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Supported living services for developmentally disabled persons in Montana.

Joseph (Joseph Wilson

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SUPPORTED LIVING SERVICES FOR
DEVELOPMENTALLY DISABLED PERSONS IN MONTANA

By
Joseph Wilson

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Approved by:

[Signatures]
Chairman, Board of Examiners
Dean, Graduate School

[Date]
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CHAPTER 1

INSTITUTIONAL AND COMMUNITY-BASED SERVICES IN MONTANA

Introduction

This paper assesses the community-based services for developmentally disabled (dd) Montanans. Data is reviewed and analyzed from statistical reports produced by the Montana Legislature and the Division of Developmental Disabilities (DDD) of the Department of Social and Rehabilitation Services (SRS) on de-institutionalization from 1975 to 1988. The current system is not meeting all of the goals and objectives originally intended by the Montana Legislature and SRS; thus, alternatives to the existing method of providing services to developmentally disabled persons must be found. One such alternative, a program that has proven successful in other states, is the supported living program.

The review of the supported living program includes a fiscal and programmatic analysis of the North Dakota operation and the cost to implement and operate a similar program in Montana. Based on the results of this analysis, recommendations will be made to the Developmental Disabilities Planning and Advisory Council and to SRS.

Early History of Montana Mental Health Institutions

The history of Montana's institutions for the mentally retarded is a troubled one. Institutionalization in Montana began in September 1893 when the Montana School for the Deaf and Blind was founded in Boulder. Although the Montana Legislature authorized the establishment of a school for "feeble minded persons" as
early as 1889, the physical structure was not opened to enrollment until November 10, 1905. For 33 years the Montana School for the Deaf and Blind and the Montana School for the Feeble Minded shared a common campus, superintendent, and medical and maintenance personnel, but were otherwise segregated internally.

The School for the Deaf and Blind was moved to Great Falls in 1937. The campus at Boulder then became known as Boulder River School and Hospital (BRS&H). Boulder's history parallels the attitude of the public toward the mentally retarded person, that is, that dd persons belong in institutions. During its early and middle years of operation, BRS&H was attached to the State Board of Education. The history of BRS&H and the circumstances surrounding its creation, development, and internal changes also reflect the belief that the mentally retarded should not be seen in communities, but housed in institutions.

As this attitude changed, so did the dynamics of institutional treatment. As the popularity of the institution as the proper setting for mentally retarded persons grew, so too did the resident population. For example, the Boulder institution opened in 1905 with a class of 15 mentally retarded students. By 1910, the enrollment was 79; a decade later, it had increased to 118. The first surge in enrollment occurred between 1920 and 1925. By 1925, 280 mentally retarded students were residents of Boulder. By 1935, the figure was 404. By the mid-1930s, institutional overcrowding was a matter of concern.¹

For the first 30 years, the institution was viewed as little more than a warehouse for persons with developmental disabilities. After another 30 years, it
became socially acceptable to admit to having a family member with disabilities. People became comfortable with placing family members in institutions where they could receive formal education and training. Since few realistic alternatives to institutionalization had been developed, most residents faced the prospect of lifetime institutionalization. The number of demands for more admissions continued to increase.

During the 1940s and 1950s, institutions were caught between public demands for increased admissions of handicapped persons and the unwillingness of state and federal governments to aid in the provision of dollars to meet such demands. Interest in institutional treatment of the mentally retarded during in the 1960s and 1970s evolved from the development which had begun in the 1940s and 1950s.

1967 was a pivotal year in the history of Montana's services for the mentally retarded. In that year, the Legislature appropriated funds for the development of Eastmont Training Center in Glendive, Montana. By so doing, elected officials formally recognized the validity of regionally-based residential and training services for the mentally retarded (MR), opening the door for provision of services in Montana communities.

In 1967, as a result of the Legislature's involvement, the philosophy of the institution began a long and difficult restructuring of purpose because people were not willing to accept de-institutionalization. The concept of the client as the primary focus of concern, and the consequent shift from regimentation as its own self-directing force, changed the internal structure of the institution.
Nationally, the 1970s represented an era of litigation and judicial decisions for all social concerns. In Montana, elements of what is now commonly referred to as the "developmental disabilities system," were finally combined. From 1973 to 1975, 18 separate pieces of legislation relating to the rights of, or services for, the state's mentally retarded were enacted or amended.

De-institutionalization in Montana

A state program to de-institutionalize persons with developmental disabilities (dd) in Montana was formally enacted in April 1975. At this time, the State of Montana defined a developmentally disabled person as:

...one suffering from a disability attributable to mental retardation, or any other neurological handicapping condition closely related to mental retardation that has continued or can be expected to continue indefinitely and constitutes a substantial handicap of such a person.

