

Testimony
before the
Subcommittee on the Handicapped
of the

Labor and Human Resources Committee

United States Senate

Senator Lowell P. Weicker, Jr., Chairman

Offered by

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This packet contains a synopsis of testimony, a curriculum vita, and two recent papers that elaborate specific issues raised in the testimony.

I appreciate the opportunity to offer testimony today. Although I understand the impetus for this hearing comes from Connecticut, the issues to be addressed are generic ones that represent critical policy and program decisions. Consequently, I want to thank you, Mr. Chairman, and the subcommittee for providing a forum in which the issues can be discussed on the record.

The focus of my testimony is on the potential of severely handicapped adults to participate in the life and work of their communities. I will concentrate on adults because it is at that age, after entitlements to childrens' services run out, that evaluation of final service success must be made. The implied promise of school and other services is that, upon reaching adulthood, an individual will be prepared to partake in the responsibilities and benefits of community life. I will concentrate on severely handicapped adults because the extreme service needs presented by this group bring into focus several basic issues relating to community services and government support.

Severely Handicapped People

Definitions of severe handicaps differ widely, and rightly so. Disabilities handicap people differently in different aspects of life. An individual's condition may result in severe handicaps in school that do not affect work, in work that do not affect independent living, and so on. Labeling the condition tells only the beginning, especially for adults, who face multiple life demands. I will refer to people as severely handicapped who are typically labelled severely and profoundly mentally retarded, autistic, and multiply handicapped. Historically, these individuals have been most likely to be placed in institutions, denied

access to school as children and to vocational rehabilitation as adults, and seen by families and service providers as creating extreme hardships.

Quality of Life

The basic human issue raised by a discussion of alternative service strategies is what sort of life is appropriate or desirable for severely handicapped citizens. While each of us would no doubt emphasize slightly different things in defining quality of life, history suggests that the constitutional guarantees of life, liberty, and pursuit of happiness are so important that our society will enter major conflicts to preserve them. Like everyone else, severely handicapped people enjoy quality living only as these basic values are operationalized in the opportunities of daily living.

No single view of quality in adult living is likely to capture the richness and diversity of modern aspirations. Nevertheless, a growing worldwide consensus provides a useful framework for operationalizing fundamental aspects of quality living for individuals with severe handicaps. Deriving in large part from the concept of normalization, these include provision for basic health and safety, development of personal skills and independence, integration and participation in community life, and productive work.

Effects of Community Alternatives

After more than a decade in which deinstitutionalization has been a professed national priority, where do we stand in efforts to provide opportunities for quality living to severely handicapped individuals? The decade saw repeated situations where community service providers were confronted with unfamiliar service problems and developed technologies

to solve those problems, creating opportunities not previously thought possible for severely handicapped people. The cumulative result has been widespread demonstration of the potential competence, productivity, and community participation of people with severe handicaps. In the comments to follow, I will illustrate the depth of this contribution to quality of life. But first a reminder: The generation of severely handicapped individuals of whom I am speaking have not benefitted from the education available to handicapped children today. Thus, their success in community services may be only a fraction of that for which we should now be planning.

Community Living

Residence in small community residences has been associated with several improvements in the lives of severely handicapped people. In the area of health and physical well-being, an expectation of any service system, an important report was recently completed in the state of Washington. All retarded residents released from state institutions in 1979 were studied after a year in the community. During this period, the health status of more than a third of these individuals had changed significantly, with improvements recorded in needed weight changes, chronic medical conditions, correction of previous misdiagnosis, and use of needed prosthetic devices. The records of individuals leaving the Pennhurst institution near Philadelphia is consistent with these findings.

The record on development of personal independence is similar. For most severely handicapped individuals, the exercise of personal autonomy requires both programming for skill development and regular opportunities to use skills that have been mastered. Although a technology for teaching needed skills has been available for some time, several recent studies

have observed more rapid development of skills needed for personal autonomy in small community residences. For example, a carefully designed effort is now underway to compare the progress of individuals leaving the Pennhurst institution with matched behavioral "twins" who have remained in the institution. Measures of both groups were taken over a two year period with a widely recognized behavior rating scale. Those in the community showed highly significant gains in personal self-sufficiency, community self-sufficiency, and personal-social responsibility; those remaining in the institution showed no significant gains in any area. Successful skill development is so widespread in well-managed community programs that it is now commonplace to expect previously dependent severely handicapped individuals to contribute to and participate in daily activities in both home and community settings.

Improvements in personal skills contribute meaningfully to quality of life only when the environment affords opportunities to use them according to individual interests and goals. It is in this area that the dramatic potential of the community-based services become clear. Development of skills in small programs can and does allow individuals to travel independently in the community, select and purchase personal items, work outside the home, attend church independently, jog with non-handicapped individuals, enjoy work breaks in downtown coffee shops, and so on. The proximity to community opportunities and the potential flexibility of community services allow severely handicapped people to enjoy the benefits of their skills. Rather than endure treatment as eternal children expected continuously to learn new skills, severely handicapped individuals in community settings have the opportunity to use the skills they have to enhance the quality and enjoyment of their lives.

