An Independent Assessment of Minnesota's Medicaid Home and Community Based Services Waiver Program

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EXECUTIVE SUMMARY

This Executive Summary highlights key findings of an independent assessment of Minnesota's Medicaid Home and Community Based Services (HCBS) program for persons with mental retardation and related conditions (MR/RC). HCBS programs allow states to finance under Medicaid certain "non-institutional" services for Medicaid-eligible individuals who would without those services be at risk of remaining or being placed in a Medicaid certified institution (i.e., an Intermediate Care Facility for the Mentally Retarded [ICF-MR] or a nursing home). In requesting approval to provide HCBS, states must make assurances that total Medicaid expenditures under an HCBS waiver will be no more than total Medicaid expenditures would have been in the absence of an HCBS program. States must also make other assurances regarding access to and quality of the services they provide. An independent assessment of a state's HCBS program, providing evidence of satisfactory compliance with federal HCBS regulations, is required prior to the approval of a state's request every 5 years for a renewal of their authority to provide Medicaid Home and Community Based Services. The purpose of this assessment was to evaluate the overall success of Minnesota's HCBS program in meeting the required federal standards, as well as a number of specific state goals. The assessment is organized into three areas: 1) access to services, 2) cost-effectiveness, and 3) quality of services.

Data Collection

Data collection for this assessment included a sample of 129 HCBS recipients living in 18 counties of Minnesota and people important in their lives, interviews with people playing key roles in the delivery of HCBS, and extensive use of state databases. Data collection, based on the HCBS recipient sample, involved structured interview and/or questionnaire responses with 129 direct care providers (paid staff and foster family or natural family members), the 60 case managers of 118 of the sampled individuals, 82 family members, and 54 HCBS recipients themselves. Data gathered included information on the functional skills, activities, services received, needs, relationships, choices and preferences, and other aspects of daily life of the HCBS recipient, the quality of and satisfaction with services of recipients, their families and case managers, and recommendation for improving services from those involved. In addition to the structured data collection, over two dozen other interviews about program implementation and quality were conducted with a wide range of individuals playing key roles in the delivery of HCBS, including county officials from almost all sampled counties, present and former state Medicaid and Developmental Disabilities officials, directors of HCBS provider agencies, and direct services providers. Finally, extensive use was also made of the state's existing data bases, especially those containing screening data on HCBS and other Medicaid recipients' characteristics and needs and those containing HCBS expenditures for each individual recipient.

General Program Trends

Minnesota's HCBS program is one of the largest in the U.S. and has been one of the most rapidly growing.

- In FY 1985, Minnesota's first year of providing HCBS, 278 individuals with MR/RC received waiver services; in FY 1987, 991 individuals were served; in FY 1991, 2,690 persons with MR/RC received HCBS including 2,466 who were receiving services on the last day of FY 1991.

- In June 1990, the last year of comparative national data, Minnesota's HCBS program for persons with MR/RC (2,184 recipients) was fourth largest in the U.S., behind California (3,628 recipients), Florida (2,615 recipients) and Pennsylvania (2,221 recipients).

- In June 1990, Minnesota's relative utilization rate of 49.9 HCBS recipients per 100,000 of the state's population was also fourth largest nationally, behind North Dakota (165.1), Utah (69.6) and Colorado (55.9).

Growth in Minnesota's HCBS program since 1985 reflects a controlled substitution of HCBS for earlier reliance and steady growth of ICF-MR residential services.

- Between 1987 and 1991, Minnesota achieved a 17% decline in ICF-MR residents from 7017 to 5851; ICF-MR residents decreased by 1166 persons, while HCBS recipients increased by 1699 persons.

- Between 1987 and 1990 Minnesota's total ICF-MR residential population decreased by 14.0%, as compared with a national decrease of 0.2% and an increase of 0.6% when Minnesota is excluded from the national statistics.

- Between 1987 and 1990 Minnesota's total ICF-MR and HCBS recipient populations grew by 5.9%, as compared with a national increase of 13.2%.

Access to Services

Access to Minnesota's HCBS program is in line with federal requirements and generally meets state standards.

- HCBS recipients were all confirmed to be Medicaid eligible.

- HCBS recipients were all documented to be at risk of ICF-MR placement.

- HCBS recipients and community (small) ICF-MR residents were found to have remarkably similar characteristics, presenting strong evidence that HCBS recipients are persons who, in the absence of HCBS services, would have received ICF-MR services. For example, 16.1% of HCBS recipients and 14.9% of community ICF-MR residents have occasional or frequent major seizures or frequent minor seizures; 25.3% of HCBS recipients and 24.6% of community ICF-MR residents need substantial assistance or total care and support in toileting; 55.3% of HCBS recipients and 57.6% of community ICF-MR residents are judged as not being fully capable of independent self-preservation; and 17.2% of HCBS recipients and 18.0% of community ICF-MR residents exhibit moderate or severe aggression toward other persons.

The period that people had to wait for services once they had been determined to be eligible did not appear to be a serious problem.

- Families and case managers of current HCBS recipients reported that half received services within 6 months of screening; waits of 2 years or more were extremely rare.

- There is within the state no source of complete data on the length of waiting for people not presently served.

- Some counties reported deferring screening of persons requesting HCBS when services were not presently or reasonably soon to be available for them. Counties' officials reported deferring screenings to avoid "raising expectations about unavailable services".

There have been shifts over time in the relative access to HCBS for people being discharged from Regional Treatment centers and other ICFs-MR (called "conversion" enrollees) and people who avoid institutionalization through HCBS (called "diversion" enrollees).

- In 1985, there were nearly twice as many diversion enrollees as conversion enrollees; between 1986 and 1989, the majority of new enrollees were conversions; in 1990, diversion enrollees made up the

majority of the HCBS population; in 1991 there were slightly more conversion enrollees than diversion enrollees. Diversion enrollees have increased at a fixed rate of 165 per year.

- Cumulative enrollment patterns have caused a gradual increase in both conversion and diversion enrollees, with June 30, 1992 total enrollments projected to be 1,818 conversions (58%) and 1320 diversions (42%).

- The major factor in the greater access to HCBS by Regional Treatment Center (RTC/ICF) and community ICF-MR residents than persons in the community has been the role of HCBS as the primary program for supporting of Minnesota's overall efforts to depopulate its RTC/ICFs.

- The greater number of conversion than diversion allocations, and the limited access to other community services has created a substantial desire and need for diversion allocations to provide HCBS to persons already in the community but in need of services.

Additional efforts are needed in Minnesota's commitment to equal access to HCBS for eligible persons without regard to race or ethnic background.

- Compared with racial/ethnic distributions reported in the 1990 census, racial/ethnic minorities (Blacks, American Indians, Alaskan Natives, Asians and Hispanics) receiving HCBS were only 55% of the number that would be expected.

- State and County officials acknowledged a need to develop ways to improve program awareness among minority communities, their leaders and their members with disabilities and their families.

Children and youth screened as needing long-term care services have greater likelihood of access to HCBS than adults, because Minnesota has used HCBS relatively extensively to keep children in their homes.

- Minnesota has used HCBS as an important instrument in its commitment to keeping children at home and above all out of RTCs (only 3 young people 17 and younger were left in RTCs in June 1991).

- About 76% of all children and youth (0-17 years) receiving Medicaid long-term care services (RTC, ICF-MR or HCBS) receive HCBS; 29.5% of persons 18-40 years old receiving Medicaid long-term care services receive HCBS; 24.4% of persons 41 years and older receiving Medicaid long-term care services receive HCBS.

- Although children and youth with long-term care needs have greater relative access to HCBS, they make up only 19% of all HCBS recipients.

Minnesota's reliance on county administration and the absence of specific state-policy for county level HCBS allocations to eligible individuals, has led to different approaches to granting access to different groups across counties. Counties demonstrate wide variation in the nature and systematization of their policies and practices in prioritizing eligible persons to receive HCBS.

No families or individuals in the sample reported being denied a desired opportunity to choose among different authorized HCBS or HCBS providers.

- Despite not being denied choice of services or providers authorized for the HCBS program, about 24% of families identified one or more services (not necessarily HCBS services) that their family member needed, but did not receive.

- Unmet needs reported included communication training, integrated recreation, occupational therapy and physical therapy for adults, more appropriate vocational and habilitation services and respite care.

Case managers indicated that there is an inadequate supply of some types of HCBS providers, particularly in some areas.

- About half of the case managers reported an insufficient supply of HCBS providers.
- Shortage of providers was most often reported in rural areas.
- The largest identified need was for providers willing, trained and well-supported to serve persons with special physical/health needs and/or behavior problems.

In summary, access to Minnesota's HCBS program appears equitable and consistent with federal and state regulations. Some pockets of limited accessibility have been pointed out. Some are obviously more easily addressed than others. Many of the problems in accessibility appear related to the high desirability of this program. The number of persons seeking access simply exceeds the number of persons Minnesota has been authorized to serve. Clearly establishing adequate access to this program as "access" is understood by families, case managers and county officials will mean continuing to steadily increase the overall opportunities for enrollment in the program, particularly for persons requiring diversion allocations.

Cost-Effectiveness

Minnesota's expenditures for HCBS have been considerably below those estimated in the original application.

- Minnesota's applications estimated that between FY 1987 and 1991 its total HCBS expenditures would be $275 million; actual expenditures were $263 million dollars (more than 4% below projections).
- HCBS expenditures were maintained below approved levels for all years except FY 1989, when actual expenditures exceeded estimates by $2.4 million.
- In FY 1991, actual HCBS expenditures were only $64 million, as compared with the projected $79 million dollars.

In 1991 HCBS per recipient costs were just over half of the ICF-MR per resident costs.

- The average annual cost of HCBS per recipient in 1991 was $23,702 as compared with an average of $44,964 per ICF-MR resident.
- Between FY 1989 and 1991 the ratio of all Medicaid costs for HCBS recipients to all Medicaid costs for ICF-MR residents decreased from .69 to .58.
- HCBS has indirectly contributed to increasing per person ICF-MR costs in Minnesota by playing such a substantial role in the reduction of RTC residents over whom are spread the fixed costs of operating the institutions.

Persons receiving HCBS had higher costs for Medicaid acute care services (e.g., inpatient hospital care, physician services, therapeutic services) than persons in ICFs-MR.

- In 1991 Medicaid acute care costs for HCBS recipients averaged $12.16 per day as compared with $8.01 in ICFs-MR; this difference both in terms of percentage and actual dollars has been decreasing

every year since 1988 when acute care services cost an average of $10.31 per day for HCBS recipients and $5.18 per day for ICF-MR residents.

- Part of this difference was attributable to ICF-MR residents (particularly those in larger facilities) having access to acute care services as part of their basic ICF-MR reimbursement rate.

Persons who entered the HCBS program from ICFs-MR (primarily RTCs) had considerably higher average annual costs than people who entered from the community.

- In 1991 HCBS recipients entering from ICFs-MR ("conversion" enrollees) had annual Medicaid costs (HCBS and acute care) of $31,486 as compared with $22,963 for HCBS recipients from the community ("diversion" enrollees).

- Two factors in the difference were that about half of the diversion enrollees lived with their families who contributed much of the care and services that had to be purchased for people living outside their natural homes; and that over one-third of the diversion enrollees were children and youth whose major day programs were still educational (not Medicaid funded).

The substantial variability in the program costs of individual HCBS recipients suggested considerable targeting of resources to individual needs and circumstances and considerable use of the flexibility available to counties in the requirement that they work within an *average* reimbursement rate rather than fixed cap on HCBS expenditures.

- A total of 237 HCBS recipients had program costs of less than $5,000 per year in 1991; these 9% of all HCBS recipients were served with less than 1% of the total HCBS expenditures.

- In 1991 31% of all HCBS recipients had programs that cost less than $15,000; these programs made up about 10% of all HCBS expenditures.

- In 1991 about 23% of HCBS recipients had programs that cost more than $40,000, including 2% with programs costing more than $60,000; programs costing $40,000 or more made up about 29% of all HCBS expenditures.

Even though the HCBS program has clearly been instrumental in slowing the rate of growth in ICF-MR utilization and expenditures, Minnesota remains one of the heaviest users of and highest spenders for ICF-MR care.

- In 1987 Minnesota ranked first nationally in the number of ICF-MR residents per 100,000 of the state's population (154 as compared with a national average 59); by 1990 Minnesota's ranking had dropped to only to second but its placement rate per 100,000 had decreased substantially (129 as compared with 58 nationally).

- Although Minnesota ranked third nationally in both 1987 and 1990 in ICF-MR expenditures per state resident, Minnesota's per capita ICF-MR expenditures decreased from $57.70 to $53.12.

- In 1990 Minnesota ranked fourth nationally in per capita expenditures for combined ICF-MR and HCBS; between 1987 and 1990 as combined expenditures grew 38.2% nationally they grew only 24.9% in Minnesota.

- The Department appears to have developed good internal policies and monitoring mechanisms to assure continued control over the total expenditures for HCBS.

Using relatively conservative assumptions, but excluding costs outside the Medicaid program, between 1987 and 1991 the HCBS program yielded an estimated net savings of $29.3 million federal and state dollars over expenditures that would have occurred had Minnesota not developed its HCBS program.

- Estimated Medicaid savings to the State of Minnesota due to the HCBS program between 1987 and 1991 were approximately $14 million state dollars.

- According to Department of Administration, computations Minnesota Supplemental Aid payments to HCBS recipients between 1987 and 1991 were approximately $20 million dollars.

- It appears that much of the Minnesota Supplemental Aid for HCBS recipients, perhaps as much as 8 million dollars in 1991, funds "supervision" that could be legitimately reimbursed as an HCBS under Minnesota's authorized service category, Supported Living Services.

In summary, the cost-effectiveness of Minnesota's HCBS is well within the definitions established in federal regulations and within the assurances provided in Minnesota's application to provide HCBS. Since the initial application in 1984 and through the most recent four-year period covered by this assessment, the HCBS program has played a central role in removing Minnesota from the position of the nation's most extensive user of ICFs-MR relative to the State's population. Minnesota's HCBS program has been operated with expenditures well below projected levels and with per recipient Medicaid costs that are less than 60% of ICF-MR costs. The state has established policies and monitoring mechanisms which assure continued ability to control HCBS costs.

Quality of Services

HCBS recipients receive a wide range of medical, non-medical, and behavioral and mental health services primarily from typical community clinical practices and caregivers and recipients overwhelmingly rated these services as adequate or better than adequate.

- An estimated 93% of HCBS recipients saw a physician in the previous 6 months, with adults usually seeing family physicians and children seeing pediatricians in typical community clinics.

- Very few HCBS recipients were hospitalized or went to emergency rooms during the previous 6 months.

- An estimated 75% of HCBS recipients received medications, primarily to control seizures and other minor ailments. Only 11% received psychotropic medications, less than half the proportion reported in the 3 largest studies of medications used by community residents with MR/RC.

- An estimated three-quarters of HCBS recipients had seen a dentist at least once in the previous 6 months.

- Children were more likely to receive services from physical therapists, speech/language therapists and occupational therapists than adults, presumably because those services are more readily available in schools than in adult service settings.

Primary care providers indicated that no additional services were needed for an estimated 65% of HCBS recipients.

- The service most commonly reported as needed but not received was speech or communication training (26%), a service not directly authorized as an HCBS.

- Psychological and behavioral analyst services were reported as needed by 17% of HCBS recipients; physical therapy by 10%

Families expressed high levels of satisfaction with HCBS provided to their family members.

- Case managers were rated as excellent by 48% of families, good by 37% and poor by only 2%.

- In-home family support was the only service which was not rated as either excellent or good by at least 80% of the applicable responses.

- Family ratings of quality of services rarely differed by the type of county in which people lived (i.e., Twin Cities urban, outstate urban or rural).

- Typically families reported there were no problems with their members' HCBS, but when problems were reported they most commonly related to the bureaucracy of receiving services and the need for improvements in staffing of services (amount, training, qualifications, and retention/replacement).

Case managers were reported by care providers and families to visit with reasonable frequency and to offer a wide range of assistances to HCBS recipients, families and service providers.

- Careproviders reported an average of 3 visits from case managers in the previous 6 months, with no notable differences by type of placement or type of county.

- When compared with a national sample of case managers of people living in small community residences the case managers of HCBS recipients in Minnesota were more often reported to a) help solve recipient's problems (84% vs. 73%), b) review each aspect of the recipient's program plan (75% vs. 55%), c) make a point of talking directly to the HCBS recipient (87% vs. 74%), d) provide training or advice of meeting the recipients' needs (63% vs. 47%), and e) arrange special training and support when needed (48% vs. 29%). Areas of similarity included a) asking if the individual was having any problems (92% vs. 91%) and b) assisting service providers and families with applications and other paper work (63% vs. 61%).

Case managers expressed considerable satisfaction with the quality of services and the place of residence of their clients.

- About 55% of HCBS recipients had services rated as better than adequate by their case managers; only 2% had services rated as less than adequate.

- About 91% of the HCBS recipients were living in places that were considered to be the most appropriate kind of place at present for their client; by far the HCBS recipients who were most commonly considered not to be living in the most appropriate kind of place (36%) were adults living in their families' homes.

HCBS recipients participated in a wide variety of day activities.

- An estimated 23% of HCBS recipients were engaged in integrated work settings as a primary day activity; 57% participated in segregated settings.

- An estimated 4% of HCBS recipients (5 in the sample) had no day program. All were adults; one was over 65 years and was not interested in a day program. Persons most likely not to have day programs were adults living with their families.

- Children and youth younger than 22 in education programs made up a third of HCBS recipients; these individuals could have significant cost implications for the HCBS program as they move into adulthood and no longer receive educational services, particularly if vocational opportunities funded by programs other than Medicaid are not available.

HCBS recipients had a variety of people involved in their lives, but most people in their social networks were family members, people they lived with and service providers.

- An estimated 85% of HCBS recipients not living at home visited and/or were visited by family members in the previous 6 months; this compares with 69% of community residents in a recent national sample survey. An estimated 40% were visited more than 8 times in the previous 6 months.

- An estimated 14% of HCBS recipients were reported to have no friends other than family or people paid to provide services to them.

HCBS recipients participated in a wide range of community settings.

- In a one month period HCBS recipients participated an average of 20 times in activities in recreation, leisure and commercial activities in integrated community settings. Participation ranged from 2 times to 65 times. Persons with mild, moderate and severe mental retardation averaged 22 separate involvements, persons with profound mental retardation averaged 12 separate involvements.

- During the previous 6 months over 80% of HCBS recipients had at least one time visited a park, a restaurant, a grocery store, a clothing or department store, a medical office and a dental office; at least 60% had visited a corner store or deli, a drug store, a movie theater, a bank, a bowling alley, a library, a playing field, a church and a public beach.

- When compared with a national sample of community residents with MR/RC on the use of 6 community resources, Minnesota HCBS recipients were more likely to have gone shopping, gone to a library, gone to a park and gone to a restaurant. There was no difference in the proportion attending movies or church.

- Although HCBS recipients participated in a wide variety of activities, an estimated less than 5% participated in these activities with friends who did not themselves have disabilities.

Careproviders of HCBS recipients, especially adults living in non-family settings, appeared to provide considerable autonomy and opportunity for choice.

- Corporate foster care settings provided the most autonomy and choice to HCBS recipients. About 80% of recipients living in corporate foster care settings were reported to be able to choose their own bedtime, as compared to half the recipients living in family foster care or in their family's home. Corporate foster care residents were also reported to have considerably greater control over their money, their friends, and their personal activities.

- Children and youth living in their own homes appeared to have relatively few opportunities to make choices about activities and schedules.

HCBS recipients report themselves overwhelmingly to be satisfied with their lives.

- About 85% of HCBS recipients interviewed indicated they were happy most of the time; 89% report liking where they live.

- Over 85% of HCBS recipients reported liking their HCBS providers and how they are treated by those providers.

Case managers reported considerably greater preference for the HCBS approach to services as opposed to the ICF-MR approach.

- Case managers generally considered the HCBS to better provide opportunities for more normal, homelike and/or less restrictive living arrangements than ICFs-MR.

- Case managers generally observed that the HCBS approach offers more and better options to support community interaction than ICFs-MR.

- Case managers viewed the HCBS program as providing more flexibility and individualization to respond to individual needs and preferences than ICF-MR.

- A few case managers indicated that HCBS could be considerably preferable to ICF-MR but that because of current regulation and congregate care approaches the actual difference between the approaches was minimal.

Case managers recommended 4 primary ways that Minnesota could improve its HCBS program.

- Paperwork associated with HCBS management and service provision could be reduced, including revision of Rule 42.

- There could be an expansion of diversion allocations and other support services to meet the needs of Minnesotans with MR/RC living in the community.

- There could be increased flexibility in the financing of HCBS services to increase service options and reduce the amount of total program costs going for provider agency administration and fees.

- The State could steadily increase the average reimbursement rate toward the maximum allowable level under federal regulations.

In summary, Minnesota has established comprehensive standards for all HCBS and has established procedures for at least annual review of compliance with those standards and for the correction of observed deficiencies. Overall, the quality of services received by Minnesota's HCBS recipients was rated as generally high by case managers, family members and HCBS recipients themselves. Recipients were active in their communities, had adequate health and dental services and had relatively few services identified as needed but not received. However, HCBS recipients participated in few activities that included typical community members. Concerns about service quality tended to be expressed in terms of the extent to which HCBS services can avoid unnecessary similarities with the highly regulated ICF-MR model which has been dominant in Minnesota and which appears to have affected the regulatory approach taken toward HCBS in the state. There is growing interest in Minnesota, including staff members within DHS, for efforts to rethink Minnesota's traditional, highly regulated licensing and monitoring approaches to "quality assurance." This interest is focusing on more comprehensive and positive approaches to enhancing the quality, including a balance between licensing, monitoring, training, technical assistance, increasing the numbers of providers to increase for choice, providing better supports for families and small providers, and any other promising practices to increase community and social involvements of persons with developmental disabilities.

Recommendations

The State should implement strategies to improve awareness of certain requirements of the HCBS program regarding access and enrollment.

- Evidence is clear that family members are initially informed that HCBS are an option to ICF-MR services and that they may choose ICF-MR services. However, most fail to remember this option after HCBS have been provided for a period of time. Even when access to ICF-MR services is limited to large institutions, periodic reminders should be provided to HCBS recipients and their families of the right of choice they retain.

- "Deferred screenings", that is when people are not screened for their eligibility for HCBS until HCBS allocations are available, should be eliminated; such practices are out of compliance with state regulations, cause underestimation of the need for HCBS and may affect access to HCBS for persons deferred.

The State should work to establish more consistent and systematic policies among counties in the prioritization of individuals to receive HCBS.

The State should work with counties and minority community organizations to improve knowledge about and utilization of HCBS by individuals from racial and ethnic minority groups.

The Department of Human Services should work with counties and with other Departments to improve access to needed HCBS and related services.

- Respite care and employment services are the most frequently identified general services needs, while speech and communication training and psychological or behavioral services are the most frequently identified professional service needs.

- The State should seek to increase the number of individuals and agencies providing services, especially through the recruitment and development of new providers.

- The State should consider alternative requirements for the training, licensing and/or approval of potential providers of non-technical services such as respite care.

The State should carefully examine its use of state-only funds through Minnesota Supplemental Aid (MSA) to fund supervision services that could be legitimately cost-shared with the federal Medicaid program.

- The current practice of funding supervision with MSA appears in conflict with existing state regulations limiting MSA contributions for HCBS recipients to "room and board" which as defined in state regulation does not include supervision.

- Although including the supervision costs currently paid for by MSA under HCBS could increase average HCBS costs by about $7 or $8 per day, those costs a) would still be under Minnesota's allowable HCBS expenditures, b) would have no adverse effect on the nature of quality of supervision; and c) would be shared with the federal government at the State's Medicaid matching rate and thereby reduced by 53% to the State.

The State should better communicate about and solicit input from counties into the process of requesting and negotiating allocation and distribution of allocations for diversion and conversion enrollees.

- Forums should be expanded to assure that county officials,' case managers' and families' opportunities to receive accurate information about the various constraints and choices in the HCBS application process and ample opportunity to make suggestions on how the State might respond to them.

- The State should communicate balance and sensitivity between the use of HCBS for its goals of deinstitutionalization and the counties' concerns about the growing numbers of unserved individuals and families.

The State should work with counties and providers to prevent overuse of the 3 or 4 person group home to deliver HCBS.

- In many counties the financing and operation of "corporate foster care" homes is very similar to that of ICFs-MR, with the individual's home and services under the control of his/her service provider; potential HCBS benefits of individual control over housing, choice of services and service providers or the potential cost implications of competition and service alternatives are often substantially reduced under this model.

- Choice and personalization of HCBS should be enhanced by efforts to reduce the economic interest that service providers have in the places HCBS recipients live.

The State should develop a concerted effort with counties to increase the pool of potential service providers.

- The State should become directly involved in and provide technical assistance to counties in the recruitment of potential HCBS providers.

- The State should consider a revolving account to assist new providers with loans of "start up" costs until the reimbursement for services cash flow is established.

- The State should develop information and technical assistance programs on getting started as a HCBS provider and dealing with the financial and administrative aspects of a HCBS business.

The State must begin soon to develop the kind of decentralized capacity for providing training, technical assistance, resource development and other quality enhancement activities that is needed to support the rapid growth and increasing dispersal of community service sites.

- At current projections by the end of this decade Minnesota's HCBS program will be its largest Medicaid program for persons with MR/RC. Despite this decentralization of services and dispersal of service recipients to rapidly growing numbers of different sites, the State has done little to improve the access of families and HCBS providers to the kinds of training, technical assistance, and basic supports needed to assure the potential benefit of community living.

- Minnesota has a current and rapidly growing need to decentralize its efforts to assure, enhance and maintain quality in community services through the development of 8-10 localized programs that are integrally involved in service provision in geographically localized areas of the State.

- The move to more geographically localized systems of assistance and support to community providers should be balanced with careful consideration of areas in which regulatory and paper compliance burdens can be replaced by more cooperative and productive commitments to improved quality of services.

- Localized quality enhancement programs should be independent entities governed by a broadly representative Board including key constituencies (e.g., state, county, provider and consumer

representatives) with renewal based on performance. It is critical to their success that the selection and continuation of programs be based on objective assessment of their ability to understand the community needs of HCBS recipients, families, HCBS providers, county case managers and others and to generate the programs and resources that can meet these needs in local communities. A State Support System Project involving Minnesota professionals of the highest levels of knowledge, skill and recognition in assisting others to deal with the many challenges of providing community services should be developed to provide training, technical assistance, resources and support to the area quality enhancement programs.

- Funding for the quality enhancement system should be pegged to a firm standard of commitment to quality management and improvement, minimally 2% of total community Medicaid program expenditures, with the state and federal governments each contributing 1% through the Medicaid cost sharing of administrative expenditures.

PART I: INTRODUCTION

Overview of the Medicaid Home and Community Based Services Waiver Program

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), was enacted on August 13, 1981, and granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid (Title XIX) statutory requirements to permit states to receive federal financial participation (FFP) for "non-institutional" long-term care services for Medicaid-eligible individuals. The program was designed to provide home and community-based services (HCBS) to persons who were aged/disabled or mentally retarded/developmentally disabled and, who, but for these services, would remain in or would be placed in a Skilled Nursing Facility (SNF), Intermediate Care Facility (ICF) or an Intermediate Care Facility for the Mentally Retarded (ICF-MR).

The Medicaid HCBS authority gives states greater flexibility in providing cost-effective services that respond to the needs of individuals, rather than focusing efforts solely on authorizing institutional placements and then monitoring conditions of care in those facilities. The HCBS authority responds directly to two major criticisms of the Medicaid ICF-MR program: 1) that Medicaid reimbursement is more readily available to finance care in large, structured and socially segregated institutions than in more culturally normal, less restrictive and socially integrated settings; and 2) that rapidly increasing ICF-MR expenditures are being driven by the institutional requirements of uniform, comprehensive and costly services for all residents, irrespective of their need or desire for them or their ultimate benefit from them. Not only does the HCBS option allow states greater latitude in terms of the specific services they can provide to meet the needs of individuals, it allows even greater latitude in how they would determine standards for those services and assure their quality. With its greater flexibility, reduced regulatory oversight, and maintenance of Federal Medicaid cost-sharing, it is not surprising that the HCBS program has generated considerable interest among the states. By January 1, 1983 16 states had been granted authority to provide HCBS to persons with mental retardation and related conditions; by January 1, 1985, 33 states; and by January 1, 1991, 43 states.

HCBS Waiver Options

In addition to providing federal reimbursement for services not otherwise covered under the regular Medicaid program, the HCBS legislation and regulations allows states considerable flexibility in designing their HCBS programs within specific restrictions controlling their size and cost. Specifically, the federal government is authorized to waive Medicaid requirements on states regarding: 1) statewideness, 2) comparability, 3) 300% rule for non-institutionalized recipients, and 4) excess costs.

Statewideness. Medicaid Law (Sec. 1902(a)(1)) requires that all services offered under the State's Medicaid program be offered statewide. A "waiver" of this requirement allows states the right to restrict services to limited geographic locations.

Comparability. Medicaid law requires that services available to categorically needy individuals be not less in amount, duration, and scope than services available to medically needy persons; in addition, services must also be equal in amount, duration, and scope for all categorically needy beneficiaries. This provision may, however, be waived and as a result, states are free to establish programs for specific target populations.

Use of institutional eligibility criteria. Under current Title XIX regulations, states are permitted to establish higher income and resource standards for institutionalized persons to qualify for Medicaid than exist for individuals not residing in Medicaid certified facilities. The HCBS program permits states to use the same institutional income eligibility standard for persons receiving HCBS as for ICF-MR residents.

Excess costs. Another option that states have under HCBS is the authority to deny home and community-based services to an individual in the event that those services would cost more than maintaining him/her in an institution.

Authorized Services Under the Waiver

States are specifically authorized to provide seven basic services in an approved HCBS program: 1) case management, 2) homemaker services, 3) home health aid services, 4) personal care services, 5) adult day health services, 6) habilitation services, and 7) respite care. Specific operational definitions of these services were not provided in the regulations. States were given wide latitude in defining the services for their own purposes. Other services may be approved if the state demonstrates that they are necessary to avoid institutionalization and are cost effective. Specifically authorized services are noted below.

Case management. The HCBS regulations identify case management as "a system under which responsibility for locating, coordinating, and monitoring a group of services rests with a designated person or organization."

Homemaker services. The regulations describe homemaker services as "general household activities provided by a trained homemaker when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for himself or others in the home."

Home health aide services. In the regulatory definition, home health aide service involves performing "simple procedures such as the extension of therapy services, personal care, ambulation, exercise, household services essential to health care at home, assistance with medications that are ordinarily self-administered, reporting changes in the patient's condition and needs and completing appropriate records."

Personal care. In the HCBS regulations personal care services are "services furnished to a recipient in his or her own home that are prescribed by a physician in accordance with the recipient's plan of treatment that are provided by a qualified person who is not a member of the recipient's family."

Habilitation services. Habilitation services are defined only as "health and social services needed to insure the optimal functioning of the mentally retarded or persons with related conditions."

Respite care. The regulations define respite care as a service provided "to individuals unable to care for themselves . . . on a short-term basis . . . because of the absence or need for relief of those normally providing care."

Other services. The regulations cite a number of "other services" that states may request to offer (including nursing care, medical equipment and supplies, various therapies, and adaptations to one's home and vehicle) by demonstrating their cost effectiveness and necessity to avoid placement in a Medicaid facility. (Authorized basic and other services and their utilization will be shown in Table 2.)

Current HCBS Recipients, Costs and Services Nationwide

Table 1 shows the number of HCBS recipients in states providing HCBS in June 1990 with Fiscal Year 1990 total state expenditures and average state expenditures per recipient. In all, the 41 states providing HCBS reported 39,838 HCBS recipients on June 30, 1990. State-federal expenditures totalled $846,404,031. Table 2 summarizes utilization by states of the specific services authorized under the Medicaid Home and Community Based Services option in June 1990: 1) case management, 2) homemaker services, 3) home health aid services, 4) personal care services, 5) adult day health services, 6) habilitation services, and 7) respite care, as well as other services that have been approved for the states to provide in their HCBS programs.

Nationwide, as in Minnesota, the most frequently reported HCBS services were case management, residential habilitation and day habilitation.

In Fiscal Year 1990 the average cost of HCBS services per recipient at the end of the year was $21,246. Average daily per recipient costs ranged from over $100 per day in 5 states (Connecticut, Maryland, New Hampshire, Pennsylvania, Rhode Island) to less than $25 per day in 5 states (Alabama, Arkansas, Florida, Idaho, Oklahoma). The single service that best discriminates between higher and lower cost states was residential habilitation. Higher cost states are much more likely to provide habilitation services, in almost all states including supervision as well as training.

Table 1: Number of HCBS Recipients with MR/RC in June 1990,
State Fiscal Year 1990 Costs for HCBS and Average HCBS Cost per Recipient

State	No. of HCBS Recipients in June 1990	Combined state and federal $: HCBS SFY 90	Average HCBS expenditure (1990) per recipient
AL	1,839	$10,503,596	5,712
AR	91	425,000	4,670
CA	3,628	50,496,572 [1]	13,919
CO	1,841	38,720,290	21,032
CT	1,555	59,179,791	38,058
DE	196	3,585,131	18,291
FL	2,615	17,766,000	6,794
GA	160	3,819,509 +	23,847
HI	123	1,915,378	15,572
ID	346	1,648,019 [2]	4,763
IL	724	19,100,000	26,381
IA*	5	41,998	8,400
KS	361	4,372,992	12,114
KY	743	10,066,379 +	13,548
ME	454	15,000,000	33,040
MD	858	34,346,756	40,031
MA	1,539	47,183,000	30,658
MI	1,658	41,500,000	25,030
MN	2,184	55,185,013	25,268
MO	989	13,817,994	13,972
MT	276	5,235,640	18,970
NE	658	18,185,838	24,589
NV	133	1,587,500	11,938
NH	822	31,564,800	38,400
NJ	3,270	78,600,000	24,037
NM	160	2,400,000	15,000
NC	731 [3]	6,826,343	9,338
ND	1,055	13,360,819	12,664
OH	245	4,070,507	16,614
OK	621	5,499,237	8,855
OR	1,282	34,838,377	27,175
PA	2,221	107,984,235	48,620
RI	277	14,336,750 +	51,757
SD	721	10,388,196	14,408
TN	581	7,909,045	13,613
TX	485	12,139,200	25,029
UT	1,200	13,308,843	11,091
VT	323	7,959,645	24,643
WA	1250 [3]	18,464,904	14,772
WV	316	4,504,258 +	14,254
WI	1,302	18,566,476 [4]	14,260
Total	39,838 **	$846,404,031 **	$21,246 ++

* Iowa provided Medicaid HCBS for persons with MR/RC under a "model" waiver only.
** Forty-one states
+ Data from HCFA-64 report for fiscal year October 1, 1989 to September 30, 1990.
++ Average cost per participant (total HCBS cost/total # recipients) nationally.

Table 2: Types of HCBS Services and Number of Recipients/Service Type

State	No. of HCBS Recipients in June 1990	No. of HCBS recipients receiving indicated HCBS in June 1990***							
		Case mgt.	Home-maker	Home health aide	Personal care	Habil., resid.	Habil., day	Respite care	Other services
AL	1,839						1,839		See below
AR	91	91			10	45	83	45	See below
CA	3,628		1	5	3,259	329		25	See below
CO	1,841	1,841				1,751	686	83	
CT	1,555	1,555				1,555	684		
DE	196	196				196	72	30	See below
FL	2,615	330						39	See below
GA	160		64	32	32	93	123	64	See below
HI	123	123			46	77		1	See below
ID	346				346				
IL	724	724				643	609	46	
IA*	5		5	3			2		
KS	361	361	10		43	289	282	18	See below
KY	743	Not available							
ME	454	Not Available							
MD	858	858				858	858		
MA	1,539	1,539				1,062	427	36	See below
MI	1,658					1,605			See below
MN	2,184	2,184	69			1,722	1,112	423	See below
MO	989					937	512		See below
MT	276	102	NA			167	120	NA	See below
NE	658	658				658	658		
NV	133	133				133	91		See below
NH	822	822			822		245		See below
NJ	3,270	3,270			1,917		2,664		
NM	160	160	36			77	76	69	See below
NC	731 [3]	421	2		142		379	117	See below
ND	1,055	1,055	10	10	90	514	298	57	See below
OH	245	223	1		206	182	120		See below
OK	621	621				196		61	
OR	1,282					1,282 [6]	1,089 [6]		
PA	2,221	2,221				2,220	1,573	37	See below
RI	277	Not Available							
SD	721	721				584	721		
TN	581	543			38	543	543	28	
TX	485	485	NA			NA	NA	485	See below
UT	1,200	1,200				788	830	42	See below
VT	323	323				323	323	66	See below
WA	1250 [3]	Not available							
WV	316	Not available							
WI	1,302	Not available							
Total	39,838 **	22,773	198	50	6,951	18,829	17,019	1,772	

* Iowa provided Medicaid HCBS for persons with MR/RC under a "model" waiver only.

** Forty-one states

*** Thirty-five of 41 states (with a total of 35,496 HCBS recipients) reporting.

Notes. [1]As of 11/28/90
[2]1-1-89 to 12-31-89
[3]Approximate
[4]Calender year 89 (1100 persons)
[5]includes education services
[6]includes prevocational and supported employment services

OTHER SERVICES: (# of recipients in 6/90)
Note. NA means # of recipients is not available.

Alabama
- residence-group home (136)
- residence - SCLA (60)

Arkansas
- combined homemaker/home health aide/personal care (10)
- transportation (91)
- adaptive equipment (27)
- consultative services (18)

California
- adult day services (205)
- non-medical transportation (548)

Delaware
- supported employment (38)
- pre-vocational (66)

Florida
- transportation (1172)
- training and therapies (1049)
- developmental training (1378)
- family placement (4)
- diagnosis and evaluation (63)
- case management by direct care staff (243)

Georgia
- supported employment

Hawaii
- adult day/health (123)

Kansas
- wellness monitoring (7)
- Med alert (7)

Massachusetts
- transportation (185)

Michigan
- non-vocational (out-of- home) day habilitation (142)
- pre-vocational day habilitation (444)
- supported employment (160)
- transportation to day habilitation (477)

Minnesota
- adaptive aids (111)

Missouri
- occupational therapy (87)
- physical therapy (90)
- speech therapy (95)
- home modification (3)
- transportation (93)
- behavior therapy (44)

Montana
- transportation (145)

New Hampshire
- supported employment (99)
- adult day activities (281)

New Mexico
- companion home (9)
- behavior management (26)
- behavior implementation (16)
- family education and training (1)
- occupational therapy (30)
- physical therapy (29)
- speech therapy (46)

North Carolina
- screening (11)
- home mobility aides (1)
- mr waiver supplies (104)
- adult day health (2)

North Dakota
- adult day care (47)
- supported employment (37)
- infant development (40)

Ohio
- equipment (150)
- transportation (74)
- nursing respite/LPN (10)
- private duty nursing/LPN (17)

Oregon
- residential habilitation includes educational service
- day habilitation includes prevocational and supported employment services

Pennsylvania
- transportation (1121)
- special therapies (1635)
- physical adaptations (90)
- prevocational supported employment
- permanency planning (1)

Texas
- occupational therapy (NA)
- physical therapy (NA)
- speech therapy (NA)
- audiology therapy (NA)
- psychological therapy (NA)
- social services (NA)
- nursing services (RN, LVN) (NA)
- age appropriate day programming (485)

Vermont
- day activities (2)

Utah
- family support (25)
- supported employment (154)

Overview of the Minnesota Home and Community Based Services Waiver Program

In 1984, the Minnesota legislature authorized the Department of Human Services (DHS) to seek approval from the U.S. Department of Health and Human Services to provide Medicaid-funded Home and Community Based Services to persons with mental retardation and related conditions (MR/RC). The application was subsequently approved, with 278 individuals receiving HCBS in 1985. From that initial group, the number of HCBS recipients with MR/RC in Minnesota grew to 2,466 persons by the end of state FY 1991. In June 1990, Minnesota's HCBS program for persons with MR/RC (with 2,184 recipients) was the fourth largest in the U.S., behind California (3,628 recipients), Florida (2,615), and Pennsylvania (2,221). Minnesota's relative utilization rate of 49.9 recipients per 100,000 of the state's population was the 4th largest, behind North Dakota (165.1), Utah (69.6) and Colorado (55.9).

Minnesota's authorized HCBS include case management, residential habilitation (supported living services and in-home support services), day training and habilitation (including supported employment), homemaker services, respite care (both in-home and out-of-home), and adaptive aids for the individual (including modifications to the person's home and vehicle). All persons with MR/RC receiving HCBS are provided case management.

Administration of the MR/RC Waiver

The HCBS program for persons with MR/RC in Minnesota is managed and monitored by the state Department of Human Services (DHS), but is administered by the human services agencies of the 87 counties. Within the state DHS, primary responsibility for program management of HCBS for persons with MR/RC is assigned to the Division for Persons with Developmental Disabilities (DPDD), with a number of other DHS divisions having specific responsibilities in the program's management and monitoring as well. At the county level, the county human service agency acts to plan, provide or arrange, and monitor HCBS for eligible persons within limits of budget and state and federal standards. Case management is provided by county human service agencies' social workers, or in a limited number of cases, employees of contracted agencies.

Each state fiscal year, Minnesota has a limited number of HCBS "allocations" to serve persons with MR/RC, an allocation being authority to provide HCBS to one person with MR/RC. Minnesota's HCBS authority from the federal government has permitted those allocations to increase each state fiscal year. In practice, once an individual receives HCBS they continue to receive such services so long as they remain eligible and HCBS are judged to be able to adequately meet their needs in an appropriate manner within legislatively established cost constraints (i.e., a per recipient average daily cost of $80.17 in FY 1991 and $87.41 in FY 1992). The state's total number of allocations has increased in each year of Minnesota's waiver to meet the federal authorized limit. These allocations are awarded to counties by the state based on a number of factors including the county size (population and total persons with MR/RC being served), county efforts to pursue state and county priorities for its long-term care system for persons with MR/RC (e.g., downsizing large state ICFs-MR, closing large community ICFs-MR, preventing out-of-home placement of children), the number of persons requesting and determined eligible for HCBS, historical ICF/MR use, and county plans to develop new resources.

Financing of HCBS

In addition to assigning HCBS allocations to counties, the state DHS establishes budget limits for counties in their provision of HCBS. These limits are established as an allowable *average* daily reimbursement rate within which counties must stay as they purchase services for their HCBS recipients as a group. Therefore, counties have latitude in "averaging" HCBS costs, within the allowable daily reimbursement rate. This gives them the flexibility to allow for differences in the levels, types and costs of services needed by individuals, and to provide HCBS costing more than the allowable rate for some individuals, to the extent

other HCBS recipients receive services costing less than the allowable rate. Adults with MR/RC receiving HCBS while living in a residence other than their family home typically receive federal Supplemental Security Income (SSI) and Minnesota Supplemental Aid (MSA) funds to provide room, board, supervision and related expenses. Room and board costs of children living outside their family home are reimbursed through Federal Title IV-E and county funding.