The intent of the Legislature in defining developmental disabilities was to allow more people to receive services. Further, the Legislature defined de-institutionalization as the transfer to the community of institutionalized persons who are adequately prepared for such a change, and the establishment and enhancement of community facilities for providing some combination of living arrangement, livelihood, and continuing care and/or support of them. This definition allows for community-based services.

The impetus for de-institutionalization in Montana stemmed from several factors. Labor strikes in the early 1970s at Montana's institutions forced the governor to call out the National Guard to operate the facilities. This in turn gave the press the opportunity to reveal the conditions in BRS&H. Limited selections of poorly-prepared
food, unsanitary living conditions, and inhumane treatment of persons with
developmental disabilities were among the issues raised by the press.

In 1972, the United States District Court of Alabama ruled in its Wyatt v.
Stickney decision that mentally retarded persons have a constitutional right to
treatment in the least restrictive environment. This ruling placed Montana on notice
to begin de-institutionalizing. In 1975, the U.S. Justice Department brought suit
against the State of Montana alleging violation of the rights of Montana’s
developmentally disabled persons. At that time, the Montana Association of Retarded
Citizens, an advocacy group for persons with developmental disabilities, became
increasingly vocal in expressing concerns for the quality of life and services provided.
These factors culminated in the passage of enabling legislation for Montana's de-
institutionalization program.

The intent of the legislation was to secure for each person treatment and
habilitation, and to assure that treatment and habilitation were skillfully administered
with respect for the person's dignity and personal integrity within a community-based
setting. The Montana Legislature developed goals and objectives for the Department
of Social and Rehabilitation Services which included 365-day per year treatment,
direct care staff, maintenance and operation of living environment, acute health care,
training, treatment, and education in the least restrictive environment.
Community-Based Services in Montana

By 1988, approximately 1,400 persons with developmental disabilities from both institutions and homes in Montana communities were placed into community-based services. A community-based program includes residential, vocational, transportation, family training, respite care, and special education services. Residential services range from intensive group homes for adults with very low self-help skills or serious maladaptive behaviors to transitional and independent living with support which provides follow-along care for persons with developmental disabilities who live in their own apartments.

All residential services provide training for each person with developmental disabilities residing in the community-based service. The training is designed to promote mutual communication, interaction, stimulation, socialization, and access to other community-based programs and services, as well as to provide training in personal and independent living skills. Over time, as the State Legislature and the Department of Social and Rehabilitation Services (SRS) observed the progress of community-based services, attention became focused on questions concerning what, in fact, was being provided to persons in the community programs, and whether these programs provided a better alternative than institutionalization.

The goal of community-based programs is to provide persons the opportunity to move from group homes to more independent life styles. The more independent the person becomes, the less supervision required and the greater the opportunity for living in the community unsupervised. However, evaluations of de-institutionalization in
Montana commissioned by the Legislature and SRS in 1977, 1981, 1983, and 1984 show that fewer than 25 percent of the persons with developmental disabilities in the community-based programs were moving from group homes to independent living.\textsuperscript{11}

The system is not working as hoped for three reasons. First, while some developmentally disabled persons acquire the training needed to move to a less structured environment, there are not enough openings in the independent living services. This is due to an overcrowded system not anticipated by social workers, providers, and state agency personnel when community-based programs were first initiated. Because of overcrowding, the advancement of persons residing in group homes who had acquired the skills to move to a less restrictive environment was blocked. For most dd persons, current placements will remain for the foreseeable future.

Since dd persons were not moving through the system as hoped, a waiting list for those needing services has developed. As of March 1, 1992, the Developmental Disabilities Division (DDD), in its monthly report on persons with developmental disabilities needing services, reported that there were 244 needing residential services, with 873 being served. There were 85 on the waiting list for intensive group home services, with 291 being served. For senior community homes, there were 40 on the waiting list, with 85 being served. Independent living training services had a waiting list of 91, with 157 being served. There were 110 on the transitional living waiting list, with 63 being served.\textsuperscript{12} The number of people still on the waiting lists indicates that the system is not working.
A second major factor preventing the system from working as was hoped is that developmentally disabled persons require varying kinds of services and support. As the system grew, an increased number of severely retarded persons and persons with severe behavioral problems (referred to as "lower functioning dd persons," as defined by the Developmental Disabilities Division of SRS) have been placed in community-based services. As these lower functioning persons move into the programs, providers are faced with problems of deciding which developmentally disabled person will receive training. Since those with behavioral problems cannot be forgotten, it is often the dd person with no behavioral problems, and who is higher functioning, who receives inadequate service.

A third reason for the delay with which many persons have moved through the system is that providers have fewer financial incentives to provide services to the lower functioning person. The cost for training a lower functioning client is approximately five times higher, and the staff to client ratio is one to one, as opposed to a one to five ratio for the higher functioning person. Because of this funding difference, dd persons have fewer opportunities to move to a more independent environment. For residential community-based services, the average costs are $8,852 a year, or $24 per day, for each person served. Intensive community-based services, like some of those in Missoula, cost $25,000 per person per year, or $69 per day, for services.  

