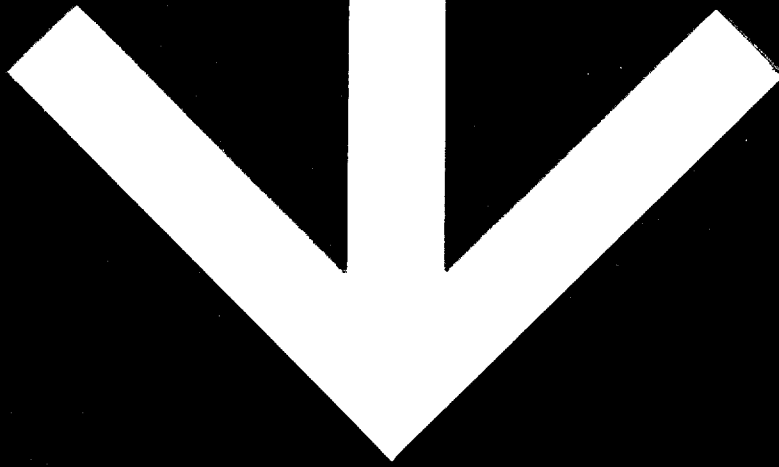


ASSURING FUTURES
OF QUALITY



FOREWORD

This book is about the relationship among values, policies and services provided to people with developmental disabilities.

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PREFACE

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.

In Minnesota, residential, developmental achievement services, and case management are usually only provided to people with mental retardation.

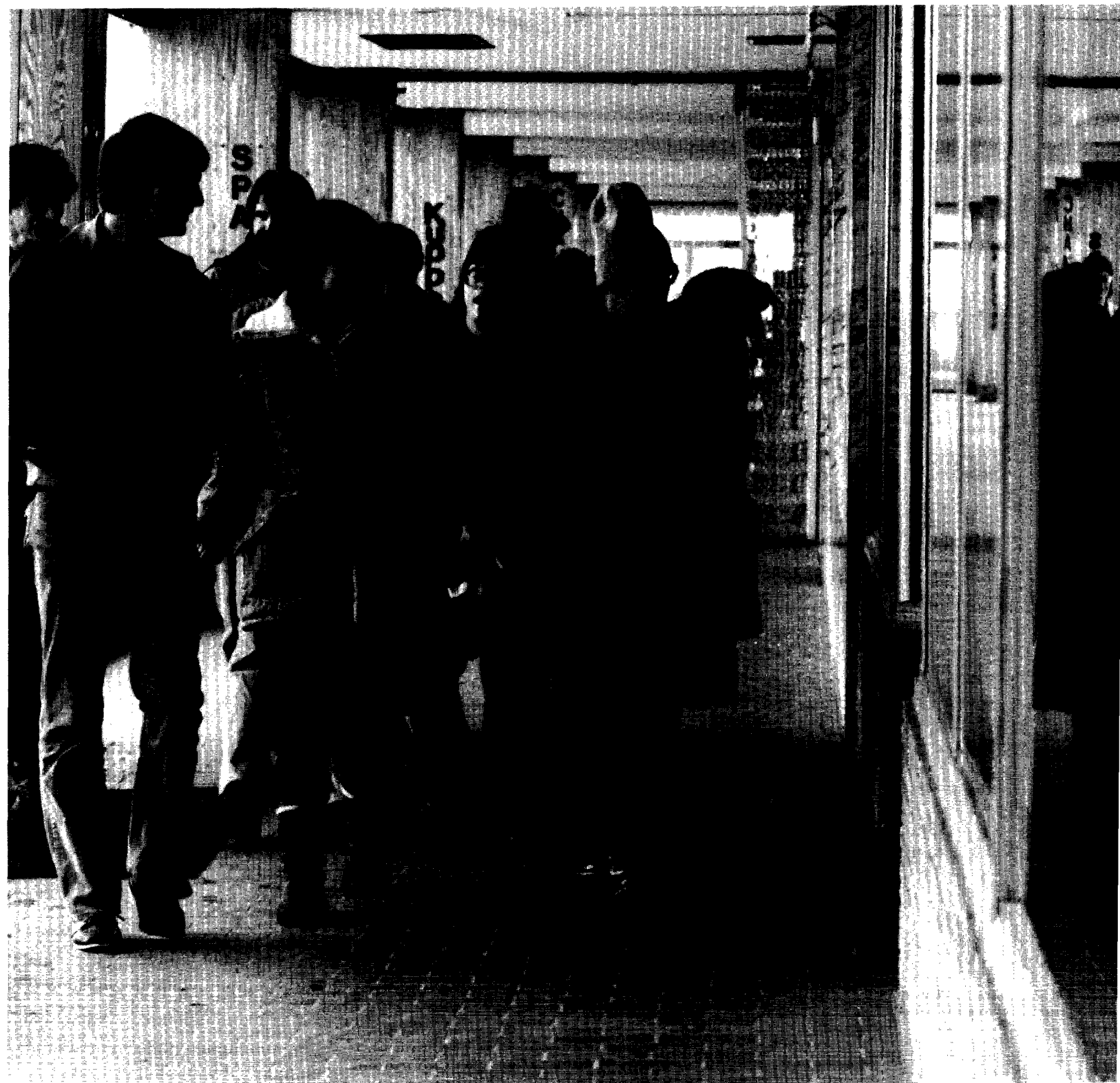
A developmental disability is defined by Public Law 95-602 as:

"severe, chronic disability of a person which— (a) is attributable to a mental or physical impairment or combination of mental and physical impairment; (b) is manifested before the person attains age 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self direction, (vi) capacity for independent living, and (vii) economic sufficiency; and (e) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."



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OVERVIEW

Living and building a future in the community can be very complicated for persons with developmental disabilities. It involves those things that we all value—family life, respect, making choices, caring relationships, a sense of purpose, sufficient resources, a place to live, a job, good health, and good times.

Persons with disabilities must rely on their own abilities and the help of family, friends, and caring people. Many will also require the assistance of services of many types: educational, residential, employment, counseling, and others. Just as the individual must put all the pieces of his or her life together, services must be organized to provide systematic support to the individual. They must also operate so that the individual achieves what is valued.

The goal of human service systems should be to assist individuals with disabilities to grow, develop, live, learn, work and participate to the fullest extent possible in community life. Underlying principles of effective service delivery are **responsiveness** to individuals, **community integration** and **quality** of services.

A system of services must encourage the inclusion of the individual in the community. Services need to support the involvement of the individual, family, friends, and fellow citizens rather than replacing that involvement. There is no question that the place for people to learn to live in the community is in the community with and beside other citizens. Services that assist people to build futures of quality in the community, therefore, must ensure that people with disabilities are not only present in the community but live, learn, work, and participate with other citizens who are not disabled.

Most of the services needed by people with disabilities are the same as those needed by other citizens—housing, education, employment and health services. The organizations which provide those services to others should provide them to people with disabilities.

Effective human services are characterized by competence and quality. Services are delivered through people—staff, volunteers, parents and administrators. People who are caring, competent, value people with disabilities, and are willing to utilize new knowledge and skills should be recruited, trained and employed. Agencies that comprise the service system need to understand its goals, the role of their particular services, and what constitutes quality and excellence.

Policies, regulations, staff selection, and funding are essential elements in ensuring competence and quality. Most critical, however, are advocacy and organized, systematic monitoring of what happens to and for individuals. Advocacy and monitoring at the system level require structures and processes to ensure accountability to the individuals, families and funding agencies.

These principles—responsiveness, community integration and quality of service must pervade the system and component services. During the past two decades, the number of services in the system has increased from dozens to hundreds, and may increase to thousands in coming years. Values undergird the goals or direction of public policy; those values which are vital to futures of quality for persons with developmental disabilities are explored in Part II. Current status, exemplary programs and steps toward a policy agenda are detailed in Part III.

DIRECTIONS FOR THE FUTURE

PREVENTION PROGRAMS EARLY INTERVENTION SERVICES LICENSURE

LEAST RESTRICTIVE ENVIRONMENTS TRANSITION SERVICES REMOVE DISINCENTIVES

REAL WORK, WAGES & EMPLOYMENT OPTIONS HOUSING OPTIONS

RESIDENCE SIZE GUIDELINES CRISIS INTERVENTION

FAMILY/HOME SUPPORT TECHNOLOGY WELLNESS LIFE STYLES

CASE MANAGEMENT INSERVICE TRAINING STAFF INCENTIVES

VALUES AND FUTURES OF QUALITY

Communities—Where Futures Are Built

Communities—the counties, cities, towns, villages, and crossroads of this state—are the places in which Minnesotans develop their lives and futures together. Having a sense of community means having a sense of belonging, of being included. Living as part of a community means belonging to a family; going to school; learning a trade or profession; finding and holding a job; and belonging to a number of organizations and groups. It means taking advantage of the many opportunities available to us in the communities in which we live.

Each member of a community has unique qualities—different ages, incomes, political affiliations, abilities and disabilities, cultural and racial backgrounds. Some Minnesotans have disabilities caused by severe physical or mental conditions that limit their intellectual functioning or abilities to adapt to the demands of everyday life. The causes of these conditions are many—environmental, heredity, injury, disease—and so are the effects. Most persons with disabilities live quite independent lives in the communities of Minnesota. Some have greater needs, however, and require assistance so that they can participate to the fullest extent possible in the life of the community. Fundamentally, however, Minnesotans who are also disabled are more like their fellow citizens than different.

