TECHNICAL REPORT

An Independent Evaluation of the Quality of Services and System Performance of Minnesota's Medicaid Home and Community Based Services for Persons with Mental Retardation and Related Conditions

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EXECUTIVE SUMMARY

About this Report

This report summarizes the findings of a comprehensive evaluation of Minnesota's Medicaid Home and Community-Based Services (HCBS) "waiver" program. This Executive Summary presents key findings, positive accomplishments, remaining challenges and recommendations from the full report. The full report may be obtained by request at the addresses listed on the inside cover of this document.

Purpose of the Evaluation

In April 1999, the Minnesota Department of Human Services, Division of Community Services for Minnesotans with Disabilities (DHS/CSMD) contracted with the University of Minnesota to conduct an independent evaluation of its Medicaid Home and Community Based Services (HCBS) "waiver" program for persons with mental retardation and related conditions (MR/RC). This program is by far Minnesota's largest for persons with MR/RC. State officials commissioned this evaluation to gather information on the status of current program implementation, identify challenges in meeting program goals, and assist in strategic planning for the future. Information used in this study came from a number of sources, including: existing state data sets with information on characteristics of HCBS recipients, expenditures, and reports of maltreatment; interviews with adult recipients of HCBS; written surveys of families, case managers, direct support staff, residential providers, and vocational providers; telephone interviews with county HCBS coordinators in counties; focus group meetings with representatives of key stakeholder groups; and reviews of relevant documents.

What are HCBS Services?

The Medicaid HCBS was approved by Congress in 1981 to assist people with MR/RC in their homes and communities, when without such assistance they would need the level of care provided in an institutional placement such as a community Intermediate Care Facility for the Mentally Retarded (ICF-MR), or a Regional Treatment Center (institution). Minnesota has been authorized to provide HCBS to people with MR/RC since 1984 through a wide range of options. These include residential supports in one's own home or in a small shared living setting, day programs, supported employment, respite care, assistive technology, home modifications, crisis assistance, transportation, and various programs of training and counseling.

Since its introduction in 1984, the HCBS program has been the primary means of support for Minnesota's dramatic shift from institutional to home and community services (See Figure 1). During this period, Minnesota reduced its state institution population from over 2,400 people to fewer than 50. HCBS supported reductions of residents in other ICFs-MR for persons with MR/RC from nearly 5,000 to less than 3,000, including a reduction of more than 50% in the number of people living in non-state ICFs-MR with 16 or more residents. This reduction in state institutions and large ICF-MR residents is among the most notable in the United States.

Who receives HCBS Services?

Approximately 8,000 Minnesotans benefit from HCBS. They represent the full range of ages, levels of mental retardation, and race/ethnicity (see Table 1). As the HCBS program has matured, more people with severe intellectual disabilities, challenging behavior and/or serious medical and health needs have also received HCBS.

What are the costs of HCBS services?

The average annual expenditure in 1998 for each HCBS recipient was $51,545. In the same year, the average annual expenditure for each ICF-MR resident was $60,600, and for Regional Treatment Center residents was $197,465. Average annual HCBS expenditures vary according to a number of factors. The most significant is where a recipient lives. The average 1998 cost for people who lived in their own homes ($21,454) or with their family ($19,568) was much less than the annual cost for people who lived with a foster family ($31,518) or in a small ("corporate foster care") group home ($54,733).

How have Minnesotans benefited from HCBS services?

This evaluation identified many important benefits from the HCBS program for Minnesotans with MR/RC, including: 1) people moving from institutional settings into homes in their local communities, 2) people improving the quality of their lives, 3) people reconnecting with family and friends, 4) children remaining with their family despite disabilities that would have once led to out-of-home placements, 5) people having many more choices in their lives, and 6) people participating as full citizens and contributors to their communities. Overwhelmingly, participants in this study (people with MR/RC, family members, case managers and others) reported substantially greater satisfaction with HCBS than with the ICF-MR and state institution services that HCBS have been replacing.

2000 HCBS Recommendations

This executive summary includes all of the recommendations made by the research team and stakeholder advisory group after receiving the overall findings of this evaluation. These recommendations appeared to center around several broad themes including: quality of services; choice and respect; individualized supports; direct support staff crisis; protection from maltreatment; access to HCBS and affordable housing. Please review the large technical report for this information regarding the extent to which the recommendations made in 1992 had been attended to and improvements made and specific recommendations made by various stakeholder groups as identified in focus groups.

Quality of Services

- Stakeholders argue that quality assurance/enhancement activities for HCBS should be improved. A new system is recommended in which families and consumers are active participants in the development, implementation and on going review of a redesigned quality assurance program that integrates health and safety monitoring, quality of life assessment, and quality improvement assistance.
- The state should institute a program to share public information regarding service quality, outcomes and issues (e.g., licensing citations, substantiated maltreatment reports, employment outcomes, choice making, respect and satisfaction data) so that individuals and families can make informed decisions about service options and providers of services.
- Case managers need to be better able to contribute to the quality of life of HCBS recipients through improved training on options and creative ways to use them, greater commitments and higher expectations for individualized service outcomes, smaller average "caseloads," greater amounts and better quality of interactions with HCBS recipients and families.

Choice and Respect

- People who receive HCBS should have choice in where and with whom they live, where they work and who provides their support.

- DSS must be better trained to respect the people they support and to exhibit this respect in assuring control over homes, their daily lives and basic choices.
- Support options that promote choice and respect must be expanded (e.g., consumer directed support options, consumer-controlled housing).
- Choice and respect are primary service outcomes that need to be systematically monitored in all quality assurance programs and publicly reported to assist in choosing service providers.
- Choice of case managers should be treated with the same respect for individuals choice as other HCBS.

Individualized Supports

- Minnesota needs to promote a greater array of individualized HCBS options (e.g., host families, consumer controlled housing, consumer directed service options, development and management). This will require eliminating systemic barriers that perpetuate the use of group home models (e.g., lack of GRH-like subsidies for individuals, dependency on shift staff models).
- Consumer-directed community supports (CDCS) should be available to all HCBS recipients. The state should provide technical assistance and training to counties to enable them to offer CDCS to all HCBS recipients who want this service option. Additional efforts to provide information and training to individuals and families about CDCS are needed.
- Families need substantially improved access to high quality in-home respite and personal care supports. If the present system cannot provide families with those services it recognizes as needed, families should be empowered and supported to use their authorized resources to meet their own needs.
- A mechanism is needed to adequately support people whose needs change over time due to their age and/or disability. This mechanism should not solely rely on counties to provide increased support to people with changing needs by giving people with lower support needs access to HCBS “slots” or by “forcing” people to move to a new provider in order to get an increase in services. A method should be developed to periodically re-determine a person’s needs and adjust the amount allowable resources to the counties based on this re-determination.
- The state should develop a system for accurately identifying and tracking the amount, type and costs of service needed by and promised to individuals and their families versus the actual amount and costs of the services received. The state should use the system to monitor and provide trend analyses regarding this important issue.

Direct Support Staff (DSS) Crisis

- Given the pervasive, long-term and detrimental effects of the direct support staffing crisis on individuals, families and the ability of counties to develop new services, the state should make it a priority to create a coordinated workforce development system with resources to significantly increase DSS and frontline supervisor wages, reduce turnover, improve recruitment, and support and train DSS and their supervisors.

Protection from Maltreatment

- Minnesota’s maltreatment reporting system needs improved communication between agencies and individuals in the system (e.g., DHS Licensing and Investigations units, State Ombudsman Office, county MR/RC services, common entry points, county foster care licensing units, provider agencies, case managers, direct support staff, and the individuals and families who receive supports).
- The maltreatment reporting system should be designed to systematically respond to concerns voiced by stakeholders regarding maltreatment reporting and follow-up.

- A statewide method for tracking and conducting trend analyses of all incidents reported, irrespective of whether they involve substantiated maltreatment or whether they are investigated further by the investigations unit should be developed.
- Consumer-to-consumer violence must be reduced. Most people do not choose to live with people who hurt them. All people should be given the freedom to choose with whom they live, but the right must begin with victims of current household violence.
- Further investigation should occur to better understand the proportion of individuals with certain characteristics that are prescribed psychotropic and other mood altering medications, why these medications are being prescribed and the extent to which the use of these medications increases, decreases or remains the same over time for HCBS recipients. Consideration should be made for adding fields to the screening document that would enable this information to be systemically tracked.