Community-based service was expected not only to provide residential services, but also day programs, which include sheltered workshops, educational programs, and
senior activities. The 1977, 1981, 1983, and 1984 Evaluation of De-institutionalization of Montana reports show that these community-based services were being provided to fewer people than intended. Six states are operating a new program known as supported living, which has proven successful. North Dakota is one of those states. The next chapter provides the basis for my recommendations for a supported living program in Montana similar to that of North Dakota.
CHAPTER 2
THE SUPPORTED LIVING PROGRAM

Supported Living, "A New Era"

In many ways, supported living shows the inadequacy of existing community-based residential services. The supported living model argues that community-based, professionally-dominated and directed services ought to be supplanted by consumer driven, highly individualized support, and should be furnished in integrated living arrangements. This model is defined by specific key principles and characteristics. Persons with developmental disabilities should be supported in the same living arrangements typical of the general population. Supported living programs reject the notion that persons with developmental disabilities should live in specialized settings or that they must be admitted to such facilities as a precondition to receiving services.¹⁴

Supported living services thus redefines the aims and technology of community residential services for developmentally disabled persons and challenges conventional views regarding "best practices" how to serve people with severe, life-long disabilities. It is an outgrowth of the movement to organize services along "person-centered" lines.

Frustration with the lack of individuality and choice for the dd person under the community-based services model was a prime factor in initiating the movement toward supported living. The freedom of choice for persons with developmental

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disabilities is a key principle of supported living. Practical concerns regarding affordability and effectiveness of community-based services encourage the development of this model.

Supported living represents a move from short-term development planning to life-long functional planning; rather than moving persons through a predefined system as they achieve goals set for six-month periods, long-term plans are made to allow persons to progress while living in a conventional setting. Residential, day training, and education services are integrated into one service system in which it is possible to create programs geared to each individual’s needs. Supported living programs also shift from payment based on facility budgets toward reimbursement based on provider performance and individual needs.\textsuperscript{15}

**North Dakota’s Supported Living Program**

North Dakota’s Supported Living Program offers a practical example of how a state can reconfigure its community residential options in order to enhance opportunities for people with developmental disabilities to lead integrated and independent lives in their home communities. Initiated in April 1987, the Supported Living Program has grown rapidly and was serving more than 520 participants as of mid-1990.\textsuperscript{16}

In the 1980s, two key events occurred. The North Dakota Legislature adopted comprehensive legislation that called for substantial reduction in the number of people served in State facilities and a parallel expansion of community-based services.
Concurrently, a complaint filed in the U.S. Federal District Court enumerated substantial deficiencies in service to the state's developmentally disabled persons (ARC of North Dakota v. Olsen). The ensuing settlement agreement, coupled with the directions adopted by the legislature, put the state on a course of expanding community-based services while simultaneously reducing substantially the number of people served in its institutions.

During the 1980s, North Dakota, like Montana, reconfigured its developmental disabilities system from an institutional-dominated to a community-based system. In 1980, there were 1,069 persons residing at Grafton State School, North Dakota's principal institution for persons with developmental disabilities. In the same period, Montana's institutions at Boulder River School and Hospital and Eastmont at Glendive had a total of 311 persons. The cost per day in North Dakota was $56. In Montana, for the same year, the cost was $128 per day. North Dakota ranked last in the nation in its relative level of public expenditures on behalf of dd persons while having the highest number of dd persons per capita residing in public institutions.

By the end of 1986, Grafton's population had been reduced to less than 400, while the number of persons with developmental disabilities receiving community-based services had risen to 1,190. Meanwhile, North Dakota's ranking among the states in terms of per capita spending on behalf of persons with developmental disabilities rose to first in the nation.

In comparison, Montana's institutions had a population of 255 dd persons in 1986. The number of dd persons living in community-based services was 819. The
total monies spent for developmental disability services in Montana for 1986 was $29 million; North Dakota's budget was $57 million for developmental disability services.\(^{20}\)

In May 1986, in the wake of rapid changes which had occurred in only six years, a statewide forum was conducted by North Dakota providers, staff of the Developmental Disabilities Division, families of consumers, representatives of the Governor, and legislators to reassess the fundamental mission and goals of the state's developmentally disabled service delivery system. As an outgrowth of this forum, the following statewide mission statement was adopted by the State Developmental Disabilities Planning and Advisory Council, the Governor's Office, and the Developmental Disabilities Division of the Department of Human Resources:

The state of North Dakota is committed to providing its developmentally disabled persons a comprehensive system of services that will promote independence in self-care and daily living, and economic self-sufficiency provided in the most normalized and integrated community environment.\(^{21}\)

To fulfill the framework of the mission statement, the forum determined that all persons with developmental disabilities would be assured appropriate support for attaining maximum access to the mainstream of community life. Those capable would live independently, and publicly supported residential facilities would be limited to four persons.\(^{22}\)

The supported living program is a direct outgrowth of the adoption of these goals. State officials, primary and secondary consumers (dd persons and family members or advocates), and service providers agreed to redirect service delivery to a
"system centered around supports designed to meet each dd person's needs to live, work, and participate like other peers in the community." Community services would be guided by a "non-insular" approach which:

...does not assume that one prepares to live in some pre-planned setting; it simply begins in individual settings, and we build in supports. As development takes place and needs of individuals change, the amount and type of supports which they receive also change. In a non-insular approach to services, we move our funds supporting buildings and programs to supporting the individuals with services they need, wherever they may need them.