For a variety of reasons, all too often having a disability has meant that our fellow citizens have **not** been included in our communities. Some have grown up and lived extremely isolated lives away from their home community. Others have lived in communities, but not as part of them. They have gone to special schools, special places to work, and have lived in special places.

Times, opportunities, and ideas are changing. There have been significant changes in the ways that we see the needs of our disabled fellow citizens, the ways in which we allocate resources to respond to their needs, and what we hold to be right and just for them.

Building the Future—Creating A Vision

Disabilities create complexity in people's lives. One of the unfortunate complexities is having to deal in different ways with much of what everyone else takes for granted—living with a family, having friends, going to school with the other kids in the neighborhood, thinking about a career. On the other hand, thinking about the future, having a vision of what is desirable, often becomes remarkably simple.

The vision is of people with disabilities being and becoming valued and contributing members of communities—being respected for one's abilities and what one does with them; making choices about one's life; always growing and developing as a person; living and working with people who care; being able to enjoy a decent home, job, friends, and good times.

Increasingly, public policy supports the idea that the place for people with disabilities to build their futures is in the community.

Supporting Families:

Making that vision a reality often hinges on whether or not children are able to grow up with a family. For people with disabilities, the future is frequently affirmed or denied at this very basic level. Ritchie's and Cindy's futures have been significantly affected by the ways assistance was provided to their natural or alternative families.

Ritchie is a young man with a developmental disability. His family was having a number of problems caring for Ritchie at home. Their feelings about Ritchie and themselves were suffering. They were considering placing Ritchie in a state institution.

We spoke to Ritchie and his parents and asked them what it would take to keep Ritchie at home. The answer developed into a live-in aide, someone to support the family and help Ritchie. The live-in aide also did some of the housework and arranged for Ritchie to participate in some recreational and educational opportunities.

After nine months, Ritchie's behavior had changed so dramatically a live-in aide was no longer needed. Now, someone comes into the home only for specific periods of time during the day.

This relatively simple "intervention" has meant that Ritchie has stayed at home with his family. The parents' marital problems have been eliminated. Ritchie continues to have a future in the community.

Cindy used to spend the school year at the regional deaf/blind center. She went to the local institution for holidays and the summer. She has no natural family, and an adoptive home could not be located.

At the age of fourteen, however, Cindy left the center and the institution and started to live in the community. An alternative family was arranged for Cindy. She now lives with Carl and Sharon. She has new brothers and sisters who care about and love her. She enjoys white water rafting, camping, dancing, and hot Mexican food. She enjoys being part of a family, belonging.

Earning Respect/Being With Others:

The people who care about us, our families and friends, give us love. The people we learn and work with respect us, at least to the extent that they see us struggling, striving, achieving. A number of people have come to know and respect Shawntell. Doug is a young man who had and caused a lot of trouble until he had to earn respect.

Shawntell was six when she started horseback riding. She rode with a group of ten little girls, ages six to eight. Shawntell was the only child with a developmental disability. To ride a horse, for instance, Shawntell needs one person on each side of her to support her and another person to guide the horse.

Shawntell is an equestrian. The only difference between her and her friends is the amount of support she requires to be a rider.

Shawntell is eleven now and attends her neighborhood school. She rides the regular bus to school each day with a little help from her friends. The other kids sit with her on the bus and help her get in and out. There is usually a 'fight' to see who can sit with Shawntell on the bus.

She attends a special education class in the school, but spends a lot of time with typical children during the day—at lunch, phys ed, art, music, and recess. There's a buddy system in the school as well, so non-handicapped children spend time in Shawntell's special class all during the day. Part of the week is spent out of the school and out in the community working on those skills Shawntell needs to know. Typical children are involved in this activity with Shawntell. Shawntell goes on field trips with all the other fifth graders. After school she often walks home with the other kids and plays with them.

Doug is a young man who not only presented some challenges in learning, but also in controlling some aggressive behavior. Because of this, it was thought Doug needed 'sheltered work.' Doug tried this kind of work. His behavior consistently led to his being suspended or dismissed.

This obviously was not the answer. So, we got him a job in a large mall doing maintenance work. He would be right in the thick of things. He started out getting one-to-one supervision, and over time he was really enjoying and learning from the experience. The other maintenance workers began providing assistance and instruction to Doug. Doug does not require one-to-one supervision any more. He is part of the maintenance staff and a valued employee who is liked and respected.

Making Choices/Having Resources:

Being a disabled person often means having a lot of other people make important decisions about your life—where to live and with whom, whether you are considered “employable” or “trainable,” whether you are worth the effort or not. Being included in a community means having access to the same opportunities as others and being supported in taking advantage of those opportunities. Judy is a woman who had to make some hard choices and then fight even harder to have them respected.

Supportive Communities:

These people—Shawntell, Doug, Ritchie, Cindy and Judy—are **not** unusual people. They do have special needs because of developmental disabilities.

The communities in which they now live, grow and develop, participate, learn, and work are **not** unusual communities. The people involved in their lives are simply fellow citizens who share a vision of what is possible for their friends.

What is unusual is that these individuals with disabilities and members of their communities have been assisted to make that vision a reality.

Judy can talk and move her thumb. When I first met her she was living in a chronic care hospital. The place was traumatized by this spunky, vital woman who left the hospital and went to work every day just like a ‘normal’ person. Judy’s job was Director of the Centre for Handicapped Students at the University.

Against all odds she fought the hospital mentality and went to work daily, but she was getting psychologically worn out. When my husband and I met her she was frantic to get out of the stifling hospital environment. We were simply amazed that such an energetic, competent and normal person as Judy could stand to live in such a place.

Later we were invited to a celebration party—Judy’s first year out of the hospital. Unbeknownst to us, people like us had helped her leave the hospital. Simply by responding to her plight, by saying we’d feel all cooped up, we legitimized her own feelings. Most of the people around her—the professionals, her nurses, social workers, doctor—kept telling her she had no choice, she should adjust. Telling her she was better off where she was. When she got depressed or upset, she was called manipulative, bossy, etc.

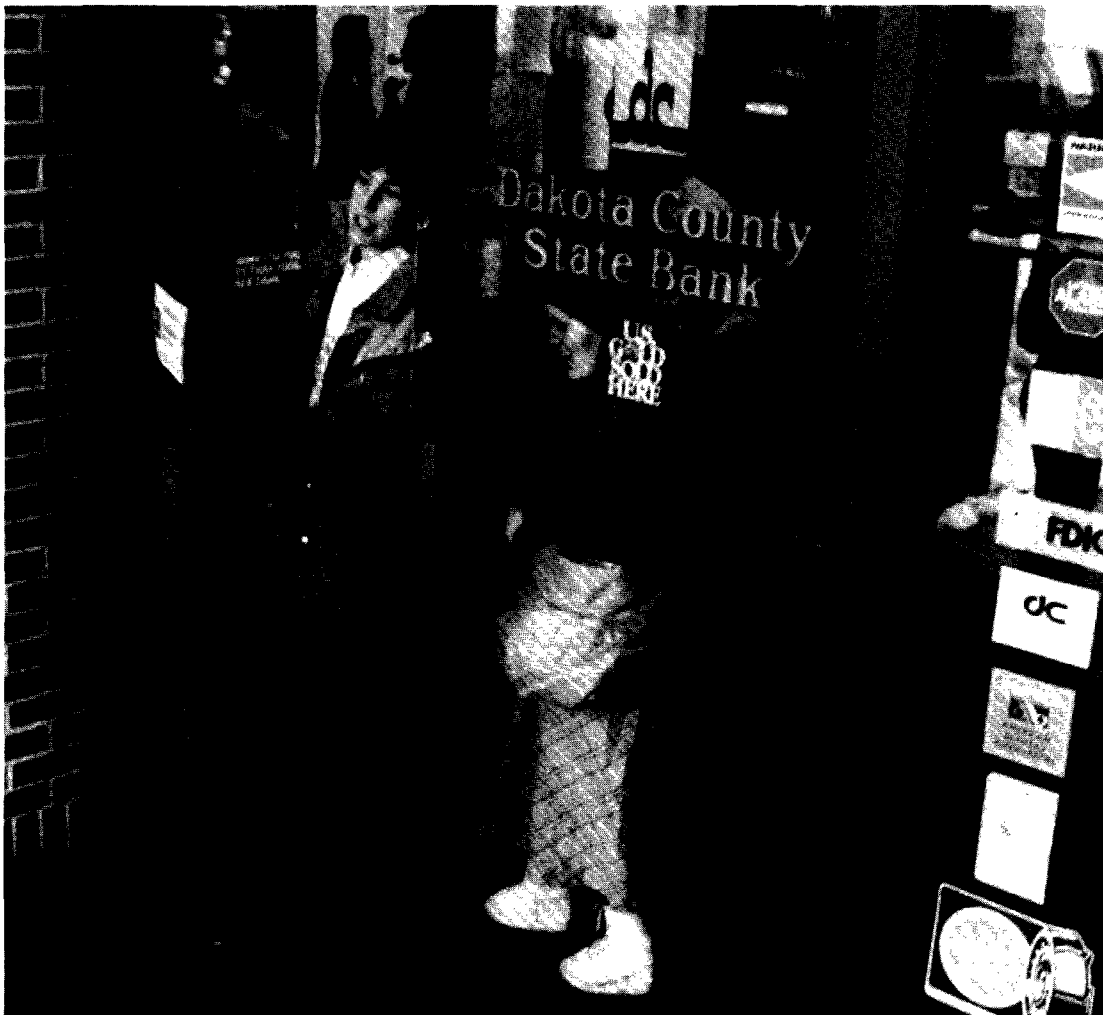
She left the hospital and so ensued a one year battle with the social service bureaucracy for the simple right to live as a human being in the home and community **of her choice.**

She now lives in a one-bedroom apartment. Her attendant coordinator has an apartment in the same building. A number of people work part-time to help Judy to get out and about. Her apartment is “rigged” with a number of devices so she can do a lot on her own. The efforts of a network of friends and associates make sure that things don’t fall apart. You see, the social service system is still in a bit of a panic. Arrangements continually have to be renewed and renegotiated. Judy simply wants the right to choose where and how she lives. This simple choice requires an on-going battle for dignity and self-respect. (Forest and Snow, 1983)

What Kind of Community is Responsive to People With Disabilities?

