



A
***NATIONAL PROFILE
OF CHANGES
IN SERVICES FOR ADULTS
WITH DEVELOPMENTAL DISABILITIES***

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CHAPTER III

A PROFILE OF THE FUTURE

FOR SERVICES TO ADULTS WITH DEVELOPMENTAL DISABILITIES

The decisions in the past were based on assumptions that are currently out of date and out of touch, with today's philosophy and technology.

The most reliable way to anticipate the future is by understanding the present" (Naisbitt, 1982). Understanding the present, however, requires more than the analysis of a set of descriptive statistics. It involves the interpretation of current information to detect changes that will prepare society for the future. Values, lifestyles, expectations, and economic conditions are constantly changing. The nature and direction of change is a common theme in popular literature but futurists, such as Toffler and Naisbitt, who provide glimpses of the future, have had little or nothing to say about the impact of such change on disadvantaged people, specifically those who have disabilities.

The current system of services to adults with developmental disabilities is based to a large extent on information and technology that is more than 50 years old. Many of the decisions in the past were based on assumptions that are currently out of date and out of touch with today's philosophy and technology. Much time, money, and effort has been expended trying to update this system and there are many examples of such efforts. The hospital improvement programs of the 1960s were attempts to improve the standard of care for individuals in institutions. In many respects, these efforts either tinkered with the problem or increased an investment of time and resources in an inappropriate system. This in

itself has made it increasingly difficult to change. As a consequence, many states have a dual system consisting of both institutions and community services. Social systems, like people, are difficult to change. With existing funding patterns there is generally little incentive to "cut the losses" and modernize.

Changes in social systems are seldom in a single direction, they do not occur quickly and they are not evenly distributed. State-of-the-art programs often exist side by side with traditional programs making it difficult to determine the direction of the future. As

the Cheshire Cat remarked in Alice's Adventures in Wonderland, "Where you ought to go from here...depends a great deal of where you want to get to." The principle of normalization and its corollaries providing not only the goal of where we "want to get to," but some of the intermediate objectives. The remainder of this chapter will discuss changes in the mental retardation, developmental disabilities program during the past and changes that we can anticipate in the future. Changes are discussed in three broad areas: the individual, the environment, and the adult service delivery system.

CHANGES IN INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Who Will They Be?

The exact number of people with developmental disabilities can only be estimated. A developmental disability can be defined in many different ways and the number of people with disabilities varies with each definition (Kiernan & Stark, 1985, Chapter 2). The Developmental Disabilities and Bill of Rights Act of 1984 utilized a "functional definition" instead of a "categorical definition" as used in the past. This functional definition focuses on the type of disability, the onset of disability, and the degree of functional loss and its relationship to other factors. Categorical definitions emphasize discrete characteristics such as IQ scores, genetic abnormalities, and other physical factors that are generally used to determine eligibility.

How a person adapts and adjusts to a handicap is often more important than the handicap itself. Two people with the same handicap may adjust and develop differently depending on the environment in

which they grow and the opportunities for learning, therapy, and other services available. Even though both may be considered to have developmental disabilities under a categorical classification scheme, a functional definition would differentiate between them if one needs sustained, contin-

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uing support while the other is able to lead a relatively independent life.

The use of a functional definition is logical and practical to people with handicaps and their parents. However, a functional definition is difficult to use in program planning since it is more complex and more given to subjectivity than a categorical definition (Kiernan & Stark, 1985, p. 29). As a consequence, census data and demographic reports generally use categorical definitions for collecting information regarding people with handicaps.

During the past two decades, significant advancements have been made in the prevention and treatment of developmental disabilities (Kiernan & Stark, 1985, p. 58). Even so, the prevalence of developmental disabilities has remained relatively constant since advances in medical science have saved the lives of many handicapped infants who would not have lived in earlier times. The Communicable Disease Center of the Public Health Service reports that the birth rate of children with birth defects has not changed significantly over the past 10 years (Buehler et al., 1985).

While the number of individuals born with developmental disabilities each year is relatively constant, there has been a decline in their death rate. As a result, the average age of people with developmental disabilities is getting older. Because the death rate was higher at an earlier age two decades ago, there are comparatively few elderly people now with developmental disabilities. However, this number can be expected to increase rapidly in the future as people with handicaps live longer.

The number of people with developmental disabilities is increasing as the general population increases, but it is not declining at the same rate at the middle and

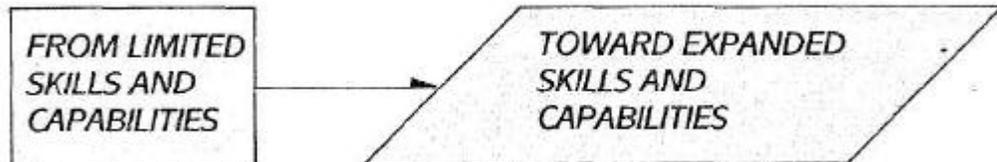
upper end. Consequently, there is a population bulge of young adults similar to the "baby boom" that is moving year by year through the service delivery system. Based on these data, it appears that in the future there will be a greater number of individuals with severe and profound handicapping problems and these individuals with severe handicaps can expect a near normal life span. These two factors will place additional economic and service demands on the system.

Besides the age distribution characteristics, changes are also occurring in the skills and behaviors of these people. Many of today's young adults with disabilities have received educational and early therapeutic benefits that were unavailable a decade ago. Health services, including medication, surgery, improved nutrition, and prosthetics, have assisted them in significant and sometimes spectacular ways (Technology and Handicapped People, 1982). Therapeutic services have helped them overcome or circumvent many barriers and limitations, thus enhancing development and participation in the mainstream of society and allowing them to learn, adjust, and be self-sufficient (Hardman, Drew, & Egan, 1984).

Equally important are the recent developments in instructional methodology and technology which have benefitted probably the largest number of people with handicaps. Advances in instructional technology have expanded teaching effectiveness and increased learning and retention. These advances will help people with developmental disabilities acquire and use more information in decision making and accept additional responsibility for their lives. Such technical advances will make it possible for many individuals with developmental disabilities to learn, adjust, and contribute to society far beyond that which was previously expected.