In 1989, the State received approval to provide "enhanced" funding for persons leaving state-operated, ICF-MR certified Regional Treatment Centers (RTC/ICFs) and moving into the community to receive HCBS. This amendment to Minnesota's HCBS program provided for DHS rather than county management of these funds to assist individual counties in providing HCBS to former RTC residents when this could not be done within the allowable average reimbursement rate. Counties request this funding from DHS which are approved within an enhanced average daily reimbursement rate which is substantially higher than the general allowable average reimbursement rate (i.e., $170 per day and $83 per day in 1992 respectively), allowing for the typically higher costs of serving former RTC residents in the community (Tables 6 and A-6 show the substantially greater service needs of RTC residents than community ICF-MR residents or HCBS recipients). Despite the "enhancements" of allowable costs for persons leaving RTCs, expenditures of the combined regular and enhanced waiver options remain within the projections of Minnesota's approved application and its subsequent amendments.

Organizational Roles

County human service agencies play the key role in the implementation of Minnesota's HCBS program. Counties may act as direct providers of HCBS services; all counties provide case management, some provide homemaker and respite care services. County human services agencies play the primary role in selecting individuals to receive HCBS and in purchasing services for them from private for-profit or non-profit service providers. Some counties have a number of private service providers from which to choose while other, often rural, counties are dependent on one or two service provider agencies.

Minnesota's DHS provides some training and technical assistance to county human services agencies, service providers, and others to maintain and improve the quality of services to persons with MR/RC receiving HCBS. Periodic, statewide training is conducted by central office DPDD staff and outside consultants. A small network of 9 regional DPDD staff is responsible for on-site training and technical assistance as requested by counties and providers. Some counties also participate in conducting training and technical assistance, but for the most part private service providers and provider organizations carry out their own training activities and secure their own technical support. Staff of the Minnesota state institutions are also available as consultants and conduct training from time to time.

Monitoring the quality and appropriateness of services received for HCBS recipients is primarily the responsibility of the individuals' county case managers. Targeted monitoring of service quality as defined in formal licensing rules is conducted by the Division of Licensing of the state DHS, sometimes with delegation to county social services. State rules specify training and experience requirements for providers of HCBS and establish standards and procedures for county administration of HCBS. "Rule 41" describes the funding and administration of HCBS, and specifies qualification requirements of providers. Continuing oversight by the DHS Medicaid Surveillance, Utilization and Review unit and periodic reviews by the Office of the Legislative Auditor are among measures to assure appropriate use of federal and state funds for HCBS recipients. A number of state and private oversight and advocacy organizations (Office of the Ombudsman, Legal advocacy Office, Developmental Disabilities Council, MNARC) maintain an ongoing interest and participation in HCBS program monitoring as well.

In addition to a fully computerized billings and payments system, Minnesota maintains an extensive system of computerized and manual information management for its HCBS program for persons with MR/RC, providing current data on individual recipients, services, cost and allocation use. Monthly reports from these data bases to each county assist local agencies in administering their home and community based services and budgets within required state limits.

PART II: APPROACH AND METHODOLOGY

The independent assessments required of state HCBS programs prior to their renewal must address three specific areas: 1) access to services, 2) cost-effectiveness of services and 3) quality of services. Each of these areas has a limited, federally-required operational conceptualization that must be included in all independent assessments, but at the request of the State this particular assessment went considerably beyond those minimal requirements. This section briefly outlines the general approach taken to gathering data in this assessment.

Research Questions and Data Sources

Access to Services

A required component of the independent assessment was an analysis of state compliance with federal requirements that a) persons with MR/RC receiving HCBS are persons who in the absence of those services require the level of care provided in an ICF-MR and b) that HCBS recipients are given opportunities to choose between HCBS and institutional services, and to choose their providers of HCBS. In discussions with state officials it was clear that their concerns were considerably broader than the minimum federal requirements. Based on those discussions, the evaluation of access to care was designed to answer four basic questions:

1) Who has access to the HCBS program? Is it the intended population?

2) How does the supply of HCBS allocations compare with demand? How are access decisions made when demand is greater than supply?

3) How long must eligible persons wait to receive services?

4) Do HCBS recipients have access to the services that are needed by them and intended for them?

The paragraphs below describe the approach to addressing these questions.

1) Who has access to the HCBS program? Is it the intended population?

Access restricted to Medicaid eligible who meet ICF-MR criteria. Federal regulations and the state's HCBS application stipulate that only Medicaid eligible persons who have disabilities commensurate with the need for ICF-MR care are eligible for HCBS. This assessment documented, through use of state data bases, the Medicaid eligibility status and disability status of HCBS recipients and the extent to which their characteristics meet ICF-MR admission criteria.

"At risk" analyses. A series of analyses compared characteristics of the HCBS sample with the characteristics of persons residing in ICFs-MR during the evaluation period. These analyses examined whether HCBS recipients could reasonably be expected to be ICF-MR recipients in the absence of HCBS. The primary source of data for these analyses was the State Medicaid Screening Data Base containing assessment data on all HCBS recipients, 69% of community ICF-MR recipients and 66% of Regional Treatment Center (RTC) residents. These analyses compared the characteristics of the HCBS recipients with those of persons residing in different types of ICFs-MR, including large and small private ICFs-MR and the RTCs.

2) How does the supply of HCBS allocations compare with demand? How are access decisions made when demand is greater than supply?

County allocation priorities. Minnesota rules require that each county prepare a document which specifies its priorities for providing HCBS access to eligible individuals. These were reviewed and summarized. Case managers of the recipients were also questioned about how allocations are actually determined in their counties.

Access by the institutionalized and non-institutionalized populations. Since 1987, it has been the policy of the Department to use HCBS to assist in deinstitutionalization. In practice this has translated into greater numbers of conversions allocations than diversions. As part of the evaluation, historical trends in allocations were documented, along with the characteristics of persons served under conversions and diversions.

Minority access. Minnesota is committed to equal program access for eligible persons without regard to race or ethnic background. Assurances that this principle was reflected in the HCBS program was requested by the state. Using the racial/ethnic status of HCBS recipients from the Medicaid application (Form 106), the proportion of HCBS recipients of minority status was determined and compared with 1990 Census data on the state population as a whole.

Informed choice. According to Medicaid regulation potential waiver clients or their legal guardians must be informed that HCBS are an alternative to ICF-MR placement. The independent evaluation is required to determine that recipients were made aware of their prerogative to choose between HCBS and ICF-MR. Therefore questions about informed choice were included in the HCBS Recipient, Family/Guardian and Case Manager surveys.

3) How long must eligible persons wait to receive services?

Time lapse between screening and service initiation (waiting list). The length of time current program clients waited for services following the initial determination of eligibility and need was determined from the date of screening prior to the beginning of services and the earliest date of invoice for utilized services. Case managers and family members were also questioned about the amount of time the HCBS recipient sample members waited between application and receiving services.

4) Do HCBS recipients have access to the services that are needed by them and intended for them?

Choice among types of services and providers. HCBS recipients must have the freedom to choose the types of services and providers of their care. It is the responsibility of the independent evaluator to certify that this occurs. HCBS recipients and their families were asked directly if they have received the services they need, whether they are currently receiving what they want and whether they have had free choice among providers.

Access to necessary Medicaid state plan services. Under federal regulations HCBS recipients must have access to needed services provided under the State Medicaid Plan. HCBS recipients, families and case managers in the sample were asked if there were services which they needed but are not receiving.

Access of child HCBS recipients to in-home/family settings. A goal of Minnesota DHS is that children with MR/RC will be raised in natural or adoptive families and provided with necessary family supports; and that out-of-home placements if they are unavoidable will be short-term and in stable, nurturant family situations, with specific plans to return the child to its own home. HCBS contributions to this goal were assessed using state data on the distribution of in-home and out-of-home placement of children in Minnesota and the uses of HCBS to support children in their natural families.

Access to community services and physical/social settings. Another DHS goal is that citizens with MR/RC will have access to the same community services and the physical and social settings as all other Minnesotans. The HCBS Recipient/Case Manager Surveys posed questions about access to non-HCBS services and settings.

Cost-Effectiveness

The second component of the assessment of Minnesota's HCBS program was an analysis of "cost-effectiveness." Congress initially approved the Section 2176 HCBS legislation on the presumption that it would be "budget neutral," that is that total Medicaid long-term care expenditures in states providing HCBS would be **no more** than Medicaid expenditures had HCBS not been available. Evaluation of "cost-effectiveness" to meet federal requirements involves examination of how the relative cost of HCBS compares with the costs of the ICF-MR care that would have been necessitated in the absence of HCBS.

Based on the federal requirements and state concerns about cost-effectiveness, evaluation of cost-effectiveness was designed to answer 3 general questions:

1) How do Minnesota's total Medicaid costs since utilization of HCBS compare with its projected costs in its absence?

2) What are the utilization and costs of HCBS and other Medicaid services? How do these vary for different groups of recipients?

3) What has been the full impact of the HCBS program on overall utilization of and expenditures for Medicaid long-term care services in Minnesota?

The paragraphs below describe the approaches taken to address these questions.

1) How do Minnesota's total Medicaid costs since utilization of HCBS compare with its projected Medicaid costs in its absence?

Projected versus actual utilization and expenditures. To assess the congruence between projected and actual utilization data on the actual number of HCBS recipients, average costs per recipient, and total expenditures for the first four years of the HCBS renewal (FYs 1988-1991) were compared to projections made in the original (and revised) HCBS application. Similar comparisons were made of actual versus projected ICF-MR utilization and expenditures.

2) What are the utilization and costs of specific HCBS and other Medicaid services? How do these vary for different groups of recipients?

Utilization and costs of waiver services, by type of service. State data were used to examine utilization and expenditures for specific HCBS services over the four years covered by the evaluation as well as reasons for changes in waiver service utilization and expenditure patterns.

Average Medicaid costs per day of coverage for different groups of HCBS and ICF-MR recipients. "Average daily costs" to the Medicaid program of serving HCBS and ICF-MR recipients with MR/R were computed and compared. (Daily costs rather than annual costs were used because of lower average service days of HCBS recipients.) Cost categories included: (1) ICF-MR costs; (2) HCBS costs; and (3) other Medicaid costs.

3) What has been the full impact of the HCBS program on overall utilization of and expenditures for Medicaid long-term care services in Minnesota.

Impact of the HCBS program on ICF-MR utilization and expenditures. Analyses using state data bases examined trend data on ICF-MR utilization and expenditures prior and subsequent to the implementation of the HCBS program in 1984. Rates of change in ICF-MR utilization and expenditures in Minnesota over the period were also compared to rates of change in the entire United States during the same time period.

Utilization and expenditure patterns of HCBS recipients. Net HCBS claims were merged with the Medicaid Screening Data Base to permit more detailed cost analyses of waiver utilization and expenditure patterns than previously available, including analyses of the distribution of costs across HCBS recipients (e.g., the distribution of "high-cost" versus low-cost clients by location, the variation in HCBS costs by recipient characteristics).

Quality of Services

A required component of each state's independent assessment is an examination of state efforts to assure protection of health and safety of HCBS recipients. Discussions with Minnesota DHS officials requested a much more comprehensive view of quality of care than required or typically taken in HCBS evaluation studies. Because quality of care/quality of life is a complex topic it was approached through detailed data collection which included 129 HCBS recipients, their service providers, their case managers and their family members and guardians. A summary of this data collection follows this brief outline of research questions. The approach to the assessment of quality of care included 4 basic questions:

1) How well is the basic health and safety of HCBS recipients protected?

2) Do HCBS recipients have a reasonably high quality of life as reflected in sufficient and appropriate opportunities for:
   a) personal growth and development,
   b) social and familial relationships afforded,
   c) appropriate and culturally valued community participation, and
   d) personal autonomy, choices and self expression?

3) Are HCBS recipients satisfied with their lives and services?

4) How do case managers evaluate the overall quality of HCBS received? How do they compare the HCBS and ICF-MR alternatives?

1) <u>How well is the basic health and safety of HCBS recipients protected?</u>

Sufficiency of existing rules and protections. These analyses involved direct examination of the specific rules for HCBS and interviews with key informants of the effectiveness of the rules. They also involved the frequency of monitoring of HCBS recipients' well-being.

Frequency of and satisfaction with health services. A great deal of information was gathered on the medical, dental and other health needs of individuals and their extent of their access to and utilization of services related to these needs. Data were provided in surveys of family/guardians, providers and case managers about the overall satisfaction with these services and the extent to which they met the needs of HCBS recipients.

2) <u>Do HCBS recipients have adequate opportunities and quality of life?</u>

Chances for growth and development. This analysis drew primarily on the HCBS Recipient Survey record of services received, and goals and services identified in each person's Individual Service Plan (ISP). The quality of these programs and activities were evaluated by case managers and parents/guardians.

Social and familial relationships. This analysis drew primarily on the detailed questions in the HCBS Recipient Survey on the nature and frequency of relationships with family, friends and other members of the social networks of individuals in the HCBS Recipient sample. Complementary data were also gathered from the family members.

Community participation. Data on participation in activities and in valued social roles in the community were drawn primarily from the HCBS Recipient Survey. These data included access to the community, the nature and frequency of participation in a wide range of activities, specific provider activities to promote community participation, and so forth. Satisfaction with quality and amount of community participation and factors affecting participation were also gathered in Parent/Guardian and Case Manager Surveys.

Personal autonomy and self-determination. Data on the opportunities of HCBS recipients to exercise choice and self-determination were gathered from the HCBS Recipient Survey, the Case Manager Survey and the HCBS Recipient Satisfaction Interview. The HCBS Recipient Survey contained questions regarding the amount of autonomy in ten personal activities of daily living. It also asked about other areas of daily living in which HCBS recipients can exercise choice. Related indicators were also integrated into data collection, including field interviewers ratings of the degree of "personalization" of individual bedrooms.

3) Are HCBS recipients satisfied with their lives?

A special interview was developed to ask HCBS recipients about their own satisfaction with key aspects of their lives. The interview was based on previously developed successful scales.

4) How does the HCBS program compare with the alternatives? How can it be improved?

All through the assessment process, people were asked about how the HCBS program was working in Minnesota and what could be done to improve it. Data were gathered from key informants, care providers, family members, case managers and HCBS recipients themselves.

Sample Design

The bulk of a data collection and analysis regarding the Minnesota HCBS program was centered around 18 purposely selected counties and included a controlled sample of 130 HCBS recipients from these counties. Data collection included extensive interviews with administrators, case managers and service providers in these counties; analyses of expenditure and HCBS recipient data from relevant state data bases; and comprehensive series of interviews and questionnaires. Surveys focused around the lives of the sample of 130 HCBS recipients and key informants about their lives, needs and the quality and effectiveness of the HCBS program for them. These surveys included a comprehensive description of the physical, behavioral, medical and other characteristics of these individuals, the nature and amount of their community participation and social relationships, the services received, including case management, residential, habilitation, medical and other, the costs of those services, the perceived needs, characteristics and background of service providers, satisfaction with services, recommended changes in the HCBS program and a range of other topics related to the evaluation objectives. They included a total of 328 structured interviews and questionnaire responses, including 129 HCBS service providers, 57 HCBS recipients (of which 54 were completed), 82 family members, and 60 case managers (of 118 of the 129 sample members).

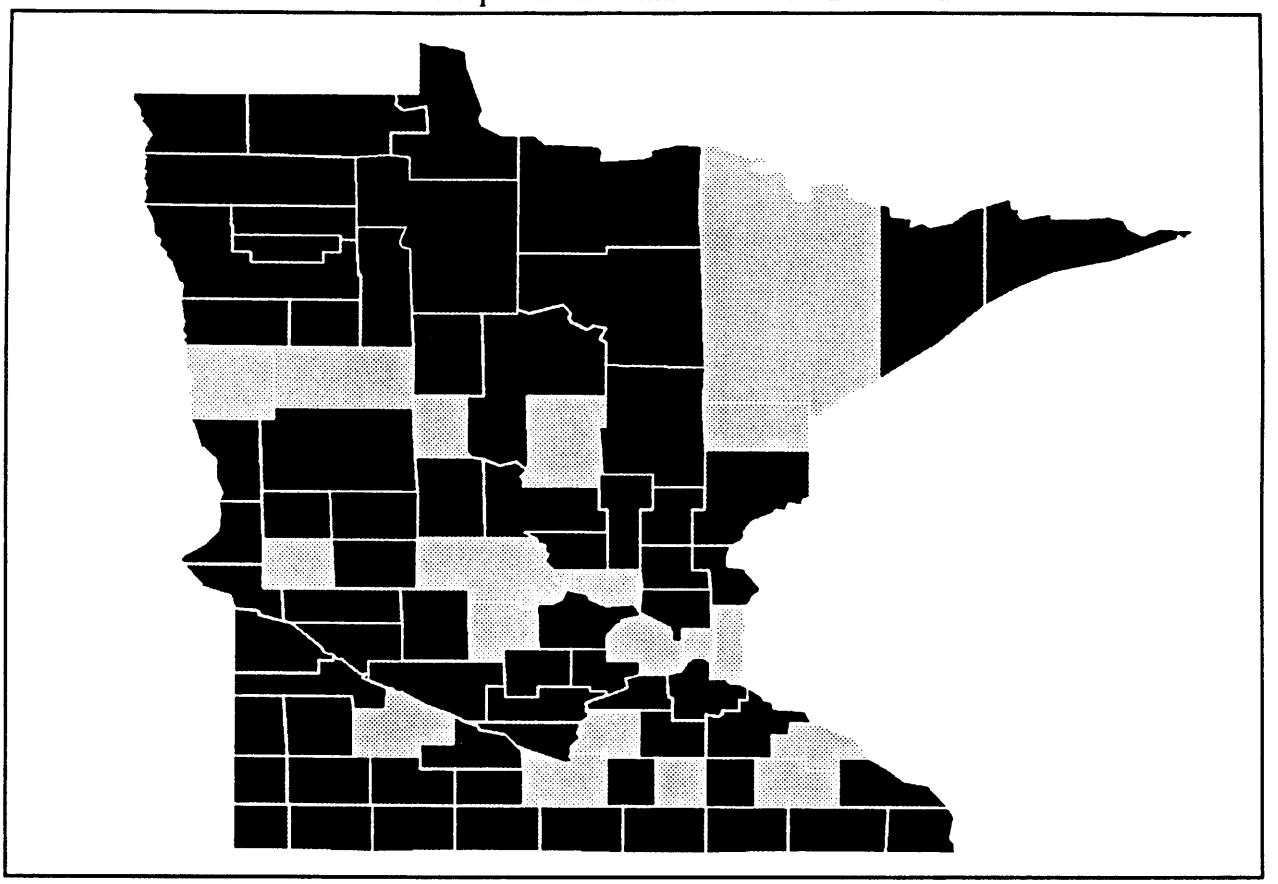
County Sample

Because Minnesota's HCBS program is county administered, the sampling design involved controlled sampling of HCBS recipients within a cluster sample of counties. Adequacy of sample and the cost limitations suggested that about 20% of counties (18 of 87 total) could be included in the sample. Sampling of counties was controlled to include 3 of 7 Twin Cities metropolitan area counties, including the state's 2 largest counties, Hennepin and Ramsey (with a combined 34.7% of the state's total population and 32.9% of HCBS recipients) and Washington County (3.3% of the total state population and 2.9% of waiver recipients). In addition, 5 urban counties (i.e. with a population center of 30,000 or more residents) outside the Twin Cities metropolitan area ("outstate") were also included in the sample. These included Stearns (with St. Cloud as the urban center), St. Louis (Duluth), Olmsted (Rochester), Clay (Moorhead) and Blue Earth (Mankato) (with a combined total of 12.1% of Minnesota's population and 14.5% of its HCBS recipients).

Ten of the remaining 75 "rural counties" were also sampled. Because of the costly logistics of data collection in out-state areas, "cluster samples" of these counties were selected, but only if there were no perceived relationship with a neighboring that might affect the county's "independence". Rural counties in the sample included 5.7% of Minnesota's total population and 6.8% of the state's HCBS recipients. The geographic distribution of sampled counties is shown in Figure 1.

Because the sampled counties were specifically controlled to include the more urban counties of the state, there was some concern that the HCBS recipients from the sampled counties might in some ways be different than Minnesota's HCBS recipients generally. Special analyses of Medicaid Screening Document data on age, gender, type of residence or in a wide range of functional, medical or behavioral characteristics of HCBS recipients demonstrated that this was not the case. Tables A-1 and A-2 in the Appendix show the high degree of congruence in the characteristics of the HCBS recipients statewide with the HCBS recipients in the sampled counties.

Figure 1
Counties Sampled in the Minnesota HCBS Evaluation



Individual Subject Selection

The selection of a sample of individual HCBS recipients from within the sampled counties was controlled along 2 dimensions: 1) county type (Twin Cities metropolitan counties, out-state urban counties and rural counties), and 2) type of residence (corporate foster care licensed under Rule 42; family foster care and family home/own home). Generally the distinction between corporate foster care homes and family foster care homes is that the former are staffed residences (typically, group homes of 4 or fewer people) operated under a provider agency's foster care license while the latter are traditional foster care homes in which persons with MR/RC live in the homes of the persons providing supervision and services to them. Family home/own home indicates a residence with one's own family members or in a home in which the individual and/or his family is the lease or mortgage holder. Table A-3 presents the breakdown of HCBS recipients in the sample counties along the 9 county type by residence type cells, with the number of children 17 years and younger shown in parentheses.

Briefly summarized, 55.3% of sample county HCBS recipients were in corporate foster care arrangements. These included 60.4% of HCBS recipients in the Twin Cities metro counties, 48.2% in out-state metro counties and 44.5% in rural counties. Among all HCBS recipients in sample counties with place of residence data, 16.4% were in family foster care. In Twin Cities metropolitan counties, 8.2% of HCBS recipients were in family foster care as compared with 32.2% in out-state metro counties and 24.4% in rural counties. Among all HCBS recipients 28.3% lived with their family or in their own homes. This included 31.4% of HCBS recipients in Twin Cities metro counties, 19.6% of HCBS recipients in out-state metro

counties and 31.1% of recipients in rural counties. Children 17 years or younger made up 16.9% of Minnesota's HCBS recipients including 15.4% of HCBS recipients in sampled counties. In all eighty-two percent of these children receiving HCBS in Minnesota and 81% in the 18 sample counties were living in their family home.

Controlled Sampling by Residence

In selecting individual sample members the sampling strategy was controlled so that minimally 10 HCBS recipients would be selected for each county-type by place of residence cells. Because of the relatively high presence of children in the "family/own home" category (the only category with substantial numbers of children), separate "family/own home" categories were developed for children and adults, creating the 12 county-type by residence categories in all. Because of the large number of HCBS recipients in Twin Cities corporate foster care settings (492 people in an estimated 200 separate settings), the sample size for these individuals was set at 20 persons. In all, then the sample for the client-based survey included 130 persons. Table A-4 in the Appendix shows the distribution of these sample members by county-type and place of residence and the sampling ratio for each cell.

Controlled Random Sampling Procedure

To generate a random sample of individuals in the 12 county type by residence cells, HCBS recipients were sorted into the appropriate county-type by residence cell using the state HCBS data base. The names of cell members were then randomized and then selected by counting down the list of names within each cell by the computed sampling ratio shown in Table A-4.

Comparison of Sample and Sample Frame

Studying a sample instead of the whole population raises the possibility that the people randomly selected will not be like the whole group of people they were selected to represent ("the sample frame"). To make sure the sample representing Minnesota's HCBS recipients was like the group they were chosen from (i.e., the sample frame), the two groups were compared on 10 key health, functional, behavioral, and program variables from the Medicaid Screening Document for individuals with mental retardation and related conditions. In the 40 tests conducted, (10 variables x 4 places of residence) only one statistically significant difference ($p < .05$) between the sample and the sample frame. (Table A-5 presents the comparison of service related characteristics of the sample members and all of the HCBS recipients in the sampled counties). People in the sample were more likely to be reported to need "total care and support" than were people in the sample frame (30.4% vs. 9.0%). However, in combining the two most intensive levels of support ("substantial care needed" and "total care and support needed.") the two groups were very similar (47.8% vs. 47.2%). Given that in the 40 comparisons only one yielded a statistically significant difference, (actually 1 or 2 was expected by chance), the sample was judged to provide a representative picture of HCBS recipients.

Instrumentation

A total of 6 existing and adapted instruments were used in this study. Five of these were new or adapted instruments developed for data collection in this assessment; one, a data base including information from the State Medicaid Screening Document file and the net HCBS payment file, was created for this assessment from existing state data files. These are briefly described below.

HCBS Recipient Survey

The HCBS Recipient Survey provided the bulk of information on the daily lives, activities, services, relationships of HCBS recipients. Respondents for the HCBS Recipient Survey were primary careproviders for persons foster care and family members of people living at home. The instrument has undergone extensive review by individuals from state and county social service agencies, the state protection and advocacy agency, local service providers, and other researchers and has been extensively field-tested. It has been used in the Minnesota Longitudinal Study with 200 RTC and community ICF-MR residents

Inventory for Client and Agency Planning

The *Inventory for Client and Agency Planning* (ICAP) is a comprehensive, structured rating scale instrument designed to record developmental and diagnostic status, functional limitations, adaptive behavior skills, problem behaviors, and judged service needs of individuals with mental retardation and related conditions (MR/RC). It has been extensively tested for reliability and has been nationally normed. Respondents for the ICAP were the same as for the HCBS Recipient Survey.

Family/Guardian Questionnaire

The Family/Guardian Questionnaire was an expanded, modified from an instrument originally developed by Systemetrics for its evaluation of another state HCBS program. This instrument gathered information from families in their perceptions of the quality, appropriateness and sufficiency in scope and amount of the services received by their family members.

Case Manager Questionnaire

The Case Manager Questionnaire used in this evaluation was expanded, modified version of an instrument originally developed by Systemetrics for use in previous HCBS assessments. It collected information on the role, and characteristics, and activities of case managers, factors perceived to affect access to and quality of services and evaluation of the specific services received by HCBS sample members.

HCBS Recipient Satisfaction Interview

The satisfaction scale was developed for HCBS recipients over 10 years old who were judged by their case managers to be able to understand and reliably respond to the items. The items were modeled after items contained in the 1988 National Study of Consumer Satisfaction (Conroy & Feinstein, 1990) and the Lifestyle Satisfaction Scale (Heal, Amado & Rusch, 1989). The Recipient Satisfaction Interview and respondent selection criteria were field-tested with success before use in the study.

Minnesota Screening Document and Net Payment File Data Base

A primary source of information on persons receiving HCBS services in Minnesota was the Minnesota Screening Document for individuals with mental retardation. This instrument is used to gather demographic, functional, medical and behavioral data on all individuals with mental retardation and related conditions being considered for eligibility for Medicaid long-term care services, including ICF-MR and HCBS. For HCBS recipients the Screening file was merged by Medicaid identification number to create a file with HCBS characteristics and payments for HCBS and other Medicaid Services.

Response Rates

HCBS Recipient Survey and ICAP. The intended initial sample of 130 individuals ended up as 129 sample members. Altogether there were three refusals to participate (2%). Seven other of the initial selections were also replaced, 3 because private guardians could not be reached with a minimum of 4 calls over a two week period, including evening hours; 2 because they were in statuses of unresolved guardianship; 1 because although the financial responsibility of a sampled county, he lived nearly 100 miles outside that county; and 1 because she stopped receiving HCBS between the time of sample frame development (June) and contact for study participation (September). In all the loss of initial sample members was viewed as remarkably low.

Recipient Satisfaction Interview. In all 71 of the 108 sample members 11 years or older were judged by their case managers as reliable respondents to the Recipient Satisfaction Interview (children 10 years and younger were arbitrarily excluded). Interviews were pursued with all 57 of these individuals, but only 54 of these were completed. Six of these individuals declined to participate. One parent refused permission. One interview could not be scheduled during the interviewer's stay in a rural county. One provider indicated that the potential respondent who was not at home could not understand the questions being posed. Interviews determined that six individuals did not understand the questions or were unable to respond reliably prior to or at the initiation of the interview and 3 interviews were terminated in mid-course because the respondent was unable to understand the questions asked. In all, 50% of the HCBS sample members who were older than 10 years responded to the satisfaction interview.

Family/Guardian Satisfaction Questionnaire. A total of 106 Family Satisfaction Questionnaires were mailed to parents or guardians of HCBS recipients. Families of persons under public guardianship were not pursued. Following a minimum of two follow-ups per nonrespondent and the offer of completing the questionnaire by telephone, 82 (77.4%) were completed.

Case Manager Questionnaires. The designated case manager of all 130 HCBS recipient sample members received a questionnaire specifically regarding the services for the individual recipient. Of these 130 questionnaires, following a minimum of two follow-ups per nonrespondent and the offer of completing the questionnaire by telephone, 118 (90.8%) were completed. The 130 HCBS recipients had a total of 67 separate case managers. Each of the individual case managers received a questionnaire about the HCBS program generally and their roles in it. Of these, following a minimum of 2 follow-ups and the offer of completing the questionnaire by telephone, 60 (89.6%) were completed.

Key Informants

In each of the three evaluation areas described above, specific quantitative data collection approaches have been described. Data collection also involved gathering and synthesizing interview data from key informants. In addition to the individuals specifically sampled, persons in the following roles were interviewed:

1) 5 direct care providers of HCBS services,
2) 3 current or former DHS employees with direct administrative responsibility for HCBS,
3) 2 officials of the state Medicaid agencies,
4) 7 county case managers,
5) 11 county social service administrators (case managers, supervisors, program analysts, program managers, and planners)
6) 4 HCBS provider agency owners and/or administrators.

Document Review

A final source of information used in this evaluation were the findings of related studies, reports and public hearings in Minnesota. These documents included:

Minnesota Department of Administration (1991, February). *Minnesota's case management system for persons with developmental disabilities.* St. Paul: Author.

Minnesota Department of Administration (1991, April). *Public expenditures for services to persons with developmental disabilities in Minnesota.* St. Paul: Author.

Minnesota Department of Human Services. (1990, January). *Services to Minnesotans with developmental disabilities: The 1990-1991 State Plan.* St. Paul: Author.

PART III: FINDINGS

This chapter reports the specific findings of this assessment under its 3 basic topical headings: 1) access to services, 2) cost-effectiveness and 3) quality of care.

Overview

In the 7 years of its existence, Minnesota's Medicaid HCBS program has grown substantially and is currently one of the largest HCBS programs nationally. On June 30, 1982 Minnesota had a total of 6,899 Medicaid Title XIX recipients receiving services for persons with MR/RC (all in ICFs-MR). Of these 9.5% lived in settings of 6 or fewer residents. On June 30, 1991 Minnesota had 8,166 (est.) Medicaid Title XIX recipients (5,700 ICF-MR and 2,466 HCBS). Of these 38.0% were living in settings of 6 or fewer residents, including their own or their family home. This rapid shift toward community based long-term care has occurred as Minnesota's average annual growth in total ICF-MR and HCBS recipients (2%) has remained substantially below the national average growth of 4% between 1982 and 1989.

In comparing Minnesota's HCBS program with those of other states (Prouty & Lakin, 1991), a number of similarities are noted. For example, in June 1990 like most states Minnesota's most frequently and universally provided services was case management with residential support/habilitation and day habilitation the next most frequent. In FY 1990 Minnesota's HCBS services cost an average of $25,268 per recipient per year. Nationally the average for the 41 HCBS states costs was $21,246.

Compared with the 11 states reporting the level of mental retardation for 10,588 HCBS recipients on June 30, 1990 and this assessment's sample of HCBS recipients, Minnesota's HCBS recipients were as a group slightly *less* impaired: 26% were mildly impaired (20% in the 11 states), 32% were moderately impaired (27%), 29% were severely impaired (30%), 13% were profoundly impaired (22%), and 0.9% had a related condition but no mental retardation (0.6%). However, caution must be exercised about such comparisons in that the states being compared are not necessarily representative of the 43 states providing HCBS.

In Minnesota as nationally (based on 22 states with about 20,000 HCBS recipients) most HCBS recipients were adults, but Minnesota was considerably more likely to serve children and youth under 22 years (21% in Minnesota, 13% nationally). The average age of HCBS recipients in Minnesota was 32.6 years. Also, most Minnesotan's (72%) receiving HCBS lived in supervised residential settings (group or foster care arrangements) as was the case for most HCBS recipients nationally (82%). A higher percentage of Minnesota HCBS recipients lived in their family home (19%) or their own home (8%) than was the case for HCBS recipients nationwide (14% and 4%, respectively). However, the distinction between family home, own home and supervised residence appeared not to be always reliably coded on the Minnesota data base and presumably difficulties in such distinctions are found in other states as well.

Primary Research Questions

- Who has access to the HCBS program? Is it the intended population?
- How does the supply of HCBS allocations compare with demand? How are access decisions made when demand is greater than supply?
- How long must eligible persons wait to receive services?
- Do HCBS recipients have access to the services that are needed by them and intended for them?

Who has access to the HCBS program? Is it the intended population?

Documentation of HCBS recipients being Medicaid eligible individuals who meet ICF-MR criteria. When a potential HCBS recipient is screened for program participation, the person completing the documentation of the screening is required to note whether or not the applicant is at risk of placement in an ICF-MR and whether or not s/he is eligible for Medicaid. This document is reviewed by the State's Regional Services Specialist who makes the final eligibility determination based on diagnosis and assessment information and the proposed plan of care. The most recent (as of June 30, 1991) computerized screening documents for current MR/RC recipients were reviewed. All but two current recipients (99.92%) were documented to be Medicaid eligible and at risk of ICF-MR placement. Given the size of the state data base (2,466 individual HCBS recipients), it is likely that these two cases of program "ineligibility" are the results of data entry error.

Evidence that HCBS recipients are like people placed in ICFs-MR. To further validate that current HCBS recipients meet ICF-MR criteria, HCBS recipients were compared with persons currently residing in community ICFs-MR and in the state institutions for persons with MR/RC (Regional Treatment Centers or RTCs) on various characteristics. Data presented in Table 3 below were derived from analyses of the Minnesota Medicaid Screening data base file of June 30, 1991. Depending on the data element these data included between 92.5% and 96.7% of HCBS waiver recipients on June 30, 1991, between 63.8% and 66.2% of the RTC population, and between 66.9% and 69.4% of the ICF-MR population. Detailed information on the demographic, functional, medical and behavioral characteristics of members of all three groups, including a separate breakdown for small (15 or fewer residents) and large ICFs-MR is presented in Table A-6. In this report "ICFs-MR" is generally used to refer to community ICFs-MR and "RTC/ICF" is used to refer to the state institutions which are also ICF-MR certified.

As shown in Table 3 HCBS recipients are similar in their disability profiles to persons residing in ICFs-MR. For example, nearly 43.0 percent of HCBS recipients and 55.8 percent of residents of ICFs-MR were reported to need either substantial or total care in self-care activities; 25.3% and 31.2, respectively, in toileting. The respective proportions of program participants reported to need substantial or total care in household management were 77.0% and 85.3%; in money management, 94.8% and 97.7%; in leisure activities, 61.8% and 72.8%. Similar patterns hold for the proportion of persons in each group reported to have behavior problems. For example, approximately the same proportion of HCBS recipients and ICF-MR residents were reported to be mildly to severely withdrawn (43.5% and 43.6% respectively); 15.1% of HCBS

recipients and 14.7% of ICF-MR residents were reported to display sexually inappropriate behavior towards others, and 71.5% of HCBS recipients and 72.4% of those living in ICFs-MR to present mild to severe problems because of noncompliant or rebellious behavior. The same proportion of waiver recipients and ICF-MR residents require specialized medical services (65.4%), and the need for services such as occupational therapy, physical therapy, communication therapy, and special transportation was also similar among these two populations. Although the HCBS recipient population in general appeared to be slightly less disabled than their total ICF-MR counterparts, the differences tended to be small. The similarities between the HCBS recipient population and the small ICF-MR population (shown in Table A-6), are considerably more notable and probably much more relevant. Minnesota would have been very likely to have limited ICF-MR growth to small ICFs-MR in the absence of the HCBS alternative, as it was doing at the time the HCBS program was initiated. It appears, then, clear that persons served in the HCBS program are ones who in the absence of the HCBS alternative would be appropriate for the ICF-MR level of care as it has been utilized in Minnesota.

Variations in access for conversion and diversion allocations. Over the years of Minnesota's HCBS program implementation, the ratio of diversion allocations to conversion allocations has shifted. Table 4, which shows the number of new conversion and diversion *enrollees* by year beginning in 1985, depicts these shifts. In 1985, 230 persons were enrolled in the program, 70% of whom occupied diversion allocations and the remaining 30% occupying conversion allocations. It was not until 1990 that diversion enrollees are again in the majority. During the intervening years between 1986-1989 the majority of new enrollees came from the conversion group, i.e., persons entering the program from either ICFs-MR or RTC/ICFs. In 1991 the proportion of conversions and diversions new enrollees was more evenly split with 44% being diversions and 56% being conversions. With respect to these shifts it should be noted that the State has for each Waiver Year requested federal authorization for more conversion recipients than diversion recipients. The substantial shifts in proportions noted above reflect shifting patterns of enrollment at the county level.

Table 3: Characteristics of Recipients of Medical Long-Term Care Services for Persons with Mental Retardation/Developmental Disabilities

CHARACTERISTIC	HCBS	Community ICF-MR	RTC/ICF
Serious/Specialized Medical Need	66.2	67.1	84.8
Seizures	28.5	23.5	33.6
Serious/Not Correctable Hearing Impairment	3.4	4.0	6.3
Vision Impairment	32.0	33.5	31.7
Mobility Impairment	21.8	24.2	39.8
Communication Impairment	65.3	73.4	85.1
Substantial or Total Care in:			
Self Care	42.6	55.8	73.0
Toileting	25.3	31.2	51.2
Leisure	61.8	72.8	84.0
Household Management	77.0	85.3	89.5
Money Management	94.8	97.7	98.3
Incapable of Self Preservation	55.3	64.7	87.1
Withdrawn	43.5	43.6	48.2
Physically Injurious to Others	38.4	43.6	59.4
Injurious to Self	36.9	41.2	58.4
Inappropriate Sexual Behaviors - Self	14.4	12.3	22.3
Inappropriate Sexual Behaviors - Others	15.1	14.7	14.5
Property Destruction	35.9	36.4	51.3
Disrupts Others' Activities	58.6	61.6	73.1
Noncompliant/Rebellious	71.5	72.4	79.3
Needs Specialized Medical Services	65.4	65.4	81.5
Physical Therapy	28.6	31.4	40.5
Occupational Therapy	35.3	34.9	54.9
Communication/Speech Training	55.9	59.9	74.1
Special Transportation	69.9	72.6	80.5
Behavior Management Program	43.1	59.9	78.0

Note: See Table A-6 for detailed breakdowns of these categories by severity of impairment, including further breakdown of HCBS recipients by place of residence and ICF-MR residents by small (15 or fewer residents) and large facilities.

Table 4: New Diversion and Conversion Allocations by Year

Year	Total Number of Slots	Diversions		Conversions	
		Number	Percent	Number	Percent
1985	230	161	70	69	30
1986	337	133	39	204	61
1987	397	190	48	207	52
1988	647	180	28	467	72
1989	395	152	38	243	62
1990	246	168	68	78	32
1991	366	162	44	204	56

The cumulative effect of these enrollment patterns has been a gradual increase in the number of both diversions and conversions. As shown in Table 5, in 1985 161 diversions and 69 conversions were in use. By 1991, Minnesota had 2618 persons enrolled in its HCBS program for persons with MR/RC; 1146 had diversion status and 1391 had conversion status. The projected enrollment for 1992 is 3138 with 1320 diversion enrollees and 1818 conversion enrollees. Table 5 also illustrates the proportional distribution between conversion and diversion enrollees over time. In 1985 70% of all enrollees were diversions, but by 1991 the proportion of diversion enrollees had dropped to 44%, and the projected proportion of diversion enrollees for 1992 is 42%.

Table 5: Number of Enrollees by Conversion/Diversion Status by Year

Date	Total	Conversions		Diversions	
		Number	Percent	Number	Percent
July 1, 1985	230	69	30	161	70
July 1, 1986	567	273	48	294	52
July 1, 1987	964	480	50	484	50
July 1, 1988	1,611	947	59	664	41
July 1, 1989	2,006	1,190	59	816	41
July 1, 1990	2,252	1,268	56	984	44
July 1, 1991	2,618	1,391	56	1,146	44
July 1, 1992[1]	3,138	1,818	58	1,320	42

[1] July 1, 1992 enrollees are projected

Between 1986 and 1989, and again in 1991 and 1992 the number of persons with conversion status entering the HCBS program reflects the state's priority of depopulating the Regional Treatment Centers and large ICFs-MR. Current DHS policy on HCBS allocations to counties is to almost always grant the number of conversion allocations requested, but to limit the number of diversion allocations. This is the result of the number of county requests compared with the number of allocations available based on the federal authorization. For example, in the state's last allocation to counties the Department received over 500

requests for diversion authorizations but only had 165 diversion allocations available to distribute. The Department attempts to grant at least one diversion allocation to each county which requests any diversion allocations.

Among key informants around the state there was sentiment that persons already in the community who are eligible for, and desire, HCBS services do not have access to the program comparable to persons in the RTCs and ICFs-MR. What is more, there were several counties which reported that although conversion allocations were available, they were difficult to fill. A major impediment to using conversion allocations appears to be the counties' estimation of the cost of meeting the service needs of currently institutionalized persons. In general counties see these costs as so large that substantial increases in enrollment of persons coming from institutions, would likely cause them to exceed their HCBS allowable average reimbursement rate. This fear has been confounded by the aggressive action taken by the State following widespread over-spending by counties in FY 1989. Thus, county respondents observed that potential conversion enrollees encounter access limitations even though conversion allocations may be readily available. It should be noted, however, that 64% of Minnesota counties are spending on average $10 or more *below* their per person authorized average daily allowance for HCBS.

Another approach to examining the relative access that potential conversion and diversion recipients have to the program is to compare the functional skill/disability levels of the two groups of recipients currently enrolled in the program. As Table 6 shows, HCBS recipients with diversion status tend to be somewhat more impaired than conversion recipients. The major factor in this difference is that the majority of diversion recipients are children and children receiving HCBS are more impaired as a group than are adult HCBS recipients. Data indicate, for example, that children receiving HCBS are much more likely to have occasional or frequent major seizures than are adults and are more likely to use wheelchairs or not be mobile. In fact, in virtually every disability category children receiving HCBS are more severely impaired than adult HCBS recipients, except in vision and hearing impairments.