Access to HCBS

- Access to individualized HCBS supports that meet the needs of citizens with MR/RC from ethnic, racial and cultural minority groups should keep pace with the numeric growth of these groups in the general population.
- The state should develop a specific initiative to address the issue of access for minority groups and should provide information and technical assistance to counties on specific outreach and support methods designed to increase information for and access to individuals and families from ethnic and racial minority groups.
- This initiative should specifically investigate these issues as they relate to people from minority groups who currently receive HCBS services as well as people from these groups who are not receiving HCBS.
- Efforts should be made to better understand why HCBS is under-utilized by these groups, and modifications to current services should be made so that HCBS can be individualized to meet the needs of people from minority groups.
- Systematic efforts are needed to better understand the specific needs of the people who are waiting for HCBS, and to identify people who may need HCBS but are not yet recognized as waiting. Minnesota should respond to the reasonable desires of large numbers of people currently living in ICFs/MR who seek HCBS.
- The state should develop a process that would increase the consistency and fairness throughout the state in decisions about who and how people get access to HCBS are made.
- Substantial efforts are needed to increase the availability of supported employment opportunities (e.g., community group work, individual community work) to all HCBS recipients who want to work. Additionally the state should systematically code and use data collected on the screening documents to measure progress in this area.
- Continued efforts are needed to increase the availability and access to dental services, specialized medical and specialized therapies (e.g., speech therapy, occupational therapy, counseling, behavioral therapy) for all HCBS recipients, especially those with significant challenging behavior.
- The tracking system developed by the state to provide counties feedback regarding authorized and paid expenditures should be improved so that more accurate and timely information is provided in a manner useful to counties. The state should increase the amount of DHS staff support and technical assistance provided to counties and should improve the system to coordinate and provide this support. The state should also explore the possibility of making this a Web based system.

Affordable Housing

- Consistency and fairness should be increased in the county processes and priorities for decisions about HCBS access.
- Minnesota needs to increase access to affordable housing options for HCBS recipients who desire to own or rent their own homes through expanded access to housing subsidies such as Section 8 and GRH-like assistance for non-licensed homes.

Project Methods

Several different research methodologies were used to maximize the validity and reliability of the findings in this evaluation. These methods included: 1) analyses of data from existing state data sets including information on HCBS recipients, expenditures and maltreatment reports; 2) direct interviews with 372 individual recipients of HCBS; 3) written surveys of 184 residential and 82 vocational provider agencies, 183 families, 468 case managers and 288 direct support staff; 4) telephone interviews with 21 county MR/RC HCBS coordinators; 5) meetings with representatives of stakeholder groups (e.g., Minnesota Habilitation Coalition [MHC], Association of Residential Resources of Minnesota [ARRM], Minnesota Developmental Achievement Centers Association [MNDACA], the Minnesota Disability Law Center [MDLC], Legal Aid, DHS-CSMD, Arc-Minnesota); and 6) document review. These methodologies along with the research questions, description of the sample, access to the sample members, instrumentation, data analyses, and the limitations of the study are reviewed in this section.

A Stakeholder Advisory Committee (SAC) was created to assure that the MR/RC HCBS evaluation attended to the information needs, perspectives and concerns of the program's various constituents. The SAC consisted of 38 individuals representing a variety of organizations, agencies and stakeholder groups including: DHS – CSMD; the Minnesota Governor's Council on Developmental Disabilities (GCDD); the MDLC, Arc-Minnesota, county social services, the Minnesota Ombudsman office, parents, consumers; ARRM, MHC, MNDACA, the STAR Program, and other interested individuals.

The Stakeholder Advisory Committee served four primary functions for this study; 1) identifying questions to be asked of the various people surveyed; 2) reviewing, editing and providing feedback on all instruments; 3) communicating to the stakeholder groups they represented about the purpose, design and outcomes of the evaluation, and 4) assisting in the interpretation of the results of the evaluation and in formulating and prioritizing recommendations based on these results.

This study used a representative sample of 474 current HCBS waiver recipients to answer many of the research questions. Other research questions were based on data provided for all HCBS recipients in Minnesota. To select participants, Minnesota's 87 counties were stratified into three categories: Twin Cities Metropolitan Area (7 counties), counties in greater Minnesota urban centers with populations of 50,000 or more residents (11 counties) and counties in greater Minnesota rural areas with populations of less than 50,000 residents (69 counties). From these groups, 24 representative counties were selected and invited to participate in the study.

The sample frame included all eligible HCBS recipients in the selected counties that were identified in the screening document data file provided by DHS-CSMD. Eligible HCBS recipients met following criteria: 1) their county of financial responsibility was one of the 24 counties in the sample, 2) their county of residence was one of the 24 counties included in the sample, 3) they were living at the time the study was conducted.

An initial group of 665 people was randomly selected. To that random sample, a controlled over-sample of 35 people was selected from among racial or ethnic minority group members receiving HCBS. The additional selections from ethnic and racial minority groups were controlled to reflect the proportion of minority group members receiving HCBS recipients in each of the three county types. The first 101 people selected who were not eligible for the study or who declined to participate were replaced resulting in a total of 801 individuals who were invited to participate.

Access to information about the services received by a sampled individual depended on that individual or his/her legal guardian providing informed consent to participate. Obtaining consent required the involvement of each sample members' county case manager. Case managers were asked to verify the eligibility of sampled individuals, explain the study and its demands to them, and request consent to participate from HCBS recipients, family members or other legal representatives as appropriate. For individuals under guardianship of the Commissioner of the Department of Human Services, county case managers exercised the power of consent. When individuals or their legal guardians declined to participate, a replacement was randomly selected from the same county type and sampling group (general or the minority over-sample). Until individuals provided consent to participate, they remained anonymous to the interviewers.

The state DHS-CSMD provided four types of existing data sets for this evaluation:

Screening Document Files. The Minnesota screening document data set provided a wide range of demographic, diagnostic, functional, behavioral, health and service need information on all 6,548 individuals with MR/RC receiving HCBS (including the 474 people in the sample). The available files contained the most recent screening as of April 1999.

Administrative Reports. Information from the Health Care Financing Administration (HCFA) Form 372 and Form 64 cost reports were used to compare expenditures of HCBS and Intermediate Care Facility for the Mentally Retarded (ICF-MR) recipients, including expenditures for related Medicaid state plan services. Information from the October, 1999 Report to the Legislature, "Home and Community Based Services for Persons with Mental Retardation and Related Conditions" provided background on the goals of DHS-CSMD for the HCBS programs, information on challenges faced in the programs and statistical trends in state and county service days, allowed expenditures, authorized expenditures and actual service payments between FY 1995 and FY 1999.

HCBS Payment Files. Department of Human Services payment files were made available to analyze payments for fiscal years 1997 and 1998. These data sets included information on: 1) total paid costs of HCBS; 2) paid costs of HCBS by procedure code for each service recipient; 3) county authorized and state "allowed" expenditures for each HCBS recipient; and 4) a range of analysis related variables including county, conversion/diversion status, resource allocation grouping (1-4 or base for persons entering prior to FY 1996), provider code and service procedure codes.

Maltreatment Data. The Department of Human Services Licensing Division Investigations Unit provided 1995 – 1998 data logs which included information about maltreatment reports. These included reports that were received by the investigations unit, which after initial disposition were determined to not be maltreatment and were either screened out or referred to another agency. This data was used to summarize the types of maltreatment reports that are screened out or referred to other agencies. Additional summary information obtained from a Department of Human Services report on the number and outcomes of maltreatment reports that were referred for investigation and their final dispositions. This information also included the number of direct support staff members who applied to work in licensed programs who were disqualified based on background studies.

Quantitative data provided in extant data sets and obtained through interviewing were analyzed using SPSS statistical software package. The types of statistical methodologies and variables, including derived variables, used in each analysis is described with the relevant findings. The responses to open ended questions in the surveys and interviews were entered into data base software packages, coded and then analyzed by two separate researchers to identify themes and patterns. The responses of county MR/RC Waiver Coordinators were also analyzed separately by two researchers and independent summaries of outcomes were reviewed for common themes in an effort to ensure reliability of findings.

Strengths and Limitations

Several strengths and limitations of the evaluation design, its implementation and outcomes should be noted. Among the strengths were:

1. The state data sets available to describe the characteristics of recipients and the costs and utilization of HCBS services included 100% of the people with MR/RC receiving HCBS services in Minnesota.
2. The controlled over-sampling of HCBS recipients from ethnic and racial minority groups permitted analysis that included proportional representation of minority community members.
3. The random selection of sample members from stratified groups of service recipients and from different county types yielded a sample that was strikingly similar to the population of all HCBS waiver recipients.
4. The use of varied quantitative and qualitative research methods (extant data sets, written surveys, face-to-face interviews, telephone interviews, group interviews) increased the validity of findings by identifying issues concerns and trends with multiple methods and sources of information.
5. Perspectives of varied and knowledgeable informants (HCBS recipients, family members, case managers, residential providers, vocational providers, direct support staff members, county HCBS Waiver Coordinators, various stakeholder groups) provided comprehensive attention to important aspects of the HCBS program.
6. The response rates for consumer interviews, individual case manager and general case manager surveys were sufficiently high to increase representativeness of the respondents.
7. Key instruments in the evaluation have been extensively tested for reliability and validity as part of the multi-state Core Indicators Project.

