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

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FOREWORD

In the fall of 1983, a network of professionals from University Affiliated Facilities (UAFs) undertook a comprehensive initiative to study the needs of adults who have developmental disabilities. This initiative was supported by the Administration on Developmental Disabilities of the Office of Human Development Services in the U.S. Department of Health and Human Services. As an outcome of the study, twelve separate publications were prepared. The first series of documents consisted of six Technical Reports written by the members of workinggroups and special issues committees. They addressed the residential services, the employment options, and the learning/adjustment process of adults. Also included were special studies that examined medical issues, the personnel training needs, and the Health Care Financing Administration's (HCFA) approved home and community-based service waivers which relate to services for adults with developmental disabilities. Background information and the procedures utilized throughout the project are presented in an *Executive Summary of the Technical Reports.* Also included in this document is a brief summary of each of the Technical Reports and an integrated summary.

The second series of documents comprise the Planning and Implementation Resource Guides. These documents were designed to provide a link between the findings of the Technical Reports and appropriate action at the state level. Four documents were prepared for this component: a facilitator's guide, a planner's guide, a listing of federal programs and resources available for expanding services to adults, and a listing of UAF programs and projects which serve the needs of adults with developmental disabilities.

The process used in developing these publications involved the participation of many researchers, administrators, and service providers from the UAF network. In addition, practitioners from vocational rehabilitation, special education, medicine, and other related fields participated. Broad input was solicited to ensure that the findings and recommendations would be applicable to a wide audience.

This document, *A National Profile of Changes in Services for Adults with Developmental Disabilities,* is the final publication of the project. The profile is intended to highlight selected findings of the Technical Reports, analyze the changes that have occurred during the past two decades and identify trends of the future. The profile also presents a number of issues for which action is needed if service options are to be expanded to better meet the needs of adults with developmental disabilities.

A complete set of the twelve documents has been distributed to each State Developmental Disabilities Council, Protection and Advocacy Agency and to each of the 54 UAFs as a courtesy by the Administration on Developmental Disabilities. The Technical Reports and other publications are listed along with instructions on how they can be obtained on page 49 of this document.

PREFACE

The UAF Networking Initiative for Services to Adults with Developmental Disabilities was designed to address four deceptively simple questions:

- **What is the status**
  of services and programs designed to meet the needs of adults with developmental disabilities?

- **To what extent**
  are such services and programs successful?

- **What are the barriers**
  to more effective service options?

- **What action is needed**
  to expand and improve service options?

As is often the case, these simple questions have complicated answers and there is little information on which to base answers. To answer the questions, research tasks were assigned to working groups and special committees. Each group studied and reported on a selected dimension of the service needs:

- **Residential**
  Where do adults with developmental disabilities live?

- **Vocational**
  What do adults with developmental disabilities do to earn a living?

- **Learning/Adjustment**
  How do adults with developmental disabilities learn and adjust at home, at work and in the community?

- **Medical Issues**
  What medical problems do adults have and how can medical care be most effectively accessed in community settings?

- **Personnel Training Issues**
  What changes need to be made in training to prepare people to work with adults?

- **Home and Community-Based Service Waivers**
  What do these waivers mean to UAFs and for the delivery of community services?

The decision to focus this profile on change instead of a more traditional descriptive profile was made to enhance its utility for program planners and developers. A true profile of service to adults with developmental disabilities cannot be static because the field is changing so rapidly. Furthermore, planners need to know the trends of the future in order to overcome the deficits of a decade ago. By examining some of the changes that are occurring programmatically and attitudinally, it appears possible to predict some of the directions and trends of the future. From this information, it is hoped that it will be possible to effect, control, and direct the future in a more systematic manner.

This initiative has been a demanding yet very stimulating and rewarding experience. The project has provided the opportunity to bring researchers, administrators, and adult service providers together from across the nation to focus their efforts on developing these publications. It is hoped that the reader will find each document as informative and stimulating as the participants did.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of
Human Development Services

Administration on
Developmental Disabilities
Washington DC 20201

Dear Reader:

Helen Keller once said, "It is not enough to give the handicapped life, they must be given a life worth living." Although there is no concensus on what represents 'a life worth living,' it is widely accepted that the elements which comprise the quality of life do change as one gets older. As children, dependency is accepted, but as we become adults, independence and self reliance grow along with the need to be a contributing member of society. People with developmental disabilities experience these same needs.

When children with developmental disabilities become adults, their desires, hopes, and sense of worth changes. In the past, we have concentrated most of our services on meeting the needs of children and have not taken these changes into account. What we need now is an equal effort to develop appropriate services for adults with developmental disabilities. Their needs and how they can most effectively be addressed are issues which were considered in the Administration on Developmental Disabilities' University Affiliated Facility Networking Initiative for Services to Adults with Developmental Disabilities. This project used an analysis of current programs as a foundation to examine changes in service delivery and social policy, and their impact on persons with developmental disabilities.

The enclosed 'National Profile' is an examination of certain basic principles and how the implementation of these principles is changing services to individuals with developmental disabilities. It is a profile of movement and change based on data from the technical reports.

As the Commissioner of the Administration on Developmental Disabilities, it was my pleasure to sponsor and work closely with this project. The technical reports and planning and implementation guides are substantive and I recommend them to you for reading.

Sincerely,

Jean K. Elder, Ph.D.
Commissioner
Administration on Developmental
   Disabilities

ACKNOWLEDGEMENT

CHAPTER I
A TIME OF CHANGE

In society change often occurs as a consequence of dissatisfaction with the opportunities and benefits distributed by that society.

T h e 1980s have been described as a period of accelerated change. Naisbitt (1982) refers to this as "the time of the parenthesis"—a time between eras, not the way it was in the past and not like it will be in the future, but a time of change. Change is seldom spontaneous, but generally occurs as a result of external factors. In the business world, change is often the consequence of economic factors. In science, change occurs as the result of new information and technology. In society change often occurs as a consequence of dissatisfaction with the opportunities and benefits distributed by thatsociety.Such dissatisfaction usually results in a distinct shift in individual values, attitudes and expectations.

In the human service field, the phenomenon of change has gained energy from the dissatisfaction of parents, professionals, and many others concerned with the lives of people with handicaps. Dissatisfaction with the benefits and options society offers to individuals with developmental disabilities has been shaped and directed by a series of events including:

• **The human rights movement.**
  This movement has sparked renewed concern about equity and access to services along with equal and appropriate treatment in more humane and normalized environments (Meyen, 1982. p. 7).

- **Increased evidence of the inadequacy of institutionalized care.**
  This evidence has included reported instances of abuse and neglect of people placed in institutions (Blatt & Kaplan. 1966).

- **The growing body of knowledge and technology.**
  These advances have expanded the effectiveness of efforts to habilitate individuals with developmental disabilities and have enhanced their capabilities for self-sufficiency (Paine. Bellamy, & Wilcox, 1984; Sailor & Guess, 1983).

Dissatisfaction and efforts to change the services system for individuals with developmental disabilities have not come about suddenly. Successive efforts are indicated by the following federal laws that have been designed to provide services to people with handicaps:

- **In 1963,** Public Laws 88-156 and 88-164 provided for comprehensive maternal and child care and for state planning and construction of facilities for research and clinical services for people with mental retardation. These two public laws have served as the foundation for subsequent programs that have expanded services to individuals with several typesof handicaps (MR Construction Program, 1 969).

- **In 1 967,** the mental retardation amendments (P.L. 90-170) authorized federal grants for the initial costs of training professionals and technical personnel to serve persons with mental retardation.

- **In 1970,** Public Laws 90-21 1 and 91-517 expanded governmental participation in serving persons with cerebral palsy, epilepsy and other related conditions, expanded training for professionals, authorized the construction of community mental retardation facilities, and assisted comprehensive state planning.