Children with substantial disability appear to be more likely candidates for diversion allocations for at least two reasons. First, the cost of providing HCBS services to children, even with severe disabilities, is substantially moderated by the "free" care provided to the substantial majority of them by their families. An adult HCBS recipient with comparable disability being discharged from an RTC/ICF or an ICF-MR is not as likely to have a family support system able and willing to provide the kinds of support and assistance that children living at home receive. Second, many counties give priority to children in their allocation processes. In sum, then, among the persons with more severe disabilities who have more frequent access to HCBS in Minnesota are children living at home. This suggests that HCBS in Minnesota is fulfilling one of the primary goals, that of supporting families so that they are able to keep their children at home ("permanency planning"). Over the long run, however, some counties recognize that their long-term financial commitments to children and youth with severe impairments who receive HCBS while living at home and attending public schools may increase substantially when these children reach adulthood and request HCBS programs that include costly residential and day program services.

Table 6: Characteristics of Waiver Recipients by Conversion/Diversion Status

CHARACTERISTIC	% Conversions	% Diversions
Serious/Specialized Medical Need	57.4	62.5
Seizures	16.5	28.0
Serious/Not Correctable Hearing Impairment	2.6	3.6
Vision Impairment	23.9	26.8
Mobility Impairment	12.7	25.9
Communication Impairment	58.1	70.5
Substantial or Total Care in:		
Self Care	30.1	57.7
Toileting	11.2	38.6
Leisure	92.9	95.9
Household Management	98.4	99.5
Money Management	99.7	99.9
Incapable of Self Preservation	37.8	65.7
Withdrawn	39.5	40.7
Physically Injurious to Others	40.2	35.7
Injurious to Self	31.3	34.9
Inappropriate Sexual Behaviors - Self	12.1	11.5
Inappropriate Sexual Behaviors - Others	17.2	11.2
Property Destruction	32.9	34.5
Disrupts Others' Activities	53.0	57.0
Noncompliant/Rebellious	71.4	65.7
Needs Specialized Medical Services	53.6	64.8
Physical Therapy	16.8	42.1
Occupational Therapy	21.1	51.0
Communication/Speech Training	48.8	71.5
Special Transportation	61.3	65.6
Behavior Management Program	62.5	52.6

Understanding by potential recipients and their family members (or their guardians) that HCBS are an alternative to ICF-MR placement. Every time a person is screened for HCBS it is recorded on the screening document and on a signed form which acknowledges that the HCBS recipient, his/her family or guardian was informed that HCBS were an alternative to ICF-MR services and that the individual had a right to choose between the two alternatives. There was a substantial discrepancy between the observations of family members and case managers about whether the families and HCBS recipients understood that HCBS were an alternative to placement in an ICF-MR or a Regional Treatment Center. As Table 7 shows, while 83% of case managers reported that the sampled HCBS recipients and/or their families/guardians understood the alternative to ICF-MR nature of the program, only 44% of family members who were involved in the program decisions of people in the HCBS recipient sample indicated that they understood this to be the case. Of course, between 1984 and 1989 there was a legislatively imposed moratorium on new ICF-MR development, restricting ICF-MR capacity to existing levels. With extremely high occupancy in ICFs-MR other than the Regional Treatment Centers and certain larger private institutions, and the high reluctance on the part of most families and case managers to accept such placements as a viable alternative, the explanation of the ICF-MR alternative may have been taken somewhat lightly. Even though readily acceptable institutional alternatives (i.e., small community ICFs-MR) are likely to be unavailable, other strategies may be needed to ensure that recipients and their legal representatives clearly understand the "choices" available. Along these lines the State is currently developing a brochure which specifically lays out the choices available to applicants. Once developed, counties should provide individuals with MR/RC and their legal representatives with this brochure prior to each scheduled service planning meeting and screening, and the state should assess whether this approach is effective in improving HCBS recipients' awareness of other options available to them.

Table 7: Percent of Family Members/Guardians and Case Managers Perception of Informed Choice

Do Families/Guardians Understand that the Waiver is an Alternative to ICF-MR Placement?	Family Respondents	Case Manager Respondents
YES	48.8%	83.1%
NO	26.8	6.8
DON'T KNOW	24.4	10.2

Comparability of access for minorities to the HCBS program. Table 8 compares the racial/ethnic distribution of the Minnesota population in the 1990 census with that of Minnesotans receiving Medicaid Home and Community Based Services. Both populations are overwhelmingly white, but the 84 minority members receiving HCBS are only 54.5% of the number that would be expected to receive HCBS (154) if the racial/ethnic distribution of HCBS recipients reflected the Minnesota population as a whole.

Table 8: Distribution of Minnesota Citizens and Minnesota HCBS Recipients by Race

		White	Black	American Indian/ Alaskan Native	Asian/Pacific Islander	Hispanic	Total
All Minnesota Citizens	Number	4,098,000	95,000	50,000	78,000	54,000	4,375,000
	Percent	93.7%	2.2%	1.1%	1.8%	1.2%	100.1%
Minnesota HCBS Recipients	Number	2,351	38	23	13	10	2,435
	Percent	96.6%	1.6%	0.9%	0.5%	0.4%	100.0%

Source: *U.S. Bureau of the Census (1991) Statistical Abstract of the United States,* Washington, DC: U.S. Government Printing Office.

Comparability of access for children and adults to the HCBS program. To assess the relative access to HCBS for children and adults, the ages of persons receiving HCBS and persons residing in ICFs-MR and RTCs were compared. As shown in Table 9, children and youth (0-17 years) are much more likely to be served in the HCBS program than either in either community ICFs-MR or RTC/ICFs. In June of 1991 HCBS recipients as a whole constituted less than one-third (32%) of all persons with MR/RC receiving Medicaid long-term care services (MLTC), but over three-quarters (76%) of those age 17 and younger receiving MLTC were HCBS recipients. In contrast, by June 1991 the RTCs had virtually been eliminated as a service option for children and youths. And only about 24% of those age 17 and under receiving MLTC services were in ICFs-MR. The higher access to HCBS for children and youth reflects the state's and most counties' commitment to keeping children and youth in family settings, preferably their natural family. In fact state data prepared by Jim Franczyk of the Department of Human Services show that between 1980 and 1990 the number of children with developmental disabilities in out-of-home placement decreased from 1,430 to 654. The case manager survey showed that the HCBS program is viewed as one means of carrying out this commitment, with 22% of the case managers surveyed reporting that children are given priority for HCBS allocations in their counties.

Table 9: Number* and Percentage of Medicaid Long-Term Care (MLTC) Service Recipients by Age and Program

Age	Medicaid Long-Term Care Program			
	HCBS	ICF-MR	RTC/ICF	Total
0-17 Years Old				
MLTC Recipients in Age Group	447	139	3	589
% Within Program by Age Group	18.7%	3.4%	0.3%	7.8%
% of Age Group by MLTC Program	75.9%	23.6%	0.5%	100.0%
18-40 Years Old				
MLTC Recipients in Age Group	1,231	2,322	617	4,170
% Within Program by Age Group	51.5%	56.9%	55.8%	55.0%
% of Age Group by MLTC Program	29.5%	55.7%	14.8%	100.0%
41 Years and Older				
MLTC Recipients in Age Group	714	1,609	485	2,808
% Within Program by Age Group	29.8%	39.4%	43.9%	37.1%
% of Age Group by MLTC Program	24.4%	57.3%	17.3%	100.0%
All Ages	2,392	4,080	1,105	7,577

*Age data were missing on 74 HCBS recipients, 78 ICF-MR residents, 85 RTC/ICF residents and 237 total Medicaid recipients. Most of these missing data are likely the result of differences in the recorded Medicaid ID numbers on which two data files were merged.

Children and youth constituted only 19% of all HCBS recipients. The majority of HCBS recipients (like the majority of ICF-MR and RTC/ICF residents) were young adults between 18 and 40 years of age. Persons in the 18-40 age range constituted nearly the same proportion of HCBS recipients (51.5%) as of ICF-MR and RTC/ICF residents (57% and 56%, respectively). However, a somewhat higher proportion of

ICF-MR and RTC/ICF service recipients were over 40 than was the case among HCBS recipients (39%, 44%, and 30%, respectively). The major factor in this difference appears to be that most ICF-MR and RTC/ICF service recipients over 40 years old were already residing in ICFs-MR or RTC/ICFs as the waiver program was being developed in the mid- and late 1980s. Over three-quarters of children and youth receiving Medicaid long-term care services were HCBS recipients and over three-quarters of these recipients were living in their family home. In summary, then, children and youth are more likely to gain access to HCBS as an alternative to ICF-MR and RTC/ICF placement than adults. This reflects both the state policy of supporting families so that they can raise their children at home, but also the nature of the HCBS program itself. One of the major goals of home and community-based services in Minnesota as in most states is keeping people out of institutions. Children and youth make up a substantial, although unknown proportion of people not yet institutionalized, but who in the absence of HCBS likely would be.

Comparability of access for males and females to the HCBS program. As shown in Table 10, the gender distribution of HCBS recipients was generally quite similar to that of Medicaid long-term care recipients as a whole; 59% of HCBS recipients were males as compared with 56% of MLTC recipients as a whole. Among HCBS recipients, as with MLTC recipients generally, the proportion of males was higher among children and youth than among adults. Among adults over 40 about 60% of HCBS recipients were male. This was similar to the distribution of males among RTC/ICF residents over 40 (58% are males), but considerably higher than among ICF-MR residents. Among ICF-MR residents over 40 years the majority was actually female (48% are male). This reflects (and contributes to) the much more nearly equal distribution of males and females among all MLTC service recipients in the 40 years and older age group (53% males as compared with 63% males among children and youth and 56.5% males among young adults 18-40 years old). Counterbalancing the higher representation of females in the ICF-MR residents over 40 years old has been the substantially higher representation of males among HCBS recipients over 40 (59%). Together persons over 40 provided "community services" through either the HCBS or ICF-MR option were 52% males. The more common use of HCBS option for males among adults is largely a reflection of its use for deinstitutionalization of adult RTC/ICF residents who are 62% male.

Table 10: Distribution by Sex and Age of HCBS, ICF-MR and RTC/ICF Recipients in Minnesota, June 1991

Age and Gender	Type of Service							
	HCBS		ICF-MR		RTC/ICF		Total	
0-17 Years Old								
Male	279	(62.4%)	88	(73.3%)	2	(66.7%)	369	(62.6%)
Female	168	(37.6%)	51	(36.7%)	1	(33.3%)	220	(37.4%)
Total	447		139		3		589	
18-40 Years Old								
Male	697	(56.6%)	1,261	(54.3%)	396	(64.2%)	2,354	(56.5%)
Female	534	(43.4%)	1,061	(45.7%)	221	(35.8%)	1,816	(43.5%)
Total	1,231		2,322		617		4,170	
41 Years and Older								
Male	427	(59.8%)	778	(48.4%)	282	(58.1%)	1,487	(53.0%)
Female	287	(40.2%)	831	(51.6%)	203	(41.9%)	1,321	(47.0%)
Total	714		1,609		485		2,808	
All Ages								
Male	1,403	(58.7%)	2,133	(52.3%)	680	(61.5%)	4,216	(55.6%)
Female	989	(41.3%)	1,947	(47.7%)	425	(38.5%)	3,361	(44.4%)
Total	2,392		4,080		1,105		7,577	
Missing Data	74		78		85		237	
All Recipients	2,466		4,158		1,190		7,814	

How does the supply of HCBS allocations compare with the demand? How are access decisions made when demand is greater than supply?

Comparability of HCBS allocation procedures across counties. Two approaches were taken in addressing the comparability of HCBS allocation procedures across the counties. First, a sample of case managers was surveyed about their perceptions of whether their counties had a written procedure for prioritizing HCBS waiver allocations, and how opening were actually prioritized (regardless of whether or not a written policy existed). With regard to whether a written allocation policy existed in the county, 50% of the case managers surveyed indicated that one did exist, 18.3% said that one did not exist; interestingly, 31.7% reported that they did not know whether one existed.

Table 11 reports findings regarding case managers' perceptions of how diversion allocations are prioritized in their respective counties. Because some respondents indicated more than one priority proportions sum to more than 100%. The most frequently indicated priority is that persons with the greatest

need are given preference (77%), although specificity cannot be provided about how "greatest need" is operationalized from county to county. The second most frequent priority identified was preference being given to those in jeopardy of immediate institutionalization (73%). About three in five case managers reported that prioritization was based, at least in part, on cost considerations. That is, nearly two-thirds of the case managers surveyed reported that sometimes persons with lower costs must be chosen over those with higher costs in order to balance the high costs of recipients already on the program, and/or to lower the county's average HCBS cost. About 22% of case managers reported that children are given priority over adults. Only about 18% reported that their counties use a first-come/first served priority system in allocating opportunities to receive HCBS. It seemed notable that 20% of case managers reported that potential recipients with "pull" or "connections" were likely to be served before those in greater need or who had been waiting longer, particularly given the likelihood of underreporting of such an observation. Examination of the county type in which those case managers worked revealed statistically significant differences (X^2 [2, N=60] = 12.4, $p < .01$), with the Twin Cities metropolitan area counties being most likely to report "connections" or "pull" as a factor in prioritizing HCBS service recipients (38% vs. 8% in the other county types). In one Twin Cities metropolitan county a majority of case managers reported connections and pull to be a prioritizing factor.[2]

Table 11: Case Managers' Report of County Allocation Priorities

Priority	Percent of Case Managers Reporting This As a Priority
First come, first served	18.3
Clients with the greatest needs are usually served first	76.7
Client in jeopardy of imminent institutionalization are given first priority	73.3
Clients with "connections" or "pull" sometimes get served before those with greater need or those who have been waiting longer	20.0
It depends on available funds (e.g., sometimes clients with lower waiver costs must be chosen over those with higher cost in order to balance high cost clients and/or to lower the county's average waiver cost	61.7
Children (under 18) are given priority	21.7

In 1991 the Minnesota Department of Human Services requested that counties provide the Department with a copy of their procedures and criteria for selecting individuals for HCBS allocations. A review of these policies and procedures indicates, first, that out of 87 counties only 49, plus the counties comprising Region VIII North Welfare Department, reported on written policies that in some way prioritize how HCBS allocations are distributed. The allocation priorities reported by these counties is summarized in Table 12. Counties not represented in Table 12 are ones whose responses did not specifically address the issue of prioritization (i.e., when an allocation becomes available who receives priority in getting it?), counties which did not have a written policy about allocation, and the several counties that did not respond to the Department's request. Because there was an understanding on the part of counties that they would not be specifically identified in this public report, they are indicated by a number only, although this same table has been provided to the Department with the counties indicated.

[2]It should be noted that these percentages do not necessarily reflect the proportion of counties with or without a written allocation policy. They merely represent the proportion of case managers in the survey reporting their perceptions about county policy.

The summary that appears in Table 12 depicts counties' priority schemas as accurately as possible. Nonetheless, some of the finer points of counties' priority policies are obviously lost in the effort to categorically summarize them. Review of these documents revealed a wide range of approaches to prioritizing applicants. At one end of the spectrum are counties that do not have specific criteria for prioritizing applicants or have vague criteria (column "a" in Table 12). An example is a Twin Cities metropolitan area county's policy regarding prioritization:

> . . . criteria in client selection for eligibility (is recommended to) be based on, but not limited to, the following variables where applicable:
>
> Length of time at home and/or on waiting lists
> Need for transition
> Severity and type of behavior problems
> Risk for placement
> Level of services needed
> Medical condition
> Level of family stress
> Risk of abuse
> Age
> Need for crisis/emergency services
> Availability of alternative services
> Availability of community resources.

In such counties it is essentially up to case managers and/or county officials to decide which of the above conditions is more or less important, in that they provide little in the way of guidelines for the prioritization of applicants.

In contrast one rural county has devised a point rating system for prioritizing diversion applicants on its waiting list. Four criteria are used in this rating system: current residence, type of move, existence of special needs, and whether the person would benefit from HCBS funding. With respect to the residence criteria, for example, 30 points are given if the applicant is a child in a state RTC/ICF, 15 points for an adult in a state RTC/ICF, 10 points for an adult in a large ICF-MR, and only 5 points for an adult in a small community ICF-MR. With respect to the other criteria, the highest number of points are given for court-order moves, a person with a severe special need or a number of special needs, and for individuals where HCBS funding is the only real alternative. Points across criteria are then summed, and applicants rank-ordered by score for diversion allocations. While many of the counties reporting fall in the former category (no specific criteria), only one county submitted policies on prioritization that describes a largely objective ranking system. Many counties report criteria somewhere in between these two approaches where risk of institutionalization or current residence in an ICF-MR or RTC/ICF are used as factors for prioritizing.

Given the preeminence of county governance in Minnesota it is not surprising to find a great deal of variation among the counties that do have operational priorities. Such diversity across the state does pose concern for equity of access to the HCBS program. Since determination of allocations and prioritizing applicants is within the purview of counties, an applicant in one county may be considered a priority for HCBS, while an applicant with very similar characteristics and in similar circumstances in another county may have a considerably different chance of becoming a HCBS recipient. More specific state guidelines for county allocation policies may be a means of demonstrating how counties might establish equity of opportunity for eligible individuals to become HCBS recipients, although obviously other issues would arise (e.g., the higher costs of serving individuals with similar characteristics in Metro counties than in rural counties).

While there is a good deal of variation in county allocation policies, a majority of counties have one criteria in common--i.e, reliance on the cost of the plan of care. Twenty eight of the counties summarized in Table 12 reported that cost considerations play a role in choosing HCBS recipients. This finding is consistent with the results of the case manager survey which also found cost considerations to be one of the determining factors in selecting from among potential HCBS recipients.

Table 12: County HCBS Allocation Priorities for Persons with MR/RC

County*	Priority																			
	a	b	c	d	e	f	g	h	i	j	k	l	m	n	o	p	q	r	s	t
County 1	X																			
County 2		X		X		X[1,K,2,A]	X[1,K]	X[3]	X[4]											
County 3		X					X						X							
County 4		X																		
County 5				X																
County 6		X[1]	X[2]																	
County 7		X				X[1,K 3,A]	X[1,K]	X[3]	X[4]											
County 8	X	X	X																	
County 9	X						X[1]			X[1]										
County 10		X					X						X							
County 11		X	X																	
County 12											X	X								
County 13	X																			
County 14		X			X[2,D,M,4,P]	X[2,C]			X[1,C]			X[1,D]		X[3,D]						
County 15		X																		
County 16		X[C,D]								X[1,C]	X[2,K,C,3,C,1,D]		X[4,C,2,D]							
County 17		X[1]	X[2]																	
County 18	X	X																		
County 19						X[3]		X[2]	X[1]											
County 20		X				x[3]	X[4]	X[2]	X[5]	X[6]					X[1]					
County 21	X																			
County 22		X																		
County 23		X	X																	
County 24		X[6]							X[3]	X[4]	X[5]					X[1]	X[2]			
County 25						X[3]	X[4]	X1	X[2]	X[5]										

County*	Priority																			
	a	b	c	d	e	f	g	h	i	j	k	l	m	n	o	p	q	r	s	t
County 26	X																			
County 27	X	X																		
County 28		X					X													
County 29									X[1,K,C, 2,A,C]	X[3,C]								X[D]		
County 30	X[6]					X[2]	X[5]		X[1]	X[4]									X[3]	
County 31		X		X	X[1]	X[2]		X[3]	X[4]											
County 32						X[1,D,A, 2,D,K]	X[1,D,A, 2,D,K]		X[1,C]	X[2,C]										
County 33		X																		
County 34		X				X					X		X							
County 35	X	X																		
County 36		X									X		X							
County 37	X[C,D]	X[C,D]	X[C,D]					X												
County 38		X[1]	X[2]																	
County 39					X	X[1,K, 2,A]	X[3,K, 4,A]		X[1,C]	X[2,C]										
County 40						X[3]	X[3]	X[2]	X[1]											
County 41	X																			
County 42		X					X						X							
County 43	X																			
County 44	X																			
County 45									X											X
County 46			X[R]																	
County 47	X																			
County 48		X																		
County 49						X[2]	X[3]	X[1]	X[4]	X[5]										
Regional	X[A]			X		X[2,K]	X[4,K]		X[1,K]	X[3,K]							X[5]			

Notes for Table 12:

*County names have not been used because counties submitted reports without explicit agreement to public disclosure of responses. The numbers used do not refer to Minnesota county numbers. Questions involving identification of specific counties should be addressed to the Department of Human Services, Division for Persons with Developmental Disabilities.

KEY

a: No specific criteria/priority; county decides which client can best be served with allocation
b: Priority based on cost
c: First come, first served (within priority rating)
d: Funding of last resort
e: Children
f: At-risk of RTC/ICF placement
g: At-risk of ICF-MR placement
h: Persons in closing/down-sizing ICFs-MR or RTC/ICF
i: Persons in RTC/ICFs
j: Persons in ICFs-MR
k: Persons at risk of out-of-home placement
l: Parents relinquishing responsibility/older parents
m: Would allow person to move to a less restrictive setting
n: Young adult approaching high school graduation
o: Court or DHS mandated
p: At risk in present living arrangement
q: Nursing home resident with no physical need
r: Point system
s: Persons in skilled nursing facilities
t: At risk of imminent placement in a more restrictive setting

1,2,3, etc.: Priority number

C: Conversions
D: Diversions

K: Children
A: Adults

M: With maladaptive behaviors
P: With physical disabilities requiring respite
R: Slots allocated to adults/children based on ratio of adults to children on waiting list

Difficulties in placing potential conversion enrollees. Key informants in the various counties, noted repeatedly that the supply of conversion allocations to the counties was, in general, substantially more ample than the supply of diversion allocations. It is clear that the State has intentionally used the HCBS program as the major mechanism for carrying out its commitment to reducing the populations of RTC/ICFs and large ICFs-MR. However, sentiment in some counties is that persons who remain in the RTC/ICFs and targeted ICFs-MR will be difficult to place, either because of the intensity of the services that they require and/or because the cost of services to them in the community under the auspices of the HCBS waiver would result in the county exceeding or coming uncomfortably close to the allowable average daily reimbursement rate, even with the benefit of the enhanced fund. On the other hand, 50 Minnesota counties (57%) are far enough below their allowable average to be currently able to provide for at least one more new HCBS recipient at two or more times the current average cap of $83 per day. Thus, although access to HCBS for ICF-MR and RTC/ICF residents may appear somewhat greater than for people already living in the community, there are economic and precautionary limitations affecting their program access as well.

Improvement of awareness of HCBS application and allocation processes. Finally it might be noted that the county officials and case managers interviewed did not always appear aware of the process involved in requesting federal authorization for HCBS allocations, particularly with respect to obtaining authorization for diversions. While state officials should attend carefully to the perspectives of county officials and case managers as summarized above, it should also be helpful if they continue and expand their efforts to educate their constituencies in the counties about the specific limitations and negotiations that go into establishing diversion and conversion allocations. It seems that many people in the counties view those allocations as entirely under the control of state officials.

How long do eligible persons wait for services?

Estimated waiting period of current recipients. Two data sources were used in estimating how soon the HCBS sample members actually gained access to services once they had been determined eligible. One source of data was the families of sample members, and the other was their case managers. Both the case manager and family sample members were answering questions about the same HCBS recipients, except that the number of family members responses (82) was somewhat smaller than the case manager responses (118), because family members were not surveyed if they were not involved in (i.e., informed about) the family member's life. Table 13 shows the responses to the question about time elapsing between initial application for HCBS and the initiation of services.

Table 13: Waiting Time Reported by Family Members and Case Managers

Waiting Period	Family Member's Report	Case Manager's Report
Less than 6 months	43.3%	58.2%
6 to 12 months	20.0	20.2
1 to 2 years	23.3	15.2
2 to 4 years	13.2	6.3

Although both sets of respondents report reasonably similar estimates, the estimates did vary by type of respondent; family members report longer waiting times, on average, than do case managers. The differences between family members and case managers may reflect a lower average waiting period for people whose families are not active in their lives (e.g., as is the case for a higher proportion of people eligible for conversion allocations, or conversely a longer wait for families with children at home who request diversion allocations); they may reflect a different perception of the amount of time between application and service delivery, which might expectedly seem longer to family members. In any case, waiting periods of six months or less were indicated for about half of HCBS recipients, with waits of over two years appearing quite rarely (about 10%). Neither group of respondents reported waits of more than four years.

Improvement of data on people waiting for services. The majority of persons who are currently HCBS recipients had to wait no longer than one year before receiving services. However, an equally important question that could not be answered through the available data is how long persons who are not currently receiving HCBS but who want them must wait. Counties have been required by the legislature to advise the state on the number of persons waiting for services. Complete statistics are not yet available at the State level presently and a survey of counties indicated that a minority of counties even maintain these statistics internally. Although waiting lists do exist in some counties, any estimates of waiting time derived from them would probably be erroneous since we have been told the lists are not necessarily up-to-date (i.e., persons whose names are on the waiting lists may no longer be waiting). Also, several county case managers pointed out that there are some individuals who are on the waiting list because they will eventually want HCBS, but are not actually in need of them at the present time; this group consists of children as well as adults who will eventually be leaving home, but for whom such a move is neither an immediate need nor desire. Although the current waiting list data where available, appeared to have limited usefulness to this evaluation, it seems an effort to establish a reliable reporting system would be of considerable use to the state and its counties. Such a system should be capable of separating people waiting for HCBS who are residents in institutions, people at home with immediate need, and people at home with need in a relatively short period (e.g., 2-3

years). It could also include specification of the nature of services needed (e.g., by adding vocational services to the existing HCBS categories). Given the current data bases it is possible to use historical records of initial date of screening and initial HCBS payment date to estimate waiting periods, except for the practice of "deferred screenings."

"Deferred screening." During site visits it became apparent that some counties do not follow one of the Department's application procedures. Specifically, some counties will not recommend an applicant for HCBS, and thus do not place the individual on a waiting list, until it is clear that a place will be available for the individual in the county's HCBS program sometime in the near future. This occurs even when the individual clearly meets all eligibility requirements for the program. It is not possible to estimate how many counties have this unwritten policy, but the survey of case managers (not necessarily representative of all the counties) found that 24% of case managers (at least 1 from 39% of the sampled counties) reported that their county "defers" screenings for persons who are potentially appropriate for the HCBS program until an allocation becomes available. In discussing this matter with some of the county case managers the reason given for either not recommending HCBS or in deferring screenings mostly reflected concern about not raising the expectations of families about the possibility of services when they were unlikely to receive them in the near future.

Information about HCBS for public audiences. One of the ways that families of potential clients may learn about the HCBS program and other services available for an individual with mental retardation or a related condition is through written materials and brochures explaining the services and where and how to seek them. The vast majority of case managers in the sample reported that their respective counties do have information or brochures about the HCBS program available, and they are distributed to anyone who shows interest. Brochures, training opportunities, information bulletins, and manuals have been provided to counties by the State DHS to assist in dissemination of information. There are also informational materials on HCBS developed by advocacy groups (e.g., "Title XIX Waiver, What it is and how to get it" by ARC-Minnesota). Still, 20% of case managers reported that they were not aware of the availability of such information. It would be of benefit for the state to work with counties to improve access to and/or awareness of such basic information.

Influences on HCBS participation by ICF-MR providers. During initial site visits to the counties on more than one occasion it was observed that there is resistance on the part of some ICF-MR providers and some personnel at the RTCs to discharging residents to residential settings supported with HCBS. Officials, case managers and HCBS providers in those counties suggested that this resistance is due, for the most part, to concerns about the economic viability of ICF-MR institutions as increasing numbers of their residents are moved into the community. When directly questioned about this phenomenon, 45% of case managers reported that they sometimes encounter ICF-MR providers who try to influence parents/guardians to maintain an individual in an ICF-MR instead of opting for waiver services. A much smaller proportion of case managers reported that they experience a similar problem with RTC staff, although this may reflect less contact in the RTCs by the case managers surveyed (all case managers of HCBS recipients surveyed).

Concerns about family co-payment requirements. Another potential barrier to program entry or program maintenance concerns the relatively new requirement of family co-payment for HCBS. This has been developed using a sliding fee and is also applicable to other Medicaid-financed services. In order to understand if this policy has any adverse effect on access, family members of sampled HCBS recipients were asked about their ability to finance these co-payments. Only 8.5% of family members reported that they currently participate in the parental co-payment program. Of those participating, 12.5% said that it was an "enormous" burden, but no one reported their inability to continue paying the co-payment fee was a threat to their family member's opportunity to continue to receive services. However, there were a small number of reported instances of people dropping out of the HCBS program because of co-payment costs in the sampled counties. The remainder of family respondents with co-payment requirements reported it as either

not being a burden or said it was somewhat of a burden but that they could handle the payments. While such findings with a representative sample suggest co-payments have not had much of an impact on access to services, it is important to assure that the best interests of the individual with MR/RC are protected over what might be an economic decision of family members.

Finally, in nearly all interviews about HCBS programs in the sampled counties there was concern about access for persons with diversion status. There is a great deal of concern in the counties about the relatively small number of allocations becoming available each year for persons already living in the community, usually with their families. This sentiment was also reflected in the case manager survey. As will be noted again in the "Quality of Services" section, when asked about their recommendations for improving the HCBS program over the next two years, one of the most frequent recommendations of case managers was to expand the number of diversion allocations available. This response reflects the highly positive regard for the HCBS program found all through Minnesota, but makes clear that good programs are no better than the access to them.

Do HCBS recipients have access to the services that are needed by them and intended for them?

In addition to questions about initial access to the HCBS program, this assessment was concerned about whether HCBS recipients have adequate access to other services they need once they have been enrolled in the HCBS program. This examination included access to medical, residential, social, education and case management services as well as appropriate employment opportunities. It also examined the extent to which HCBS recipients encounter difficulties taking part in recreational, leisure and other program services available to all other Minnesotans.

Family perspectives on needed services. Family members were asked about their ability to choose services and whether the services received were meeting all the needs of HCBS recipients. First, there were no reports about recipients being denied choice among types of services or providers, evidence of full compliance with HCBS standards requiring that such choice be available. However, about 24% of families and guardians reported that HCBS recipients needed services that they were not receiving. Based on family responses about 21% of recipients needed but were not receiving help in communication and speech training, 12.5% needed increased services that would result in leisure and recreation activities that are better integrated with the wider community, and 8.3% needed occupational and/or physical therapy services. About 13% of family members surveyed complained there were not enough respite care hours available each month and/or sufficient numbers of respite care providers, although notably, during the time period that this assessment was completed, Minnesota received approval of an HCBS plan amendment expanding the availability of respite care from 30 to 90 days per year. Other types of services that were mentioned less frequently by families included help with family dynamics, in-home overnight respite, respite with the recipient's own age group, crisis center services, more private duty nurses, and assistance with purchasing adaptive equipment.

Family members also raised concerns about employment opportunities for HCBS recipients. Thirteen percent of family members surveyed reported that either the type of day training/habilitation services or supported employment services were not appropriate to the HCBS recipient's abilities or needs. Although families' perceived level of unmet need in this area is not overwhelming, it is an area that warrants attention both because of a significant level of perceived dissatisfaction and because of the substantial benefits to the individual HCBS recipient in having productive, integrated work experiences.

Case mangers' perspective on needed services not received. Table 14 presents the responses of case managers of 117 of the HCBS sample members regarding any services that those individuals might need but

were not receiving at the time of the assessment. Case managers reported that 71% of the sample members were receiving all needed services. No differences in access to all needed services were found by the type of county in which people lived. However statistically significant differences were found for people living in different kinds of settings. Specifically people living in family and corporate foster homes were more likely to be viewed as receiving all needed services than were children and adults living with their families or in their own homes (82% versus 57%). Services most commonly viewed as needed, but not received by adults living with their family or in their own home were supported living services (18%) and supported employment services (9%) or competitive employment (9%). Supported living services were viewed as needed by adults who are living with their families.

Children living at home were most commonly seen as needing personal care attendants (14%), normal respite care (14%) or respite care from a provider able to provide an ICF-MR level of care (7%). Persons living in corporate foster care settings were most commonly reported to need employment services, including supported employment (11%), competitive employment (2%) and sheltered employment (2%). Among services indicated to be needed by less than 2% of sample members were in-home family support, training for independent living, community recreation/integration support, day habilitation and training, occupational therapy, physical therapy, support in establishing friendship, a retirement day program, a physical adaptation to a home, a communication device, increase support at work, and psychological services.

Table 14: Percentage of HCBS Recipients Needing Services Not Presently Received According to Case Managers (in percentage)

	Place of Residence				County Type			
Additional Services Needed	Family Foster (n=19)	Corporate Foster (n=47)	Own Home-Adults* (n=22)	Family Home-Children (n=29)	Urban Metro (n=39)	Urban Outstate (n=37)	Rural (n=41)	Total (N=119)
None needed	78.9	83.0	54.3	58.6[1]	64.1	67.6	80.5	70.9
Personal care attendant	0.0	0.0	4.5	13.8	5.1	5.4	2.4	4.3
Respite care (non-ICF-MR)	5.3	0.0	4.5	13.8	5.1	8.1	2.4	5.1
Respite care (ICF-MR) level	0.0	0.0	4.5	6.9	5.1	2.7	0.0	2.6
Supported living services	0.0	0.0	18.2	0.0[2]	0.0	8.1	2.4	3.4
Sheltered employment (long-term)	5.3	2.1	0.0	0.0	2.6	0.0	2.4	1.7
Supported employment	0.0	10.6	9.1	0.0[3]	05.1	10.8	2.4	6.0
Competitive employment	0.0	2.1	9.1	0.0	0.0	5.4	2.4	2.6
Other	10.5	17.0	9.1	6.9	17.9	8.1	2.4	9.4

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (3, N = 117) = 8.9, p < .05; [2] X^2 (3, N = 117) = 11.2, p < .01; [3] X^2 (3, N = 117) = 14.0, p < .01

Need for improved housing. Although case managers report that 90.7% of HCBS recipients were living in the setting they considered most appropriate setting to the individuals' needs, they also reported problems in securing appropriate housing stock for HCBS recipients generally. Over half of case managers reported that the absence of adequate rental stock (apartments and homes) posed a problem when developing living

arrangement plans for HCBS recipients; although only 18.3% indicated that this was "often" a problem. The most frequently cited problem was physical accessibility--the lack of homes with physical adaptations. Other problems included the short supply of rental property in general and the high cost of that which is available. Also mentioned was the poor quality of housing stock, the frequent lack of rental property in rural areas, unsafe neighborhoods, and community resistance to the perception of "dangerous clients." Four of 34 case managers who were asked why they considered finding rental property to be a problem in developing community living arrangements for HCBS recipients, indicated resistance or reluctance to rent to persons with developmental disabilities.

Insufficient supply of services providers. A major concern among case managers which directly affects access is the inadequate supply of service providers in some areas or of specific types of service. Close to half of the case managers surveyed (47%) reported that there is not a sufficient number of providers for their HCBS clients. Case managers of 77% of the sample members reported that they had encountered difficulty in recruiting providers for their clients at one time or another. The most often-cited problem was in recruiting and keeping providers to work with persons with severe disabilities. Major areas of specific shortages of specialized support reported by case managers included people with skills to work with persons with aggressive or challenging behaviors and/or their HCBS providers (21% reporting shortages in this area), respite care developers and providers (18%), and personnel to work with recipients with severe physical disabilities and their HCBS providers (14%). These shortages are most frequently noted in rural counties. Clearly to the extent that DHS intends to support equal access to HCBS services to persons with MR/RC throughout the state, it must attend to building a system of support for HCBS providers and families that includes minimally the 3 areas of greatest perceived need: 1) responding to aggressive and challenging behavior, including crisis response services; 2) responding to the specialized needs of persons with severe physical disabilities, including technological supports; and 3) developing respite care resources throughout the state.

Access to community settings. One of Minnesota DHS' articulated goals for citizens with MR/RC is that they have access to the same community services and the physical and social settings as all other Minnesotans. In documenting the extent to which this goal is being achieved with HCBS recipients case managers were asked about two issues. First, they were asked whether *due to the attitudes of others* the HCBS recipients they worked with had experienced any difficulty gaining access to services available to the general population (e.g., public parks, facilities, restaurants, transportation), or whether they had experienced any discrimination in attending social events open to the public. They reported that about 15% of HCBS recipients had such negative experiences; in many instances the response was precipitated by what was described as the recipient's behavior problems. Case managers were also asked whether their clients had encountered any difficulty in gaining access to public services *due physical access problems*. Case managers reported that nearly 19% of HCBS recipients, almost all of whom are mobility-impaired had experienced such difficulty.

Primary Research Questions

- How do Minnesota's total Medicaid costs since utilization of HCBS compare with its projected Medicaid costs in its absence?
- What are the utilization and costs of specific HCBS and other Medicaid services? How do these vary for different groups of recipients?
- What has been the full impact of the HCBS program on overall utilization of and expenditures for Medicaid long-term care services in Minnesota?

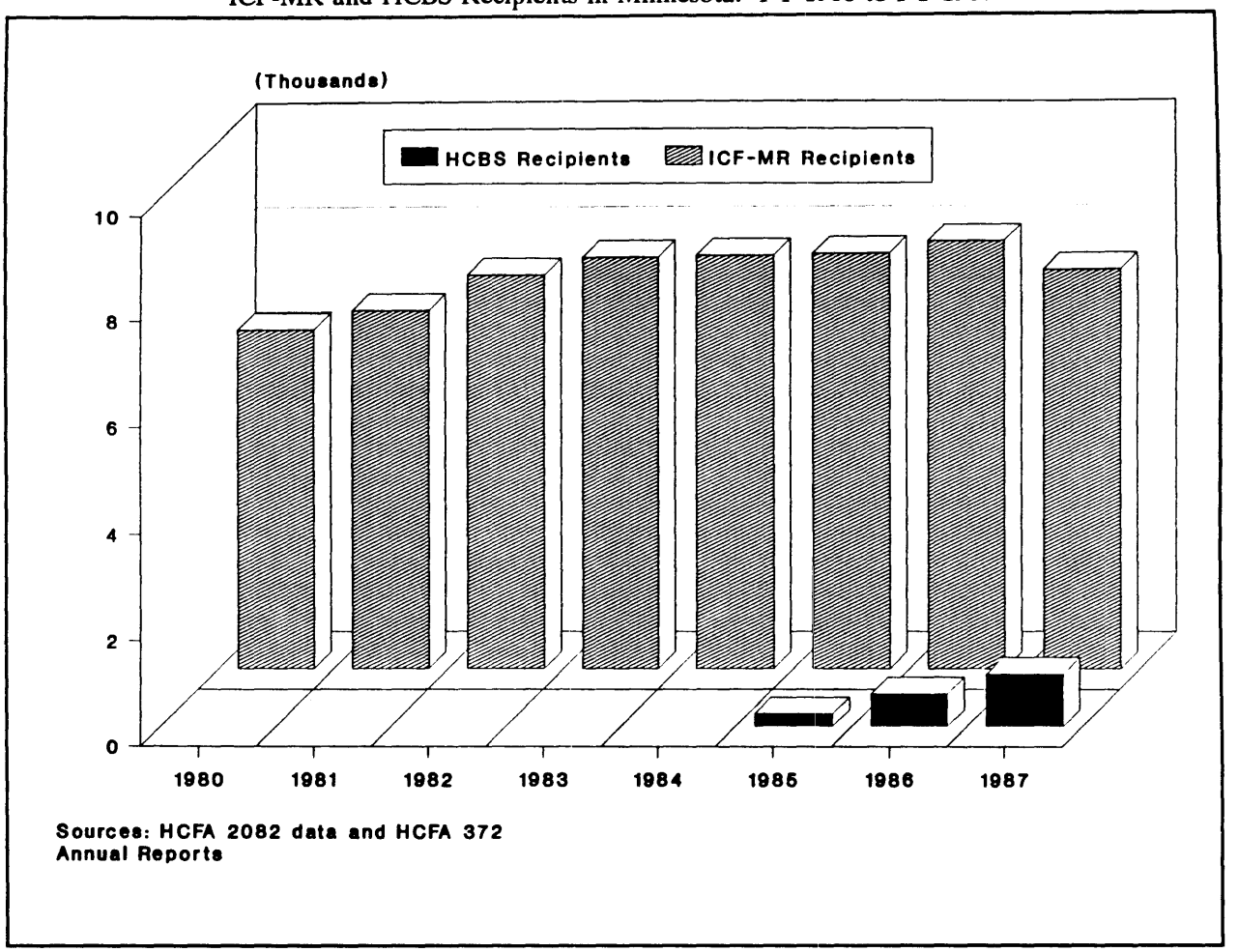
How do Minnesota's total ICF-MR and HCBS costs since utilization of HCBS compare with its projected Medicaid costs in the absence of HCBS?

Minnesota's Medicaid program for persons with MR/RC prior to HCBS. Prior to its authorization to provide Medicaid Home and Community-Based Services, Minnesota was more heavily invested in the ICF-MR program than any other State in the country. This investment began in the early 1970s, shortly after Congress enacted the ICF-MR program in 1972. By 1977, Minnesota had 154 ICF-MR certified facilities (including RTC/ICFs), more than *one in four* of the total number of ICFs-MR which were then certified in the country (Lakin et al, 1991). Minnesota was also the first State to extensively use the ICF-MR program as a means of financing smaller, private facilities. In June 1977, Minnesota had 113 ICFs-MR with fewer than 16 residents (*77 percent* of all ICFs-MR in this size category in the country) and the 1,052 Minnesotans living in these facilities made up 61.5% of small ICF-MR residents nationwide.

By June 1982, the number of ICFs-MR in Minnesota had again doubled, to 310 facilities. Minnesota's 2,412 residents in 260 small ICFs-MR were still 24% of the national total. By July 1, 1987, the starting date for the renewal of the HCBS program (and for this evaluation), Minnesota had 361 ICF-MR certified facilities with 6,549 residents, 2,847 of whom lived in 301 ICFs-MR of 15 or fewer residents. Figure 2 shows the growth of ICF-MR recipients in Minnesota from 1980 through 1987, as well as the initial growth of the HCBS waiver program in the first three years of its operation, beginning in 1984.[3]

[3]Figure 2 presents data on the number of annual ICF-MR recipients in Minnesota based on HCFA 2082 reports. These data include all persons who received at least one day of ICF-MR care during the reporting year. These reports differ slightly from survey data on ICF-MR utilization, which generally report the residents of ICFs-MR on a specific day. Thus, according to HCFA 2082 data, the number of ICF-MR recipients in Minnesota peaked in the year 1986, at 8,035 recipients. Annual recipient data can be conceived as including the average daily caseload in ICFs-MR *plus* the number of new admissions for that year. HCFA reports always require data on annual recipients, although single day census surveys of average daily population tended to better reflect the size and growth of the program as a whole.

