programs for severely handicapped students: Teacher training and classroom instruction. Focus on Exceptional Children, (3, 2).
- Certo, N., Schwartz, R., & Brown, L. (1975) Community transportation: Teaching severely handicapped students to ride a public bus system. In L. Brown, T. Crouner, W. Williams, & R. York (Eds.), *op. cit.*
- Certo, N., & Swetlik, B. (1976) Making purchases: A functional money-use program for severely handicapped students. In L. Brown, N. Certo, K. Belmore, & T. Crouner (Eds.), *op. cit.*
- Corte, H., Wolf, M., & Locke, B. (1971) A comparison of procedures for eliminating self-injurious behavior of retarded adolescents. J. Appl. Behav. Anal., 4, 201-13.
- Enrikin, D., York, R., & Brown, L. (1975) Teaching trainable level multiply handicapped students to use picture cues, context cues, and initial consonant sounds to determine the labels of unknown words. In L. Brown, T. Crouner, W. Williams, & R. York (Eds.), *op. cit.*
- Fox, R., & Azrin, N. (1973) The elimination of autistic self-stimulatory behavior by overcorrection. J. Appl. Behav. Anal., 6, 1-14.
- Francis, R., & Rarick, L. (1959) Motor characteristics of the mentally retarded. Amer. J. Ment. Defic., 63, 792-811.
- Fredricks, H., Riggs, C, Furey, T., Grove, D., Moore, W., McDonnell, J., Jordan, E., Hanson, W., Baldwin, V., & Wadlow, M. (1976) The teaching research curriculum for moderately and severely handicapped. Springfield, 111.: Charles C Thomas.
- Frye, V., & Peters, M. (1972) Therapeutic recreation: Its theory, philosophy, and practice. Harrisburg, Pa.: Stackpole Books.
- Garcia, E. (1974) The training and generalization of a conversational speech form in nonverbal retardates. J. Appl. Behav. Anal., 7, 137-49.

- Gold, M. (1972) Stimulus factors in skill training of the retarded on a complex assembly task: Acquisition, transfer and retention. Amer. J. Ment. Defic., 76, 517-26.
- Johnson, J., & Johnson, G. (1972) Modification of consonant speech-sound articulation in young children. J. Appl. Behav. Anal., 5, 233-46.
- Kale, R., Kaye, J., Whelan, P., & Hopkins, B. (1968) The effects of reinforcement on the modification, maintenance, and generalization of social responses of mental patients. J. Appl. Behav. Anal., 1, 307-14.
- Kenowitz, L., Gallaher, J., & Edgar, E. (1977) Generic services for the severely handicapped and their families: What's available? In E. Sontag, J. Smith, and N. Certo (Eds.), Educational programming for the severely and profoundly handicapped. Reston, Va.: CEC.
- Koegel, R., Firestone, P., & Kramme, K. (1974) Increasing spontaneous play by suppressing self-stimulation in autistic children. J. Appl. Behav. Anal., 1, 521-28.
- Malpass, L. (1960) Motor proficiency in institutionalized and non-institutionalized retarded children and normal children. Amer. J. Ment. Defic., 64, 1012-15.
- Martin, J. (1975) Generalizing the use of descriptive adjectives through modeling. J. Appl. Behav. Anal., 8, 203-9.
- Mills v. Board of Education of the District of Columbia, 348 F. Supp. 866 (D.D.C. 1972).
- Morris, R., & Dolker, M. (1974) Developing cooperative play in socially withdrawn retarded children. Ment. Retard., 12, 23-28.
- Neisworth, J., & Smith, R. (1973) Modifying retarded behavior. Boston: Houghton Mifflin.
- Nietupski, R., Certo, N., Pumpian, L., & Belmore, K. (1976) Supermarket shopping: Teaching severely handicapped students to generate shopping tasks and make purchases functionally linked with meal preparation. In L. Brown, N. Certo, K. Belmore, & T. Crowner (Eds.), op. cit.
- Paloutzian, R., Hasizi, J., Streifel, J., & Edgar, C. (1971) Promotion of positive social interaction in severely retarded children. Amer. J. Ment. Defic., 75, 519-24.
- Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania, 343 F. Supp. 279 (E. D. Pa. 1972).

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- Sontag, E. (1976) Federal leadership. In M. Angele Thomas (Ed.), Hey, don't forget about me: A report from the CEC Invisible College on the severely, profoundly, and multiply handicapped. Reston, Va.: The Council for Exceptional Children.
- Stokes, T., Baer, D., & Jackson, R. (1974) Programming the generalization of a greeting response in four retarded children. J. Appl. Behav. Anal., 7, 599-610.
- Weisberg, P., Passman, R., & Russell, J. (1973) Development of verbal control over bizarre gestures of retardates through imitative and nonimitative reinforcement procedures. J. Appl. Behav. Anal., 6, 487-95.
- White, O., & Haring, N. (1976) Exceptional teaching. Columbus, Ohio: Charles E. Merrill Publishing Co.
- Williams, W. (1975) A comparison of two procedures for teaching severely handicapped students to differentially respond to individual components of language cues. In L. Brown, T. Crowner, W. Williams, & R. York (Eds.), *op. cit.*
- Williams, W., Brown, L., & Certo, N. (1975) Components of instructional programs for severely handicapped students. *Ibid.*
- Williams, W., Pumpian, I., McDaniel, J., Hamre-Nietupski, S., & Wheeler, J. (1975) Teaching social interaction skills to severely handicapped students. *Ibid.*