- **In 1973,** amendments to the Rehabilitation Act (Section 504 of Public Law 93-380) addressed the physical, attitudinal, and programmatic barriers to employment and services to individuals with handicaps.

- **In 1975,** The Education for All Handicapped Children's Act (P.L. 94-142) became law. This act and subsequent amendments established the basic right of children with handicaps to accessa free and appropriate education in the public schools. This legislation not only ensured educational services to children with handicaps, butalso made provisions forrelated health and social services.

- **Also in 1975,** the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103) revised and extended programs for people with handicaps, broadened eligibility for participation, and established a protection and advocacy system. The Developmental Disabilities Act has been renewed three times. Each revision has addressed gaps in services and broadened programs to focus on specific areas of need. The 1984 amendments (P.L. 98-527) stressed the need for alternative community living arrangements and employment activities (Fifield & Smith, 1985a). (For additional information about the above program, see Middendorf, 1985a.)

These legislative actions were the result of a strong advocacy network consisting of consumers, professionals, and many socially conscious citizens who fought tirelessly to expand rights and improve service programs and options. Their efforts are giving people with handicaps the opportunities to learn and adapt so they can function fully as members of society.

During this past 20-year period, several philosophical principles have evolved that have influenced proposed legislation and, consequently, how services are delivered. The most basic of these is the principle of normalization. This concept originated in

Scandanavian countries where it was promoted by professional groups in an effort to make the life-styles and the environments of people with handicaps similar to those of people without handicaps (Nirje, 1 976). In the United States the concept was incorporated into the human rights movement during the late 1 960s and broadened to include the right to receive services in the least restrictive environment (Kaufman & Morra, 1978).

Much of the effort toward normalization has focused on deinstitutionalization in which people with developmental disabilities are provided community placements and services. These efforts prevent institutionalization or move people from institutions into community-based service programs (Bruininks et al., 1 985, pp. 9-11). In education, normalization efforts stress mainstreaming children with handicaps into educational programs or placing them in the least restrictive instructional alternative (Kaufman & Morra, 1978).

In the last few years, normalization efforts have shifted away from an emphasis on placement toward the use of "normal" as the standard by which services, activities, and programs are planned and evaluated (Bruininks et al., 1985, pp. 22-23; Flexer, 1983). As a result, services and activities for people with developmental disabilities are increasingly being evaluated on the same basis as activities and services for their nonhandicapped peers. Service programs are now being designed to develop strengths instead of just to accommodate disabilities. The normalization concept focuses efforts on providing a normal environment in which people with disabilities can grow, develop, and enjoy life (Perske & Perske, 1980).

Normalization is a broad principle which has several corollaries including:

- **Developmental Progress**
  A developmental disability is not just a "health problem" that can be treated by providing health care. It is a condition stemming from physiological and/orpsychological handicaps that affect a person's development. However, all people, including those with developmental disabilities, have potential for continuous growth and development. The assumption underlying this principle is that life changes continuously. Therefore, the primary goal of service programs should be to increase the adaptive behaviors of people with developmental disabilities to enhance their growth and development (Kozlowski, Hitzing. & Helsel, 1983).

The most basic philosophical principle in the developmental disabilities movement has been normalization.

- **Right to Services**
  People with developmental disabilities have a right to services that promote growth and development. This right cannot be compromised by the fact that they learn and adjust differently than others. People with handicaps should not be confined to restrictive *environ-*

merits where treatment and service are limited or not available. Furthermore, they should not be retained in holding programs in which they wait for services to become available nor should they be placed in inappropriate programs because they are the only programs available (Kozlowski, Luteran, 6 Reynolds, 1983).

- **The Least Restrictive Environment**
  All services should be appropriate to the age and culture of the individual and should not impose unnecessary restrictions or deny personal rights. Programs should teach skills and behaviors that promote independence, develop social competence, and help integrate the person into the community. From a human rights standpoint, the least restrictive principle requires that placement in a more restrictive setting should be undertaken only if that setting is more appropriate to the needs of the person.

- **Equal Justice**
  Persons with developmental disabilities should receive services and support that allow them the opportunities for growth and development equal to those for other members of society. Equal justice implies that all people, including those with developmental disabilities, have a right to publicly supported services and that such services should be accessible to all.

- **Human Dignity**
  People with handicaps have human value and this value deserves recognition. Since people with handicaps may have difficulty gaining the same degree of dignity and respect that others can through self-sufficiency and contribution, it is important that people with handicaps be treated with respect and served in settings that are positively valued.

- **Effectiveness and Economy**
  This principle implies that any adult who is independent, self-sufficient, and productive will contribute more to society than a person who is dependent. Thus, self-sufficiency and productivity are considered as inherently "good." These qualities should be desired goals for every person and the development of these qualities should be a component of every service program (Kozlowski, Hitzing, & Helsel, 1983; Wehman & Hill. 1985).

During the past 20 years, advances in medical science have prolonged life, facilitated learning, freed movement and communication, and reduced the effects of handicaps in many ways. New social systems have integrated people with handicaps into society and expanded public awareness of their needs and capabilities. The skills and abilities of people with developmental disabilities have also been expanded through educational changes (Wehman & Hill, 1 985). Thus, technological advances in many fields have enabled people with developmental disabilities to live more independently (Technology and Handicapped People, 1982).

Federal legislation signed into law during the past 20 years has been driven by progressive efforts to normalize the lives of individuals with developmental disabilities. Medical, educational, and social research has pushed the frontier of knowledge steadily forward. However, as in all social change, progress has not occurred evenly in all areas nor has it been widely accepted. Philosophy, knowledge, and technology have far outstripped the service delivery system. It is this imbalance between what we **believe** and **know** on the one hand and what we **do** about it on the other hand that is resulting in an emerging crisis.

CHAPTER II
AN EMERGING CRISIS

The emphasis on
services to children
with handicaps is
appropriate
because early
detection and
intervention hold
the promise that the
disability can be
corrected.

The primary focus of services designed for people with developmental disabilities has been on the needs of children with handicaps. Examples of such programs include:

- Maternal and Child Health and Crippled Children's Services are supported by the Public Health Services. These and several other programs are designed to provide assistance to mothers and infants for prevention and early detection of handicapping conditions.

- A variety of infant and early childhood programs provide stimulation and health, social, and instructional intervention. Federal support to these programs is provided through Title XX, the Developmental Disabilities Act, and Special Education.

- The most comprehensive federally mandated services to children with handicaps are provided through Public Law 94-1 42, the Education for All Handicapped Children's Act. This act not only ensures free and appropriate education, but also establishes the public school as the lead agency for serving children between the ages of 5 and 22.

- Many volunteer organizations and private foundations such as Easter Seals, Muscular Dystrophy Association, and the March of Dimes also focus on children's services.

Added to this *array* of services are the research efforts primarily directed toward children and sponsored by the federal government such as the Mental Retardation

Research Centers which are supported through the National Institute of Child Health and Development (NICHD). Research is also supported through the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Early Childhood Research Institutes supported by the Department of Education (Tjossem, 1985).

Personnel training to staff service programs for people with handicaps also emphasizes services for children. The primary focus of University Affiliated Facility (UAF) programs supported by the Administration on Developmental Disabilities is on children. The Personnel Preparation Division of Special Education Programs is to prepare professional personnel to serve school-age children. The depth and scope of the service, research and staff training activities designed for children have not been matched by service, research and staff training designed to meet the needs of adults. (For a description of federal programs for the handicapped, see Middendorf, 1985a). The emphasis on service to children with handicaps is appropriate because early detection and intervention hold the promise that a child's disabilities can be corrected and thus the need for services and dependency can be reduced or eliminated.

