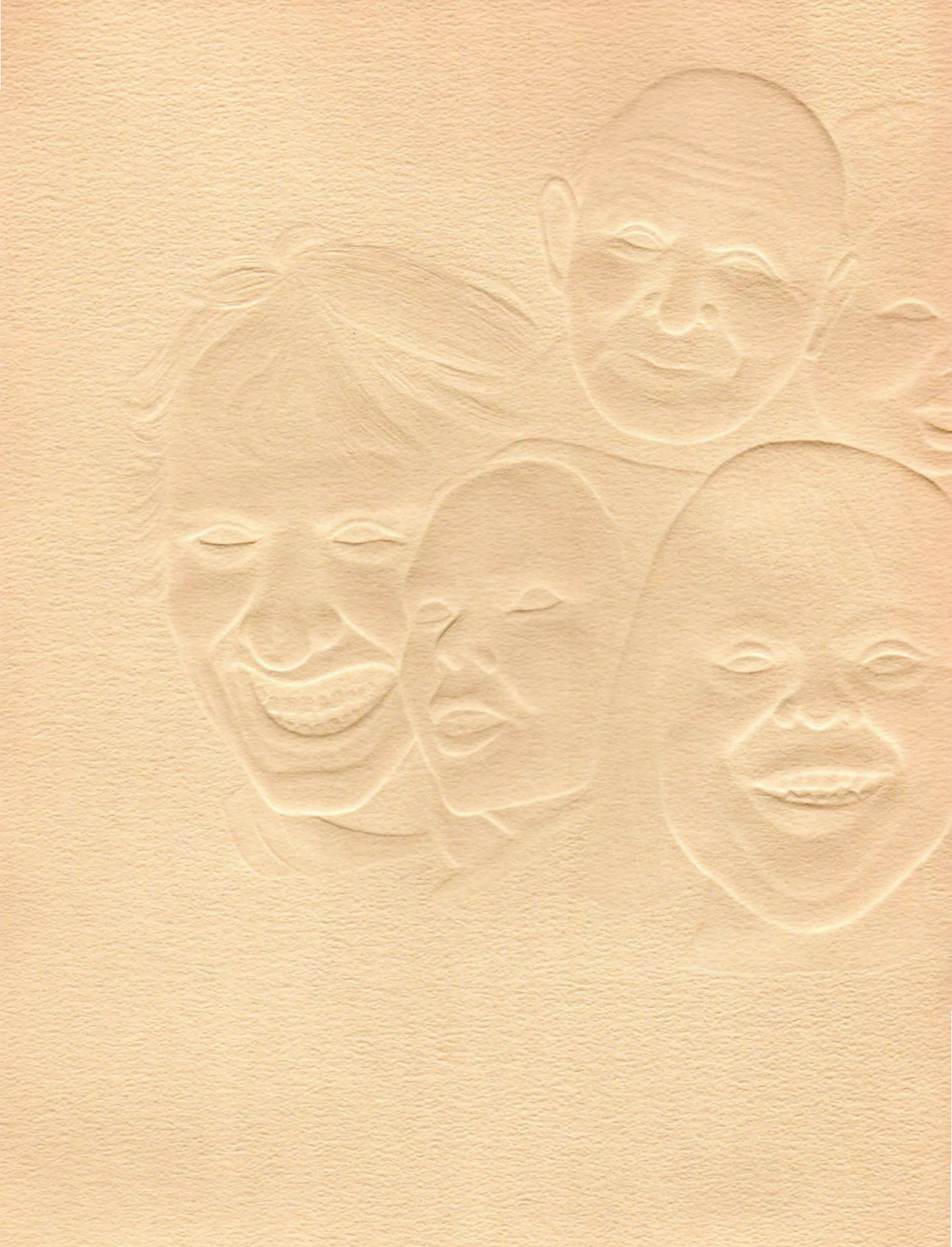




# **Developmental Disabilities and Public Policy**

A REVIEW FOR POLICYMAKERS









*At times in all of our lives we need the support of others, either to achieve independence or to maintain a measure of it. For most of us those times are when we are young, temporarily disabled, or very old. Some of us need continuing help because of our disabilities. In this group are persons with developmental disabilities resulting from long-term mental or physical conditions beginning early in life.*

# Developmental Disabilities and Public Policy

## A review for policymakers

### Presented by

State of Minnesota, Department of Energy, Planning, and Development  
The Governor's Planning Council on Developmental Disabilities  
Richard Nelson, M.D., Chair  
Colleen Wieck, Ph.D., Executive Director  
St. Paul, Minnesota 55101

### Members of the Governor's Planning Council

Jeff Alexander, M.D.	Ray Lundgren
Rick Amado, Ph.D.	Virginia Marolt
Doug Butler	Cynthia Obinger
Roger Deneen	Ruth Rafteseth
Eric Errickson, Ph.D.	Elaine Saline
Marian Greiner	Glenn Samuelson
John Groos	Ernest Silbernagel
Virginia Hanel	Kurt Strom
Mary Hinze	Kathleen Sturre
Jan Jenkins	Marvin Tritz
Robert Johnson	Marge Wett
Mary Kudla	

### With Preparation by

The University of Minnesota, College of Education  
The Center for Educational Policy Studies  
Charles H. Sederberg, Ph.D., Director  
Nancy Wangen, Ph.D., Project Director

January 1983

Graphic design by Destiny 2, Inc., St. Paul, MN

## Contents

Foreword	3
Summary	4
PART I	8
Human Dignity — The Foundation of Policy Development	
Definitions of Developmental Disabilities. Causes of Developmental Disabilities. Changes in Treatment. How Policies Change. Helpful Government Actions. Federal Policies' Effect on Treatment. The Service System Today: Reallocation or Redesign. Barriers to Change.	
PART II	14
Help for More Normal Lives — Community Services	
A Short History. Service Models: Continuum or Array. Living at Home. Homes in the Community. Learning and Working in the Community: DACs, Work Programs, Education for the Disabled. Support Services, Case Management, and Advocacy. Community Programs That Work. Frequent (and Tough) Questions.	
PART III	30
Toward a Secure Future	
Policy Alternatives for the 1980s	
Service Systems: Consumer-Powered or Resource-Powered. Two Models for Providing Services. Barriers to Change. Policy Alternatives for the Future. Choosing Among Alternatives. Today: What's Right About Services. Tomorrow: The Challenge of the Eighties.	
APPENDIX	38
Acronyms Used in This Book.	
References. Index.	



# Foreword

The purposes of this book are to provide background on persons with disabilities, to illustrate trends in community services, and to identify policy issues for the 1980s.

Many people made significant contributions to this book's design and content. We are grateful to members of advocacy and advisory groups, employees of various state departments, counties, and private organizations; service providers; social workers, legislative staff, legislators, lawyers, doctors, and teachers.

Most of all, we are indebted to those persons with disabilities and their families who were willing to share their experiences and concerns with us.

Illustrations by Martha Perske from *New Life in the Neighborhood* and *Hope for the Families* by Robert Perske, used with permission of the publisher, Abingdon Press.

Photographs by Opportunity Workshop, 5500 Opportunity Court, Minnetonka, MN used with permission.



# Summary

*The moral test of government is how it treats  
those who are in the dawn of life, the children;  
those who are in the twilight of life, the aged;  
and those who are in the shadows of life, the  
sick, the needy, and the handicapped.*

**Hubert H. Humphrey**  
at the dedication of the H.E.W. building  
in his honor, 1977



## **Human Dignity The Foundation of Policy Development**

A belief in human dignity, that each person is unique and capable of development, underlies protection of the basic rights of individuals. Developmental disabilities such as mental retardation, cerebral palsy, epilepsy or autism, put obstacles in the way of development. While the majority of people with disabilities live independently, some whose problems are severe and chronic need either temporary or long-term help from society.

Over the past 15 years, both society's view of disabled people and the help offered to individuals and their families have changed. Community programs have grown to provide alternatives to placement in state hospitals. Minnesota statutes and court decisions document the changes and show a long history of concern for vulnerable people. The Federal presence in both policies and dollars shaped the design of services available.

Newer principles call for more normal and less "institutional" program settings, integration with nonhandicapped people, less structure in homes and programs, and client participation in decisions about their lives. These changes were the result of many events including the growing concern for individual rights, the effectiveness of advocacy groups, and the successes of disabled people in community programs.

The years of experience with community programs provide direction for the future. Effective programs that promote client development in cost-effective ways are identified and can be emulated if barriers to change can be removed.



## **Help for More Normal Lives Community Services**

Community services grew throughout the 1970s. The current system is still evolving, incomplete, and threatened by cutbacks, although evidence shows that community programs work. There are two models for designing the necessary range of community services: a continuum with developmental steps that clients move through or an array of flexible services shaped to meet clients' changing needs. The continuum was the early choice of communities, but that may be changing. In either model services are highly interconnected. A cutback in one program affects other services.

People with developmental disabilities live, learn, and work in Minnesota communities with support from special programs and some help from generic or existing services used by everyone. The first choice for a home is with one's family and in-home support programs keep families together. The help families need is varied, often

short term, and far less costly than institutional care. Minnesota's Family Subsidy Program serves 200 families and has a long waiting list.

Preferences for homes in the community are that they be family-sized, close to transportation and services, and provide individual attention to residents. In Minnesota, the more independent adult clients live in their own homes or are in Semi-Independent-Living Services (SILS) where they learn skills they need to care for themselves. A few adults and children live with foster families. Over 4500 people live in community Intermediate Care Facilities for the Mentally Retarded (ICF/MR). Residents of ICF/MRs must have a plan of care and 24 hour supervision. Estimates are that from 200-1000 people in ICF/MRs are ready for less-restrictive alternatives like foster care or SILS. A barrier to people's movement is that more restrictive options like ICF/MRs have more stable, less limited funding.



Day programs for people with disabilities include limited preschool offerings, special education for ages 4-21, and for adults, developmental achievement centers, work activity, sheltered work, and regular employment. Two goals of cost-effective programs—early intervention with young children and movement of adults toward independence—are frustrated by the lack of preschool programs and by waiting lists for adult programs. Slumps in the economy are reflected in sheltered workshop layoffs, declining subcontract business, and a shortage of jobs for handicapped people. Day programs may need to be redesigned to reflect changing realities.

Support services increase a system's efficiency and effectiveness. Case managers assist people to and through services acting as brokers, linking services across agencies, and especially coordinating services across county lines. In Minnesota, some case managers have more clients than they can reasonably serve. Case managers are a client's primary advocate although other groups and individuals do serve as either formal or informal advocates.

Community programs cited by the President's Committee on Mental Retardation meet cost effectiveness goals primarily through prevention and early intervention, support of families, use of volunteers, and work for people with disabilities. People's concerns about community services to the handicapped often include questions about the cost of services, clients with behavior problems, the effect of group homes on property values, and differences in rural and urban services.

### ***Toward A Secure Future Policy Alternatives for the 1980s***

A broad policy goal for people with handicaps is that their home life and day activity be as close to normal patterns as their disabilities allow. This goal is best met in a consumer-powered system or one that starts with a client's needs and strengths, identifies the resources needed, and evaluates the system by the client's progress. In practice, policy is contradicted by disincentives that reallocation of funds could solve. The result is a resource-powered system where clients choose from services available and spend time on waiting lists. Two side effects are big dollar investments in bricks and mortar and difficult evaluations because of inappropriate placements.

Davis and Trace (1982) would change the model for community services from a continuum to a flexible array of services they call The Support Model. Funds could be directed toward services rather than facilities and clients would not be forced to move as they became more independent and their needs changed.

During the 1970s, life improved for many people with disabilities. Maintenance of services or continued improvement will require creative responses to economic pressures. When goals are clearly stated, strategies for maintenance, reform, or redesign can be identified.

The policy choices possible will depend on how people view some basic issues:

(1) The trend toward decentralization of governmental responsibilities is one apparent issue. There will be greater pressure on state and local governments to continue services viewed as necessary.

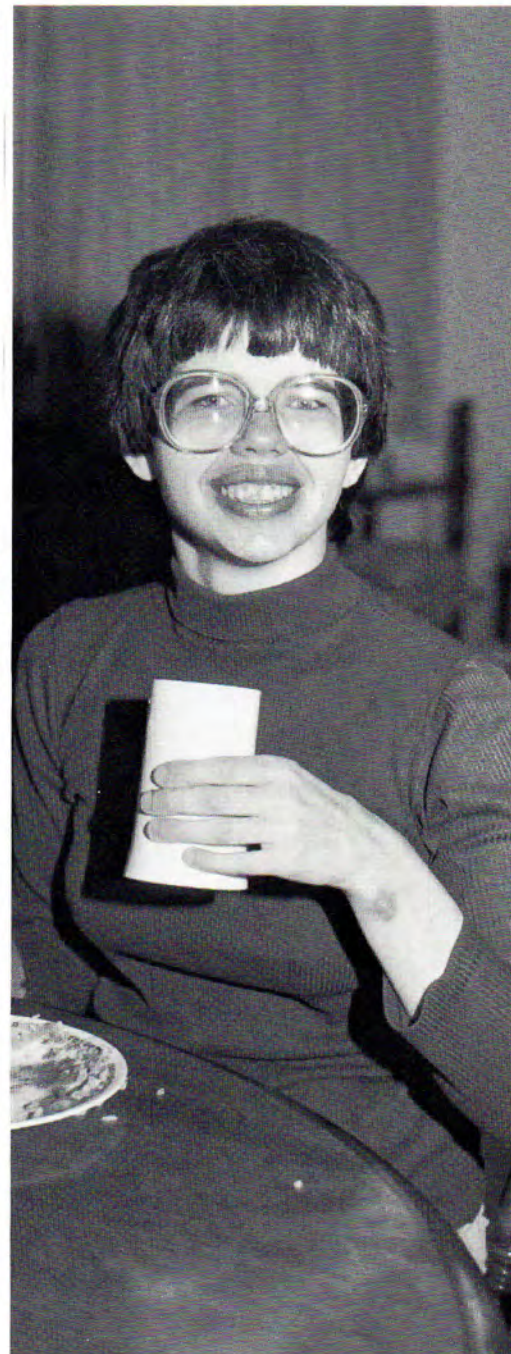
(2) The issues of funding disincentives and deficits in open entitlement programs are linked. The possibility of Minnesota's use of the Title XIX waiver to allow Medicaid for home and community care will be reexamined. Other states are attempting to control rising hospital and nursing home costs through cost effective alternatives to long-term care.

