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Services for People with Developmental Disabilities:

A Guide for Private Funders



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with
Developmental Disabilities:
A Guide for Private Funders**

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- **WHAT IS A DEVELOPMENTAL DISABILITY?**

**Focus on Service Needs—
Not Medical Labels**

The concept of "developmental disability" evolved in the early 1960s because people with mental retardation, cerebral palsy, autism and other severe disabling conditions were seen to have more similarities than differences in their need for services. Professionals decided that these service needs should take precedence over the medical labels for their disabilities.

Hence the term "developmental disability (DD) to signify mental or physical impairments that show up before the age of 22, are severe and chronic, and substantially interfere with at least three basic life activities such as the ability to work, to learn and to care for one's self. The emphasis is on the person's ability to function rather than on his or her specific medical diagnosis.

In the Metropolitan Area, roughly three-quarters of people with developmental disabilities are mentally retarded. Others have cerebral palsy, epilepsy, autism or one of several other disabling conditions that severely impair everyday activities. Developmentally disabled people often have multiple handicaps.

"Normalization" the Philosophy

Throughout the '60s, it became apparent that the most important needs were social not medical—a normal environment in which to live and go to school, a place to work and the opportunity to use the same community services as the general population.

These needs and the shortage of services to meet them, fueled a social philosophy—"normalization"—which implies that the burden of proof should be shifted to those who feel handicapped people can't live in the community.

While normalization encompasses all aspects of life, the most visible thrust has been returning developmentally disabled people from state hospitals and similar institutions to their home communities. Here, Minnesota was an early leader.

Improvements, Benefits Apparent

Since 1960, the developmentally disabled population of our state hospitals has been reduced from 6,100 in 1963 to 2,400 today, not to mention hundreds of people who were never placed in state hospitals because an alternative in the community was available.

The emphasis on active treatment in community settings has produced dramatic improvements in self-esteem, independence and social behavior of developmentally disabled **citizens**. For example, about 600 Minnesotans who were once in state hospitals are living in their own apartments and need little or no supervision.

Similarly, because education and training through the local school are now available, most parents are able to keep their developmentally disabled child at home. These are just a few of the benefits of a shift in philosophy and practice that is barely 20 years old.

- **HOW MANY PEOPLE HAVE DEVELOPMENTAL DISABILITIES?**

Although estimates vary, a 1980 Metropolitan Health Planning Board survey found that 16,500 Metropolitan Area residents—8.4 out of every 1,000—had a developmental disability.

17,085 Developmentally Disabled People by 1985

Based on this ratio, 17,085 people with developmental disabilities will live in the Metropolitan Area by 1985. More than 75 percent of developmentally disabled people in the Metropolitan Area are mentally retarded. The rest of the developmentally disabled population includes people with cerebral palsy, autism, epilepsy or other physical handicaps.

Many with More Than One Handicap

It's important to remember that many developmentally disabled people have multiple handicaps. In fact, a 1978 Health Planning Board survey concluded that in addition to their primary disability, 25 percent of disabled people also had trouble walking, and up to 50 percent had an additional learning disability.

- **HOW ARE PEOPLE MATCHED WITH THE RIGHT SERVICES?**

County the Responsible Agency

In Minnesota, counties are responsible for obtaining services for developmentally disabled people. The county appoints a case manager who develops an individual service plan for each person.

This service plan incorporates the recommendations of the interdisciplinary teams that monitor the progress in each setting where the person receives service.

The team is made up of the client, the parent or guardian, the county case manager and other professionals, such as social workers, speech therapists or psychologists, depending upon the type of services the person needs. The purpose of the services selected is to reduce the person's level of dependence.