A developmental disability, however, by definition "...is a severe chronic mental or physical impairment which is manifested before age 22, ...is likely to continue indefinitely...resulting in limitations in major life activities...which reflects the person's need for services which are life long or of an extended duration" (Public Law 95-602). If the criteria of this definition are met, it is not reasonable to expect that children with developmental disabilities will no longer need services when they become adults.

It is ironic that just when individuals with developmental disabilities become ready to take advantage of the benefits and services provided through childhood intervention programs, they "age out" of eligibility for many of the services they need to attain or maintain the desired level of independence and self-sufficiency these programs were designed to develop (Wehman & Kregel, 1 985, p. 1 98). Another elusive, but obvious, fact is that people with developmental disabilities are adults at least three times longer than they are children, thus the consequences of this lack of service follow-up for adults are significant both economically and in terms of the loss of human potential.

The concern for continuity and follow-along in the service system has not gone unnoticed. The White House Employment Initiative, which accompanied President Reagan's proclamation of the 1980's as a decade for persons with handicaps, focused greater attention on expanding opportunities for employment and self-sufficiency for individuals with developmental disabilities. The Developmental Disabilities Act of 1984 identified priority services as: alternative community living arrangement services, employment related activities, child development services, and case management services. The Act further defines employment related services and supported employment in a broad sense, focusing on services that are needed to improve the quality of life of adults with developmental disabilities:

Sec. 102. (11) (e), The term "employment related activities" means such services as will increase the independence, productivity, or integration of a person with developmental disabilities in work settings, including such services as employment preparation and vocational training leading to supported employment, incentive programs for employers who hire persons with developmental disabilities, services to assist transition from special education to employment, and services to assist transition from sheltered work settings to

supported employment settings or competi-
tive employment.

(f) the term "supported employment" means paid
employment which—

(i) is for persons with developmental disabilities
for whom competitive employment at or above
the minimum wage is unlikely and who, because
of their disabilities, need intensive ongoing sup-
port to perform in a work setting;

(ii) is conducted in a variety of settings, particu-
larly work sites in which persons without disabili-
ties are employed; and

(iii) is supported by any activity needed to sustain
paid work by persons with disabilities, including
supervision, training, and transportation.

The intent of the above initiative and legisla-
tion is to expand the service options and follow-
along activities to facilitate the movement of
individuals with developmental disabilities from
children services into the adult service system.
The term "transitional" is currently being used to
imply the process and the services necessary to
successfully move the handicapped individual
from children services (in which the public
schools take lead responsibilities) to the adult
human service delivery system. Assistant Secre-
tary Madeline Will defined transition as:

An outcome-orientated process encompass-
ing a broad array of services and experiences
that lead to employment. Transition is a period
that includes high school, the point of gradua-
tion, additional post-secondary education or
adult services, and the initial years of employ-
ment. Transition is a bridge between the
security and structure offered by the school
and the opportunities and risks of adult life.

The transition from school to work and adult life
requires sound preparation in the secondary
schools, adequate support at the point of school
leaving, and secure opportunities and services, if
needed, in an adult situation. ...programming for
transition involves using different kinds and
amounts of support with different individuals, so
that each has the opportunity to work and enjoy
the life-style benefits of working. There is a nearly
infinite set of services and experience that could
lead successfully from school to work for some
individuals...For practical purposes, transition ser-
vices can be grouped into three classes that reflect

> The service needs
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> support services
> and intervention
> services.

the nature of public services used to provide sup-
port as the passage is completed. The first involves
movement from school either without services or
with only those that are available to the population
at large; the second involves use of time limited
services that are designed to lead to independent
employment at the termination of services; and the
third involves use of ongoing services for those
individuals who do not move to unsupported work
roles. Each of these transitional strategies, or
bridges from school to work, is necessary if all
individuals with disabilities are to move success-
fully to working roles. (Programs for the Handi-
capped. March/April, 1984 (No. 2).

In response to the above initiatives and
legislation, a *variety* of projects and activi-
ties have been stimulated, some of these
supported by funding from the federal gov-
ernment, others through private resources,
and still other activities have been stimu-
lated through existing resources at the state
and local level. Unfortunately, most of the
current attention is upon employment as
the outcome and, as important as this may

be, employment represents only one of the major life activities of individuals with developmental disabilities. Furthermore, the success of efforts to find and maintain employment are highly dependent upon success in other life activities.

The service needs of adults with developmental disabilities can be separated into two broad areas. The first area can be called support services. These services should be designed to meet many of the needs of the adult with developmental disabilities that a family would provide for their child. They should have varying levels of service intensity and duration. Support services should be ongoing and flexible to meet the changing needs of individuals (Wehman & Hill, 1985). Such services must have effective case management components to guide clients progressively toward less dependency as they continue to grow and develop.

Most federal programs for adults with developmental disabilities are designed to provide support services. However, these systems were designed to serve a different target group such as those served by Social Security (Moran, 1984; Fifield, 1983b; Kiernan & Stark, 1985, pp. 96-97; Middendorf, 1985a). Eligibility is generally determined by income level rather than the needs of the individual. Recipients with developmental disabilities receiving these services represent only a small percentage of all service recipients. Although many of the needs of individuals with handicaps are similar to those of the poor, eligibility by virtue of poverty focuses programs on the consequence of the handicapped instead of its cause or its nature. As a result, many services are heavily invested in detection, diagnosis, and eligibility instead of continued growth and development. Medical care and income maintenance are by far the largest federally supported programs in

which adults with developmental disabilities participate. Active treatment and intervention services are only a small part of these services (Moran, 1 984).

The second basic area consists of intervention services. Intervention services include medical services, therapy, and instruction designed to overcome the handicap or circumvent its consequences. These services should be designed to provide continuous opportunities for adults to learn and maintain the skills necessary for independence and self-sufficiency. Intervention services emphasize therapy and instruction, and they should be provided in an environment that encourages the use of these skills once they are mastered (Calkins et al., 1 985).

When intervention services which focus on social, behavioral, and instructional services are available at all, they are supported primarily by state funding or through federal block grant funds allocated by states as in the case of Title XX. As a consequence, the quality and comprehensiveness of intervention services to adults has depended almost exclusively on state support. Those states that have been willing to spend state tax dollars on services for people with handicaps, generally provide more services to this population than states that rely on federal funds. Thus, the system of services to adults differs from state to state and within the agencies that provide services (Braddock et al., 1984a).

Most existing service programs for adults fall short in both of these areas. Eligibility for support services is generally determined by an all-or-none principle—total disability or no disability. The fear of losing eligibility for these services, thus, is a disincentive for the continued growth and development of the individual.

The current system not only discourages continued development, but it is inadequate in scope since it provides services to only a small percentage of those needing service. More and more individuals with developmental disabilities will enter the adult services system and, with the current system's inability to move people toward less dependency, a crisis has developed. The extent of this crisis is made evident by the data in Table 1 .There are approximately 3,805,500 people with developmental disabilities living in the United States. The most prevalent single disability is mental retardation followed closely by epilepsy and autism. Most individuals have multiple handicaps and more than 62%are over 17 years of age and legally considered to be adults.

Each year between 250,000 and 300,000 people with handicaps graduate or leave the public schools (Will, 1 985). Of those leaving school, Wehman, Kregel, and Seyfarth (1985, p. 249) report over 90,000

are students with developmental disabilities. The critical nature of this problem was emphasized by Congress in the 1 983 Education Amendments of Public Law 98-1 99:

...the subcommittee [on the handicapped) recognizes the overwhelming paucity of effective programming for these handicapped youth, which eventually *account* forunnecessarily large numbers of handicapped adults who become unemployed and therefore dependent upon society. These youth historically have not been adequately prepared for the changes and demands of life after high school. In addition, few, if any, are able to access orappropriately use traditional transition services. Few services have been designed to assist handicapped young people in their efforts to enter the labor force or obtain their goals of becoming self-sufficient adults and contributing members of society (Section 626, P.L 98-199).