The new wave of young adults with handicaps will be more skilled, have a more normalized life expectancy, and possess significantly more potential than previous generations. In addition, both they and their parents will expect the same opportunities for jobs, community living, and education

that are available for their nonhandicapped peers. In all probability this is only the beginning. Future research will advance information and technology much farther. Clearly the more that is known and understood, the more the capabilities of people with handicaps will be revealed.



Where Will They Live?

Historically, large state institutions have been the primary publicly supported residence for individuals with developmental disabilities. Even though the population living in these facilities has steadily declined, large institutions are still the primary location of publicly supported residential services (Bruininks et al., 1985). During the past decade, there has been an increase in the number of Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) which are smaller in size and receive most of their funding from Medicaid. However, these programs also treat residents as patients and follow a medical care model. Health Care Financing Administration (HCFA) regulations have reinforced the use of the medical care model. Only recently have procedures been authorized that permit states to purchase services for residents in locations outside the actual residential facility. This is currently possible through the Home and Community-Based Service Waiver. Unfortunately, obtaining federal approval for such waivers is a time-consuming and difficult procedure which acts as a disincentive to

community-based services (Gardner, 1985)

It is estimated that almost 79% of individuals with developmental disabilities live in their natural home or an alternative family-type setting (MacMillan, 1977). Although many of these are school-age children and young adults under 21 years of age, the majority are 21 years and over. Only 13% of the total population are residing in publicly supported residential settings. Of those, 70% still reside in large publicly supported institutions. The number of individuals in group homes or other alternative living arrangements is small (Bruinink et al., 1985). (See Table 2.)

The trend is toward smaller, family-type residential programs, however, large institutions continue to serve a large portion of those in publicly supported residential services. Only six states have more mentally retarded residents in facilities with fewer than 16 beds than in facilities with 16 or more beds. Less than half the people with

Table 2

Place of Residence of the Developmentally Disabled Population^a

Family/Home and Other	3,006,345 ^b
Public Institutions including ICFs/MR	536,580 ^c
Community Facilities	235,940 ^c
Foster Homes	26,635 ^c
TOTAL	3,805,500

^aBased on U.S. Census population.

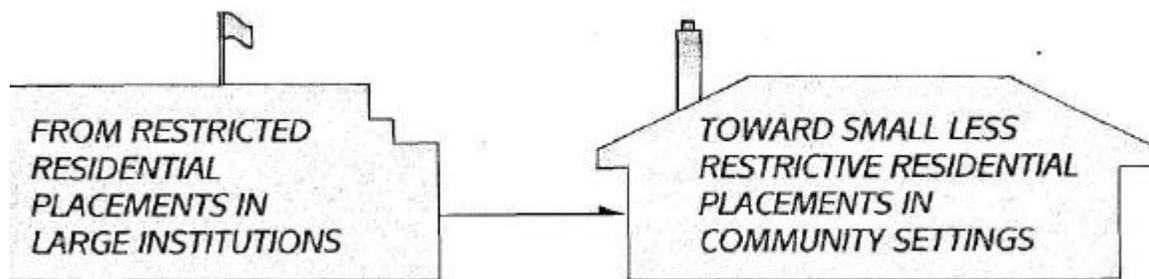
^bPrevalence from Moran (1984), Office of Inspector General.

^cPrevalence from Bruininks (1985), Technical Report #1.

developmental disabilities who live in ICFs/MR are in facilities with fewer than 16 beds. This is true even though more effective, less expensive options have been designed, implemented, and evaluated (Bruininks et al., 1985).

Cost is the most frequent reason cited for maintaining and placing people in large institutions and nursing homes. Proponents often justify continued institutional care on the basis that it is not cost effective to provide the intensity of services needed by profoundly handicapped people in any other type of setting. Research does not support this position (Wieck & Bruininks,

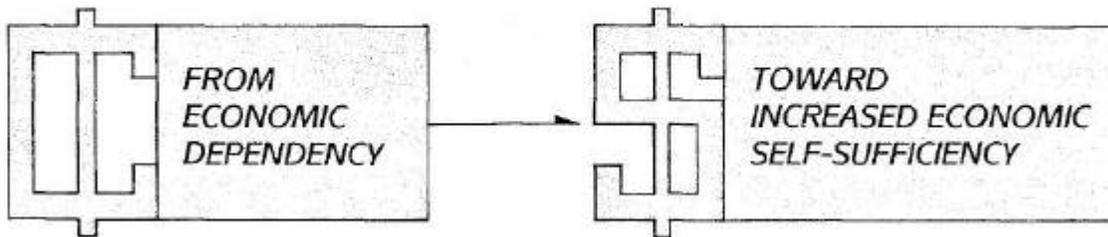
1980; Intagliata, Wilier, & Cooley, 1979; Binsberg & Smith, undated). On the contrary, many institutions have extensive hospital and clinical facilities and provide medical expertise needed by only a small fraction of the population in the institutions. Large institutions are under attack for three different reasons: (1) over-care of their population, (2) lack of needed opportunities for growth, development and progress toward self-sufficiency, and (3) service provisions to only a small portion of the total population with developmental disabilities (Dazey, Fifield, Hardman, Hill, & Berger, 1985).



Family-like residences are clearly the direction of the future. Various residential program models have successfully demonstrated that equal or higher quality residential services can be provided in the community at reduced costs for people with the widest possible range of disabilities including severe behavior and medical problems. These program models, although they are demonstration projects, exist in virtually every state. They have shown successful practices and procedures, but they have not been replicated on a wide scale. Efforts are currently underway to change the regu-

lations that govern how title XIX funds a distributed in order to increase the financial incentives for states to develop small residential programs in community setting (Chafee, 1984). In addition, court ordered deinstitutionalization is giving addition strength to this movement (Halderman vs. Pennhurst State School and Hospital, 1977). It is unlikely that the institutional model will cease to exist, but a sustained and strong trend is in progress toward residential services in smaller less restrictive community settings.

What Will They Do?