Several limitations and potential threats to the reliability and validity of the data collection should also be noted. These include:

1. The response rates for certain surveys was not as high as was desired. Factors affecting response rates included: project timelines that limited opportunities to conduct an adequate program of follow-up of late and non-respondents for certain surveys; limited resources for providing incentives for completing the surveys and interviews; and inadequate efforts to achieve fully visible endorsement of the project from all major stakeholder groups. Among the surveys affected were the provider, direct support staff and family surveys. Thus the reader should be cautioned that the returned surveys from these groups may not be representative of the total populations being surveyed.
2. Because the sample members could only be approached through their county case managers, case managers who refused or made half-hearted attempts to recruit participants and to gain their consent (or that of their guardians and family members) affected the rate of participation and possibility the representativeness of those who did participate.
3. Most but not all of the questions included in the various surveys were pilot tested prior to their use in the evaluation. Although efforts were made to develop questions that were valid and reliable, no formal testing of the psychometric properties was conducted for certain questions. Questions which were determined to be “problematic,” whether field-tested or not, were excluded in the analyses.

Results and Discussion

This section presents an overview of the key findings of the evaluation across a number of important topical areas including: HCBS use and expansion, access, quality, supports and services, health, case management, providers, quality assurance, utilization and costs. Additional information on what is working and what challenges still exist within each of these areas is discussed.

Real life examples are used throughout each key findings section to illustrate what is working well and what challenges still exist regarding that specific topical area. These were obtained through open ended survey questions asked of case managers, family members, direct support staff and individual service recipients. These examples were obtained with an assurance of anonymity to the respondents. Once the data were received, the names of the respondents were eliminated in order to protect confidentiality of the respondents.

Home and Community Based Services Use and Expansion

This section of the evaluation reviewed information to determine the use and growth of HCBS in Minnesota. It also made comparisons between ICF/MR and HCBS use in Minnesota and the United States as a whole.

Key findings

- In 1999, nationally, 41.2% of HCBS recipients lived in homes that were owned, rented or managed by an agency that provided residential supports compared with 73.6% of HCBS recipients in Minnesota.
- In 1999, more than twice as many Minnesotans received HCBS funded supports as lived in ICF-MR facilities (7,102 vs. 3,101).
- In 1999, 91% of all Minnesotans are members of white non-Hispanic racial or ethnic groups as compared with 96.6% of ICF-MR residents and 94.8% of HCBS recipients.
- Between 1992 and 1999 the proportion of Minnesotans from non-white, non-Hispanic racial or ethnic groups grew faster than the proportion of ICF-MR residents and HCBS recipients in those groups.
- Between 1992 and 1999, Minnesota reduced the number of people in state operated large ICF-MR settings from 1,033 to 72.
- Of the 3,101 ICF-MR residents in 1999, 34% lived with 16 or more other people.
- Of the 3,101 ICF-MR residents and the 7,102 HCBS recipients in 1999, 79.2% of persons with mild intellectual disabilities received HCBS as compared with 50.6% of persons with profound intellectual disabilities.
- While more people with various health-related and other support needs now receive HCBS funded supports than live in ICF-MR settings, ICF-MR residents have proportionately greater health-related and other support needs.
- The HCBS program in Minnesota now supports more people with serious or very serious challenging behavior and a higher proportion of such individuals than the ICF-MR program.
- Child HCBS recipients were most likely to report needing assistance with independent living skills.
- Adult HCBS recipients have greater overall needs than children who were HCBS recipients.
- Among adult HCBS recipients, older adults were proportionately more likely than younger adults to report needing assistance with independent living skills.
- HCBS recipients from non-white racial and ethnic groups were more likely to report needing various specialized services such as specialized medical services, programs to address challenging behavior, and speech or communication training.

What's working?

Continued expansion of HCBS has supported the downsizing and closure of many ICFs-MR and state institutions since HCBS began in 1984, but especially between 1992 and 1999. In 1995, Minnesota passed the milestone of HCBS recipients (4,897) exceeding the total number of ICF-MR recipients (4,445). By June 1997, HCBS recipients made up 63% of the combined total ICF-MR residents (3,604) and HCBS recipients (6,097). By June 1999, HCBS recipients had increased to 70% of the ICF-MR (3,101) and HCBS (7,102) recipients. As Minnesota developed its HCBS program, it was able to decrease the number of people living in large (16 or more people) ICFs-MR from 2,618 people to 1,056 people (60% decline). It was also able to decrease the number of people living in small (4-15 people) ICFs-MR from 2,584 to 2,045 (21% decline). Today, the HCBS program serves more people with severe challenging behavior, more children, more adults, more people with the most severe intellectual impairments (profound mental retardation), more people with significant support needs, more people with significant medical needs, and a higher proportion of people from racially diverse groups than the ICF-MR program.

Challenges and concerns

Despite its notable successes Minnesota exhibits unusually high reliance on congregate care as its method of community service delivery when compared with the U.S. as a whole. In June 1998, based on reports from 42 states, nationwide an estimated 41.2% of HCBS recipients lived in residential settings that were owned, rented or managed by the agency that provided residential supports to HCBS recipients. In MN this average is 73.6%. Likewise nationwide estimates of HCBS recipients who live with family members is 33.6% compared to 15.4% in Minnesota. Additionally, nationally an estimated 15% of HCBS recipients rent or own their own home/apartment as compared to only 4.9% in Minnesota.

Clearly the current pace and productivity of outreach, identification and enrollment of people from ethnic and racial minority groups, will not close the gap between majority and minority populations having access to HCBS in Minnesota. Even though the number of people from racial and ethnic minority groups who are receiving HCBS increased between 1992 and 1999, with the exception of Native Americans racial and ethnic minorities were substantially less represented in the HCBS program than would be expected based their presence in the general population in Minnesota.

In Minnesota, the HCBS program serves more people at each level of intellectual disability than the ICF-MR program. However, people with more severe intellectual disabilities are less likely to have access to HCBS than are people with less severe intellectual disabilities. Possible reasons for this include concern about the higher expense of supporting individuals with more extensive support needs while maintaining the total cost of services under a county's allowable total expenditures. An effort was made to address this concern in 1995 with the implementation of the Waiver Allocation Structure which added more resources to a county's allowable expenditures for persons with more extensive support needs. Arguably this has contributed to there now being more persons with severe or profound intellectual disabilities receiving HCBS than living in ICF-MR settings. Five years after this change, however, persons with severe or profound intellectual disabilities are still proportionally less likely to receive HCBS funded supports (rather than ICF-MR services) than are persons with mild or moderate intellectual disabilities.

Access to Services

This part of the evaluation gathered and reviewed information about how people get HCBS in Minnesota and the issues they face in gaining access to the program's services. Also, issues related to the state's waiting list for HCBS were explored.

Key Findings

- There was a waiting list of 4,321 individuals with MR/RC for HCBS in October 1999. Many of these persons (1,687) were children living with their families, needing in-home and respite care. Of those waiting, 1,151 were adults living alone or with their families who were not currently receiving long-term care services.

- County practices varied a great deal with respect to the criteria for who gets HCBS.
- All counties reported maintaining waiting lists for HCBS services. Most counties reported trying to find alternative ways to meet current needs of individuals waiting for HCBS services.
- While 81% of case managers reported that their county has a written policy for prioritizing persons on the waiting list, only 37% said that copies of the policy were available to parents or other members of the general public.
- Although HCBS supports are intended to meet individual needs, some counties reported selecting new HCBS participants based at least partly on how well the person might match or "fit in" with people currently supported in an SLS setting.
- Only two counties (both in the metro area) reported having specific outreach plans to communicate about service options for individuals from racial and ethnic minority groups.
- Many counties only complete HCBS waiver screenings if specifically requested. One case manager reported their county defers screenings until a "waiver slot" is available.
- Over one-quarter (25.9%) of families receiving HCBS reported that they first heard about HCBS from someone other than county.
- Overall, case managers reported the most common reasons for awarding a new HCBS "slot" were a) emergency or crisis situations or b) people having the greatest impairments of all those waiting.
- Among the 468 sample members, almost 30% were living with their families prior to entering the HCBS program. The metro area had substantially higher proportions entering the HCBS program from large ICFs-MR or nursing homes (26.1%).
- Families receiving HCBS supports reported significant difficulty accessing respite services, crisis respite supports, and in-home family supports (either they did not meet their needs or they were not available).
- When asked about access to services for HCBS recipients in general, case managers reported that the most difficult services to access were crisis/respite, information on cutting edge innovations, assistance on how to manage own services, regular respite care, and transportation.
- Case managers for more than 23% of individual study participants reported having difficulty finding a provider for one or more needed services. The most difficult services to find were dental services, non-health specialists, and supported living services.
- Dental services were reportedly most difficult to access in greater Minnesota urban counties, and generic community services were most difficult to access in greater Minnesota rural counties.
- Parents reported relatively greater difficulty getting information about adaptive equipment or environmental modifications, in-home supports, out-of-home residential supports and crisis respite services than for other types of services.

What's Working?