• **WHAT SERVICES DO PEOPLE REQUIRE?**

Needs Vary Over Broad Range

Many people need only a few services, while others may depend totally on the service system for all aspects of daily living—at least for a portion of their life. In general, the services that disabled people use fall into the following three categories:

Residential

State hospitals
Community group homes
Foster homes
Semi-independent living
Support services in the family home

Day Programming

Public schools
Developmental achievement centers
Work activity
Sheltered work

Support

Diagnosis
Referral
Therapy
Medical treatment
Case management
Respite care
In-home services

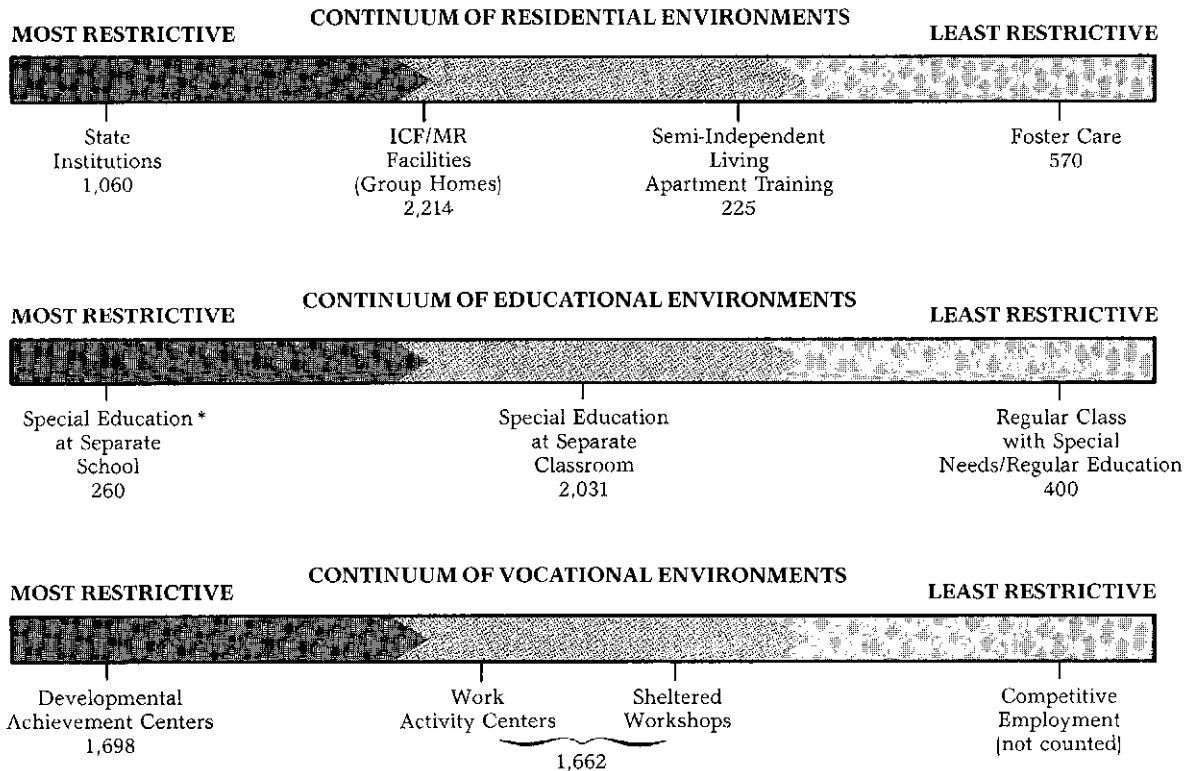
The mix of services changes as the person ages. As with nonhandicapped people, when individuals grow or gain new skills, they move to settings more suited to their needs and abilities.

With active treatment and skills training, developmentally disabled Minnesotans have made dramatic improvements in their capacity to live in the community.

Settings Vary—Most to Least Restrictive

Because people do progress, DD services are usually organized in a continuum from most restrictive to least restrictive. Least restrictive settings are usually those that most closely resemble normal patterns of daily life for people without handicaps (see accompanying definitions).

Figure 1. TYPICAL SERVICE CONTINUA IN THE METROPOLITAN AREA AND THE NUMBER OF PEOPLE SERVED IN EACH SETTING



*Service settings for physically handicapped, autistic, and trainable mentally retarded students only.

Sources: Department of Public Welfare, Mental Retardation Program Division. State Department of Education, *Special Education Unduplicated Child Count (1981)*. Developmental Disabilities Program, Minnesota Department of Energy, Planning and Development.