(3) Prevention and early intervention programs are often targeted for cuts although they represent the best possibility for long-term cost savings. Well designed and coordinated services also save money.

(4) Minnesota like many states currently funds two service systems—a network of state hospitals and one of community services. A number of states in recent months have closed some of their large public institutions for the mentally retarded. Reasons cited relate to cost savings and declining hospital populations.

Much is right about Minnesota's services to people with disabilities. Preserving the gains of the 1970s during tough economic times defines the challenge for the 1980s—to reshape services and provide them in an efficient and coordinated way. A decade of experience gives direction.







PART I  
THE FOUNDATION OF  
POLICY DEVELOPMENT

# Human Dignity

*This book is about those who need  
society's help—some only temporarily  
and some for a lifetime.*

---

DEFINITIONS AND CAUSES OF DEVELOPMENTAL DISABILITIES. CHANGES IN TREATMENT. HOW POLICIES CHANGE.  
HELPFUL GOVERNMENT ACTIONS. FEDERAL POLICIES' EFFECT ON TREATMENT. THE SERVICE SYSTEM TODAY:  
REALLOCATION OR REDESIGN. BARRIERS TO CHANGE.



---

**D**onna is a young woman with Down's syndrome. Her parents are disappointed that she now must live in a group home many miles from the family farm because there were no appropriate placements in her home county. They are aware that there is some local opposition to community care, presumably because counties must pay more than they do for state hospital services. A neighbor's son, also retarded, is transported out of the county every day, not to the nearest developmental achievement center, but to the least expensive one. Some school districts in the area, concerned about transportation expenses, are pulling out of special education cooperatives and setting up local K-12 programs with one teacher. Donna's parents know how important good services are to Donna and wonder what will happen to other families.

---

**G**eorge, who is mildly retarded and has epilepsy, looks and feels like a success story. Less than a year ago he lived in a group home unable to work or do much of anything because of repeated, uncontrolled seizures. About 20% of people with epilepsy need help such as that available in the Epilepsy Treatment Unit at the University of Minnesota. George was monitored there to identify the kind of seizures he had. His medication was adjusted and he was able to move into semi-independent living. Now, months later, his seizures controlled by the right medication, George has his own apartment, a fulltime job he likes, and is proud to be completely self-supporting.

---

**J**im's difficulty with speech and movements, a problem so severe that he is able to walk only with great effort, slows him physically but does nothing to limit his sense of humor and obvious intelligence. For Jim, who started his education in a special segregated class, getting into regular education classes has changed his life. The school psychologist helped Jim, his parents, and school personnel to make the changes for Jim. He needs some extra patience from people and a little help getting around, but he is a good student, thriving in an atmosphere appropriate for his abilities.

---

**J**ane was recently returned to the state hospital where her family had placed her as an adult 25 years ago. With a successful behavior modification program and medication to control occasional seizures, Jane had functioned well and was released to community care. However, after several months she came back to the hospital—labeled as a behavior problem and a threat to others. Less than two weeks later, free of tranquilizers and back on a behavior plan, Jane's behavior was under control. Staff training and a commitment to work with people like Jane are important to her success.

---

**T**om looks like any healthy 14-year-old. You wouldn't notice his autism unless you were alert to its signs. You might think him withdrawn and a bit slow because he interprets everything so literally. Tom is not retarded. In his special education class, he functions well—relatively free of the stress that brings out hyperactivity and some self-injurious behavior. Tom's vocational future is uncertain. He likes working with computers but his low tolerance of stress and occasional temper tantrums may affect his choice of jobs. He might also need some kind of residential supervision, but nothing like the medical setting of a hospital or some group homes. With the right kind of supports, Tom could pay his own way.

---

These brief stories suggest the concerns consumers, family members, advocates, service providers, and policymakers have about needs of people with developmental disabilities. Of these approximately 120,000 people in Minnesota, the majority are independent and self-supporting.



## Definitions of Developmental Disabilities

**Mental retardation** is a condition of inadequately developed intelligence that lessens ability to learn, to care for oneself, and to make sound decisions about everyday problems. While retardation has strikingly different levels of severity from mild to profound it is:

Long term, usually appearing at birth or early in childhood, Frequently complicated by physical and emotional problems,

Widespread, disabling 10 times as many children and adults as polio did before research provided a vaccine (Association for Retarded Citizens).

**Cerebral palsy** is a term describing a variety of disabling conditions resulting from damage to the central nervous system. "Cerebral" refers to the brain, and "palsy" describes the lack of muscle control that is often present. Symptoms vary from strong uncontrolled body movements to slight speech impairment. Up to 1,000 Minnesota babies are born each year with central nervous system disorders. Others acquire cerebral palsy early in life through injury or illness (United Cerebral Palsy of Minnesota, Inc.).

**Epilepsy** is a chronic tendency for recurring seizures. Seizures are defined as uncontrolled electrical discharges of the brain. About 80,000 people in Minnesota have epilepsy; many of them have their seizures totally controlled by medication. About 30% are impaired by frequent seizure activity or have multiple handicapping conditions including mental retardation (Minnesota Epilepsy League, Inc. & Minnesota Comprehensive Epilepsy Program).

**Autism**, a set of behaviors observed in young children, may include extreme withdrawal, very inadequate social responses, language disturbances, and monotonously repetitive physical activities. Many children with autism have seriously impaired intellectual functioning (Twin Cities Society for Autistic Children, Inc.).

According to the federal definition, for disabilities to be called "developmental," they must:

- Occur before age 22,
- Be severe and chronic, and
- Limit intellectual functioning or ability to adapt.

The federal definition of developmental disabilities refers to the most substantially handicapped group of people.

Developmental disabilities are often found as multiple handicaps in the same person. Generally, more severely retarded people have more medical problems.

## Causes of Developmental Disabilities

Disabilities result from a wide range of genetic, neurological, and environmental problems—some of which are preventable. For example, mental retardation can be caused by: (a) below average genetic endowment; (b) physical damage to or maldevelopment of the brain caused by infections present in mother or child, toxic agents ingested by mother or child, birth injuries and accidents, disorders of metabolism, or chromosomal malformations; and (c) environmental deprivation.

"Congenital" cerebral palsy can be caused by prenatal infections such as German measles, RH blood incompatibility, lack of oxygen at birth, or effects of premature birth. Cerebral palsy is "acquired" if the brain damage results from abuse, injury, illness, poisoning, or accidents in childhood.

**No family is immune. About half of all disabilities are preventable.**

### NATIONAL DECLINE IN INSTITUTIONAL POPULATION

Source: *Placement and Care of the Mentally Retarded*, 1982





## Changes in Treatment

First, the location of treatment has changed. There has been a dramatic reduction in the mentally retarded population in Minnesota state hospitals from 5,500 residents in 1962 to about 2,400 in 1982.

Under the *Welsch v. Noot* Consent Decree (1980) Minnesota agreed to release people to community care and to improve living conditions in state hospitals. By 1987, the target is a reduction to 1,850 hospital residents with mental retardation. The change to community living is seen in national trends.

Second, the nature of treatment has changed. Two important beliefs underlie the changes: (a) that the handicapped are unique persons with the same basic rights as other people, and (b) that all people are capable of learning, growing, and developing, no matter how severely disabled.

Basic principles which acknowledge the social, emotional, and developmental needs of handicapped people also define the changes.

**Deinstitutionalization** is more than releasing people to their home communities. It means: (a) reducing admissions to large institutions, (b) developing care alternatives in communities, (c) returning residents to communities when their needs can be met by programs, and (d) improving institutions for those who continue to live there.

**Normalization** means providing routines and conditions of life as close as possible to the lives of other people in the community. Institutional life has often exaggerated the differences of the disabled.

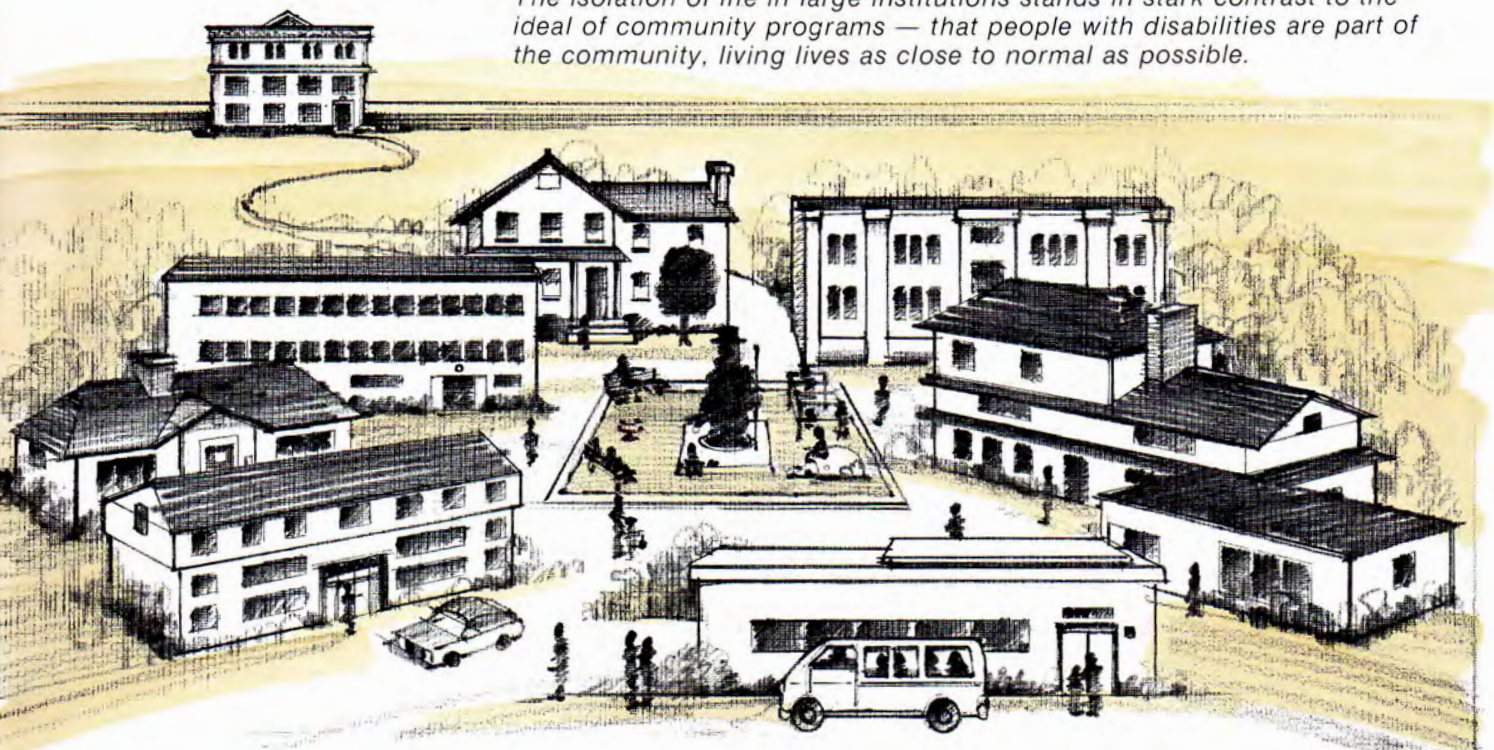
**Physical and social integration** are helped by good sound training, smaller neighborhood residences, barrier-free buildings, transportation options, a wider variety of life experiences, integration with nonhandicapped people, use of general community services rather than special ones, and education and jobs in the community whenever possible.

As individuals learn and develop they need less structure in homes and programs. Disabled people should live, work, and play in the least restrictive environments appropriate for their individual development.

**Consumer participation** in decisions about services can make a system more effective and accountable.

*Today, people with disabilities are viewed as capable of development and as having the same basic rights as other persons.*

*The isolation of life in large institutions stands in stark contrast to the ideal of community programs — that people with disabilities are part of the community, living lives as close to normal as possible.*





## How Policies Change

Service systems are a reflection of society's attitudes, beliefs, and values at a given time. A national turnaround as dramatic as the change from institutional to community care is explained by many interrelated events including:

- Growing concern for individual rights during the 1960s and 1970s;
- Handicapped persons' documented progress toward independence and productivity;
- The greater visibility and effectiveness of advocate groups;
- Prosperity, and available federal and state money for community residential care;
- Media exposure and increased public awareness;
- Successful and extensive community-based programs in other countries, especially Denmark, Sweden, Norway, and Canada; and
- Judicial and legislative actions.

Confinement in large state institutions no longer seemed the best national policy.

## Helpful Government Actions

All three branches of government—legislative, judicial, and executive—have been significant shapers of services to people with handicaps. Minnesota provides good examples:

**In education.** M.S. 1957, Ch. 120 requires every school district in the state to provide special instruction and services for handicapped residents aged 4-21. M.S. 1971, Ch. 120 included trainable mentally retarded persons in required special education services.

**In cutting opposition to neighborhood group homes.** M.S. 1975-1980, Ch. 462 and M.S. 1980, Ch. 245 require local zoning ordinances to view homes of 6 or fewer people as single family residences. Homes of 7-16 people are approved for multifamily residential use. The statutes have been upheld by the Minnesota Supreme Court.

**In encouraging community facilities.** M.S. 1963, Ch. 252 directed county boards to make grants to developmental achievement centers which allowed those services to get started.

**In creating more normal living conditions.** The *Welsch v. Noot Consent Decree*, 1980, improved state hospital conditions for people with mental retardation and provided for community placements of 850 people by 1987.

**In insuring local responsiveness.** The Department of Public Welfare Rule 185 defines county/human service board responsibilities including case management. The county has responsibility for assessment of need, development of individual service plans, arrangements to provide services, and evaluation of services received.

Any list of federal actions of consequence would include:

1. Public Law 94-142, The Education for All Handicapped Children Act (1975). This law requires a free, appropriate public education for every child.
2. Section 504 of the amended Rehabilitation Act (1973). This act prohibits discrimination against people with handicaps and opens up many kinds of opportunities for more normal life experiences.
3. The use of Medicaid (Title XIX) for institutions and community group homes. The dollars in this funding source have affected residential services all over the country.

## Federal Policies' Effect on Treatment

The federal government has defined the rights of disabled people and played a major role in funding—and, consequently, shaping—programs. Two funding initiatives show the powerful effect of dollars on program design.