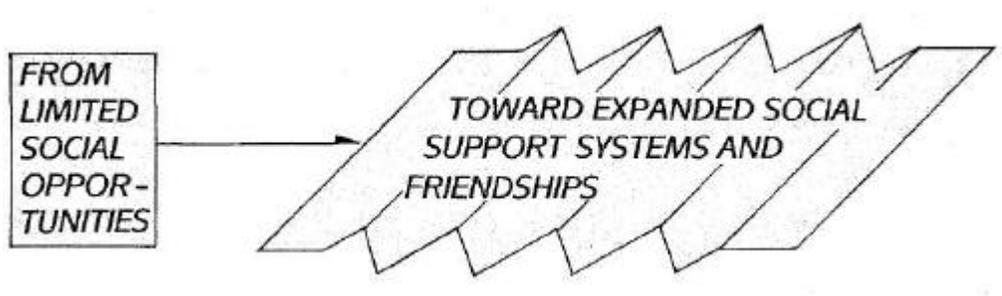


Western society places high importance on what members of society do to earn a living. Personal value is closely related to self-sufficiency and contributions to society. The importance of employment cannot be overemphasized (Kiernan & Stark, 1985).

The number of people with developmental disabilities who are employed is not known. Statistical data, however, point out that of the more than 4 million people classified as severely handicapped, of which many have developmental disabilities, only 514,000 are employed full-time (Mathematica Policy Research). Over 3,580,000 of people with disabilities are considered not in the labor force. Individuals are desig-

nated not to be in the labor force if they have not been employed in the last six months and are not seeking employment. Over 85% of those with severe disabilities are not in the labor force compared to 18 of the population without disabilities (Weiman & Hill, 1985).

With increased functional skills and reasonable accommodations, employment is a realistic goal for those with both moderate and severe disabilities (Wehm, Kregel, & Seyfarth, 1985). Data suggest that only 10.9% of those with disabilities are affected to the extent that their disability interferes with normal life activities including work (Kiernan and Stark, 1985). Enc



mous strides have been made during the last decade which have demonstrated that most individuals with developmental disabilities do have the capacity for independent community living and gainful employment. The research literature provides convincing evidence that the skills necessary for employment can and are being taught in demonstration projects throughout the nation (Paine, Bellamy, & Wilcox, 1984). One of the major barriers to entry into the labor force is the attitude of the public toward people with disabilities. More than 34% of people with developmental disabilities who are not working would like employment if given the opportunity (Kiernan and Stark, 1985). The service trend of the future is toward increased economic self-sufficiency through various types of gainful employment.

As an outcome of the Education for All Handicapped Children Act, Section 504 of the Social Security Act, and the Develop-

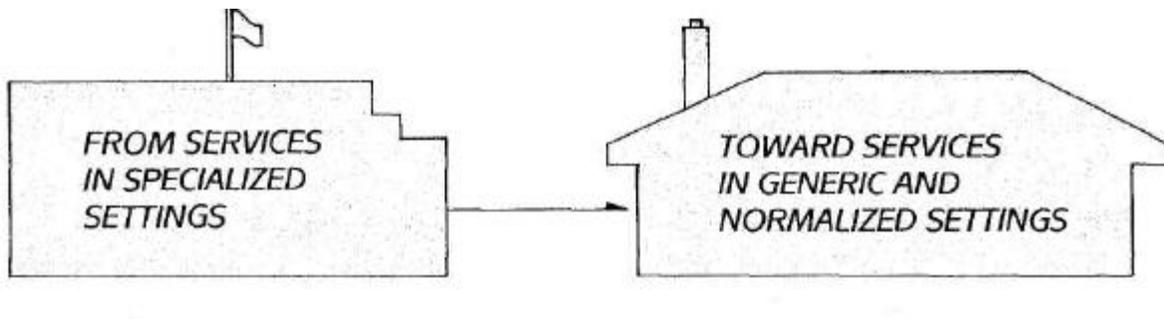
mental Disabilities and Bill of Rights Act, people with handicaps are more and more visible in virtually all areas of society. This visibility has softened public curiosity and fears and expanded acceptance and awareness. Many groups like "Big Brother" and "Big Sister," "Friends of the Handicapped," and similar advocacy, tutorial, or support organizations have been established. Most of these organizations are small, but they provide a variety of benefits including peer relationships with individuals without handicaps and expanded social opportunities (Self-determination Among People with Disabilities, 1985).

As more and more people with handicaps live, learn, and interact in our communities, fears and ignorance will be replaced by acceptance and support. One can predict that the future holds expanded social opportunities for friendship and support systems which currently are limited.

CHANGES IN THE ENVIRONMENT

Most early intervention efforts are directed toward changing the skills and behaviors of a person with a developmental disability (Calkins et al., 1985). This is generally accomplished through instruction, therapy, or medical intervention. The bene-

fits derived from these efforts are often not generalized to other settings or are not maintained over time. For example, social and behavioral skills taught in an institution are seldom generalized or maintained when the client moves to a group home. The



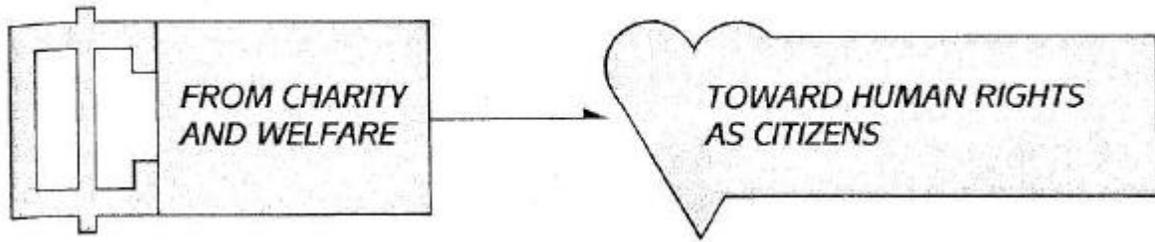
opportunity to practice appropriate social and behavioral skills in natural settings is essential to ensure mastery and maintenance of the skills over time and use of the skills in a variety of situations. Most of the recent research has emphasized the importance of the environment in which adjustment skills are learned and utilized (Calkins et al., 1985). Simulation, role playing, and contrived situations for teaching are of limited value because they are poor substitutes for role models in the real environment (Alexander, Haganir, & Zigler, 1985). Furthermore, a contrived or synthetic environment is inconsistent with the normalization concept.