PEOPLE'S SERVICE NEEDS CHANGE AS THEY AGE OR GAIN NEW SKILLS. UNDERFUNDING OF LESS RESTRICTIVE SERVICES OFTEN INHIBITS CLIENT MOVEMENT THROUGH THE CONTINUUM.

- **DEFINITIONS**

The kinds of settings include:

State hospitals are large institutions organized into smaller living units. Most education, training, medical and recreation services are provided on-site. Seven of the eight state hospitals serve DD people—primarily severely and profoundly retarded people or those with severe behavior problems.

Roughly 40 percent of the 2,400 developmentally disabled state hospital residents are from the Metropolitan Area. State hospital care for developmentally disabled people is funded by the federal/state Medicaid program.

Most **community residential facilities** or **group homes** are neighborhood homes that provide the semblance of family life/small group living for 6-16 people. In the Metropolitan Area, more than half of all homes serve six or fewer residents. The houses are staffed around the clock, often by live-in house parents. While the staff provide some special programming and skill training, residents of group homes work, go to school and receive other services outside the group home.

In the Metropolitan Area, there are 119 group homes serving 2,214 people at all levels of functioning. Group homes are funded by the federal/state/county Medicaid program. Providers are reimbursed by the Department of Public Welfare (under DPW Rule 52) for the reasonable cost of staffing, services and property-related costs (depreciation and interest).

Semi-independent living services (SILS) are a relatively new program that aims to provide intensive support and training to people who hope to live independently in the community and who don't need the intensive services of a group home. They learn practical skills necessary to function in the community.

Right now, 225 Metropolitan Area residents are receiving SILS services either from county social workers or from private providers under contract to the county. Many are "graduates" of group homes; others are coming right from their family home and, because of SILS, have been able to skip the group home transitional step. Counties apply to the state for SILS grants. The state pays 81 percent of the cost of service for clients coming from an institution or group home or at risk of being placed in these settings, and 50 percent of the cost of services for other clients. A small number of people are receiving SILS-like services from programs that are funded solely from county revenue.

Developmental achievement centers (DACs) are day programs teaching basic living skills, self-care, social behavior, basic academics and some pre-work training. In 1982 in the Metropolitan Area, 53 centers served 1,253 people who were beyond school age but not ready for work training, and 445 children under school age and infants who exhibited delays in development. In the Metropolitan Area, more than half of the people who attend DACs live in their family home, and about 40 percent live in a community group home. DACs are funded from a state/county block grant for social service. On average, counties pay roughly 60 percent of the cost of DAC services.

Most **vocational services** are provided in the 23 vocational rehabilitation facilities and sheltered workshops in the Metropolitan Area, although some school districts and DACs provide basic pre-work training. Clients progress from *work activity*—primarily training-oriented work stations at *work activity centers (WACs or DACs)*—to *sheltered work*, contract work in the facility for a wage adjusted to reflect the person's level of productivity. About 1,100 developmentally disabled people work in sheltered workshops or work activity centers in the Metropolitan Area. In 1980, about 100 of these were able to move to competitive employment. Federal, state and local funds supplement the money that rehabilitation facilities earn from contracts with private industry.