Program Description and Payments

The supported living program in North Dakota is apartment or family-home based. There are two components to the program: 1) assuring that an individual can meet his or her needs for housing and routine living expenses; and, 2) furnishing, on a person-by-person basis, the habilitation and/or personal care services that are needed to help the program participant live in an integrated setting.

The program is based on the idea that habilitation is most likely to be successful when training occurs in daily routine and in "real life" situations, not by teaching people with developmental disabilities in one environment while expecting them to transfer what they have learned to another. Supported living placements are intended to be permanent, regardless of an individual's functioning level, specific needs, or current skill level.

Since the service principles were premised on furnishing services and support in integrating living arrangements and promoting independence, the North Dakota
program was designed to place a person in an environment which meets his or her ultimate functioning level. The program of supported living rejects the community-based service model in favor of enabling a person to live in the most desirable setting by varying the services and support furnished based on his or her current needs. In supported living, developmentally disabled persons are not required to move if their needs change. As noted in the program guidelines, the physical movement of staff is preferable to the physical movement of dd persons in the program.

The availability of supported living services is not restricted to predefined dd person target groups. For example, eligibility is not based on a predetermined profile. The program is viewed as a service model which can be generalized, that is, it is appropriate for developmentally disabled persons who may have very intensive service needs, as well as for persons needing only intermittent, ongoing support.

During the first three years of operation, persons with developmental disabilities have come from North Dakota's institutions, nursing homes, and other community residential settings. Program participants exhibit a wide range of support service needs, including dd persons with challenging behaviors and multiple handicapping conditions.

Whether a person participates in the supported living program is determined at the Individual Habilitation Planning Team meeting. This team consists of the person with developmental disabilities, the family, the regional case manager, and other professionals. Services provided to each dd person, and the level of payment for such services, are based upon an Individual Service Plan (ISP). This ISP is prepared by the
planning team, which must decide in detail what the person will need in the community. Based upon these decisions, a referral is made to a community agency which decides whether it is capable of meeting the prospective client's needs.

Under the State Medicaid Home and Community-Based Waiver Program (HCB), habilitation or personal care services are offered to interested persons. The distinction between these two types of services lies in whether the person's service objectives are related principally to "training in particular areas of daily living" [habilitation] or "assisting or maintaining the dd person receiving services" [personal care]. Health care, training in safety and self care, and community awareness and integration are the areas in which support is provided. Provider agencies must be licensed to provide services and are subject to quality assurance reviews conducted by the Developmental Disabilities Division of North Dakota. In addition, these agencies must be accredited by the American Creditation Council, a nationally recognized nonprofit organization that certifies local nonprofit service provider programs.

Based on individual need and the level of support necessary to maintain an apartment or family home setting, a reimbursement rate is determined for each person on a case-by-case basis. Since the program is financed by the HCB Title XIX Amendment to the Social Security Act, the expenses associated with each person's living arrangement are divided between "room and board" (which are not allowable Medicaid costs) and "service costs" (which are allowed by Medicaid).

Room and board expenses consist of rent, utilities, food and related items. These expenses are then compared to the resources available to each dd person. Such
resources typically include federal Supplemental Security Income (SSI) benefits, food stamps, work earnings, and Housing and Urban Development (HUD) rental subsidy certificates. If anticipated room and board costs exceed the recipient's expected income, then an additional state supplementary payment is made to cover the difference. Such additional payments, however, are rarely made. In most instances, persons with developmental disabilities live with roommates of their own choosing in order to meet living expenses.

North Dakota's reimbursement model recognizes that the service agency not only needs to arrange for staff support at the dd person's home, but also must arrange for other programs in the community. North Dakota distinguishes this provider-based activity from case management services which are charged with overseeing the development and implementation of the person's individualized habilitation plan, as well as managing entry into the State delivery system. Case managers coordinate among services and service providers and case coordinators discharge the agency's responsibilities in carrying out individualized habilitation plans.