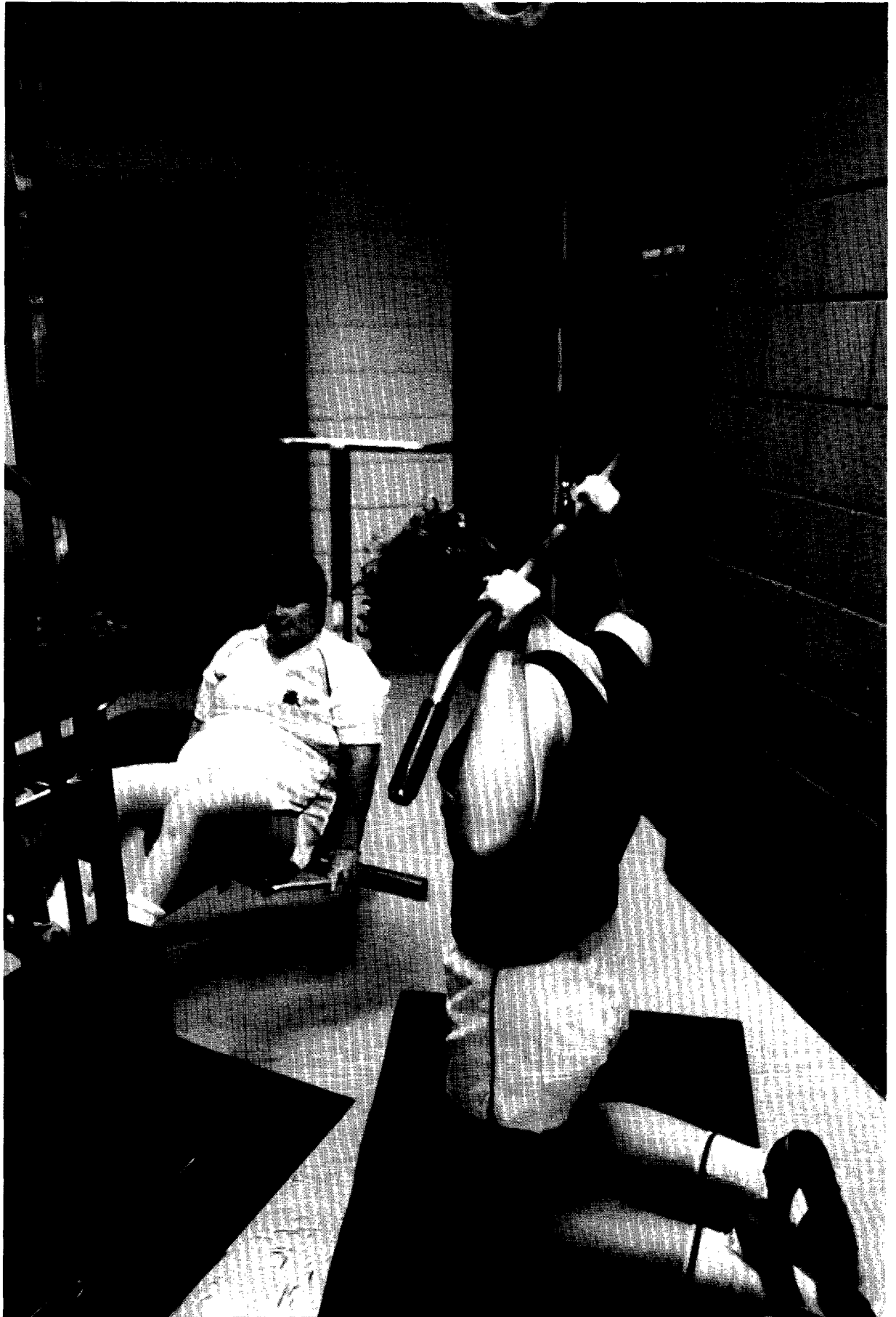
- A community where children can grow up as members of families.
- A community where children and adults can be part of loving and caring relationships.
- A community where all children can learn together and from each other.
- A community where all young people can learn what they need to know to get a job, to develop a career.
- A community where adults have a chance to work and contribute to the community, and where needed, get extra support so they can work to their fullest potential.
- A community where people can turn not only to community services, but their friends and neighbors for support.
- A community that thinks about ways to include all its citizens rather than to exclude them.
- A community that recognizes disability as a part of the human condition and as part of the challenge that competent, responsible communities must meet.

A vision of the future must involve supporting communities to act responsibly, to be competent, to recognize and support the citizenship of Minnesotans with developmental disabilities.



PART III

TOWARD A POLICY AGENDA FOR ASSURING FUTURES OF QUALITY



PREVENTION

Goal: A Statewide Prevention Agenda Should be Developed and Implemented

Current Status.

According to one Minnesota County Social Services Director, "Enough mental retardation is caused by poor nutrition, inadequate health care, drugs and alcohol to keep us all busily employed for the rest of our lifetimes." Prevention is an easy target for budget cuts since such activities do not readily produce immediately visible benefits. The following categories include the major known causes of developmental disabilities:

Heredity. Disabilities may be inherited in the same way that blood type, hair color, and other traits are transmitted through the genes and chromosomes. Two examples are Tay-Sachs disease and sickle cell anemia.

In many cases the exact genetic cause of a particular disability is unknown. Open spine defects (called spina bifida) or other neural tube defects may occur because of a combination of heredity and prenatal environmental factors working together. According to the Spina Bifida Association of Minnesota, spina bifida is the second most common birth defect, outnumbered only by heart disorders.

In some situations a woman's genetic makeup may be detrimental to her unborn child. If they do not receive special treatment, women who carry the genes for Rh negative blood, for example, have higher rates of miscarriage, stillbirth and newborns with congenital defects than women with Rh positive blood (March of Dimes, 1983).

Metabolism. Several types of metabolic conditions can be screened at birth. One metabolic disorder, phenylketonuria (PKU), affects the ability of the body to break down protein and can result in mental retardation without proper detection and treatment. PKU occurs in about 1 of 15,000 births. Congenital hypothyroidism also requires detection and medication soon after birth to prevent growth impairment and mental retardation which occurs without treatment. Hypothyroidism occurs in approximately 1 of 4,000 births (U.S. Department of Health and Human Services, 1980).

Infections. Congenital infections such as rubella (German measles), toxoplasmosis, and herpes affect the mother and can cause disabilities if transmitted to the fetus. Of the 3 million babies born annually in the United States, approximately 3,000 have congenital toxoplasma infection (Papageorgious, 1980). Rubella may cause blindness, deafness, mental retardation, and possibly autism (Thompson and O'Quinn, 1979).

Teenage Pregnancy. Babies born to teenage mothers are more likely to be premature and of low birthweight, a factor which can cause mental retardation, cerebral palsy, epilepsy and birth injuries. Teenage mothers run higher risks of toxemia and anemia during pregnancy than women in their early twenties (Moore and Burt, 1982). Although many of the health risks to pregnant teenagers can be reduced through proper nutrition and health care, the risks to the very young (15 years and younger) cannot be entirely eliminated (Moore and Burt, 1982).

Nutrition, Smoking and Drugs.

Improper nutrition, smoking and drugs may cause disabilities. While each of these factors may independently affect the fetus, the effects of all three together can be severe.

Poor nutrition can result in low birth weight babies. If a pregnant woman who does not have an adequate diet also smokes, the effects may be compounded because smoking may also deprive the fetus of nutrients. According to Garn, Shaw, and McCabe (1977), smoking during pregnancy is "the most important single preventable determinant of low birthweights," (p. 667). Finally, street and prescription drugs may also be harmful to the fetus.

*"In spite of all the ideas and all the technology and atoms in the world, it all comes down to shaping one individual at a time."**

*Reprinted with permission from Abbey Press.

Alcohol. Consumption of alcohol can cause disabilities, with the more severe effect called Fetal Alcohol Syndrome. Fetal Alcohol Syndrome includes mental retardation, microcephaly, delayed physical growth, and facial anomalies. The incidence of Fetal Alcohol Syndrome is 1 in 1,000, (Streissguth, Landesman-Dwyer, Martin, & Smith, 1980). The effects of alcohol in the newborn have been detected with pregnant women consuming as little as 1 ounce of alcohol per day (Chernoff and Jones, 1979).

Cultural Familial Causes. The social environment of children may also result in development of disabilities, particularly mild mental retardation. Cultural familial causes begin with insufficient stimulation of the newborn. If a child is neglected or abused, the result can be a disability before reaching school. Boulware (1979) estimated that more than one in ten new cases of cerebral palsy are attributable to child abuse each year.

Other Causes. Additional causes of disabilities include exposure to radiation, accidents, lead and environmental pollution. The effects on the fetus depend on the amount, length, and frequency of exposure to pollutants. The real effect of environmental toxins, such as lead, on child development is probably underestimated.