Considering the benefits derived from learning appropriate behavioral and social skills in the natural environment, it can be predicted that there will be continued and steady movement away from residential, vocational, and other types of services in specialized settings toward those provided in natural settings.

Currently, many of our specialized services are centralized in large programs. For example, teaching, diagnostic services, and therapy programs often have their own staff of highly trained professionals. As

people with handicaps are served in smaller more normalized community settings, these services will be provided by less specialized personnel. Considering these changes, it can be predicted that the professional who provides adult services in the future will be more of a generalist serving a variety of needs and utilizing highly trained specialists for consultation, backup services, program development, and inservice training (FiField, 1983). The specialists will serve generalists who in turn will provide the direct care to clients. As this trend develops, a variety of training, ethical, and service delivery system issues will need to be researched, new program models developed, and evaluation data collected. Naisbitt (1982) predicts this trend from specialists to generalists in virtually all service professions.

Organized care for people with mental retardation and other handicaps was first provided by churches and other charitable organizations. "Alms for the poor, crippled, and maimed" conveyed the message that people with handicaps need charity and that God encourages and blesses those that give. This attitude reflected the belief that little could be done for people with handicaps other than relieving some of the



misery. The titles of many of our early service programs included the words "charity," "mercy," "benevolence," and "welfare." Today people with handicaps are thought of much less as recipients of charity and much more as people who need greater opportunities and have a right to such opportunities (Wolfensberger, 1980). The titles of many programs today contain words such as "developmental," "training center," "school," "employment," "industry," and "living center." The changes in these titles are more than cosmetic adjustments. They not only reflect progress in attitudes but also the goal and purpose of the types of programs available today.

Public awareness of the needs and abilities of people with handicaps was heightened by the Human Rights Movement which challenged existing conditions of and attitudes toward all minorities. The Human Rights Movement stressed that all people have human rights protected by the constitution and that such rights cannot be denied.

The Protection and Advocacy Program, supported by the Developmental Disabilities and Bill of Rights Act of 1984, provides an agency in each state that is charged with the responsibility for monitoring and ensuring the rights of individuals with developmental disabilities. Through advocacy, due process hearings, and legal action, people with developmental disabilities are winning more and more access to community ser-

vices, employment, housing, and other benefits that the average person takes for granted.

Having already obtained educational opportunities for children with handicaps in the public schools, professionals and parent groups have recently stressed the right of persons with handicaps to expect gainful employment and opportunities for participation in general community services such as health care, education, transportation, recreation, and cultural and

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social events (Caparosa, 1985). Acceptance and integration will not occur rapidly, especially where special accommodations are needed to provide access and opportunity. There has, however, been a shift toward the acceptance of people with developmental disabilities as full citizens with the right to social services. The trend is clearly in this direction. Additional responsibility will be shifted to parents and professionals to pro-

vide the leadership and the methodology to ensure that this movement is of benefit to both people with handicaps and people without handicaps (Griffith, 1985). The social system of the future must provide means through which individuals with handicaps can be accepted as full citizens and can have access to appropriate opportunities.

CHANGES IN THE SERVICE DELIVERY SYSTEM

Each of the changes discussed in the previous sections have many implications for the service delivery system. In this section, those changes having the greatest impact on service delivery will be analyzed and the implications for the future will be discussed.

The relationship between the system that provides service and the needs of the recipients should be very close. However,

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significant changes have occurred in the acquisition of skills and abilities by individuals with developmental disabilities as an outcome of teaching, therapy, and medical intervention. The adult service system has not changed appreciably to accommodate these advances.

Organizations tend to have a life of their own that transcends the purpose for which they were originally established. For example, large institutions which 50 years ago served what was then thought to be the essential needs of people with developmental disabilities continue to be the primary recipient of federal funds even though more effective, less expensive options are available. Systems and organizations, like people, are difficult to change mainly because people run the system and make up the organizations.

Currently, the focus of federal and state programs, designed to meet the needs of children with developmental disabilities, is on early detection and intervention with the goal to promote learning, growth, and development through instruction, therapy, and medical intervention. On the other hand, the focus of the service programs for

adults is maintenance and care. Federally supported services to adults with developmental disabilities are generally provided through programs designed to meet the needs of a different population since legislators prefer to expand the eligibility for existing service programs instead of creating new programs to meet the specific needs of a particular group. As a result, much of the current legislation under which adults are served was enacted for other purposes and serves a broad spectrum of the population of which adults with developmental disabilities are only a small part (Moran, 1984). By meeting the needs of the much larger group of recipients, the benefits needed by those with handicaps are often compromised (Fifield, 1983b).

Federally supported programs for adults with developmental disabilities have focused primarily on health care through Medicaid and income maintenance through Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) in Title XVI and Title II, respectively, of the Social Security Act. (For additional information on these programs, see Middendorf, 1985a). Eighty-six percent of the federal funding for individuals with developmental disabilities has been provided through these channels (Moran, 1984). Federal support for services is significant not only because of the amount of money it provides but also because it has a profound influence on all other levels of services and support..

The service system of the future will increasingly reflect the basic principles of normalization and its corollaries: developmental progress, right to services, least restrictive environment, equal justice, and human dignity. This system will be driven by efficient and economic methods. Each of these principles will shape and influence the system in varying ways. However, the

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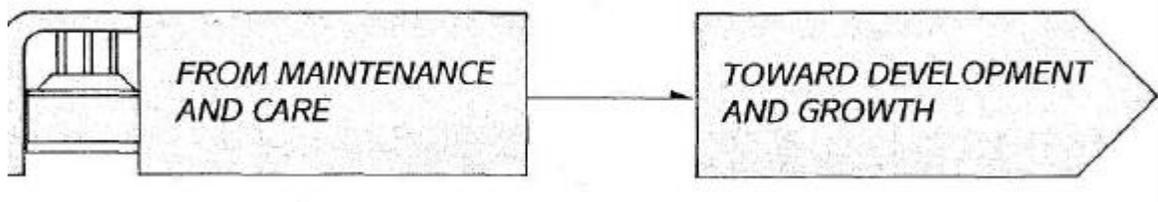
human rights principle and the issues of economic and efficient methods will probably have the greatest impact on the system as a whole. The human rights principle will not only influence the thinking and behavior of parents, professionals, and adults with developmental disabilities, but will also be reflected in court ordered and possibly court supervised changes in the service system. Court ordered changes set precedents that reverberate through the total system. Thus, they not only result in specific change but also dictate systemic change as a consequence of efforts to avoid legal action. The importance of efficiency and economics lies in the fact that human service resources are finite and will have to compete more and more with other priorities in society. Demonstrated effectiveness and cost containment will be increasingly important in setting priorities (Hill, Hill, Wehman, & Banks, 1985).