North Dakota's supported living program directly links payment to the services and support contained in each person's individual service plan by way of a specific contract and that person's daily payment rate for habilitation or personal care to be furnished. If services can be provided more economically, the provider agency benefits. The rate, however, is revised after actual provider cost experience is reviewed. No payment "caps" or "ceilings" are imposed on the program rates that may be paid in the supported living program, although limits for provider agency
administration costs are imposed. Contracts are developed at the regional office and forwarded to the Developmental Disabilities Division central office for final approval. Initial contracts are written for a period of three months. Renewal contracts may be written for a period of three to twelve months, although most cover six-month periods, corresponding with the periodic review of each person's plan.

Accountability for public dollars is maintained through standard methods, namely, provider agencies must account for program revenues and expenditures. Overpayment is subject to recovery. In addition, provider agencies must be able to demonstrate on a person-by-person basis that the services and support upon which each individual contract is based were furnished.

The program's philosophy, requirements, contracting and accountability measures are set out in DDD's Individualized Supported Living Arrangement Provider Handbook (1987). These services are furnished under North Dakota's Medicaid Home and Community-Based Waiver Program.

Growth of the Supported Living Program

As noted, the supported living program in North Dakota began in April 1987. By December 1987, there were 182 persons participating in the program. Persons with developmental disabilities entered the program from a variety of settings. Eighteen months later, 300 dd persons were being served. By early 1990, the program was serving 495 participants; by mid-1990, the program was serving 520. Supported living services are being provided by 22 provider organizations in North Dakota.26
Since 1990, the average State payment for supported living was $39.25 per day per person, exclusive of room and board expenses. In December 1987, payments averaged $34.49. Individual payment rates have ranged from as low as $10 per day to as high as $286 per day. Payments for provider agency training time varies from an average of $16.04 per day per person served to a high of $67.83 per day.\textsuperscript{27} While North Dakota's payment policies permit the State to supplement a person's resources to meet room and board expenses, such supplements represent less than one percent of total program expenditures.

The average supported living payment rate of $39.25 per day compares to an average cost of $52.95 for the previous community-based services for dd persons in North Dakota. It is estimated by North Dakota officials that the supported living program will save about $2.5 million per year over the cost of the community-based program.\textsuperscript{28}

Moreover, an analysis of individual payment rates over a five-year period reveals that payment rates decline an average of $.50 to $1 per day.\textsuperscript{29} More significant declines in payment rates have been experienced when the principal focus of supported living services is on habilitation and not personal care. State officials expect that habilitation costs will decline further as the training offered to persons with developmental disabilities equips them with the skills needed to live more independently. Personal care expenses will tend to be more stable over time.

North Dakota officials regard the supported living services as affordable, since the services and support can be tailored to each dd person's needs and circumstances.
The affordability of these services stems from the ability to target dollars on a person-to-person basis, as well as the increased use of friends, family, and care providers to help meet the needs of persons with developmental disabilities. In addition, State officials note that they have not encountered serious problems in separating funding for services from funding for housing. Although North Dakota does supplement federal SSI payments, the resources for dd persons are usually adequate to meet daily living needs.

North Dakota's officials also emphasize that two aspects of its supported living payment methods have been crucial to the program's success. First, coverage of expenses for the "case coordinator," the one responsible for the implementation and direction of each individual's long-range plan, is a key ingredient in ensuring that provider agencies have the resources to manage their supported living programs. Second, State payment policies recognize that provider agencies have legitimate administrative expenses in operating any program and should be compensated for such expenses.

Although the practice of renewing individual participation contracts every six months or so might appear to engender considerable administrative overhead, State officials report that ensuing paperwork has been manageable. A good deal of this paperwork is handled at the State regional office level. In addition, if resources are to be tied to program goals, State officials believe it makes sense to revise contracts concurrently with periodic reviews of program plans.
Program Results

The rapid expansion of the supported living program indicates that it is an attractive alternative to more conventional community-based residential services. There have been positive results due to the supported living program.

The program means that services and support can be tailored to individual needs and circumstances. Persons with developmental disabilities served in the program receive direct staff support, ranging anywhere from 20 to 800 hours per month. Translating program goals into staff support hours and individualized payment rates is practical and straightforward.

It is practical to separate housing considerations from the delivery of services and support to persons with developmental disabilities who live with families or lease their own apartments. Where they live and with whom they live are matters of personal choice. At the same time, North Dakota's program is cost effective when two or more dd persons in the program live together or with a family.

Provider agencies have been enthusiastic about the supported living program, particularly with the opportunities to furnish higher-quality services in more integrated environments with flexible funding levels. These agencies have learned about supported living as their own programs have grown and progressed. Agencies now provide services to individuals they were incapable of serving during the early stages of the program. These clients are now served as agencies develop better techniques for supporting people with more challenging needs. In turn, planning teams and families have gained confidence in the program.
Caseworkers and representatives of the DDD have stated that consumers express support for the "new way of thinking." Nearly all individuals who are offered the opportunity to participate in the program select this service option. Once such living arrangements are established, families come to be enthusiastic supporters.