Figure 2
ICF-MR and HCBS Recipients in Minnesota: FY 1980 to FY 1987



As a result, in 1987, Minnesota had more ICF-MR residents per capita than any state in the country. (Table A-7 provides per capita utilization and expenditures for all states on July 1, 1987.) In comparison to a national average of 59.3 ICF-MR residents per 100,000 population, Minnesota had a utilization rate of 154.3 residents per 100,000 population. In terms of Medicaid spending for ICF-MR services, Minnesota ranked fourth nationally in 1987, spending $53.12 per State resident, compared to a national average of $23.04 per capita.

The fact that Minnesota ranked first in terms of ICF-MR utilization rates, but only fourth in terms of ICF-MR spending per capita, reflects the fact that average annual costs for ICF-MR residents in Minnesota were below those of many other States ($36,300 in Minnesota and about $45,000 nationally). Lower ICF-MR costs per recipient in Minnesota were reflective of its large number of private ICFs-MR, which typically have considerably lower Medicaid payment rates than large public institutions, which house the majority of ICF-MR residents nationwide.

The projected effects of HCBS in Minnesota's original application. Minnesota's application to provide HCBS to persons with mental retardation and related conditions was originally approved with an effective date

of July 1, 1984. In March of 1987, Minnesota submitted its request for renewal of the HCBS program for another five years. In its application, the State included its HCBS formula projections, which documented how the renewal would meet the test of "cost-effectiveness." Table 15 shows the final formula projections that were authorized by HCFA in its notification to the State on June 23, 1987 that the HCBS renewal request had been approved.

Minnesota estimated that in FY 1987, the final year of the initial three-year HCBS program, that approximately 7,490 persons received ICF-MR services. If the HCBS renewal were not approved, Minnesota projected that the ICF-MR population would increase to 8,965 recipients by FY 1992, an increase of 20%. With the opportunity to substitute Home and Community Based Services, however, Minnesota estimated that the ICF-MR population would decline to about 5,764 recipients by 1992, a reduction of about 18%.

In its application, Minnesota estimated that its HCBS population would increase from about 1,000 recipients in 1987 to 3,000 recipients in 1992. Most of this growth would occur in the first two years of the renewal (FY 1988 and FY 1989). HCBS recipients were projected to increase by 665 in the first year, 622 in the second year, 461 in the third year, 252 in the fourth year, with no increase in recipients in the fifth year.

In FY 1987, total Medicaid spending for HCBS equalled $13.2 million. Minnesota projected that spending for HCBS would increase to $30.0 million in 1988, $45.1 million in 1989, $59.2 million in 1990, $68.0 million in 1991, and $71.6 million in 1992. Average costs per HCBS recipient were projected to increase about 9.2% annually in the first three years of the renewal (when the program was enrolling many new recipients discharged from ICFs-MR, especially RTC/ICFs) and about 5.2% per year in years four and five of the renewal.

Table 15: HCBS Formula Projections for Original Renewal Request

State Fiscal Year	ICF-MR Recipients in Absence of Waiver	ICF-MR Recipients With Waiver	HCBS Waiver Recipients	HCBS Waiver Expenditures	Average Annual Cost Per Waiver Recipient
1988	8,255	7,040	1,665	$30,060,675	$18,054
1989	8,397	6,600	2,287	$45,129,371	$19,733
1990	8,626	6,248	2,748	$59,197,945	$21,542
1991	8,795	5,995	3,000	$68,046,000	$22,682
1992	8,965	5,764	3,000	$71,622,000	$23,874

Source: State of Minnesota, Department of Human Services, *Home and Community-Based Services Waiver Renewal Request*, Submitted March 1987, Amended with Additional Information, May 15, 1987.

The 1989 amendment of the HCBS formula. In December 1989, 18 months after the start of the HCBS program renewal, Minnesota submitted an amendment request to expand the HCBS program for persons with MR/RC beyond its original projections. This amendment was approved by HCFA on February 28, 1990. The amended HCBS formula, as shown in Table 16, permitted Minnesota to increase its HCBS waiver population by another 572 recipients by 1992, and total HCBS spending by another $39.1 million over the last three years of the renewal. In addition to increasing its number of HCBS recipients, Minnesota requested higher than originally requested increases in the average cost per recipient, since many of the added recipients were projected to enter the program directly from RTCs, and as was shown in Table 3 and Table A-6 RTC residents tend to have more severe functional, behavior and medical impairments than the typical HCBS or community ICF-MR recipient.

Table 16: Revised Formula Projections for Amended HCBS Waiver

State Fiscal Year	ICF-MR Recipients in Absence of Waiver	ICF-MR Recipients With Waiver	HCBS Waiver Recipients	HCBS Waiver Expenditures	Average Annual Cost Per Waiver Recipient
1988	Same	Same	Same	Same	Same
1989	Same	Same	Same	Same	Same
1990	8,473	6,130	2,633	$59,808,595	$22,715
1991	8,760	5,916	3,114	$79,341,606	$25,479
1992	9,052	5,730	3,572	$98,880,400	$27,682

Source: Minnesota Department of Human Services, Formula Revision, HCBS ICF/MR Waivered Services Worksheets, December, 1989

Comparison of actual and projected utilization and costs. Table 17 shows actual utilization and expenditures in the Minnesota HCBS program in FY 1988 through FY 1991 in comparison to the state's formula projections. The top half of the table presents data on actual ICF-MR use and costs, in comparison to projected use and costs. The bottom half of the table shows HCBS use and costs in comparison to projections.

Table 17: Projected Versus Actual ICF-MR and HCBS Utilization and Expenditures: FY 1988 to 1991

State Fiscal Year	ICF-MR Recipients		ICF-MR Costs Per Recipient		Total ICF-MR Expenditures	
	Projected	Actual	Projected	Actual	Projected	Actual
1988	7,040	6,652	$34,498	$36,001	$242,865,920	$239,477,892
1989	6,600	6,173	$36,778	$37,602	$242,734,800	$232,116,027
1990	6,248	5,948	$41,695	$41,286	$260,510,360	$245,568,862
1991	5,995	5,851	$45,815	$44,964	$274,660,925	$263,085,705
1992	5,764	NA	$50,728	NA	$292,396,192	NA

State Fiscal Year	HCBS Recipients		HCBS Costs Per Recipient		HCBS Expenditures	
	Projected	Actual	Projected	Actual	Projected	Actual
1988	1,665	1,666	$18,054	$17,727	$30,060,675	$29,532,565
1989	2,287	2,108	$19,733	$22,560	$45,129,371	$47,556,174
1990	2,633	2,347	$22,715	$23,513	$59,808,595	$55,185,013
1991	3,114	2,690	$25,479	$23,702	$79,341,606	$63,758,621
1992	3,572	NA	$27,682	NA	$98,880,400	NA

Sources: Minnesota Department of Human Services, Revised Waiver Formula Projections and HCFA 372 Annual Reports.

The number of persons who actually used ICF-MR care has been consistently below what was projected in the HCBS renewal request. This is partly due to the fact that the actual number of recipients in the "base" year (FY 1987) was actually less than estimated in the HCBS application. (When Minnesota was preparing its HCBS request in the spring of 1987, it did not have actual data on the number of persons

receiving ICF-MR care in FY 1987, which did not end until June 30, 1987.) The State estimated that there would be approximately 7,490 ICF-MR recipients in 1987, while subsequent data show that, in actuality, there were only 7,017 ICF-MR recipients in that year. When Minnesota amended its HCBS plan for 1990-1992, it corrected the base statistics for the Health Care Financing Administration.

Despite starting from a higher "base" utilization statistic in its renewal application than was actually the case, the *rate* of decline in ICF-MR use has stayed very close to projected rates of decline. Between 1987 and 1991, Minnesota projected a 20% decrease in ICF-MR use. The actual decrease realized was about 17%. In 1991, Minnesota served 1,166 fewer persons in ICFs-MR than it served in 1987. Among the policies that have played a role in Minnesota's ability to reduce ICF-MR utilization have been "domino conversion" requirements, whereby when people left ICFs-MR to receive HCBS their place had to be filled by people coming from places where ICF-MR "beds" were being closed (notably RTC/ICFs) and the freezing of admission of children to RTC/ICFs and the decertification of certain community ICFs-MR, which although incidental to HCBS policy assisted in its realizing its goals.

Not only was Minnesota quite accurate in predicting ICF-MR utilization, it has also been reasonably accurate in projecting average ICF-MR costs per recipient, with the exception of 1988, when actual costs exceeded projections by about $1,500. Total expenditures for ICF-MR care, due to lower-than-projected ICF-MR use, have also been less than projected in the amended HCBS formula.

It should be noted that with respect to the HCBS utilization, Minnesota did encounter a period of difficulty in keeping to its formula projections. By the second year of the renewal, average costs per recipient were beginning to exceed projections. Projected costs per recipient were estimated at $19,733 in 1989, while actual costs per recipient equalled $22,560, about 14% higher. Thus, in the second waiver renewal year, total spending for HCBS exceeded projected spending by about $2.4 million.[4]

There were three major reasons why the average cost of serving HCBS recipients exceeded projections. The first reason is that Minnesota served more "conversion" recipients than projected in the first year of the renewal. Table 18 shows the actual number of conversion and diversion recipients served under the waiver, in comparison to formula projections.[5] In the first year of the program renewal, Minnesota served 32 more conversion recipients than projected, and 21 fewer diversion clients. This did not affect total HCBS expenditures in the first year, since many people entered the program fairly late in the year, but it had a more substantial impact on program costs in FY 1989.

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[4]Under Federal law, HCFA cannot deny Federal reimbursement to States which exceed their projected expenditures for waiver services, as long as States remain within their HCBS caseload projections. In other words, Federal law does not penalize States which underestimate the average annual cost per waiver recipient.

[5]"Conversion" HCBS recipients are individuals who enter the HCBS program directly from an ICF-MR (including RTCs). "Diversion" recipients are persons who were not being served in an ICF-MR program when they entered the HCBS program.

Table 18: Projected Versus Actual Conversion and Diversion HCBS Caseload: FY 1987 to FY 1992

State Fiscal Year	Conversions		Diversions		% Conversions
	Projected	Actual	Projected	Actual	Actual
1987	--	489	--	502	49%
1988	938	970	717	696	58%
1989	1,378	1,227	899	881	58%
1990	1,614	1,333	1,019	1,038	56%
1991	1,913	1,492	1,200	1,198	55%
1992	2,190	NA	1,382	NA	NA

Sources: Minnesota Department of Human Services, Waiver Formula Projections (Revised) and HCFA 372 Annual Reports.

The second reason that average HCBS costs exceeded projections is that several counties developed service plans for conversion recipients that consistently exceeded the "average per diem rate" set by the State for HCBS program management. During field interviews, some county administrators claimed that State officials had assured them that the cost of individual service plans was not a primary consideration, and that the first priority was to develop new residential programs for individuals being discharged from RTC/ICFs. State officials agree that development of new placements for deinstitutionalized persons was indeed a priority that was aggressively pursued, and that in fact a "Commissioner's Special Projects" fund was created to assist counties with HCBS costs for deinstitutionalization that exceeded established limits. However, they observed that counties were not granted latitude or authority to absolve themselves from managing their programs within the constraints of the average per diem rate without prior authorization by the state agency. Nevertheless, as a result of this misunderstanding, many counties assumed access to additional supplemental state resources without submitting a specific request, while the state agency had no plans nor resources for these additional service costs.

The third reason that costs began to overrun projections is that the State lacked an adequate information system for tracking HCBS program encumbrances. During 1988 and the early part of 1989, the State was under the impression that HCBS spending was running significantly below projections. However, it gradually became clear that this was partly due to the fact that many counties were failing to submit claims for HCBS services on a timely basis, and that many of the claims that were submitted were being rejected by the Medicaid Management Information System (MMIS) due to improper completion. Thus, reports on HCBS program expenditures obtained through the MMIS system were an inaccurate representation of the true level of program spending.

After the Department realized the extent of the spending problem, corrective actions were taken. These actions were summarized in a letter to HCFA in January 1989.[6] In addition to providing technical assistance to counties to improve cost management of the HCBS program, the Division for Persons with Developmental Disabilities implemented its own cost tracking system, so that it no longer had to rely entirely on the State MMIS system to track county spending for services. That system is now fully operational and

[6]Letter from the Minnesota to Department of Human Services to Robert Wren, Health Care Financing Administration: "Minnesota's Efforts with Counties Regarding Cost Management of the Waiver (MR). Overview of Spending Overruns, Corrective Action Strategies and Results." January 10, 1989.

represents in the experience of the assessment team one of the most effective systems for monitoring present claims and projecting future claims now available to an HCBS administrating agency.

It was this set of circumstances that led the State to submit an amendment to its original HCBS application. Since the State had accelerated discharges from RTC/ICFs and community-based ICFs-MR, ICF-MR utilization was declining faster than projected. The State used these data to support a request for an expansion in the number of HCBS recipients, and for an increase in the average projected cost per recipient. As previously discussed, the amendment request was approved in February 1990.

In the third and fourth years of the renewal program (FYs 1990 and 1991) growth slowed considerably. Whereas in the first two years of the renewal, the number of recipients increased by over 1,100 (from 991 to 2,108), the number of HCBS recipients increased by only another 582 recipients during the third and fourth years, to a total of 2,690. As was shown in Table 18, HCBS spending was also brought under control, so that by 1991, average annual costs per recipient were running below projected levels. It should be noted that the increased ratio of diversion to conversion recipients admitted by counties to HCBS programs in the third and fourth years appears to be a factor in this outcome (see Table 18).

What are the Utilization and Costs of the Specific HCBS and Other Medicaid Services? How do they vary for different groups of recipients?

Utilization of different authorized services. Although the total number of HCBS recipients has grown substantially over the past 4 years, the proportion of HCBS recipients using the different authorized services has remained fairly stable, as shown in Table 19. Consistently, between 1988 and 1991, nearly three-quarters of HCBS recipients received Adult-Supported Living Services, which is the core residential support service for adults in Minnesota. Between 20% and 23% of recipients received In-Home Family Support Services as their core waiver service. Most of these recipients are children, as are the 8% of HCBS recipients who receive Child-Supported Living Services.

Just under 50% of all HCBS recipients receive day habilitation services financed under the HCBS program. About a third of all persons who receive Adult-SLS services do not receive HCBS-financed day services. Based on the sample of 129 HCBS recipients, almost all of these persons receive vocational services which cannot be financed as an HCBS. A small number are young adults, 18 to 21 years old, who are still eligible for education services. In the HCBS recipient sample survey 3% of adults under 66 years old were not participating in any education, day habilitation or vocational program, including 2 (or 10%) adults living in their families' or their own homes. Elderly HCBS recipients may be considered retired and are not required to participate in day programs. Children, of course, all participate in educational programs during the day which by law cannot be funded by Medicaid.

All HCBS recipients in the sample received case management services as is required in Minnesota statute and monitored by the State. The reason why the percentage of HCBS recipients reported to be receiving case management for billing purposes was 96% is unclear. It seems likely that these services are being provided, but not billed. Approximately 20% of HCBS recipients receive respite care services, primarily those who also receive In-Home Family Support. The number of persons receiving homemaker services declined from 7% in 1988 to only 2% in 1991. About five percent of recipients receive special payments for minor adaptations to their home or vehicles under the HCBS program.

Table 19: Percentage of HCBS Recipients Receiving HCBS by Type of Service: FY 1988 to FY 1991

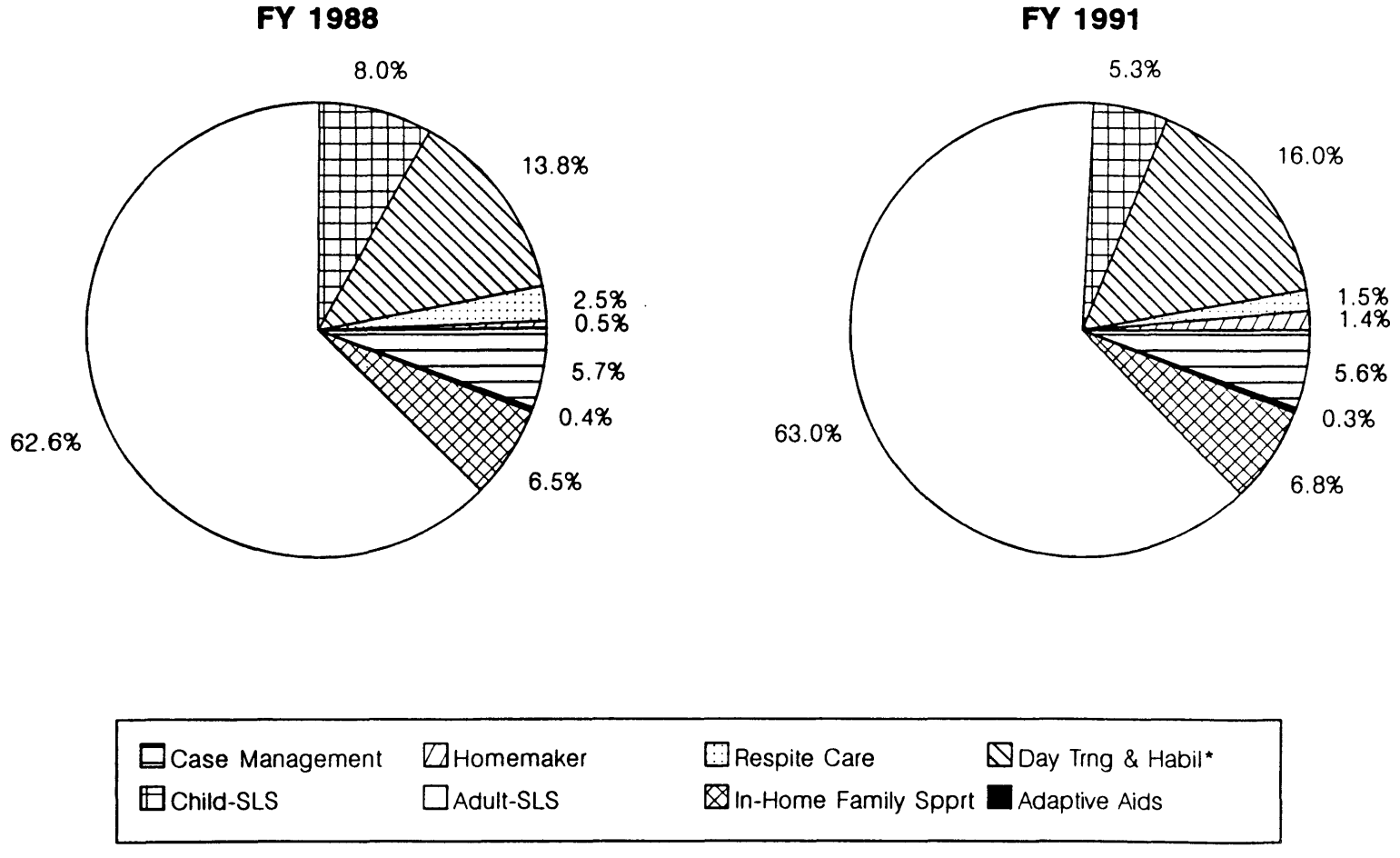
	FY 1988	FY 1989	FY 1990	FY 1991
Case Management	91.2%	94.6%	92.7%	95.7%
Homemaker Services	7.0%	5.8%	5.1%	2.2%
Respite Care	21.9%	21.1%	21.4%	20.6%
Day Training and Habilitation	48.8%	49.5%	49.5%	48.4%
Child-SLS	7.7%	8.1%	7.3%	7.7%
Adult-SLS	74.2%	74.1%	72.5%	73.9%
In-Home Family Support	20.1%	20.0%	22.3%	22.9%
Adaptive Aids	7.1%	6.5%	5.7%	5.4%
Total Recipients	1,666	2,108	2,371	2,690

Source: Minnesota Department of Human Services, HCFA 372 Annual Reports.

Figure 3 shows that the distribution of HCBS expenditures across service categories changed very little between FY 1988 and FY 1991. There was a slight increase in spending for day habilitation services as a percentage of total spending, and a slight decline in spending for Child-SLS services. Otherwise, the spending across service categories remained remarkably constant over this four-year period.

Comparison of costs of HCBS and ICF-MR services in Minnesota. The cost-effectiveness of the HCBS program for persons with MR/RC is not only dependent upon whether the program reduces utilization of ICF-MR facilities, but also upon the *relative* costs of the HCBS and ICF-MR alternatives. In comparing the costs of serving individuals with HCBS versus serving individuals in ICFs-MR, it is most appropriate to use the "average Medicaid cost per day" as the unit of analysis. Data on average annual costs do not adjust for differences in the number of days a year in which individuals are receiving ICF-MR or waiver services. For example, if someone receives HCBS for only one month during a particular year, it is inappropriate to compare that "annual" cost with the cost of serving someone living in an ICF-MR for the entire year. In addition, when examining comparisons of costs it is important to recognize differences that may exist because of differences in "coverage" across programs. As previously indicated, the test of cost-effectiveness for HCBS waiver programs, according to federal statute, is only based on their cost-effectiveness *to the Medicaid program.* Services received by either HCBS recipients (e.g., SSI payments and State supplementation payments) or ICF-MR recipients (e.g., case management) that are not covered under Medicaid, are not included in the federal government's assessment of cost-effectiveness.

Figure 3
Distribution of HCBS Expenditures by Service Category: 1988 and 1991



***Includes vocational services for some former institution residents**

Source: HCFA 372 Annual Reports

Table 20 presents data on the average days of coverage for HCBS recipients and for ICF-MR recipients for 1988 through 1991. In 1988, HCBS recipients averaged significantly fewer service days than did ICF-MR recipients. This was particularly true for "conversion" recipients. Thus, comparison of average annual costs for HCBS recipients and ICF-MR recipients in 1988 would not be a true measure of the cost-effectiveness of the HCBS program. In subsequent years, average days of coverage for both populations were more comparable.[7]

Table 20: Average Days of Coverage for ICF-MR and HCBS Waiver Recipients: FY 1988 to 1991

State Fiscal Year	ICF-MR Recipients	HCBS Recipients	
		Conversions	Diversions
1988	330	257	308
1989	332	323	306
1990	335	339	320
1991	329	330	326

Source: Minnesota Department of Human Services, HCFA 372 Annual Reports

Table 21 presents summary information on the average Medicaid cost per day of coverage for HCBS recipients and ICF-MR residents, including the costs of acute care services, for 1988 through 1991.[8] In 1988, the average Medicaid cost per day of coverage for HCBS was $63.63. In 1989, the average cost per day increased 12% to $71.41. From 1989 to 1990, there was a 3% *decrease* in the average cost per day of waiver services, from $71.41 to $69.35. This decrease no doubt reflects the corrective actions taken by the State to limit the growth in spending in 1990. From 1990 to 1991, the average cost per day for HCBS recipients increased 4% to $72.27.

Average Medicaid costs per day for ICF-MR recipients totalled $109.12 in 1988, and climbed to $136.62 in 1991. Costs increased 3.8% from 1988-1989, 8.5% from 1989-1990, and 11.5% from 1990-1991. This acceleration in the average daily cost of ICF-MR care reflects primarily the effect of distributing the fixed costs of operating the RTC/ICFs over a declining population, the high average costs of new ICF-MR development, the interim rates for closing a number of community ICFs-MR, and the increased costs associated with upgrading existing ICFs-MR for more severely disabled populations. As the number of persons served in the RTCs declines, the costs of operating the RTCs do not decline proportionately. Rather, fixed costs are simply spread over an increasingly dwindling population, increasing the average daily cost of care for those who remain in large institutions. Thus, the average cost per day of ICF-MR can be expected to continue to accelerate as the residual ICF-MR population in the RTCs continues to decline, unless, of course, whole RTCs are closed.

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[7]Note that the lower days of coverage in 1988, particularly for conversion clients, may have contributed to perceptions of under-spending for the waiver program in that year, which then contributed to the overspending problems in 1989 when most waiver clients were enrolled in the program for the entire year.

[8]It is important to note that the average cost per day for individual waiver services is computed by dividing total annual costs for that service by the total days of coverage for *all* waiver recipients, whether or not they received that particular service.

Table 21: Average Cost Per Day of Coverage for ICF-MR and HCBS Recipients: FY 1988 to FY 1991

	FY 1988		FY 1989		FY 1990		FY 1991	
	ICF-MR	HCBS	ICF-MR	HCBS	ICF-MR	HCBS	ICF-MR	HCBS
Case Management		$3.63		$3.68		$4.24		$4.11
Homemaker Services		0.31		0.23		0.19		0.10
Respite Care		1.59		1.15		1.06		1.10
Day Habilitation		8.76		10.34		10.64		11.69
Child-SLS		5.09		4.63		4.25		3.89
Adult-SLS		39.86		46.38		44.21		46.11
In-Home Family Support		4.17		4.75		4.54		5.01
Adaptive Aids		0.23		0.25		0.22		0.25
Total Waiver Cost		$63.63		$71.41		$69.35		$72.27
ICF-MR Costs	$109.12		$113.28		$122.86		$136.62	
Inpatient Hospital	$.97	$2.47	$1.05	$2.67	$0.97	$2.16	$1.08	$1.81
Physicians' Services	0.53	0.84	0.61	0.84	0.60	0.81	0.68	0.84
Outpatient Hospital	0.20	0.32	0.27	0.30	0.22	0.26	0.30	0.34
Laboratory and X-Ray	0.02	0.02	0.03	0.02	0.04	0.01	0.04	0.01
Prescribed Drugs	0.86	1.18	0.98	1.12	1.11	1.17	1.36	1.35
All Other Acute Care	2.60	5.48	2.97	5.74	3.94	6.57	4.55	7.80
Total Acute Care Costs	$5.18	$10.31	$5.92	$10.69	$6.88	$10.99	$8.01	$12.16
Average Total Medicaid Cost Per Day	$114.31	$73.94	$119.20	$82.10	$129.74	$80.34	$144.63	$84.43

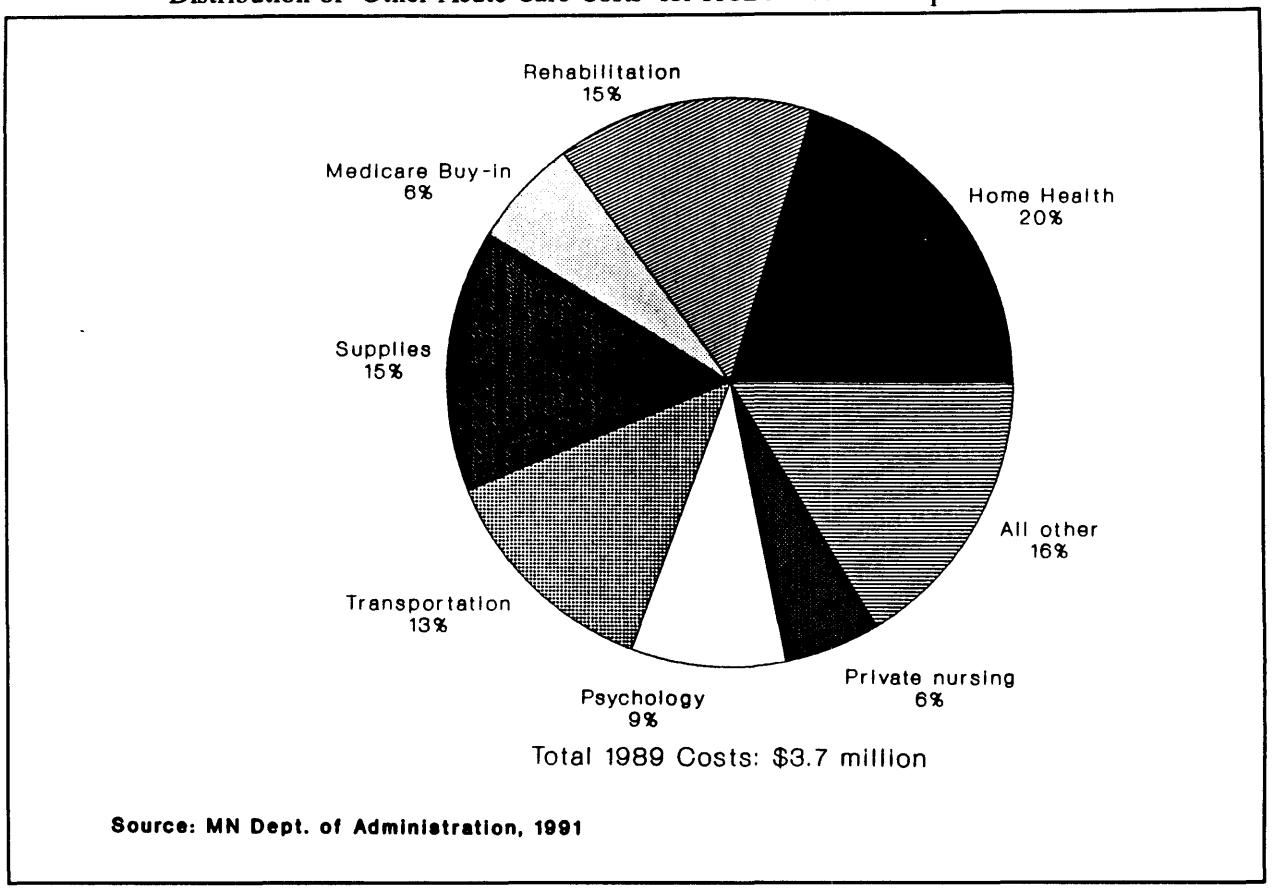
Source: Minnesota Department of Human Services, HCFA 372 Annual Reports

Acute care costs for HCBS and ICF-MR recipients. Acute care costs for HCBS recipients have consistently exceeded acute care costs for ICF-MR recipients over the last four years, as shown in Table 21. In 1988, the average daily cost of acute care services for HCBS recipients was $10.18, more than twice that for ICF-MR recipients. By 1991, however, acute care costs were only about 50 percent higher for HCBS recipients.

The difference in acute care costs was attributable primarily to higher hospital costs for HCBS recipients, as well as higher costs for "all other acute care services." However, inpatient hospital costs for HCBS recipients actually declined over the four-year period, from $2.47 per day of coverage in 1988, to $1.81 per day of coverage in 1991. Although HCFA reporting data do not include detailed information on "other acute care costs" some information is available from a study conducted by the Minnesota Department of Administration (Minnesota Department of Administration, 1991). The distribution of these "other acute care costs," as reported by the Department of Administration in 1989, is presented in Figure 4. Home care, rehabilitation, supplies, medical transportation, psychological services, private nursing, and Medicare buy-in costs comprised the major service categories for these other services, which totalled $3.7 million in 1989. It might be expected that HCBS acute care costs would average somewhat more than those of ICF-MR residents

since ICF-MR residents cannot access home care services. Nursing services are a required ICF-MR service, and many ICFs-MR also provide psychological and other therapies within the facility per diem rate rather than through separate billings as State Plan medical assistance services.

Figure 4
Distribution of "Other Acute Care Costs" for HCBS Waiver Recipients in 1989



Ratio of HCBS costs to ICF-MR costs. Table 22 shows the ratio of total Medicaid costs per recipient (per day of coverage) for HCBS recipients and for ICF-MR for the first four years of the waiver renewal. In 1988, average Medicaid costs for HCBS recipients were about two-thirds the average ICF-MR cost per recipient. The ratio increased slightly in 1989 for the reasons previously described, but then declined again in 1990 and 1991. By 1991, average waiver costs per recipient were only 58 percent of the average cost of serving those persons remaining in ICFs-MR. Under current policy it would be reasonable to expect that this ratio would continue to decline as the average cost of serving those persons remaining in ICFs-MR (particularly the RTC/ICFs) continues to escalate as the ICF-MR population dwindles.

Table 22: Ratio of Average Total Medicaid Cost Per Day of HCBS Recipients to ICF-MR Recipients

Fiscal Year	Ratio of Costs
1988	.65
1989	.69
1990	.62
1991	.58

Source: Minnesota Department of Human Services, HCFA 372 Annual Reports

Cost variations between conversion and diversion recipients. In 1991, there 1,440 conversion clients and 1,204 diversion clients receiving Home and Community-Based Services. As shown in Table 23 these two groups utilized waiver services in very different ways. Virtually 100% of conversion clients received residential care (either Adult-SLS or Child-SLS) as their core waiver service. Almost two-thirds also received day habilitation services as a HCBS. Only a small percentage received either homemaker, respite, in-home family support, or adaptive aids.

Table 23: HCBS Costs for Conversions and Diversions: 1991

Service	Conversions (n=1,440)			Diversions (n=1,204)		
	Percent Using Service	Annual Cost Per User of Service	Average Cost Per Day of Waiver Coverage (Users)	Percent Using Service	Annual Cost Per User of Service	Average Cost Per Day of Waiver Coverage (Users)
Case Management	96%	$1,240	$3.66	96%	$1,604	$4.87
Homemaker	0% [1]	537	1.47	5%	1,481	4.54
Respite	6%	1,450	4.16	38%	1,626	4.82
Day Habilitation	64%	8,138	23.80	30%	7,820	22.87
Adult - SLS	96%	21,180	63.17	46%	18,688	55.49
Child - SLS	3%	22,070	62.72	13%	14,963	45.45
In-Home Family Support	4%	3,702	11.12	47%	7,511	23.07
Adaptive Physical Aids	3%	1,193	3.53	9%	1,538	4.47
All HCBS Services	100%	27,748	82.88	100%	18,800	57.79
Personal Care	1%	9,103	29.44	11%	5,309	17.51
All Other Medicaid Services	100%	3,578	10.68	96%	3,171	9.67
Total Medicaid	100%	$31,486	$94.04	100%	$22,963	$70.58

Source: Minnesota Department of Human Services, Division for Persons with Developmental Disabilities, Waiver Net Claims Files, FY 1991.

[1] Only six conversion clients (0.4%) received homemaker services.

The utilization patterns of diversion HCBS recipients were more diverse. Only about 60 percent received out-of-home residential services, while 47 percent received in-home family support.[9] Less than a third of diversion recipients received day habilitation services. However, in comparison to conversion recipients, much higher percentages of diversion recipients received respite services, homemaker, and adaptive physical aids.

Diversion HCBS recipients were also much more likely to receive personal care services as a regular Medicaid service outside the HCBS program. Average costs for other services covered under the Medical Assistance Program (including hospital and physician services) were only marginally higher for conversion recipients than for diversion recipients. Overall, the total Medicaid cost for conversion HCBS recipients in 1991 was $31,486 per recipient, about 40 percent higher than the average cost per diversion recipient, which was $22,963.

Cost variations between children and adults. Since most children receiving HCBS services are diversion recipients, and most adults are conversion recipients, a similar pattern emerges when examining HCBS costs by age group, as shown in Table 24. Almost all adults receive SLS services, compared to only about one third of all children participating in the HCBS program. Most adults receive day habilitation services, and only a small percentage receive any of the other HCBS services, including in-home family support, homemaker,

[9]Some clients received **both** SLA services and in-home family support in 1991, either because they transitioned from one service setting to another, or because people were served in "shared caregiver" arrangements where an individual lives part-time in the natural families and part-time in a foster care setting.

respite or adaptive physical aids. On the other hand, 72% of children receive in-home family supports, 59% receive respite services, 16% receive adaptive physical aids, and 9% receive homemaker services.

Overall, the average daily cost of providing HCBS services to children under the waiver program was $46.24 in 1991, only about 60% of the average daily cost of providing HCBS services to adults, which was $78.11. On the other hand, it is interesting to note that children used more services under the regular State Medicaid plan, including personal care services, than did adults. Average daily costs for other Medicaid services in 1991 equalled $13.19 for children, and $10.69 for adults. When total Medicaid costs are compared, therefore, the average daily cost for children ($61.71) was 69% of the average daily cost for adults ($89.09). The primary area of difference in children's costs and adults' costs is "day training and habilitation," because children's educational programs are paid for by educational agencies. In fact, the difference between the average daily costs of HCBS for children and adults ($27.38) was quite similar to the adults' average annualized daily cost of day training and habilitation ($23.61).

Table 24: HCBS Costs for Children and Adults: 1991

Service	Children ≤ 17 (n=551)			Adults ≥ 18 (n=2,093)		
	Percent Using Service	Annual Cost Per User of Service	Average Cost Per Day of Waiver Coverage (Users)	Percent Using Service	Annual Cost Per User of Service	Average Cost Per Day of Waiver Coverage (Users)
Case Management	97%	$ 1,577	$ 4.85	96%	$ 1,361	$ 4.04
Homemaker	9%	1,015	3.05	1%	2,739	8.66
Respite	59%	1,682	5.03	10%	1,477	4.26
Day Training and Habilitation	1%	2,287	6.27	61%	8,072	23.61
Supervised Living Services	36%	17,302	52.16	93%	20,371	60.64
In-Home Family Support	72%	8,119	24.87	11%	5,464	16.77
Adaptive Aids	16%	1,623	4.68	3%	1,205	3.58
All HCBS Services	100%	14,904	46.24	100%	25,982	78.11
Personal Care	17%	5,688	18.80	2%	5,672	18.52
All Other Medicaid Services	93%	4,295	13.19	99%	3,564	10.69
Total Medicaid	100%	$ 19,891	$ 61.71	100%	$ 29,635	$ 89.09

Source: Minnesota Department of Human Services, Division for Persons with Developmental Disabilities, Waiver Net Claims Files, FY 1991

Distribution of HCBS recipients by their individual HCBS costs. A fundamental principle of community-based financing programs for persons with disabilities is the goal of designing *individualized* service plans according to each person's unique talents and limitations. Thus, if this principle is truly adhered to in HCBS waiver programs, one would expect to see greater variation in costs from person to person. Little or no variation in costs across HCBS recipients would reflect a "cookie cutter" approach to service plan development rather than an approach which tailored services to individual needs and circumstances.

Table 25 shows that there is indeed significant variation in average annual costs across the HCBS population. There are both a significant number of HCBS recipients whose average costs are less than $15,000 per year, as well as recipients whose average costs exceed $40,000 annually. In fact, persons whose average

annual costs were less than $15,000 accounted for over 30% of the total HCBS population in 1991, which accounted for only about 10% of total HCBS costs. At the other extreme, individuals whose average costs exceeded $30,000 per year accounted for 29% of recipients, but over 51% of total HCBS expenditures.

Table 25: Distribution of HCBS Recipients by Total HCBS Costs: 1991

Total Waiver Costs	Number of Recipients	Percent of Recipients	Percent of Total Expenditures
< $5,000	237	9.0%	0.9%
$5,000 - $14,999	577	21.8%	9.4%
$15,000 - $19,999	320	12.1%	8.9%
$20,000 - $24,999	388	14.7%	14.0%
$25,000 - $29,999	361	13.7%	15.7%
$30,000 - $39,999	398	15.1%	21.9%
$40,000 - $59,999	319	21.1%	24.2%
> $60,000	44	1.7%	5.0%
Total	2,644	100.0%	100.0%

Source: Minnesota Department of Human Services, Division for Persons with Developmental Disabilities, Waiver Net Claims Files, FY 1991.

As shown in Table 26, conversion allocation recipients were much more likely to fall into the high cost groups, while diversion recipients were more likely to fall into lower cost categories. This occurs because of the much larger proportion of diversion recipients who are children (with the education paid) and who live at home (with the basic cost of living paid). About 46% of diversion recipients had costs of under $15,000 in 1991, while only 18% had costs over $30,000. In contrast, only about 18% of conversion recipients had costs of less than $15,000, while 38% had costs in excess of $30,000.

Table 26: Distribution of Conversion and Diversion HCBS Recipients by Total HCBS Costs: 1991

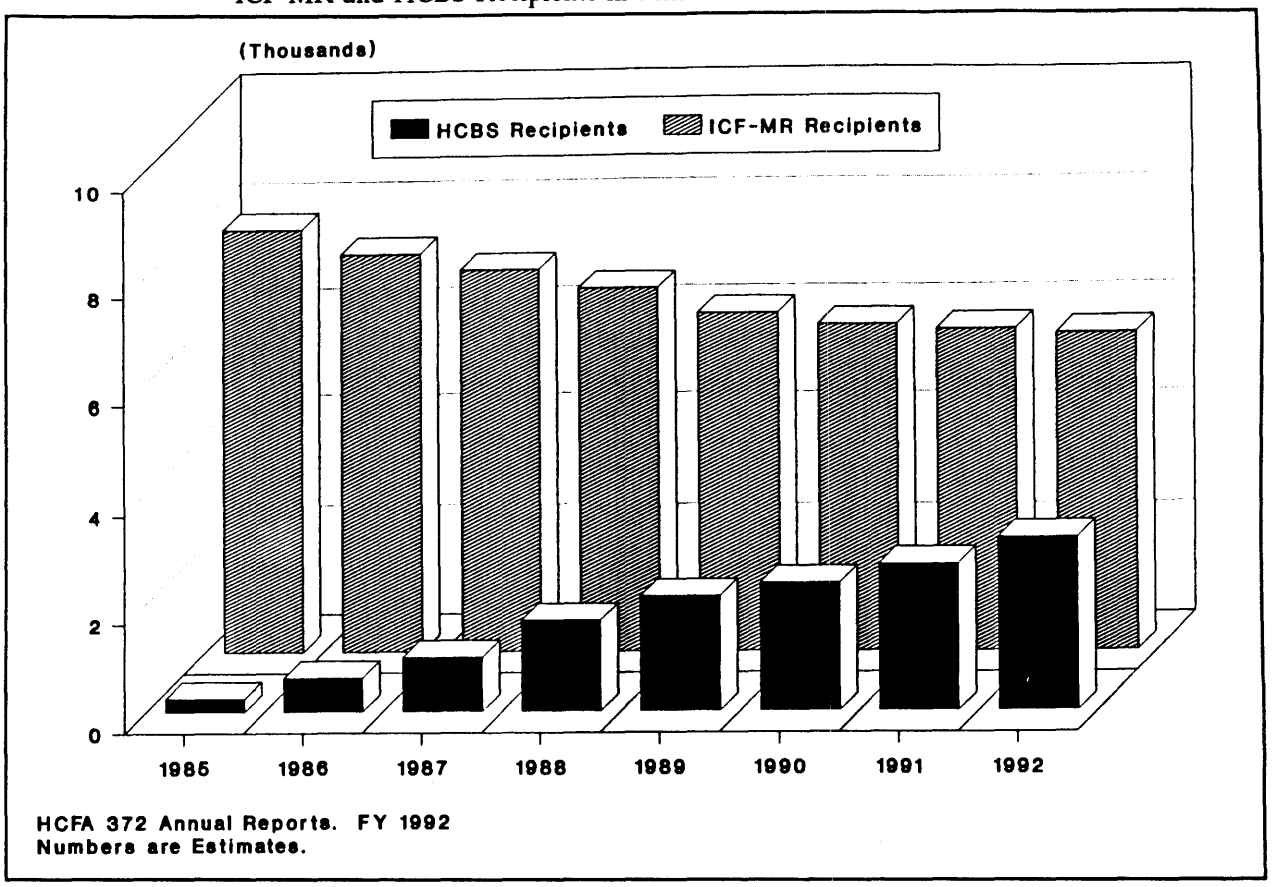
Total Waiver Costs	Conversion Recipients	Percent Distribution	Diversion Recipients	Percent Distribution
< $5,000	72	5.0%	165	13.7%
$5,000 - $14,999	188	13.1%	389	32.3%
$15,000 - $19,999	171	11.9%	149	12.4%
$20,000 - 24,999	217	15.1%	171	14.2%
$25,999 - $29,999	251	17.4%	110	9.1%
$30,000 - $39,999	271	18.8%	127	10.5%
$40,000 - $59,999	236	16.4%	83	6.9%
> $60,000	34	2.4%	10	0.08%
Total	1,440	100.0%	1,204	100.0%

Source: Minnesota Department of Human Services, Division for Persons with Developmental Disabilities, Waiver Net Claims Files, FY 1991.