A stable funding base (Medicaid, Title XIX) for Intermediate Care Facilities for the Mentally Retarded (ICF/MR) encouraged their development in Minnesota communities—sometimes even when less restrictive, nonmedical settings would be more appropriate for some people.

Counties save local dollars by using ICF/MRs rather than other options such as foster care or semi-independent living. The less restrictive, less costly housing options depend on a blend of funding sources including client Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) payments, state funds, Housing and Urban Development (HUD) Section 202 loans and Section 8 rent supplements, food stamps, parent/resident fees, county or local funds, and private donations (*Placement and Care of the Mentally Retarded: A Service Delivery Assessment*, 1982).

Federal funding for educating handicapped students in local school districts has helped keep children out of state hospitals. Taken together, federal policy statements and funding programs both stimulated placement out of state hospitals, but the funding programs had a greater impact on design of community services.

The federal policy conflict—funding incentives work against programming in the least restrictive settings—is also apparent in cuts in SSI payments. Many disabled people who have become independent and are working in competitive employment need some wage supplement to maintain themselves. When SSI payments are



lost, people are forced to give up independent living quarters and return to more costly—but subsidized—residential alternatives.

The “New Federalism’s” shift from categorical funding to block grants will continue to affect programs. Whether federal funding cuts represent decreasing policy commitment to community care is uncertain. Any retreat from community to state hospital care would confront several realities:

- Community programs generally cost less than state hospital programs;
- There is evidence that development of disabled people is enhanced in community settings; and
- There is growing interest in controlling costs and preventing institutionalization by supporting family efforts to keep members at home.

While the overall outlook for federal funding is not encouraging there is an exception cited by the National Association of Counties Guide in *Developmental Disabilities: A Guide for County Officials* (1982). The Medicaid Title XIX waiver authority allows federal payments for other services such as in-home care or day programs (p. 1). Over half the states have applied to date.\*

## The Service System Today

A 1982 report by the U.S. Department of Health and Human Services discussed a number of observations about the national scene:

- Some states, including Minnesota, have relied heavily on the ICF/MR model while less costly residential models are underdeveloped.

- There has been greater individual progress than expected, especially among severely and profoundly retarded persons.
- There is a serious lack of support services that prevent institutional placements such as infant stimulation programs, respite care, and parent training or counseling.
- Monitoring processes that assure correct placement in residential facilities are not working well.
- Public institutions are not all being closed, but their role is being reexamined.

(*Placement and Care of the Mentally Retarded*, 1982)

## Reallocation or Redesign

Interest in reallocation or redesign grows when revenue problems or service complaints increase. As an alternative to cutting services or raising taxes, redesign offers cost efficiencies so that services continue to meet needs. In response to complaints about services, redesign offers competition among alternatives and more choices to consumers.

Representative John Brandl writing in *Corporate Report* (June, 1982), suggests restructuring spending to encourage use of effective programs. Brandl discusses principles that apply to services for the disabled including: keeping disabled people at home, returning institutionalized people to more normal lives, fostering self-help programs, and having government provide money but not services. Programs supporting such principles could include: in-home care, medical assistance to keep disabled people at home, prepaid health care plans, and work opportunities in the private sector (pp. 41-42). When

government dollars are involved, service providers would have to be accountable for effectiveness of services and for cost containment.

A Report of the President's Committee on Mental Retardation (1977) reviewed successful programs. Their characteristics are consistent with redesign principles and meet requirements of cost effectiveness as well. They include supporting disabled people in their homes, early intervention with “at risk” children, parent and volunteer training, effective case management, lower cost residential alternatives, and getting people into competitive employment.

## Barriers to Change

Efforts to redesign services will need to recognize barriers to change.

- Federal programs are not unified and may even be contradictory.
- Community alternatives emerge haphazardly often in response to funding initiatives rather than being planned in an integrative, cost effective way.
- Group interests conflict. Unions and local community leaders may want to preserve state hospital use while some advocacy groups favor community treatment.
- Cost figures may need to be available on a per-person, per-service basis in order to compare alternatives.
- Advocacy groups are not always unified in their interests or efforts.
- State and county agencies and their managers will need skills and techniques to monitor and improve services in a decentralized system.

\*Minnesota has not applied for the waiver for other noninstitutional services primarily because of concern over the state Medicaid deficit.



PART II  
COMMUNITY SERVICES

# Help For More Normal Lives

*Any change in a program should be  
examined for its effect on other services.*



## A Short History

Community services for children with handicaps developed and expanded throughout the 1970s. The current community system is, according to observers, still evolving. Concerned advocates describe a fragmented, incomplete system with service gaps and threatened cutbacks. Fears are balanced, however, by growing evidence that community treatment works and that thoughtful people are searching for ways to improve services.

## Service Models—Continuum or Array?

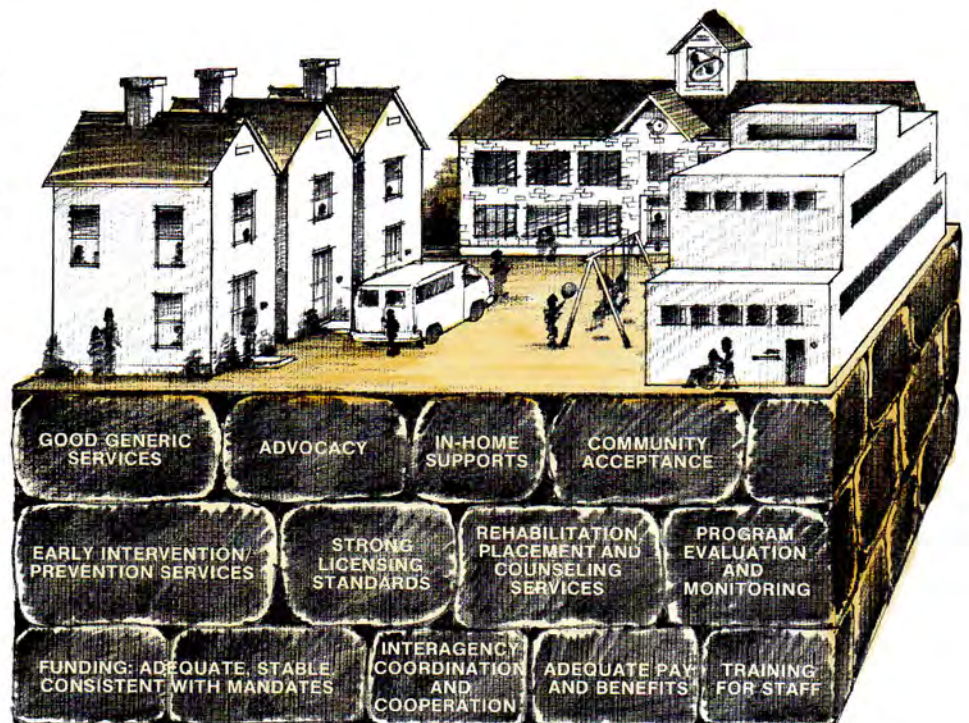
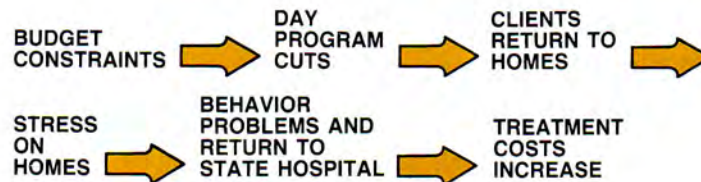
A continuum of residential and day services has developmental steps which clients follow. In practice, client movement toward independent living and competitive employment has been restricted by: fiscal disincentives, program waiting lists, service providers' reluctance to take the more handicapped clients, and a shortage of case management services. Some advocates would prefer an array of flexible services provided to individuals and families instead of the present continuum approach.

Loop and Hitzing (1980) cite what they call dangerous trends within the continuum approach.

- "Different groups need different environments." At present, people must fit the system rather than the reverse.
- "Disabled persons must 'earn' their way through the system." This places the major burden of movement on the consumer rather than the system.
- Cost. A comprehensive continuum of services requires huge expenditures for capital construction or renovation and once homes and centers are in place, their maintenance can become the focus of the system (pp. 24-26).

A flexible, individualized array of services responsive to needs of the family and consumer may be the direction of the future.

Whether continuum or array, the interconnectedness of services is the primary feature of community programs. Gaps and cutbacks in one area can have consequences in another as the following sample scenario illustrates.



*Necessary community services — case management, normalized living situations, day programs, recreation, health and medical services, and transportation — rest on adequate supports and on strong state, county and agency commitments.*



## Living at Home

### Keeping Families Together— A Goal of In-Home Supports

**Family Care.** What support services do people need? A key service is respite care, short-term help provided on a temporary basis. It could be a trained in-home caregiver, foster care, or temporary placement in a group home. Respite care provides help during an emergency or a much needed vacation.

Broader definitions of respite care or in-home supports for all groups with disabilities include:

- Homemaker assistance with housecleaning or cooking,
- Chore services for shopping, repairs, or personal care,
- Home management services such as instruction in child care, home maintenance, cooking, and finances.

Some examples illustrate the services communities could develop.

NEED	RESPONSE
Parent unable to toilet train 8 year-old child who needs to be trained to attend school	In-home trainer Toilet training aids Parent training Physical evaluation of child
Parents divorcing. Mother adjusting to new employment needs temporary help with two children one of whom is autistic	Professional homemaker services Parent trainer, counselor
Child with severe cerebral palsy and retardation. Mother pregnant, considered at risk for premature delivery	Instruction in care skills to father and other relatives Respite services during day Professional homemaker visits

**M**artha's earliest memories of her son Tommy as an infant were that he couldn't be allowed to cry because of the strain on his heart. Tommy had surgery to repair a heart defect but during the surgery he suffered brain damage that left him mentally retarded with some neurological problems. Another of the family's three children has severe learning disabilities with emotional complications.

With Tommy's surgery, the family entered a crisis period—lasting about 3 years. The father lost his job; medical costs mounted; Tommy had vision and mobility problems; and the child with learning disabilities became a behavior problem. Under severe stress, Martha became verbally and physically abusive to the children, repeating behaviors present in her family background. The county provided family supports—needed counseling for Martha and her husband, help with behavior management, some respite care, and money for the special shoes and glasses Tommy needs.

Today, the family is committed to keeping Tommy at home. The father is employed. Martha meets regularly with a support group of other mothers of children with disabilities. Tommy's development has exceeded the doctors' prognosis; and at age 5, he is walking, talking, and learning some self help skills. The child with learning disabilities is responding to good behavior management at home and at school. Both husband and wife know there will be other crises, but they are stronger because of the support available when they needed it.

**J**amie would have been institutionalized years ago without the determination of her family and the support of respite care and education programs. The youngest of eight children, she was diagnosed at age 2 as being profoundly retarded with complications of cerebral palsy. Family members recall severe financial stress, medical bills, special equipment, not to mention the hard work of caring for Jamie. Jamie is 21 now. Five years ago, her parents enjoyed their first trip away from home in 16 years. As they are getting older, they wonder what kind of services might enable them to continue to keep Jamie at home, and if such help will be available.

A full array of flexible resources and support services for families with handicapped children or long term care responsibilities includes: health care, parent training, family support groups, information and referral, insurance coverage, legal assistance, consumer lobbying groups, in-home training and developmental services, special equipment, recreation, financial help, counseling, crisis intervention, education, work and employment services, day programs, in-home supports, advocacy services, transportation, respite care, and case management.





While difficult to get, in-home care is much less expensive than alternatives.

A single parent has a 12-year-old severely retarded daughter who requires tube feeding and needs continuous care. The mother will have to research and apply for five different funding alternatives with no guarantee of getting the in-home help she needs. Without respite care the mother has two choices: She could quit her job to care for the child fulltime, living on public assistance; or she could place the child in a state institution. There is a two-year waiting list for appropriate community residential facilities.

(Testimony, Governor's Planning Council on Developmental Disabilities Public Hearing, May, 1982)

#### Minnesota's In-Home Support Programs.

The state funded Family Subsidy Program is designed to keep disabled children in their homes and out of institutions. Monthly grants went through county social service agencies to 200 families, as of July 1, 1982. Another 100 families are on a waiting list at the State Department of Public Welfare. Funds pay for special needs identified in a written service plan for each child.

Total state appropriations for fiscal year 1982-83 were \$525,800. Some counties such as Brown and Faribault-Martin-Watonwan Human Services Board sponsor their own in-home programs tailored to family needs.

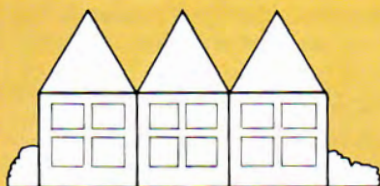
***Although home-based services appear to reduce costs of care in the community, they currently receive less than 1% of the total federal budget expended for health and social services.***

(Loop & Hitzing, 1980, p. 17).





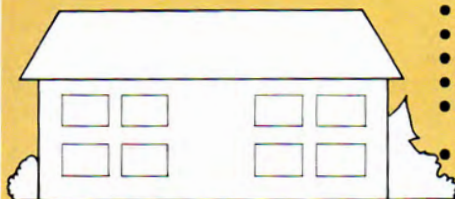
# CHOICES IN MINNESOTA FROM LEAST TO MOST RESTRICTIVE



OWN HOME OR APARTMENT

- Minimal or no support services are needed
- Adult residents often are employed or retired

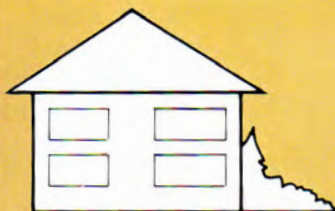
PEOPLE IN PLACEMENT  
NOT COUNTED



SEMI-INDEPENDENT  
LIVING SERVICES

- Apartments are in one location or on scattered sites
- Units are supervised by a licensed agency
- Adults live in units of 2-4
- Counselor and consultants are available
- Services are based on need: skills of cooking, shopping, hygiene, using public transportation
- Purposes are to train for independence or to maintain in semi-independence

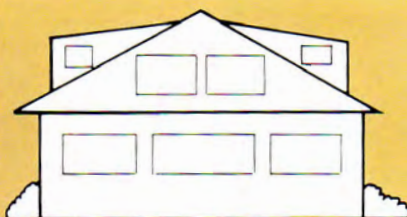
500  
PEOPLE IN PLACEMENT



FOSTER CARE

- For children who cannot live with their families
- For adults who would benefit from a family setting
- Licensing standards for child foster care are additional provider training and experience and written individual programs for each child
- With strong model standards and monitoring, adult foster care could be expanded

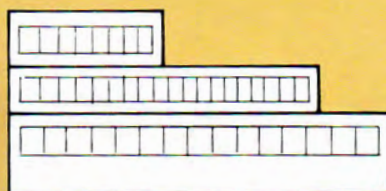
ADULT: 200  
CHILD: 400



CONTRACT GROUP HOMES

- Usually licensed as Intermediate Care Facilities for the Mentally Retarded
- Residents have similar handicaps
- Residents must have a plan of care with active treatments and 24 hour supervision
- When care and supervision needs decline, resident could move to a less restrictive home
- Preference is for family sized homes
- Most Minnesota group homes are licensed for 6-15, 44 are larger, 6 exceed 100 beds

ABOUT 4,790  
PEOPLE IN  
PLACEMENT  
IN 301  
LICENSED HOMES



HEALTH-RELATED FACILITIES

- Usually nursing homes
- Most restrictive community environment
- Residents are more severely retarded and/or have medical needs requiring frequent attention
- Placement out of the community is in one of seven state hospitals.