In addition to the more than 90,000 students with developmental disabilities leaving school, approximately 6,000 people

Table 1

Approximate Age Distribution of the Developmentally Disabled[a]

Age	Number[b]
< 17	1,442,040
17-64	2,232,660
65+	130,800
TOTAL	3,805,500

[a]Adjusted for noninstitutionalized (1 3.8% in public institutions) and interpolated to adjust for age groups and year.

[b]Prevalence rate from Boggs & Henney (1981)

Population size from Mathematica Policy Research (1984)

U.S. Census Bureau (1985)

leave large publicly operated institutions each year to join those in community settings (Bruininks et al., 1985). These two groups of people are converging on an adult service system that is already overburdened, underfinanced, and understaffed.

To complicate this situation further, the young adults with handicaps who are currently leaving the public school system represent a different population than those already in the adult system (Kiernan & Stark, 1 985). They are different due primarily to the additional services they have received as children. Their handicaps are generally detected much earlier, and they have benefitted by early stimulation and intervention provided under the auspices of the Education for All Handicapped Children's Act.

The first generation of students served by P.L. 94-142 are now graduating and theirparents have higherexpectations than earlier generations of parents (Caparosa, 1 985). It is unlikely that parents and caregivers who have invested heavily in children's services will be satisfied with an adult service system that can only produce a 20% employment level or a service system in which 80% of the recipients will be living below the poverty level oneyearafterseparation from high school (Kiernan & Stark, 1 985; Wehman & Moon, 1 985). On the contrary, students and parents have become accustomed to regular individualized educational services from schools and are becoming increasingly dissatisfied with the lack of coordination among relevant service delivery agencies, the longwaitinglists.and the major gaps in needed services for their adult children. The current adult service system is characterized by the following factors:

- **Most rehabilitation services**
  require a reasonable expectation of employability. Due to this requirement, many severely handicapped individuals are not eligible. Furthermore, the time needed for diagnosis and training often exceeds the limits established by vocational rehabilitation regulations (Hill, Hill, Wehman, & Banks, 1985; Middendorf, 1985a).

- **The adult service system**
  is fragmented with no single agency assigned to take the lead responsibility (Moran, 1984; Fifield, 1983b).

- **Eligibility requirements**
  for Social Security Disability Insurance (SSDI), Supplemental Security Income(SSI),and Medicaid benefits require dependency. People are not eligible to receive continued benefits if they grow, develop, or contribute to their own independence and self-sufficiency (Moran, 1984; Middendorf, 1985a).

- **In many states,**
  case management services are extremely limited, thus the fragmentation of the service system is severe. The type of service an individual receives is dependent on the willingness and tenacity of parents to seek, discover, and demand needed services (Bruininks et al., 1985).

- **Eligibility varies**
  widely between various service programs and between states. There is also extensive variance in the comprehensiveness and quality of services both between states and within them (Fifield & Smith, 1985c).

- **Descriptive information**
  on the location and operation of quality programs is seriously limited (Karan & Berger. 1985).

- **There are no specific federal legislative mandates**
  or appropriations to provide services to adults with developmental disabilities (Middendorf, Fifield & Smith, 1985).

- **There is no consensus**
on what services should be provided and how they should be delivered. Service providers and professionals are still debating the issue of what is an appropriate set of coordinated services (Karan & Berger, 1985).

- **The existing services**
provided in large institutions serve only about 10% of the adult population with developmental disabilities though approximately 70% of the federal funding is channeled into these large institutions (Bruininks et al.. 1985; Mac-Millan, 1977).

The most recent revisions to the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 98-527) in 1984 reflect a consensus that expanding service options for adults with developmental disabilities is in society's best interest. Expanding services for adults will not only provide economic advantages through decreased dependency on public support, but will also enhance the quality of life of persons with handicaps (P.L. 98-199).

However, to realize these goals, services and programs must be designed to dignify and enhance life, not just to save and protect it. Current attitudes and programs which stress care and dependency must be replaced with those that stress increased expectations and opportunities.

Continued pressure on the current system can be expected because it is dependency oriented, inordinately expensive, and sometimes provides "over care" for a few and limited or no services for the majority.

Meeting the needs and expanding service options for adults with developmental disabilities means more than simply providing funding for programs to train professionals or establishing model group homes that can take care of the problems locally. Communities must establish mechanisms whereby friendship, acceptance, personal interest, and individual responsibility of one person for another can be enhanced.

Contentment with the current complex, poorly focused, unconnected and overlapping service system for adults, will become less and less tolerable.

The developing crisis is evidenced by the following:

- The gap between the state-of-the-practice (current system of providing services) and the state-of-the-art (what research and technology have demonstrated is possible) is widening.

- Increasing numbers of youth with developmental disabilities are entering the adult system and remaining there for longer periods of time.

- The characteristics of the adult population are changing due to advances in services to children

Generally handicapped students are not guided into employment opportunities by the schools that have educated them. There are varying degrees of training and educational experiences available to many students, but systematically planned transition to community-based employment is usually not available. Not coincidentally communication between school personnel and adult service providers is limited. This void of transition planning probably contributes to the continued high unemployment rate of handicapped persons.

New frontiers are seldom conquered on a broad front. They are usually breached by many small changes occurring here and there. As the frontier of services to individuals with handicaps is moved forward and normalization becomes more broadly understood and adopted, acceptance of and contentment with the current complex, poorly focused, unconnected, and overlapping service system for adults will become less and less tolerable. Many professionals and parents clearly desire a much more systematic and organized system of services. They realize that the lead responsibility needs to be assigned and resource incentives need to be reevaluated and more equitably distributed. Efforts must be made to breach the barriers imposed by special interest groups, public attitudes, and ignorance.

Parents are becoming increasingly dissatisfied with the lack of coordination among relevant service delivery agencies, the long waiting lists, and the major gaps in needed services for their adult children.

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 todetectchanges thatwill 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 1 960s were attempts to improve the standard of care forindividuals 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 on where you want to get to." The principle of normalization and its corollaries provide 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.
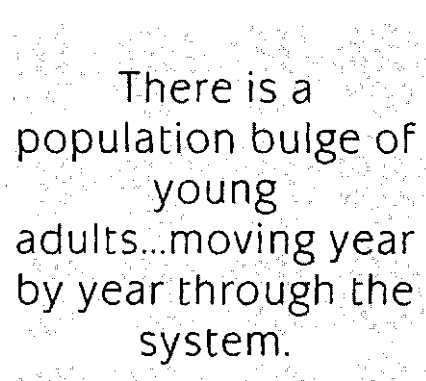
CHANGES IN INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

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 1 984 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-

There is a population bulge of young adults...moving year by year through the system.

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.