- **WHO PAYS FOR SERVICES? WHAT DO SERVICES COST?**

Combination of Public and Private Sources

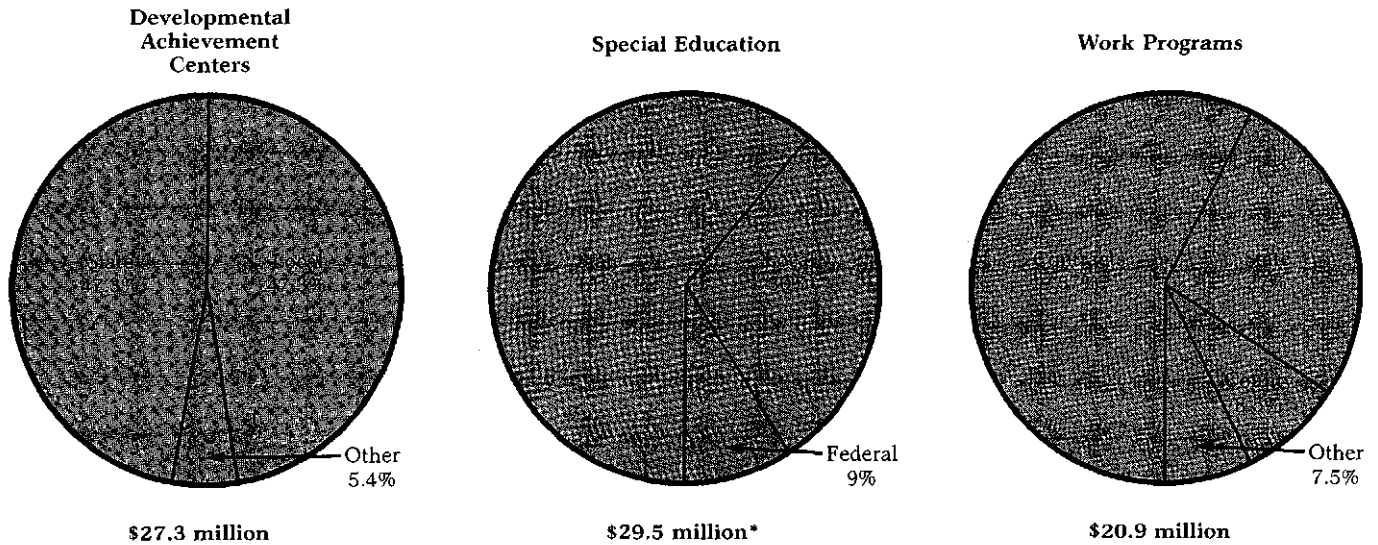
Although DD services depend on public subsidy, most are financed by a combination of public dollars supplemented by client income, parent contributions (when the client is under 18 years old), and private or corporate funds. For example, nearly 60 percent of the operating revenue of rehabilitation facilities came from contracts with private industry.

All levels of government and nearly a dozen public programs finance services for people with developmental disabilities, though the mix of sources changes with the service. In fact, how costs are shared creates different placement incentives for each level of government involved.

Fragmented Funding Structure

Services vary widely in their daily cost, and comparison of daily rates is difficult. Some services are not provided 365 days a year. Other programs charge by the hour depending upon the intensity of the client's need. Still others include a broader array of activities than the services to which they are usually compared.