*"There has been a marked decrease in early prenatal care for pregnant women over the past three years....Of 33 states reporting prenatal care data for all women, 26 states showed increased percentages of women receiving late or no prenatal care in 1982 over preceding years."
(Children's Defense Fund, 1983)*

Each PKU screening costs \$2.50. Incidence is one case per 10,000 tests costing \$25,000. Extra cost of care for a PKU child for life is at least \$720,000—about 30 times the cost of screening (U.S. Department of Health and Human Services, 1980).

What's Possible

Disabilities can be prevented. At minimum, a statewide policy agenda should include Crocker's (1982) Golden Twenty Prevention Strategies which have been adapted as follows:

1. Are all children and women in Minnesota immunized for rubella (German measles)?
2. Do all pregnant women receive proper prenatal care with special attention to teenagers and other at-risk pregnancies?
3. Do premature babies receive special diagnosis or treatment in intensive care units?
4. Is genetic counseling provided to families in need of these services?
5. Do pregnant women strictly limit use of alcohol?
6. Are children being screened for lead poisoning and protected from high concentrations of lead?
7. Are pregnant women who are Rh negative immunized when necessary to prevent Rh disease of the newborn?
8. Are special car seats used to prevent head injuries to infants and young children?
9. Are education and counseling services available to make adolescents aware of the medical risks of pregnancy during the teen years?
10. Are identification and intervention services available for neglected and abused children?
11. Are adequate nutrition and child health education available to pregnant women?
12. Are newborn infants routinely screened for treatable metabolic conditions?
13. Are newborn infants screened for hypothyroidism and provided appropriate treatment?
14. Is proper testing for diagnosis of chromosomal disorders available to all pregnant women over age 35?
15. Are pregnant women being screened to identify neural tube defects (spina bifida)?
16. Are screening and follow-up programs in place to identify and counsel carriers of Tay-Sachs and sickle cell anemia?
17. Are early identification and intervention provided to infants to reduce the severity of disabilities that do occur?
18. Are support services available for families with children who have disabilities?
19. Is there financial support of research into causes and prevention strategies for disabilities?
20. Are physicians aware of new research findings and procedures developed to prevent disabilities?

The Future of Genetic Screening

Amniocentesis and ultrasonography, advances in prenatal screening introduced in the early 1970s, have allowed the detection of over 190 genetic and chromosomal disorders prior to birth. While chemical analysis can detect "errors of chemistry," such as PKU, researchers are exploring direct analysis of the structure of specific genes. Such research is presently making its greatest impact in prenatal diagnosis of inherited blood diseases.

Researchers believe that within 3 to 5 years advances in genetic research will enable them to predict prenatally a number of inherited diseases. Much further in the future, researchers hope to replace detrimental genes with normal ones, or induce malfunctioning genes to produce normal chemical products.

(McAuliffe & McAuliffe, 1983)

Fragile-X Syndrome—A New Cause of Mental Retardation?

Researchers are reporting what appears to be a newly identified cause of mental retardation, estimated to be about half as common as Down's Syndrome,* the most frequent chromosomal cause of mental retardation. The syndrome is called Fragile-X because of a narrowing and sometimes breakage in a specific region of the X chromosome.

Interest in this area started with the recognition that males were over-represented among the mentally retarded population, whether institutionalized or living in the community (Turner & Turner, 1974). It was also documented that mentally retarded males more often had affected male relatives than affected female relatives. Such a genetic pattern, where males are more frequently represented than females on a particular trait and are also more severely affected, suggests that it is a sex-linked trait and carried on the X chromosome.

The Fragile-X is probably just one of a number of possible sex-linked causes of mental retardation without accompanying major physical malformations, since the Fragile-X is not found in all members of this population.

*Trisomy 21 (extra chromosome 21)



Part of a set of human chromosomes. The arrow indicates the fragile site of an X chromosome. (Courtesy of Drs. J. Cervenka and B. Hirsch, Oral Pathology and Genetics, University of Minnesota)

Steps Toward the Policy Goal

1. A lead agency should be designated within state government to develop and implement a prevention agenda.
2. Information should be disseminated to health care personnel and families regarding available prevention services and newly discovered syndromes.
3. Medical insurance and medicaid should be extended to include prevention services.
4. Screening programs should be comprehensive and funded on a long-term basis to allow for follow up.
5. Prenatal diagnosis should be made more widely available to women. While amniocentesis has the potential for reducing the prevalence of disabilities, it is estimated that only 1 percent of women in the U.S. over age 35 have access to amniocentesis (Warburton, 1980).
6. An annual state "report card" on prevention activities should be issued to the Governor and State Legislature.





Madeleine Will, Assistant Secretary for Special Education and Rehabilitative Services of the U.S. Department of Education, in a recent interview stated:

I see a real need to disseminate information about the effectiveness of early childhood, early intervention programs. It is clearly cost beneficial. And I think the real benefit accrues to the school systems that have to spend less money in the future on children who spend less time in special education and require less intensive services because they have had early intervention programs (1983).

EARLY INTERVENTION

Goal: Early Intervention Services (Birth Through Age Three) Should be Available for Children with Disabilities

Current Status.

Early intervention is the identification, assessment and provision of special programs for development of very young children with handicaps or potential handicaps.

Early intervention services help teach parents how to provide a stimulating and caring environment for infants and young children. Effective intervention services must begin as early as possible, provide support to parents, improve the interactions between parents and children, and be least intrusive and most accessible to the parents.

Cost Effectiveness of Early Intervention. Recently, the cost of providing special education services to children entering at various age levels was calculated. The following results were given by Garland, Stone, Swanson and Woodruff (1981):

Provisions for Early Intervention in Minnesota.

- Minnesota State Law (M.S. 120.17) mandates special instruction and service for handicapped children from ages 4-21 or completion of secondary school or its equivalent. Permissive legislation allows for provision of special instruction and services under age 4.
- The 1984 Minnesota Legislature will consider mandatory special instruction for handicapped children from birth through age 3. Eight states currently have legislation guaranteeing early education services to handicapped children from birth through age 3.
- The Minnesota Departments of Health, Education, and Welfare are working toward an inter-agency agreement for services to the birth through age 3 population.

Minnesota Agencies Providing Early Intervention Services.

Services to handicapped children from birth through age 3 are currently being delivered by many service providers:

● Department of Health

Services for Children with Handicaps (SCH)

Supplemental Security Income Disabled Children's Program (SSI-DCP)

Early and Periodic Screening (EPS)

Community Health Services (CHS)

● Department of Education

Preschool Screening (PSS)

Early special education programs in local school districts

● Department of Welfare

Early and Periodic Screening, Diagnosis and Treatment (EPSDT)

Developmental Achievement Centers (DAC)

Day Care and Nursery Programs

● Office of Economic Opportunity

Head Start

In 1982, 220 Minnesota school districts served at least one handicapped child from birth through age 3, and a total of 1,057 handicapped children in that age range. Fifty-one DACs served 1,396 handicapped children from birth through age 3 in 1982. Duplication of counts between agencies is possible because some schools contract with DACs for services. DACs reported 82 children (birth through age 3) on waiting lists. There may be as many as 5,000 handicapped children who need services or are underserved, according to Minnesota Department of Education estimates.

Cost of Special Education per Child to Age 18

Birth	\$37,273
2 Yrs.	\$37,600
6 Yrs.	\$46,816
Over 6 Yrs.*	\$53,340
Age of Intervention	Cost

*no movement to regular education

What's Possible

Parent Training Network

The Oregon Parent Training Network is an early intervention program. Serving as many as 450 families during a 12-month period, the network staff trains parents to stimulate their child in areas such as self-help skills, language and communication development, pre-academic skills development, and socialization. Network staff work with the parents and child at home or outside the home. Sometimes the setting is extended to the classroom if the child is of school age and the classroom teachers concur.

Therapy services for infants are provided by physical and/or communication therapists who assess the need and design programs for the parents to conduct at home. Self-help, communication, and socialization are emphasized for the preschool handicapped child.

Programming in the area of social behavior problems follows a slightly different format. Parents are assisted at the clinic in identifying problem behavior and obtaining baseline data on behaviors they would like changed. When objectives have been set, parents are assisted with treatment strategies designed to meet these objectives. These treatment strategies are monitored on a weekly basis. When the objectives have been met, follow-up contacts are made in three-month intervals.

In addition to the core training clinic at the Teaching Research Division of the Oregon State System of Higher Education in Monmouth, Oregon there are 30 parent trainers at the 21 training sites located in 21 of Oregon's 36 counties.

This Oregon program has been in operation for almost ten years and has been successfully replicated in Iowa, New Hampshire, Rhode Island and Washington; however, no other state has implemented the model on a statewide basis.

"We started Matthew at 3 weeks in the Parent Training Clinic and are pleased with that guidance. Now our son is 13 months old. Our family and relatives are proud of his interest in learning. He is crawling everywhere and is standing up to furniture. He's drinking by himself and working with a spoon. All in all, he seems to be a regular kind of kid.

We realize now how strongly preconceived and old-fashioned ideas have affected thoughts of this handicap. Knowledge has changed so much in past years and with early stimulation a child with this handicap can succeed remarkably!"
(Nancy and Mike Robinson, Parents)

Steps Toward the Policy Goal

1. State and local health, education, and welfare agencies should coordinate their efforts to provide early intervention services.
2. The Minnesota Department of Education should be designated as the lead agency responsible for providing early intervention services.





FAMILY SUPPORT

Goal: Support Not Supplant the Family

Current Status.