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│ FROM LIMITED     │         ╱  TOWARD EXPANDED       ╱
│ SKILLS AND       │ ──────▶╱   SKILLS AND           ╱
│ CAPABILITIES     │       ╱    CAPABILITIES        ╱
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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., 1 985). 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 1 3% 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 (Bruininks **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]

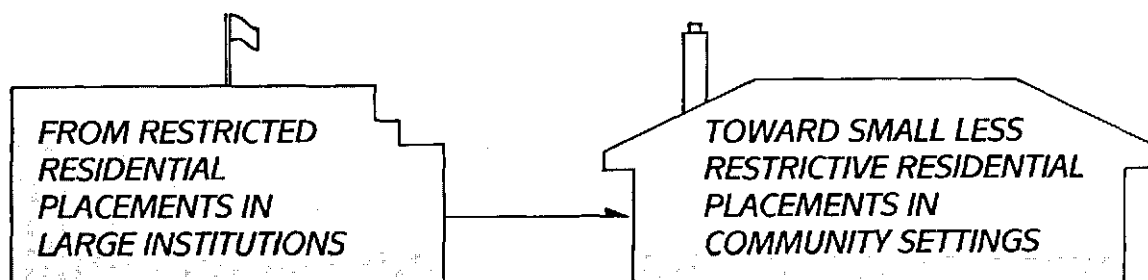|	
Family/Home and Other	3,006,345[b]
Public Institutions including ICFs/MR	536,580[c]
Community Facilities	235,940[c]
Foster Homes	26,635[c]
TOTAL	3,805,500

[a]Based on U.S. Census population.
[b]Prevalence from Moran (1984), Office of Inspector General.
[c]Prevalence from Bruininks (1985), Technical Report #1.

developmental disabilities who live in ICFs/MR are in facilities with fewer than 1 6 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, & Bergera, 1985).

FROM RESTRICTED RESIDENTIAL PLACEMENTS IN LARGE INSTITUTIONS

TOWARD SMALL LESS RESTRICTIVE RESIDENTIAL PLACEMENTS IN COMMUNITY SETTINGS

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 are distributed in order to increase the financial incentives for states to develop smaller residential programs in community settings (Chafee, 1984). In addition, court ordered deinstitutionalization is giving additional 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?
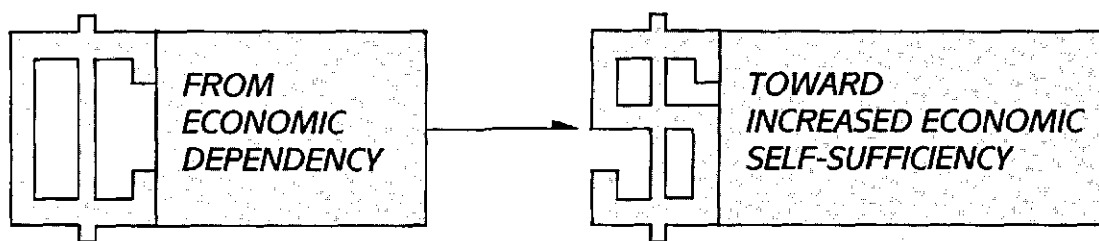
Western society places high importance on what members of society do to earn a living. Personal value is closely related to self-sufficiency and contributions to society. The importance of employment cannot be overemphasized (Kiernan & Stark, 1985).

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 1 8% of the population without disabilities (Wenman & Hill. 1985).

With increased functional skills and reasonable accommodations, employment is a realistic goal for those with both moderate and severe disabilities (Wehman, 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). Enor-

FROM LIMITED SOCIAL OPPOR-TUNITIES → TOWARD EXPANDED SOCIAL SUPPORT SYSTEMS AND FRIENDSHIPS
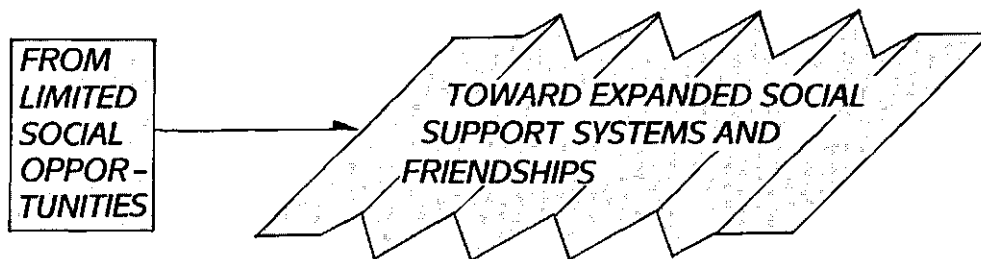
mous strides have been made during the last decade which have demonstrated that most individuals with developmental disabilities do have the capacity for independent community living and gainful employment. The research literature provides convincing evidence that the skills necessary for employment 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., 1 985). 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

FROM SERVICES IN SPECIALIZED SETTINGS → TOWARD SERVICES IN GENERIC AND NORMALIZED SETTINGS
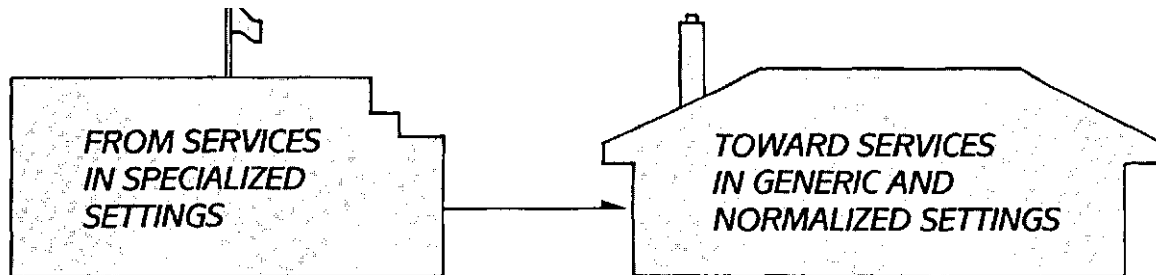
opportunity to practice appropriate social and behavioral skills in natural settings is essential to ensure mastery and maintenance of the skills over time and use of the skills in a variety of situations. Most of the recent research has emphasized the importance of the environment in which adjustment 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, Huganir, & Zigler, 1 985). 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 (1 982) 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 thatGod encouragesand blesses those that give. This attitude reflected the belief that little could be done for people with handicaps other than relieving some of the
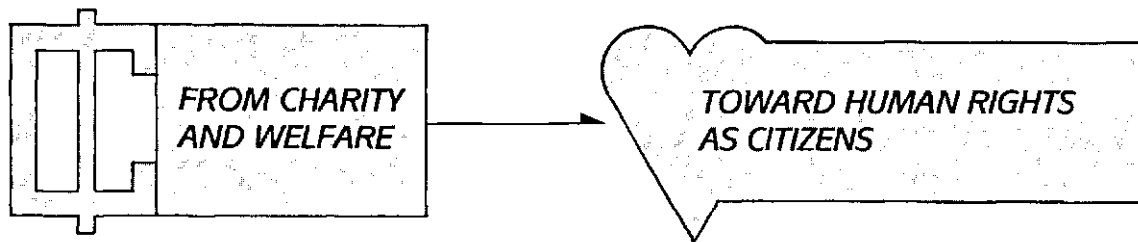
misery. The titles of many of our early service programs included the words "charity," "mercy," "benevolence," and "welfare." Today people with handicaps are thought of much less as recipients of charity and much more as people who need greater opportunities and have a right to such opportunities (Wolfensberger, 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 1 984, 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 services, 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

The social system of the future must provide means through which individuals with handicaps can be accepted as full citizens and have access to appropriate opportunities.

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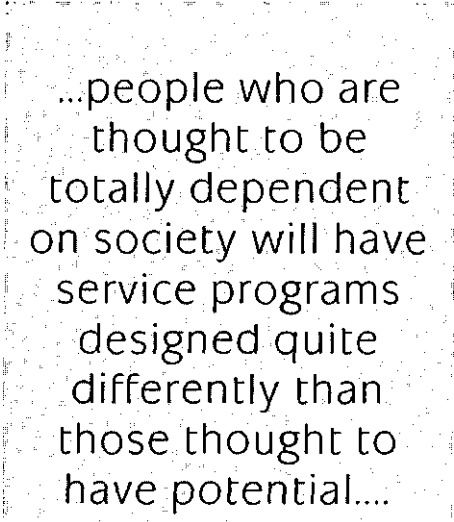
Currently, the focus of federal and state programs, designed to meet the needs of children with developmental disabilities, is on early detection and intervention with the goal to promote learning, growth, and development through instruction, therapy, and medical intervention. On the other hand, the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

> ...much of the current legislation under which adults are served was enacted for other purposes...and emphasizes care and maintenance.