Figure 2. REVENUE SOURCES FOR DAY PROGRAM SERVICES IN MINNESOTA

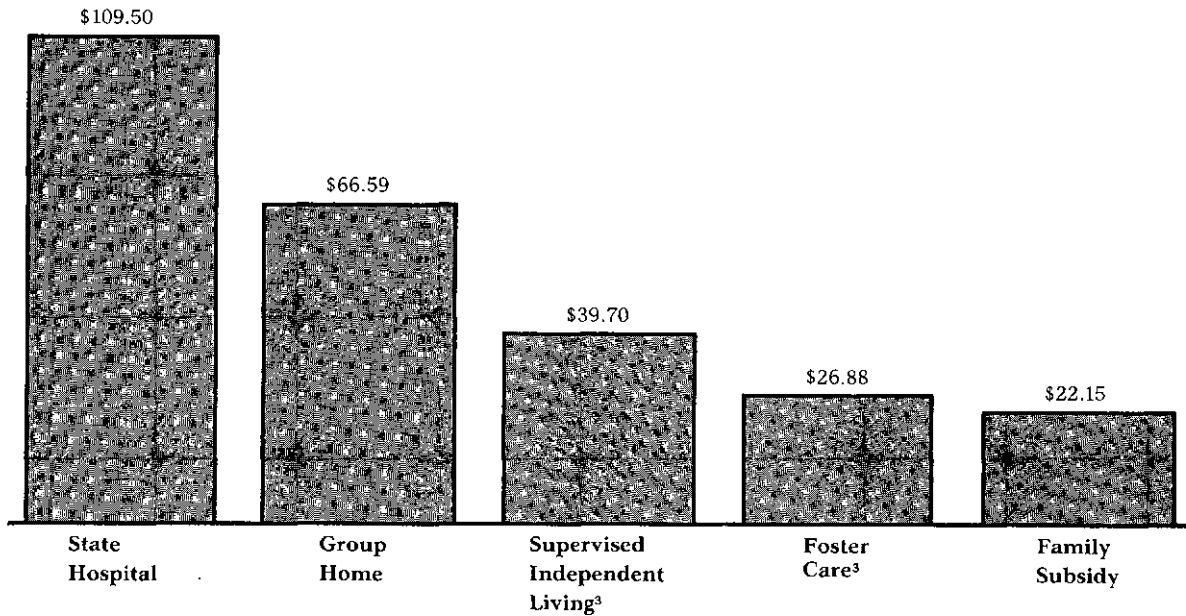


*Includes expenditures for physically handicapped, autistic and trainable mentally retarded students only.

Source: Developmental Disabilities Program (1983).

DAY PROGRAMS SERVE OVER 25,000 PEOPLE IN MINNESOTA AND ARE FINANCED THROUGH A COMBINATION OF PUBLIC, PRIVATE AND CLIENT FUNDS.

Figure 3. AVERAGE DAILY COST OF RESIDENTIAL SETTINGS IN MINNESOTA ^{1,2}



Funding comes from:⁴

MA

MA
CSSA

SILS
CSSA
MSA/SSI
Rent Subsidy
(Sect. 8)

CSSA
MSA/SSI
COUNTY
REVENUE

CSSA
Family
Subsidy

¹Average daily cost for each setting as reported in Office of Legislative Auditor (1983). Assumes governments share costs of service as per Table 1.

²Daily cost for all community settings includes annualized day program cost of \$14.88 per day.

³Includes cost of room and board.

⁴See accompanying definitions for description of programs and acronyms.

RESIDENTIAL SERVICES DIFFER IN COST AND IN THE METHOD OF FINANCING. IN GENERAL, THE LESS RESTRICTIVE THE SETTING, THE LESS EXPENSIVE THE DAILY COST, THE LESS STABLE THE FUNDING, AND THE MORE COMPLEX THE ADMINISTRATIVE STRUCTURE.

The major sources of public support for DD services include:

Medicaid (Medical Assistance, Title XIX of the Social Security Act). A federal-state funded program that finances medical services and long-term care for poor and disabled people. Medicaid pays for state hospital care and funds the system of community group home in Minnesota. The federal government pays roughly half the cost. The state and the counties share the nonfederal expenses (90 percent state, 10 percent county). (42,45 CFR; Minn. Stat. 256B,393)

Community Social Services Act (CSSA). A state block grant to counties for social services that the counties match with at least equal amounts of their own revenue. Because it is a block grant, different counties plan and use the money to finance different services. Generally, some CSSA money is used to finance DACs, foster care, the county portion of SILS expenses, in-home support projects and respite care. While the state theoretically pays half the cost of CSSA services, the demand for these services is so high that counties often overmatch the state grant by a ratio of 2 to 1. (Minn. Stat. 256E)

Title XX. A federal grant to states to help finance social service costs. These funds are allocated according to formula. Local governments supply one dollar for every three of a federal grant. Title XX defined a group of mandatory and optional services, but many of these restrictions have been lifted, and Title XX money is generally combined with the CSSA grant to counties. (Title XX, Social Security Act, DPW Rule 160)

Supplemental Security Income (SSI). A totally federal program to provide minimum levels of income to aged, blind or disabled people. Developmentally disabled people who are eligible for SSI receive a monthly grant of up to \$284.30 depending upon their income and resources. Recipients who have moved from state hospitals and group homes to less restrictive settings use SSI funds to pay for room, board and personal needs. SSI is a consolidation of three federal categorical programs for aged, blind and disabled people. (Title XVI, Social Security Act, 20 CFR)

Minnesota Supplemental Assistance. A state/county program to supplement SSI benefits or to help aged, blind or disabled people who are ineligible for SSI because of excess income or resources. The monthly MSA benefit is calculated by subtracting the individual's net income from a county determined "need standard." Net income includes wages and benefits from other government programs. The need standard is the county's determination of the monthly amount required for rent and basic necessities. (Minn. Stat. 256D,393; DPW Rule 57)