Support for families has emerged as a recent response to the spiraling costs of out of home placements and to a heightened awareness of the service functions that families perform for their members. As of January 1, 1984, sixteen states provided some type of family support program. The sixteen states are: Connecticut, Florida, Idaho, Illinois, Michigan, Minnesota, Montana, Nevada, New York, North Dakota, Ohio, Pennsylvania, Rhode Island, South Carolina, Washington, and Wisconsin. Florida has the highest stipend allowing up to \$680 per month.

The Minnesota Family Subsidy Program was established for children living at home at risk of out of home placement and children residing in a state institution or community residential facility who would return to their own home under this program. Priority for selection is given to families of severely and multiply handicapped children who are experiencing a high degree of family stress and show the greatest potential for benefiting from the program. Grants of up to \$250 a month are made to cover the costs of assessments, homemaker services, specialized equipment, therapists, preschool costs, transportation, and respite care. Currently 187 Minnesota families receive Family Subsidy at a total cost of \$550,800, with approximately 130 families on the waiting list.

When randomly selected families participating in the program were asked about the program's effectiveness, 97 percent reported that the program was of great or very great help. The subsidy enables families to keep their disabled child at home, relieves financial, social, and psychological stresses, and allows purchases to meet the child's needs (Policy Analysis Paper #18). Minnesota's Representative John Brandl (1982) noted in **Corporate Report** that family support can be a cost-effective as well as a humane alternative to institutional care in a period of fiscal cutbacks.

What's Possible

Follow-up Intervention for Normal Development

The Follow-up Intervention for Normal Development (F.I.N.D.) in San Bernardino, California is a family support program.

F.I.N.D. is a group of counselors from public health and nursing backgrounds and a program manager. When a child is born who is ascertained by hospital staff to be at-risk, a project counselor is contacted. Before the baby is released from the hospital, the counselor will offer F.I.N.D.'s services to the parent. If the offer is accepted, the counselor will assemble a team which includes medical staff, public health nurses, and representatives of programs which might be called upon to work with the child during the first year. This team, with the parents, draws up an individual program plan for the coming twelve months which will be updated on a quarterly basis.

The F.I.N.D. counselor thereafter coordinates the execution of the program plan. Over the next year, the counselor will meet with the parents to discuss program revisions or progress and make sure the plan is implemented. The counselor also facilitates the sharing of information so that all members of the team can truly coordinate their efforts for maximum effect.

The words of one F.I.N.D. counselor best sum up the nature, effect, and cost-benefit advantages of the project:

"I don't feel we are introducing any new interventions. All of these specialties have been in the region for a long time... We don't seem to need a larger bureaucracy to handle the coordination; we seem to get along very well without it... I guess you might say that the "at risk" baby is really the center, and we manipulate our systems to help that little girl or boy develop. The only difference may be that whatever it is we each are doing, we are doing it together ...better than we've ever done it before."

Steps Toward the Policy Goal

1. The current Family Subsidy program should be re-named "Family Support" and greatly expanded in the number of families served. Age restrictions should be changed to allow young adults to be included. The maximum stipend should be raised from \$250.
2. Direct family participation should be an integral part of local planning, service delivery, and monitoring of services.



*Family-style mealtimes—Residence One
Group Home, Shoreview*

LEARNING IN THE COMMUNITY

Goal: Special Education Should Ultimately Prepare Students for Independent Living

Current Status.

Federal and state legislation guarantees each child with a handicap the right to a free, appropriate public education in the least restrictive environment.

- Free means provided at public expense.
- Appropriate means a program with specially designed instruction and services based on individual needs.
- Least restrictive environment means the specially designed instruction and service must take place in the most integrated setting possible.

In 1982, a total of 77,455 children from birth through age 21 received special education services provided by the 436 Minnesota school districts in public and non-public settings.

Numbers of Minnesota Children in Special Education By Primary Handicapping Condition

Speech Impaired	19,091
Educable Mentally Retarded	9,993
Trainable Mentally Retarded	3,578
Physically Handicapped	1,385
Hearing Impaired	1,488
Visually Impaired	421
Learning Disabled	34,765
Emotionally Disturbed	5,807
Deaf and Blind	22
Autistic	148
Other Health Impaired	757

SOURCE: Minnesota Department of Education



Cost of Special Education in Minnesota. The Minnesota Department of Education estimated that special education services cost \$179,605,000 in Fiscal Year 1982. About \$163,787,000 or 91 percent of total expenditures from state, federal and other sources were for special education personnel. Distribution of special education personnel expenditures by primary handicapping condition indicates that the largest expenditures of resources were for 1) learning disabled, 2) educable mentally retarded, 3) other essential personnel and 4) trainable mentally retarded.

The balance, approximately \$15,818,000, or 9 percent, was for books, supplies, contracted services, etc.

Expenditure for Special Education Personnel and Other Costs in Minnesota School Districts, 1982

Speech Impaired	\$16,679,000
Educable Mentally Retarded	22,615,000
Trainable Mentally Retarded	19,113,000
Physically Handicapped	4,874,000
Hearing Impaired	4,053,000
Visually Impaired	1,154,000
Learning Disabled	53,398,000
Delinquents	2,600,000
Emotionally Disturbed	9,487,000
Preschool	6,504,000
Autistic	8,720,000
Homebound	9,000,000
Other	3,144,000
*Other Essential Personnel	22,446,000
Personnel cost total	\$163,787,000
Other costs	15,818,000
Total cost FY 1982	\$179,605,000

*includes directors, psychologists, social workers and others
SOURCE: Minnesota Department of Education

Transition between school and adult services. A major need in Minnesota and most states is transitional services which help high school graduates who are disabled move from school to adult life.

Special education must go beyond a concentrated thrust on academics since the ultimate goal is developing a student's capacity for independence. "Commercial kits and irrelevant paper and pencil tasks should be faded out; real money, real streets and cars, real people, real stores, real world settings must replace them." (Brown, Nietupski, & Hamre-Nietupski, 1976, p. 14)

In a recent survey of Minnesota special education directors by the Minnesota Severely Handicapped Service Delivery Project, several problems were identified which prevent effective transition between schools and adult services. These problems include:

- Inadequate resources in adult service agencies to provide programs comparable to that provided by schools.
- Need for locally available adult service programs.
- Need for a formal process for transition.
- Need for awareness and planning for a student's post-school options.
- Need for vocational programming for students while in school.
- Poor case management by adult service agencies.
- Transportation difficulties.

Of the special education directors responding to this survey, over one-half reported some level of transition planning occurred for graduates with a higher proportion of assistance provided by special education cooperatives than by single districts.

The services that were cited as most important to successful transition were joint IEP (Individual Education Plan) planning between the school and the adult service provider especially during the senior year; informing families on how to access services; case management to minimize service disruption and involvement of Vocational Rehabilitation to emphasize employment as the first option.

According to a recent interview with Madeleine Will (1983):

A tremendous amount of productivity is being wasted because 50 to 75 percent of disabled adults are unemployed. If people at the state level—and at the federal level—will look at the cost of supporting disabled individuals who are unemployed, but perhaps live in the most restrictive possible kind of setting, they will see that there is not only a clear need from a humanitarian standpoint but a clear need from a fiscal standpoint to provide these services.

We are saying some things that are somewhat radical. We are saying that severely handicapped people can work. And that has not been the operative assumption in the past.

What's Possible

Parental Involvement Project.

In Kansas, severely mentally retarded youth and their families are involved in life-long planning and implementing individual education plans (IEPs) based on life-long planning goals. The project will extend over a three year period and will involve 15 families.

The goals of the project are three-fold: (1) to train families and educators in the identification of skills that are critical for functioning in adult environments, (2) to train families and educators to form an effective partnership in IEP planning, implementation and evaluation and (3) to prepare families to make legal, ethical and effective life-long planning decisions that will improve the student's quality of life.

Families will select places where their child would like to live and work as an adult. Site visits will be made to identify the adult life skills needed in these homes and programs. Families, educators and community resource persons will participate in training for the development of future life skills needed by the students. Families will also receive training on how to participate more effectively in the IEP process. The project will develop a series of seminars to assist families in making other life-long planning decisions. Dissemination of the life-long planning seminars will be conducted through the Association for Retarded Citizens/USA.

The Community Classroom.

The Technological Employment Project is a secondary education, vocational training program of the Richmond (California) Unified School District that trains 30 severely handicapped students to gain vocational skills in high technology fields of employment. The program uses the "community classroom" model where a special education teacher works with small groups of students in real work settings. In essence, the classroom is the work setting.

On-the-job training is provided at a number of work sites in the Richmond area including American Telephone & Telegraph Company and Chevron Research Company. The jobs include measurement of the viscosity of petroleum fluid and conducting "aeration" and "foam" tests. Project results after the first year indicated that students with a variety of disabilities can learn a number of challenging work tasks that meet industrial as well as educational standards. Mobility and social skills were as important to learn as were the specific work tasks.

Although this project is only in its second year of demonstration and research, the community classroom concept appears to be an effective vocational training model for secondary students with serious disabilities. The main challenge to implementing this model is to sell it to policy makers in local school districts. School personnel must also assertively approach the business community to elicit their cooperation.