What has been the full impact of HCBS on overall utilization of and expenditures for Medicaid long-term care services in Minnesota?

Changes in ICF-MR and HCBS in Minnesota. There can be little doubt that the HCBS program for persons with mental retardation and related conditions has had a major impact on reducing the size and cost of Minnesota's ICF-MR program. Figure 5 shows both the growth in the HCBS program and the decline in the number of persons served in ICFs-MR in Minnesota since the HCBS program began in 1985. The ICF-MR population has been in a state of steady decline since 1985, although the rate of decline appears to have slowed somewhat in more recent years. By 1992, over one out of three persons eligible for ICF-MR services will be provided alternative services under the HCBS waiver.

Figure 5
ICF-MR and HCBS Recipients in Minnesota: FY 1985 to FY 1992



Changes in Minnesota compared with U.S. It is particularly interesting to compare the interrelated patterns of HCBS and ICF-MR utilization in Minnesota with comparable national trends. Table 27 presents the data on Minnesota's ICF-MR utilization and costs in 1990 in comparison to other states.[10] These are the same data as were presented for 1987 in Table A-7 and discussed earlier on page 60. In 1990, in contrast to 1987, Minnesota no longer ranked first among all States in ICF-MR utilization rates, and its utilization rate was considerably closer to the national average in 1990 than three years previously. Similarly, although Minnesota still ranked third among all States in ICF-MR spending per capita in 1990, its spending rate was moving steadily in the direction of the national average and to the per capita spending rates of many other States between 1987 and 1990 ($57.70 per Minnesota resident in 1990 as compared with $29.92 per U.S. citizens nationally; $53.12 per Minnesota resident in 1987 as compared with $23.04 per U.S. citizen nationally).

[10]1990 data are presented since 1991 data on ICF-MR use and expenditures are not yet available from HCFA for other States.

Table 27: ICF-MR Residents and ICF-MR Expenditures by State Population: FY 1990

State	ICF-MR Residents 1990	ICF-MR Residents per 100,000 Population	Rank	State	ICF-MR Expenditures per State Resident	Rank
Louisiana	5,841	133.7	1	New York	$84.85	1
Minnesota	5,635	128.7	2	Rhode Island	78.43	2
North Dakota	671	102.0	3	Minnesota	57.70	3
D.C.	612	101.5	4	Massachusetts	56.69	4
Wisconsin	4,739	96.9	5	North Dakota	54.32	5
New York	16,961	94.9	6	Connecticut	49.26	6
Illinois	10,864	93.0	7	Louisiana	46.60	7
Oklahoma	2,894	90.7	8	D.C.	45.45	8
South Carolina	3,229	90.7	9	Iowa	42.96	9
Iowa	2,512	89.3	10	South Carolina	36.10	10
Indiana	4,930	87.8	11	Pennsylvania	35.65	11
Rhode Island	809	81.1	12	Kansas	34.67	12
South Dakota	568	79.3	13	Ohio	34.62	13
Kansas	1,979	78.5	14	South Dakota	34.39	14
Ohio	7,991	73.3	15	Maine	34.33	15
Texas	11,262	66.0	16	Oregon	34.13	16
Mississippi	1,716	64.8	17	New Jersey	33.81	17
Delaware	434	63.6	18	Vermont	32.81	18
Pennsylvania	7,116	59.1	19	Oklahoma	32.51	19
Utah	989	57.2	20	North Carolina	31.08	20
North Carolina	3,799	56.8	21	Illinois	30.38	21
Massachusetts	3,360	56.7	22	Arkansas	30.22	22
Arkansas	1,340	55.3	23	Washington	29.62	23
Maine	654	52.9	24	Idaho	29.48	24
New Jersey	3,822	48.9	25	Indiana	28.59	25
New Mexico	751	48.8	26	Delaware	28.19	26
Washington	2,219	46.3	27	Texas	26.03	27
Idaho	468	46.2	28	Wisconsin	25.07	28
Nebraska	731	45.6	29	Michigan	22.98	29
Virginia	2,830	45.4	30	Virginia	20.31	30
Tennessee	2,256	45.0	31	Alaska	19.67	31
Connecticut	1,443	44.2	32	Utah	18.13	32
Vermont	231	40.5	33	New Mexico	18.12	33
Missouri	2,034	39.1	34	Missouri	17.52	34

State	ICF-MR Residents 1990	ICF-MR Residents per 100,000 Population	Rank	State	ICF-MR Expenditures per State Resident	Rank
California	10,890	37.2	35	Nebraska	17.32	35
Oregon	966	34.2	36	Mississippi	17.19	36
Michigan	3,073	33.1	37	Tennessee	16.72	37
West Virginia	596	32.4	38	Georgia	16.06	38
Alabama	1,329	31.9	39	Alabama	15.41	39
Kentucky	1,191	31.8	40	Maryland	14.47	40
Montana	245	30.7	41	Colorado	14.31	41
Georgia	1,932	29.3	42	Kentucky	14.02	42
Colorado	974	29.2	43	California	13.87	43
Maryland	1,258	26.4	44	West Virginia	13.24	44
Florida	3,179	24.6	45	Montana	13.21	45
Hawaii	220	19.4	46	Nevada	12.20	46
Alaska	98	18.7	47	Florida	11.98	47
Nevada	192	17.0	48	Hawaii	5.74	48
Wyoming	67	14.3	49	New Hampshire	4.71	49
New Hampshire	128	11.2	50	Arizona	0.00	50
Arizona	0	0.0	51	Wyoming	0.00	51
U.S. Total	144,028	57.7			$29.92	

Sources: Lakin et al. (1989) and HCFA 2082 data.

Table 28 presents more detailed information on ICF-MR and total Medicaid spending trends in Minnesota and in the United States between 1987 and 1990. In the nation as a whole, the number of residents in ICFs-MR declined only very slightly, by 0.2%. In Minnesota, the ICF-MR population declined by 14%. Adjusted for changes in population growth, the number of ICF-MR recipients per 100,000 population declined 2.7% in the nation as a whole, but by 16.6% in Minnesota. While ICF-MR expenditures per capita increased almost 30% in the United States over this three-year period, expenditures in Minnesota increased by only 8.6%.

Since reductions in ICF-MR use and costs are offset by increases in HCBS utilization and expenditures, Table 28 also presents utilization and cost trends for the ICF-MR and HCBS programs *combined* over the three-year period. In the United States overall, the number of ICF-MR *plus* HCBS recipients increased by 13.2% over this period, but only 5.9% in Minnesota. Adjusted for population growth, the number of ICF-MR plus HCBS recipients per 100,000 population increased 10.3% nationally, but only by 2.6% in Minnesota. Total spending per capita for ICF-MR care and HCBS combined increased 38.2% in the nation as a whole, but only 24.9% in Minnesota. Thus, it is clear that the use of Medicaid-financed services for persons with mental retardation and related conditions and Medicaid spending for those services rose at a much more moderate pace in Minnesota than in the country as a whole between 1987 and 1990. This trend should continue into the future given Minnesota's cost control mechanisms and its ongoing ability to monitor the effectiveness of those mechanisms.

Table 28: Percent Change in ICF-MR and Total Medicaid Utilization and Spending United States and Minnesota, FY 1987-1990

	United States	Minnesota
Percent Change in ICF - MR Residents	-0.2%	-14.0%
Percent Change in ICF-MR Residents per 100,000 Population	-2.7%	-16.6%
Percent Change in Total ICF-MR *Plus* HCBS Recipients	+13.2%	+5.9%
Percent Change in ICF-MR *Plus* HCBS Recipients per 100,00 Population	+10.3%	+2.6%
Percent Change in Total Medical Spending for ICF-MR & HCBS Services Per Capita	+38.2%	+24.9%

Sources: HCFA 2082 data, HCFA 372 Annual Reports, Lakin et al (1991) and G. Smith (unpublished data).

Cautions about conclusions on "cost effectiveness." In looking at average Medicaid costs per recipient for persons in the HCBS program and for persons residing in ICFs-MR, it is clear that *on average* persons receiving HCBS services have significantly lower Medicaid costs than persons in ICFs-MR. In 1991, the average total cost to Medicaid (including acute care costs) was $84.63 per day of coverage for waiver recipients, and $144.63 per day for ICF-MR recipients, over a 40% difference. Even when other non-Medicaid costs, including Federal SSI payments and State MSA payments are included in cost calculations, costs for waiver recipients are still substantially below those for persons in ICF-MR care. Specifically data from the state's Waiver Eligibility File show that the average SSI and MSA payments for HCBS recipients in 1991 were $19.59 per day for conversion recipients, and $12.43 per day for diversion recipients. The difference would be even greater if case management costs, averaging $4.11 per day for HCBS recipients in 1991, were included in the ICF-MR cost computations.

Two caveats need to be applied to these data on cost differences. First, although *average* costs for HCBS recipients were substantially below *average* costs for ICF-MR recipients, this was not true for all individuals. Sometimes, but obviously well less than half the time, it cost more to provide an appropriate program with HCBS than to secure an ICF-MR placement. Indeed during field interviews, several providers indicated that they appreciated that the HCBS option sometimes, when necessary, provided more financial resources (Medicaid *and* non-Medicaid) for certain individuals than would have been available through an opening in an existing ICF-MR with an already established rate. Of course, it must be recognized that although an ICF-MR operates with an established rate per person some residents within the facility use considerably more of the facility's resources than others, that is, they, too, cost more than the average per diem rate. The essence of this caveat is then simply that while the HCBS program is on average a less expensive approach to financing community-based services in Minnesota, it is not inherently less expensive and that costs must be monitored to be contained. It is clear that when costs were not aggressively monitored, as occurred in 1988 and 1989, spending can get out of control and/or arrangements can be made with certain providers that do not reflect the economic best-interest of the state or use well the funds available to provide HCBS to people with MR/RC. This said, the State is currently clearly committed to such cost monitoring and containment and has created excellent internal monitoring mechanisms to carry out both functions.

The second caveat that must be applied to cost comparisons is that the average ICF-MR costs may not be an ideal standard for establishing the "cost-effectiveness" of HCBS. Total ICF-MR costs in Minnesota continue to increase even as fewer persons are being served in ICF-MR settings. The driving force in this trend is obviously the Regional Treatment Centers, which during the period of this study cost $270 per day per resident or roughly $100,000 per year. As the population of the RTCs continues to dwindle, the average costs of caring for those who remain will continue to spiral upward, due to the amount of fixed costs that

come with the operation of a large institution. Thus, even if average HCBS costs were to increase at a rapid rate, these costs may still remain substantially below the average cost of ICF-MR care, which may continue escalate at an even more dramatic rate. As such, the fact that HCBS cost less than ICF-MR may appeal to one definition of cost-effectiveness (i.e., HCFA's), but being more cost-effective than what appears to be a remarkably expensive and inefficient system may not appeal to more exacting standards of "cost-effectiveness."

Overall impact on Medicaid long-term care expenditures. In examining the cost-effectiveness of the Minnesota HCBS program, it is also important to look at the program's impact on Minnesota MR/DD system as a whole. "Bottom line" estimates of HCBS program impacts at the aggregate level are always highly dependent upon assumptions about what would have happened in Minnesota in the absence of the HCBS option. However, using relatively conservative assumptions, Table 28 presents estimates of total system impacts. The key to these estimates are assumptions about the level of growth in ICF-MR utilization and expenditures in the absence of the HCBS program. The assumptions used were considerably more conservative than those used in Minnesota's HCBS formula projections[11], and were as follows:

1) It was assumed that the HCBS program had *no impact* on ICF-MR utilization and expenditures in the first two years of its implementation (FY 1985 and 1986).

2) It was assumed that ICF-MR utilization rates would have remained *constant* at the level they were at in FY 1986. In brief, we assumed no additional development of ICF-MR beds beyond increases for population growth over the 1986-1991 period.[12]

3) It was assumed that the average annual cost of ICF-MR care would increase at the same average rate, relative to the Consumer Price Index (CPI), that it increased over the prior five-year period, from 1981 to 1986. Over the 1981-1986 period, the cost of ICF-MR care increased at an average rate of 3.6 percent over the CPI. Thus, for the years 1986 through 1991, we assumed that the price of ICF-MR care would increase by 3.6 percent per year over the CPI for the relevant year. This assumption yielded smaller annual increases in the annual cost of ICF-MR than actually occurred under the waiver program.[13]

Given these assumptions, Table 29 presents estimates of the level of growth in ICF-MR expenditures that would have occurred in the absence of Minnesota's HCBS participation, the amount of savings in ICF-MR expenditures that occurred with the implementation of the HCBS program, and the net total Federal/State savings to the Medicaid program produced by the HCBS waiver program from 1987 to 1991. Except for 1988, the estimates showed that the HCBS program yielded Medicaid savings for every single year. Total estimated annual savings by 1991 exceeded $15 million. Total savings over the entire five-year period were just under $30 million. Thus, given what we believe to be conservative estimates about ICF-MR program growth in the

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[11]The assumptions used are considerably more conservative than what would be allowable under state law and rule related to reimbursement and RTC/ICF population reduction; nor did these assumptions consider the fiscal impact of the *Welsch Decree* which required more aggressive depopulation of state RTC/ICFs than the estimates used here.

[12]Thus, whereas the waiver formula assumed that the ICF-MR population would have increased to 8,760 recipients by 1991 in the absence of HCBS, this assumption led to an estimated ICF-MR population of 7,668 recipients in the absence of HCBS by 1991.

[13]As previously discussed, it was assumed that the average annual cost of ICF-MR care per recipient would not have increased at the same rate in the absence of HCBS because a larger ICF-MR population (particularly in RTCs) would have spread fixed costs over a larger number of recipients.

absence of HCBS, there is strong evidence that the HCBS program has indeed been a cost-effective financing mechanism for providing a broader range of service alternatives to persons with mental retardation and related conditions.

Table 29: Total Net Medicaid Savings/(Costs) of Minnesota HCBS Waiver

State Fiscal Year	Estimated ICF-MR Expenditures Without Waiver	Actual ICF-MR Expenditures	Estimated ICF-MR Savings	HCBS Waiver Expenditures	Total Net Medicaid Savings (Costs)
1986	---	$221,954,917	---	---	---
1987	$239,790,121	$224,688,923	$15,101,198	$13,169,399	$1,931,799
1988	$262,185,887	$239,477,892	$22,707,995	$29,532,565	$(6,824,570)
1989	$286,627,281	$232,116,027	$54,511,254	$47,556,174	$6,955,080
1990	$314,881,636	$245,568,862	$69,312,774	$55,185,013	$14,127,761
1991	$341,872,476	$263,085,705	$78,786,771	$63,758,621	$15,028,150
Total Net Savings (Costs)					$29,286,421

Sources: HCFA 372 Annual Reports, and Bureau of the Census, *Statistical Abstract of the United States, 1990.*

Quality of Services

Primary Research Questions

- How well are the basic health, monitoring and service needs of HCBS recipients protected?
- Do HCBS recipients have adequate opportunities and quality of life, including: a) chances for growth and development, b) social and familial relationships, c) community participation, and d) personal autonomy and self-determination?
- Are HCBS recipients satisfied with their lives?
- How does the HCBS program compare with alternatives? How can it improve?

How well are the basic health, monitoring and service needs of HCBS recipients protected?

Regulations and Monitoring

Minnesota's Medicaid HCBS program for persons with MR/RC is authorized by Minnesota Statutes 256B.092 and governed by rules of the Department of Human Services. Such rules, once promulgated, have

the force of law. Some of these rules apply broadly to a variety of individuals and groups which may include HCBS recipients, while others are specifically limited to HCBS (MR/RC).

Broadly applicable rules. In Minnesota HCBS for persons with MR/RC are governed, as are all county administered social services, by Minnesota Rules 9550.0010 to 9550.0092. All persons with MR/RC receiving social services in Minnesota, including HCBS, must receive case management services (MN Rules 9525.0015 to 9525.0165), including HCBS recipients who live in their own or family homes. In addition, HCBS recipients may live in a variety of licensed residences, including child foster care (MN Rules 9545.0010 to 9545.0240) and adult foster care (MN Rules 9555.5105 to 9545.6265). Adult HCBS recipients may receive day training and habilitation (MN Rules 9525.1500 to 9525.1690). Homemaker services (MN Rules 9555.3100 to 9555.3300) may be provided HCBS (MR/RC) recipients. Issues such as public guardianship (MN Rules 9525.3010 to 9525.4035), child protection (MN Rules 9560.0210 to 9560.0234), protection of vulnerable adults (MN Rules 9555.8500), use of aversive and deprivation procedures (MN Rules 9525.2700 to 9525.2810), and definition of "related conditions" (MN Rules 9525.0180 to 9525.0190) are relevant to HCBS recipients as well.

Rules specific to HCBS (MR/RC). There are only two rules that are specifically directed to HCBS for persons with MR/RC in Minnesota. These govern the administration and funding of HCBS (MN rules 9525.1800 to 9525.1920) and the licensing of providers of HCBS residential habilitation services (MN Rules 9525.2000 to 9525.2140).

Comprehensiveness of existing rules. All services provided as Medicaid HCBS are governed by rules of the Minnesota Department of Human Services. Least specifically regulated is respite care provided in the family home and certain very limited amounts of out-of-home respite care not provided in licensed child foster care or other licensed facilities. Generally these rules and their associated annual monitoring contain adequate authority and substantial specificity to assure that basic provider competence and rule compliance meet acceptable standards of service performance and quality.

Implementation and effectiveness. The nature and implementation of applicable rules to establish, maintain and enhance the basic safety and well-being for HCBS recipients is a topic of much concern and debate in Minnesota. There is little, if any, opinion that Minnesota lacks an adequate quantity of standards for HCBS providers with respect to protecting the safety and physical well-being of HCBS recipients. The main debate focuses on whether the multitude of standards and the demands they place on providers, case managers and state employees ultimately, in an effort to protect HCBS recipients' safety and well-being, absorb resources and create rigidity that detracts from other arguably more effective methods of enhancing the quality of those services and the quality of life of their recipients. Persons working at the county level appear nearly universally convinced that the regulatory requirements on them and their providers are "overly burdensome," "expensive" with "relatively low pay off," and focus largely on "paper compliance."

Review of selected reports of violations and corrections suggests a mixed benefits of the current regulatory approach. It was possible to identify some required corrections of clear importance to providing basic protections (e.g., the need to have on file a release for medical interventions), but most violations appeared to be of requirements of relatively little, if any, consequence to the HCBS recipients' lives. In fact some may have detracted from some of the espoused non-institutional goals for the HCBS program (e.g., "The program did not post a copy of the PAPP [Program Abuse Protection Program] in a prominent place in the facility"). It was noted, too, that different licensing reports from the same licensor were sometimes remarkably similar for different HCBS providers, reflecting a boiler plate approach to licensing which probably contributes relatively little to program improvement.

In summary, while considerable effort is given to establishing and monitoring compliance with basic "protective" standards for HCBS recipients, relatively little attention is given in the licensing and monitoring process to activities and involvements that affect the quality of HCBS recipients' lives and the services they

receive. Given the very limited amount of information about the lives of HCBS recipients that can be gained by the existing licensing and violation/correction records, these topics were the primary focus of sample-based data collection on the nature and quality of services and daily activities of HCBS recipients.

Medical Services

Frequency and quality of basic medical/dental services. The primary mechanism to assuring good health is regular medical and dental care. Table 30 shows the number of primary care physician and dentist visits of HCBS recipients in the previous 6 months. (Table A-8 shows the frequency of physician visits by medical subspecialty). In all, 93% of HCBS sample members had seen a "primary care" physician (defined as practicing in general/family practice, internal medicine, pediatrics, orthopedics, neurology, obstetrics/gynecology, cardiology, otolaryngology or urology) at least once in the previous 6 months. About 43% of the children living in their own homes saw a physician at least 2 to 5 times in the previous six months, which was the primary contributing factor to the statistically significant differences among type of residence groups in the frequency of physician visits. These results reflect the substantial health needs of children receiving HCBS which were noted earlier in this report in Minnesota. There was no significant difference between frequency of physician visits and county type. As would be expected residents living primarily in adult settings (family and corporate foster homes and those living in their own homes) were most likely to see physicians specializing in family practice, children were most likely to see pediatricians. Specialists in dermatology, allergies, surgery, podiatry, psychiatry or physical or rehabilitation medicine were rarely seen during the previous six months (see Table A-8).

Dentists were seen by about 75% of the sample members in the previous 6 months. About 80% of the people living in family and corporate foster homes, and 77% adults living in their own homes had been to the dentist, as compared with only 60% of the children living with their own families. Approximately 27% of the sample members saw an optometrist during the previous 6 months.

Place of services. The vast majority of recipients received out-patient medical care within a typical community clinical practice (approximately 87% to 98%, depending on place of residence). Recipients were rarely served within a specialized clinical practice for people with mental retardation and developmental disabilities, with the most in any group being 2 of the 30 children living with their families in the sample. Most people also received dental care within a typical community dental practice, 23% of the children living at home and 18% of the adults living at home, received dental services within a specialized clinical practice, as did 4% of persons in family foster homes and 6% of persons living in corporate foster homes.

Adequacy of medical/dental services. The 82 parents and guardians of HCBS recipients who participated in this assessment were asked if they felt that their family members with MR/RC received adequate medical care for their health care needs. These respondents overwhelmingly considered medical care to be adequate (95%), with no significant differences by type of residence and county types. Only three people indicated specific problems, including physicians not accepting medical assistance patients, physicians needing additional knowledge about people with Down's syndrome, and one recipient's needing but not receiving, extensive dental care.

Hospitalizations and emergency room visits. During the previous 6 months, sample members were hospitalized 32 separate times, with the average number of overnight stays in the hospital per sample member varying from none for adults sample members living in their own homes to .4 for children at home, to .5 for family foster residents to .7 for corporate foster residents. The average number of times during the previous 6 months that people were taken to the emergency room for out-patient care ranged from 1 (family foster homes, corporate foster homes, and adults who live in their own homes) to 1.9 (children who live with their families).

Table 30: Frequency of Total Physician, Family Practice, Pediatrician, and Dentist Visits in Previous Six Months by Residence and County Types (percentage)

Type of Service (Frequency)	Type of Residence				Type of County			Total (n=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Urban Outstate (n=37)	Rural Outstate (n=42)	
Total Physician Visits								
0	15.4	2.0	9.1	6.7[1]	8.0	5.4	7.1	7.0
1	38.5	33.3	45.5	20.0	32.0	40.5	28.6	33.3
2	15.4	23.5	18.2	10.0	16.0	13.5	23.8	17.8
3-4	23.1	19.6	18.2	13.3	16.0	16.2	23.8	18.6
5-7	7.7	11.8	9.1	20.0	14.0	13.5	9.5	12.4
8-13	0.0	3.9	0.0	30.0	14.0	10.8	7.1	10.9
Family Practice								
0	19.2	15.7	22.7	53.3[2]	26.0	37.8	16.7	26.4
1	50.0	33.3	59.1	13.3	36.0	35.1	38.1	36.4
2-5	30.8	49.0	13.6	16.7	26.0	21.6	35.7	27.9
6-10	0.0	92.0	4.6	16.7	12.0	2.7	9.5	9.3
Pediatrician								
0	96.2	100.0	90.9	56.7[3]	86.0	81.1	95.2	87.6
1	3.8	0.0	4.5	13.3	6.0	2.7	4.8	4.7
2-5	0.0	0.0	4.6	20.0	6.0	10.8	0.0	5.4
6-8	0.0	0.0	0.0	10.0	2.0	5.4	0.0	2.3
Total Dentist Visits								
0	19.2	19.6	22.7	40.0	18.0	29.7	28.6	24.8
1	61.5	68.6	72.7	56.7	70.0	56.8	66.7	65.1
2-4	19.3	11.8	4.6	3.3	12.0	13.5	4.7	10.1

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (15, N = 129) = 27.67, p <.05; [2] X^2 (9, N - 129) = 30.45, p < .01; [3] X^2 (9, N = 129) = 37.54, p < .01

Sick days. There were substantial differences in the average number of days missed from school, day programs, or work for medical reasons. Averages were 8.5, 31.6, 28.2 and 46.0 days for family foster homes, corporate foster homes, and adults and children living in their own homes, respectively. Days missed for mental, psychiatric or behavioral reasons ranged from none in family foster homes, adults living in their own homes, and children living with their parents, to 5.3 days for corporate foster home residents.

Medications. About 75% of the sample received medications in the past 30 days. As shown in Table 32, recipients most frequently received anticonvulsants (22%). Use of psychotropic medications, including major and minor tranquilizers, anti-depressants and sedatives was relatively rare (11%). This was less than half the rates of 25.3% to 26.0% identified in 3 large sample studies of medications used by persons

with MR/RC living in community settings (see Hill, et al., 1989; *Psychopharmacology Bulletin, 21*(2), 1985). Presumably Minnesota's demanding standards for obtaining permission to use psychotropic medications and to monitor their effects once prescribed has had an effect on this difference. Anticonvulsant use (21.8%) was remarkable close to the 20.5% to 25.3% found in the same 3 large sample studies of persons living in community settings. There were no significant differences between type of medication and residence and county types. HCBS recipients in corporate foster care homes and children in their own homes received more different medications (2.5 and 2.0, respectively) than did residents of family foster care (1.6) or adults living in their own homes. Of the 97 receiving medications, 57.7% had a medication change in the past six months. Medication changes were least common among adults living in their own homes (13.6%), while considerably more common in corporate foster homes (54.9%), family foster homes (38.5%) and children living with their parents (50.0%) (X^2 [3, N = 129] = 11.47, p < .01).

Table 31: Type of Medication Received in Past 30 Days by Residence and County Types (percentage)

Type of Medication	Type of Residence				Type of County			Total
	Family	Corporate	Own Home-Adults	Family Home-Children	Urban Metro	Urban Outstate	Rural Outstate	
Anti-diabetic agents	0.0	0.0	0.0	1.7	0.0	0.0	1.5	<.00
Antihistamines, allergy/cough medicine	2.0	10.0	4.5	13.3	8.4	10.4	7.7	8.8
Vitamins	26.5	9.2	4.5	3.3	6.7	7.8	7.7	7.3
Antibiotics or sulfa drugs	2.0	5.4	9.1	13.3	10.1	3.9	9.2	8.0
Anti-inflammatory agents	0.0	0.8	4.5	0.0	1.0	0.0	1.5	<.00
Diuretics	2.0	1.5	0.0	0.0	1.0	0.0	3.1	1.2
Dermatological conditions	4.1	8.5	0.0	3.3	5.9	3.9	7.7	5.7
Eye preparations	2.0	2.3	18.2	3.3	7.7	1.3	0.0	3.8
Hormone or thyroid preparations	0.0	9.2	4.5	1.7	5.1	3.9	9.2	5.7
Major tranquilizers	10.2	6.2	0.0	3.3	5.0	6.5	6.2	5.7
Minor tranquilizers	0.0	2.3	0.0	1.7	1.0	2.6	1.5	1.5
Anti-depressants	4.1	1.5	4.5	3.3	3.4	0.0	4.6	2.7
Sedatives	4.1	0.0	0.0	1.7	0.0	2.6	1.5	1.1
Anti-convulsants	12.2	16.2	36.4	36.7	16.0	32.5	20.0	21.8
Cardio-vascular preparations	2.0	4.6	0.0	0.0	4.2	1.3	1.5	2.7
Analgesics	6.1	6.2	4.5	1.7	5.9	5.2	3.1	5.0
Anti-Parkinson Agents	8.2	1.0	0.0	0.0	0.0	3.9	3.1	1.9
Stomach Ailments	14.3	15.4	9.1	10.0	15.1	14.3	10.8	13.4
Average Medications	1.6	2.5	1.0	2.0	2.4	2.1	1.6	2.0

Non-Medical Professional Services

Frequency and quality of services from non-medical specialists. Table 32 presents the number of sample members who had seen a number of non-medical specialists during the previous 6 months. The most

commonly used non-medical specialists for services to HCBS recipients were speech and language therapists (32%), physical therapists (23%), occupational therapists (21%), psychologists (21%) and audiologists (17%). Children living with their families were more likely to see physical therapists, speech/language therapists and occupational therapists than people in the three other residential settings, because they received these at school. People who lived in the urban-metropolitan counties were much more likely to see psychologists and audiologists than recipients who lived in the other geographic areas. Each of these services was reported to be adequate by three-quarters of the direct care providers surveyed.

Table 32: Type and Frequency of Non-Medical Services Received in Previous Six Months by Residence and County Types (percentage)

Type of Non-medical Services	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Urban Outstate (n=37)	Rural Outstate (n=42)	
Nutritionist	3.8	3.9	4.5	13.3	8.0	8.1	2.4	6.2
Physical Therapist	15.4	13.7	22.7	48.3[1]	14.0	27.8	31.8	23.4
Speech/Language Therapist	15.4	13.7	27.3	82.8[2]	22.0	33.3	42.9	32.0
Occupational Therapist	15.4	7.8	9.1	58.6[3]	18.0	22.2	23.8	21.1
Social Worker (non-county)	3.8	2.0	0.0	10.0	4.0	8.1	0.0	3.9
Recreation Therapist	3.8	3.9	4.5	10.3	6.1	5.4	4.8	5.5
Psychologist	7.7	33.3	18.2	13.3	36.0	13.5	9.5[4]	20.9
Behavior Analyst	0.0	2.0	0.0	10.0	6.0	0.0	2.4	3.1
Audiologist	19.2	21.6	9.1	13.3	34.0	5.4	7.1[5]	17.1

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (3, N = 128) = 13.6, $p < .01$; [2] X^2 (3, N = 128) = 45.7, $p < .01$; [3] X^2 (3, N = 128) = 32.3, $p < .01$;
[4] X^2 (2, N = 129) = 10.3, $p < .01$; [5] X^2 (2, N = 129) = 16.6, $p < .01$

Professional services needed. When care providers were asked what professional services were needed respondents indicated that 65.1% of the HCBS recipients needed no additional services. However, 45 HCBS recipients were indicated to need 70 individual services. Table 33 shows services indicated to be needed by at least 5 of the sample members. The most common of these was speech/communication training. Physical therapy and behavior analyst services were needed by 10% of the recipients. There were no significant differences between type of service needed and residence and county types.

Table 33: Professional Services Needed By Residence and County Types[1] (percentage)

Type of Professional Services Needed	Type of Residence				Type of County			Total (N=70)
	Family Foster (n=11)	Corporate Foster (n=21)	Own Home-Adult (n=15)	Family Home-Children (n=23)	Urban Metro (n=17)	Urban Outstate (n=31)	Rural (n=22)	
Physical therapy	0.0	9.5	13.3	13.0	11.8	12.9	4.5	10.0
Speech therapy/ communication	18.2	14.3	40.0	30.4	17.6	32.3	22.7	25.7
Recreation therapist	9.1	14.3	13.3	8.7	5.9	6.5	9.1	7.1
Psychological services	0.0	9.5	26.7	0.0	17.6	3.2	4.5	7.1
Behavior analyst services	18.2	4.8	6.7	17.4	11.8	9.7	9.1	10.0
Occupational therapy	9.1	0.0	0.0	4.3	5.9	9.7	9.1	8.6
Other services	27.3	28.6	0.0	8.7	11.8	9.7	27.3	15.7

[1]Duplicate count.

Case Management Services

Frequency of contact between case managers and HCBS recipients. Case management is the primary mechanism in Minnesota for monitoring the well-being of HCBS recipients. Everyone in the random sample received case management services. Respondents were given a list of 18 possible functions that may have been performed by the case managers. When care providers were asked how often the case manager met with the recipient in the past six months, all reported at least once. The average number of meetings with case managers and HCBS recipients reported for the previous 6 months was very similar for people in different residential circumstances, ranging from 2.8 (corporate foster homes) to 3.1 (family foster homes). Care providers were also asked how long a typical case manager's visit usually lasted. The majority of the people said that meetings lasted 30 minutes to an hour (47%). Another large portion of respondents indicated more than one hour (35%). The remaining people said visits lasted less than 30 minutes.

Services provided by case managers. As summarized in Table 34 the most frequent and nearly universal function reported for case managers by HCBS recipients' primary careproviders was checking to see how the individuals were doing or if they were having any problems (about 92%), including almost always making a point of talking directly with the individual when visiting the person (87%). Among other roles performed by case managers included determining eligibility for services, assessing the person's abilities and needs, represented or protected the rights of the person, and gave training and advice on how to more effectively meet the recipient's needs.

Table 34: Functions Performed by Case Managers in the Previous 6 Months as Reported by Respondents by Residence and County Type (percentage)

Functions Performed by Case Manager	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Metro Outstate (n=37)	Rural Outstate (n=42)	
Determined eligibility for services	61.5	68.6	68.6	63.3	64.0	67.6	66.7	65.9
Assessed the person's abilities and needs	57.7	66.7	77.3	80.0[1]	66.0	67.6	76.2	69.8
Developed the ISP	50.0	56.9	59.1	70.0	54.0	59.5	64.3	58.9
Assisted with crisis intervention	7.7	15.7	9.1	16.7	10.0	21.6	9.5	13.2
Made referrals for service	34.6	27.5	54.5	46.7	28.0	45.9	42.9	38.0
Accompanied person to agencies	3.8	15.7	18.2	3.3	12.0	13.5	7.1	10.9
Represented or protected the rights of the person	57.7	68.6	63.6	56.7	66.0	67.6	54.8	62.8
Assessed the person's progress	84.6	90.2	90.9	83.3	86.0	89.2	88.1	87.6
Asked how the person is doing when s/he visits	88.5	94.1	90.9	90.9	90.0	91.9	92.9	91.5
Asked whether the person is having any problems	88.5	96.1	86.4	93.3	92.0	89.2	95.2	92.2
Asked if there is any way that s/he can help solve problems	76.9	86.3	77.3	90.0	82.0	83.8	85.7	83.7
Reviews each aspect of the person's IPP	53.8	84.3	81.8	73.3	70.0	81.1	76.2	75.2
Talks directly with the person when s/he visits here	84.6	94.1	81.8	80.0	84.0	91.9	85.7	86.8
Goes out to the day or work program to check on how s/he is doing	46.2	45.1	40.9	33.3	38.0	45.9	42.9	41.9
Gives training and advice on effectively meeting his/her needs	50.0	70.6	81.0	50.0	58.0	61.1	71.4	63.3
Arranges for special support/training s/he needs	34.6	42.0	81.8	46.7[2]	42.9	48.6	54.8	48.4
Assists with applications and other paperwork	50.0	58.8	77.3	70.0[3]	58.0	67.6	64.3	62.8

*Includes 15 adults living with their natural or adoptive parents.

[1] X^2 (6, N = 129) = 20.2, $p < .05$; [2] X^2 (6, N = 129) = 42.7, $p < .01$; [3] X^2 (6, N = 129) = 20.9, $p < .05$;

There were some differences found in the function of case managers for people in different places of residence. A higher proportion of case managers of children living at home were reported to be involved in assessment of strengths and specific needs than were case managers of other HCBS recipients. Case managers more often assisted adults living in their own homes (77%) and families with children (70%) with application forms and other paperwork more than those in other settings (56%). When compared with the case managers of a national sample of 335 persons in small community settings on 8 specific activities, the case managers of Minnesota HCBS recipients were reported to be more frequently involved in 5 of the activities: 1) offers help in solving recipients' problems (84% vs. 73%), 2) review each aspect of the IPP (75% vs. 55%), 3) makes point of talking directly with the HCBS recipient (87% vs. 74%), 4) provides training/advice on meeting the services recipients needs (63% vs. 47%), and 5) arranges special training and support when needed (48% vs. 29%). Areas of no significant difference were 1) assist providers with applications and other paperwork (63% vs. 61%), 2) asks how the individual is doing (92% vs. 94%), and 3) asks with the service recipient is having any problems (92% vs. 91%).

Rated Quality of Home and Community-Based Services

Family members were asked to rate selected HCBS on a scale that ranged from excellent to poor (see Table 35). The number of people who rated these services varied by type of service as shown in Table 35.

Family ratings of case management services. Over 83% of the families rated case management as good to excellent. Over 75% of the families with children rated these services as good or better. A larger proportion of families who had family members living in corporate foster homes, family foster homes and in their own homes rated these services even higher, 88%, 92% and 83% respectively. Although there was no significant difference between family satisfaction and type of county, a larger number of families living in the urban metropolitan area rated case management higher (93%) than their counterparts who lived in the urban outstate (76%) and rural outstate areas (81%).

Family ratings of in-home family support services. Most families considered in-home family support services to be good to excellent (75%). About 8% of respondents rated in-home support services as poor. Although the differences did not reach statistical significance in-home supports for family foster care providers tended to be rated more highly than for adults and children living with their natural or adoptive families. It is notable that in-home family supports were considerably more likely to be rated as less than good than any of the other HCBS asked about (26%). This quite likely reflects the relatively intrusive nature of such services and the family's clear perception of what it wants from them.

Family ratings of supported living services. Those who had family members receiving supported living services overwhelmingly rated the services as good to excellent (about 87%). There was no significant difference in family satisfaction by residence type, although the services were always rated as good or excellent for family foster residents and adults in their own homes, but were so rated by only 79% for corporate foster care residents. Families from the Twin Cities metropolitan area generally rated supported living services less favorably than outstate families, but over three-quarters of them still considered the services good.

Table 35: Family Satisfaction of Selected Services by Residence and County Types

Type of Service/ Level of Satisfaction	Type of Residence				Type of County			Total
	Family Foster	Corporate Foster	Own Home-Adults	Family Home-Children	Urban Twin Cities	Urban Outstate	Rural Outstate	
Case Management Services (n = 82)								
Excellent	41.7	57.7	38.9	46.2	56.7	44.0	40.7	47.6
Good	50.0	30.8	44.4	30.8	36.7	32.0	40.7	36.6
Sometimes good, sometimes bad	8.3	3.8	5.6	7.7	3.3	12.0	3.7	6.1
Fair	0.0	3.8	5.6	15.4	0.0	12.0	11.1	7.3
Poor	0.0	3.8	5.6	0.0	3.3	0.0	3.7	2.4
In-Home Family Support Services (n = 43)								
Excellent	50.0		30.8	30.4	41.7	16.5	35.7	31.6
Good	50.0		46.2	43.5	33.3	57.6	42.9	44.7
Sometimes good, sometimes bad	0.0		15.4	21.7	16.7	24.6	14.3	18.4
Fair	0.0		0.0	0.0	0.0	0.0	0.0	0.0
Poor	0.0		7.7	8.7	8.3	8.3	7.1	7.9
Supported Living Services (n = 42)								
Excellent	55.6	45.8	60.0		27.8	66.7	72.7[1]	50.0
Good	44.4	33.4	40.0		50.0	22.3	27.3	36.9
Sometimes good, sometimes bad	0.0	20.8	0.0		22.2	11.1	0.0	13.1
Fair	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Poor	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Respite Care Services (n = 37)								
Excellent	60.0		37.5	42.9	42.9	21.4	69.2[2]	44.1
Good	20.0		50.0	42.9	42.9	50.1	30.8	41.1
Sometimes good, sometimes bad	20.0		12.5	9.5	14.3	21.4	0.0	11.8
Fair	0.0		0.0	0.0	0.0	0.0	0.0	0.0
Poor	0.0		0.0	4.8	0.0	6.7	0.0	2.9

[1] X^2 (8, N=42) = 12.5, $p < .05$; [2] X^2 (8, N=37) = 12.7, $p < .05$

Family ratings of respite care services. The average amount of respite care per month for children living in their family homes was 50.4 hours. Similar amounts were reported for adults living at home and persons living in family foster homes (48.5 hours per month and 41.8 hours per month, respectively). Only 3% of the respondents rated these services as fair or poor; 12% rated them as "sometimes good, sometimes bad." But as with other services, the vast majority of families rated respite care services as good to excellent (85%). There was no significant difference in family satisfaction by HCBS recipient's place of residence, but urban outstate parents were less satisfied with respite care than parents from the other counties. The average number of both respite care and similar in-home services hours was 57.7 for people living in family foster residences, 64.1 for adults living in their own homes, and 83.0 for children living in their family homes. People living in the urban metropolitan area received 86.5 hours a month. Those who lived in urban outstate areas averaged 57.7 hours per month, and people living in rural outstate areas averaged 67 hours. Primary care providers receiving these services (46.5% of the sample) were asked if they could choose the time and the day they received respite and/or in-home service hours. About 15% indicated "no;" 85% said yes. There was a significant difference by type of residence (X^2 [6, N = 60] = 98.4; $p < .01$), with about 90% of the families whose children live with them saying "yes," in contrast 65.4% of family foster providers and 31.8% of families with adults living in their own or their family's homes. There was no significant difference between response and county type. Respondents were also asked if they were allowed to make changes in the scheduling of these services for special situations (e.g., vacations, emergencies). Responses were essentially identical to those for scheduling the time and day of respite care, again with statistically significant differences by residential situation. Families whose children live with them overwhelmingly said yes (90%), as compared with only 36% of the families of adults living in their own or family homes and 61.5% of the family foster care providers (X^2 [6, N = 60] = 92.5, $p < .01$).

Additional family comments. When given opportunities to comment further, only problems in their family members' HCBS, relatively only a few family members did so (see Table 36). Many families used the request to mention "problems" to make positive remarks about HCBS. Those who indicated problems typically described situations unique to the particular family member (e.g., better roommate match), to the bureaucracy (e.g., reduce paper work), and to the service delivery system (e.g., more services, quality of staff, pay and more training of staff). There were no significant differences between satisfaction and residence and county types.