Family contact represents another aspect of quality of life that is widely valued in our society. Here the data provide overwhelming and unmistakable support of small community programs. In the study of the Pennsylvania institution I mentioned earlier, the number of parents participating in individual program planning meetings - the basis of all individualized programming - increased from 11 percent in the institution to 75 percent after the same individuals were placed in the community. Visits with families tripled after leaving the institution, and the number having monthly outings with relatives increased by a factor of nine.

Work Potential and Opportunity

The importance of employment in a quality adult lifestyle in our society is chronicled in the expectations of practically every minority group whose civil rights have been at issue. Now, with clearly demonstrated ability to learn needed skills, severely handicapped individuals have joined others whose participation in our society is determined in part by the status afforded by work and in part by the opportunities provided by wages.

To illustrate progress in the area of work, let me describe some of my own research. Eight years ago I began a small vocational program for severely and profoundly retarded individuals who had been excluded because of skill deficits and behavior difficulties from all day programming. This program grew gradually to serve fifteen individuals who today are representative of the least capable individuals served in day activity programs in institutional and community settings in the Northwest. At the outset a market for electronic work was identified and a structured program was designed to provide extended employment in small parts assembly. During the ensuing eight years, the fifteen individuals have learned such complex assembly tasks as oscilloscope cam-switch actuators, cable harnesses,

chain saw components, circuit boards, computer printer frames, transformer coils, and power supply units. Their combined wages last year were \$18,371, more than four times the national average for their more capable counterparts in work activities centers. Not only can severely handicapped individuals learn the skills for remunerative work, but also can they earn significant wages when structured employment opportunity is provided. That program has now been duplicated in ten communities in six western states with similarly positive results. Parallel efforts in vocational preparation nationwide leave little doubt that severely handicapped individuals can become competent, productive workers.

Issues

These community living and work successes, and the many additional studies they illustrate, make it clear that severely handicapped individuals have the potential for skill development, community integration, and productive employment. Not all efforts to provide for deinstitutionalized living have had such success, however. In fact, many severely handicapped adults now in community settings are so sheltered that they enjoy neither independence, nor integration, nor employment opportunities.

The experience of the last decade indicates, however, that these difficulties cannot be attributed simply to the presence of severe handicaps. Too many similar people have succeeded when needed services and opportunities were available. Instead of blaming the severely handicapped individual for lack of potential or readiness, we must look for barriers to success in the service delivery system itself. The process of designing comprehensive community services has proved complex, as has the task of adapting policies and programs to new service technologies. Experience with both the successes and failures of community services for

severely handicapped individuals brings one important service design issue into focus. I believe it must be addressed if quality adult living is to be made more accessible to those with severe handicaps.

The issue is a broad emphasis on "readiness" that pervades many policies and programs affecting handicapped individuals. In essence, the readiness logic is that programs and services are needed to prepare an individual for later participation in work, community living, recreation, or other opportunities. Preparation continues until an individual is deemed "ready" for the next step, i.e. until the individual is expected to participate without further support. The result for severely handicapped individuals is all too often a sentence to indefinite preparation; in institutions, for example, getting ready for community living; in day activity programs, getting ready for work activities centers; and in sheltered workshops, getting ready for open employment.

Let me use the area of work to further illustrate the effects of this readiness strategy on severely handicapped people. The nation's vocational rehabilitation program is designed to provide services that equip a consumer so well that he/~~to~~ she can enter the labor market needing no further support from social services. To accomplish this, the program has developed an impressive array of evaluation, counseling, training, job development, and other services that have resulted in successful employment for many handicapped individuals, including some with the severe handicaps addressed here.

Despite the vocational competence demonstrated by severely handicapped people in structured employment situations, however, there is little evidence to expect many of these individuals to succeed in unsupported open employment. Neither incentives nor programs now exist for employers and social services to meet the additional needs for capitalization, training,

supervision and support that severely handicapped individuals appear to require in open employment with current treatment technologies.

With limited prognosis for totally unsupported employment, severely handicapped adults frequently are denied all access to work opportunities. Instead of receiving the needed support to work in either sheltered or open employment, severely handicapped individuals typically are assigned indefinitely to prevocational or non-vocational programs where a regimen of recreation, training in daily living, and other activities is expected ultimately to develop readiness for work. The result is that severely handicapped people, who with adequate support could be vocationally competent, are excluded from work opportunities. The attached papers describe the national scope of this problem and suggest a framework for designing an alternative. What is needed is the opportunity for severely handicapped individuals to participate in the life and work of a community, with the level of support that is needed by each individual. Financial contingencies, program regulations, and service inertia must all be reversed if the full potential of severely handicapped people for quality adult living is to be realized.

Conclusion

The technology is now available to assist previously segregated severely handicapped individuals to participate in the life and work of a community. That participation will require ongoing support for many individuals, but it will also enable them to achieve a quality of life and a measure of contribution to society that has been thought impossible. The experience of the last decade shows that most of the limits previously blamed on severely handicapped individuals must be attributed instead to the availability and quality of support services. With a commitment

To continued improvement in policies and programs to match the emerging technology of service, quality community living can be offered now to all of America's handicapped citizens