Positive results for dd persons are evident. One program manager expresses it in the following comment:

I've said that people grew by leaps and bounds in the new environments. Actually they were that way all the time. The other environment (community-based) stifled them. We just needed to let dd persons be themselves.

Persons with developmental disabilities and the staff supporting them build strong relationships as they work through problems and issues together. The use of functional training in supported living confirms one of the programs central principles: "real life" teaching/training is the most effective means of enhancing the skills of developmentally disabled persons and allowing them to exercise greater control over their personal lives.

North Dakota's supported living program has stimulated practical and positive changes in the State's community service delivery system. It is clear, however, that the supported living program is not without its problems. Tension exists between service providers and DDD officials regarding the adequacy of funding levels; providers, in many cases, underpay direct care staff to stay within the budget. Due to lack of funding, the potential for programs to be integrated into the community is less likely. There is concern that people in these programs will not become integrated into mainstream society. There are also concerns about the effect of staff turnover in the
context of a service model which depends on a positive and constructive relationship between participants and paid care givers.

In addition, the bifurcation in community-based services between the supported living program and more traditional group residences leads to practical problems. Helping one person move out of a group living arrangement into the supported living program allows for a person without services to move into the vacancy at a group home; the group home remains at full capacity, but the placement is not necessarily appropriate for the individual.

Another problem is that the development of integrated work opportunities in North Dakota has lagged behind the expansion of integrated living arrangements. State officials believe that greater emphasis must be placed on finding community-based jobs for persons with developmental disabilities. While these problems should not be discounted, they are by no means unique to supported living programs. The problems are the same as those found in group home living arrangements.

The Existing North Dakota Supported Living Program

North Dakota's supported living program is less than five years old and yet has grown so rapidly that it now stands as the single largest program of its type per capita nationwide.\textsuperscript{33} The program's premises are reflective of the basic tenets of supported living, that is, separate housing support, individualized services and support, the use of functional training, and the provision of consumer choice.
State officials report that the supported living program is being transformed into a broader-based "support" model. Persons with developmental disabilities who continue to live with their families have now become eligible to participate in the program. As a result, supported living is being broadened from community "residential" options to more completely integrated supported living. North Dakota's program has been so successful that the state of Missouri is developing a similar program. The next chapter discusses the possibilities of Montana initiating such a program.
Given present conditions, supported living would work in Montana in the form of a much more simplified model, that is, one more closely related to the state's transitional and independent living programs. By DDD definition, in the transitional service, living and training services are provided to persons with developmental disabilities who display fewer independent living skills or less preparedness for community living and usually require a more structured living arrangement and training and more supervised assistance than individuals in independent living. Transitional living is the middle step between group home living and independent living. Independent living and training services are provided to persons with developmental disabilities living in neighborhood housing located throughout the community. Developmentally disabled persons receiving independent living services require minimal supervision and guidance, but require periodic contact to maintain a more independent style of living. Only persons in these services are likely to be considered for supported living.

Montana could not provide the identical supported living program that North Dakota has. The first and most important factor is money. North Dakota spent $67 million in 1991; in the same year, Montana spent $24.8 million on services for approximately the same number of persons as served in North Dakota. Montana DDD gets 28.3 percent of its money from the State general fund. State Supplemental
Security Income (SSI) generates 2.5 percent of the total dollars spent. Other funds come from the HCB Waiver (15.2 percent of the budget); Federal Waiver SSI/ADC account for 5.8 percent of the revenue; Federal Title XX/SSBG 47.9 percent, and other federal money makes up about 2.3 percent. In North Dakota, it is a very different situation. The State general fund provides 54.5 percent of the total budget. Federal and small private funds make up 26.6 percent of the budget. HCB waiver funds account for 10.6 percent and federal waiver SSI/ADC make up 8 percent of the total budget. The remaining 0.3 percent is drawn from other federal funds. If any sort of supported living for persons with developmental disabilities is to be successful in Montana, several important components of the supported living model must be followed. For example, funding, housing, ecological inventory assessments, support from other community-based services, and community and family support are among these essential factors. A discussion of each component follows.

**Funding**

The 1990 Montana Legislature appropriated additional funds to help offset the imbalance between what State workers and providers receive for community-based services. At the eleventh hour on the last day of the session, monies were excised from the budget because of budget balancing problems. Thus, services for the developmentally disabled suffered yet another cut. To believe that the Legislature would devote an additional 30 to 40 million dollars of the general fund to adequately support a program similar to that of North Dakota is an optimistic expectation. It is
simply not going to happen without the impetus of a lawsuit similar to North Dakota's.