Semi-Independent Living Services (SILS). A state/county program to provide counseling and related community support services to maintain and improve a client's ability to function in a noninstitutional setting. The program assists people who no longer need a 24-hour supervised residential placement but are not yet able to live independently. SILS recipients live in apartments, rooming houses, foster homes and their own homes. They are provided with several hours per week of training and counseling. The county applies to the state for SILS money and contracts with private vendors or provides the service itself. The state pays 81 percent of the cost for SILS clients who are moving from institutionalized settings or are at risk of institutional placement, and 50 percent of the cost for all other SILS recipients. (Minn. Stat. 252.28; DPW Rule 18)

Table 1. HOW LEVELS OF GOVERNMENT SHARE THE COSTS OF MAJOR PUBLIC PROGRAMS

<u>PROGRAM</u>	<u>FEDERAL</u>	<u>STATE</u>	<u>LOCAL</u>
Medicaid	52.2%	43%	4.8% ¹
CSSA	—	50%	50.0% ²
Title XX	75.0%	—	25.0%
SSI	100.0%	—	—
MSA	—	85%	15.0%
SILS	—	81%	19.0% ³
Family Subsidy	—	100%	—

¹Source: State Health Planning and Development Agency (September 1982).

²Actually many counties are overmatching their state CSSA grant and contributing two local dollars for each dollar of state CSSA.

³Assumes the person is coming from an ICF-MR or is at risk of institutionalization. For all others the state pays only 50%.

ALL LEVELS OF GOVERNMENT AND NEARLY A DOZEN SEPARATE PROGRAMS FINANCE SERVICES TO DD PEOPLE. HOW COSTS ARE SHARED CREATES DIFFERENT PLACEMENT INCENTIVES FOR EACH LEVEL OF GOVERNMENT.

- **WHAT ARE THE MAJOR PROBLEMS AND SERVICE GAPS?**

In a word, the major problem the DD system faces is movement—or rather, the lack of it. People are not progressing through the continuum of services as quickly as they can and should be. Others are entering the service system late when early intervention could have eliminated or reduced the intensity of their need for services.

Funding Bias Mismatches Services and Needs

In an effort to control costs, federal programs for elderly, mentally ill or disabled people limited both the type of services and the type of client eligible for reimbursement. In the area of residential services, two unfortunate consequences have resulted. First, to maximize stable Medicaid funding and federal participation in reimbursing services, clients have been assigned to federally reimbursable programs, even when other services would more appropriately meet their needs.

Second, Medicaid rules require a medical approach even for those whose need is primarily for social services. As a result, public expenditures heavily favor institutional or restrictive settings whether or not these settings are most appropriate for the majority of clients.

Least Restrictive Settings Underfunded

Though the overwhelming majority of DD people live in their own or their family's home, and though many more could live in settings even less restrictive than community group homes, all but 10 percent of public expenditures support state hospitals and group homes. Services such as respite care, in-home care and less restrictive residential alternatives are severely underfunded.

The way that services are funded exacerbates the problem. Governments share the cost of services in many ways. As a result, services that are less expensive overall may be underused because the cost experienced by one level of government exceeds its contribution to the cost of a service with a higher daily rate.

For counties, for example, the least expensive option is the state hospital. Indeed, because of fragmented funding, the more independent the setting becomes, the more that service costs the county.