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 underwhich 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, 1 983b).

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.(Foradditional 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

> ...people who are thought to be totally dependent on society will have service programs designed quite differently than those thought to have potential....

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, 1 985).

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.

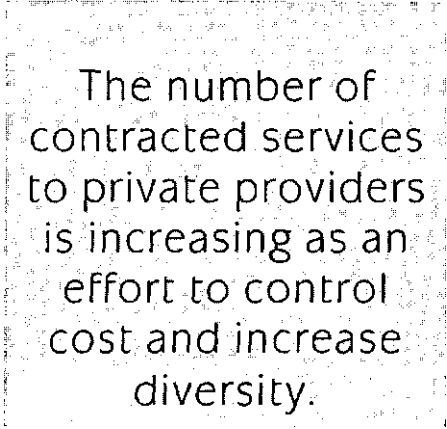FROM MAINTENANCE AND CARE ⟶ TOWARD DEVELOPMENT AND GROWTH

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 (Wehman & Kregel, 1 985). 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 agencies 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.

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

FROM PROGRAMS SUPPORTED AND OPERATED BY GOVERNMENT → **TOWARD PROGRAMS OPERATED BY PRIVATE PROVIDERS**
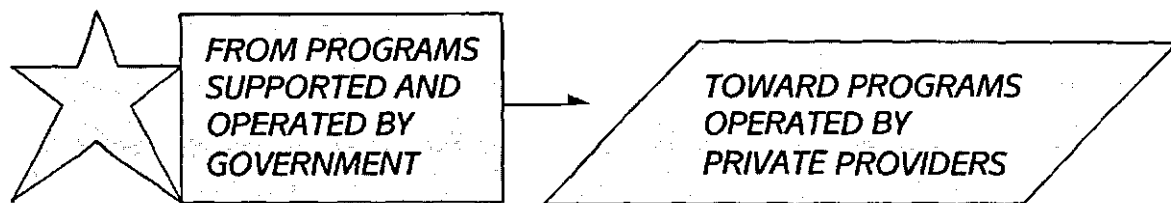
By contracting with private providers, it is generally easier to design services to fit the needs of the individual rather than the needs of the service system. The change from system-referenced services to client-referenced services allows the focus to shift from an emphasis on client weaknesses to 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.

...the needs of people with handicaps are often clustered requiring a variety of human services simultaneously.

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.

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 a

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 examp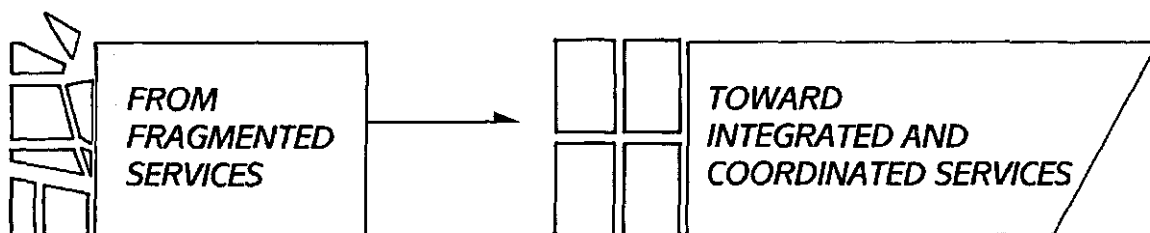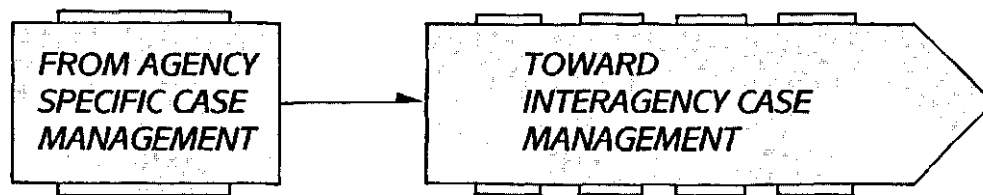le, employment, transportation, and housing. Unless these clusters of needs are addressed together, there is little likelihood that any single need will be met. Ideally, an individual program plan which considers living arrangements, day and work activities, and supported services should be put together 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., 1 985). Counselor, caseworker, 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

FROM FRAGMENTED SERVICES → TOWARD INTEGRATED AND COORDINATED SERVICES

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┌─────────────────┐        ┌──────────────────────────┐
│ FROM AGENCY     │        │ TOWARD                    ╲
│ SPECIFIC CASE   │───────▶│ INTERAGENCY CASE          ╱
│ MANAGEMENT      │        │ MANAGEMENT               ╱
└─────────────────┘        └──────────────────────────┘
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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 1 900s, 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 alternatives 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 programs toward small integrated decentralized programs.

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│ FROM               │        │  ││  ││ TOWARD SMALL    ╱
│ LARGE              │        └──┘└──┘│ INTEGRATED     ╱
│ CENTRALIZED        │───────▶┌──┐┌──┐│ DECENTRALIZED ╱
│ PROGRAMS           │        │  ││  ││ PROGRAMS     ╱
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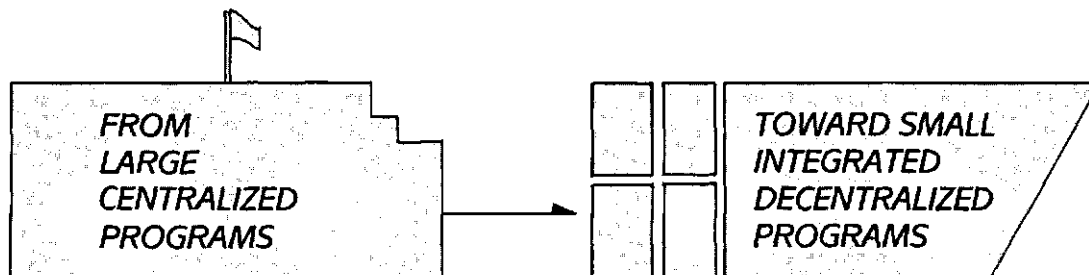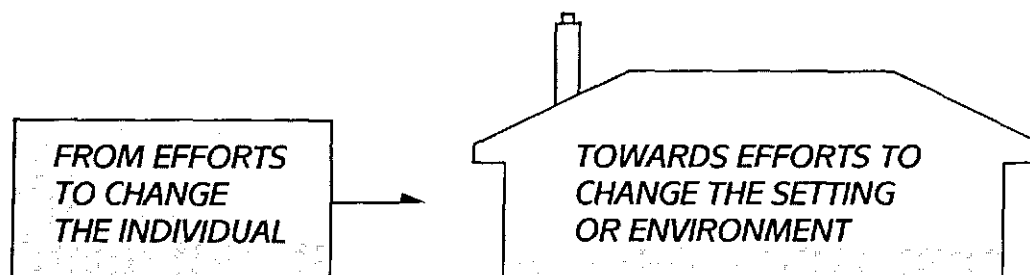
The needs of people with developmental disabilities are interrelated in various ways. Problems in one area of need often affect other areas of need. For example, adults with developmental disabilities are more likely to lose their jobs because of inappropriate social and behavioral skills than because 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 (1 965) recom-