Minnesota has an effective data system for documenting the extent of its waiting list, and the characteristics and needs of the people waiting, so that it can understand the meaning and implications of this waiting list. Establishing a baseline of who is waiting for supports and goals to reduce this list are necessary prerequisites to achieving the desired outcomes of providing supports to all who need them. Almost all Minnesotans waiting for HCBS services receive case management services and other services (e.g., school or day program supports, Medicaid state plan services for which they are eligible). Although available supports may not meet all of their needs, Minnesota has made an exemplary commitment to assuring that all eligible individuals and families have basic support even as they wait for the more comprehensive services available through the HCBS program.

Challenges and Concerns

The findings regarding access to services raise several concerns. Despite Minnesotans substantial growth in its HCBS program in recent years, there are still 4,321 Minnesotan's waiting for HCBS services. Second, while the state's waiting list report provides good information about people waiting for HCBS services, it does not contain all of the information needed to fully describe the extent of unmet needs of people with MR/RC in Minnesota.

For example, virtually all people waiting for HCBS are receiving some support services from minimum entitlements to case management, personal care and/or school services, but the extent to which those are meeting individual needs or would need to be augmented to do so is not available in the waiting list data. This evaluation also suggests that access issues are a significant issue for people even once they begin receiving HCBS services. Many families reported that respite and in-home supports did not meet their needs or were not available when they were needed. One reason for this difficulty is likely the shortage and turnover of direct support staff. Minnesota is therefore challenged to increase access to services both for people who currently receive HCBS supports and for those on waiting lists.

Case managers identified crisis respite, information on options and innovations, for creative use of HCBS assistance on how to manage one's own services (e.g., consumer directed consumer supports), and regular respite to be the services most difficult access in their counties. Their insights on the status of the service system suggest a need to enhance outreach, technical assistance and training to counties to increase the availability and effective use of HCBS supports.

Satisfaction and Quality of Services

The evaluation gathered information from HCBS recipients, families and case managers about quality and satisfaction of services. Also, information regarding community inclusion, choices and delivery of services in a respectful manner is included.

Key findings

- Adult HCBS recipients liked where they live (82%) and work (89%). They had friends (76%) and could see them when they wanted to (74%).
- Most people who receive HCBS (85%) reported almost always having a way to get to places they wanted to go.
- HCBS recipients with community jobs did not feel they worked enough hours and 22.5% were not satisfied with their earnings.
- Families were most satisfied with transportation, out-of-home residential services and case management. They were least satisfied with environmental adaptations and adaptive equipment, educational services, in-home supports, and respite services.
- While families were mostly satisfied with complaint resolution practices, providers of respite services, crisis behavioral services, in-home supports and educational services were rated lower than other types of services in satisfactorily resolving complaints.
- Families were less satisfied with planning for specialized therapy services, home and environmental adaptation agencies, respite services and in-home supports.
- Twenty-five percent of families reported that residential out-of-home providers rarely assisted their family members to find friends, family members or neighbors to add to their support networks.

- Providers reported that the most common barriers to accessing community supports were too few staff members (43%), behavioral needs (43%), and lack of consumer interest (40%).
- Providers reported that in the year prior to the survey, 34% of residential sites added a new consumer, and 22% had one or more consumer leave.
- Almost 90% of interviewed adult waiver recipients had lived in the same place for more than one year.
- Case managers and county waiver coordinators overwhelmingly rated HCBS services as superior to ICF-MR services. HCBS were considered to be superior in terms of having choices in what to do with free time, having privacy, living in places that feel like home, participating in community activities, choices in location and roommates, and growth in independence.
- The general case manager survey indicated that the highest quality HCBS services were case management, interdisciplinary planning and assessment and residential services. The lowest rated services were information on cutting edge innovations, assistance to families and individuals on managing their own services, transportation, crisis respite or emergency care, and person-centered lifestyle planning.
- Case managers of 468 sample members rated residential and in-home services highest in overall quality. The lowest quality components of the HCBS system were sharing quality assurance results, skills of DSS, number of available direct support staff (DSS), and quality of dental care.
- Case manager ratings of quality of life were higher for individuals with lower costs, metro area residents living in corporate foster care, and Greater Minnesota HCBS recipients living in family homes, own homes or family foster care settings.
- In general there were very few differences in outcomes for individuals by race or ethnicity. The most prominent difference was that case managers reported that individuals from non-white racial or ethnic groups received poorer quality dental services.

What's working?

Many of the stakeholders involved in this evaluation reported overall satisfaction with HCBS services. Consumers generally liked the places they lived and worked. Most families were satisfied with transportation, residential services and case management services. Families reported that most of the time and in most settings staff members were understanding, respectful, professional and caring. Case mangers and county waiver coordinators reported that when compared to ICF-MR services, HCBS services were superior with regard to people having choices, privacy, feeling at "home," participating in their community, picking where and with whom they live, small size of home, and staffing ratios. Eighty percent of case mangers rated HCBS supports as good or excellent.

Adults receiving HCBS services had stable living environments (10% had moved in the last year). Almost three-fourths of adults reported having friends and being able to see them when they wanted to. Furthermore, 94% of HCBS recipients who receive Supported Living Services (SLS) (typically in "corporate foster care settings") had on-going contact with their families. Almost all of the HCBS recipients participated in common community activities such as running errands, going shopping, going out to eat and going out for entertainment. More than half of the adult HCBS recipients in the sample had attended a self-advocacy meeting.

Challenges and concerns

Families report that approximately one-quarter of HCBS recipients do not receive support from formal service providers in finding and using natural supports such as friends, family members, neighbors or community groups. Achieving meaningful community inclusion usually requires both natural and paid supports in people's lives. Shortages of direct support staff, available staff working excessive overtime hours to respond to shortages, high turnover of experienced staff and limited staff development are also having effects on people's opportunities.

Several findings suggest that improvements should be made in facilitating community inclusion for HCBS recipients. For example, 25% of families reported that residential out-of-home providers rarely assisted their family members to find friends, family members or neighbors to add to their support networks. While 41% of the adult respondents reported that they were never lonely, 8% said they were always or often lonely and 51% indicated that they were sometimes lonely. Providers reported that the most common barriers to accessing community supports were too few staff members (43%), behavioral needs of the people receiving services (43%), and lack of consumer interest (40%). Increased efforts to support HCBS recipients in making friends, building support networks and becoming fully participating citizens in their communities of choice are needed to reduce the loneliness experienced by HCBS recipients.

Cultural and ethnic factors associated with perceived quality of services and community inclusion could not be adequately addressed by this study because of the practical limits on sampling respondents from ethnic and racial minority groups. However, very few outcomes were statistically different for sample members from ethnic and racial minorities. Among important statistically significant differences were that case managers reported that persons with racially or ethnically diverse backgrounds experienced significantly lower quality of dental services. Further investigation is needed to understand the quality and outcomes of services for HCBS participants and individuals waiting for HCBS supports who are from ethnically and culturally diverse backgrounds.

Choice and Respect

This part of the evaluation gathered and reviewed information reflecting the extent to which HCBS recipients and their families experienced choice, respect and sensitive support within the HCBS program.

Key Findings

- Adults reported having friends and being able to see them when they wanted. Almost all had at least some contact with their families.
- Case managers reported that 81.6% of HCBS recipients were living in the place their family preferred.
- Many adults who receive services reported that direct support staff (DSS) and other non-residents of their home entered without knocking first (25%), that there were restrictions on phone use where they live (19%) or that people opened their mail without permission (33%).
- Large proportions of adults reported having no input in major life decisions about where they would live (49%), work (57%), or with whom they would live (72%).
- Families reported that 17% of HCBS recipients were afraid of someone in their residential or work setting.
- Families reported they had the least amount of choice in selecting a case manager (95% rarely/never).
- People living in corporate foster care settings had significantly fewer choices and experienced significantly more forms of disrespect or insensitivity (e.g., people entering the home without knocking) than adults living in family homes, family foster care settings or their own homes.
- Almost 20% of consumers who were capable of using a telephone reported that their telephone use was restricted. This was more likely to be true in corporate foster care settings. Thirty-three

percent reported that someone sometimes or always opened their mail without permission. Again this was more likely to be true in corporate foster care settings.

- While going to religious services was really or somewhat important to 72% of consumers, only 55% reported going to religious services.
- Families reported having the greatest degree of choice about in-home supports and the least choice about who their case manager was, transportation services, and types of vocational supports. Only 31.5% of families reported having a range of options regarding out-of-home residential supports, and only 49.6% reported choosing which agency provided out-of-home residential supports. Families in metro counties were significantly more likely to report having a choice of vendor for residential services than those in other counties.
- While most family members reported being involved in decisions about medical, dental, safety issues, house location, and roommates, some reported never being involved in these decisions (including some who were the legal guardian for their family member).
- Many county HCBS Waiver coordinators indicated that they felt that consumers and their family members already have control over their services through the individual support plan (ISP) and opportunities to choose provider organizations. However, many counties reported that the reality in their counties is that families often have little choice in who provides them with supports.
- Most parents reported that providers respected family choices and preferences. However, educational providers, specialized therapy services and crisis behavioral services were rated as relatively less likely to respect family choices and preferences. Similarly, while most families reported that most providers respected consumer choices and preferences, educational providers and crisis behavioral services were relatively less likely to respect consumer choices and preferences.