Wanted—More Support for Less Restrictive Settings

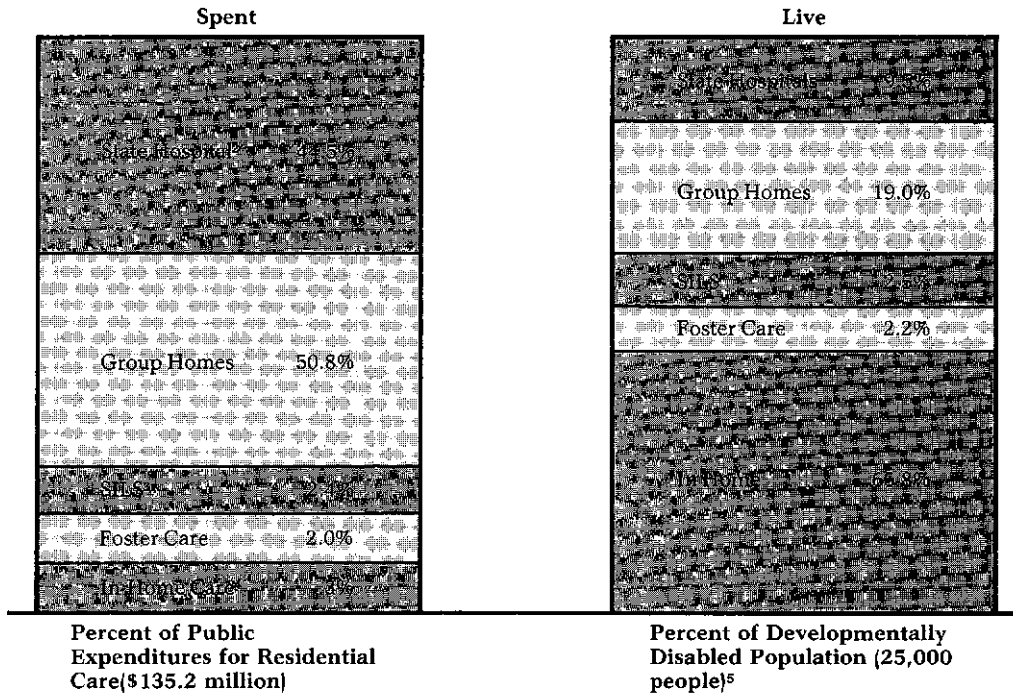
Projects that demonstrate the cost effectiveness of noninstitutional settings: in-home services and training for foster care providers so these homes can serve more difficult people.

Projects that eliminate the need to return people to more restrictive settings: respite care for families, professional intervention or consultation to help parents work with a severely handicapped child, and behavior management teams who can train group home staff so residents with behavior problems can remain in the community.

Programs Are Interdependent

Cuts in funding are a fact of life for public programs in the 1980s. In the area of developmental disabilities, however, services are so interdependent that cuts in one service adversely affect other services that have stable funding. For example, state statutes wisely require that all group home residents have a suitable day program outside the home. While money for

Figure 4. WHERE PUBLIC DOLLARS IN MINNESOTA ARE SPENT VS. WHERE DEVELOPMENTALLY DISABLED PEOPLE LIVE¹



¹Sources: Office of Legislative Auditor (February 1983). Developmental Disabilities Program, Minnesota Department of Energy, Planning and Development (January 1983).

²Cost of day programming in state hospitals (approximately 15% of the per diem) has been excluded.

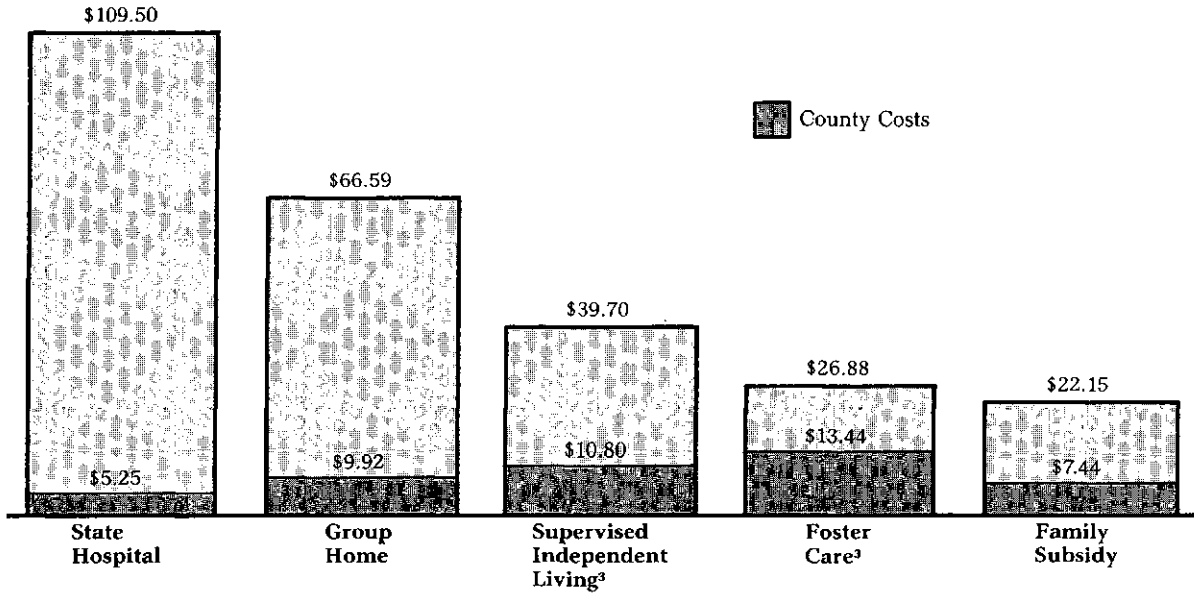
³Includes SSI/MSA funding of room and board and SILS service costs.