A scaled down program, however, is conceivable, one that provides independence over and above that which exists in Montana, but one that Montanans can afford. Initially, services could be provided for 25 persons with developmental disabilities at a cost per year of $8,854 per person in supported living services, or about $28 per day. The annual cost in HCB Waiver Title XIX funds would be $221,350. Granted, this would not provide services to a large number of persons, but it would help to diminish the waiting list and add some important new services for those who are ready for a highly independent lifestyle.37

Few persons with severe behavioral problems can live under this form of supported living. As mentioned, the costs can run as high as $67 per person per day, making it too expensive for more than a few to relocate and thereby reduce waiting lists. The $28 daily cost can be raised or lowered depending on each person's needs. Part of the $28 per day must also be used for administration and other costs; not all of it can be spent on training time.

Housing

Housing is a second obstacle to a supported living program. There are only two housing programs that are available to persons with developmental disabilities who would be eligible for supported living services. One is conventional housing, that is, the tenant pays whatever the owner requires, including damage deposits, first and
last months' rent, and utilities. North Dakota provides assistance for persons who cannot afford deposits or first and last months' rent. Montana probably would not be able to make this program available because of limited funds, so conventional housing does not offer much of a possibility for dd persons wanting to live by themselves. However, if two, three, or possibly four persons were to live together, conventional housing could be a viable option.

The other housing program, Section 8, is federally assisted. An individual certified for Section 8 housing can go into the community with a voucher and secure housing which the federal government subsidizes, based on income. The problem with using Section 8 housing in Montana is that it takes at least one year to qualify for the program. North Dakota, by using State general fund monies, provides the subsidy without depending on federal assistance. Another problem with this housing program is that the Montana housing market is tight, with less than a 3 percent vacancy ratio in most of the larger cities. It is equally difficult to find available Section 8 housing.

The best way to make this program work is through good planning. If it is known in advance what a particular person's housing needs are likely to be, an application can be made months ahead of time; when the person is given the Section 8 voucher, independent living is a closer reality.

In moving from a group home, a person with developmental disabilities loses about $95 per month of SSI, putting an added strain on an already limited income. SSI payments are based on the residential services being provided. Thus, as persons move to less restrictive environments, they receive less SSI payment. It is not
financially feasible for a person with developmental disabilities to live alone in the community. Having roommates becomes a necessity. In community-based residential services, persons are assigned roommates; in supported living, persons choose with whom they live.

**Ecological Inventory Assessments**

An ecological inventory assesses a person with developmental disabilities in all environments. It examines the activities which occur in those environments and whether a person has sufficient skill to engage in those activities. The ecological inventory is an important tool for determining who is going to be successful in supported living. North Dakota's inventory takes at least six or seven hours of interviewing for each dd person assessed. Much of it seems lengthy and cumbersome.

Focus is on the following areas:

1. expressive language skills;
2. receptive language skills;
3. cognitive/academic skills;
4. self-care skills;
5. leisure/recreation skills;
6. social skills;
7. daily, weekly, and monthly activity interests; and
8. vulnerability.
Testing and evaluating the above areas should demonstrate whether the person is ready to live in a supported living program. The ecological inventory assessment could serve as the tool needed by the local screening committee in determining who will be placed in supported living. This committee currently meets on a monthly basis to make recommendations regarding who should be placed in community-based services. The committee is comprised of a provider of residential services, a provider of day program services, a case worker, a DDD representative, and an advocate or family member.

The Screening Committee in Montana does not presently have the opportunity of seeking the right placement for each person. This committee is constrained by lack of openings for services and "crisis cases" in need of any placement other than present circumstances. Consequently, dd persons have no choice and are "thrown together" with others who often impede their progress.

Community-Based Support

For each person placed in any community-based residential service, there must be a day activity program, for example, sheltered workshop, education program, supported work program, or senior day program. A person with developmental disabilities who is being considered for supported living must, in most cases, have one of these additional services. Sheltered workshops provide several hundred dollars a month in revenue for independent living. An educational program would serve very few persons in the supported living program. Supported work would be the most
compatible service for a person in the supported living program. Supported work allows the dd person the most independence in a work environment and provides the greatest opportunity to make money. Senior day services would provide leisure and recreational opportunities for persons with developmental disabilities who wished to retire.

**Community and Family Support**

Montanans have, for the most part, been supportive of de-institutionalization and the community-based service program. There has been support for Special Olympics; schools provide special education programs; and merchants hire dd persons through the supported employment program. The list goes on, but if the community is not willing to accept people with developmental disabilities, the supported living program will not work. Providers of services must continue to monitor what neighbors and others think about their presence in the community. Good public relations are essential in maintaining community support.

Supported living for people with developmental disabilities is a long way from the days when Montana first began institutionalizing "feeble-minded persons." Supported living in Montana can work, and will work, if properly planned and nurtured.
The foregoing discussion provides support for the adoption of an independent living program for developmentally disabled persons living in Montana. Montana has struggled valiantly to care for persons with developmental disabilities, with both institutional and de-institutional models, to provide adequate and beneficial services.