"I haven't really thought about my son's future in the last six months. I have a new job and I'm bushed when I get home. We've never spent much time discussing the future. We didn't think we had options." (Father of 19 year old student with disabilities)

"With an autistic kid you just don't have time to think about the future. One minute things are fine. The next minute all hell breaks loose. . . . You don't live one day at a time. . . . It's more like one hour at a time." (Mother of 10 year old student)

"Every educational plan that was ever written for John contained the goals of increasing concentration skills and decreasing distractability. However, since he has been involved at Chevron, the problem of distractability hasn't even been mentioned." (A parent)

"Shirley used to put up quite a struggle before going to school. Every day seemed dreaded. Now that she's been going to the telephone company for training, she can hardly wait to get there in the morning." (A parent)

Steps Toward the Policy Goal

1. Children should be taught in the least restrictive environment.
2. Transition planning should occur early in high school for students who will need adult services. Transition planning should include:
 - An Individual Lifelong Plan (ILP) that sets goals for the student after graduation. The IEP should support the ILP.
 - Cooperative planning between schools, counties, and adult service providers.
 - A school curriculum that is functional and will assist students in living and working in the adult world.





WORKING IN THE COMMUNITY

Goal: Day Programs (DACs and Sheltered Workshops) Should Emphasize Community Integration and Opportunities for Competitive Employment

Current Status.

The range of day programs for developmentally disabled people in Minnesota includes the following:

- **Developmental Achievement Centers:** Pework-oriented programs focused upon social, daily living, recreation skills, and similar activities.
- **Work Activity Centers:** Included in the developmental or activities program are work activities for which consumers/participants receive pay.
- **Sheltered Workshops:** Work-oriented programs whose primary purpose is to secure current employment in a sheltered setting and/or future competitive employment.
- **Competitive Placement Programs:** Programs whose only purpose is to provide short-term training leading to placement in competitive employment and short-term follow-up after placement.
- **Competitive Employment:** Part-time or full-time work outside the programs listed above.

Developmental Achievement Centers (DACs) and Sheltered Employment Services (SESs) are the principal agencies providing work experiences and employment oriented activities for Minnesotans with developmental disabilities. During the past three years the Developmental Disabilities Program has conducted several studies of DACs and SESs. (Policy Analysis Papers #16 and #17)

Number and Cost. During 1982, 107 DACs and 28 SESs (data from 25 SESs presented in this report) provided training, habilitation and work services to 7,284 adult clients; 4,003 in DACs and 3,281 in SESs.

Total revenue for all DAC clients (children and adults) statewide in 1982 was \$27,404,614 with 93.6 percent from government appropriations, 4.6 percent from contributions and 1.8 percent from families. DAC expenditures for 1982 totaled \$27,203,598 with expenditures for personnel, 62.3 percent, transportation, 13.1 percent, occupancy, 9.7 percent, and other program expense, 14.8 percent. In 1982, 33 DACs reported operating deficits.

SES revenues totaled \$35,746,048 in 1982 and came from more diverse sources; government appropriations, 36 percent, subcontract income, 32.9 percent, sales, 19.1 percent, and other (United Way, contributions, grants, etc.), 12 percent. These resources were expended for staff and client/sheltered worker wages, 65.6 percent, occupancy, 9.7 percent, transportation, 2.4 percent, production supplies, 13.6 percent, and other program expense, 8.8 percent. Operating deficits for SESs totaled \$400,274.

In 1982, the DACs reported that 528 adult clients who were ready for placement in work activity (349), sheltered work (154), competitive employment (21) and other (4) could not be placed. Stated reasons for non-placement included the following:

Total Number of Responses, 528	Percent
Lack of Available Work Activity, 112	21.2
Lack of Available Sheltered Work, 47	8.9
Lack of Community Support Services, 30	5.7
Parents or Clients Reluctant/Unwilling to Change, 140	26.5
Clients Characteristics which Prevent Participation in WA/SWS Programs, 116	22.0
Clients are Awaiting Evaluation, Referral, or Placement, 29	5.5
Other, 54	10.2

SOURCE: Developmental Disabilities Program, State Planning Agency

One indication of the problems and issues surrounding DACs and SESs are the waiting lists. Of the 107 DACs, 28 reported a total of 402 persons (82 children and 320 adults) on waiting lists. DACs in Region 11 (Twin City Metropolitan Area) account for 88.8 percent of all people on waiting lists.

The waiting list situation in SESs was similar during 1982; 22 agencies reported waiting lists ranging from 1 to 151 persons for a total of 870. One agency that did not have a waiting list stated that it was at program capacity and no longer accepted applications. The breakdown of SES waiting lists indicated the following types of services were sought:

Work Activity, 425
Long-Term Sheltered Work, 172
Work Adjustment Training, 105
Vocational Evaluation, 99
Skill Training, 44
Other, 25
Total Number, 870

NOTE: An examination of the waiting lists for DACs revealed a duplication of 126 clients on the work activity center lists

SOURCE: Developmental Disabilities Program, State Planning Agency

The statewide studies of day programs identified the following problems.

- The lack of a stable funding base for day programs;
- Cuts in day program services, including reductions in days and hours of service and client dismissals due to fiscal constraints;
- Wide variations in program availability and levels of service across the state;
- Inability to deal with special needs clients (severely and profoundly retarded, multiply handicapped, individuals with behavior problems);
- Procuring sufficient amounts of work; and
- Lack of adequate standards and monitoring of programs.



What's Possible

Vocational Education Alternatives

Vocational Education Alternatives (VEA) in Madison, Wisconsin has provided vocational services to disabled people outside sheltered workshops since April 1980. Funded by the United Services Board of Dane County, VEA has established a reputation for its high job placement and retention rates at relatively low cost. Through cooperation with the Madison Public Schools, high school graduates with disabilities are provided with transitional vocational services leading to additional training and/or job placement. Many high school graduates are enrolled in vocational technical schools with subsequent job placements. Parents are trained to advocate for their sons or daughters. As of January 1983, VEA users were working as messengers, laundry workers, grill cooks, warehouse laborers, unit clerks, bank tellers, personal attendants, security guards, waitresses, cashiers, mechanics and others.

In 1982, VEA served a total of 265 persons with disabilities. Seventy-two clients were placed into competitive employment, with an overall retention rate of 69 percent. An additional 67 people were enrolled in their last semester of vocational technical school. The total 1982 budget for VEA was \$192,258; an average cost of \$726 per person. That amount was considerably less than the average \$3,500 per person for a traditional day program in the Madison area. VEA's cost effectiveness is a result of not having any facility (rent or purchase) or production costs. In addition, generic vocational resources are utilized rather than using traditional categorical funds.

Employment Training Program

The Employment Training Program of the University of Washington is a collection of training, research and development activities designed to enable mentally retarded adults to obtain and keep employment in the private sector. The program trains people to work in various food service operations on the University campus and has been replicated on three community college campuses in the state of Washington. The high turnover rate in food service (up to 400 percent per year) assures an adequate number of jobs for program placement.

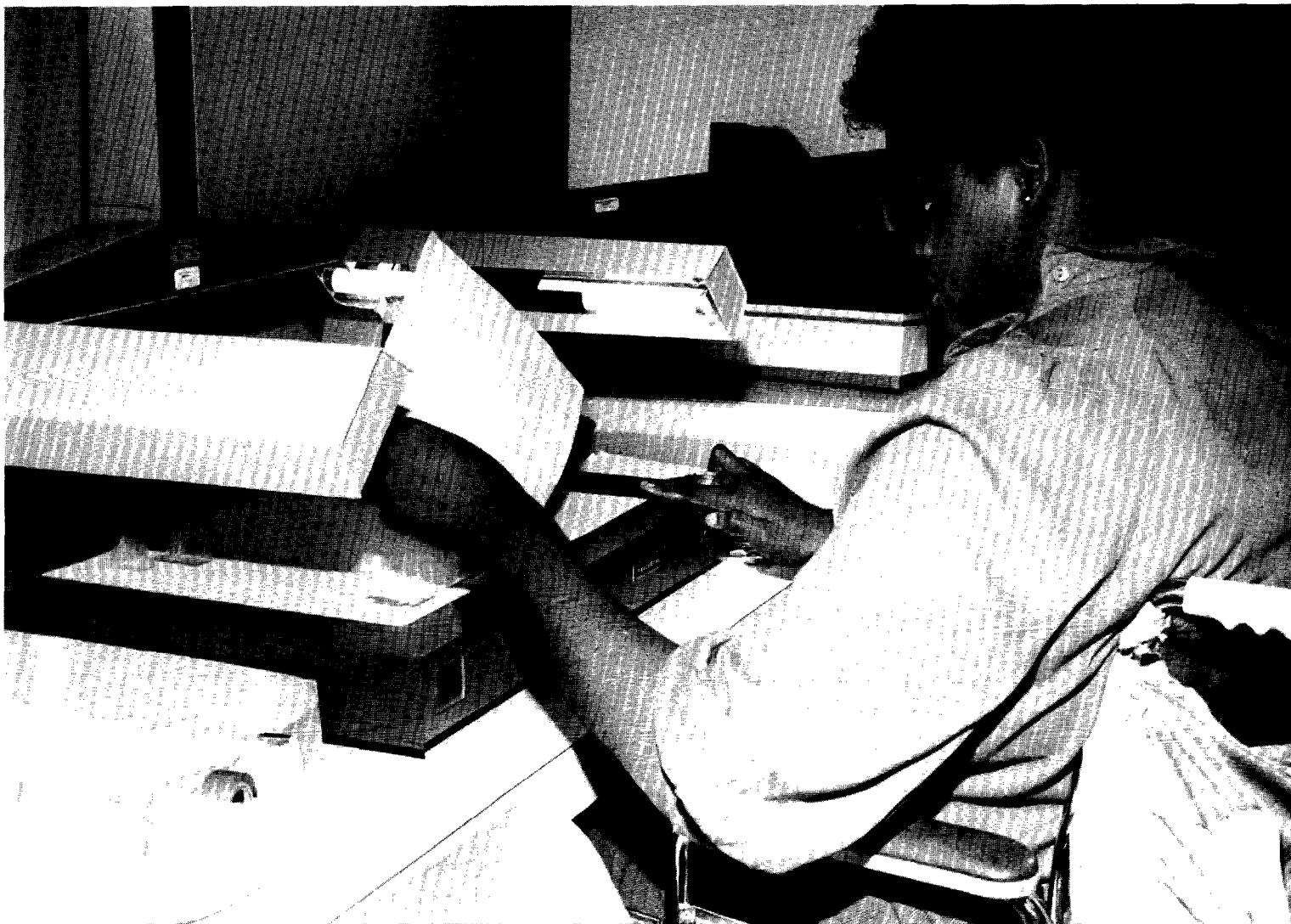
After seven years of operation, 128 individuals have completed the program. Eighty-five people have entered competitive employment elsewhere and have earned a total of \$962,368 in wages. Seventeen people are still in training. Twenty-nine failed to reach criteria for competitive employment. Thirty-nine are currently employed. The average cost of training was about \$7,000 per person with follow-up cost totaling from \$200 to \$300 per year per client. The State of Washington has introduced two new funding categories to stimulate employment of disabled adults: Specific Job Training (SJT) and Employment Support Services (ESS). SJT must take place in real-job situations and ESS is designed to follow-up and maintain workers in competitive employment. No funds may be used for SJT unless funds have also been invested in an ESS program. These programs were put into place with the recognition that training without placement is futile and placement without employment support services achieves little in the long term.