⁴Does not include county expenditures for respite care or in-home support programs.

⁵Unduplicated count of mentally retarded people served in day programs. Does not include those competitively employed.

AN INSTITUTIONAL BIAS PERMEATES THE SYSTEM. PUBLIC EXPENDITURES DON'T GO TO SETTINGS SERVING THE MOST PEOPLE.

Figure 5. AVERAGE DAILY COST OF RESIDENTIAL SETTINGS IN MINNESOTA VS. COSTS TO THE COUNTY ^{1,2}



¹Average daily cost for each setting as reported in Office of Legislative Auditor, Program Evaluation Division (February 1983). Assumes governments share costs of service as per Table 1.
²Daily cost for all community settings includes annualized day program cost of \$14.88 per day.
³Includes cost of room and board.

BECAUSE OF FRAGMENTED FUNDING, LOCAL GOVERNMENTS OFTEN PAY MORE FOR SERVICES THAT ARE LESS EXPENSIVE OVERALL.

group homes is still available, day program cuts have restricted additional group home expansion. This hurts families who find they can no longer care for a disabled family member as well as those who are waiting to return to the community from state hospitals.

Lack of employment opportunities has halted movement through the day program continuum. When sheltered workers can't move to competitive jobs, DAC/WAC clients or those

graduating from high school can't move to sheltered workshops. Surveys show that work program clients ultimately return \$1.67 for every dollar of public money invested in their rehabilitation. Because the economy can't absorb those ready for competitive employment, both sheltered workshops and DACs are filled to capacity. Right now, 250 developmentally disabled people are ready for sheltered work while 200 are waiting for DAC services.

Wanted—Flexible Employment and Day Program Options

Projects that expand the range of employment options or test new ways of providing employment or training: on-site sheltered work, on-the-job support for those who are competitively employed and group sheltered employment where a group of handicapped people in a plant produce one component of a larger product.

Projects that focus on the vocational potential of the most disabled people: cooperative ventures between DACs and sheltered workshops/private industries.

Projects that address changes in day program needs as people age: leisure time or life enrichment programs for older disabled people as an alternative to DACs.

Emphasize Prevention and Early Intervention

More than 50 percent of mental retardation is preventable. Often, milder forms of retardation are associated with inadequate social, psychological and learning environments.

Children in poverty are particularly at risk. Prevention measures that address the increase in the number of babies with low birth weights could reduce the incidence of cerebral palsy and other disabilities.

Where disabilities exist, early intervention can lessen their effect. Research shows that early intervention programs with "developmentally delayed" infants can eliminate the need for expensive special education programs later on.

Wanted—Support and Training for Families

Projects that focus on family training and counseling, or infant stimulation.

Projects that intervene immediately with babies at risk of developmental disabilities.

Projects such as respite care or crisis support teams that help keep the child in the home and the family together and functioning well.

The Metropolitan Council's Developmental Disabilities Program was established in 1972 to coordinate the development of services for residents of the Metropolitan Area who are developmentally disabled. The program operates through a contract between the Minnesota Developmental Disabilities Program and the Metropolitan Council, and is funded through a combination of federal grant and local matching funds.

The program staff is available to assist foundations, corporations, or organizations that are considering grants in the developmental disabilities area. For information or assistance, call Toni Lippert or Tom Chapel of the Council staff at 291-6363.