Efforts to improve services generally focus in two directions. First are efforts to expand the number of services available and to make existing services accessible by reducing waiting lists and eliminating holding programs. Second are efforts to fill the gaps between the state-of-the-practice and the state-of-the-art. It is this latter effort to make changes within the system that has the potential for making the most significant changes. By studying state-of-the-art programs, one can chart trends and identify appropriate action needed to systemically propel the service system forward in a desired direction.

One of the major tasks of the UAF Networking Initiative for Services to Adults with Developmental Disabilities was to identify state-of-the-art programs and to study the gaps between traditional or state-of-the-practice programs and state-of-the-art programs. State-of-the-art programs were identified in residential services, employment options, and the learning and adjustment process. Such programs are characterized by their efforts to provide services consistent with the principles of normalization and its corollaries and to provide program models that overcome or circumvent the barriers which traditional programs claim prevent them from providing more

appropriate services. Determining the gaps between state-of-the-practice and state-of-the-art is not simply the task of separating programs by a certain criteria and measuring how far they are apart. Many of the state-of-the-art practices exist within traditional programs. Furthermore, it is difficult to obtain consensus on what is or what is not a state-of-the-art program and such decisions are open to argument. To avoid these problems, best practices were examined to identify the trends. The following sections describe the direction of changes occurring in the service delivery system.

Much of the legislation which currently provides funding for services to people with developmental disabilities is based on a concept of care and maintenance. This legislation has been justified on the basis that people with developmental disabilities have limited potential for growth, development, and learning and that what they need is to be cared for. From a philosophical and practical standpoint, people who are thought to be totally dependent on society will have service programs designed quite differently than those who are thought to have potential for growth, development, and socialization.



People with developmental disabilities have more potential for development and growth than previously thought. Most can maintain employment and learn to live independently. As more and more is learned about how to teach and how they develop their skills, it can be predicted that programs will focus increasingly on individual growth and development and less on care and maintenance (Wenman & Kregel, 1985). The Community and Family Living Amendments of 1985, proposed for Title XIX (S. 873), include provisions which would encourage states to focus less on care and increase services designed to strengthen individual growth and development. Current eligibility criteria for income maintenance and Medicaid benefits are disincentives to independence. These criteria must be systemically changed in the future through new legislation, modified regulations, or different interpretations of the law in order to encourage and facilitate self-sufficiency.

Bruininks, Hill, Lakin and White (1985) point out that changes in residential services are progressing in four significant directions:

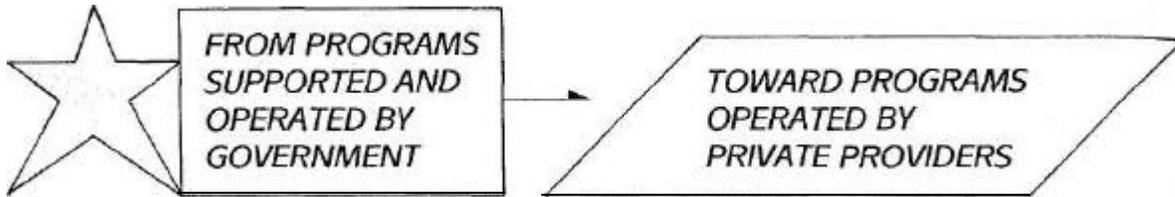
- From Large to Small Facilities
- From Public to Private Operations
- From Isolated to Integrated Community Locations
- From Self-contained to Community Resources and Generic Services

Similar changes in employment and learning/adjustment services are reported by Kiernan and Stark (1985) and Calkins et al. (1985). These changes are not only consistent with deinstitutionalization and an

expanded emphasis on growth and development, but also reflect a trend from state operated services toward an increasing number of state contracts for services with private providers. State and federal agen-

The number of contracted services to private providers is increasing as an effort to control cost and increase diversity.

cies are increasing the number of contracted services to private nonprofit providers in an effort to control cost and encourage diversity in service models. Whereas large centralized programs traditionally must invest a significant part of their resources in facilities and staff benefits, small decentralized service programs generally have more flexibility which often makes it easier to bring about desired changes. Service contracts to private providers can stipulate greater emphasis on independent living skills, community integration, the use of generic services, and client interaction in the real world.



By contracting with private providers, it is generally easier to design services to fit the needs of the individual rather than the needs of the service system. The change from system-referenced services to client-referenced services allows the focus to shift from an emphasis on client weaknesses to an emphasis on client strengths, from time-limited services to longitudinal or sustained services, and from segmented services, which may take into account only specific needs of a person, to integrated services, which can take into account the needs of the total person.

Expanded use of community medical services, either by contract or through pre-paid health arrangements, will not only have cost advantages, but also will increase the interaction of people with developmental disabilities with the mainstream of society. Small decentralized privately operated service programs can be designed to provide a more natural environment for people with developmental disabilities in which they can learn, generalize, and maintain adaptive social and behavioral skills. These programs can also adjust relatively easily to new methods and techniques for improving service delivery. At the same time, contracted services are not a panacea since they are difficult to monitor and evaluate. They necessitate effective case management and program stability and continuity is difficult to guarantee. Notwithstanding these problems, the number of contracted services is growing and the national trend will continue in this direction.