"Without job training, a retarded person is doomed to a lifetime of welfare in a make-work environment. With training, retarded individuals can work, pay most if not all of their own costs, and hold their heads high as productive members of society. It is unbelievable that job training for these people is such a low priority for most states."
(Jim Moss, Director)

Virginia Commonwealth University Rehabilitation Research and Training Center

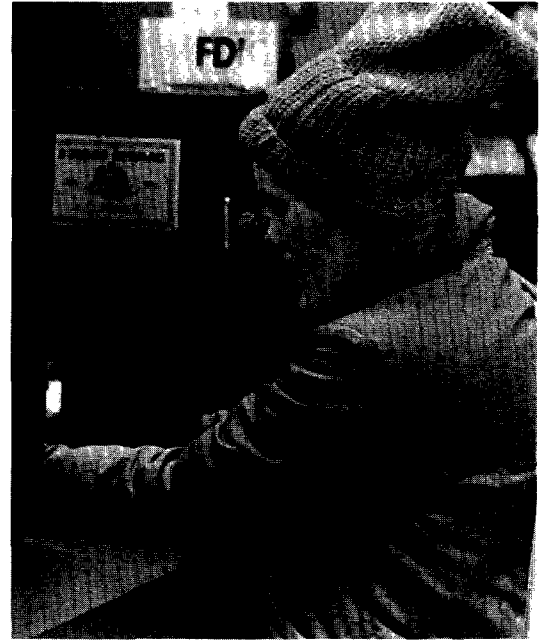
The Virginia Commonwealth University Rehabilitation Research and Training Center provides training related to employment of mentally retarded individuals. Recent accomplishments have included the following:

- Center staff worked with more than 80 local employers and over 150 severely disabled individuals (with a median IQ of 45) who have been trained and placed into competitive employment. Most of these individuals had been previously excluded from services because of the perception that they were too "hard-to-place."
- The center staff developed and implemented a "supported work model" which provided job training and follow-up by professional staff at the job site.
- The center has provided long-term tracking and follow-up of 80 clients who are still currently employed.
- A recent grant from the U.S. Department of Education has been obtained that will demonstrate an innovative vocational education program for severely physically handicapped (non-retarded) youth, ages 13-21 years old. The focus of this program will be on training for vocational skills leading to job placement in high tech industries.



Steps Toward the Policy Goal

1. Day programs (DACs and sheltered workshops) need a revised mission statement that relates to physical and social integration and work.
2. Alternatives to the current day programs should be encouraged through experimental programs supported by the state. Each new option must be flexible to maximize responsiveness to individual needs.
3. Eliminate any remaining fiscal disincentives at the county and individual levels to encourage placement in the least restrictive setting.
4. Minimum orientation and training standards (preservice and inservice) should be developed for day service staff.
5. Specialized programs and technical assistance must be developed for "hard to serve clients" such as multiply-handicapped, severe behavior problems, dual diagnosis, or severely and profoundly retarded people. These specialized services should also emphasize integration and work opportunities.





LIVING IN THE COMMUNITY

Goal: An Array of Community Residential Alternatives Must be Developed in Addition to ICF-MR Facilities and SILS. Each New Option Must be Flexible and Responsive to Individual Needs

Current Status.

Hubert Humphrey (1977) once said, "I love that word community." In Minnesota, the existing community living arrangements for developmentally disabled people and the residential services proposed in the state's Medical Assistance waiver application include the following:

In-Home Family Support Services:

Includes the provision of services such as homemaking assistance, respite care, parent training, and support groups to families. Sources of funding include the Minnesota Family Subsidy Program, county human services boards, and advocacy groups.

Semi-Independent Living Services (SILS):

The provision of SILS involves placement of adults in small units (2 to 4 people) where they are supervised by a licensed agency and provided with services based on need, including training in cooking, shopping, hygiene, and using public transportation. The purpose of SILS is to train for independence or to maintain individuals in semi-independence. SILS room and board are paid from the following sources: Supplemental Security Income (SSI), Minnesota Supplemental Aid (MSA), Social Security, Section 8 (HUD), General Assistance (GA), wages, food stamps, and combinations of these. As of December 30, 1983, there were 67 licensed SILS agencies with a total capacity of 1,290 persons in Minnesota.

Foster Care Services: Foster care services are provided for children who cannot live with their families and for adults who could benefit from a family setting. For child foster care, licensing standards require special provider training and experience and written individual programs. Foster care costs are paid in a number of ways: a) private pay by clients, b) SSI/MSA funds, c) general assistance and d) other sources. In 1982, approximately 200 adults and 600 mentally retarded children were receiving foster care services in Minnesota.

Group Living Services: In Minnesota, group homes are usually licensed as Intermediate Care Facilities for the Mentally Retarded (ICF-MR). Residents are provided with a plan of care with active treatment and 24-hour supervision. Most Minnesota group homes are licensed for 6 to 15 people; 45 are larger, of which 6 exceed 100 beds. However, 46.6 percent of all ICF-MR residents live in facilities larger than 16 beds. Costs are paid by the federal government (52.2 percent), the state (43.0 percent), and the county (4.8 percent). As of December 30, 1983, 5,113 mentally retarded persons were living in 330 licensed group homes in Minnesota.

Supported Living Arrangements

These residential settings are part of the proposed array of services to be funded under the waiver. The arrangements, as proposed, would involve maintaining up to six adults or up to three children in a residential setting, using existing housing to the greatest extent possible.

Minnesota was an early leader in the development of community-based ICF-MRs, and the number of these facilities in the state has continued to grow rapidly. According to a recent report by the Legislative Auditor, Minnesota's population in community-based ICF-MRs is, on a per capita basis, higher than that of any other state. (Legislative Auditor, 1983, p. 12)

The Legislative Audit report concluded that overreliance on the ICF-MR model has been very costly because of the state's long-term investment in property and buildings. The Audit report further noted that "alternatives to ICF-MR care, such as semi-independent living services (SILS) and foster care, lack stable funding and are not well-developed" (p. 77).

Concern over the rising Medical Assistance costs for ICF-MR facilities contributed to passage of a bill during the 1983 Minnesota legislative session which restricted further growth of the ICF-MR system. The law established a cap on the number of certified ICF-MR beds in the state and restricted further development to areas of high need and for specific populations.

Proposed federal legislation, the Community and Family Living Amendment, would shift the federal share of Medicaid funds from institutions to community-based settings. This proposed legislation, which was introduced as S.2053 on November 4, 1983, would provide federal Medicaid funds for residential services with 15 or fewer residents. Facilities for more than 15 residents would have federal Medicaid funds phased out over a ten year period. Given the size distribution of Minnesota's ICF-MR facilities, such legislation, if passed, would have a substantial fiscal impact on the state.

What's Possible

Michigan Alpine Center

The plan to phase out the northern Michigan Alpine Center was announced in June 1980. That mission was accomplished by November 1981, almost two months earlier than planned. It was the first time in the United States that a state center for persons with mental retardation had managed to move all of its residents out of an institution and into community settings.

Under the new service system, the Alpine Center has been transformed into an administrative regional service center that is responsible for more than 300 mentally retarded persons in community settings and an additional 100 persons in nursing home care. The Alpine Center will employ approximately 75 people until the local community mental health boards assume responsibility for management of the decentralized service system.

The Alpine Center also administers three satellite homes of six beds each which provide care for persons requiring intensive behavioral or medical services. The satellite homes also provide a setting for diagnostic and assessment services as well as on-site training for persons who work in community homes.

A network of residential options was created throughout the 21 county service area, which included:

- 28 alternative intermediate service homes (A.I.S.) providing group home settings for 6 to 8 persons requiring a very high level of structured programs.
- 46 community homes providing services to people who require a moderate degree of training and supervision. These are family foster care homes for no more than three persons.
- One nursing home providing care for mentally retarded persons who are elderly or who have related medical problems requiring 24-hour care and supervision.
- A number of day activity centers and sheltered workshops/work activity centers were created or expanded to serve the increased number of people who had moved out of the Alpine Center.