What's working?

The ability to seek and maintain social development and relationships is instrumental to human development and satisfaction. The majority of adult HCBS recipients reported that they had friends and could see them when desired and almost all had desired contact with their families. Minnesota HCBS recipients reported that they felt supported in developing and maintaining relationships. A majority of families reported being involved in making important decisions regarding the health, safety and well-being of HCBS recipients. Parents reported that most service providers respected their choices and preferences and that satisfactory complaint resolution occurs when there are differences.

Challenges and concerns

Adult HCBS recipients deserve to be treated with respect. Reports from 25% of sample members who said people came into their homes without knocking, 10% who said people came into their bedroom without knocking and 20% who said that although they are capable of using their phone they are restricted in when and how they can do so should be of concern. Many of the adults interviewed said that attending religious services or events was really or somewhat important to them, but they never attended religious services or events. People living in corporate foster care settings reported significantly more indications of disrespect (e.g., people entering the home without knocking) than adults living in family homes, family foster care settings or their own homes. Increased awareness, training and expectations must be made to improve the respect people with MR/RC who receive HCBS get.

A pervasive lack of choice was also evident in the experiences of consumers and family members in the HCBS program. Few consumers had choices about where and with whom they would live, where they work, how many hours they would work, how they spend their days or who would provide personal supports to them. Furthermore, many recipients are excluded from basic daily decision making about meals, bedtimes, and privacy. For example, 54% wanted more time alone. Improving sensitivities outcomes in this area should be a priority.

The lack of choice was not limited to people who receive HCBS. Only 31.5% of families reported having a range of options regarding out-of-home residential supports, and only 49.6% reported choosing which agency provided out-of-home residential supports. Families also reported having little choice among agencies for case management, transportation, and vocational supports.

Supports for families

This part of the evaluation gathered and reviewed information from family members of HCBS recipients to assess the extent to which they as family members well supported by the program's services.

Key findings

- Families reported that most of the time and in most settings staff were understanding, respectful, professional and caring.
- Families were generally satisfied with the extent to which out-of-home residential services worked with the family in planning for the future.
- While generally satisfied with the flexibility of employment, case management and out-of-home residential services, families were less satisfied with the flexibility of respite services, in-home supports, and educational services.
- In 1999 Minnesota had a combined total of more than 200 children and youth 17 years or younger living in group homes funded by HCBS of ICF-MR programs.

What's working?

Being treated with respect and dignity is a critical component of service delivery and customer service. High proportions of family members surveyed reported that in most settings staff were understanding, respectful, professional and caring. Their testimony confirms that in general Minnesota's service provider organizations and personnel are dedicated to supporting and enhancing the lives of people with disabilities and their families. Families also reported general satisfaction with the flexibility offered in employment, case management and out of home residentialservice.

Challenges and concerns

Although substantial majorities of families reported satisfaction with their services, more than 25% of families were not satisfied with in-home supports, respite services, specialized therapies, environmental adaptations, adaptive equipment and education. These families reported that in-home and respite supports were the least likely to be flexible enough to meet their needs as a family and the needs of their family member with MR/RC. This is somewhat ironic given that in-home and respite services are designed to be highly flexible and responsive to the specific needs of families and individuals and shows how failure to be so leads to consumer dissatisfaction. The perceived lack of flexibility is undoubtedly attributed to the general shortage of qualified staff to meet the needs of respite and in-home recipients. Because of that shortage families often get fewer hours than they have been authorized and are often "forced to take what they can get," the antitheses of the flexibility these services are expected to exhibit.

Families receiving respite or in-home family supports also report less support from case managers and service providers in helping them to plan for their future needs. Although 79% of families reported that most of the time case mangers helped them plan for the future, 21% of families reported that this occurred only some of the time or rarely. Continued efforts are needed to ensure that service providers and case managers are attending to and supporting families in planning for their future needs.

While the majority of families usually choose the respite provider they use, 21% reported never or only sometimes having a choice. Similarly, while most families choose the person who will come into their home to provide in-home supports, 10% rarely or never do, and 20% choose only some of the time. Given the intrusive nature of having a person provide supports in the family home, assuring such choice should be a priority. One such strategy is to increase the opportunities for families and individuals to participate in consumer directed community support options where they are given the opportunity to choose who provides them with supports.

There were differences between case manager assessments of HCBS services and the family reports of satisfaction. Case managers reported that case management services were the most likely to be of excellent quality while families reported greater satisfaction with out-of-home residential supports and transportation than with case management. Conversely case managers rated transportation services as one of the lowest quality services while families receiving transportation services rated it as the service with which they were most often satisfied. This apparent discrepancy may be related to an access issue. That is, low case management ratings may reflect relative difficulty in accessing transportation services while parent satisfaction ratings are for those who actually get transportation services. Environmental adaptations, assistive technology and adaptive equipment were rated near the bottom of the list for both families and case managers. In-home and respite services ranked in a middle range by case managers and near the bottom for families.

Minnesota should make a special commitment to assure that all possible family support and substitute family alternatives options have been exhausted before children are placed in non-family congregate settings. A formal commitment to the philosophy and goals of "permanency planning" as has been made in states like Michigan should substantially lower the number of children in Minnesota deprived of the developmental benefits of family life.

HCBS Supports and Services

The supports and services section of this report includes key findings and issues related to the types of supports and services HCBS recipients receive.

Key Findings

- Eighty-three percent of HCBS recipients receive SLS services and most (65.4%) live in corporate foster care settings.
- Overall, 26.8% of adult HCBS recipients interviewed worked in supported employment or work crew or community group work settings exclusively, 27.4% worked in both supported employment, work crew, or community group work and facility based employment, but 29.5% worked but only in a center based program, and 16.3% were reported to receive only non-vocational day program services.
- Although only 15.6% of all HCBS recipients lived with their immediate family, more than 73% of children did.
- HCBS recipients from diverse racial and cultural backgrounds were substantially younger, on average than other HCBS recipients (32.6% were birth through 19 years compared with 14.3% of other HCBS recipients)
- HCBS recipients from diverse racial and cultural backgrounds were less likely to live in corporate foster care settings (55.1% vs. 66.1%) or to live with a live-in foster caregiver (4.4% vs. 7.7%), but more likely to live with their immediate family (27.7% vs. 15.0%) or with a foster family (7.9% vs. 5.5%). Most of these differences are attributable to their younger age.
- HCBS recipients in greater Minnesota urban counties were significantly less likely to be in non-vocational day programs (8.1%).
- More than 60% of HCBS participants were indicated to have had a behavioral support plan. Prevalence for moderate to very severe challenging behaviors included: temper outbursts (37.9%),

physical aggression (27.6%), verbal or gestural aggression (31.0%), self-injurious behavior (23.3%), and property destruction (21.8%). Moderate to very severe challenging behaviors were more common among children receiving HCBS than adults.

- Sixty-four percent of vocational sites and 26% of residential sites reported consulting with a regional crisis team in the last 12 months. Twenty percent of vocational sites and 7% of residential sites supported a person who had been sent to an off-site crisis program in the last 12 months.
- During the previous year HCBS residential and vocational providers reported resorting to crisis interventions for one or more service recipients, including calling police to assist with a behavioral crisis (18.1% of sites), using an ambulance or police to transport a person to a psychiatric ward or a general hospital (13.4%), overnight stays in a hospital psychiatric ward (15.7%), suspension or demission from the program (9.7%) and temporary placement in a regional treatment center or the Minnesota Extended Treatment Options program (METO) (7.4%).
- While fewer than 6% of residential sites reported using any type of restriction or punishment controlled by Minnesota's Rule 40, 18% of vocational sites used planned physical restraints (this difference is likely explained by the fact that vocational sites on average supported larger numbers of people at any given site).
- All but two of the 21 HCBS waiver coordinators interviewed reported that the crisis prevention and intervention system was working well for their counties. One county reported hearing from providers that the prevention and response services were "not good". One county said that the crisis team was unclear about their responsibilities and that a "bed" was not always available when needed.
- Overall, 54.6% of families reported that their family member received one or more form of specialized therapy. Therapies received included occupational therapy (41.0%), speech therapy (41.0%), mental health counseling (36%), physical therapy (35%), behavioral therapy (28%) and other therapies (14.0%).
- Overall, 33.3% of families reported that their family member used some form of assistive technology. A total of 21.3% reported that their family member used environmental adaptations or modifications.
- Overall, 49.1% of all travel by HCBS recipients was provided in site vehicles and 24.5% was provided in staff vehicles. Less than 10% of travel was completed using fixed route public transportation, door-to-door public transportation, door-to-door private transportation or other modes of transportation.