NURSING HOMES: 300

Brainerd\*: 358

Cambridge: 512

Faribault: 776

Fergus Falls: 269

Moose Lake: 126

St. Peter: 191

Willmar: 163

STATE HOSPITAL TOTAL: 2,395

\*Including Minnesota Learning Center



## Homes in the Community

"I have my own apartment now and a little bird and I'm happy." (Paul)

"We're friends and we take the bus downtown to go to a movie and sometimes to shop." (Shiela)

"I'm taking karate lessons now just down the street. My girl friend and I like to take walks by the lake." (Tom)

"People are nice here and the food is good!" (Marcy)

Things that make a difference to residents seem to be: size, social interaction, transportation, programs, staff, location, and accessibility for physically disabled people.

Smaller homes are more likely to have the attributes that help clients adapt: individual attention, resident-oriented care, a home that looks like others, privacy and no unnecessary locks or security measures.

Preference is for small family sized residences.

Federal ICF/MR standards call for similar ages, developmental levels, and social needs in people living together.

Trained staff who understand people and can manage problem behavior is important. Pay and benefits should be on a par with state hospital levels.

**The Choices Available.** Choices have expanded dramatically since 1970, but not all options are available everywhere. Some of those most needed are the least restrictive and the least expensive, but the most precariously funded.

### Paying for Residential Services.

Dollars for living in the state hospitals or in the community come from state, federal, and local sources. The most restrictive options—state hospitals, nursing homes, and community ICF/MRs—have had the most stable and secure funding with federal Medicaid dollars currently paying over half the cost (52.2%). Other programs like SILS and foster care depend on blended support from many sources. A problem in the system is that less costly choices are more difficult to pay for and many use more local dollars than the most restrictive options do. Thus, current funding programs can actually work against expansion of less-costly residential choices.

Some sample per diems:

#### \$24.82 SILS per diem

This figure includes SILS services and room and board. The county share of SILS services ranges from 20-50% depending on whether the client has moved from an ICF/MR or some other living situation. Overall, SILS costs to counties have increased as the program has grown. At present, counties are actually paying 35% of the total state SILS cost. The state pays the other 65%. This example includes the dollars available to an eligible client under SSI/MSA. The state does not have records available on actual board and room costs. SILS room and board are paid from the following sources: SSI, SSI/MSA, SS, Section 8 (HUD), GA, wages or earnings, food stamps, and combinations of the above. Employed clients using SILS services pay some or all of their own board and room costs.

#### \$12.00 Foster Care per diem

Actual reimbursement rates in two large counties with foster care programs are \$11.66 in Ramsey and \$12.50 in Hennepin. No statewide cost data are available. Foster care is paid in three ways: (a) private pay by clients (b) SSI/MSA funds (SSI-federal, MSA-85% state and 15% county) (c) general assistance.

#### \$49.97 Community ICF/MR per diem

This figure is the statewide average per diem listed in the Medical Reimbursement Table as of September 9, 1982. Costs vary, often reflecting clients' ages and severity of their handicaps. The federal government pays 52.2%; the state 43%; and the county 4.8%.

#### \$109.50 State Hospital per diem

This is the rate effective October 1, 1982. The per diem includes a day program, social services, and some medical costs. Day program costs in the community average about \$21 per service day. The federal government pays 52.2%, the state, 43%; and the county, 4.8% of the state hospital per diem.

Cost averages for any program are difficult to present because the range of per diem charges is affected by client disabilities and length of stay. For example, the DPW Staff MR Program Division estimates that SILS program costs range from about \$8 per day to over \$30 per day. The most meaningful comparisons might result from starting with specific clients and determining charges for those clients in various residential alternatives.

Demand for foster care exceeds the placements available. Those who favor increasing use of adult foster care cite its cost effectiveness as an alternative to ICF/MRs as well as the advantages of more homelike settings. (Information provided by Department of Public Welfare, Ramsey County Community Human Services Department, and Hennepin County Community Services.)

### TARGETS FOR HOSPITAL RESIDENTIAL REDUCTION SET BY THE WELSCH V. NOOT Consent Decree (1980):

June 30, 1983: 2375

June 30, 1985: 2100

June 30, 1987: 1850



"Our region has a real shortage of Class B facilities for the multiply handicapped. We've also seen very slow movement to SILS because they take more county support."

(Testimony, Governor's Planning Council on Developmental Disabilities Public Hearing, May, 1982)

"About 95% of people with autism are still in institutions. We did a survey that located community placements in Minnesota for only 37 autistic people."

(Testimony, Governor's Planning Council on Developmental Disabilities Public Hearing, May, 1982)

### Problems Affecting Choice of a Place to Live

**Cost considerations can stop client progress.** The manager of a group home has been trying to get Tom placed in semi-independent living for over a year. Tom has a job in the community and advocates have even located a small apartment for him. Six months of follow-up services should be adequate to establish Tom's independence. The county has refused to give approval to the change because costs to the county would more than double even though overall costs would sharply decline.

The Quality Assurance and Review Program of the Department of Health estimates from client records that as many as 200 people in Minnesota should be ready to leave group homes for semi-independent living. Copeland and Iverson's (1981) *Fiscal and Programmatic Assessment of Minnesota* plans for deinstitutionalization cites an estimated 1000 ICF/MR residents who could move to non-medical residential care with varying levels of supervision.

## Learning and Working in the Community

- Developmental Achievement Centers (DACs)
- Sheltered Workshops, Competitive Employment
- Schools

### DACs

"Day programs are the key to community placement and keeping disabled people with their families." (parent)

"Our most critical problem is the need for a stable funding base." (DAC staff member)

"I have people who could rake leaves and do services in the community. We have to have more to offer than making potholders or practicing work skills." (DAC director)

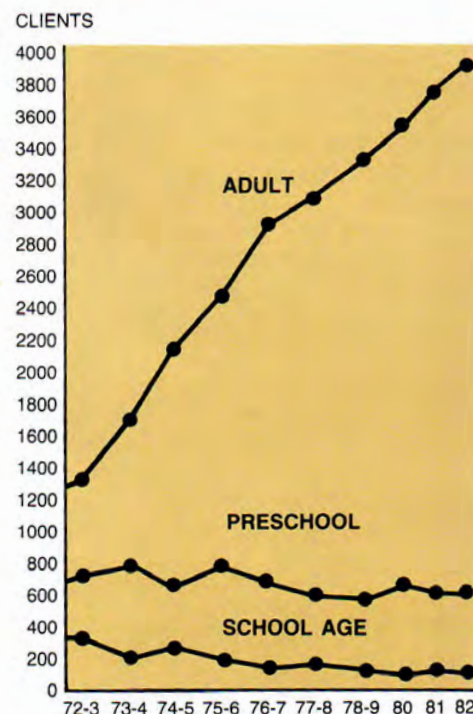
"DACs try to plan around budget decisions of several counties as 1 out of 4 clients is an out of county placement. One DAC may negotiate with 30 different counties." (DAC director)

"Each county defines its own DAC services so with 87 different counties, there can be 87 different service levels." (parent-advocate)

**Purposes of DACs.** Three kinds of programs are offered: (1) infant stimulation and preschool programs; (2) training for more independent living in skills of communication, use of leisure time, adaptive behavior or in knowledge of the community; and (3) vocational activities to help people reach entrance level criteria for sheltered workshops. DACs are usually the first community day programs for people released into the community. Others who attend are persons who have always lived at home, infants and preschoolers prior to school placement, and a limited number of school age children. There is growing interest in DACs providing more work for adult clients.

### ENROLLMENT IN DACs

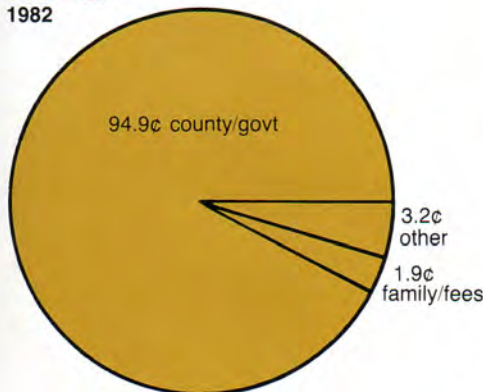
Source: Developmental Disabilities Program  
Dept. of Energy, Planning and Development  
DAC Survey Summary Statistics  
January 1982.



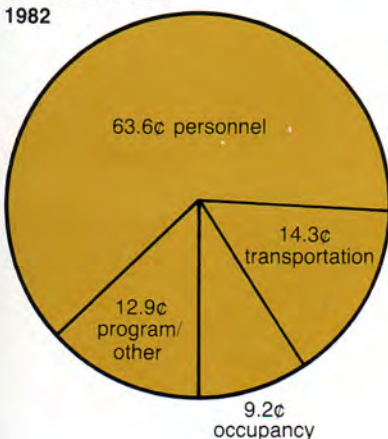


**Money for DACs.** The primary source of DAC revenue is Minnesota's Community Social Services Act. This 1979 act consolidated many separately funded programs and services into one block grant to each county. Allocation decisions are made by county boards of commissioners in accordance with requirements of federal and state regulations. Federal Title XX money comes through CSSA. Adult DAC costs currently average about \$21 per service day or about \$15 per diem if averaged over 365 days (Governor's Council on Developmental Disabilities Policy Analysis Paper #9, 1982).

#### SOURCES 1982



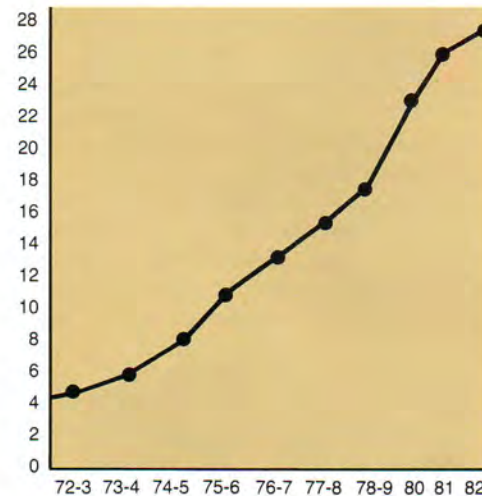
#### EXPENDITURES 1982



#### REVENUE

Source: Developmental Disabilities Program  
Dept. of Energy, Planning and Development  
DAC Survey Summary Statistics  
January 1982.

MILLION  
\$



#### DACs Problems and Policy Issues

**Licensing.** There is no current DAC program licensing rule. Proposed DPW Rule 38 is under development.

**Changing client population.** The clientele of DACs is becoming more severely handicapped and a larger proportion of adults is being served than ever before. Some program changes may be necessary.

**Out-of-county clients.** Access to services is very limited in some counties. One out of every four clients is the financial responsibility of a county other than the DAC county. In 1981, in nearly half the regions, more than 30% of clients were from another county. When counties experience fiscal distress, out-of-county placements are often cut first.

**Movement.** Lack of resources—financial, employment, support services, and homes—may restrict advancement of clients.

- about 450 clients in DAC programs who are ready for work activity services are not receiving them.
- about 240 people are ready for placement in sheltered work, and
- about 450 people are on waiting lists for DACs.

DACs experience pressure to move clients out and to take in new ones, but problems elsewhere in the system affect their capacity to respond.

**Cutbacks.** Days or hours of service are targets because of fiscal problems. Adults have averaged 5 days a week but services have been reduced to 3 or 4 days in some counties. Other cuts could come in refusals to take out-of-county clients or any new clients. Preschoolers and older adult clients may be affected first.

**Revenues.** The amount of revenue reported by DACs has increased steadily over the past several years, although increases are below inflation rates. Expanded enrollments, uncertain financing, and increasing demands for service have affected programs. Levy limits may prohibit increases even where there are client waiting lists. Annual audits, not now required by all counties that fund DACs, would clarify revenue and expenditure patterns.

**Staffing.** Staff wage schedules are important in attracting and keeping well trained people. Statewide, staff wages in 1982 averaged \$7.73 an hour for workers with a college degree and \$5.01 an hour for those with less than 4 years of college. Staff turnover was 20% in 1981 (Policy Analysis Paper #9, 1982, pp. 19-24).



## Work Programs

"Every morning I take the bus to work downtown. I work in the kitchen in a big department store. My boss says I'm one of the best workers." (Person with a developmental disability)

"I work full time, live in my own apartment, and do volunteer work. I lead consumer forums and work as an advocate for people with mental retardation. My dream is to work full time as an advocate." (Person with a developmental disability)

"Mirroring the unemployment rate, . . .sheltered workshops are facing reduced contract levels, shortened work weeks, and waiting lists of up to 1½ years." (Regional developmental disabilities coordinator)

"We need financial incentives for business to contract for sheltered work and to employ people with handicaps." (Workshop director)

### MINNESOTA'S LONG-TERM SHELTERED WORKSHOP PROGRAM: INCOME AND EXPENSES, OCT. 1, 1980 TO SEPT. 30, 1981

**Available Work Activities.** The work programs available are, from most to least restrictive:

- Work adjustment training involves real or simulated work. It develops basic skills and work habits needed to move on to other programs. Examples are learning to tell time and to be punctual.
- Work activity tasks may be the same as sheltered work but productivity levels are lower and clients spend some time in educational activities. Wages up to one-fourth the standard minimum can be paid for work. Only facilities having a Federal Wage and Hour certificate can offer work activity.