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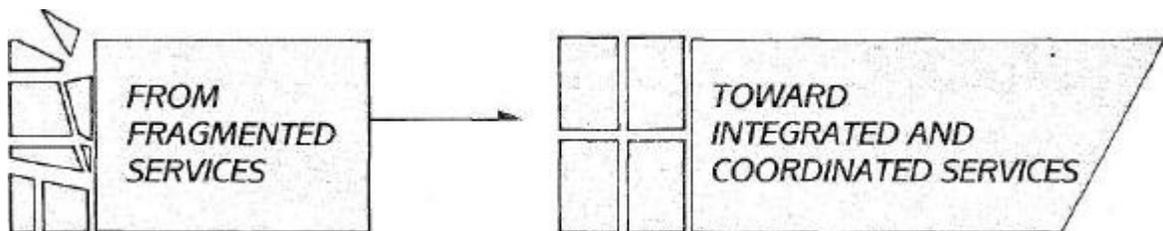
The system by which we currently serve and meet the needs of adult citizens is highly fragmented. Health, social services, education and training, mental health, rehabilitation, housing, transportation, and other services are provided by different agencies and there is comparatively little effort to coordinate them. Each agency sets its own procedures and objectives and provides services in its own manner. In addition, each agency has a source of support for which it must compete with others to maintain. For most citizens, this is not as

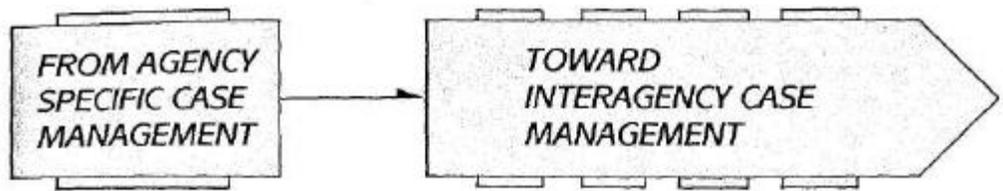
source of difficulty. The average person may require only one of many services at a time, such as housing, employment, or health services, and the need for such services is generally infrequent. However, for the handicapped, this system is particularly confusing.

Eligibility requirements for needed services often differ from agency to agency. Some agencies have no special provisions for the handicapped and many agencies have long waiting lists. Furthermore, the needs of people with handicaps are often clustered, requiring a variety of human services simultaneously, for example, employment, transportation, and housing. Unless these clusters of needs are addressed together, there is little likelihood that any single need will be met. Ideally, an individual program plan which considers living arrangements, day and work activities, and supported services should be put together with input from the client, parents, and a local agency before the client leaves school. However, the responsibility to develop and carry out such a plan is not usually assigned to a lead agency and, in practice, many needed adult services are nonexistent or hard to access. One of the major limitations of most service programs is the lack of case management through which parents and individuals can obtain the advice, information, and follow-up needed to access the adult service system.

One of the major limitations of most service programs is the lack of case management.

In most states, case management services are insufficient in both quantity and quality (Bruininks et al., 1985). Such services are often defined differently in different states and even among agencies within the same state (Wehman & Hill, 1985; Calkins et al., 1985). Counselor, case worker, and advocate are all terms which have been used to describe case management or case coordination services. What is even more confusing is that a single client may have several different case managers who are individually responsible for a single service. For example, social service case managers may concern themselves only with residential placement and know little about or take little responsibility for vocational, transportation, leisure time, or health services. Even if they tried to provide assistance in these other areas, the agency that employs them





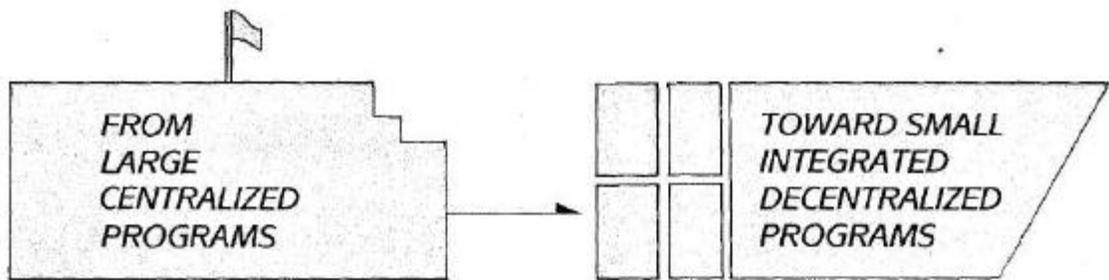
may object on the basis of their not meeting that specific agency's objectives. Furthermore, they often have little influence in obtaining services from other agencies.

Anticipated changes in the service system will be toward the assignment of a lead agency to take overall responsibility for cases and case management conducted through an interagency supported system. Case management will function more in an advocacy, information, and referral role than in a diagnostic, placement, counselor, or therapeutic role.

Controversy over the care of persons with retardation has probably always existed. Gollay et al. (1978) pointed out that in the nineteenth century, training schools were erected with the belief that retardation could be "cured" by education and training. However, by the early twentieth century, professionals were convinced that little could be done about retardation. As a result, lifetime confinement to institu-

tions became the solution. During the first half of the 1900s, the focus was on building large institutions in which people with mental retardation and similar disabilities could be maintained and cared for.

In the late 1960s, much more information was becoming available about the abilities of people with retardation and handicaps, and parents were seeking alternative to placing their children in overcrowded dehumanizing institutions. Early institutional reform focused primarily on improving the physical facilities of institutions and on upgrading staff competencies. During the 1970s, the deinstitutionalization movement gained momentum and new methods were developed to serve individuals with developmental disabilities in community based settings. Recently, the emphasis has shifted from large centralized program toward small integrated decentralized programs.