Table 36: Additional Family Comments Related to Selected Services by Residence and County Types (percentage)

	Residence Type				Type of County			
	Family Foster	Corporate Foster	Own Home-Adults	Family Home-Children	Urban Twin Cities	Urban Outstate	Rural Outstate	Total
Case Management Services (N = 35)								
Positive comment	25.0	55.6	44.4	15.4	40.0	25.0	33.3	34.3
Improve communication	25.0	11.1	22.2	7.7	6.7	25.0	16.7	14.3
More knowledge about services	25.0	11.1	33.3	15.4	13.3	12.5	33.3	20.0
Improvements in bureaucracy	25.0	22.2	0.0	61.5	40.0	37.5	16.7	31.4
In-Home Family Support Services (N = 30)								
Positive comment	0.0	0.0	22.2	0.0	11.1	9.1	0.0	6.7
Improve communication	0.0	0.0	33.3	36.8	44.4	18.2	40.0	33.3
More qualified staff	0.0	0.0	11.1	21.1	11.1	36.4	0.0	16.7

	Residence Type				Type of County			Total
	Family Foster	Corporate Foster	Own Home-Adults	Family Home-Children	Urban Twin Cities	Urban Outstate	Rural Outstate	
Staff replacement not done in timely fashion/ need more services	0.0	0.0	11.1	5.3	11.1	9.1	0.0	6.7
More competition among service providers	0.0	0.0	0.0	5.3	0.0	9.1	0.0	3.3
Staff training	0.0	0.0	0.0	100.0	0.0	9.1	0.0	3.3
More supervision of personal funds	100.0	0.0	0.0	0.0	0.0	9.1	0.0	3.3
Improve Bureaucracy	0.0	0.0	11.1	5.3	0.0	0.0	20.0	6.7
Improve quality of service providers	0.0	0.0	11.1	10.5	22.2	0.0	0.0	6.7
More Services	0.0	0.0	11.1	10.5	0.0	0.0	30.0	10.0
Supported Living Services (N = 18)								
Positive comment	14.3	40.0	80.0	0.0	0.0	18.2	0.0	41.2
More support	28.6	0.0	0.0	0.0	25.0	18.2	0.0	11.8
Services need to be more consumer-based	14.3	40.0	0.0	0.0	50.0	27.3	100.0	17.6
Smaller residential setting	0.0	20.0	0.0	0.0	0.0	9.1	0.0	5.9
Improve Bureaucracy	14.3	0.0	0.0	0.0	0.0	9.1	0.0	5.9
Need staff training	28.6	0.0	20.0	0.0	25.0	18.2	0.0	17.6
Respite Care Services (N = 15)								
Positive comment	0.0	0.0	25.0	0.0	50.0	0.0	0.0	6.7
Out-of-home respite is needed	0.0	0.0	25.0	60.0	50.0	40.0	66.7	46.7
More respite workers	0.0	0.0	0.0	10.0	0.0	0.0	33.3	6.7
Have not used respite in one year	100.0	0.0	0.0	0.0	0.0	10.0	0.0	6.7
Recipient/ provider relationship	0.0	0.0	25.0	10.0	0.0	20.0	0.0	13.3
Give respite care providers raise	0.0	0.0	25.0	0.0	0.0	10.0	0.0	6.7
Respite care in jeopardy	0.0	0.0	0.0	10.0	0.0	10.0	0.0	6.7
Providers need to improve their planning skills	0.0	0.0	0.0	10.0	0.0	10.0	0.0	6.7

[1] Duplicate count

Family ratings of residential setting. Families with members living in out of home placements were asked to rate the general living arrangement as from excellent to poor, over 97% of the family respondents rated residential setting as good to excellent. There was a significant difference between satisfaction and residence type (X^2 [6, N = 3] = 19.3, p< .01). Families who had adult family members living in their own homes but not the family home (N=7), all rated the residential setting as good. Family foster residential settings were rated from good (45%) to excellent (54%) by all respondents as were corporate foster residential (58% good, 42% excellent). There was no significant difference between family satisfaction with the residential setting and type of county. When asked if they felt residential services were adequate, over 90% of the people said yes, 7.6% said no, and 2.4% said they were not sure. There was no significant difference in perceived adequacy of residential services by place of residence or county. Only 11 families provided specific critical comments about needed improvements in the residential arrangements of their family members. These included a need for better staffing (3), improved cleanliness (2), improved meal quality (1), better roommate match (1), and more activities (1).

Case managers' views on quality of care and appropriateness of residence. Table 37 presents case manager's impressions of the general quality of care received by HCBS recipients and on the appropriateness of their current place of residence. In all 98.3% of HCBS recipients were viewed as having adequate or better than adequate quality of care, with services most often judged as better than adequate (55%). There was a statistically significant lower rating of the quality of care of adults living in their family or their own homes; in fact, all ratings of inadequate care came for the care of these individuals. This tendency was even more evident when case managers were asked if people were now living in the most appropriate residence. All children living at home were viewed as living in the most appropriate place indicating that the commitment at the state level to keep children and youth in their own families is shared by county case managers. Virtually all persons in family foster and corporate foster care (96%) were also viewed as in the "most appropriate" residence for them, but over one-third of the adults in their family home or own homes were considered not to be in the most appropriate setting. In most instances the residential situations rated as inadequate were adults living at home who case managers considered as likely to be better off if they moved away from home. Among the kinds of specific settings that in the judgment of their case managers would represent significant improvements in place of residence for these individuals varied, and included an apartment with 1 or 2 peers, a foster home, a place with a different room for each individual, and an ICF-MR able to meet the needs of a person with challenging behavior.

Table 37: Case Managers' View of the Adequacy of the HCBS Received by Sample Members

	Type of Residence				Type of County			
	Family Foster (n=19)	Corporate Foster (n=47)	Own Home-Adults* (n=22)	Family Home-Children (n=29)	Urban Metro (n=39)	Urban Outstate (n=37)	Rural (n=41)	Total (N=117)
Quality of Care								
Better than Adequate	84.2	55.3	40.9	44.8[1]	48.7	64.9	51.2	54.7
Adequate	15.8	44.7	50.0	55.2	51.3	32.4	46.3	43.6
Less than Adequate	0.0	0.0	9.1	0.0	0.0	2.7	2.4	1.7
Appropriateness of Residence								
Present most appropriate	94.7	95.7	63.6[2]	100.0	97.4	86.5	87.8	90.6
Other would be better	5.3	4.3	36.4	0.0	2.6	13.5	12.2	9.4

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (6, N = 117) = 17.4, p < .01; [2] X^2 (3, N = 117) = 23.6, p < .01

Use and costs of adaptive aids and modifications. Only about 21% of the sample members had used home adaptive aids and modifications funded by HCBS or any other source (principally Medicaid State Plan services). Only about 6% of HCBS recipients had these funded through the HCBS program. People living in corporate foster homes were somewhat more likely to have received adaptive aids or modifications (27%) than those living in other residences. Approximately 28% of the recipients living in urban metropolitan areas had received some type of aid or modification, where persons residing in urban outstate and rural outstate counties (11%) were less likely to have received such services. Only 3% of the sample members had received adaptive aids for vehicles. The average amount of money spent for adaptive aids and modifications during the previous year was $1,481 for people living in family foster homes and $529 in corporate foster homes, $1,390 for adults living in their own homes and $4,018 for children living in their own homes. Although urban metropolitan residents were more likely to receive adaptive aids and modifications the average per person expenditures for these were substantially less than for persons living outside the Twin City metropolitan area. The average cost for persons receiving such assistances during the previous year varied considerably by county; people living in rural outstate areas received almost twice the financial support for aids and modifications ($3,028) as those living in urban outstate areas ($1,611) and almost four times as much as those living in the urban metropolitan area ($818). The reasons for these patterns is unclear. In discussions with case managers some confusion was expressed about the coverage of adaptive aids through Medicaid State Plan versus HCBS (e.g., "[There's] frustration with adaptive equipment policy, we don't know what's covered, what's not;" "Reimbursement for adaptive aids is a black hole, we're never quite sure what's covered and what's not").

Do HCBS recipients have adequate opportunities and quality of life, including opportunities for: a) growth and development, b) social and familial relationships, c) community participation and d) personal autonomy and self-determination?

Growth and Development

Primary day activities. Table 38 provides a summary of sample members' primary day activities. Some duplicate counting is evident because about 19% of the HCBS recipients have more than one primary day activity. All recipients 21 years and younger, about one-third of the sample attended schools. About one recipient in five attended a work activities center (18%), a sheltered workshop (18%), or a day activity center (21%). Approximately 4% or 5 individuals stayed at home during the day, including 4 individuals for whom a day program or work was being sought.

There were some statistically significant differences in program participation by residential setting and type of county. People from the urban metropolitan area were most likely to have competitively or supported employment (35% as compared with 12% of sample members from rural areas and 8% from metropolitan outstate areas). About 20% of the adults living in their own homes attended either sheltered workshops, work activities centers or day activities centers. People living in corporate foster homes were primarily attending sheltered workshops (29%) or day activities centers (29%). Those living in family foster homes typically attended day (33%) and work (26%) activities centers.

Table 38: Primary Day Activities by Residence and County Types (percentage)[1]

Type of Primary Day Activity	Type of Residence				Type of County			Total (N=119)
	Family Foster (n=24)	Corporate Foster (n=49)	Own Home-Adults (n=21)	Family Home-Children (n=25)	Urban Metro (n=40)	Metro Outstate (n=37)	Rural Outstate (n=42)	
Competitive Employment	9.1	10.6	10.0	0.0	17.1	0.0	7.1[2]	7.9
Supported Employment	13.6	12.2	14.3	0.0	18.4	8.1	4.8	10.3
Enclave	8.3	8.5	0.0	0.0	8.1	2.7	4.8	5.2
Sheltered Workshop	13.6	29.2	20.0	0.0[3]	16.7	18.9	19.0	18.3
Work Activities Center	26.1	29.2	20.0	0.0[4]	24.3	16.2	21.4	20.7
Day Activities Center	33.3	19.1	19.0	0.0[5]	28.9	13.5	11.9	17.9
School	18.2	4.3	20.0	100.0[6]	25.0	37.8	38.1	33.6
Stay at Home/ Not Waiting for Services	4.5	0.0	0.0	0.0	0.0	2.7	0.0	0.9
Stay at Home/ Waiting for Services	0.0	4.3	10.0	0.0	2.9	5.4	2.4	3.5
Other	0.0	2.1	0.0	0.0	2.9	0.0	0.0	0.9

[1] Duplicate count; [2] X^2 (2, N = 114) = 7.3, $p < .05$; [3] X^2 (3, N = 115) = 9.8, $p < .05$; [4] X^2 (3, N = 116) = 9.0, $p < .05$; [5] X^2 (3, N = 117) = 9.4, $p < .05$; [6] X^2 (3, N = 119) = 81.4, $p < .01$

Areas covered in Individual Habilitation Plan (IHP) objectives and updates. Direct care providers were also asked to report the written service objectives of sample members. Written objectives were identified for all HCBS recipients in the sample. These are summarized into 17 broad categories in Table 39. The most common types of objectives were self-care (56%), communication (50%), household chores (45%), leisure and recreation (43%), socialization (42%), and community participation (40%). The rarest objectives were in the areas of sexuality, community safety, home safety and mobility and travel. Among the objectives with significant differences among people living in different settings were home safety, most common in corporate foster homes (20%) and family foster homes (23%); meal planning, most common among people in corporate foster homes (50%), adults living in their own homes (36%) and family foster care (27%); sensory and motor development objectives, most common among children living at home (43%) or adults living in their own or their family's home (36%); communication, most common among children living at home (83%), but also part of the habilitation plan for half of the adults living at home; reducing maladaptive behavior, more common among children living at home (40%) than among residents of family foster homes (8%), corporate foster homes (22%), or adults living in their own homes (14%); money management, most common among people living in corporate foster homes (47%) and adults living in their own homes (46%); household chore skills, most common among people living in family foster and corporate foster homes (69% and 63%, respectively), and vocational skills, evident for about half the people in family foster homes (48%) and corporate foster homes (52%), and over one third of the adults living in their own homes. Skill areas which showed statistically significant differences between county types included sensory and/or motor development, interpersonal skills, communication skills and money management. In all cases the rural county residents were more likely to have these skills objectives.

Table 39: Type of Written Objectives in Individualized Habilitation Plans (IHP) by Residence and County Type (in percentage)

Type of Written Objectives in ISPs	Type of Residence				Type of County			Total (N=129)
	Foster Family (n=26)	Foster Corporate (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Metro Outstate (n=37)	Rural Outstate (n=42)	
Community safety	11.5	21.6	9.1	6.7	8.0	13.5	21.4	14.0
Home safety	23.1	19.6	13.6	0.0[1]	8.0	16.2	21.4	14.7
Meal planning	26.9	50.0	36.4	6.7[2]	30.6	43.2	26.2	32.8
Sexuality	3.8	3.9	0.0	3.3	2.0	2.7	4.8	3.1
Self care	50.0	54.9	63.6	56.7	48.0	51.4	69.0	55.8
Sensory & motor development	19.2	5.9	36.4	43.3[3]	6.0	32.4	33.3[4]	22.5
Interpersonal skills	15.4	33.3	27.3	20.0	16.0	24.3	38.1[5]	25.6
Communication	42.3	33.3	50.0	83.3[6]	34.0	54.1	64.3[7]	49.6
Social skills	50.0	37.3	50.0	36.7	48.0	40.5	35.7	41.9
Reduction maladaptive behavior	7.7	21.6	14.3	40.0[8]	14.0	21.6	31.7	21.9
Community participation	42.3	35.3	40.9	46.7	36.0	43.2	42.9	40.3
Mobility and travel	11.5	17.6	22.7	10.0	14.0	16.2	16.7	15.5
Health care	15.4	37.3	40.0	20.0	24.0	27.0	37.5	29.1
Leisure and recreation	46.2	37.3	50.0	46.7	44.0	54.1	33.3	43.4
Money management	11.5	47.1	45.5	10.0[9]	18.0	29.7	47.6[10]	31.0
Household skills	69.2	62.7	27.3	6.7[11]	46.0	37.8	50.0	45.0
Vocational services	48.0	52.0	36.4	3.3[12]	35.4	40.5	35.7	37.0

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (3, N = 129) = 7.6, $p < .05$; [2] X^2 (3, N = 128) = 16.5, $0 < .01$; [3] X^2 (3, N = 129) = 18.1, $p < .01$; [4] X^2 (2, N = 129) = 12.7, $p < .01$; [5] X^2 (2, N = 129) = 5.9, $p < .05$; [6] X^2 (3, N = 129) = 19.6, $p < .01$; [7] X^2 (2, N = 129) = 8.8, $p < .01$; [8] X^2 (3, N = 128) = 9.5, $p < .05$; [9] X^2 (3, N = 129) = 19.1, $p < .01$; [10] X^2 (2, N = 129) = 9.4, $p < .01$; [11] X^2 (3, N = 129) = 33.3, $p < .01$; [12] X^2 (3, N = 127) = 20.2, $p < .01$

Number of ISP objectives in major life areas. The ISP written objectives of HCBS recipients were categorized into three major life areas 1) community living objectives, which included community safety, community participation, community mobility and travel, leisure and recreation; and non-domestic work; 2) personal/domestic care objectives, which included home safety, meal planning, self-care, sensory or motor development, health care, money management and domestic chores; and 3) interpersonal skill objectives, which included sexuality, interpersonal interactions, communication and speech, social/socialization skills and reduction of challenging behavior. On average HCBS recipients had 1.5 community living objectives, 2.3 personal/domestic care objectives and 1.4 interpersonal skills objectives; an average of 5.2 objectives per HCBS recipient. The lowest number or written objectives for an HCBS recipient in the sample was 2, the highest 10.

The average number of community living objectives was the same for persons in family foster care, corporate foster care and adults living in their own or their family home (1.6). Children living at home averaged 1.1 community living objectives with no significant variability by county type. People living in corporate foster care and adults living in their own or their family home were considerably more likely to have personal/domestic objectives (an average 2.8 and 2.6 respectively) as compared with 2.1 and 1.4 for family foster care residents and children in their own homes ($F[df=3] = 7.8$, $p < .01$). The relatively low rate of participation of family foster care residents in maintaining their own domestic environment has been noted in national studies of family foster care for persons with mental retardation (Hill et al, 1989). It is possible as the national study's authors hypothesized, that in family foster care homes the focus of accomplishing the basic chores and demands of daily life as quickly and as easily as possible may detract from presenting residents with the opportunity to learn skills of value to them. It appears more important that case managers and others who assist in developing objectives for family foster care residents fully attend to the kinds of participation and learning that will eventually increase the independence of an individual. There were no differences in the average number of interpersonal skill objectives for persons in family foster care, corporate foster care or adults living in their own homes ($1.3 \pm .1$). Children living at home were more likely to have interpersonal skill objectives, particularly (as shown in Table 39) in the area of communication and speech.

Review of plans. In addition to the content of service plans the last date on which they were updated was recorded. Program plans were generally current. Of 100 written plans which had a clear date of development, 84 (84%) had been developed or reviewed within the previous year.

Social and Familial Relations

Social networks of HCBS recipients. A social network description was developed for each sample member that identified individuals who were "important" to him/her, including the "importance" of that individual to the HCBS recipient. Table 40 summarizes the total number of people with some degree of importance to the sample members. Only 1 individual in the sample was reported to have no one in his social network. About 89% had 7 or more people in their social networks.

About 82% of sample members had from 1 to 6 immediate family members involved in their lives. People residing in the urban metropolitan area were considerably more likely to have no immediate family member in their social network than people living in the rural outstate areas and urban outstate areas. Approximately 73% of the people living in family foster homes 62% of those residing in corporate foster homes had no extended family involvement, where less than 7% of the children living in their own home had none.

About 14% of the sample members were reported to have no friends, other than family or staff member. About 70% had 1 to 6 friends within their social networks. There was a significant difference between the number of friends. Children living at home were particularly likely to have no friends (27%). Approximately 14% of the adults living in their own homes were reported to have no friends, as compared with 8% of people living in corporate foster home and 4.5% residing in family foster care homes. The social networks of sample members also typically include 1 to 6 service providers.

Visits from immediate family members. Direct care providers were also asked how many times immediate family members had visited recipients in the previous six months. Among sample members not actually living with their families, 15% had no visits from the immediate family and 9% had only one. The 85% of Minnesota HCBS recipients seeing their families in the previous 6 months compares with 69% reported in a recent national sample of persons living in small community settings (Hill et al., 1989). About 40% of HCBS recipients living outside their family home saw members of their immediate family more than 9 times during the previous 6 months, two to eight visits were reported or 36%. Visits with extended family members were less common, but still quite frequent. Of the 83 responses, 23% had no visits with extended

family in the last 6 months, and 5% had only one visit. The majority of people received more than 2 visits including 2 to 9 visits for 38% and 10 or more visits for 33%. There were no significant differences between frequency of visits and residence and county types. Statistics on the frequency of dating and visits with friends are included in Tables 43 and 44.

Table 40: Number and Type of People in Social Network by Residence and County Types (percentage)

Type of Person/ Frequency	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adult* (n=22)	Family-Home Children (n=30)	Urban Metro (n=50)	Urban Outstate (n=37)	Rural Outstate (n=42)	
Total Number								
0	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
1-6	7.7	7.8	4.5	3.3	12.0	2.7	2.4	6.2
7-14	34.6	51.0	50.0	43.3	50.0	45.9	40.5	45.7
15-30	53.8	37.3	40.9	46.7	32.0	48.6	52.4	43.4
31-50	3.8	2.0	4.5	6.7	4.0	2.7	4.8	3.9
Immediate Family/Frequency								
0	19.2	13.7	0.0	10.0	22.0	8.1	2.4[1]	11.6
1-6	76.9	32.4	86.4	83.3	78.0	83.8	85.7	82.2
7-14	3.8	3.9	13.6	6.7	0.0	8.1	11.9	6.2
Extended Family/Frequency								
0	73.1	62.7	45.5	6.7[2]	56.0	54.1	35.7	48.8
1-6	26.9	37.3	45.5	60.0	36.0	43.2	47.6	41.9
7-14	0.0	0.0	0.0	26.7	6.0	2.7	9.5	6.2
15-30	0.0	0.0	9.1	3.3	0.0	0.0	7.1	2.3
31	0.0	0.0	0.0	3.3	2.0	0.0	0.0	0.8
Friends/Frequency								
0	11.5	7.8	13.6	26.7[3]	16.0	13.5	11.9	14.0
1-6	53.8	80.4	72.7	63.3	74.0	59.5	73.8	69.8
7-14	19.2	7.8	13.6	10.0	6.0	16.2	14.3	11.6
15-30	15.4	3.9	0.0	0.0	4.0	10.8	0.0	4.7
Staff/Frequency								
0	11.5	3.9	0.0	0.0	4.0	8.1	0.0	3.9
1-6	61.5	58.8	81.8	76.7	68.0	73.0	61.9	67.4
7-14	26.9	37.3	18.2	23.3	28.0	18.9	38.1	28.7

*Includes 15 adults living with their natural or adoptive parents.

[1] X^2 (3, N = 129) = 13.8, $p < .01$; [2] X^2 (3, N = 129) = 56.1, $p < .01$; [3] X^2 (3, N = 129) = 17.9, $p < .05$

Opportunities for Community Participation

Use of community settings. Table 41 presents the percentage of HCBS recipients utilizing 23 community settings in the previous 6 months. As shown, participation was generally common for most activities, with over 90% of the sample using parks, restaurants, or medical offices at least once. About 80% to 90% of the sample utilized the grocery, clothing and department stores and the dental office. Approximately 60% to 80% of the recipients went to the corner store or deli, the drug store, a movie theater, the bank, a bowling alley, the public library, a playing field, the church, and the public beach. When compared on the use of 6 community resources with a national sample with MR/RC living in small community settings, Minnesota's HCBS recipients were more likely to have gone shopping, gone to a library, gone to a park and gone to a restaurant. There was no difference in the proportion of people who had attended movies or had gone to church.

Table 41: Utilization of Community Places in the Past Six Months by Residence and County Types (percentage)

	Type of Residence (N = 129)				Type of County			
	Family Foster (n=26)	Corporate Foster (n=50)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=17)	Urban Outstate (n=3)	Rural (n=22)	Total
Corner Store/Deli	61.5	72.5	59.1	56.7	74.0	67.6	50.0[1]	64.3
Drug Store	92.3	80.4	45.5	66.7[2]	76.0	70.3	73.8	73.6
Bus Stop	38.5	28.0	22.7	23.3	30.6	35.0	19.0	28.1
Grocery Store	80.8	88.2	95.2	93.3	86.0	89.2	92.9	89.1
Theater/Movie	76.9	86.3	45.5	56.7[3]	80.0	56.8	71.4	70.5
Hospital	50.0	51.0	36.4	60.0	48.0	54.1	50.0	50.4
Park	96.2	94.1	77.3	93.3	94.0	91.9	88.1	91.5
Bank	80.8	78.4	68.2	56.7	72.0	70.3	73.8	72.1
Clothing Store	88.5	82.4	81.8	79.3	81.6	78.4	88.1	82.8
Department Store	92.3	84.3	81.8	70.0	92.0	78.4	73.8	82.2
Laundromat	3.8	3.9	13.6	10.3	4.1	13.5	4.8	7.0
Restaurant	100.0	98.0	100.0	100.0	100.0	97.3	100.0	99.2
Medical Office	92.3	100.0	86.4	96.7	96.0	97.3	92.9	95.3
Dental Office	88.5	82.4	72.7	76.7	84.0	83.8	73.8	80.6
Community Education	65.4	49.0	54.5	24.1	46.9	45.9	50.0	47.7
YMCA/YWCA	26.9	17.6	31.8	24.1	22.4	24.3	23.8	23.4
Bowling Alley	80.8	72.5	54.5	55.2	65.3	64.9	71.4	67.2
Library	65.4	49.0	50.0	72.4	53.1	51.4	69.0	57.8
Playing Field	53.8	60.8	50.0	51.7	42.9	64.9	61.9	55.5
Church	73.1	66.7	72.7	69.0	65.3	64.9	78.6	69.5
Public Beach	65.4	66.7	63.6	80.0	62.0	70.3	76.2	69.0
Zoo	7.8	21.1	4.7	12.5	66.0	32.4	34.1[4]	46.1

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (2, N = 129) = 6.0, $p < .05$; [2] X^2 (3, N = 129) = 15.6, $p < .01$; [3] X^2 (3, N = 129) = 16.0, $p < .01$; [4] X^2 (2, N = 129) = 17.0, $p < .01$

Frequency of use of community places by HCBS recipients was generally similar across county types, except for the expected lower use of a corner store or deli in rural areas and zoos in outstate counties. In general there was a somewhat lower use of community recreation and leisure settings by adults living in their own or their family home. Persons living in rural areas are generally as likely to use community resources as people in urban counties, despite greater distances to these places. The primary reason for the similarity may

be, as shown in Table 42, that no matter where people live, they rely primarily on the provider agency or family vehicle to get to the places they need to go.

Table 42: Type of Transportation by Residence and County Types (percentage)

Type of Transportation	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Urban Outstate (n=37)	Rural Outstate (n=41)	
Recreation/Leisure Activities								
Walking	3.8	11.8	13.6	3.3	4.0	8.1	14.3	8.5
Public bus	0.0	7.8	9.1	0.0	6.0	5.4	2.4	4.7
Provider agency or family vehicle	88.5	74.5	63.6	93.3	80.0	81.1	78.6	79.8
Private agency vehicle	7.7	3.9	4.5	0.0	8.0	0.0	2.4	3.9
Taxicab	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Other	0.0	0.0	9.1	3.3	0.0	5.4	2.4	2.3
For Appointments								
Walking	0.0	3.9	0.0	0.0	2.0	2.7	0.0[1]	1.6
Public bus	0.0	2.0	4.5	0.0	2.0	2.7	0.0	1.6
Provider agency or family vehicle	88.5	82.4	86.4	86.7	72.0	89.2	97.6	85.3
Private agency vehicle	11.5	11.8	9.1	13.3	24.0	5.4	2.4	11.6
Work/Day Program, School								
Walking	4.0	0.0	10.0	0.0[2]	2.0	0.0	4.9[3]	2.4
Public bus	20.0	10.2	15.0	3.3	12.2	11.8	9.8	11.3
Provider agency or family vehicle	20.0	36.7	30.0	3.3	26.5	29.4	17.1	24.2
Private agency vehicle	20.0	28.6	15.0	10.0	36.7	8.8	9.8	20.2
Taxicab	0.0	4.1	0.0	0.0	2.0	2.9	0.0	1.6
School bus/Other	36.0	20.4	30.0	83.3	20.4	47.1	58.5	40.3

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (6, N = 129) = 14.8, p < .05; [2] X^2 (15, N = 124) = 45.4, p = .01; [3] X^2 (10, N = 124) = 24.1, p = .01

Frequency of social/leisure activity participation. Table 43 presents sample members frequency of participation in 20 recreation/leisure activities during the previous month. A rather high level of participation was noted among sample members. Over half of the sample participated in 12 of the 20 activities. Those with less than 50% participation included dating, attending a club meeting, hobbies, doing volunteer work, watching a sporting event, attending an adult education class or a club meeting, and participating in a sport. Although

there appeared to be a high rate of participation in solitary activities, sample members were involved in a variety of activities. For the most part rates of participation were again very similar among people living in different types of counties. Some differences of statistical significance were noted among people in the different types of residence, although many of these seemed most notable for the differences between children and adults living at home as compared with those living in family or foster care.

Table 43: Frequency of Participating in Social/Leisure Activities
in the Previous Month by Residence and County Type (in percentage)

Type of Activity/ Frequency	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Urban Outstate (n=37)	Rural (n=42)	
TV								
29 or less	7.7	9.8	13.6	3.3	8.0	10.8	7.1	8.5
30 or more	92.3	90.2	86.4	96.7	92.0	89.2	92.9	91.5
Went Grocery Shopping								
0	19.2	19.6	9.1	3.3	18.0	13.5	9.5[1]	14.0
1	15.4	9.8	9.1	16.7	20.0	5.4	9.5	12.4
2-6	46.2	68.6	68.2	66.7	60.0	64.9	66.7	63.6
7 or more	19.2	2.0	13.6	13.4	2.0	16.2	14.1	10.1
Engaged in Hobbies								
0	34.6	47.1	50.0	70.0	54.0	56.8	40.5	50.4
1-6	19.2	21.6	18.2	10.0	8.0	27.0	21.4	17.9
7-20	14.3	15.7	9.0	3.3	18.0	2.7	11.9	11.6
20 or more	30.7	15.7	22.7	16.6	20.0	13.5	26.2	20.2
Watched Sporting Event								
0	80.8	52.9	81.8	76.7	74.0	73.0	59.5	69.0
1	3.8	23.5	9.1	13.3	20.0	8.1	14.3	14.7
2-6	15.4	23.5	9.1	10.0	6.0	18.9	26.2	16.3
Went to Movie or Concert								
0	34.6	25.5	63.6	66.7[2]	24.0	64.9	47.6[3]	43.4
1	19.2	31.4	9.1	26.7	38.0	16.2	14.3	24.0
2-5	46.2	43.1	27.3	6.7	38.0	18.9	38.1	32.6
Dated								

Type of Activity/ Frequency	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Urban Outstate (n=37)	Rural (n=42)	
0	84.6	74.5	77.3	96.7	80.0	86.5	81.0	82.2
1	3.8	9.8	0.0	3.3	6.0	5.4	4.8	5.4
2-16	11.5	15.7	22.7	0.0	14.0	8.1	14.3	12.4
Visited Friends								
0	26.9	25.5	31.8	30.0	32.0	27.0	23.8	27.9
1	23.1	7.8	9.1	16.7	12.0	13.5	14.3	13.2
2-6	42.3	52.9	31.8	40.8	46.0	37.8	47.6	44.2
7-30	7.7	13.7	27.3	13.4	10.0	13.5	4.8	7.0
Attended a Community Event								
0	46.2	45.1	63.6	66.7	40.0	64.9	59.5	53.5
1	30.8	19.6	18.2	20.0	26.0	24.3	14.3	21.7
2-9	23.1	35.3	18.2	13.3	34.0	10.8	26.2	24.8
Attended a Club Meeting								
0	76.9	68.6	72.7	80.0	70.0	91.9	61.9[4]	73.6
1	0.0	13.7	13.6	13.3	8.0	5.4	19.0	10.9
2 or more	23.1	17.7	13.6	6.7	22.0	2.7	19.1	15.5
Attended a Religious Service								
0	26.9	39.2	40.9	46.7	38.0	43.2	35.7	38.8
1	0.0	7.8	13.6	3.3	4.0	10.8	4.8	6.2
2 or more	73.0	52.9	45.5	50.0	58.0	45.9	59.5	55.1
Ate Out								
0	0.0	2.0	0.0	3.3	4.0	0.0	0.0	1.6
1	3.8	3.9	9.1	10.0	2.0	5.4	11.9	6.2
2-7	65.4	78.4	63.6	73.3	66.0	78.4	73.8	72.1
8 or more	30.8	15.7	27.3	13.3	28.0	16.2	14.3	20.2
Went for a Walk								
0	26.9	15.7	27.3	13.3	22.0	18.9	16.7	19.4
1-7	30.7	37.3	27.3	43.3	30.0	32.4	45.2	35.6

Type of Activity/ Frequency	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Urban Outstate (n=37)	Rural (n=42)	
8-20	23.1	25.5	18.2	23.3	30.0	29.7	9.5	23.3
21 or more	19.2	21.6	27.3	20.0	18.0	18.9	28.6	21.7
Played Cards								
0	23.1	41.2	81.8	56.7[5]	44.0	62.2	40.5	48.1
1	7.7	5.9	0.0	3.3	4.0	2.7	7.1	4.7
2-9	42.3	35.3	9.1	26.7	38.0	18.9	31.0	30.2
10 or more	26.9	17.7	9.1	13.3	16.0	16.2	21.5	17.1
Read/Looked at Magazines								
0	3.8	23.5	18.2	6.7	22.0	10.8	9.5	14.7
1-9	30.7	33.4	31.8	20.0	24.0	35.1	31.0	29.4
10-20	23.1	2.0	18.2	23.3	14.0	10.8	16.7	14.0
30 or more	42.3	41.2	31.8	50.0	40.0	43.2	42.9	41.9
Did Volunteer Work								
0	84.6	90.2	100.0	100.0[6]	90.0	97.3	92.9	93.0
1 or more	15.4	9.8	0.0	0.0	10.0	2.7	7.1	7.0
Shopped for Personal Items								
0	11.5	7.8	27.3	43.3[7]	8.0	32.4	23.8[8]	20.2
1	11.5	15.7	22.7	13.3	8.0	24.3	16.7	15.5
2 or more	76.9	76.5	50.0	43.3	84.0	43.2	59.5	64.4
Went to Bank								
0	34.6	23.5	50.0	86.7[9]	40.0	51.4	45.2	45.0
1	34.6	9.8	4.5	3.3	8.0	18.9	11.9	12.4
2 or more	30.8	66.7	45.5	10.0	52.0	29.7	42.9	42.7
Attended an Adult Education Class								
0	65.4	66.7	100.0	100.0[10]	72.0	86.5	83.3	79.8
1	7.7	9.8	0.0	0.0	6.0	2.7	7.1	5.4

Type of Activity/ Frequency	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Urban Outstate (n=37)	Rural (n=42)	
2 or more	19.2	23.5	0.0	0.0	22.0	10.8	9.5	14.8
Participated in Sports								
0	65.4	62.7	86.4	86.7	80.0	73.0	64.3	72.9
1	3.8	3.9	0.0	6.7	2.0	2.7	7.1	3.9
2 or more	30.8	33.4	13.6	6.7	18.0	24.3	28.6	23.3
Other Leisure Activities								
0	42.3	70.6	50.0	53.3	50.0	64.9	59.5	57.4
1	7.7	11.8	4.5	3.3	6.0	10.8	7.1	7.8
2-8	30.8	13.7	36.4	33.3	32.0	18.9	23.8	25.6
9 or more	19.2	4.0	9.0	10.0	12.0	5.4	9.5	9.3

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (8, N = 129) = 17.0, $p < .05$; [2] X^2 (6, N = 129) = 23.2, $p < .01$; [3] X^2 (4, N = 129) = 18.1, $p < .01$; [4] X^2 (6, N = 129) = 14.1, $p < .05$; [5] X^2 (12, N = 129) = 21.0, $p < .05$; [6] X^2 (6, N = 129) = 12.4, $p < .05$; [7] X^2 (9, N = 129) = 22.7, $p < .01$; [8] X^2 (6, N = 129) = 19.4, $p < .01$; [9] X^2 (9, N = 129) = 51.8, $p < .01$; [10] X^2 (9, N = 129) = 28.9, $p < .01$

Coparticipants in leisure activities. Direct care providers were also asked with whom, if anyone, did the sample member, participate in the 20 leisure activities summarized in Table 43. Table 44 summarizes these coinvolvements among some of the leisure activities most frequently participated in by sample members. HCBS recipients typically attended activities with family members, staff members and/or friends with disabilities. Seldom did sample members have friends without disabilities who attended activities with them. Significant differences were frequently found in participants in activities by residence type, in most cases attributable to adults and children living in their own homes or in foster homes doing things with their families while people in corporate foster care homes were doing things with staff. Few activities were participated in independently (e.g., only 3% of sample members had attended a community event independently in the past month). The low rates of leisure activity coinvolvement were found in other activities as well. For example only 4% of sample members had watched TV in the past month with nonfamily, nonstaff or nondisabled friends; 4% had engaged in hobbies, 3% had attended a club meeting, 1% had played cards, and 1% had gone to an adult education class. In short, while the leisure lives of HCBS recipients are generally quite active, their level of integration in these activities is notably low.

Table 44: Others Who Took Part in Selected Leisure Activities in the Previous Month by Residence and County Types (percentage)

Type of Activity/ Coparticipants	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban/ Metro (n=50)	Urban/ Outstate (n=21)	Rural (n=42)	
Grocery Shopping								
Family member	65.4	2.0	54.5	83.3[1]	30.0	48.6	52.4	42.6
Friends with disabilities	15.4	25.5	13.6	10.0	20.0	18.9	14.3	17.8
Friends without disabilities	0.0	0.0	0.0	3.3	0.0	2.7	0.0	.8
Paid staff	23.1	78.4	45.5	20.0[1]	48.0	51.4	45.2	48.1
By self	3.8	0.0	0.0	0.0	2.0	0.0	0.0	.8
Concert								
Family member	50.0	5.9	4.5	20.0[1]	22.0	8.1	21.4	17.8
Friends with disabilities	46.2	47.1	13.6	6.7[1]	42.0	16.2	33.3	31.8
Friends without disabilities	0.0	3.9	9.1	0.0	4.0	0.0	4.8	3.1
Paid staff	15.4	62.7	18.2	13.3[1]	52.0	21.6	23.8[1]	34.1
By self	0.0	2.0	0.0	0.0	0.0	2.7	0.0	.8
Dated								
Family member	7.7	0.0	4.5	0.0	2.0	2.7	2.4	2.3
Friends with disabilities	11.5	21.6	18.2	0.0[2]	14.0	8.1	19.0	14.0
Friends without disabilities	0.0	2.0	0.0	3.3	2.0	2.7	0.0	1.6
Paid staff	0.0	2.0	4.5	0.0	2.0	0.0	2.4	1.6
By self	0.0	2.0	0.0	0.0	2.0	0.0	0.0	.8
Visited Friends								
Family members	30.8	7.8	27.3	50.0[1]	18.0	45.9	16.7[1]	25.6
Friends with disabilities	26.9	33.3	22.7	0.0[1]	26.0	10.8	28.6	22.5
Friends without disabilities	7.7	9.8	13.6	23.3	10.0	10.8	19.0	13.2
Paid staff	19.2	31.4	22.7	20.0	26.0	24.3	23.8	24.8

Type of Activity/ Coparticipants	Type of Residence				Type of County			
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban/ Metro (n=50)	Urban/ Outstate (n=21)	Rural (n=42)	Total (N=129)
By self	7.7	17.6	4.5	3.3	14.0	2.7	11.9	10.1
Attend a Community Event								
Family members	30.8	2.0	13.6	26.7[1]	22.0	10.8	11.9	15.5
Friends with disabilities	30.8	35.3	13.6	3.3[1]	32.0	13.5	21.4	23.3
Friends without disabilities	3.8	2.0	9.1	3.3	2.0	2.7	7.1	3.9
Paid staff	19.2	43.1	13.6	10.0[1]	34.0	18.9	21.4	25.6
By self	0.0	5.9	4.5	0.0	4.0	2.7	2.4	3.1
Attend a Religious Service								
Family member	69.2	21.6	54.5	53.3[1]	44.0	45.9	42.9	44.2
Friends with disabilities	23.1	15.7	0.0	0.0[1]	16.0	5.4	9.5	10.9
Friends without disabilities	3.8	13.7	0.0	0.0[3]	12.0	0.0	4.8	6.2
Paid staff	0.0	17.6	0.0	0.0[1]	8.0	5.4	7.1	7.0
By self	7.7	9.8	9.1	0.0	4.0	5.4	11.9	7.0
Ate Out								
Family member	92.3	11.8	72.7	76.7[1]	46.0	56.8	59.5	53.5
Friends with disabilities	53.8	66.7	18.2	10.0[1]	48.0	37.8	40.5	42.6
Friends without disabilities	0.0	7.8	9.1	0.0	10.0	0.0	2.4	4.7
Paid staff	11.5	78.4	59.1	53.3[1]	50.0	59.5	59.5	55.8
By self	3.8	5.9	0.0	0.0	6.0	0.0	2.4	3.1
Went for a Walk								
Family member	50.0	0.0	36.4	63.3[1]	24.0	40.5	31.0	31.0
Friends with disabilities	19.2	39.2	0.0	6.7[1]	26.0	13.5	21.4	20.9
Friends without disabilities	3.8	2.0	0.0	6.7	2.0	5.4	2.4	3.1
Paid staff	26.9	54.9	36.4	50.0	46.0	54.1	35.7	45.0

Type of Activity/ Coparticipants	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban/ Metro (n=50)	Urban/ Outstate (n=21)	Rural (n=42)	
By self	19.2	29.4	22.7	3.3[3]	22.0	8.1	28.6	20.2
Shopping for Personal Items								
Family member	73.1	5.9	50.0	53.3[1]	40.0	35.1	38.1	38.0
Friends with disabilities	19.2	29.4	0.0	0.0[1]	16.0	10.8	19.0	15.5
Friends without disabilities	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Paid staff	19.2	90.2	45.5	10.0[1]	64.0	37.8	42.9	49.6
By self	3.8	5.9	0.0	0.0	4.0	2.7	2.4	3.1
Sport Participant								
Family member	11.5	5.9	0.0	0.0	8.0	2.7	2.4	4.7
Friends with disabilities	11.5	25.5	4.5	10.0	6.0	8.1	33.3	15.5
Friends without disabilities	11.5	5.9	0.0	0.0	4.0	5.4	4.8	4.7
Paid staff	11.5	15.7	9.1	10.0	6.0	13.5	19.0	12.4
By self	3.8	5.9	0.0	0.0	4.0	5.4	0.0	3.1

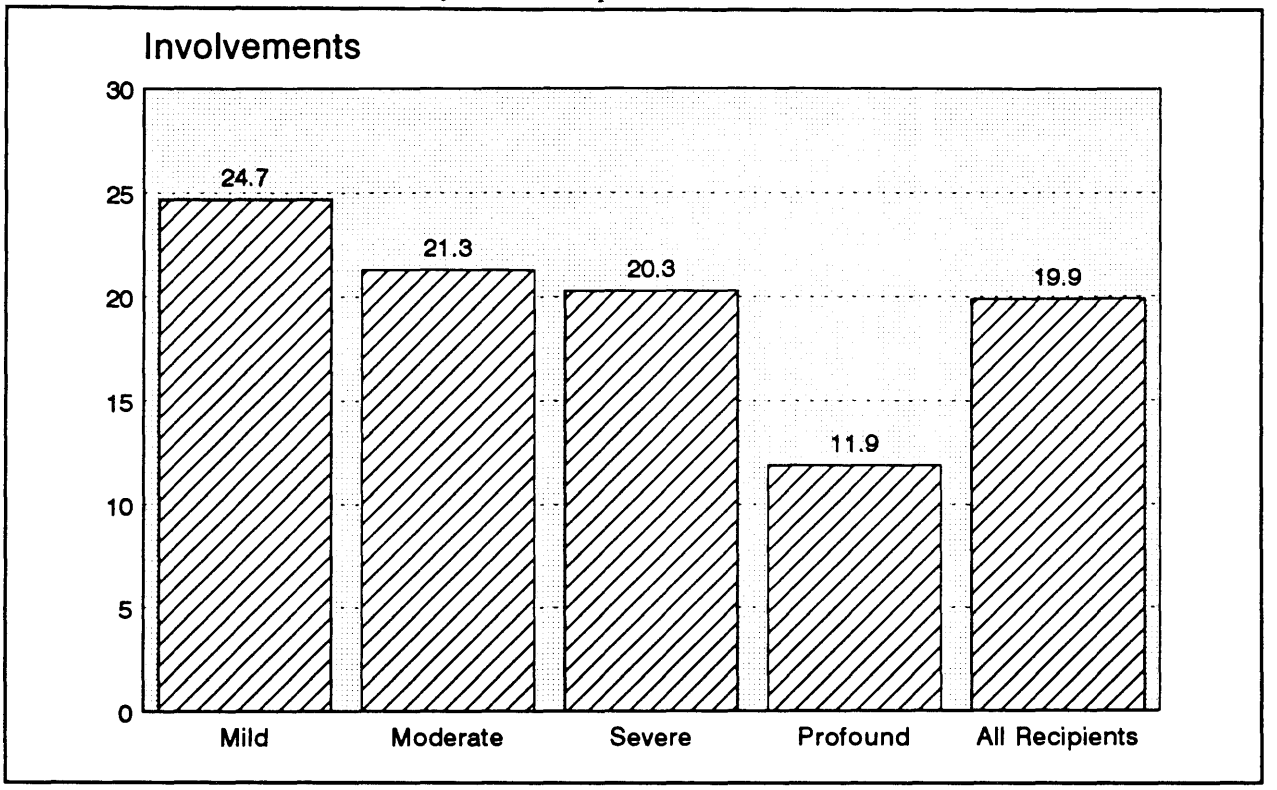
*Includes 15 adults living with their natural or adoptive parents.
[1] $p < .01$; [2] $p < .05$

Frequency of involvement in community settings. To examine the levels of involvement of HCBS recipients in community settings, the total number of times during the past month that people a) had gone shopping for groceries, clothing of personal items, b) went to a sporting event, c) went to a movie or concert, d) attended a community event, e) went to a meeting of a community club or organization, f) went to a religious service, g) went out to eat, h) went to a bank, or h) went to adult education classes. The total frequencies of these community involvements ranged from 2 to 65. The average number of involvements among the 128 persons with complete data was 19.9; half had participated in 17 or more of these activities in the previous month. Averages for the four types of living arrangements were different ($F[3df] = 4.12$, $p < .01$): family foster care (25.1 activities/month), corporate foster care (21.3), adults in their family home or own home (17.4) and children in their family home (15.1). Again no statistically significant differences were evident by geographical location: Twin Cities urban (21.4 activities/month), outside urban (17.3) and outstate rural (20.5).