- Sheltered work operates as a business or industry. Differences are: more supervision, lower pay levels set by productivity, and location in a workshop setting. Some workers are on crews that work in the community. Much contract work has been assembly or packaging, but technology may provide new options. One example is work with micrographics, preparing microfilm and microfiche.
- Competitive employment is open to many people with mild retardation or other disabilities who can go directly to regular jobs.

#### TOTAL INCOME: \$20,923,811

Sales and Subcontract Income	\$11,921,781, 57%
DVR Support	\$5,689,524, 27.2%
County Support	\$1,780,991, 8.5%
United Way	\$572,188, 2.7%
Other	\$485,011, 2.3%
Fees	\$263,436, 1.3%
Grants	\$145,922, .7%
Contributions	\$64,958, .3%

#### INCOME

#### TOTAL EXPENSE: \$21,735,768

Staff Salaries	\$7,197,622, 33.1%
Client Wages	\$5,657,931, 26%
Other Expenses*	*Other Taxes, Benefits, Insurance, Telephone, Postage, Organization Dues \$3,179,148, 14.7%
Production Supplies	\$2,417,320, 11.1%
Occupancy	\$1,637,614, 7.5%
Payroll Taxes	\$1,119,513, 5.2%
Transportation	\$526,620, 2.4%

#### EXPENSE



All choices are subject to slumps in the economy reflected in sheltered workshop layoffs, declining subcontract business, and cuts in government support. A major problem has been the reduction in work available to disabled people.

### Enrollment in Work Activities

#### 1981 DEVELOPMENTALLY DISABLED CLIENTS SERVED IN SHELTERED EMPLOYMENT OR WORK ACTIVITY

by Disability	No.	% of Total Caseload
Mental retardation	708	14.3
Hearing impaired*	253	5.1
Epilepsy	233	4.7

\*Some of this group fit the definition of developmentally disabled

Source: Minnesota Division of Vocational Rehabilitation, 1982

The Division of Vocational Rehabilitation (DVR) directly supports workers with disabilities in several ways:

- Providing employment and training services in a network of regional offices,
- Directing flow-through money to work programs, and
- Giving information on housing accessible to handicapped people, doing training for attendant care, and offering peer counseling in three Centers for Independent Living.

### Work Problems and Policy Issues

**Matching changing clients to appropriate programs.** The rehabilitation services structure was developed for quite capable people (about 80% of persons with mental retardation are mildly retarded), but client disability levels are changing as more people leave state institutions. According to *Vocational Rehabilitation in Minnesota, a 1980 Overview*, every dollar spent on vocational rehabilitation in Minnesota that year returned \$1.67 in increased taxes and reduced public assistance. DVR's 1981 economic analysis by disability groups, however, shows success is lower and more costly with clients who have severe disabilities. What kinds of programs work best for people who need more security or extended support?

**Conflicting private and public interests.** A basic conflict exists between the private employer's interest in high productivity workers and the public sector's interest in jobs for workers with varied handicaps and productivity levels. What incentives might encourage private sector participation?

**Unemployment.** We have never been a full employment society. The job needs are always greater than the labor market. Jobs become an equity issue. How should scarce work opportunities be allocated? How will people stay employed during uncertain economic times? What useful activities could unemployed people be engaged in?

**Federal changes.** Provision of programs could change with contemplated federal actions: cuts in dollars for services, possible elimination of sections 501-504 of the Rehabilitation Act (sometimes called the Bill of Rights for Handicapped People), and block granting of rehabilitation services.

### New Directions for Day Programs and Work.

No really complete models of day and work services exist. According to Bellamy (1982), the day programming or vocational system needs to be redesigned. He suggests looking beyond fragmented existing programs. The question, "If you were a consumer would you rather have government buy you a job or buy you services?" suggests new goals: wages, jobs, and job-related benefits, not development of skills in a training setting.

He indicts the system for failure to move clients and for failure to confront the issue of a limited labor market. People with disabilities cannot be blamed for not being ready if no jobs are available. Bellamy would broaden the concept of work, collapse the continuum into county systems with extended and transitional services rather than vocational and nonvocational, and measure success by average wages paid in each county. The trend in work and day programs is toward increased use of community resources for training. A wider choice of options would better match client diversity. Two bridges between sheltered work and competitive employment are:

- External Sheltered Work—work arranged by the workshop but done in a business or industry setting with workshop support and company supervision.
- Enclave Work—a unit of 10-15 people producing part of a product as a mini-workshop within a business.

A wider range of options could include new examples such as:

- Sheltered Industry—mostly handicapped, partly subsidized, minimum wage or better
- Semi-Sheltered Group Employment—groups of handicapped in industry, most people nonhandicapped
- Competitive Work With Support—individual handicapped person with supports, in industry, has case manager or overseer



**W**hen I went to school, we ate lunch in our rooms, used the play-ground at different times, and had to take afternoon naps even as teenagers. If I could tell teachers what I think is important to teach, I would say that children should be taught how to get along with other people, how to use community resources, and how to meet problems that I am now facing in my adult life. For example, I'm 40 years old and I am now learning how to cook food such as hamburgers and pork chops. For me hash-brown potatoes are tragic. Let's just say they are crispy. . . I have to face these problems and so parents and teachers should realize that they shouldn't pamper us, but give us freedom and guidance to let us think for ourselves.

Interview with a man with a developmental disability

## Education for the Disabled

### Special Education. What, Who, and How

**What?** Legislation—both state and federal—assures handicapped children the right to a free, appropriate public education.

Free means provided at public expense.

Appropriate means a program with specially designed instruction and services to meet each person's unique needs.

**Who?** Special education services are mandatory for persons ages 4 through 21 who have any of the following handicaps: speech, hearing, or vision impairment; physical handicaps; mental retardation; learning disabilities; behavior problems; or emotional disturbances. Federal law includes other health impairments (e.g., autism, epilepsy, diabetes).

**How?** Services are determined at the local level by parents and professionals working together. Planning begins with identification of the child and parental consent for an assessment performed through the school district.

At a team conference, parents and professionals design an Individual Education Plan (IEP) which sets out annual goals, short term objectives, a list of services to be provided, and a plan for program reviews. The IEP is reviewed annually.

Children are served in either regular programs, special programs or a combination of both according to the level of service that best meets the child's needs.

Some important principles are early screening, parent involvement, parent-professional interaction, individual programs, right of appeal, appropriate services, and least restrictive setting.

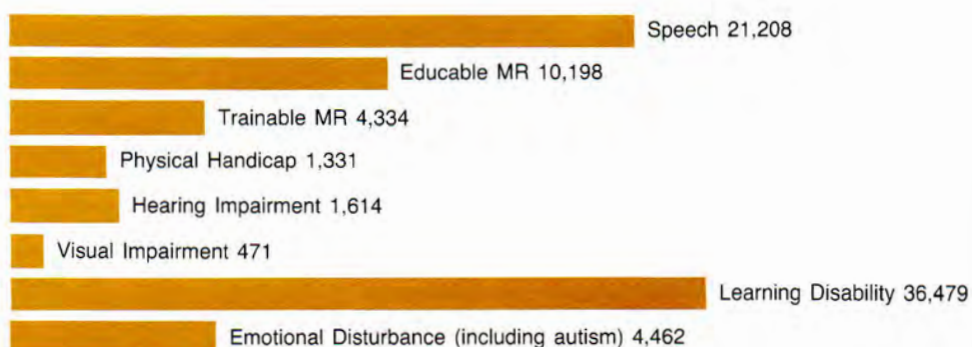
#### Enrollments in special education.

In 1981, 77,777 children received special education services through home school districts which are responsible for assuring programs. In 1981, special education served 9.5% of all children enrolled in public (10.3%) and non-public (2.7%) schools.

### REPORT OF MINNESOTA CHILDREN RECEIVING SPECIAL EDUCATION SERVICES, BY DISABILITY:

Total receiving services in 1980-81 = 81,566

Source: Minnesota State Dept. of Education, 1981



1980 Unduplicated Child Count\*

\*Unduplicated child count. Although children may receive more than one service (e.g., a TMR child may receive speech and OT in addition), they are counted only in the area of primary disability.



## Special Education, Problems and Policy Issues.

**Cost issues.** Costs are determined by local action—in identification of those eligible and in services provided. Minnesota's present formula is cost-based; that is, payment is made when districts expend money. Districts are required to pay a portion of the costs, much like the deductible feature in an insurance policy. Program costs rose faster than inflation as more children were identified as needing services. Some people, concerned about differences in services, in child identification, and in costs, are suggesting actions such as:

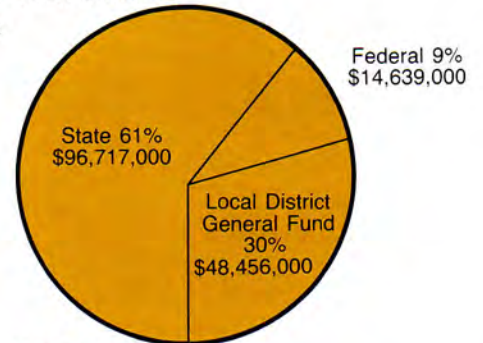
- Preserve federal and state mandates as essential guarantees of rights of children with special needs.
- Establish a statewide uniform level of services.
- Support special education adequately to avoid putting undue pressure on a school district's general fund (see *Revenue and Expenditures for Special Education Services in Selected Minnesota School Districts*, April, 1982).
- Consider ways that costs might be contained without loss of direct services to children, for example, differentiated staffing for the various teaching and care functions involved for special education children.

**Increased litigation.** Program cuts or weakened regulations will result in more case law to define statutes. Advocates see P.L. 94-142's greatest safeguards as the Individual Education Plan (IEP) and due process procedures. Without these basic guarantees, many parents and educators fear that the isolated programs of the past could return.

**Unmet needs.** The cost effectiveness of early intervention programs is well documented, yet programs for children under age 4 are being eliminated. Evidence from early childhood programs shows that many at-risk children who receive infant stimulation and other intervention never need special education services.

Vocational education that prepares special students for job placement is urgently needed. "Community-referenced education," learning by doing in the community, is one way of effectively building skills for competitive employment.

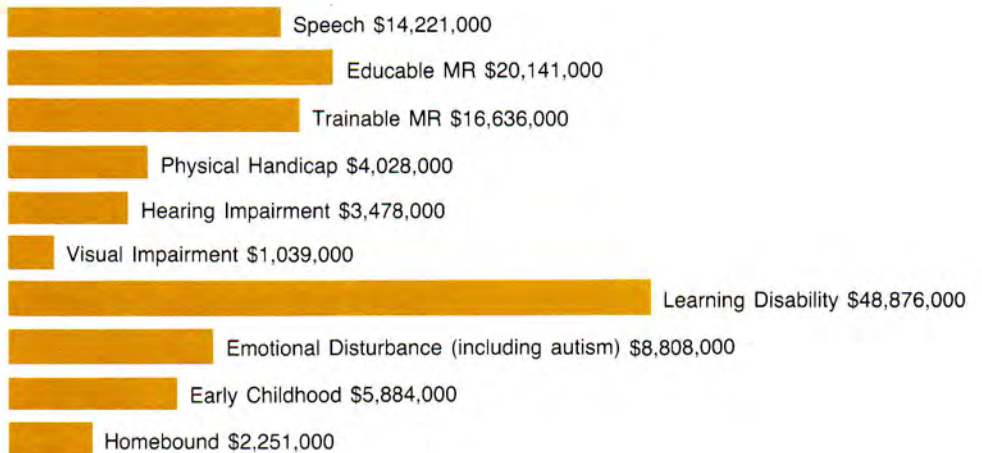
## PAYING FOR SPECIAL EDUCATION IN MINNESOTA



**TOTAL: \$159,812,000**

Each handicapped child also generates formula allowance funds that go to the general fund.

## COST BY DISABILITY (INSTRUCTIONAL PERSONNEL)



Subtotal \$125,362,000

Other essential personnel \$20,908,000<sup>a</sup>

Other<sup>b</sup> \$13,542,000

**Total: \$159,812,000**

<sup>a</sup>Includes directors, psychologists, social workers, and others.

<sup>b</sup>Supplies, books, contracts, etc.



## Support Services, Case Management and Advocacy

Case managers assist people to and through needed services. Their responsibilities include:

- To act as brokers, advocates, administrators, providers of service
- To observe responsibilities and standards defined by DPW Rule 185
- To link and monitor services across agencies

Effective case management should be the glue that holds the system together.

### NECESSARY INGREDIENTS TO SIMPLIFY CASE MANAGEMENT

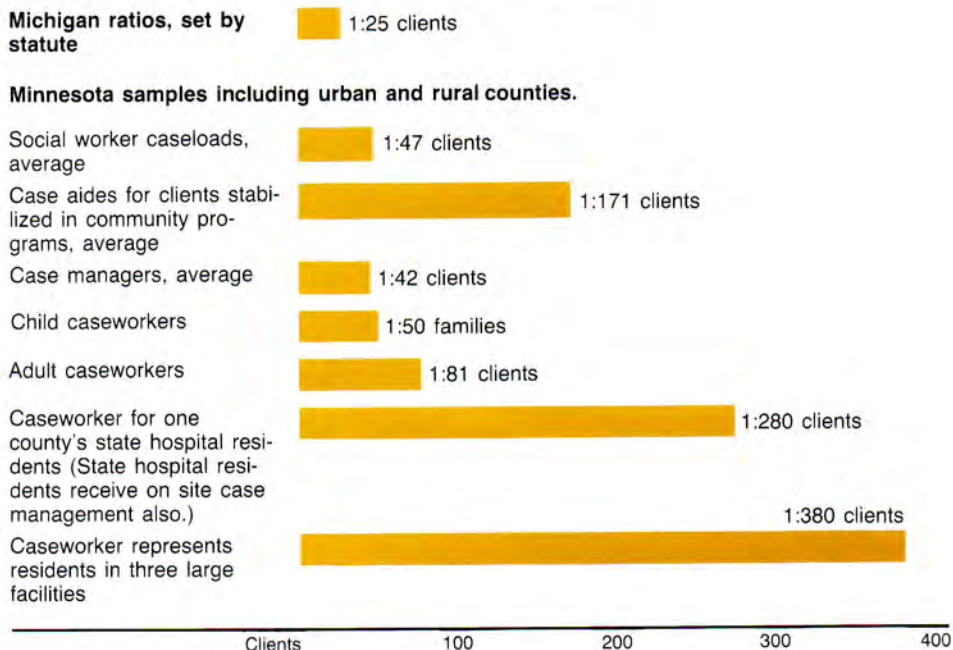
#### WELL-DEFINED PROCESS

#### PRIMARY CASE RESPONSIBILITY

#### GOOD INFORMATION ABOUT CLIENT & SERVICES

#### CLEAR INTERAGENCY AGREEMENTS

### A COMPARISON OF CASE MANAGEMENT SERVICE RATIOS



Source: Interviews with county case managers

### Case Management Problems

**Lack of services to manage.** Case managers are powerless when services are cut back or people are laid off. Some case managers expressed a fear that we could be "warehousing people in group homes if DAC and sheltered work programs are lost."