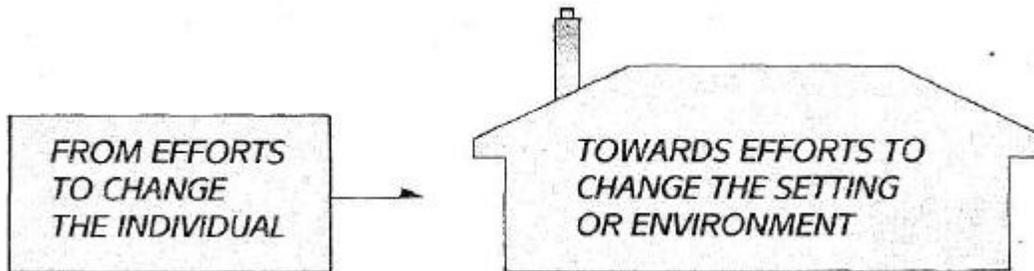


The needs of people with developmental disabilities are interrelated in various ways. Problems in one area of need often affect other areas of need. For example, adults with developmental disabilities are more likely to lose their jobs because of inappropriate social and behavioral skills than because of lack of job skills (Kiernan and Stark, 1985). The most frequent reason given for the return of clients to institutions from community placement is that of behavioral problems (Bruininks et al., 1985). Social skills, independence, and the ability to adjust to different settings are strongly related to successful employment and success in living in less restrictive residential settings. Following directions, accepting criticism, asking for information, and punctuality are among the skills needed in virtually every setting and the responsibility to teach, practice, and maintain these skills should be integrated into all service programs (Calkins et al., 1985). This interrelatedness is reflected in several future service trends including increased numbers of small community-based programs that will meet residential, vocational, learning and adjustment, and other needs. There will also be a greater utilization of staff who are generalists using backup consultation and specialized services. Funding for services will be channeled to the client via the parent and case manager rather than by the program staff.

Calkins et al. (1985) report that the characteristics of specific environments are better predictors of a client's success in residential and vocational programs than are the strengths and weaknesses of the client. These data suggest that the setting or the environment is of the utmost importance to the effectiveness of services. To date, most research and intervention have been geared toward fixing the deficits or the problems of the individual. Comparatively little effort has been spent studying and improving the match between individuals and the environments in which they are expected to function (Calkins et al., 1985). Additional attention must be given to the environment in which the person with handicaps is placed to live, learn, work, and adjust.

In the future there will be increased efforts in both research and service delivery to address problems using an ecological approach and to pursue a balance between individuals and environments (Romer & Heller, 1983). Changes in the environment and the match between an individual's skills and the demands of a given environment will be important components of placement and evaluation decisions in the future (Calkins et al., 1985).

More than 20 years ago, the President's Panel on Mental Retardation (1965) recom-



mended a "continuum of care" based on the concept that various levels of care are needed and that individuals with developmental disabilities should move from one level of care to another. One of the major objectives of this model was to avoid gaps between care programs and to facilitate a continuum of service. The "continuum of care" concept was applied initially to health services resulting in primary, secondary, and tertiary diagnostic care. Later, program planners utilized the concept to identify hierarchies for other services. The residential service hierarchy has developed to include: institutions, nursing homes, group residences, semi-independent living programs, supported independent living programs, board and supervised facilities, foster homes and natural homes (Bruininks et al., 1985). Bruininks (1985) identifies more than 120 residential program titles for which state licensing is available. The continuum of vocational activities includes institutional day-care, community day-care, work activity centers, sheltered workshops, sheltered employment, supported employment, and competitive employment (A Marketing Approach to Job Placement, 1985). The educational continuum of care as outlined by Deno (1970) identifies a cascade

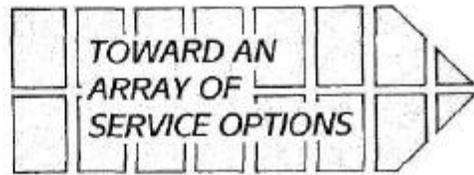
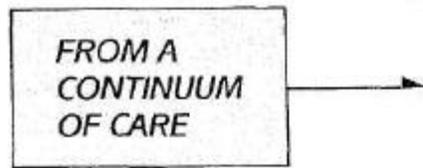
of services including: special instruction hospitals, homebound teaching, classes special settings, full-time special classes placement of students in regular classes but with support services, and regular class placement of children with handicaps.

Most states have adopted the continuum of care concept based on the assumption that different programs in different settings are necessary to meet the full range of service needs. It has also been presumed that those with the most severe disabilities must be served in more restrictive settings which persons with less severe disabilities can be served in more socially and physically integrated settings.

Although the continuum of care concept, sounds reasonable, many problems are encountered in its implementation.

- Most resources tend to go to the more social and physically restrictive and isolated setting such as institutions, ICFs/MR, adult day-care centers, and sheltered workshops. As such a few resources are left to support less restrictive and more integrated residential, vocational, training and health services (Kozlowski, Hitzing, & Helsel, 1983).
- Movement through the continuum of care model is a function of improvement in the client's behavior and skills, thus a client graduates from one program level to another (Kozlowski, Luteran, & Reynolds, 1983). Although this sounds logical, research indicates that seldom occurs for two primary reasons: First there are few incentives for a client to move through a continuum. As a matter of fact, more economic incentives for clients and their families work in the opposite direction. Furthermore, there are few incentives for staff to help clients move through the system. Each time a high functioning and, thus, easy to serve client moves on, the staff is left to work with more difficult clients who require additional costs in time and resources. Second, seldom are the service options of the continuum actually available where and when they are needed.

Many problems are encountered with the implementation of the continuum of care concept.



The questions most frequently asked by staff are "Where are the group homes?" and "Where are the services in less restrictive environments?"

The trend away from the continuum of care model toward an array of service options will affect the service system in several significant respects (Davis & Trace, 1982). First, resources will be distributed to a variety of services, not just those designed for the most restrictive settings. Payments for services will follow clients rather than programs (Bruininks et al., 1985). Clients will be placed directly in the highest level of service possible. As such, the task of the staff will be to teach the skills that enable the client to function at that level. Payments for services will be designed to provide incentives for movement toward less restrictive settings and greater independence.

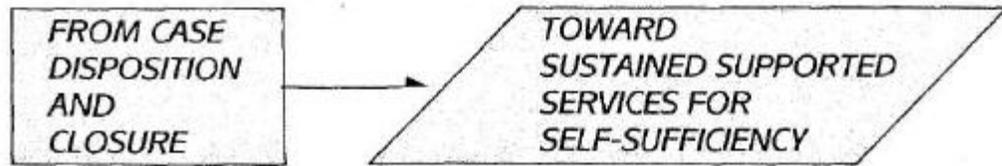
The array of service options model will require effective case management and parent and advocacy involvement along with shared decision-making (Calkins et al., 1985). It represents a systemic change that will provide an opportunity to redirect resources to appropriately accommodate the increasing number of adult clients entering the system.