What's working?

Most adults in the sample reported working in community settings at least part of the time. Overall, 26.8% of adult HCBS recipients interviewed worked in supported employment or group work crews exclusively, 27.4% worked in both supported employment or work crew and facility based employment, 29.5% worked but only in a center based program, and 16.3% were reported to only receive non-vocational day program services.

At the time of Minnesota's last HCBS evaluation in 1991-1992, the state still had over 1,100 people in large state institutions. One barrier to moving those individuals to community homes was the lack of an adequate crisis prevention and intervention system for community services. Since that time, Minnesota has developed a crisis prevention and intervention system using a mix of private and public specialists to assist families and provider agencies in supporting individuals with challenging behavior. This evaluation found that in 1999, providers not only reported access to the crisis prevention and intervention system, almost half (42.3%) of all providers in the study reported using this system in the last

12 months (37.6% reported consulting with regional crisis services, and 22% reported using on-site intervention by crisis team members).

The HCBS program is supporting in the community people who would have once been institutionalized and is doing so without state institutions as a "safety net." In 1999 the extent of challenging behavior among HCBS recipients exceeds that of ICF-MR residents and include people who have significant challenging behaviors including temper outbursts (37.9%), aggressive-verbal/gestural behavior (31%), physical aggression (27.6%), self-injury (23.3%), property destruction (21.8%), inappropriate sexual behavior (12.5%), running away (9.9%), eating non-food substances (6.6%), and breaking laws (4.1%). Over 60% of HCBS recipients now have behavioral support plans, but very few people are reported to present behavior challenges that exceed the expertise within their provider agencies.

Challenges and Concerns

The most common living arrangement for HCBS recipients is a "corporate foster care" home with shift staff (65.4% of all recipients). This is also the most costly type of service. To assure resources to reduce waiting lists and to serve those children who are currently receiving HCBS in their family when they become adults and seek to move to their own homes, service initiatives should focus alternatives to corporate foster care as the predominant mode of support.

Children who receive HCBS and are from racially and ethnically diverse groups are more likely than children who are white to receive out-of-home supported living services. Investigation of this difference may help in better understanding the reasons and perhaps assist with developing outreach strategies to diverse racial and ethnic communities to increase the proportion of people from these communities who receive HCBS.

The majority of HCBS recipients still receive facility based work or non-vocational services (59.5%), in Greater Minnesota rural counties this percentage is significantly higher (71.4%). Additionally, many individuals reported that they wanted to work in a community job but did not. Greater emphasis on increasing supported, community and competitive work/day opportunities is needed.

Although most of the providers surveyed indicated that they could internally meet the behavior support needs of the people they served, 28% used other crisis intervention techniques in the 12 months before the survey. For example, 11.2% sent people to an off-site crisis program, 18.1% called police to assist with a crisis, 13.4% used overnight stays in a hospital psychiatric ward, 9.7% suspended or demitted a person from a program and 7.4% temporarily placed a person in a state operated crisis center, a psychiatric unit or Minnesota Extended Treatment Options (METO).

Health Supports

The evaluation gathered and reviewed information regarding the health status of HCBS recipients and access to various health care services.

Key findings

- Overall, 98% of adults living in corporate foster care settings, and 84% of adults living in family foster care, with their families or on their own had had a physical exam in the last year.
- Overall, 89% of adults had been to the dentist within the previous 6 months. People with less severe mental retardation and less challenging behavior were more likely to have been to the dentist.
- Overall, 74% of adult women had received a gynecological exam in the past year. Older women, women with mild or moderate mental retardation, and women living in corporate foster care settings were more likely to have had a gynecological exam in the last year.

- Case managers reported the overall quality of health care supports for individuals in the HCBS program was good. They reported that people with special medical needs experienced higher quality health care supports.
- Overall, 43% of adults interviewed reported receiving medication for mood, anxiety or behavior problems. Providers reported that 34% of all individuals they supported were receiving psychotropic medications.
- Case managers reported that the overall quality of dental care was between fair and good. Case manager assessments of quality of dental care were lower for people living with family members, lower for non-ambulatory people, higher for people who were white, and higher for people who needed more intense medical supervision.
- Case managers reported that dental care was more difficult to access than health care and physician services. They also reported that dental services were less available to persons in Greater Minnesota urban counties than in the other county types.
- Families whose family member with MR/RC lived with them were less likely to report that their family member was healthy than families whose member lived elsewhere (79% vs. 90%).

What's Working?

The majority of families reported that their family member was usually healthy and case managers reported that the overall quality of health care available to HCBS recipients was above average (mean 3.06; 0=poor, 4=excellent). Almost 92% of adult HCBS recipients had a physical exam within the past year, and 89% had been to the dentist. As a point of comparison the National Health Interview Survey, Disability Supplement found that a total of 60% of all non-institutionalized people with mental retardation or developmental disabilities in the U.S. had seen a general practitioner in the previous 12 months, 36% had seen a specialist physician and 89.7% had seen one or the other or both.

Challenges and Concerns

Across indicators, health care access and quality were reported to be better for HCBS participants living in corporate foster care settings than those living in other types of settings. Access to dental care was reported to be worse for people with severe or profound mental retardation, people with more serious challenging behaviors, and people in urban counties of Greater Minnesota. The quality of dental care was reported to be better for people in corporate foster care settings, people who were ambulatory, people who were white, and people who required more medical supervision. Quality of medical care was reported to be better for individuals with special medical needs. Efforts should be made to more fully evaluate access to medical and dental care (including gynecological care) across the state, especially for persons with more severe intellectual and behavioral disabilities. Access to gynecological care for younger women, women with severe or profound mental retardation, and women not living in corporate foster care settings may also need improvement.

The final concern is the high use of medications for mood, anxiety or behavior for persons in HCBS settings. Both providers and individual consumers (and their proxies) reported high rates of psychotropic medication use (33% and 43% respectively). In 1999, ICF-MR providers reported 34.4% of 2,945 Minnesotans living in ICF-MR settings received "drugs to control behavior" (Karon & Beutel, 2000). In the National Health Interview Survey Supplement on Disability sample, 10.5% of people with MR/DD were taking prescription medication for an ongoing mental or emotional condition. Since the screening document does not ask about the use of psychotropic medication, however, further analysis is beyond the scope of this study. Further research is required to examine changes in patterns of medication use over time. Also an effort to better understand the specific types and classes of mood altering drugs that are being used and for what reason they are prescribed. It is important to determine whether the mood altering drugs (psychotropic medications) that are being prescribed to HCBS recipients today have high rates of extra-pyramidal side effects (e.g., tardive dyskenisia) or whether they are the newer anti-depressant, anti-anxiety or anti-psychotic medications whose side effect profiles are much less severe. Further examination of this issue should also consider the extent to which psychotropic medications are being used without a mental health diagnosis, and to what extent they are prescribed by general practitioners as opposed to psychiatrists, neurologists or other specialists.

Service Coordination/Case Management

The service coordinator/case management component of the evaluation gathered and analyzed in formation on case management services to identify aspects of their quality and availability. The roles and functions that case managers play in the lives of HCBS recipients were also studied.

Key Findings.

- Eighty-four percent of HCBS recipients had at least one visit from their case manager in their home in the previous 6 months and 93% had at least one visit in their work setting.
- About half of HCBS recipients had one or more nonscheduled visits from their case manager to their home (48%) or to their day program (50%) in the last six months.
- Overall, 75% of consumers said they could talk to their case manager whenever they wanted to, 85% said their case manager helps them with their needs and 67% said it is easy to contact their case manager.
- Eighty-seven percent of consumers reported they had a planning meeting in the last year. Of those, 90% attended the meeting, 44% reported choosing the things in their plan, and 21% chose who came to the meeting.
- Almost all of the case managers had developed an ISP for the recipient in the last 12 months (94%) and assessed the person’s progress (86%). About three fourths had supported family, staff and administrators to meet needs (79%), had determined eligibility for services (77%), or had reviewed the health or safety of the person in context (74%).
- Case managers reported average caseloads of 53 people, with a range of 22 to 89 people. The average caseload included HCBS recipients, ICF-MR recipients, people who receive SILS, and individuals who did not have mental retardation or related conditions.
- The typical case manager had supported individuals with MR/RC for 100 months, and supported persons receiving HCBS funded supports for 76 months.
- Families reported that most of the time case managers provided culturally appropriate service (2.93 out of 3), delivered satisfactory outcomes (2.86), and were responsive to the family needs (2.78). However, families of HCBS recipients who were non-white reported significantly less satisfaction with the extent to which case management services were delivered in a culturally appropriate manner.
- Families were less satisfied that their case managers knew about the availability of services, supported what the family wanted or needed or provided information in a manner that was easy to understand.
- While both residential and vocational providers rated case management services as good overall, residential providers were significantly less satisfied than vocational providers with conflict resolution involving case managers.
- Case managers in rural counties were more likely to have assisted in determining eligibility, developed a HCBS budget, made a nonscheduled visit to a day program, and made more frequent contacts (e.g. phone, letters, meeting attendance) than case managers from other types of counties.