It was exactly at 12:05 p.m., November 5, 1981, when the last resident left the Alpine Center for a new home in the community. At that time, C. Patrick Babcock, Acting Director of the Michigan Department of Mental Health, stated:

"This is a unique, historic occasion. For the first time in the nation, a system of community services has been developed which is so comprehensive that the institution is no longer needed as a residential setting."

In introducing S.2053 Sen. Chafee, stated:

The need for an examination of the care provided to the severely disabled is desperately needed, and I strongly believe that this bill is an appropriate starting place.... Not only will this bill provide a new way of caring for those in our society who have disabilities, it will also provide protection for those people.

Steps Toward the Policy Goal

1. An array of community residential alternatives must be developed in addition to ICF-MR facilities and SILS. Each new option must be flexible to maximize responsiveness to individual needs.
2. Residential services should be defined by intensity of staffing (ratios and training levels) allowing changes of support in response to client needs and increases in independence.
3. Eliminate any remaining fiscal disincentives that require counties to pay a greater share of less restrictive placements.
4. Minimum orientation and training standards should be developed for residential service staff.
5. Specialized programs and technical assistance must be developed for "hard to serve clients" such as multiply-handicapped, severe behavior problems, dual diagnosis, or severely and profoundly retarded people.





TECHNOLOGY

Goal: All Persons With Developmental Disabilities Should Have Access to Applications of Technology Which Could Improve Their Quality of Life.

Current Status.

Modern technology offers major potential for improving the quality of life for disabled persons. In programs throughout the United States, technological devices have been developed and adapted to assist disabled people, especially severely disabled people, in many activities. Technology provides disabled people with improved means of communication, mobility, and control over their environment. It also provides access to a range of educational and vocational opportunities previously closed to disabled people.

Currently, in Minnesota, there are several resources which provide disabled people with information about technology and/or direct access to technological aids. These resources include:

Courage Center, Golden Valley.

The Center's programs include a Communication Resource Center which provides evaluation, recommendation of communication systems, system modification when necessary, training, and follow-up services. Courage Center's Rehabilitation Engineering Program assesses an individual's need for special devices, recommends and modifies available commercial devices and designs new devices when necessary. Rehabilitation engineering services are available in the areas of independent living, vocational accommodations, and nonverbal communications. The Center has also established a Pediatric Rehabilitation Engineering Clinic with five areas of emphasis: functional therapeutic, mobility, and educational aids; activities of daily living adaptations; and recreational equipment.

Gillette Children's Hospital, St. Paul.

Gillette Children's Hospital provides clinical services in orthotics (braces, standing frames, etc.), prosthetics (artificial limbs), and adaptive equipment to children and young adults with various disabilities. The program employs a rehabilitation engineer; seating and positioning are special areas of emphasis. Services are provided to individuals from Minnesota as well as from other states.

Closing the Gap, Henderson.

Closing the Gap is a bimonthly publication devoted to use of microcomputers by persons with disabilities. It is an excellent resource on hardware and software useful for children and adults with various disabilities. **Closing the Gap** is edited and published by Dolores and Budd Hagen, who also conduct workshops to train special education staff and others in the use of microcomputers as educational tools for disabled children.

Minnesota Educational Computing Consortium (MECC), Roseville.

MECC provides educational computing services and products, including in-service training and microcomputer courseware, to Minnesota schools and colleges. MECC courseware includes programs specifically created for disabled children, such as Blissymbols; in addition many other MECC programs have been modified for use by vision impaired, hearing impaired, and physically handicapped individuals.

Department of Physical Medicine and Rehabilitation, University of Minnesota Hospital, Minneapolis.

The Department provides services, including rehabilitation engineering, medicine, occupational, physical, and speech therapy to individuals with various disabilities. In addition to clinical services, the Department provides outreach services to public schools and developmental achievement centers throughout the state.

In spite of numerous innovative programs and resources and expertise available in the area, many disabled persons still do not have access to technology with potential for impacting on their quality of life. Lack of knowledge and training regarding new technology on the part of professionals and lack of funding for devices not considered "medically necessary" by third party payers are the primary reasons for this lack of access.

What's Possible

Trace Center, University of Wisconsin

The Trace Center provides communication systems to persons who are non-vocal or whose speech is inadequate for communication. The Center assesses children and adults, recommends communication systems for them, and provides training and follow-up services. Trace was an early leader in providing disabled people with access to microcomputers for many purposes, such as advanced communication devices, educational devices, and environmental control and security systems. In addition to conducting research on communication problems, developing new aids and fostering the commercialization of existing aids, the Center also disseminates current information in the field via publications and national workshops. Through cooperative programs with the University of Wisconsin hospitals and the county surrounding Madison, Trace provides disabled people with direct access to the Center's expertise.

Artificial Language Laboratory, Michigan State University

The Artificial Language Lab provides communication systems and microcomputer access to severely disabled persons. The Laboratory has worked with Michigan schools for the past several years to bring microcomputer technology to severely disabled students. The Lab has developed software packages and special electronic devices, and trained professional staff in several school districts. In cooperation with the Trace Center, the Artificial Language Laboratory publishes **Communication Outlook**, a quarterly publication on developments in the field of communication.

Rehabilitation Engineering Center at Stanford Children's Hospital

The Rehabilitation Engineering Center (REC) at the Children's Hospital at Stanford conducts research and development activities on technological aids as well as providing clinical services. The REC program is quite extensive with service departments in seating, mobility, orthotics, prosthetics, communication, control of devices, and prevention of tissue trauma due to pressure sores. The REC also has a clinical internship program in rehabilitation engineering and an information service which collects, organizes, and disseminates information on rehabilitation equipment and adaptive devices and aids.

National Rehabilitation Information Center (NARIC)

NARIC maintains ABLEDATA, a rehabilitation equipment and technical aids data base, and disseminates product information, bibliographies and journal abstracts on rehabilitation through a network of information specialists and brokers.

The Maryland Rehabilitation Center

The Maryland Rehabilitation Center works with adults who are multiply and severely disabled, providing devices to access microcomputers (such as switches operated by a person's hand, foot, or head movement), evaluation, remedial training, and help with job placement. Many of the individuals with whom the Center now works would have been "untrainable" in the past, because of inadequate communication abilities.

"Currently, only a fraction of disabled Americans are able to benefit from existing technologies that would improve the quality of their lives. A national commitment is needed to assure that all disabled Americans regardless of the nature of their disabilities or their financial status, can secure and utilize any proven technologies that will enable them to lead more productive, functional, and satisfying lives."
(LaRocca and Turem, 1978)

Computers to Help People, Inc.

Computers to Help People, Inc. is a small business which does accounting, billing, data entry, consulting, software development, and offers courses and one-to-one tutoring to disabled persons on buying and using microcomputers. The founder of the company is a computer programmer with twelve years experience. He is also deaf and blind. His coworker is a programmer who has limited speech due to cerebral palsy. Special hardware and software adaptations to their standard computers enable them to communicate with each other and run their business. Recent funding from the city of Madison and from Access to Independence (a nonprofit organization also in Madison that helps the disabled live independently) will allow them to hire two part-time employees, putting into action their motto, "We employ the unemployable."

Bioengineering Program, Association for Retarded Citizens (ARC) of the United States

The purpose of the ARC Bioengineering Program is to improve the quality of life for mentally retarded persons, especially severely/profoundly retarded persons, through technology. Program activities consist of adapting currently available assistive devices for use by retarded persons, developing new assistive devices when needed, and consolidating information on the use of technological aids into a technology resource library.

Biomedical Engineering Center, Tufts-New England Medical Center

In addition to developing communication devices for non-vocal severely disabled persons, Center staff have developed a series of short courses on rehabilitation engineering topics to provide clinicians in the field with an opportunity to gain technical skills. Topics covered have included design, microcomputers and robotics. Under a contract with the Massachusetts Department of Public Health, the Center director also provides rehabilitation engineering services in mobility, communication and computer access to children in the Massachusetts Hospital School.

Committee on Personal Computers and the Handicapped (COPH-2)

COPH-2 is a consumer based organization which provides members with technical assistance, personal computer loans, use of a resource library, and networking opportunities. The organization also designs and produces keyguards to prevent inadvertent striking of keys, publishes a quarterly newsletter, and conducts public education meetings.

*"In a world where human beings and the machines they command have the power to control the quality of life, handicapping conditions can only be the result of a failure to properly apply technology or the neglect of its development."
(Rahimi, 1981)*

Steps Toward the Policy Goal

1. A state policy agenda for use of technology by disabled people in Minnesota should be developed and implemented.
2. Awareness of technological advancements should be increased among disabled persons and their families, professionals, policymakers, and the general public.
3. Professionals from a range of disciplines should receive up-to-date training on the uses of technology for disabled persons.
4. Disabled individuals who need technological aids should have access to adequate assessment, prescription, and follow-up services within a reasonable distance from their homes.
5. Funding mechanisms should be changed to cover the purchase and maintenance of technological aids as well as the support services necessary to fully utilize the aids.



IN CLOSING

Minnesota has moved ahead with prevention and appropriate services for persons with developmental disabilities, but more needs to be done. Increased efforts for prevention and early intervention to reduce the effects of disabling conditions need to be first-level priorities. Existing and new services should be of high quality, responsive to unique individual needs and strive to integrate persons with disabilities into the mainstream of their communities. Our achievements and our aspirations for the future need to be combined in a state policy agenda that increases both equity and access to service through community-based delivery systems. Continued progress means redirecting the focus from facilities to clients. Guided by a policy agenda we can move toward futures of quality for all Minnesotans.



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Computers to Help People, Inc.
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Employment Training Program
Child Development and Mental
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University of Washington
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