FROM EFFORTS TO CHANGE THE INDIVIDUAL

TOWARDS EFFORTS TO CHANGE THE SETTING OR ENVIRONMENT

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

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

of services including: special instruction in hospitals, homebound teaching, classes in 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 while 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 socially and physically restrictive and isolated settings such as institutions, ICFs/MR, adult day-care centers, and sheltered workshops. As such, 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, 6 Reynolds, 1983). Although this sounds logical, research indicates that it seldom occurs for two primary reasons: First, there are few incentives for a client to move through a continuum. As a matter of fact, most 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. The questions most frequently asked by parents and institutional and nursing home

FROM A CONTINUUM OF CARE

TOWARD AN ARRAY OF SERVICE OPTIONS
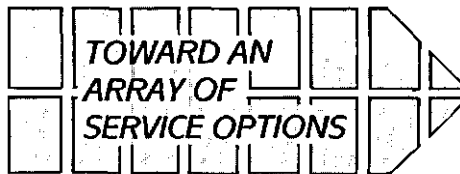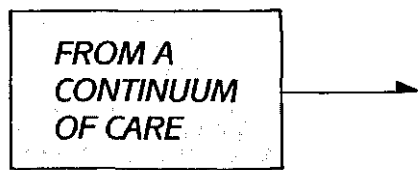
staff are "Where are the group homes?" and. "Where are the services in less restrictive environments?"

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 6 Trace, 1 982). 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.
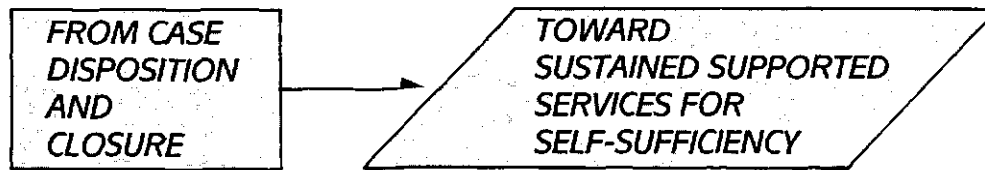
The array of service options model will require effective case management and parent and advocacy involvement along with shared decision-making (Calkins et al., 1985). It represents a systemic change that will provide an opportunity to redirect resources to appropriately accommodate the increasing number 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

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-

Adulthood may be the most effective time to provide instructional intervention.

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│ FROM CASE       │         ╱  TOWARD               ╱
│ DISPOSITION     │────────▶  SUSTAINED SUPPORTED  ╱
│ AND             │       ╱  SERVICES FOR         ╱
│ CLOSURE         │      ╱  SELF-SUFFICIENCY     ╱
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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 para professional 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

Service programs
will never be
better than the
competencies of
those who provide
the service.

with limited opportunities to work on inter-disciplinary teams. Most of the training of professionals emphasizes clinical or direct therapy skills rather than supervision of para professionals 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 focusingon 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 turn-over 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 turn-over 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 para professionals. 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.

CHAPTER IV

ISSUES FOR ACTION

Implementation
strategies focus
upon dissatis-
faction, awareness,
influence,
incentives, and,
most important,
action.

Chapter III presented a profile of changes currently in progress that will continue to shape the future of the delivery of services to adults with developmental disabilities. Each of the six Technical Reports derived from the UAF Adult Initiative provides recommendations that address training, service, research, and policy. The reader is encouraged to examine the Technical Reports. Discussed in this section are two broad issues: (a) how can change be effected in the developmental disabilities service delivery system? and (b) what action will be necessary to assure that such change reflects progress?

As in most fields, the gap is significant between the state-of-the-art, or what we know and have demonstrated can be done, and the state-of-the-practice, or what we are currently doing. As information and technology expand, the task of using this information and technology and applying it also increases.

We know many of the changes that must be made if services to adults are to be expanded. Furthermore, the information and technology are available which can bring services much closer to that objective. What seems to be lacking is a way to implement the desired changes in the service system.

The responsibility for providing human services rests with state service agencies. States have different philosophies, priorities, and histories concerning the provision of services. Each of these influence, how states respond to the needs of their citizens and how they react to national initiatives and directions. In human services, there are few clear indices of effectiveness. Success is claimed by a variety of techniques, some of which differ significantly from each other. Consequently, change tends to occur in a variety of directions. The task is not simply to separate successful techniques from those that are not successful. It is more a matter of agreeing on the philosophy, establishing priorities, and then identifying the techniques and procedures which reflect the accepted philosophy and priorities (Wieck & Wray, 1985).

Even a clear understanding of the pending adult service crisis and the direction of the future provides little assurance that needed changes will occur or continue in a positive direction. Just because something works, saves money, or meets objectives does not necessarily mean that it will be implemented or replicated. Strategies for implementation are not controlled by information or effectiveness. Implementation strategies focus on dissatisfaction, awareness, influence, incentives, and, most important, on action. If, indeed, the future is to be brighter for people with developmental disabilities, a variety of actions are needed to propel successful practices into the service delivery system.

Peters and Waterman (1982) point out that large organizations have a built-in resistance to change. Resources become invested in established ways of doing things, usually determined on the basis of what seemed like a good idea at the time. Change challenges what was once thought to be a good idea. In all organizations, the greatest resistance to change is the fear of a redistribution of benefits, usually economic ones. Modernization in the form of reorganization is one way through which benefits and advantages become redistributed. Bankruptcy proceedings reflect the courts' recognition of the occasional need for businesses and industries to renegotiate their distribution of benefits among employees, suppliers, and consumers. There is a need for similar provisions in human services. Like industry, human services must forget what they invested in past years, cut their losses, and modernize. Hawken (1983) points out that economic factors generate greater influence on proposed change than any other variables. This is not just a matter of the total cost of change, but also of the issue of who pays, who benefits, and how the proposed change will affect the balance.

The quickest and possibly the most effective method for implementing change in the delivery system for serving adults is to change the economic base and how funding is distributed. This can occur either by the addition of new monies to the system or by the redistribution of existing monies to create different benefits and incentives. Action is needed in both areas.

> Economic factors generate greater influence on proposed changes than any other variable.

NEW MONIES TO SUPPORT ADULT SERVICE PROGRAMS

There is agreement among parents, professionals, legislators, and concerned citizens that additional money will be needed to expand service options for adults. The important issue is: where will this new money come from?

At this point, federal, state, and local agencies are not as concerned about the total cost of the needed services as about what it will cost them. Each government level justifies its inability to assume greater financial responsibility on the basis of other priorities, limited resources, and the protest of taxpayers. Until recently, conflicting priorities have been less of an obstacle to obtaining federal program support than state support. This has occurred because federal support was generally added to existing service legislation and there was no national debt ceiling. Advocacy groups, supported by the human rights movement and court orders, have found it more effective to make major changes in the services to people with handicaps with a single federal campaign directed toward national legislation rather than separate campaigns in each state.

Many states have not been willing to assume a greater share of the costs of providing services. State legislators in these states have had greater concern for saving state tax dollars by accessing federal dollars than for the adequacy of the services they were providing. In many states, local support amounts to little more than the required match to access federal dollars (Braddock et al., 1984b). In this respect, federal support has served as a disincentive to the development of a state and local financial support base. It is easy to blame the federal government and argue that it is not providing sufficient financial support or not providing appropriate flexibility. In those states where more than half of the support for services is from state taxes, service programs reflect broader service options and more flexibility than in other states. Also, the services provided are more in keeping with the current philosophy of normalization and more service programs are based on current information and technology.

Certainly one of the major issues needing concentrated action is the expansion of financial support to meet the service needs of adults with developmental disabilities. If service programs for adults are to catch up with those provided for children, action will be needed at each level of government.