- Case managers in metro counties were significantly more likely to have presented families and individuals with options for new services, taken action to protect the rights of a person they served, and to have received, reviewed and responded to vulnerable adult reports.
- Case managers in metro and greater Minnesota urban counties were significantly more likely to have assisted with a crisis situation than case managers in the rural counties.
- Case managers were more likely to have arranged diagnostic assessments and to have made individual contact with HCBS recipients from diverse racial or ethnic groups than with other HCBS recipients.
- Case managers were more likely have developed a HCBS budget, presented options for new services or arranged for new service providers, assisted with completing forms or required paperwork, and assisted in a crisis for individuals living in their family homes.
- Metro area case managers were more likely to have a caseload of only people with developmental disabilities (90%) than were case managers of urban counties of greater Minnesota (82%) or of rural counties (50%).

What's working?

Despite the caseload size and demands on case managers, families, providers and individual recipients all report general satisfaction with case management services (on average "good," but rarely "excellent"). Most families are satisfied with case manager services and supports most of the time and find their case manager responsive to family needs most of the time. Case mangers are reported generally to be able to find opportunities to visit HCBS recipients in their homes (84% of sample members were visited in the previous 6 months), and 50% of sample members were visited more than twice. About 45% of case manger visits lasted an hour or longer.

Challenges and Concerns

Case managers for individuals living with their families were more likely to develop budgets, help fill out forms and paperwork, present options for new service providers, arrange for new services and assist with crises. Individuals who receive services in the family home were least likely to satisfied with their services. This raises questions about the function of case management with respect to people who receive in-home supports and the extent to which the supports provided by case managers respond to special circumstances and needs of families.

Clearly, case manager roles varied significantly by type of county region. This variation likely creates different experiences, expectations and outcomes for service recipients and their family members. But stakeholder group interviews and surveys indicate that across the state case managers have a great deal of responsibility. They are a viewed as having an essential role in assuring quality and outcomes for HCBS recipients. Many counties report that their case managers make decisions about who is the greatest priority to receive HCBS services. They are the county's link with service recipients and with the service providers with which the county contracts.

Given the significant role of case managers in developing and following up on the implementation of individual support plans as well as in ensuring quality of services the average Minnesota caseload is high (average of 53 with a range of 22-89). In a 1996 survey of states by the National Association of State Directors of Developmental Disabilities Services only 12 of 42 reporting states had average caseloads greater than 53 including 5 that were slightly higher (53.3 to 55.5) (Cooper & Smith, 1996). Stakeholders perceive caseloads as too high. High caseloads are reflected in the finding that 33% of HCBS recipients report that it is not easy to contact their case manager.

Not only are caseload sizes high, there is great diversity in the people on those caseloads. But only 51% of case managers report that their county has a process to determine appropriate caseload size. Variations in service recipient needs also require case managers to have eclectic skills and a great deal of knowledge. In that regard, it is notable that 40% of case managers reported that they found their education to be of limited or no use in preparing them for their current roles.

Although satisfaction with case management is generally "good," it was rarely rated as excellent. Obviously meeting people's expectations for individualized case manager support while maintaining caseloads that average more than 50 people is difficult regardless of individual skills, knowledge and commitments. Among the areas which case management services tended to be rated less positively were those related to receiving information from case managers that is easy to access and understand (lowest in family satisfaction), support for creative ideas (lowest in provider satisfaction), presenting options for new services and/or providers (provided to only 50% of sample members in the year prior to the survey), or visiting new potential service sites with HCBS recipients (provided to only 18% of sample members in the previous year). These are areas of essential performance in increasing consumer control and implementing the Consumer Directed Community Supports HCBS service option. Of related concern was that 45% of HCBS recipients interviewed reported that they were not involved at all in choosing who attended their planning meetings. Only 18% of the people interviewed reported that they have a role in changing the goals in their individualized plan. Obviously attention to the knowledge, attitudes, skills and working conditions of case managers will need to be part of any state effort to fulfill the state's commitment to person-centered HCBS.

Provider Agencies

The evaluation gathered and analyzed information from provider agencies at the service site level to identify the nature and scope of services provided, and the demographics and characteristics of direct support staff who provide HCBS services.

Key findings

Provider agency size/scope

- Sixty-nine percent of residential Supported Living Services (SLS) sites supported four people. The typical site employed 6.5 direct support staff (DSS), one supervisor, and three on-call DSS.
- The typical vocational site supported 29 people and employed 11.6 DSS, one supervisor and 2.5 on-call DSS.
- With few exceptions county waiver coordinators and case managers reported that they considered individual recipient and family opinion when selecting provider agencies for HCBS recipients. This was particularly true for in-home services, respite and other more individualized services. More variation exists in the extent to which individuals and family opinion was considered when SLS services are selected.
- Almost all HCBS waiver coordinators reported substantial difficulty finding existing providers to meet the amount and type of demand for HCBS services.
- Many county waiver coordinators noted particular difficulty in finding providers qualified to address the needs of people with high medical and/or behavioral support needs.
- Some counties reported difficulty in finding providers to support individuals in very rural areas and on American Indian reservations.

DSS recruitment and vacancy

- In this study, 75% of all providers reported finding qualified applicants for DSS positions was a challenge compared to 57% of residential providers in 1995.

- Despite families reporting serious problems getting in-home supports, case managers said families not getting authorized or needed services, and families not finding people to hire was a moderately serious to serious problem.
- Providers reported paying for an average of 46.1 hours of overtime per site in the month prior to the survey. Overtime hours constituted substantially higher proportion of total hours paid in residential site than in vocational settings.
- Average costs for recruitment of a new DSS included $334 per month per site for overtime and $250 per month for local advertising (excluding advertising costs paid by parent agencies).
- While 43% of vocational providers reported using temporary agency employees, only 4% of residential providers did.
- Residential provider vacancy rates were 13.9% in metro counties, 6.0% in urban counties of greater Minnesota, and 8.4% in rural counties. About 4.5% of all DSS hours went unfilled (due to vacancies or staff absences) in the week prior to the survey.
- Residential providers received 2.5 applicants per position in metro counties, 4.1 applicants per position in urban counties of greater Minnesota, and 3.0 applicants per position in rural counties.
- The number of applicants per opening was higher in vocational agencies, and agencies that paid higher DSS starting wages.

DSS wage and benefits

- Starting wages for residential DSS averaged $8.13 and mean wages of all staff averaged $8.81.
- Starting wages for vocational DSS averaged $8.89 and mean wages of all staff averaged $10.49.
- Starting wages in residential settings grew 15% between 1995 and 2000; average “top wages” rose only 9.6% during those years. According to the Minnesota Department of Economic Security, the average wage for all Minnesotans increased by 22.4% between 1995 and 1999.
- Overall, 64% of residential DSS and 83% of vocational DSS were eligible for benefits.
- Thirteen percent of DSS were currently students. While 32% said their employers offered tuition reimbursement, only 6% actually received tuition reimbursement in the previous year.
- Metro area DSS were significantly less satisfied with their pay than DSS in greater Minnesota.

DSS retention

- Forty-six percent of providers said DSS turnover was a problem, and 28% reported DSS training was a problem for them.
- Case managers reported that the high number of different DSS in the lives of consumers, recruiting family foster providers, and recruiting residential and in-home staff were serious to extremely serious problems facing the HCBS program.
- While 40% of DSS said their job responsibilities and working conditions turned out to be what they expected, 45% said they were only somewhat as expected, and 10% said they definitely were not as expected.
- DSS turnover for 1999 averaged 44% in residential settings and 23% in vocational settings.
- Turnover was significantly higher in sites offering lower average wages, serving people with more intense support needs, and in metro counties.

- Forty percent of all residential DSS and 35% of vocational DSS had been in their jobs for less than one year.
- Many families reported turnover was a problem including 50% of families whose family member received out-of-home residential services, 48% of families receiving in-home supports, and 35% of families receiving respite services. Families in urban counties of greater Minnesota were more likely to say that turnover was a problem.
- DSS were most satisfied with their relationships with their co-workers, the availability of their direct supervisor, and the attitudes of consumers about their agency. They were least satisfied with their pay, the support they received from agency administrators and managers, the support they received from case managers, the benefits they received, and the morale in their office or program.

DSS demographics

- DSS in vocational settings were more likely to have a four-year degree than DSS in residential settings (42% vs. 20%).
- Twenty percent of DSS were from non-white racial or ethnic groups.
- Overall, 49% of residential DSS, and 72% of vocational DSS were full-time employees.