Frequency of involvement in community settings by level of impairment. Clearly an HCBS recipient's level of impairment is associated with his/her involvement in community settings ($F[3df] = 3.7$, $p < .01$). As shown in Figure 6 people with mild mental retardation averaged 24.7 activities in the previous month as compared with 21.3 for persons with moderate mental retardation, 20.3 for persons with severe mental retardation, and

11.9 for persons with profound mental retardation. The finding of relatively low community involvement by persons with the most severe impairments may reflect a strain in the adequacy of resources (staffing ratios, training, technical assistance and other needed supports) to provide relatively active integrated lifestyles for those HCBS recipients who have the most severe impairments, while still meeting their basic care and supervision needs. Concerns about such strains were voiced in interviews with a number of case managers and county social services supervisors.

Figure 6
Average Frequency of Involvement in Community Settings
in One Month by HCBS Recipient's Level of Mental Retardation



Autonomy and Self-Determination

Direct care providers were asked specifically about household activities and practices which would represent opportunities for people to express autonomy and choice. In general, as shown in Table 45, choices and personal control were often available to HCBS recipients, but obviously not to an extent that might be desired. Corporate foster care settings most frequently provided adult HCBS recipients with personal control over basic aspects of their lives. Adults living in foster homes or their own homes were more frequently tied to the routine of the household and, of course, children at home were least likely to be given substantial choice or independence. Reflective of the limited autonomy of HCBS recipients, almost 70% had others who made arrangements for them to see their family and over 50% had others make arrangements for them to visit friends. About 58% of the sample were reported to have no choice in how to spend money for items and entertainment because arrangements are made for them. Only 28% of the sample members who received medications took them independently with or without supervision (16% and 12%, respectively).

Table 45: Opportunities for Recipients to Make Choices by Residence and County Types (percentage)

Opportunities for Recipients to Make Choices	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Metro Outstate (n=37)	Rural Outstate (n=42)	
Recipient decides his/her bedtime								
No, everyone goes to bed at the same time	30.8	7.8	31.8	70.0[1]	26.0	37.8	31.0	31.0
Yes, only on weekdays	0.0	2.0	0.0	0.0	0.0	2.7	0.0	0.8
Yes, only on weekend/non-work days	11.5	5.9	4.5	6.7	4.0	5.4	11.9	7.0
Yes, everyday week	50.0	80.4	54.5	20.0	66.0	54.1	45.2	55.8
Other	7.7	3.9	9.1	3.3	4.0	0.0	11.9	5.4
Recipient decides his/her time to get up in the morning								
No, everyone gets up at the same time	19.2	19.6	31.8	33.3	18.0	32.4	26.2	24.8
Yes, only on weekend/non-work days	34.6	29.4	13.6	20.0	28.0	16.2	31.0	25.6
Yes, everyday	46.2	51.0	54.5	46.7	54.0	51.4	42.9	49.6
Recipient decides when (s)he will take a bath								
No, everyone takes a bath within an hour of one another	53.8	27.5	45.5	86.7[1]	40.0	62.2	50.0	49.6
Yes, only on weekdays	0.0	0.0	4.5	0.0	0.0	2.7	0.0	0.8
Yes, only on weekend/non-work days	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Yes, everyday	30.8	68.6	45.5	13.3	54.0	32.4	42.9	44.2
Other	15.4	2.0	4.5	0.0	4.0	2.7	7.1	24.1
Recipient decides when (s)he will eat								
No, everyone eats within an hour of one another	88.5	68.6	72.7	76.7	62.0	81.1	85.7	75.2
Yes, only one weekdays	0.0	0.0	0.0	3.3	0.0	0.0	2.4	0.8
Yes, only on weekend/non-work days	3.8	2.0	0.0	0.0	4.0	0.0	0.0	1.6
Yes, everyday	3.8	29.4	27.3	20.0	32.0	18.9	11.9	21.7
Other	3.8	0.0	0.0	0.0	2.0	0.0	0.0	0.8

Opportunities for Recipients to Make Choices	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Metro Outstate (n=37)	Rural Outstate (n=42)	
Recipient decides when (s)he will visit family								
No, arrangements are made for recipient	65.4	56.9	77.3	90.0	52.0	78.4	83.3	69.8
Yes, only on weekdays	3.8	3.9	0.0	0.0	2.0	2.7	2.4	2.3
Yes, only on weekend/non-work days	3.8	19.6	18.2	6.7	22.0	5.4	9.5	13.2
Yes, everyday	26.9	15.7	4.5	0.0	18.0	13.5	2.4	11.6
Other	0.0	4.0	0.0	3.3	6.0	0.0	0.0	2.4
Recipient decides when (s)he will go out with friends								
No, arrangements are made for recipient	69.2	33.3	54.5	76.7	42.0	67.6	57.1	54.3
Yes, only on weekdays	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Yes, only on weekend/non-work days	0.0	7.8	9.1	6.7	8.0	0.0	9.5	6.2
Yes, everyday	23.1	47.1	31.8	6.7	44.0	18.9	23.8	30.2
S/he has no friends	3.8	5.9	0.0	10.0	4.0	8.1	4.8	5.4
Other	3.8	4.0	4.5	0.0	0.0	5.4	4.8	3.1
Recipient decides when (s)he will spend money for personal items & entertainment								
No, arrangements are made for recipient	57.7	35.3	59.1	93.3[1]	50.0	73.0	52.4	57.4
Yes, during the week	0.0	2.0	0.0	0.0	0.0	0.0	2.4	0.8
Yes, during the weekend/non-work days	3.8	2.0	4.5	0.0	2.0	0.0	4.8	2.3
Yes, during the entire week	38.5	60.8	31.8	6.7	48.0	27.0	38.1	38.8
Don't know	0.0	0.0	4.5	0.0	0.0	0.0	2.4	0.8
Recipient decides what clothes to wear								
No, arrangements are made for recipient	15.4	11.8	31.8	46.7[2]	14.0	37.8	23.8	24.0
Yes, only on weekdays	0.0	0.0	4.5	0.0	0.0	2.7	0.0	0.8
Yes, only on weekend/non-work days	0.0	0.0	0.0	3.3	2.0	0.0	0.0	0.8

Opportunities for Recipients to Make Choices	Type of Residence				Type of County			Total (N=129)
	Family Foster (n=26)	Corporate Foster (n=51)	Own Home-Adults* (n=22)	Family Home-Children (n=30)	Urban Metro (n=50)	Metro Outstate (n=37)	Rural Outstate (n=42)	
Yes, everyday	80.8	88.2	63.6	50.0	82.0	59.5	76.2	73.6
Other	3.8	0.0	0.0	0.0	2.0	0.0	0.0	0.8
Recipient decides what social/leisure activities to attend								
No, arrangements are made for recipient	53.8	27.5	50.0	76.7[1]	34.0	70.3	45.2	48.1
Yes, only on weekdays	0.0	0.0	0.0	3.3	2.0	0.0	0.0	0.8
Yes, only on weekend/non-work days	0.0	2.0	4.5	3.3	4.0	0.0	2.4	2.3
Yes, everyday	46.2	68.6	36.4	16.7	58.0	29.7	47.6	46.5
Other	0.0	2.0	9.0	0.0	2.0	0.0	4.8	2.4

*Includes 15 adults living with their natural or adoptive parents.
[1] X^2 (12, N=129) = 39.9, $p < .01$; [2] X^2 (12, N=129) = 43.0, $p < .01$; [3] X^2 (12, N=129) = 33.6, $p < .01$; [4] X^2 (12, N=129) = 27.3, $p < .01$

Are HCBS recipients satisfied with their lives?

About 42% of the HCBS recipient sample was interviewed about their personal satisfaction with their lives. As noted earlier other recipients were not interviewed because of their age, ability to understand the questions posed or their willingness to participate. Of the fifty-four people who completed the interviews, 12 resided in family foster care homes, 30 lived in corporate foster care homes, and 12 resided with their families or in their own homes. Table 46 presents the summary of responses regarding the satisfaction of HCBS recipients with their quality of life.

The vast majority of interviewees liked the people they lived with. When asked what they liked about their roommates, the most common response was that they were "nice" and they were considered friends. People who lived in corporate foster homes were more likely not to like their roommates than their counterparts who lived in the other settings. Those who were dissatisfied with their roommates most often noted behavior related problems (disruptions, arguments, stealing, intrusiveness, aggression). Roommates' friends were also noted as problems for some individuals. The vast majority of respondents also liked staff members and the way staff members treated them. Respondents who said they liked the staff stated the staff were very helpful and were considered friends. Those who did not like staff gave a variety of reasons most often related to a relationship with a single staff member. But not wanting to be "bossed around" and "fights" with staff members were also mentioned. Staff smoking in the recipients' home and staff use of personal items without permission were cited examples of a certain level of presumptiveness on the part of some staff members that offended some corporate foster residents.

Almost everyone enjoyed the food in their homes. Special likes included accessibility to certain favored foods and the chance to cook one's own meals.

Table 46: HCBS Recipients' Responses to Close-Ended Questions About Their Satisfaction With Their Lives by Residence Type

Close-Ended Question	Type of Residence											
	Family Foster Home (n=12)				Corporate Foster Home (n=30)				Family/Own Home (n=12)			
	Yes	No	Some-times	Don't know	Yes	No	Some-times	Don't know	Yes	No	Some-times	Don't know
1. Do you like the food here?	91.7	8.3	-	-	96.7	3.3	-	-	91.7	8.3	-	-
2. Are you happy most of the time?	83.3	16.7	-	-	86.7	3.3	6.7	3.3	75.0	8.3	16.7	-
3. Are you by yourself most of the time?	66.7	25.0	8.3	-	60.0	36.7	3.3	-	50.0	41.7	8.3	-
4. Do you have friends here?	91.7	8.3	-	-	86.7	6.7	-	6.7	50.0	25.0	-	25.0
5. Do you have friends who do not live here?	100.0	-	-	-	90.0	10.0	-	-	83.3	16.7	-	-
6. Do you go visit your friends outside of your home?	66.7	33.3	-	-	80.0	16.7	3.3	-	83.3	16.7	-	-
7. Are you with other people most of the time?*	50.0	25.0	25.0	-	72.4	17.3	10.3	-	58.3	25.0	25.0	-
8. Do you like living here?	91.7	8.3	-	-	86.7	6.7	6.7	-	91.7	-	8.3	-
9. Do you like the staff here?	83.3	16.7	-	-	90.0	6.7	-	3.3	75.0	25.0	-	-
10. Do you like how the staff treat you?*	91.7	8.3	-	-	82.7	10.3	6.9	-	75.0	-	-	-

Note: Questions 7 and 10 had, respectively, 1 and 2 inapplicable or ambiguous responses.

About 9 or 10 respondents said they liked where they lived. The most commonly given reasons for people to like their residence were unique advantages of their home (e.g., the spaciousness of the house or the pool located in the apartment complex). Among the small group that did not like their residence, the given reasons were a desire to live alone or for a different location.

In general respondents indicated that they liked their neighborhoods, usually because they were quiet and safe, because neighbors were considered friendly, and they were close to community events or other places of interest. Most HCBS recipients report that they are happy most of the time. They reported liking their day/work program or school for reasons including the money they earned, their specific jobs, extracurricular activities, and/or their supervisors and co-workers. Very few people said they did not like their program or school. For free time, people said they participated in solitary activities, exercising, sports, hobbies, and religious services.

How does the HCBS compare with the ICF-MR alternative? How can it be improved?

Case managers' comparisons of HCBS and ICF-MR models. Since the HCBS program began in Minnesota, State policy has been that it wanted it to replace the community ICF-MR program as the primary method of funding and delivering new community services for persons with mental retardation and related conditions in Minnesota. At the time of this evaluation, the HCBS program has grown to a nearly equal number of recipients as community ICF-MR residents (i.e., people living in ICFs-MR of 15 or fewer residents). Because case managers usually are familiar with both programs and the lives of people served by them, we asked case managers to make direct comparisons between the HCBS and ICF-MR approaches to providing opportunities for community living and community integration. In all 47 of the 60 case managers surveyed volunteered comparisons. These are presented in an almost entirely verbatim format in Table 46. (Minor editing was done to clarify referents, correct misspelling, and to reduce the length of some responses). In general, Table 47 summarizes the strong support from case managers from all across Minnesota for the general policy of turning to HCBS as an alternative to community ICF-MR development. Of the 47 respondents only one expressed general preference for ICF-MR services over HCBS. Seven respondents suggested in one form or another that HCBS or ICF-MR program participation per se was not among the variables associated with service quality, noting specifically that service provider and residential circumstances were more important. Four other respondents directly noted or implied that, while HCBS holds greater potential to support opportunities for integrated community living, intervening factors, in particular regulatory burdening and insufficient funding, are preventing that potential from being realized.

These important observations not withstanding, the overwhelming majority of case managers (83%) expressed the judgment that the HCBS program is superior to the ICF-MR option for delivering integrated community services. In addition to their general expressions regarding the preferability of HCBS, case managers identified HCBS as specifically preferable in its tendency to support living in typical homes, having fewer restrictions on the individual, providing for more frequent community activities and relationships with community members, increasing acceptance of persons with developmental disabilities by the general public through interaction, and providing greater flexibility and individualization to respond to the specific needs, preferences and choices of people.

We found the very strong support of the preferability of HCBS over the ICF-MR option very impressive. But just as notable was the sense among case managers that HCBS could be even more preferable to ICF-MR than is currently the case. Specifically, about one-in-five case managers noted with concern the tendency for HCBS and ICF-MR services to be less distinguishable than might be expected, given the individual orientation of the one (HCBS) and the facility-orientation of the other (ICF-MR). These individuals tended to see state rules and regulations as a primary (and undesirable) leveler of the basic conceptual distinctions between HCBS and ICF-MR.

Case managers' recommendations about HCBS administration. The case managers of sample members were asked specifically what recommendations they would make to the Department of Human Services to pursue over the next two years. A total of 70 recommendations were made by 48 case managers who responded to this question. Over 80% of the recommendations made by case managers can be summarized into the 4 broad categories shown in Table 48. These categories are further broken down by the type of county in which the case managers worked.

Table 47: Case Managers' Comparisons of the HCBS and ICF-MR Models in Supporting Integrated Community Living

HCBS Is Better Than ICF-MR

- **Generally the HCBS program is better than the ICF-MR.**

  -Not even close-the waiver is much, much better.

  -The waiver program is far superior to ICF-MR because of the size of facilities and the staffing patterns.

  -Waiver is better, but ICF-MRs sometimes provide more opportunities for group community outings.

  -Most ICF-MR facilities are nothing more than community-based mini-institutions!

  -I feel overall the waiver provides an advantage to clients. There are, however, some clients who do better in the ICF setting.

  -There is no doubt in my mind that the waiver is superior to an ICF-MR in providing integrated community experiences and a much more "normal" life to individuals.

  -Waiver program clients seem to be happier with their placements.

  -I think there is a great advantage to waivered services.

- **The HCBS program provides a more normal, homelike, and/or less restrictive environment than ICFs-MR.**

  -The difference? An ICF is a "facility," a waiver situation is "home."

  -I do believe that the waiver program offers a less restrictive living arrangement than ICF/MR.

  -Although both are 24 hr. supervised, waivered services is more normalized than ICF-MR.

  -The waiver offers a much more family oriented system for people, which the ICF-MR does not [The] community support services [approach] is much more normalized.

  -The smaller the site the better for the residents.

  -Typically foster homes have a more home-like atmosphere and are more able to do things with the clients on a more personal basis.

  -The waiver program allows for a more "normal" home setting: Our local ICFs-MR do a good job integrating clients into the community but the home setting is more like a "dorm" in the ICF.

  -[HCBS] is less restrictive and more normal for people

  -Waiver program is a definite bonus. It allows/demands a less restrictive/more normalized setting in most cases.

  -[HCBS] is less costly as well as normally being a more "homelike" atmosphere.

  -Since [HCBS] clients remain in their own homes or live in settings that are not specifically designed as facilities, there seems to be much more normalization in living environments.

  -[HCBS recipients] are in more normalized settings and the programs seem to be more individualized.

  -The waiver program has allowed many people to live as independently as they can in the community in programs designed for them. The rules and regulations of ICF-MR's can restrict people and make them dependent on staff.

  -I think the [HCBS] program has afforded many people the opportunity to move into a less structured living situation and a chance to be far more integrated into the regular community.

- **HCBS provides more or better opportunities for community integration.**

  -People living in a SLS have more opportunities [than ICF-MR residents] to become part of a neighborhood and interact with their neighbors, whereas the general population tends to shy away from "group homes".

  -The waiver program provides for more 1 to 1 experience in the community.

  -The general public is better educated when an individual is living in a waiver program as they can see the person with developmental disabilities has similar needs and desires as they do. They begin to look at that person as other than handicapped and gain insight into the need for quality of life for everyone.

  -There are more opportunities for integration with the waiver.

  -The focus of the waiver a lot of times concentrates on community recreation experiences in the "mainstream of the population".

  -The waiver program has greatly increased opportunities to have residents more integrated into the community.

  -Since the clients live in the community in a home that looks like others in the neighborhood, it makes it much easier for them to have contact with other people. It gives them a chance to attend more community gatherings in smaller groups which cause less attention being paid to them as there would be in a larger group.

  -I believe that waiver sites can offer more normal community outs for [their] residents, e.g., spontaneous shopping, leisure activities, doctor visits, etc.

- **There is more flexibility and individualization to respond to individual needs and preferences in the HCBS program than in ICF-MR.**

  -Flexibility in when things are done is a definite plus in the waiver program.

  -[HCBS] offers more flexibility in doing "normal" community activities.

  -Waiver is much more able to be flexible; have 1 to 1 outings and training while ICF-MR is usually grouped (#12).

  -The waiver has more flexibility and offers more opportunities for integration. There is more opportunity for one to one time between the provider and the client.

  -The benefit of the waiver program . . . is that it allows programs to be more client drive . . . and . . . it allows for more individualization in program development. As a result clients can more easily attend "normal" community activities even if their need for supervision is high.

  -The use of staff time, particularly in the provision on In-home services seems to allow more flexibility.

  -The rich staff to client ratios in SLS enables the individuals to be involved in more activities of choice in the community.

  -The waiver program gives more opportunities to our clients in terms of all their experiences because they have fewer people to live with and be around all the time, and so they have more time by themselves to do things they want to do.

  -The waiver provides more of a 1:1 or 1:2 [residents to staff ratio] community experience as opposed to small groups [so that HCBS recipients] can do more individualized activities, e.g., Scouts with a 1:1, going swimming, etc.

  -The waiver program provides more client flexibility with less funds but still seems to be more "real life" in terms of how clients live their lives.

Neither HCBS Nor ICF-MR is Categorically Preferable

- **The HCBS program may have more potential than ICF-MR to support normal integrated community living, but that potential is impeded.**

  -It has the potential to bring about a great deal of community citizenship, offers more opportunity to be independent and to make decisions, and to function more "normally"—if the provider can be freed to be more natural in providing the service.

  -Waiver only works when enough staff are available. Far too often the entire "household" must go shopping together, to a community event together, etc.

  -Things are starting to work more and more the same unfortunately. Causes: regulations, rules, funding. [HCBS] providers are beginning to focus on paper compliance like ICF/MRs which takes them away from individualized services, use of community resources, etc.

  -In the beginning the waiver was a great way to assist persons to live within their community. However, at this time the paper work and other rules and regulations have made the waiver program exactly like living in the restrictive ICF/MRs.

- **Differences between HCBS and ICF-MR depend on the service provider or specific setting, not the "program" type.**

  -[It] all depends on the provider. Some ICF-MR sites give more "integration" and training than waivered sites.

  -The advantages of waiver for a person are high (personal space, more intimacy, more social opportunities, etc.), but I see many ICF/MRs that are smaller, more personal, nicer, etc. [than other ICF/MRs] that make them attractive, too.

  -There is more flexibility [with HCBS], but the quality depends on the provider.

  •Persons who reside in their family homes and receive in-home services are able to experience more community integration than persons living separate. Persons living in ICFs or SLSs tend to become more isolated from family and rely on paid staff to mainstream them into community activities.

- **There is not an appreciable difference between HCBS and ICF-MR.**

  -I see that 6 bed ICF-MR facilities with adequate staffing provide very comparable and positive integrative experiences. I do not see that waiver clients have substantial advantages in that area.

  -The ICF/MR facilities that I deal with provide [opportunities for community integration] as well as (sometimes better than) than the SLS sites I deal with.

ICF-MR is Better Than HCBS

- **Generally ICF-MR is better than HCBS.**

  -I prefer ICF-MR programs.

The first and by far most common recommendation of case managers was to reduce the paperwork associated with HCBS management by case managers and/or required of services providers (39% of recommended program changes fell in this broad category). Case manager responses regarding excessive paperwork and over-regulation ranged from the impassioned to more restrained expressions of the same sentiment. Along the general lines of reducing administrative demand, review and revision of Rule 42 was specifically mentioned by several respondents.

The second most common recommendation was to increase generally the diversion allocations to counties and/or, more specifically, to increase the availability of HCBS for family support. This category of response is largely self-explanatory and in most instances was not elaborated on by case managers. Many case managers, not unlike the county officials interviewed, feel particularly strong need to increase HCBS allocations for children and adults living at home.

Table 48: Most Common Recommendations of Case Managers to DHS Regarding HCBS Administration[1]

Recommendation	Type of County			Total (N=58)
	Urban Metro (n=19)	Outstate Urban (n=19)	Rural Outstate (n=15)	
Reduce paperwork associated with HCBS management and/or service provision; revise Rule 42 to this end	11	11	5	27
Expand access to diversions generally and/or family support services[2]	4	5	6	15
Increase flexibility in use of HCBS services funding, reduce amount of costs going to provide agency administration	4	1	2	9
Increase average per diem toward maximum allowable by federal regulations	3	2	2	7

[1]Duplicate count of 48 respondents' suggestions.
[2]Specifically mentioned families needing improved access to services were those with members with medical needs and families of low income.

A third relatively frequent recommendation of case managers was to increase the flexibility of case managers, families and consumers in utilizing authorized services and funds. Of interest to some case managers was increasing family choice options in which "case managers and family decide what services are necessary," especially to the extent that there could be options that were less reliant on provider agencies. One case manager hypothesized that, "If individuals/families were allowed to secure their own services from neighbors and friends we could probably reduce in-home program costs by half." Others expressed concerns about the high proportion of HCBS funds that go for administrative costs in the agencies providing those services. One case manager provided documentation of 35% of HCBS expenditures for an individual being paid to persons actually providing those services.

A fourth general area of relatively frequent mention was to increase the average allowable expenditures for all or for specific groups of HCBS recipients. There were a range of case manager concerns subsumed under this category. One case manager noted the cost difficulties faced when youth and young adults with relatively high need are ready to leave the family home, but cannot be served out of the family home with the available HCBS funds. Others noted that the maximum allowable average expenditure is not high enough for persons with high needs. A number of respondents noted the difficulty of serving people with comprehensive service needs (including out-of-home residential, day program and other services) within the allowable average limit; in fact, one respondent noted that day programs alone sometimes consume over half

the average allowable funding for all HCBS for an individual. Two case managers considered a firm limit on expenditures per individual (as opposed to the use of an average) to be a way to resolve the ambiguities in financing services to people with a wide range of needs. While generally being able to work within an average per diem limit allows flexibility in serving relatively high needs individuals, as one case manager noted, once a county approaches that limit much of the flexibility is gone.

A significant number of suggestions by case managers about how to improve the State's HCBS program included topics and issues which could be addressed through the development of a statewide training program. For example, case managers noted a) the need for assistance in what to look for in monitoring service quality and cost effectiveness, b) how to find and develop community jobs, c) how to effectively negotiate the cost of services, d) practical implementation of the criteria for determining eligibility and appropriate program use, e) clarification of existing rules, and f) expansion of opportunities for case managers to meet with one another to discuss experiences, problem solve and learn of examples of creative program use. In short, case managers not only frequently note the limitations of others who provide services, they also recognize numerous training needs for themselves.

There were three specific services identified by two or more case managers as being needed in greater supply to support persons receiving HCBS services: supported employment; temporary crisis management services; and assistive equipment/technology, including, specifically, augmentative communication devices ("Many times Medicaid denies equipment that would be very beneficial in keeping an individual out of an ICF/MR," observed one case manager). To the limited extent that a problem was identified in obtaining assistive equipment and devices for HCBS recipients, it seems to be more one of assuring that case managers and families are fully aware that HCBS funding is readily available for accommodative equipment, devices or modifications than of actual limitations in access. There seems to be a general commitment on the part of the DHS to use HCBS for any reasonable purchases that are denied by Medicaid. Some case managers are not fully appreciative of the rationale of requiring that Medical Assistance authorization of such expenditures be pursued before HCBS, nor do they seem to understand the benefits of such an approach to the county (i.e., the expenditures do not affect the county's average HCBS expenditures).

PART IV. SUMMARY AND RECOMMENDATIONS

Minnesota's Medicaid Home and Community-Based Services (HCBS) program is one of the largest and most rapidly growing in the United States. In FY 1985, its first year of operation, it provided services to 278 Minnesotans with mental retardation and related conditions (MR/RC); in FY 1991 it provided services to 2,690 Minnesotans with MR/RC, 2,466 of whom were enrolled on June 30, 1991. As of June 30, 1990 Minnesota's HCBS program was fourth largest in the U.S., behind California, Florida and Pennsylvania. Minnesota's relative HCBS utilization rate of 49.9 recipients per 100,000 total state residents ranked fourth nationally, behind North Dakota (165.1), Utah (69.6) and Colorado (55.9).

Despite its relative size and rapid growth, the HCBS program has worked effectively as part of an overall strategy in Minnesota to control growth in Medicaid long-term care services for persons with MR/RC. Between 1987 and 1990 Minnesota's total ICF-MR population decreased by 14.0% as compared with an increase of 0.6% in all other states excluding Minnesota. Between 1987 and 1990 Minnesota's combined ICF-MR and HCBS recipient populations grew by 5.9%, less than half the national average increase of 13.2%. Over that same period Minnesota's per capita growth rate of 2.6% was only one-quarter of the national per capita growth rate of 10.3%

Access to Services

Overall access to HCBS in Minnesota appears to meet all applicable requirements, although the program has minor technical accessibility problems. There are also substantial problems in meeting the overall demand for services, which is largely a reflection of the program's popularity. It is important to highlight that throughout the data collection activities families, case managers, county officials and service providers commented extensively about the substantially greater number of people needing "diversion" allocations than they were able to serve, and within that context a perceived relative imbalance between diversion allocations and conversion allocations. Of course, although access to HCBS for persons with MR/RC in the community is relatively more restricted than for persons in RTCs and community ICFs-MR, the State's policy of using distribution of conversion and diversion allocations to support deinstitutionalization is a legitimate policy goal, one clearly endorsed by the Minnesota legislature. One might also note that although "diversion allocations" seem restricted given the high demand for access to them, few states offer more HCBS allocations to community applicants than does Minnesota. While the proportion of new enrollee placements allocated to diversions was 43% in 1991 and is projected to be 39% in 1992, the number of diversion allocations was increased consistently by 165 in each year covered in the renewal application being evaluated. Still there is a huge desire and widespread conviction about a need for a greater number of diversion allocations to improve overall access to HCBS for several hundred or more eligible community residents currently waiting for HCBS enrollment.

A number of areas were detected in this assessment which should receive some specific attention by the State. In certain of these areas the State should implement strategies to assure continuous compliance with basic access requirements of HCBS participation. First, Minnesota should improve efforts to assure that family members of persons being offered HCBS fully understand that they have and retain a choice of the ICF-MR alternative. This is required by federal regulation. Even though the alternative ICF-MR service is seldom available in places other than large institutions, which are unlikely to be desired by those seeking HCBS, the choice must be explained fully. Second, the State needs to improve its access to HCBS for persons in racial and ethnic minority groups. Doing so will require improving program awareness in minority communities and among the social and health organizations that are part of those communities. It will also involve working directly with counties that have substantial minority memberships to improve minority access to HCBS. Third, the State should work to eliminate the practice of "deferred screening" of people for eligibility for HCBS until HCBS allocations are available. This practice not only violates State regulations, it prevents adequate data on the number of people waiting for services and may ultimately jeopardize equal access to services for people whose screenings have been deferred.

Improvements should be pursued in county-related differences in access to HCBS. At present a person's county of residence has considerable association with his/her likelihood of receiving HCBS. This relates in part to the State's methods of distributing HCBS allocations, but also to intra-county "procedures" for deciding who will receive limited HCBS allocations. The State should work to establish some consistency across or minimally formal policy within counties in establishing priorities on how limited HCBS allocations will be distributed to individuals. Many counties have no policy and a substantial number of case managers suggest that "pull" and "connections" are contributing factors to the selection of recipients.

Families and case managers identified a number of general service types and specific professional services needed by substantial numbers of persons with MR/RC and their family members. Among these were increased access to respite care, employment services, communication training, psychological and behavior analyst services, and physical and occupational therapy. Providers of such services are viewed as too few in number all through the State, with shortages most frequently noted in rural areas. Concerted efforts on the part of the State to increase the number of service providers are likely to be needed to sustain the recent and projected program growth. Such efforts are also needed if the pool of providers is to be expanded to enhance diversity of opportunity, choice and competition.

In highlighting these problem areas it is recognized that some can be addressed more easily than others, and that some are under the direct control of the Department and/or counties, and some require more collaborative efforts with other state agencies and/or the provider community. Changes in some areas (e.g., improving the quantity, quality and support of HCBS providers) will take considerably more effort, more time, and many more participants to effect than others. In general, however, the State and the counties can be generally commended for ensuring fairly equitable access to enrollment as well as generally sufficient access to providers and services once HCBS recipients are enrolled.

Cost-Effectiveness of Services

Overall cost-effectiveness of Minnesota's HCBS is well within federal requirements. Expenditures for Minnesota's program are considerably below those estimated in the original application. In fact, Fiscal Year 1991 expenditures were nearly $15 million less than originally projected. The HCBS program has had a substantial impact in lowering total Medicaid long-term care costs for persons with MR/RC, although on a per capita basis Minnesota still ranks as the third highest spending state for ICF-MR services and the fourth for combined ICF-MR and HCBS. Nevertheless, largely due to increased reliance on HCBS as the primary method of providing and financing services for persons with MR/RC, between FY 1987 and 1990, Minnesota's combined ICF-MR and HCBS costs increased only 24.9% as compared with 38.2% for the U.S. as a whole.

It was observed in this assessment that there are currently substantial costs of providing "supervision" to HCBS recipients that are presently paid for by the Minnesota Supplemental Aid (MSA) cash supplement to federal Supplemental Security Income. These supervision costs are clearly within the scope of services Minnesota is authorized to provide as HCBS and thereby to cost-share with the federal Medicaid program. It is in the state's best economic interest to subsume these services in their HCBS program, thereby paying only 47% of their total cost as compared with 100% currently. In fact, it appears that present MSA financing of supervision is in conflict with existing State law and regulations which limits the use of these cash assistance funds for HCBS recipients to room and board expenditures, which by regulation (Minnesota Rule 41, Subpart 21) includes only "A. normal and special diet food preparation and service; B. linen, bedding, laundering and laundry supplies; C. housekeeping, including cleaning and laboratory supplies; D. maintenance and operation of the building and grounds, including fuel, electricity, water, supplies and parts and tools to repair and maintain equipment and facilities; and E. allocation of salaries and other costs related to these areas." It is also in conflict with responsibilities written into the Department's mission by the Minnesota Legislature to maximize the use of federal financial contributions to appropriate services. Should the state choose to treat supervision as a service under its existing Supporting Living Services, as is recommended, there will be some required increase in the average HCBS cost per day (probably about $7). This recommended approach to

financing "supervision" would bring Minnesota into compliance with the implications of its own laws as well as common HCBS financing practices nationally. Although total HCBS costs would increase about $7 per day, true per person service costs would not be effected; they would merely be cost-shared as an HCBS service already authorized for Minnesotans.

Quality of Services

Overall, the quality of HCBS for persons with MR/DD in Minnesota appears generally good both in terms of the nature and frequency of services received and in terms of the expressed satisfaction of case managers, family members and HCBS recipients themselves with those services. HCBS recipients received a wide variety of health care services and the vast majority of people (93%) had seen a physician and about 75% had seen a dentist in the previous six months. For the most part, HCBS recipients are integrated into the typical community clinical practices for medical and dental care. Respondents overwhelming agreed that medical services were at least adequate, with only a few respondents seen as needing additional medical services.

Every sample member received case management services, from case managers engaged in a wide variety of activities of assistance to HCBS recipients, their families and HCBS providers. Almost half (48%) of the families/guardians of HCBS recipients rated case managers as excellent and 84% rated them as good or excellent. Families and guardians also expressed generally high levels of satisfaction with other HCBS, with only in home family support services being rated by less than 75% of respondents as good or excellent (66%). The most common critical comments of parents/guardians about HCBS were related to the number, quality and training of staff, but such comments were provided by a small portion of the total respondents.

A third of the sample members were children and youth attending school. The vast majority of adult recipients participated in traditional, segregated day activity, work activity or sheltered work centers, but about 29% spent some part of their day in working in competitive employment, supported employment or in an "enclave" in a regular place of employment. About 3% of the sample was waiting for a day program.

Almost all HCBS recipients had habilitation objectives that were oriented toward independence, interpersonal skills and community involvement. The vast majority of sample members had interpersonal relationships with more than 6 people of importance to them. For 88% of HCBS recipients these people included members of the immediate family. Family visits were fairly frequent. Among persons not actually living with their immediate families, 85% had been visited by or went to see members of their immediate family in the previous 6 months.

HCBS recipients were active users of community places. During the previous 6 months, over four-fifths of the sample members had used grocery stores (89%), parks (92%), clothing stores (83%), department stores (82%), and restaurants (99%). HCBS recipients also participated in a wide variety of leisure activities with a range of people. In the previous month most had been grocery shopping at least once (86%), visited friends (72%), attended a religious service (61%), ate out (98%), went to a bank (55%) or went shopping for personal items (80%). Perhaps typical of the culture 91% of HCBS recipients watched TV on a daily basis. Most commonly the people who took part in leisure activities with HCBS recipients were family members, paid staff or friends with disabilities. HCBS recipients rather uncommonly participated in activities with friends or acquaintances who themselves did not have disabilities.

Although most sample members were provided with opportunities to make choices and exercise control over aspects of their day-to-day life, there was more regimentation and control than might be expected in an individual-centered service approach. Although most adults were able to choose their own bedtimes, a significant minority were not. It was generally the case that persons living in corporate foster care settings were afforded more frequent opportunities for choice and personal control.

For the most part HCBS recipients seemed quite happy with their lifestyles. About 89% reported liking where they live, and 81% reported liking the way the service providers treat them. HCBS recipients overwhelmingly reported themselves to be happy most of the time (83%). In short, a substantial majority of people receiving HCBS in Minnesota enjoy active lives in which their basic health and well-being are protected and enhanced by service providers who are individually given good marks by case managers, family members and the HCBS recipients themselves.

Broad Areas Deserving Attention

The data gathered in this assessment suggest that Minnesota's general strategy of steadily replacing ICF-MR capacity with Medicaid funded Home and Community-Based Services is one which is generally well-supported by both the quantitative and qualitative data gathered on the costs and quality of services. However, two broad problems with the implementation of this strategy were frequently identified in the assessment. These were 1) the difficulty in Minnesota in shifting from small group, facility-based approach to service provision to an approach in which services are planned and provided in response to the specific capabilities, limitations and life circumstances of each individual HCBS recipient, and 2) the need to develop a more comprehensive and decentralized program of quality enhancement that substitutes training, technical assistance and other support to providers and families for much of the current dependence on regulation as the means of promoting quality in HCBS. With respect to regulation there appears to be a nearly universal perception that services are overregulated, that the current regulations have too little to do with quality of life and that the current approach is poorly suited to respond to the dramatic increase and dispersal of small service "sites."

Moving the HCBS Program Toward More Recipient-Centered Orientation

In interviews with direct care service providers, agency directors, state officials and family members, there was wide-spread concern about whether HCBS, particularly as provided to people living in corporate foster care settings (staffed group homes of 4 or fewer people) represented as much improvement over the small ICF-MR group home as would be desirable and reasonable to expect. Indeed, the similarities tend to be much deeper than just the fact of people living in congregate settings with paid shift-staff and similar regulatory demands. Although the HCBS approach is generally expected to differ from ICF-MR in the fee-for-services-reimbursement of the former versus daily facility per diem charge rate for the latter, in corporate foster care it appears standard practice that rates are negotiated in the same manner as ICFs-MR, that is, first by establishing a program for a specific small group of people and then using various "waiver service" configurations to obtain the per person revenue ("per diem") needed to equal a predetermined level of program revenue (these revenues include not only the cost of services, but housing charges, agency administrative costs and fees as well). In this approach the HCBS "package" of services and costs are developed as an administrative process required to generate the agreed to costs of operating the group home. To the revenues directly obtained through HCBS, a "supervision" component typically is added to room and board costs with the total paid by the recipients' cash assistance from federal Supplemental Security Income (SSI) and Minnesota Supplemental Assistance (MSA). By using individuals' cash assistance to fund "supervision" Minnesota has clearly been funding services which might be cost-shared with the federal Medicaid program; few if any other states fund solely such services which could be cost-shared for HCBS recipient supervision (i.e., basic direct care). At the same time, Minnesota's "negotiated rate" which utilizes the HCBS recipients' cash assistance for "room, board and supervision" costs appears to have had few if any controls on amounts or appropriateness of expenditures in some areas.

It is wholly appropriate to use an individual's SSI and MSA to pay reasonable room and board costs, but efforts should be made to gain control over the use of these funds, both to assure that State only funds (MSA) are not used when federal cost-sharing is available and to assure appropriateness of expenditures for room and board (SSI and MSA payments can easily exceed $2,500 a month for 3 people). Probably the most direct method of gaining such control would be to establish a ceiling on total room and board expenditures available to HCBS recipients. Those expenditures could be capped around the full SSI payment or some other

appropriate level in the least costly rural areas with a relative cost inflator for areas in which housing and food are more costly. This inflator would be available from MSA funding. A special fund might be established for extenuating circumstances, but it is in the State's economic interest, as well as its responsibility in state regulation to limit non-HCBS spending strictly to approved, reasonably priced room and board (and, of course, services that cannot be HCBS funded).

A second reasonable step in improving the individualization and efficiency of HCBS would be to limit service providers' vested financial interest in the housing, furnishings, food purchases and other basic components of the room and board charge. It does not serve the personal interest of the HCBS recipient (nor probably the economic interest of the State) to have service providers with a primary economic interest in where people receiving HCBS live. Making HCBS a more personalized service program, which was viewed as desirable by most of the state and county officials, case managers and direct care staff interviewed, requires that each individual's housing be as much of a personal option as is feasible, with choices dictated primarily by personal interests, not the economic interests of another individual. Relatedly, when providers of service control (either own or rent) the housing in which service recipients reside, they establish a tacit monopoly on service provision to those individuals, in that it is the "provider's door" through which direct service staff must pass. The HCBS recipients who in interviews in this assessment complained about staff smoking in their homes or using their possessions without permission are symptomatic of such problems. While virtually everyone interviewed in this assessment encouraged efforts to support an evolution toward a service rather than facility-based model, most appeared to appreciate the difficulty and slowness of change in a community service system that for 15 years has been dominated by a group home model. Among the steps in planting seeds of movement from a facility-based to an individual-centered service model are demonstrations that begin with independent control of the housing, where the door to be crossed by a service provider is the door of the HCBS recipient(s), their families and/or an independent housing agent acting in their behalf. Such efforts may further assist in reconceptualizing an approach to HCBS service delivery in which the individual services needed by people are provided in a manner that allows specific delineation of the kinds, amounts, durations and qualities of services needed, the options for meeting these needs in terms of potential providers, their rates, and/or their alternative approaches for meeting the specific service needs. Clearly such approaches will require increased involvement of case managers, families, HCBS recipients and other advocates for an individual recipient.