#### Intercounty service problems.

There is no statewide policy on levels of service to be provided to clients in day programs. A resident of County A who goes to County B for day programs may have DAC services cut to 3 days a week in County B, forcing County A to provide inresidence services for an additional 16 hours a week. In the present system, host counties generally provide case management and the county-of-origin retains financial responsibility.

**Efficiency and effectiveness.** With inadequate services, duplication becomes a problem. In-house residence and day program managers may be setting conflicting goals for a client.

Persons may be tested two or three times for the same purpose. A primary case manager should eliminate such problems.

Advocacy services are lost when systems are overloaded. Service evaluations of case managers are often tied to completion of forms and reports rather than client progress. Reviews of client movement and development should be the measure of the system's effectiveness.

**Lack of information.** Knowledge of case management in Minnesota needs to be updated. Information about caseloads, manager experiences, turnover, and efficacy should be collected and published regularly.

**Need for variety in service models.** Could services be provided by generic case managers, especially in sparsely populated areas, or by parents trained as case managers for their offspring?



## Protection and Advocacy Services

People with disabilities may need help or protection against the actions of others or the consequences of their own actions. Advocacy is the representation of the interests of one person or a group. Case managers are a client's primary advocate within the system. There are others:

- Clients may be their own advocates, often with the support of special training in how to get their message across.
- Families and friends may be voluntary advocates.
- Guardians are "protectors" who have legal authority and the duty to care for another person or a "ward." "Conservatorship" is a more limited form of protection in which a person or ward retains more independence.
- Ombudspersons respond to requests for help. They may be designated public officials who serve a class of people or someone who works within a single agency or residence.
- Groups and associations are advocates for entire classes of people. There are many in Minnesota representing categories of developmental disabilities including mental retardation, autism, epilepsy, cerebral palsy, and/or learning disabilities. Some groups such as The Minnesota Committee for the Handicapped are broad coalitions of organizations with similar goals.
- Legal advocates were provided in Minnesota even before the passage of federal legislation required services. Since 1980, Legal Aid Society of Minneapolis, Inc. has provided civil legal representation to Minnesota residents with developmental disabilities.

## Community Programs That Work

Successful community programs are cited by the President's Committee on Mental Retardation. Cost effectiveness goals are met through prevention and early intervention, support of families, use of volunteers, and provision of work for the disabled as the following samples illustrate.

- All "at risk for DD" newborns leaving hospital intensive care units receive follow-up care in one year of intensive case management. Less than ¼ of infants ultimately are diagnosed as disabled, parenting skills are improved, and no child abuse has been found. (FIND—San Bernardino, California)
- A traveling teacher makes in-home educators out of parents of new-born children with Down's syndrome. At 30 months, developmental milestones are close to those of normal children. (Eugene, Oregon)
- A state contracts directly with persons providing in-home services. Only 1.3% of the funding pays overhead. The University of Washington and the Red Cross train home-aid providers. (Olympia, Washington)
- Macomb-Oakland Regional Center was slated to become a 650 bed institution. The Superintendent requested that building plans be deferred while staff looked for community alternatives. Foster care with training, group homes limited to six residents, and in-home supports for family care are the residential alternatives. Half of all families keep disabled members at home, with 24 hour service available if necessary. All home managers are trained by MORC. (Mt. Clemens, Michigan)
- A rural project set aside 4 apartments in a small mountain town of 950 people. Nine handicapped persons live there, well-integrated

into the community. Volunteers administer the nonprofit corporation whose next project is a group home for six severely and profoundly handicapped residents now in a state institution. (Jamestown, California)

- A crew of five adults with mental retardation and a nonhandicapped worker with construction experience does building projects for the price of materials. In 16 months, they have constructed sheds, built wheelchair ramps, painted interiors and exteriors of buildings, remodeled rest rooms for people with handicaps, and built playgrounds. Workers earn \$60 per month to supplement SSI payments. Professionals have produced easy-to-understand blueprints and creative work ideas. (Community Redevelopment Center, California State University, Los Angeles, CA)
- The Donut Shop is a work training program for mentally retarded adults—with real donuts and real customers. Twelve trainees work side by side with regular employees in sale and bakery training. Other "mainstreamed" vocational efforts are planned including a house-keeping program in a 54 unit motel. (The Donut Shop, La Mesa, CA)
- Families of disabled children receive help through "pilot parents" who give information on services and become advocates when services are not available. They also speak to service clubs and provide information for doctors to share with patients. (Omaha, Nebraska)
- Parents train as case managers for their children through formal application to a 10-week community college program and a one-year apprenticeship teamed with a professional. (Orange, California)

(Report from the President's Committee, *Mental Retardation: The Leading Edge*, 1977)



## Frequent (and Tough) Questions

Knowing the philosophy behind services to people with disabilities doesn't answer all of peoples' questions. The frequently-asked questions reflect some basic concerns:

### **Services for mentally retarded people are expensive. Isn't the public paying for special rights that really can't be justified?**

It is important to all of us that even the most vulnerable among us have legal and constitutional rights—the only rights guaranteed to disabled people or to anyone else. Persons who in the past would have had no chance now can have an opportunity to live productive lives. Employability potential is greater than we once thought and education has improved skills.

It is important to remember that 97% of the disabled already live in communities, most of them without public assistance. The best way to keep costs down is through cost effective programs; early expenditures may be the most effective ones. "Competing equities" in tight fiscal times are more humanely addressed by redesign rather than by retreat.

### **Why do some parents of handicapped persons oppose community based services and the closing of state hospitals?**

A survey by the Minneapolis Association for Retarded Citizens (1973) of parent opposition to community placement identified three concerns:

- Parents' son or daughter was severely or profoundly retarded and had complicating physical problems. Programs in the community might not be available or provide adequate care.
- Parents feared the possibility that old frustrations and inability to cope with their offsprings' problems would return.
- State hospitals have a permanency that offers some security if parents die before their children do.

A 1981 survey conducted by Cambridge State Hospital found a high degree of parent satisfaction with their offsprings' placements and care at Cambridge State Hospital. The survey analysis revealed that parents did not know about alternatives. Parents of state hospital residents, like the rest of us, need information about the potential of more normal, less restrictive community care. Legitimate anxiety about (a) the security and permanency of community care, (b) the availability of needed advocacy, monitoring, and guardianship to protect offspring when parents are gone, and (c) hostile community attitudes toward the handicapped need to be addressed in program design and by stable funding.

### **Aren't people with behavior problems better off in state hospitals than in the community?**

The key to most successful behavior management in any setting is care providers' willingness and skill. While behavioral problems are a major reason for admissions and readmissions to state hospitals, the solution is help for families and community care providers who deal with problem behavior. Some ways of providing that help are respite services,

homes which specialize in clients with behavior problems, training programs, and special short term diagnostic and behavior management services.

### **Are property values affected when people with handicaps move into neighborhoods?**

In a word, NO. Common fears about integration of people with disabilities are not supported by the many studies of group homes and property values.

A 1982 Minnesota study used assessed valuation to measure property values around seven Twin Cities homes and seven homes in the rest of the state. The sample of 14 group home neighborhoods confirmed that neither changes in property values nor the number and timing of sales appear to be related to the establishment of group homes. Studies in other parts of the United States are unanimous in their conclusion: Group homes do not reduce surrounding property values (*Policy Analysis Paper #11, 1982*).

Minnesota's state zoning law eases integration of persons with disabilities by classifying homes of 6 or fewer residents as single family dwellings and homes with 7 to 16 residents as multifamily dwellings.

### **Do rural areas need different service models?**

Yes. Population sparsity and distance between communities complicates service delivery. Both families of disabled persons and professionals feel isolated from information and need technical assistance. Some service ideas are appropriate to sparsely populated areas:

- Programs that adapt to a variety of handicaps due to developmental disabilities, chronic illness, injury, or age
- Providing single point of entry access to services in, for example, schools or cooperative extension services



- Flexible service delivery procedures that minimize any transportation time and distance
- Well publicized regional or state toll free hot lines to provide information and advocacy services to parents and consumers and technical backup to professionals
- Support for professionals through regional or state service centers and innovative training approaches, e.g., individualized packaged training materials
- Parent training to work effectively with their children by local special education teachers, health nurses, cable television, or packaged instruction
- Training service personnel as generalists and using paraprofessionals and volunteers

**Couldn't we save money by coordinating services to groups like the mentally ill, the disabled elderly, or the physically handicapped with programs for developmentally disabled people?**

Human services could benefit from more intergovernmental and inter-agency cooperation. All programs have some services that could be more cost effective if interconnected. These services include:

- Preadmission screening. These programs perform a gate-keeping function to prevent placements in nursing homes and hospitals. Community service options decrease the need for institutions. Homemaker services to the elderly with disabilities are an example.
- Case management. This coordination of services to individuals includes assessment of client need, an individual care plan, arrangement of services, monitoring, and reassessment.
- Alternative care. Care delivered outside of institutions or group homes may range from homemaker services to respite care. People in their own homes, foster homes, or semi-independent living benefit from alternative care.
- Long-term care. These services encompass health, social, housing, and income programs provided over an extended period of time for chronic conditions. Care may range from intermittent services in an individual's own home to 24-hour supervision in institutions. A complex package of services from therapy to psychological support to nutrition services may be needed.

- Day programs. These include all the education, developmental activities, sheltered work, and day care programs that exist in the community to support people's developmental and social needs.
- Transportation and access. Movement of people within the community depends on available public or special transportation services. Access to public buildings and barrier free residences are essential to anyone with certain physical handicaps.
- Advocacy services. Advocates are partisans outside the service delivery system who defend and promote the rights of vulnerable persons. They work to redesign or amend policies with adverse effects or to change institutions or agencies giving inadequate services.





PART III  
POLICY ALTERNATIVES FOR THE 1980s

# **Toward A Secure Future**

*The policy goal of the developmental disabilities service system is to meet individual needs and strengths with the least restrictive choices in the community.*



## Service Systems, Consumer-Powered or Resource-Powered?

Home life and day activity should be as close to normal patterns as people's disabilities allow. This goal, appropriate to any group with handicaps, is best accomplished in a consumer-powered system.

Most states, Minnesota included, find developmental disability policy goals frustrated by contradictory

funding incentives. Counties, where individual needs are determined, contend with financial incentives that favor placement in the most restrictive and expensive settings. It is to the credit of the counties that they have worked to develop community services for their residents in spite of built-in monetary penalties and levy limits.

By paying for a medical model of residential care, Medicaid's Title XIX has favored development of Intermediate Care Facilities for the Mentally

Retarded (ICF/MR) as the most common community residential option in Minnesota. Having smaller groups of people live in existing family homes could limit investment in bricks and mortar. Funding disincentives produce the reverse of intended policy, a resource-powered system.

In a resource-powered system, consistency between policy and reality is difficult to achieve.

**On the policy level**, Minnesota has model statutes and rules including Rule #185 defining case managers' responsibilities.

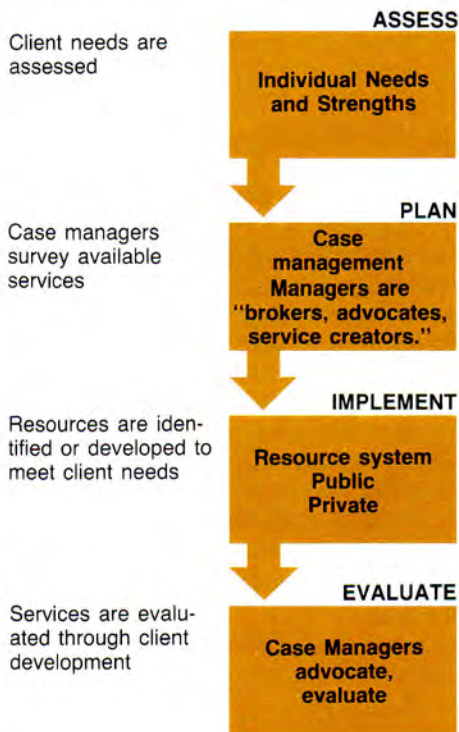
**In reality**, case managers, on whom a consumer-powered or client centered system depends, have heavy caseloads and are under-trained in the complexities of brokering appropriate services.

**On the policy level**, counties are expected to meet client program needs as outlined in individual plans.

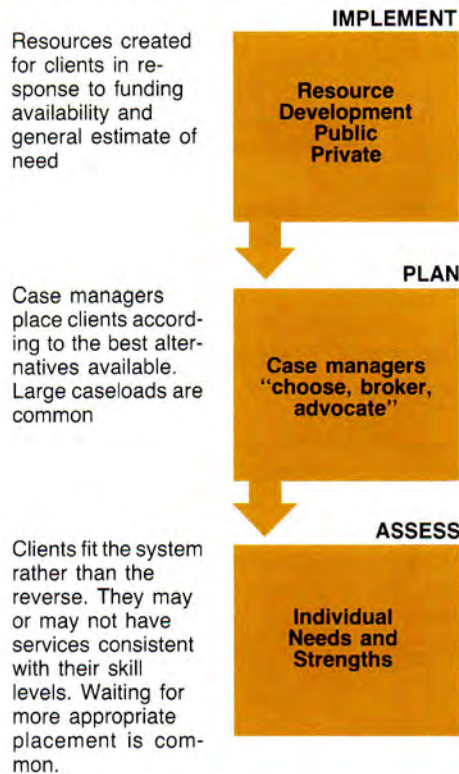
**In reality**, clients are placed in the alternatives that exist and programs are jeopardized by uncertain funding.