As new proposals for the care of the developmentally disabled have been advanced, Montana has made progress in responding accordingly. As with most such proposals, the issues of politics and finances often intrude. The time has come for the Montana Legislature, the Governor's office, and those State agencies that oversee the care and service of the developmentally disabled in Montana to again act in positive and creative ways to develop new models of care. A supported living program funded by adequate resources, and one that is properly administered and regularly evaluated and updated, is necessary for persons with developmental disabilities.

The supported living program currently employed in North Dakota is proving itself to be a worthy program. It is, in some ways, a pattern for other programs being developed throughout the country, for example, in Missouri. The North Dakota program has had its own difficulties in remaining viable, but following a successful class action lawsuit filed on behalf of persons with developmental disabilities, the North Dakota program now enjoys success and provides good and valuable service,
while at the same time remaining cost effective. This program may well serve as a model for Montana.

Since the needs of all people are not always the same, including those developmentally disabled, the North Dakota model may have to be revised to suit the needs of Montanans. The creation and adaptation of a supported living program for Montanans provides a provocative challenge to all involved. State and legislative officials, directors of providing agencies, directors of local programs and their staffs, those in supportive roles, for example, doctors and nurses, and the recipients of services themselves, have the opportunity to demonstrate both a willingness to meet the needs of a large segment of society and to do so in a spirit of cooperation and creativity. However, Montana will have to accept the fact that supported living will not have the financial commitment found in other states. Economic conditions have placed the state in a large deficit spending cycle. The State government does not have the financial capability to provide the total service needed for the developmentally disabled population. There are several alternatives Montana should consider that offer the best utilization of money available to the largest number of persons with developmental disabilities. The following recommendations are offered:

First, Montana should continue to match Title XIX funds with State general fund monies. Title XX monies that could be used do not have the best return on State monies. In the case of Title XIX funds, for a 25-percent allocation, the state receives 75 percent in matched federal monies. Title XX funds have a 60-percent/40-percent return on dollars invested.
Title XIX monies cannot be the sole source of funding since they can be utilized only for those over 55, or for those classified as intensive, that is, persons who require more staff to serve them. The Legislature must explore ways to provide more money for persons with developmental disabilities who do not receive Title XIX funds.

Second, Montana providers must be aware that housing is not affordable for just one person needing services. Several people must live together to share expenses. Providers must be ready to secure Section 8 or other federally-assisted housing for persons with developmental disabilities/physical handicaps (barrier free, wheelchair access). Access to shopping, recreational opportunities, work, and social interaction must be considered. Public transportation must be available for community access in larger Montana communities.

Third, ecological inventory assessments must be used to determine individual skill deficits, what support will be needed, and how to aid the developmentally disabled with roommate selection. To maintain the spirit of the program, compatibility of persons with developmental disabilities living together is essential. Efficient use of the ecological inventory assessment will eliminate the possibility of persons with developmental disabilities being placed in an environment which renders the offered training ineffective.

Fourth, day programs which are suited to the needs of dd persons must be made available. Retirement programs such as leisure and recreation services
for those who do not work are needed. Choices for sheltered workshops, supported employment, or educational opportunities must be offered.

Fifth, family and community support is vital. Family members, advocates, and friends must be encouraged to take active roles in long-term planning and day-to-day support. The State and providers should initiate programs that will ease the integration of persons with developmental disabilities into the community. For example, liaisons with churches, schools, and retiree organizations could be the mechanism for integration.

Because of the number of people on the waiting lists for services, Montana is at risk for a lawsuit which would accord all Montanans with developmental disabilities equal treatment under the law. While the waiting lists seem proportionately small, any waiting list could be considered a violation of dd persons' rights. Quality of life for persons with developmental disabilities would not be the sole effect of instituting a supported living program. The implementation now of supported living has the potential of staving off a lawsuit which might demand an immediate investment of funds, and hence, cause a financial crisis for the state. A supported living program would benefit both Montana and its citizens with developmental disabilities.
ENDNOTES


3. McCarty, p. 32.

4. McCarty, p. 36.

5. Montana Codes Annotated, MCA 53-20-201(3).


7. McCarty, p. 53.


11. Ibid., p. 11.

12. Interview with Daphne Crosbie, Department of Social and Rehabilitation Services, Developmental Disabilities Division, April 2, 1992.


14. Smith, p. 16.


16. Smith, p. 16.


20. Ibid., 63.

21. *North Dakota's Individualized Supported Living Arrangement Program*, Appendix C.

22. Ibid., p. 2.

23. Ibid., p. 3.

24. Ibid., p. 3.


26. Ibid., p. 376.

27. Ibid., p. 3.

28. Ibid., p. 3.

29. Smith, p. 77.


31. Smith, p. 79.


34. Contract between Montana Department of Social and Rehabilitation Services (SRS) and Spring Meadow Resources.


36. Ibid., p. 287.

37. Ibid., p. 373.

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