Another major step toward moving the focus of the Minnesota system to a more individualized system is increasing the pool of providers. When agency directors were interviewed about their concerns about the HCBS program, one candidly spoke of his agency's symbiotic relationship with its county human services agency. This provider noted that the county consistently turned to his agency when the state issued the county new HCBS allocations and the county had chosen the individuals it would like to serve. While the provider enjoyed the good faith and good will this relationship represented, he also noted that it had brought the size of the clientele and staff of the agency past the point at which it was (once) most effective. These and related comments, and the general sense that ultimately the quality, cost-effectiveness and ability to continue expansion of the Minnesota HCBS program depends on a growing pool of potential providers raise questions that were added later into the survey of case managers, specifically, "what is needed to increase the pool of providers?" In interview and questionnaire responses, two areas were repeatedly identified as needing attention to favor the existence and further growth of new individuals and agencies to provide HCBS: 1) financial assistance for providers and 2) support to providers and counties.

With respect to financial assistance to providers attention must be given to the start-up costs and the substantial costs of services provided before reimbursements are received. Attracting new providers, particularly ones whose primary motivation is professional rather than potential to profit and who are not highly capitalized will require financial assistance. A 3 to 4 month revolving account would be helpful to new providers. Relatedly there needs to be improved assistance to new providers in identifying and securing basic necessities, from required licensing and training to insurance, including loans and grants to individuals who need them to enter the field. There also needs to be available to providers technical assistance with the

financial aspects of a service business, including financial management, billing and record keeping. To involve in service provision more people whose primary training and orientation is service delivery rather than business per se, there needs to be much more assistance to providers in the business aspects of the role.

Providers and case managers also noted the need for substantially increased support to counties and individual service providers if the pool of providers is to be increased. Among specific help needed is assistance to counties for their efforts at recruiting and training staff. Providers and counties also need help in developing systems of locating, hiring and purchasing needed assistance from people ranging from professional specialists to neighborhood respite providers. Service providers need support in meeting crises of both behavioral and economic nature. Often a difficult HCBS recipient requires far more time and expense than was allocated. Relatedly if a single recipient is lost because of illness or a behavioral crisis a substantial part of the small program's income is lost. This can have a devastating effect in a small provider's income and cash flow and reflects an inherent disincentive within the system for small programs that have much less flexibility in moving staff from site to site than larger programs. By attending to the special circumstances of the small provider through promoting mechanisms like personnel or commodity purchasing cooperatives, the state could assist in the realization of its own espoused goals in increasing the provider pool.

Developing a Decentralized Capacity for Quality Assurance and Continuous Quality Improvement

This assessment found Minnesota's HCBS program to be successful in meeting the basic health and welfare needs of HCBS recipients in community settings. The program also exhibited relative success in supporting community lifestyles that reflect the qualities of community integration, personal development, productive participation, and opportunities for choice and self-determination. But clearly it is in this latter area that the challenges are currently the greatest and will be most rapidly increasing in the future. As the State prepares for that future it should strive to establish a strong and vital system of training, technical assistance, licensing review and other quality assurance and continuous quality improvement efforts that can affect the lives of HCBS recipients in the many hundreds of separate places in which they live.

Over the past decade Minnesota has promoted and supported a major relocation of people and services from RTCs and large private ICFs-MR to small ICFs-MR and HCBS (and to a lesser extent Semi-Independent Living Services or "SILS") provided in small housing units, natural and foster families and individual homes. Through these efforts over 4,000 more Minnesotans are receiving community services than was the case 10 years ago. As the number of these dispersed service sites has multiplied over and over again, the State's general capacity and available mechanisms to contribute to the quality of life in these homes and in the surrounding community has changed little if any. For the most part state involvement in quality enhancement has been limited to licensing and related regulatory activity. Most State officials recognize the limitations of this approach. However, in the absence of alternative methods and resources for improving the quality of community service, when the complexities of delivering decentralized services have become apparent through evidence of poor quality of services in some settings, the response has typically been increased regulatory requirements for of all settings. Disenchantment with such approaches as truly enhancing quality of services, not to mention the increased difficulty of simply providing meaningful periodic monitoring of the dramatically increased number of service sites in Minnesota, raises important concerns about the adequacy of Minnesota's largely regulation driven approach to promoting quality in its services.

Among individual service providers and service settings in Minnesota, non-monitoring activities to promote quality in services such as training or technical assistance, where available at all, are differentially available and largely unmonitored with respect to appropriateness, effectiveness, efficiency and general accessibility to all who might benefit. Indeed, the State's primary commitment to non-regulatory quality enhancement, the Regional Support Specialists (RSS) system, has been diminished over the past several years with central administrative functions slowly absorbing opportunities for involvements in the actual services being provided to HCBS and other community service recipients. As new administrative tasks and functions

have been created in recent years by the Legislature or by the Department, they have frequently required using the extremely limited RSS resources for additional central administrative activities.

The tendency toward slightly reduced State resources committed to supporting and improving the quality of community services at the time of dramatic program growth (e.g., from 0 HCBS and SILS recipients in 1983 to about 4,000 today to over 7,000 by 1997) has actually reduced the Department's ability to contribute to the quality of its program. As the State continues on its path to increasingly decentralized and dispersed services, the State's ability to make meaningful contributions to the quality of those services will ever more depend on developing a system of quality assurance and continuous quality improvement that matches the reality of the service delivery system. By the end of the decade HCBS will be the primary program for delivering services to Minnesotans with MR/RC. The HCBS, along with the smaller SILS program, have taken Minnesota from a system in which services were delivered to Minnesotans in 318 ICFs-MR and RTCs in 1982 to a system in which 10 years later Minnesotans with MR/RC were living in about 1,500 separate, non-family residential settings in which supervision was provided, not to mention the hundreds of individuals receiving services while living in the family home. By 1999 the total number of non-family settings in which Minnesotans are receiving residential services, supervision and/or support is likely to increase by another 1,000 homes, including residences that will house hundreds of persons with severe impairments who currently reside in RTCs. Over 1,000 additional new service recipients are likely to be living with families who themselves frequently need training, technical assistance, information and other supports. For the State to have a serious influence on the quality of those services it must develop a program that increases the amount and quality of its field-based capacity to deliver the training, technical and informational assistance, crisis management, and other programmatic and business supports needed by the people providing HCBS and other services to these individuals. To the extent it wishes to act on the perception that increasing the number of service providers can increase quality and cost-effectiveness through competition and choice, it must incorporate within that system assistance in the recruitment, initial and ongoing training and other support to new providers. To the extent it wishes to increase the social and community integration of persons with MR/RC it must incorporate skills and commitments in establishing and maintaining ongoing organizational commitments to and interpersonal relationships with people with MR/RC.

Minnesota has a range of nationally recognized centers of expertise in the kinds of supports needed throughout the state by HCBS providers and by HCBS recipients and their families (e.g., The Institute on Community Integration; the PACER Center, the Governor's Planning Council on Developmental Disabilities). These centers are all committed to improving the quality of community living for Minnesotans with MR/RC. An important challenge facing the State is to develop the mechanism to work with these organizations in the diffusion of their knowledge, expertise and services to the places all across the state in which services are delivered. One way to develop and sustain a program of support to community service providers and families would be for the Department of Human Services to seek legislative approval of and a direct appropriation for state-wide, area-based training, technical assistance and support programs. Such programs would be responsible for training, technical assistance and related support services to agencies, individuals and families providing services and supports to Minnesotans with developmental disabilities in specific geographical areas within the State. They would have a major responsibility for identifying and responding to the specific needs of individual HCBS recipients and their primary service/care providers. But they could also play a major role in meeting the general needs of a geographical area, including initial and ongoing training for service providers; assuring that parents of service recipients and persons needing services and their families know of the options available to them; providing recruitment of and information to potential new providers; providing and/or supporting crisis management services; maintaining, coordinating and disseminating common calendars of training; working with local civic, religious and other organizations and with individuals to build and support relationships between service recipients and other community members; supporting citizen and consumer monitoring activities, and so forth.

A relatively modest expenditure (e.g., 2% of the total HCBS and community ICF-MR expenditures) could bring rather substantial increases in the State's ability to affect the quality of services at the most distal,

but by far the most important part, of its services system. A 2% State commitment to a system of continuous quality enhancement would mean basically that for every 50 dollars spent on direct services in ICF-MR and HCBS programs in the previous year, 1 dollar would be allocated to a pool to establish and sustain a field based system to support the quality of those services. Because these costs could be reimbursed as a direct service cost at the Medicaid matching rate or the Medicaid administrative rate, Minnesota's contribution would be no more than 1% of its community Medicaid budget to establish and fund a decentralized program of training, technical assistance, provider support, community development and other activities to make those services of high quality. In other words, for every 100 dollars spent on Medicaid community services, Minnesotans would contribute 1 dollar to support and improve the quality of those services through a decentralized program of training, service monitoring, technical assistance, provider support, crisis management, community development and other activities. Operating from the 2% of community ICF-MR and HCBS standard, 8 Area Programs could be funded with approximately $350,000 per year to cover the costs of their personnel, training (materials, space, speakers), evaluation projects, community monitoring and involvement activities, administrative functions, space, and so forth.

Area Programs could be contracted non-profit agencies, ideally with the state RSS (a state employee) and representatives of licensing housed in each center to provide the kinds of coordination of technical and informational assistance, program development and regulatory review that are needed for a more substantive, less punitive approach to quality assurance and continuous quality enhancement. In fact a major role of the Area Programs should be to assure that all programs in its area are fully prepared for all regulatory inspections, and the success of each Center could be judged in part by the success of the area's service providers in demonstrating compliance to state standards. While the geographical areas covered by Area Programs should obviously be considered carefully, far more important would be that they are staffed by people who have extensive experience and high credibility in meeting the needs of individuals, families and agencies in the community. As such Area Programs might ultimately be operated by a range of different private or public agencies (e.g., a university, a vocational technical institute, a consortium of counties, a group of experienced community service providers).

In addition a State Support System Project would be an important component to such an effort. Its function would be to provide trainer support, curriculum development, expert consultation, program evaluation advice, annual training conferences and workshops on key topics, and other support needed by the Area Programs, including areas such as provider recruitment or identifying relevant research and other literature. This Project could bring together the substantial resources available in the Twin Cities metropolitan area, into a concerted effort linked to each of the Area Programs.

The outline presented here is, of course, just one of several possibilities. While the structure of a program ultimately developed might vary considerably from that described, as Minnesota continues the expansion of its community services the need for such a program will grow commensurately. But the inevitable expansion of community services is only one of the considerations suggesting a growing need for such a program. There is an increasing disaffection and loss of faith with regulation as the State's primary means to ensure quality. Evidence is available from a number of recent state studies that a dwindling number of people today identify Minnesota regulations as attending and contributing to what is important in the lives of Minnesotans with MR/RC; and a growing number of people view them as impediments. The State can neither dismiss the disaffection with regulations, nor its ultimate responsibility for the quality of services. Therefore, the time seems right for reconsideration of the State's role in quantity assurance and continuous quality improvement. It seems likely that the most effective role that the State might adopt is that of sharing responsibility for the quality of services and experiences with the wide range of individuals and agencies in Minnesota who can contribute to the day to day quality of life of persons receiving HCBS and similar services. A well-supported, area-based program of training, technical assistance and on-going support for service providers and families, along the lines outlined above, seems an essential aspect of that new State role.

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APPENDIX A

Table A-1: Characteristics of Recipients of Home and Community-Based Services in All of Minnesota and in 18 Sample Frame Counties

Characteristics	HCBS Recipients[1]	
	All HCBS Recipients in Minnesota (N = 2,466)	All HCBS Recipients in Sample Frame (N= 1,408)
SEIZURES		
Never or none recently	76.6	78.2
Occasional minor seizures	7.3	6.7
Occasional major seizures	9.4	9.2
Frequent minor seizures	3.1	2.8
Frequent major seizures	3.6	3.1
MEDICAL NEEDS		
No serious/specialized needs	33.8	30.4
Specialized or Frequent need attention	56.4	60.6
On-call medical attention	6.6	6.1
On-site medical attention, >24 hrs	2.7	2.4
On-site medical attention, 24 hrs	0.5	0.4
MOBILITY		
No impairment	78.2	80.1
Moves with assistance	8.6	8.6
Moves with self-propelled wheelchair	3.9	3.4
Moves w/wheelchair-propelled by others	8.3	7.1
Not mobile due to overriding medical condition	1.0	0.8
SELF-CARE		
Independent	12.9	13.7
Minimal Care needed	44.5	45.4
Substantial care needed	29.8	29.6
Total care and support needed	12.8	11.2
TOILETING		
Independent	56.2	57.2
Minimal care needed	18.4	19.4
Substantial care needed	12.6	12.7

Characteristics	HCBS Recipients[1]	
	All HCBS Recipients in Minnesota (N = 2,466)	All HCBS Recipients in Sample Frame (N= 1,408)
Total care and support needed	12.7	10.7
SELF-PRESERVATION		
Capable of self-preservation	43.6	46.7
Not capable of self-preservation	55.3	52.3
Unknown	1.1	0.9
PHYSICALLY INJURIOUS TO OTHERS		
No	61.6	60.2
Mild	21.1	21.9
Moderate	12.9	13.2
Severe	4.3	4.7
PROPERTY DESTRUCTION		
None	64.1	61.8
Mild	20.3	21.6
Moderate	10.3	9.7
Severe	5.4	6.9

Table A-2: Distribution of HCBS Recipients in Sample Counties by County Type and Place of Residence

Type of County	Place of Residence					
	Corporate Foster Care	Family Foster Care	Family/Own Home		No Data	Total
			Children	Adults		
Twin Cities Metro	492 (5)	67 (8)	115	141	68 (3)	883 (131)
Out-state Metro	165 (7)	110 (11)	34	33	15 (3)	357 (55)
Rural	73 (2)	40 (9)	19	32	4 (1)	168 (31)
Total	730 (14)	217 (28)	168	206	87 (7)	1,408 (217)

Note: Numbers in parentheses indicate children 17 years or younger.

Table A-3: Distribution and Sampling Ratio of Sample County HCBS Recipients for HCBS Field Study

Type of County	Type of Residence				
	Corporate Foster Care	Family Foster Care	Family/Own Home-Adults	Family Home-Children	Total[1]
Twin Cities Metro Counties					
Sample members	20	10	10	10	50
Sampling ratio	1:24.6	1:6.7	1:14.1	1:11.5	1:16.3
Out-State Urban Counties					
Sample members	10	10	10	10	40
Sampling ratio	1:16.5	1:11.0	1:3.3	1:3.4	1:8.9
Rural Counties					
Sample members	10	10	10	10	40
Sampling ratio	1:7.3	1:4.0	1:3.2	1:1.9	1:4.1
Total					
Sample members	40	30	30	30	130
Sampling ratio	1:18.2	1:7.2	1:6.9	1:5.6	1:10.2

Table A-4: Comparison of Characteristics of HCBS Evaluation Sample Members and HCBS Recipients in Sample Frame Counties

Characteristics	Sample Members				Sample Frame			
	Corpor. Foster	Family Foster	Family/Own Home		Corpor. Foster	Family Foster	Family/Own Home	
			Child	Adult			Child	Adult
AGE								
Mean	37.3	34.5	10.2	29.9	36.6	38.2	10.2	28.0
SD	16.3	21.7	4.2	9.3	15.4	19.1	4.2	9.8
SEX								
Male	39.2	56.0	38.5	48.1	38.5	45.6	32.4	51.1
Female	60.8	44.0	61.5	51.9	61.5	54.4	67.6	48.9
SEIZURES								
Never or none recently	82.0	82.6	65.4	77.8	81.0	80.2	63.0	72.7
Occasional minor seizures	6.0	0.0	15.4	7.4	5.7	5.8	13.8	6.8
Occasional major seizures	10.0	17.4	15.4	7.4	9.2	10.5	8.7	4.5
Frequent minor seizures	0.0	0.0	8.0	7.4	2.0	2.3	0.0	4.5
Frequent major seizures	2.0	0.0	3.8	0.0	2.1	1.2	6.5	11.4
MEDICAL NEEDS								
No serious/ specialized needs	29.4	26.1	15.4	40.7	30.8	39.3	20.5	36.4
Specialized or Frequent need attention	64.7	56.5	73.1	59.3	60.0	49.4	72.6	54.5
On-call medical attention	5.9	17.4	7.7	0.0	6.7	4.5	3.4	4.5
On-site medical attention, >24 hrs	0.0	0.0	3.8	0.0	2.3	6.7	2.7	1.1
On-site medical attention, 24 hrs	0.0	0.0	0.0	0.0	0.2	0.0	0.6	2.6
MOBILITY								
No impairment	80.4	72.7	57.7	84.6	84.0	79.8	62.0	75.9
Moves with assistance	15.7	9.1	11.5	3.8	9.0	6.7	5.6	8.0
Moves with self-propelled wheelchair	3.9	9.1	0.0	3.8	3.2	4.5	4.9	1.1
Moves w/wheelchair-propelled by others	0.0	9.1	26.9	7.7	3.4	9.0	23.2	14.9
Not mobile due to overriding medical condition	0.0	0.0	3.8	0.0	0.4	0.0	4.2	0.0

Characteristics	Sample Members				Sample Frame			
	Corpor. Foster	Family Foster	Family/Own Home		Corpor. Foster	Family Foster	Family/Own Home	
			Child	Adult			Child	Adult
SELF-CARE								
Independent	9.8	8.7	3.8	25.9	15.1	10.1	3.5	22.7
Minimal Care needed	64.7	43.5	15.4	33.3	50.3	42.7	23.1	35.2
Substantial care needed	19.6	17.4*	34.6	25.9	29.2	38.2*	35.0	25.0
Total care and support needed	5.9	30.4*	46.2	14.8	5.3	9.0*	38.5	17.0
TOILETING								
Independent	66.7	39.1	15.4	59.3	63.6	61.4	20.3	58.0
Minimal care needed	25.5	26.1	7.7	11.1	20.2	14.8	20.3	15.9
Substantial care needed	5.9	17.4	30.8	11.1	11.5	13.6	20.3	9.1
Total care and support needed	2.0	17.4	46.2	18.5	4.7	10.2	39.2	17.0
SELF-PRESERVATION								
Capable of self-preservation	60.8	30.4	0.0	48.1	54.0	39.3	8.2	52.3
Not capable of self-preservation	37.3	69.6	100.0	51.9	45.1	59.6	90.4	46.6
Unknown	2.0	0.0	0.0	0.0	0.9	1.1	1.4	1.1
PHYSICALLY INJURIOUS TO OTHERS								
No	58.8	73.9	42.3	77.8	59.2	67.4	52.4	72.4
Mild	27.5	8.7	30.8	22.2	22.0	22.5	21.7	17.2
Moderate	13.7	13.0	23.1	0.0	13.7	6.7	16.8	10.3
Severe	0.0	4.3	3.8	0.0	5.0	3.4	9.1	0.0
PROPERTY DESTRUCTION								
None	56.0	73.9	57.7	66.7	61.5	67.4	52.4	74.4
Mild	24.0	8.7	7.7	25.9	22.8	19.1	19.6	20.9
Moderate	14.0	13.0	11.5	7.4	9.7	10.1	11.9	2.3
Severe	6.0	4.3	23.1	0.0	6.0	3.4	16.1	2.3
WAIVER TYPE								
Diversion	75.0	69.6	0.0	37.0	72.9	56.3	1.6	33.7
Conversion	25.0	30.4	100.0	63.0	27.1	43.7	98.4	66.3

* There was a statistically significant difference between sample members and sample frame members from family foster care settings on the "self-care" variable (X^2 [N = 112, df = 3] = 7.85, p = .049), specifically with respect to the proportions of individuals reported to need "substantial" versus "total" care. (Statistics on all comparisons are shown in Appendix A.)

Table A-5: Characteristics of Recipients of Medicaid Long-Term Care Services for Persons with Mental Retardation/Developmental Disabilities

Characteristics	HCBS Recipients[1]					State RTC Residents[2]	ICF-MR Residents[3]		
	Corp. Foster	Family Foster	Own Home-Children	Own Home-Adults	All HCBS		Small ICF-MR Residents	Large Private ICF-MR Residents	All ICF-MR
AGE									
Mean	36.6	37.5	10.2	28.5	32.6	41.2	41.6	38.5	40.3
SD	15.4	19.1	4.2	9.8	14.3	12.0	13.3	15.6	14.4
SEIZURES									
Never or none recently	80.9	71.5	58.4	78.4	76.6	66.4	79.4	71.6	76.5
Occasional minor seizures	5.8	9.7	14.0	5.5	7.3	3.4	5.7	8.8	6.8
Occasional major seizures	9.1	11.4	12.3	5.9	9.4	23.6	10.7	11.9	11.1
Frequent minor seizures	1.9	4.4	7.8	3.1	3.1	1.1	1.5	3.5	2.3
Frequent major seizures	2.3	3.0	7.5	7.1	3.6	5.4	2.7	4.3	3.3
MEDICAL NEEDS									
No serious/specialized needs	35.1	36.3	18.1	42.7	33.8	15.2	35.3	28.9	32.9
Specialized or Frequent need attention	55.4	53.5	69.1	50.6	56.4	42.3	50.6	50.8	50.7
On-call medical attention	6.9	5.9	7.6	4.3	6.6	20.3	8.9	9.1	9.0
On-site medical attention, <24 hrs	2.5	3.6	4.6	0.8	2.7	17.3	4.8	9.5	6.5
On-site medical attention, 24 hrs	0.2	0.1	0.7	1.6	0.5	4.9	0.3	1.8	0.8
HEARING									
No impairment	74.8	79.9	84.5	84.6	77.7	79.3	77.3	79.2	77.6
Loss present, no correction needed	11.9	12.3	11.3	8.7	11.5	11.1	13.2	12.2	12.8
Impairment-correctable w/aid	9.4	4.8	2.1	4.0	7.4	3.3	5.5	5.5	5.5
Impairment-not correctable	1.9	1.4	1.4	2.0	1.8	2.9	2.6	2.1	2.4
Only responds to loud sounds	0.3	0.0	0.0	0.0	0.2	0.1	0.2	0.2	0.2
No useful hearing/deaf	1.5	1.7	0.7	0.8	1.4	3.3	1.3	1.6	1.4
VISION									
No impairment	70.3	59.2	60.1	72.6	68.0	68.3	68.8	62.5	66.5
Difficulty at level of print	19.1	22.2	17.1	16.9	19.0	15.0	20.6	20.2	20.5
Difficulty at level of obstacles	7.4	12.7	14.8	7.3	8.9	7.2	7.7	9.2	8.3
No useful vision/blind	3.3	6.0	8.0	3.2	4.2	9.4	2.8	8.0	4.8
MOBILITY									
No impairment	82.9	76.4	54.0	80.5	78.2	60.2	82.5	64.9	75.8
Moves with assistance	8.9	7.6	10.4	5.5	8.6	9.2	8.7	11.8	9.9

Characteristics	HCBS Recipients[1]					State RTC Residents[2]	ICF-MR Residents[3]		
	Corp. Foster	Family Foster	Own Home-Children	Own Home-Adults	All HCBS		Small ICF-MR Residents	Large Private ICF-MR Residents	All ICF-MR
Moves with self-propelled wheelchair	4.3	4.7	5.0	3.5	3.9	6.2	3.6	6.6	4.7
Moves w/wheelchair-propelled by others	4.3	10.0	25.5	10.2	8.3	23.0	4.9	15.4	8.8
Not mobile due to overriding medical condition	0.3	0.2	0.6	0.4	1.0	1.3	0.3	1.2	0.5
COMMUNICATION									
No impairment	38.1	32.2	15.2	40.3	34.7	14.9	27.7	24.8	26.6
Speech difficult to understand	35.4	36.5	30.7	38.8	35.4	19.5	35.7	26.2	32.2
Uses sign language primarily	1.7	1.3	0.7	0.4	1.4	1.3	1.8	0.8	1.4
Uses gestures, some signs	10.9	11.0	19.9	10.5	12.0	22.8	15.9	15.7	15.8
Uses alternative comm. devices	5.2	5.0	6.1	2.7	5.0	2.9	5.6	6.6	6.0
Does not make needs known	8.7	14.0	27.4	7.4	11.6	38.6	13.3	26.0	18.0
SELF-CARE									
Independent	14.6	9.3	2.0	19.8	12.9	4.4	7.4	5.9	6.9
Minimal Care needed	50.8	41.1	17.9	43.2	44.5	22.5	42.2	29.0	37.4
Substantial care needed	28.2	35.8	35.5	25.3	29.8	42.0	42.1	40.0	41.4
Total care and support needed	6.4	13.9	44.5	11.7	12.8	31.0	8.2	25.0	14.4
TOILETING									
Independent	63.2	53.2	15.6	66.7	56.2	27.8	51.0	39.4	46.7
Minimal care needed	19.6	18.9	16.3	13.6	18.4	20.9	24.3	18.4	22.1
Substantial care needed	11.3	13.9	21.9	8.1	12.6	21.7	17.2	18.6	17.8
Total care and support needed	5.9	14.2	46.2	11.6	12.7	29.5	7.4	23.6	13.4
LEISURE									
Independent	4.5	2.7	2.0	9.0	4.4	0.7	3.4	2.1	2.9
Minimal care needed	36.8	35.2	9.0	43.4	33.7	15.3	27.2	19.8	24.5
Substantial care needed	48.0	45.8	42.0	34.8	45.5	41.8	55.0	51.3	53.8
Total care and support needed	10.7	16.3	47.0	12.9	16.3	42.2	14.4	26.8	19.0
HOUSEHOLD MANAGEMENT									
Independent	0.7	0.7	0.3	1.6	0.8	0.1	0.6	0.3	0.5
Minimal care needed	24.6	20.2	3.0	33.7	22.3	10.4	16.4	10.7	14.3
Substantial care needed	57.0	50.7	24.5	42.7	50.5	32.8	56.8	44.6	52.3
Total care and support needed	17.6	28.5	72.1	22.0	26.5	56.7	26.3	44.5	33.0
MONEY MANAGEMENT									
Independent	0.2	0.3	0.0	0.4	0.2	0.0	0.0	0.1	0.0+

Characteristics	HCBS Recipients[1]					State RTC Residents[2]	ICF-MR Residents[3]		
	Corp. Foster	Family Foster	Own Home-Children	Own Home-Adults	All HCBS		Small ICF-MR Residents	Large Private ICF-MR Residents	All ICF-MR
Minimal care needed	5.2	5.0	0.3	9.0	5.0	1.6	1.7	3.2	2.2
Substantial care needed	49.9	40.7	10.4	47.1	43.3	16.2	36.3	29.9	33.9
Total care and support needed	44.8	54.0	89.3	43.5	51.5	82.1	62.0	66.9	63.8
SELF-PRESERVATION									
Capable of self-preservation	50.7	35.6	4.6	57.4	43.6	12.3	41.0	22.4	34.0
Not capable of self-preservation	48.4	62.4	94.7	40.7	55.3	87.1	57.6	76.8	64.7
Unknown	0.9	2.0	0.7	1.9	1.1	0.5	1.5	0.7	1.2
WITHDRAWN									
No	55.1	59.3	59.4	57.6	56.5	51.8	57.2	55.2	56.4
Mild	21.9	26.0	14.4	21.6	21.4	18.3	19.5	19.0	19.3
Moderate	14.3	9.0	11.4	15.3	13.4	13.5	13.8	13.6	13.7
Severe	8.7	5.7	14.8	5.5	8.7	16.4	9.5	12.2	10.5
PHYSICALLY INJURIOUS TO OTHERS									
No	62.0	63.2	52.8	78.4	61.6	40.6	55.5	58.0	56.4
Mild	21.9	23.8	21.6	12.9	21.1	21.8	26.5	24.9	25.9
Moderate	13.7	9.3	17.6	7.1	12.9	24.2	13.0	12.4	12.8
Severe	4.2	3.6	8.0	1.6	4.3	13.3	5.0	4.7	4.9
INJURIOUS TO SELF									
No	62.2	68.5	54.7	71.7	63.1	41.6	60.2	56.4	58.8
Mild	22.0	18.9	21.0	18.5	21.1	19.1	20.8	21.3	21.0
Moderate	9.4	9.6	15.7	6.7	9.9	19.3	12.6	13.3	12.8
Severe	6.5	3.0	8.7	3.1	5.9	20.1	6.4	9.1	7.4
INAPPROPRIATE SEXUAL-SELF									
None	84.3	84.4	88.4	91.4	85.6	77.7	84.2	82.8	83.7
Mild	9.4	11.9	6.0	5.1	8.8	11.2	8.0	8.9	8.3
Moderate	4.4	2.6	3.3	2.4	3.8	5.3	5.4	4.3	5.0
Severe	2.0	1.0	2.3	1.2	1.8	5.7	2.4	4.0	3.0
INAPPROPRIATE SEXUAL-OTHERS									
None	82.4	84.7	95.0	87.8	84.9	85.5	83.7	88.1	85.3
Mild	11.5	9.3	2.3	7.1	9.6	6.5	10.3	8.3	9.6
Moderate	4.4	3.0	1.3	4.7	3.9	4.7	4.6	2.9	4.0
Severe	1.6	3.0	1.3	0.4	1.6	3.3	1.4	0.7	1.1
PROPERTY DESTRUCTION									
None	63.2	64.1	55.5	79.4	64.1	48.7	62.3	65.9	63.6

Characteristics	HCBS Recipients[1]					State RTC Residents[2]	ICF-MR Residents[3]		
	Corp. Foster	Family Foster	Own Home-Children	Own Home-Adults	All HCBS		Small ICF-MR Residents	Large Private ICF-MR Residents	All ICF-MR
Mild	21.7	20.3	17.6	15.1	20.3	22.1	22.7	18.5	21.2
Moderate	10.3	10.6	15.0	4.0	10.3	16.5	10.5	11.7	11.0
Severe	4.8	5.0	12.0	1.6	5.4	12.6	4.4	3.8	4.2
DISRUPTS OTHERS' ACTIVITIES									
No	42.0	40.4	35.1	46.9	41.4	26.9	36.3	41.9	38.4
Mild	23.1	22.5	14.7	28.0	22.4	23.6	23.9	20.9	22.8
Moderate	21.5	21.5	17.7	16.9	20.5	24.2	24.8	22.7	24.0
Severe	13.4	15.6	32.4	8.3	15.6	25.3	15.0	14.5	14.8
NONCOMPLIANT/REBELLIOUS									
No	26.4	26.2	34.1	36.6	28.5	20.7	26.9	28.7	27.6
Mild	30.9	31.5	17.1	27.2	28.8	22.3	30.1	26.3	28.7
Moderate	28.4	28.1	21.7	28.0	27.5	27.0	27.0	25.1	26.3
Severe	14.3	14.2	27.1	8.3	15.2	30.0	15.9	19.9	17.4
NEEDS SPECIAL SERVICES									
Specialized medical services	62.9	65.3	85.0	57.1	65.4	81.5	62.3	70.7	65.4
Physical therapy	21.2	27.1	69.0	25.5	28.6	40.5	26.5	39.7	31.4
Occupational therapy	27.6	33.0	82.4	27.0	35.3	54.9	28.4	45.8	34.9
Communication/Speech training	50.3	56.4	94.1	42.5	55.9	74.1	56.0	66.6	59.9
Special transportation	71.3	61.1	78.8	62.2	69.9	80.5	66.6	82.6	72.6
Behavior management program	39.2	45.5	47.1	58.3	43.1	78.0	61.1	58.0	59.9

[1]Of the total 2,460 persons listed on the June 30, 1991 HCBS waiver file, screening data were available on from 2,379 (96.7%) to 2,275 (92.5%) depending on the variable.

[2]Of the total of 1,177 persons listed on the June 30, 1991 RTC data file, screening file data were available on from 779 (66.2%) to 739 (62.8%) depending on the variable.

[3]Of the total 4,099 persons listed on the June 30, 1991 ICF-MR data file, screening data were available on from 2,843 (69.4%) to 2,743 (66.9%) depending on the variable. Screening file data were more likely to be available on small ICF-MR residents (between 62.2% and 59.3% depending on the variable). Statistics in the "All ICF-MR" column are based only on individuals with screening data and have not been adjusted for the different response rates within small and large facilities.

Table A-6: Distribution of Minnesota Home and Community-Based Services Recipients Statewide and in 18 Sample Frame Counties

	HCBS Recipients in Sampled Counties		All Minnesota HCBS Recipients	
	N	%	N	%
AGE				
17 years and younger	217	15.4	415	16.9
18 years and older	1,067	75.8	1,835	74.4
No data	124	8.8	214	8.7
	1,408	100.0	2,466	100.0
GENDER				
Male	823	58.5	1,404	56.9
Female	544	38.6	990	40.1
No data	41	2.9	72	2.9
	1,408	100.0	2,466	100.0
PLACE OF RESIDENCE				
Corporate foster care	730	51.8	1,270	51.5
Family foster care	217	15.4	408	16.5
Family's home	267	19.0	453	18.4
Own home	107	7.6	195	7.9
No data	87	6.2	140	5.7
	1,408	100.0	2,466	100.0

Table A-7: ICF-MR Residents and ICF-MR Expenditures by State Population: 1987

State	State Population 7/1/87 (thousands)	ICF-MR Residents Per 100,000 Population 7/1/87	Rank	State	ICF-MR Expenditures per State Resident 7/1/87	Rank
Minnesota	4,243	154.3	1	North Dakota	$77.22	1
North Dakota	674	132.3	2	New York	61.25	2
Louisiana	4,502	117.1	3	D.C.	58.66	3
D.C.	621	101.9	4	Minnesota	53.12	4
Rhode Island	982	101.2	5	Rhode Island	52.68	5
New York	17,759	97.4	6	Massachusetts	51.29	6
South Dakota	707	96.2	7	Louisiana	37.21	7
South Carolina	3,420	91.8	8	Connecticut	30.62	8
Oklahoma	3,295	89.2	9	Pennsylvania	28.64	9
Kansas	2,469	87.5	10	New Jersey	28.03	10
Illinois	11,569	81.3	11	South Dakota	27.45	11
Wisconsin	4,791	74.5	12	Iowa	27.27	12
Indiana	5,518	73.7	13	Ohio	26.96	13
Ohio	10,767	71.4	14	Maine	25.62	14
Texas	16,937	70.3	15	Washington	25.46	15
Delaware	641	69.3	16	Vermont	24.96	16
Utah	1,694	67.9	17	Kansas	22.35	17
Pennsylvania	11,874	63.5	18	South Carolina	21.79	18
Massachusetts	5,838	63.3	19	North Carolina	21.76	19
Iowa	2,826	61.4	20	Arkansas	21.39	20
Arkansas	2,386	61.2	21	Oklahoma	20.72	21
Mississippi	2,643	60.7	22	Michigan	20.42	22
Maine	1,184	58.1	23	Delaware	20.09	23
Washington	4,514	56.6	24	Virginia	19.38	24
Virginia	5,883	53.9	25	Texas	19.35	25
Nebraska	1,595	51.2	26	Illinois	18.77	26
Oregon	2,716	51.0	27	Idaho	17.34	27
North Carolina	6,422	50.2	28	Wisconsin	16.45	28

State	State Population 7/1/87 (thousands)	ICF-MR Residents Per 100,000 Population 7/1/87	Rank	State	ICF-MR Expenditures per State Resident 7/1/87	Rank
New Jersey	7,687	49.8	29	Tennessee	16.10	29
Tennessee	4,848	47.2	30	Nebraska	16.01	30
Vermont	547	45.7	31	Oregon	15.70	31
Idaho	1,006	44.2	32	Utah	14.66	32
Connecticut	3,212	42.4	33	Maryland	14.44	33
Missouri	5,100	42.1	34	Colorado	14.42	34
New Mexico	1,518	41.7	35	New Mexico	14.09	35
California	27,531	41.6	36	Indiana	12.82	36
Colorado	3,308	37.7	37	California	12.57	37
Michigan	9,191	37.3	38	Montana	12.48	38
Alabama	4,086	32.8	39	Alabama	12.33	39
Montana	814	32.4	40	Georgia	12.14	40
Maryland	4,532	32.3	41	Kentucky	11.34	41
Kentucky	3,733	32.1	42	Missouri	10.70	42
Georgia	6,244	31.2	43	Florida	10.58	43
Hawaii	1,081	27.5	44	New Hampshire	10.46	44
Florida	11,962	26.4	45	Mississippi	10.06	45
New Hampshire	1,058	25.0	46	Nevada	9.11	46
West Virginia	1,902	21.2	47	Alaska	6.11	47
Nevada	993	19.1	48	West Virginia	3.67	48
Alaska	544	17.1	49	Hawaii	2.09	49
Arizona	3,432	0.0	50	Arizona	0.00	50
Wyoming	506	0.0	51	Wyoming	0.00	51
U.S. Total		59.3		U.S. Total	$23.04	

Sources: Lakin et al. (1989) and HCFA 2082 data.

Table A-8: Frequency of Specialist Visits by Specialty in the Previous Six Months

Type of Specialty (Frequency)	Type of Residence				Type of County			Total
	Family	Corporate	Own Home Adults	Own Home Children	Urban Metro	Urban Outstate	Rural Outstate	
Family Practice, M.D.								
0	19.2	15.7	22.7	53.3[1]	26.0	37.8	16.7	26.4
1	50.0	33.3	59.1	13.3	36.0	35.1	38.1	36.4
2-5	30.8	49.0	13.6	16.7	26.0	21.6	35.7	27.9
6-10	0.0	92.0	4.6	16.7	12.0	2.7	9.5	9.3
Internal Medicine Specialist								
0	100.0	90.2	95.5	96.7	96.0	94.6	92.9	93.8
1	0.0	9.8	4.5	0.0	4.0	5.4	4.8	4.7
2	0.0	0.0	0.0	3.3	0.0	0.0	2.4	1.6
Pediatrician								
0	96.2	100.0	90.9	56.7[2]	86.0	81.1	95.2	87.6
1	3.8	0.0	4.5	13.3	6.0	2.7	4.8	4.7
2-5	0.0	0.0	4.6	20.0	6.0	10.8	0.0	5.4
6-8	0.0	0.0	0.0	10.0	2.0	5.4	0.0	2.3
Orthopedic								
0	88.5	92.2	95.5	66.7	86.0	89.2	83.3	86.0
1	11.5	7.8	4.5	23.3	14.0	5.4	14.3	11.6
2-5	0.0	0.0	0.0	6.7	0.0	2.7	2.4	1.6
6	0.0	0.0	0.0	3.3	0.0	2.7	0.0	0.8
Neurologist								
0	76.9	80.4	86.4	60.0	74.0	75.7	78.6	76.0
1	15.4	17.6	13.6	23.3	18.0	13.5	21.4	17.8
2-5	7.7	2.0	0.0	13.4	6.0	10.8	0.0	5.4
6	0.0	0.0	0.0	3.3	2.0	0.0	0.0	0.8
Obstetrician/Gynecologist								
0	100.0	92.2	95.5	100.0	96.0	94.6	97.6	96.1
1	0.0	5.9	4.5	0.0	2.0	5.4	2.4	3.1
2	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Cardiologist								

Type of Specialty (Frequency)	Type of Residence				Type of County			Total
	Family	Corporate	Own Home Adults	Own Home Children	Urban Metro	Urban Outstate	Rural Outstate	
0	100.0	96.1	95.5	96.7	94.0	100.0	97.6	96.9
1	0.0	2.0	4.5	3.3	4.0	0.0	2.4	2.3
2	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Urologist								
0	96.2	96.1	90.9	96.7	96.0	97.3	92.9	95.3
1	3.8	3.9	9.1	3.3	4.0	2.7	7.1	4.7
Ear, Nose, Throat Specialist								
0	96.2	90.2	86.4	83.3	92.0	89.2	85.7	89.1
1	3.8	5.9	13.6	10.0	2.0	10.8	11.9	7.8
3-4	0.0	1.9	0.0	6.7	4.0	0.0	2.4	2.3
6	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Total Physician Visits[3]								
0	15.4	2.0	9.1	6.7	8.0	5.4	7.1	7.0
1	38.5	33.3	45.5	27.3	32.0	40.5	28.6	33.3
2	15.4	23.5	18.2	10.0	16.0	13.5	23.8	17.8
3-4	23.1	19.6	18.2	13.3	16.0	16.2	23.8	18.6
5-7	7.7	11.8	9.1	20.0	14.0	13.5	9.5	12.4
8-13	0.0	9.8	0.0	30.0	14.0	10.8	71.	10.9
Dermatologist								
0	96.2	90.2	95.5	96.7	96.0	86.5	97.6	93.8
1	3.8	7.8	0.0	0.0	4.0	5.4	2.4	3.9
2-5	0.0	2.0	4.5	3.3	0.0	8.1	0.0	2.3
Allergist								
0	100.0	98.0	100.0	100.0	98.0	100.0	100.0	99.2
2	0.0	2.0	0.0	0.0	0.0	0.0	0.0	0.8
Surgeon, General or Plastic								
0	100.0	92.2	100.0	80.0	62.0	86.5	73.8	92.2
1	0.0	5.9	0.0	6.7	28.0	10.8	26.2	3.9
2-3	0.0	1.9	0.0	13.3	8.0	2.7	0.0	3.1

Type of Specialty (Frequency)	Type of Residence				Type of County			Total
	Family	Corporate	Own Home Adults	Own Home Children	Urban Metro	Urban Outstate	Rural Outstate	
20	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Podiatrist								
0	96.2	94.1	95.5	100.0	92.0	100.0	97.6	96.1
1	3.8	3.9	4.5	0.0	6.0	0.0	2.4	3.1
2	0.0	2.0	0.0	0.0	2.0	0.0	0.0	0.8
Psychiatrist								
0	80.8	80.4	81.8	93.3	86.0	83.8	81.0	83.7
1	15.4	7.8	9.1	3.3	2.0	10.8	14.3	8.5
2-5	3.8	9.8	4.5	0.0	10.0	2.7	2.4	5.4
6-10	0.0	2.0	4.5	3.3	2.0	2.7	2.3	2.3
Optometrist/Ophthalmologist								
0	69.2	66.7	81.8	80.0	62.0	86.5	73.8	72.9
1	26.9	29.4	13.6	13.3	28.0	10.8	26.2	22.5
2-5	3.9	3.9	0.0	6.7	8.0	2.7	0.0	3.9
15	0.0	0.0	4.5	0.0	2.0	0.0	0.0	0.8
Physical Medicine/Rehabilitation Specialist								
0	96.2	98.0	95.5	86.7	100.0	94.6	88.1	94.6
1	3.8	2.0	4.5	13.3	0.0	5.4	11.9	5.4
Dentist								
0	19.2	19.6	22.7	40.0	18.0	29.7	28.6	24.8
1	61.5	68.6	72.7	56.7	70.0	56.8	66.7	65.1
2-4	19.3	11.8	4.6	3.3	12.0	13.5	4.7	10.1

[1] $X^2 = (9, N=129) = 30.45, p < .01$
[2] $X^2 = (9, N=129) = 37.54, p < .01$
[3] "Total physician visits" is computed from the number of visits to general/family practitioners; internal medicine specialists; pediatricians; orthopedic specialists; neurologists; obstetricians/gynecologists; cardiologists; ear, nose and throat specialists and urologists.