Could the system work more effectively for clients? Would reallocations make a difference?

### CONSUMER-POWERED SYSTEM

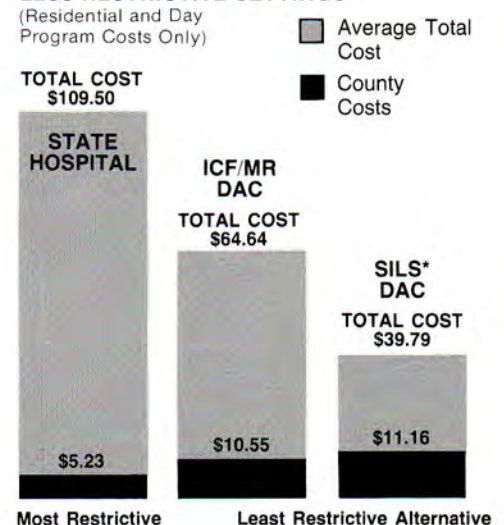


### RESOURCE-POWERED SYSTEM



### COUNTY SHARE OF ALTERNATIVE RESIDENTIAL CARE COSTS: FISCAL DISINCENTIVES TO PLACEMENT IN LESS RESTRICTIVE SETTINGS

(Residential and Day Program Costs Only)



\*This comparison assumes the SILS client has come from an ICF/MR, receives SSI payments and attends a day program. For such a client the county would pay 20% of SILS services costs. Actual overall county payments for SILS are 35% of the total spent in the state.



## Two Models for Providing Services

The way services are offered can create either a consumer-powered system or a resource-powered system. Davis and Trace (1982) suggest that the continuum approach fails to meet an individual's needs in the least restrictive environment. They discuss reasons for the problems in the continuum approach:

Emphasis is placed on developing separate classes of services/ facilities with differing levels of restriction. Day programs provide an example:

**MOST  
RESTRICTIVE**

**DACS**

**WACS**

**SHELTERED  
WORK**

**LEAST  
RESTRICTIVE**

**COMPETITIVE  
EMPLOYMENT**

Specific program services are assigned to each category. Problems exist because:

- Both client's liberty and development are restricted if appropriate placements do not exist or are filled.
- Progress requires a client to move which means relearning skills in a new environment, a difficult task for disabled people.
- People are not integrated when they live in special residences and work in sheltered settings.

Davis and Trace would substitute what they call The Support Model because it focuses on supporting an individual's needs from an array of community services. They discuss the characteristics of the array:

- Clients are placed in the least restrictive setting and given all the supports necessary to succeed.
- Supports are gradually withdrawn as they are no longer needed.
- Because the setting is modified to meet their needs, clients move less often and fewer special purpose facilities are built. More funds are directed to services rather than facilities.
- Generic (or broad, existing) services can be used as needed.

## Barriers to Change

- The continuum is easier for people to visualize.
- Current accreditation rules may require separation of services. For example, DACs need proper certification to organize work crews for activities like leaf raking.
- Consumer-powered systems need well-trained case managers.
- Funding patterns are more compatible with a continuum and might actually favor institutions.

## Policy Choices for the Future

How might policymakers approach the design, implementation, and funding of services for the disabled in the 1980s? The challenge of the Seventies was to upgrade the rights of and services to handicapped people. For many people with developmental disabilities, life has improved and opportunities have grown. Now, inflation and economic pressures force reevaluation of all kinds of programs. Services for society's vulnerable people depend on improving the alternatives to high cost institutional care and encouraging greater independence, family care with society's support, and participation of the private sector. A range of policy choices can be identified when goals are stated clearly.

An example of a policy goal could be to provide support to keep more disabled people at home with their families. Care and treatment decisions are made at the county level

where program dollars can dictate the choices available. Therefore, reaching the goal requires changes in funding programs that can range from maintaining current programs to reform or reallocation to system redesign.

### Maintain

Increase funding for the state Family Subsidy Program which currently has a long waiting list. Make more dollars available for day programs.

### Reform

A reform strategy some states are using is the Title XIX waiver process that approves federal Medicaid funds for less restrictive care such as in-home supports and community day programs. This could direct program dollars away from institutional care toward in-home care.

### Redesign

Redesign strategies go further. An example would be to block grant all federal and state dollars to counties who would select services from hospital care to in-home supports from free standing providers. The assumption is that counties would select the most economical alternative—supporting disabled people at home—if their choices were not restricted by funding disincentives.

Another goal could be to increase work opportunities for disabled people.

### Maintain

Create more places in the present system to accommodate people on waiting lists.

### Reform

Change certification so DACs could do community work projects. Offer financial incentives to industry to train and employ individuals and groups of people with handicaps.

### Redesign

Encourage a fundamental rethinking of adult day services. Bellamy (1982) discusses characteristics of one possible redesign alternative. Collapse all funds for day and work programs into county systems with extended



and transitional services. Measure success by average wages earned by disabled people in the county. No such programs exist at present.

Because programs are so interconnected, a policy change anywhere in the system has effects on other services. Keeping an eye on goals, both short and long term ones, and viewing the system as a whole are essential.

## Choosing Among Alternatives

Making choices will depend on how people view basic issues such as decentralization of responsibility, fiscal disincentives, cost effectiveness, and the future of existing institutions.

### Decentralization

**Government's responsibility for the disabled—what level, what role?** The New Federalism appears headed toward a realignment of responsibilities in complex intergovernmental programs. Withdrawal of regulations, budget cuts, and reshaping of grants and aids will affect programs for the disabled. Some actions would increase state and local autonomy in program design. The Title XIX waiver authority is one example; block grants, another. There is little agreement on what state and local responsibilities ought to be. Federal mandates have been highly significant in insuring rights of disabled people, but mandates without funds can be devastating.

The deinstitutionalization of the mentally ill is an example of a federal mandate made and a local implementation missed. Thousands of people leaving institutions for community care found services were not available. While people with developmental disabilities have not experienced "dumping," their community care systems are extremely fragile at present. Mandates are, at times, in conflict. A current problem for counties results from state levy limits which forbid local tax increases in the face of court mandates for full local services.

Governors, state legislators, county officials, and mayors welcomed general revenue sharing as decentralization. But enhancing the authority of state and local governments will require that they have adequate taxing power and good fiscal and program management. Success of a larger funding and program role for states will be linked to:

- Growing interstate and inter-regional fiscal disparities as the states with high taxes and few natural resources confront different realities than states with booming economies
- Incentives to private service vendors to keep costs down. Rapid increases in nursing home rates are a national phenomenon
- What happens in the courts
- Good monitoring and accountability systems

If "decentralization" becomes a system of "passing the buck"—asking lower levels of government to do what is unpopular or expensive—the result can only be disintegration, as needed services are not in place. Turning a system around from one that currently offers fiscal incentives for institutional care to one that can flourish with less restrictive and potentially less costly care requires attention to both short and long term costs and benefits of government actions.

### Disincentives and Deficit.

**Fund less restrictive, more cost-effective care.** Funding shapes programs. Existing funding is biased in favor of more intensive care. Fiscal disincentives result from different sets of circumstances:

- *Limited funding programs are in competition with open ended entitlements.* Services covered by Title XIX thrive, while those dependent on Title XX, Community Social Service Act and local funding are squeezed.
- *Programs provide different matching rates.* The least restrictive options are the most expensive for counties.

- *Eligibility for one program is linked to other services.* People who work for low wages and are cut from SSI may need to give up a job and apartment and move back into more restrictive, but funded, group homes.

Block grants can provide funding flexibility. Problems arise when categorical funding is combined into one block grant and the total dollars are reduced substantially. Counties can be caught between service mandates on the one hand and too few dollars on the other. Attempts to reduce day programs for some consumers are an example of a response that saves county dollars but can drive up total system costs.

Federal action to allow use of Medicaid Title XIX for some home and community-based care is another attempt to deal with disincentives. States can apply for a waiver of certain statutory requirements if they provide assurances that client interests are protected and that community services will not cost more on an average per capita basis than services in a state hospital or ICF/MR. Approval of a state's waiver could make Medicaid money available for adult day programs, case management, respite care, and some in-home supports.

Innovations like Michigan's programs of in-home chore services and adult foster care are a success story. Combined enrollment in the two programs is 34,000 or 4,000 more than the number in nursing homes. "Michigan spends only 29 cents of its Medicaid dollar on nursing home care, compared with nearly 45 cents nationally." These two programs are estimated to save Medicaid \$300 million a year (Demkovich, 1981, pp. 44-49).

The link between Medicaid costs and long-term care is a growing concern. The 1979 nursing home cost of 45 cents of every Medicaid dollar represented an increase of 50 percent



over fiscal 1977 (Demkovich, 1981, p. 49). While the population with developmental disabilities is fairly limited, the number of elderly people in need of assistance has increased. Medicaid's strong institutional bias has helped limit growth of less expensive programs. The Title XIX waiver is one way to address that problem. New York tried a ceiling on rates, improved auditing, and is now focusing on finding alternatives to hospitals and nursing homes for long-term care (Demkovich, 1981, p. 46).

#### **Too Little Too Late Costs Too Much**

**How can we get long-term cost savings.** Costs may be deferred by line-item budget cuts which postpone or eliminate services. But better for society and individuals, long-term costs can be reduced. Cost effectiveness or long-term savings are possible through:

- Prevention
- Early intervention
- Well designed and coordinated services

Balanced investments in prevention and rehabilitation are cost effective.

#### **How to save \$1.5 billion.**

Prevent all fetal alcohol syndrome or alcohol related birth defects for one year. Sen. Orrin Hatch estimates the lifetime costs of the children born with alcohol caused birth defects in a single year are \$1.5 billion. (Hatch, 1982).

**Prevention.** It is a recognized fact among health professionals that 50% of mental retardation is preventable using present knowledge (Report of the Presidents Committee, *Mental Retardation: The Leading Edge*, 1977, p. 74). Yet, each year more than 100,000 children will be diagnosed as retarded. Prevention measures that address the increase in the number of babies with low birthweight could reduce the incidence of cerebral palsy and other disabilities as well as retardation.

From 75-85% of cases of mental retardation are listed as cause unknown. However, causes for the milder forms of retardation (about 80-90%) are highly associated with inadequate social, psychological, and learning environments. Children can suffer devastating effects on brain development in an environment that fails to meet emotional and sensory needs. "This is particularly true in the first year or two of life" (Fotheringham & Morrison, 1976).

Children living in poverty face much higher risks. For example, effects of poor nutrition, inadequate supervision and stimulation, high lead levels in the environment, poor health care, and other hazards are compounded by interaction to create lasting damage. Even children who escape retardation may have their potential permanently limited—an additional effect to be considered in any cost-benefit analysis of prevention programs. In testimony at a public hearing, the director of a community service group discussed evidence of cultural familial retardation and "five-year-old Anne who had a five-word vocabulary . . . but knew how to do the dishes." He went on to say:

I've known so many children who at birth had decent APGAR scores, normal Denvers and then at 18 months, the decline begins to show. It makes its first appearance as anxiety, impulsivity, and clinging to strangers. By about 4 years of age, they test as developmentally disabled—etiology unknown. Certainly, there are other factors—sometimes physical and verbal abuse, sexual abuse, poor nutrition, incessant health problems like ear infections, flu, bronchitis, red-eye—but the operant mechanism, the common denominator as . . . studies have shown, is neglect.

(Testimony, Governor's Council on Developmental Disabilities Public Hearing, May, 1982)

Sometimes problems develop before birth. High-risk mothers, especially adolescents, need good prenatal care to give birth to healthy children. Of Minnesota births, 15% fall into at-risk categories because of maternal characteristics (Minnesota Health Statistics, 1979, 1982). Prevention of developmental disabilities in a high-risk family usually requires work with parents as well as their children.

Children with disabilities due to adverse genetic factors are fewer in number, usually more severely affected, and from all socioeconomic backgrounds. Technological advances offer more hope of prevention of severe forms of disabilities.

The need for a broad spectrum of activities to prevent cerebral palsy is evident in the changing origins of cases. Over the past 25 years there has been a marked decrease in children born with congenital cerebral palsy. Increases are among infants with low birthweight (three and a half pounds or less) who have a 40% chance of some neurological disability. There are also increases in acquired cerebral palsy in preschool children because of head injuries from automobile accidents, falls, child abuse, or neglect (Sternfeld & Berenberg, 1981).



While prevention is worth doing for ethical reasons, the practicality is that it also saves dollars. In 1980-81 the United States spent an estimated \$10 billion dollars on special education and related costs (Kakalik et al., p. 6). Evidence from Headstart studies shows that early education programs significantly reduced the number of children assigned to special education. Children's families also seem to have been positively affected (*Lasting Effects After Preschool*, 1979, pp. 19-20). The French Ministry of Health's Perinatal Care Program was a plan to reduce birth related problems. An evaluation of the cost over 15 years related to the number of deaths and handicap conditions avoided concluded that in economic terms there would be a return of 5 to 10 francs for every franc invested (*Economics of Disability: International Perspective*, 1981, p. 81).

**Early intervention.** Where disabilities exist, early intervention can lessen their effects. Even people with severe problems may require fewer services if treatment begins early. Working with families is more effective than working with children alone. It also helps keep a child in the family home—a preferred and less costly alternative.

**Well designed and coordinated services.** Program strategies can minimize costs. Some characteristics of successful cost effective programs were identified in *Mental Retardation: The Leading Edge*.

- Support the home first. Do everything possible to keep children with families and in the community.
  - Intervene immediately with children at risk for developmental disabilities.
  - Use parent and volunteer help.
  - Use a single point of access to services and good case management to conserve resources.
  - Find alternatives to high cost group homes.
  - Get people into competitive employment.
- Another could be added:
- Don't just treat. Prevent. (Shneour, 1974)

#### **State Hospitals and the Resolution of Complex, Competing Interests**

The future of state hospitals is but one piece in the "puzzle" of a comprehensive—and realistic—state service plan for disabled people. Any action on state hospitals affects the system as a whole and the lives of people and communities.