In many service programs, the index of success is the number of cases closed. For some agencies, this means placement in an institution, nursing home, or a community program. For others, it means placement in a sheltered workshop or work activity center or referral to some other agency. Once a disposition has been made, a case is closed because it is assumed that the appropriate

parents and institutional and nursing home service has been provided (Hill, Hill, Wehman, Revell, Dickerson, & Noble, 1985). This assumption has been a major source of anxiety for clients and families who often find that the placement or disposition falls far short of meeting the continuing needs of the client. Furthermore, once a case has been closed or determined inactive, the task of reopening and reevaluating is time consuming and costly. Most adults will not become totally self-sufficient but neither must they be totally dependent. The range between dependency and self-sufficiency is wide and, for various levels, there are varying amounts of continued support needed. When a client moves from one level of independence to another, support services should not stop even though the type and intensity of service might change.

The trend toward sustained supported services reflects the fact that most individuals with developmental disabilities have a continuous need for education, residential services, supported employment ser-

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the most effective.
time to provide
instructional
intervention.**



vices, and health services regardless of their ages. Learning, growth, and development does not stop when a person becomes an adult. In fact, in many instances, arrival at adulthood may be the most effective time to provide such services. The indices of success in the future service system will be increased independence, decision-making, and economic self-sufficiency (Kiernan and Stark, 1985).

It is unlikely that a service program will ever be better than the competence of those who provide the services. The competence of staff is clearly related to the training received both at preservice and inservice levels. Programs which serve children with developmental disabilities tend to utilize a large number of professionals. Most diagnosis, therapy, instruction, and medical intervention is provided by staff with graduate training, often at the doctorate level. The training of professionals to provide such services was a major component of health and special education legislation through the 1960s and 1970s. Although much of the funding for training was directed toward preservice training, inservice and continuing education, funding has also been encouraged by federal health agencies and the U. S. Department of Education in an effort to help service providers keep abreast of new information.

Service programs for adults with developmental disabilities utilize direct care providers trained at the paraprofessional level to a much greater extent than do programs for children. Approximately 80% of the staff

members who interact with adult clients are trained either on the job or at a pre-bachelor degree level (National Institute on Mental Retardation, 1972; Schalock, 1983). The information explosion, improved technology, and changes in the skills and capabilities of individuals with developmental disabilities have had their most profound effect on these direct care providers. Direct care staff are increasingly expected to carry out sophisticated assignments of teaching, monitoring, and managing behavior (Richardson, West, & Fifield, 1985).

This situation is made even more difficult by the fact that most professional staff who are assigned responsibilities for the supervision and inservice training of paraprofessionals have had little or no training for these assignments. Most professional training programs are in single disciplines

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with limited opportunities to work on interdisciplinary teams. Most of the training of professionals emphasizes clinical or direct therapy skills rather than supervision of paraprofessionals or treatment planning. The need for interdisciplinary training and leadership training in the developmental disabilities field was recognized in 1962 and recommendations for such training programs resulted in the University Affiliated Facilities program. Currently, there are more than 58 UAF centers focusing on interdisciplinary and leadership training. Unfortunately, until recently, the primary focus of the UAF programs, like most other programs, has been on training relevant to services for children (Middendorf, 1985b).

Very little federal support has been available to train personnel at less than a professional level. Even the inservice training funds available through Title XIX and Title XX have been hard to come by because of the growing need for funding for direct services. There is evidence that the better the training of staff members for assignments, the more likely they will succeed in those assignments and the less likely they will leave.

Considering the performance expectations for direct care staff along with the inadequacy of programs to train them at both preservice and inservice levels, the limited supervision and professional staff support, and the few opportunities available for advancement in status or pay, it is easy to understand why the annual turnover rate is approximately 70% in residential, vocational, and other types of community programs (George & Baumeister, 1981). Even in large institutions which generally provide state personnel benefits, the direct care staff turnover rate is approximately 50% (Bruininks et al., 1985). High staff turnover represents one of the major barriers to

...the better the training of staff members for assignments, the more likely they will succeed and the less likely they will leave.

the adequate expansion and improvement of service options for adults with developmental disabilities.

As the adult service system changes, the need for better trained and more skilled direct care providers will increase. The changes occurring in individuals with developmental disabilities, in the environment in which they live and work, and in the systems designed to meet their needs, all have implications for direct care staff training. Federal support for personnel and manpower training efforts to staff programs for children must be matched for training of personnel to serve adults. Expanded paraprofessional and inservice training with accompanying career ladders and other incentives will be necessary to meet the future personnel needs of programs for adults. In addition, the training programs for professionals need to be extended to provide opportunities for developing necessary skills in leadership, management, staff supervision, and staff development (Richardson, West, & Fifield, 1985).

Considering the information explosion and increased technological skills needed by staff, the trend away from specialists providing services toward generalists providing services may seem inconsistent. However, Naisbitt (1982) points out that although technology and information is expanding rapidly, this information is becoming increasingly available to consumers and first level technicians. In the service field, much of the information which was once available only in the minds of highly skilled professionals can now be organized into data bases that can be accessed and utilized by consumers, technicians, volunteers, and paraprofessionals. The availability of this information at the direct care staff level has expanded many times over. Utilizing computer technology, expert systems, and artificial intelligence will reduce the need for specialized professionals to make routine treatment and diagnostic decisions (Fifield & Smith, 1985).

Not only are there major changes in information dissemination, but also economic factors are encouraging greater use

of generalists. Collins (1979) points out that many professional organizations are, through increased specialization, pricing themselves out of the service market. Small privately operated decentralized service programs are not likely to be able to afford an array of high level specialists as regular staff.

As these changes take place, the role of the professionals will also change. Highly trained specialists will work less and less directly with clients and will work more and more as consultants or resource persons with staff, providing them with supervision and evaluation. Specialized staff will become increasingly responsible for the development of new information and technology and for the dissemination of information through data base systems and inservice training. In addition, there will be an increase in the number of human service consulting agencies which provide either part-time or full-time staff from a variety of specialties who will be available to provide backup services and other special services to small programs.