At the federal level, new legislation is needed which stimulates new state incentives and provides support for personnel training and research. The federal research effort which is currently focused on the needs of children with handicaps should be matched with research activities targeted on the needs of adults. Special research institutes are needed for systemic research on adult issues and existing research centers and programs need to expand their research activities to include the adult population. Federal support is also needed to increase and expand training programs for personnel to staff new adult service programs. Training is needed particularly for direct care staff. In addition, training components must be developed which can be used either in preservice or continuing education programs. Modifications are needed in the training of profes-

> What is planned and implemented must be designed for evaluation and change.

more effectively provided at the state level than at the federal level.

Local or county tax support for developmental disabilities services has been used in only a few states, although this is an accepted and encouraged partnership in other human service programs. The expansion of local financial support has the spinoff effect of increasing local awareness and commitment. This spinoff advantage is seldom realized when programs are supported by federal funds.

The greatest amount of change in the adult delivery system might be realized from increased support and commitment from states and local governing bodies. Probably the most effective program development activities to be engaged in at this time are those which encourage individual states and local communities to support programs for adults with developmental disabilities. Only when such support is secured will states and communities be in control of the programs they offer. Furthermore, it is generally easier to change and upgrade small locally supported programs and to keep them abreast of current technology than it is to change federally sponsored programs.

sionals. They need training not only in how to serve adults with developmental disabilities, but also in how to perform supportive, supervisory, and technical assistance roles with direct care generalists. Special continuing education programs need to be developed to better prepare medical, legal, mental health, and adult educators to serve adults with developmental disabilities in community settings.

In essence, the financial plan is the service plan since the source, the amount, and the direction of funding determines who will be served, by whom they will be served, and how they will be served(Wieck & Wray, 1985). Recently, financial data has become available which permits a comparative analysis of the relationship of state and federal funding to community and institutional programs on a state-by-state basis (Braddock et al., 1984a). In many states, action is needed to achieve a more equitable balance between federal, state, and local support. Continued support to particular programs may also need to be challenged. Increased state support generally provides more options for meeting the service needs of adults. Family home-care incentives, respite care, and expanded relationships with the private sector may be

Finally, much has been said about program models, state-of-the-art services, and the need to replicate best practices. As valuable as this may be, it must be remembered that many of the programs which were thought to be state-of-the-art ten years ago are outdated today. Program development must consist of more than finding outstanding programs and replicating them. Mechanisms must be put in place in program development whereby service outcomes can be continuously evaluated against program objectives and standards. Service objectives and standards are not static, they evolve and change just as do

service techniques and technology. Now more than at any other time in the past, what is planned and implemented must be designed for evaluation and change (Wieck & Wray, 1985). Program designs and staff skills are becoming obsolete much faster today than a decade ago and obsolescence will accelerate in the future. The only solution to this problem is to increase the commitment of staff and resources to the constant examination of goals and objectives, to the conduct of ongoing evaluation and to the provision of continuous staff training.

REDISTRIBUTION OF EXISTING FUNDING

Of the four questions the Adult Initiative was designed to address, the question, "What are the barriers to more effective service options to adults with developmental disabilities?" received the clearest and most consistent response. As reflected in the responses, the number one barrier to change and improved services is the fear that current benefits will be lost (Kiernan & Stark, 1 985, p. 1 65). Some fear the loss of economic benefits such as SSI, SSDI or Medicaid. Others fear the loss of security, for example, discontinuation of a service program, loss of a job or its accumulative benefits, and the need to take additional training. Still others fear that a cause or a program in which they have made significant personal commitments and investments will be lost. In essence, the major barrier to change is the fear of letting go of the known to pursue the unknown.

On the other side, the voice calling for change comes from those who receive few or no benefits from the existing system and those who believe that the current benefits do not match the cost of the investment. Change is also being promoted by those who see the possibility for better, more effective, and economical ways of providing service delivery.

One of the most important activities needed to improve and expand service options for adults is to make appropriate changes in the existing distribution of federal funds. The "Community and Family Living Amendments of 1985," introduced by Senator Chafee but not yet passed, represent one of the most significant efforts in this direction. Proposed amendments would change the formula by which Medicaid funds are distributed to the handicapped in a manner that would provide greater incentives to states to develop and expand community-based service programs. The people who oppose these changes fear the loss of existing benefits and the replacement of a program that has been years in developing by a community-based system accompanied by uncertainties.

Fear that current benefits will be lost is the number one barrier to change.

The entitlement income and medical benefits of the Social Security system are as important to individuals with handicaps and their families as are the Social Security benefits to the elderly. Social Security is a large and complicated system and to change it could adversely affect many people who are not handicapped. On the other hand, the Social Security system is by far the largest federally supported program for people with handicaps. The system, however, is based on a concept of continued dependency. For most recipients of Social Security benefits, this concept appears appropriate, but for people with handicaps, who may have become eligible because of reduced earning capacities early in life, the manner in which these benefits are administered serves as a barrier to the development of independence and self-sufficiency (Whitehead & Rhodes, 1985). The regulations which govern the distribution of Social Security benefits must be changed in a manner which will provide incentives instead of disincentives for recipients with handicaps to continue further growth and development.

The process of changing the eligibility requirements and regulations governing the distribution of funds to people with handicaps needs careful study. The cost and benefits must be examined in the light of the normalization principle. The distribution of federal support has a major impact on state support and on each state's delivery systems. Federal funding should be dis¬ tributed in a manner that not only encourages individuals toward increased self-sufficiency but also encourages states and local governments to increase their efforts and to keep their service programs abreast of new information and technology.

If a better mouse trap is built, will people

Social security is as important to handicapped individuals and their families as it is to the elderly.

buy it? The cliche suggests they will; however, few people will buy a mouse trap if they do not have a mouse problem. Furthermore, there are limits to how much help they will give to someone else's mouse problem and it takes convincing that such help is in their best interest. More often the issue is not how much the mouse trap will cost or how effective it is but who will pay for it. A costly ineffective mouse trap might be preferred to a less expensive more efficient one, if the cost is subsidized by the federal government. Like the original mouse trap, our service system for adults with developmental disabilities is not only costly and ineffective but it only addresses a small portion of the problem. Its primary redeeming features are that the economic benefits to a small number are significant and it is subsidized by a large stable organization of the federal government.

The main issue under consideration here is not simply economics but human values. The problem is not finding and isolating people with handicaps, as was done in the early part of the century. Prevention will never be one hundred percent success-

ful and isolation is not only economically unfeasible but also inhumane. The best solution at this point in time is to develop and maximize the abilities and potential of people with handicaps to enable as many as possible to become self-sufficient and, thus, reduce their dependency. The major changes that have occurred during the past several decades, philosophically and technologically, are reflected in the movement away from an emphasis on the care and feeding of people with handicaps toward an emphasis on their training and continued growth and development.

In summary, the data and information collected and analyzed in this study suggest that individuals with developmental disabilities are capable of much more independence and self-sufficiency than was thought possible a decade ago. Currently, available technology and information are much more effective than the service system in meeting these needs. What is lacking is a way to implement successful practices into the system and a way to ensure that the system is dynamic and can respond appropriately to changes in the future. As Walt Kelly's Pogo once said, "It seems that we are now confronted with a number of insurmountable opportunities."

During the past two decades, unprecedented positive changes in the services society provides individuals with developmental disabilities has occurred. This past progress should provide the foundation upon which the difficult issues and problems of today can be addressed and resolved. The forecast for the future is thus more positive than at any other time in our history. However, these trends could change direction. If we ignore the developing crisis by refusing to heed the need for greater opportunities for a life of quality for the developmentally disabled, the economic implications and loss of human potential will be overwhelming and the bright forecast will not be realized. But, nothing will alter the direction of the future as greatly as inactivity.

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