The end goal is to have adequate treatment services in the state. That goal could be achieved a number of ways but maintenance of the present dual service systems—seven hospitals and community services—is costly. Budget constraints may reverse trends and encourage more state hospital use because: (a) counties currently pay the least for institutional care and (b) funding for community services is less stable than funding for institutions. With community service gaps, some people will seek institutional care.

Turning state hospitals over to regions is consistent with decentralization and distribution of responsibility. A state hospital system does isolate a large share of health budget from county influence. Counties could find the burdens awesome, however, as costs rise, buildings deteriorate, court suits are filed, and complex staffing and employment issues need resolution. The "catchment areas" served by existing hospitals are not the same as present state regional boundaries, so new configurations of counties would need to work together.

Opposition to hospital closings is often rooted in employment and economic concerns which can be addressed in two ways: recognizing that hospital employees are a resource to be supported and deployed into community facilities, or finding alternative uses for state hospitals. When one community loses the economic benefits of a state facility many other communities stand to gain as dollars previously spent in one place are spread over a broader area.

In recent months, a number of states have announced closings of public institutions for the mentally retarded. Reasons cited include: movement to less restrictive alternatives, budget cutbacks, availability of community options, progressive zoning statutes, court orders to deinstitutionalize, declining populations in hospitals, cost savings in community care, and aging buildings (New Directions; July, 1982).



## **Today What's Right About Services?**

a parent . . .

*"For people with handicaps, life is better than before."*

a state welfare department employee . . .

*"Two hundred families are being helped by Family Subsidy to keep their children at home."*

a special education coordinator . . .

*"Education programs have reached out to children with handicaps."*

a county commissioner . . .

*"Professional workers are dedicated and concerned."*

a psychologist working with disabled people . . .

*"Hospital programs have greatly improved."*

a case manager . . .

*"People are cooperating in the search for creative solutions to problems."*

a county welfare director . . .

*"Communities have responded with homes and day programs."*

a lawyer . . .

*"Minnesota's disabled population has good protections in statute, regulations, and court decisions."*

a member of a state planning council . . .

*"Personnel training needs are recognized."*



## Tomorrow...

The system of services to people with disabilities reflects major changes taking place in American life. For example:

Services and funding are being decentralized.

- Consumers have moved from hospitals to communities.
- Block grants have replaced categorical funding.

Responsibility is being shared more widely.

- Independent living is a service goal.
- Families are getting support to keep children with severe handicaps at home.
- The value of volunteers is gaining recognition.
- The private sector is being encouraged to hire people with handicaps.

Concern for efficient, accountable services is growing.

- Inappropriate placements and service gaps are targets for change.
- Professionals are providing alternatives to high cost institutional care.
- Case managers are increasingly the point of accountability.

Continuing scientific, economic, and social changes put pressure on policymakers to deal with short term crises without losing their long range perspective. During the Seventies communities responded to people's movement out of institutions by rapidly expanding services. The needs of the Eighties are different.

The challenge of the Eighties will be reshaping services and providing them in an efficient and coordinated way.

*The years ahead can be years of advancement or of retreat, a breakthrough of new ideas or an attempt to keep a questionable status quo. The challenge to improve belongs to all of us.*





# Appendix



## Acronyms Used in This Book

<b>DAC</b>	Developmental Achievement Center
<b>CSSA</b>	Community Social Service Act
<b>DD</b>	Developmental Disabilities
<b>DPW</b>	Department of Public Welfare
<b>DVR</b>	Division of Vocational Rehabilitation
<b>EMR</b>	Educable Mentally Retarded
<b>GA</b>	General Assistance
<b>HUD</b>	Housing and Urban Development
<b>IEP</b>	Individual Education Plan
<b>ICF/MR</b>	Intermediate Care Facility for the Mentally Retarded
<b>MSA</b>	Minnesota Supplemental Aid
<b>SILS</b>	Semi Independent Living Services
<b>SSDI</b>	Supplemental Security Disability Insurance
<b>SSI</b>	Supplemental Security Income
<b>TMR</b>	Trainable Mentally Retarded

## References

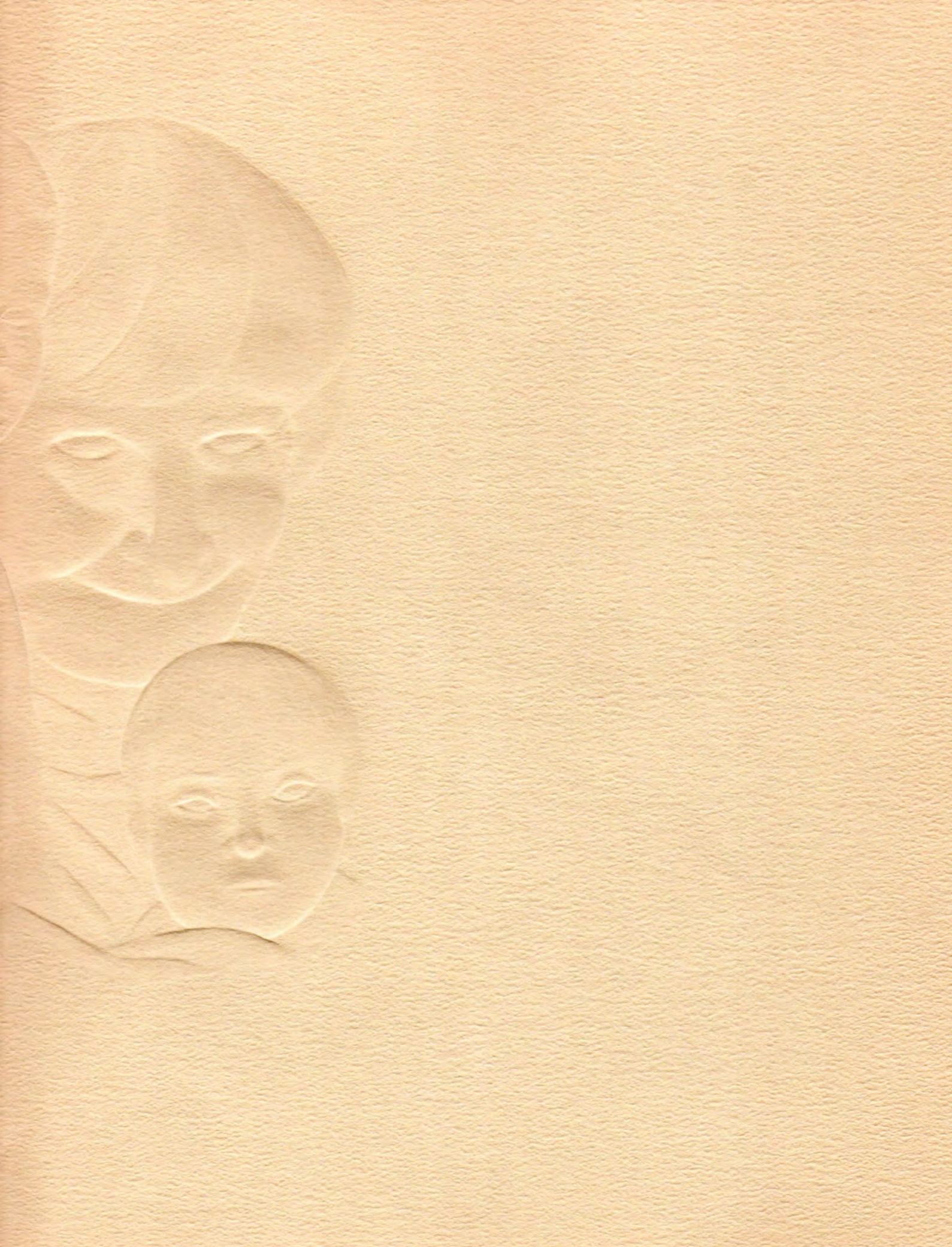
- Bellamy, T. Keynote speech presented at the McKnight Employment Program Conference. Bloomington, MN: Minneapolis Association for Retarded Citizens, July 22, 1982.
- Brandl, J. E. Toward a fiscal agenda for Minnesota. *Corporate Report*, June 1982, pp. 40-42.
- Copeland, W. C., & Iverson, I. A. *Fiscal and programmatic assessment of the DPW compliance plan and selected alternative plans for deinstitutionalization of the mentally retarded and developmentally disabled*. Minneapolis, MN: Hubert Humphrey Institute, December 1981.
- Davis, M. J., & Trace, M. W. The support model: A new approach to providing a continuum of service. Ellsworth Community College, Unpublished manuscript, 1982.
- Demkovich, L. For states squeezed by Medicaid costs, the worst crunch is still to come. *National Journal*, January 10, 1981.
- Developmental disabilities: A guide for county officials*. Washington, D. C.: National Association of Counties Research, Inc. April 1982.
- The economics of disability: International perspective*. New York, NY: Rehabilitation International, March 1981.
- Fotheringham, J. B., & Morrison, M. *Prevention of mental retardation*. Toronto, Ontario: National Institute on Mental Retardation, 1976.
- Hatch, O. G. Psychology, society, and politics. *American Psychologist*, 1982, 37(9), 1031-1037.
- Kakalik, J. S., Furry, W. S., Thomas, M. A., & Carney, M. F. The cost of special education. Summary of study findings. (mimeographed).
- Lasting effects after preschool*. Summary report. Washington, D. C.: Department of Health, Education and Welfare, September 1979.
- Loop, B., & Hitzing, W. Family resource services and supports. In J. A. Stark (Ed.), *Family resource systems: The Nebraska model*. Omaha, NB: Governor's Council on Developmental Disabilities, 1980.
- Minnesota health statistics, 1979*. Minneapolis, MN: Minnesota Department of Health, May 1982.
- New directions*. Alexandria, VA: National Association of State Mental Retardation Program Directors, Inc., 1982, 12(7).
- Placement and care of the mentally retarded: A service delivery assessment (draft)*. U.S. Department of Health and Human Services, 1982.
- Policy analysis paper #9, Summary of issues, programs, and clients in Minnesota developmental achievement centers: 1980-1982*. St. Paul, MN: Department of Energy, Planning, and Development, February 1982.
- Policy analysis paper #11, An analysis of Minnesota property values of community intermediate care facilities for the mentally retarded*. St. Paul, MN: Department of Energy, Planning, and Development, July 1982.
- Report of the President's Committee. Mental retardation: The leading edge*. Washington, D.C.: U.S. Department of Health, Education, and Welfare, 1977.
- Revenue and expenditure for special education services in selected Minnesota school districts, summary report*. St. Paul, MN: Center for Educational Policy Studies, April 1982.
- Schneour, E. *The malnourished mind*. New York, NY: Anchor, 1974.
- Sternfeld, L., & Berenberg, W. *Twenty-five years of cerebral palsy research*. Report to United Cerebral Palsy Research and Educational Foundation, Inc. June 1981.
- Testimony, Governor's Council on Developmental Disabilities Public Hearing. St. Paul, MN: Department of Energy, Planning, and Development, May 1982.
- There are six million mentally retarded people who need your help*. Arlington, TX: Association for Retarded Citizens, 1980.
- Vocational rehabilitation in Minnesota, a 1980 overview*. St. Paul, MN: Department of Vocational Rehabilitation, 1982.
- Welsch v. Noot Consent Decree*. United States District Court, District of Minnesota, 4th Division, U.S. District Judge Earl Larson. September 15, 1980.



## Index

- Advocacy services 26, 27, 29
- Array of services 15, 16, 32
- Autism 9, 20
  - defined 10
- Behavior problems 9, 28
- Block grants 13, 32, 33, 37
- Case management 13, 26, 27, 29, 31, 33, 35
- Categorical funding 13, 33, 37
- Centers for Independent Living 23
- Cerebral palsy
  - defined 10
  - causes 10, 34
- Change, barriers to 13, 32
- Community Social Services Act 21, 33
- Competitive employment 13, 22, 23, 25, 32, 35
- Consumer-powered systems 31, 32
- Continuum of Services 15, 31
- Cost effectiveness 13, 27, 28, 32
- Cultural familial retardation 34
- Day programs 20-21, 27, 29, 33
  - new directions 23
- Decentralization 33, 35, 37
- Deinstitutionalization 10, 20, 33, 35
  - defined 11
- Developmental Achievement Centers 12, 20-21, 31, 32
- Developmental Disabilities 10
- Early intervention 13, 25, 27, 34, 35
- Education, special 12, 24-25, 35
- Enclave work 23
- Epilepsy 9
  - defined 10
- External sheltered work 23
- Family Subsidy Program 17, 32
- Federal role 12-13, 33
- Fetal alcohol syndrome 34
- Fiscal incentives/disincentives 12-13, 19, 31, 32, 33
- Foster care 12, 18, 19, 33
- Individual Education Plan (IEP) 24, 25
- Infant stimulation programs 21
- In-home supports 16, 27, 32, 33
  - Minnesota program 17
- Integration 11, 32
- Intermediate Care Facilities for the Mentally Retarded 12, 13, 18, 19, 31
- Least restrictive environment 11, 24, 31, 32
- Long-term care 29, 33, 34
- Medicaid 33, 34
  - deficit 13
  - Title XIX 12, 19, 31, 33
  - Waiver 13, 32, 33, 34
- Mental retardation 9
  - defined 10
  - causes 10, 34
- Movement of clients 15, 20, 21, 32
- Normalization 11
- Nursing homes 18, 19, 33, 34
- Prevention 27, 34-35
- Private sector role 13, 23, 32
- Property values 28
- Public Law 94-142 12, 25
- Reallocation, reform 13, 31, 32
- Redesign 13, 32
- Rehabilitation 34
  - Act, Section 504 12, 23
- Residential Programs 18-20
- Resource-powered system 31, 32
- Respite care 16, 33
- Rule 185, D.P.W. 12, 26, 31
- Rural programs 27, 28-29
- Semi-Independent Living Services (SILS) 12, 18, 19, 20, 31
- Sheltered work 22, 23, 32
- Special education see Education, special
- State hospitals 11, 18, 19, 31, 33, 34, 35
- Support model 32
- Supplemental Security Income (SSI) 12, 19, 33
- Title XIX see Medicaid
- Title XX 21, 33
- Waiver see Medicaid
- Welsch v. Noot Consent Decree 11, 12, 19
- Work activity 22, 23, 32
- Work adjustment training 22
- Work programs 22-23, 27, 32
- Zoning ordinances 12, 35









---

GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES  
MINNESOTA