DSS training and education

- Seventy-one percent of all DSS were certified to administer medications.
- Residential providers offered more than five hours per year of training on crisis intervention and behavioral supports, medication administration, agency policies and procedures, health and CPR. They offered fewer than 2.5 hours of training per year on respecting people with disabilities, community services and networking, empowerment and self-determination, and advocating for people with disabilities.
- Vocational providers offered more than five hours of training per year on CPR, organizational participation, and program implementation. They offered fewer than 2.5 hours of training per year on respecting people with disabilities, blood borne pathogens, health, assessing medical conditions, rights of individuals with disabilities, and advocating for people with disabilities.
- DSS reported they were most knowledgeable about respecting people with disabilities (average rating 3.69 out of 4 with indicating “advanced” knowledge), abuse and neglect (3.56), and consumer safety (3.50).
- Direct support staff reported that they feel least knowledgeable about organizational participation (2.62), vocational, educational and career supports for people who receive support services (2.77), education, training and self-development for staff (2.91), community services and networking (2.93), and assessing medical conditions (2.96).
- Fifty-nine percent of DSS agreed or strongly agreed that their organization’s orientation and training program is excellent. However, 35% said the agency should improve its current training program and 22% said the agency should develop a new training program.

Other

- Case managers in metro area counties were more concerned about staffing issues (e.g., recruitment, retention, training) than case managers in other regions.
- Almost all county waiver coordinators reported a decline in the quality and quantity of staff being hired. Several noted that the quality of supervision provided to DSS has declined.

What's working?

Both residential and vocational service providers reported that they delivered a large number of hours of training to DSS. On average, each residential site offered 103 hours of training per year and each vocational site offered 81 hours of training per year on a variety of topics. In general, DSS reported that the orientation and training they had received helped them to complete most of their specific job responsibilities, develop interaction skills with the people who support and improve the quality of life of the people they support. About half of the DSS rated their agency's training program as excellent. Direct support staff also report that their supervision, benefits, co-workers and supervisor relationships, schedule and flexibility, opportunities for on-going development, morale, and support from supervisors and families are "good."

Challenges and Concerns

All of the stakeholders who participated in this evaluation reported concerns about the severity and effects of direct support staff vacancies, turnover, and difficulties in recruiting needed staff members. Direct support staff turnover was reported to be 44% in residential settings statewide, and vacancy rates for metro area residential providers exceeded 13%. Many families reported turnover was a problem, including 50% of families whose member received out-of-home residential services, 48% of families receiving in-home supports, and 35% of families receiving respite services. The turnover rates were higher in the urban counties of greater Minnesota.

Seventy-five percent of providers reported difficulty finding qualified applicants for DSS positions. Many counties reported an inability to develop new services and supports or significant delays in doing so because of difficulties in finding qualified staff. All county waiver coordinators interviewed reported that they had seen a decrease in the quality of HCBS because the quality of both direct support staff and supervisors is steadily declining. In addition to DSS shortages, county waiver coordinators reported nursing shortages, severe housing shortages, and difficulty finding providers qualified to address the needs of people with high medical or behavioral needs. Stakeholders perceived staffing issues as one of the greatest barriers to growth and sustainability of the HCBS program. Significant coordinated statewide efforts are needed to address the workforce crisis to ensure that the HCBS program can be sustained.

While DSS receive substantial amounts of training, relatively little of it is reported to focus on essential DSS skills such as formal and informal assessment, advocating for people with disabilities, community services and networking, and empowerment and self-determination. Over one-third of DSS said training should be improved and 22% said their employer's training program should be replaced. Today DSS are expected to assure that individuals are respected, become full citizens within their communities and are supported in achieving their desired life goals. To fulfill such expectations, DSS need skills beyond medication administration, positioning lifting and transferring. DSS need skills in advocating for people they support, and in networking within communities to assist people in developing natural supports, relationships and friendships. They need to understand principles such as self-determination and must be able to take concrete daily action to foster the self-determination of the people they support. DSS must learn to work cohesively with their peers and supervisors to get their jobs done. Efforts are needed to continually share and/or develop tools and resources for agency trainers and DSS to narrow these gaps and assure effective competency-based training for all.

There were significant differences noted in staffing outcomes (turnover, recruitment, satisfaction, training) between agencies that pay higher wages and relatedly between vocational and residential providers, and between private and public providers. These differences suggest a need for attention in policy on wage equity between service types. Additionally, while many of the people who left positions left within the first six months of employment, 59.1% had been in their positions more than a year. The average high wage for long term DSS in service sites increased only 9.6% between 1995 and 2000 an average increase in starting DSS wages of 15%. Salary compression is an important issue for retaining experienced DSS. Wage compensation also appears to be a major challenge to maintaining a skilled workforce. Systemic attention to the important challenges of worker compensation should include incentives for workers to stay in their existing positions.

Quality Assurance and Monitoring of Services

This section reviews key findings and issues in the area of quality assurance. Topics include fear, safety, victimization and injuries, deaths, maltreatment reporting and the performance of the quality assurance and monitoring system for HCBS.

Key findings

Fear and Safety

- Forty percent of DSS and 49% of provider agencies (residential and vocational) reported that consumer-to-consumer violence was a problem (8% and 10% respectively said it was a moderate or severe problem).
- When asked, "Does anybody where you live hurt you," 85% of consumers said nobody hurt them, 7% said a roommate had, 3% said staff, and 5% said someone else had.
- Families reported that 17% of individuals in out-of-home residential settings were afraid of someone (including 11% who were afraid of their roommates) and 12% of individuals were afraid of someone at work (including 8% who were afraid of a co-worker).
- Ninety percent of all consumers felt safe where they live, and 76% reported feeling safe in their neighborhoods (11% said they felt unsafe in their neighborhood).
- Twenty-one percent of families who had a family member who received crisis behavioral supports reported that their family member was afraid of someone in their crisis behavioral service setting.
- Almost all family members reported that their family member felt safe most of the time while receiving transportation supports, in their employment or day program, in out-of-home residential settings, and at school.

Victimization and Injuries

- Sampled vocational service providers reported that 17 of 3,301 individuals (0.5%) in their programs had been victims of crimes serious enough for them to report it to law enforcement in the previous year. Residential providers reported that 38 of 611 individuals (6.2%) were victims of crimes reported to law enforcement. By comparison, 31% of Minnesotans reported they were a victim of a crime in 1992.
- The most common cause for a criminal conviction in Minnesota was for larceny theft. In both residential and vocational settings the most commonly reported crime was simple assault.
- Several county waiver coordinators attributed an increase in incident and maltreatment reports to labor shortages.

Processed Maltreatment Reports

- In 1998, 508 vulnerable adult (VA) or maltreatment of minor (MOMA) reports were processed for persons in HCBS funded adult foster care settings (including "corporate foster care") and 68 were processed for HCBS recipients living in other types of settings).
- In 1998, between 16% and 18% of VA or MOMA reports processed by DHS for day program, ICF-MR, SILS, and HCBS adult foster care settings were assigned for detailed investigation as compared with 22% of DHS processed reports for other HCBS recipients.

- Reports determined not to involve maltreatment as defined by VA or MOMA statutes could either be screened out (no further action needed), or referred by the DHS investigations unit to another state unit or county agency for further action. Most reports that did not involve maltreatment for ICF-MR settings were screened out rather than referred, but almost all reports involving HCBS adult foster care settings that did not involve maltreatment were referred to county licensing units or other agencies for further action.
- In 1998, 1,856 reports reviewed by DHS and determined not to involve maltreatment were logged. Of those, 493 were screened out and 1,363 were referred to other agencies. The most common type of complaint referred to other agencies involved allegations of neglect, unexplained injuries, physical abuse, emotional/verbal abuse, or client-to-client abuse. The majority of those complaints were referred to county adult foster care or the DHS CSMD unit for further action.
- In 1998, 62 cases of maltreatment were substantiated for HCBS settings, 32 cases were substantiated for ICFs-MR, 7 were substantiated for day program settings, and none were substantiated in SILS settings.
- The rate of substantiated maltreatment per consumer was 8 per 1,000 for ICF-MR settings and 10 per 1,000 for HCBS settings in 1998. The rate of substantiated maltreatment per consumer per year averaged 15 per 1,000 in ICF-MR settings between 1993 and 1998; 10 per 1,000 in HCBS adult foster care settings between 1996 and 1998; and 4 per 1,000 in HCBS settings not also licensed as adult foster care settings between 1993 and 1998.
- In 1998, 51% of all substantiated maltreatment cases involved neglect, 16% involved physical abuse, 4% involved sexual abuse and 30% involved some other kind of maltreatment.
- Case managers for 26% of HCBS recipients reported receiving and reviewing a vulnerable adult report on that person in the last 12 months, and 21% responded to an issue raised in those reports.

Deaths

- Between 1995-98, four deaths involving people with MR/RC who received HCBS services were judged to have occurred as a result of maltreatment. The total number of HCBS recipients who died between 1995-1998 was 74.
- The average number of deaths per 1000 service recipients in HCBS between 1995 and 1998 was 3 per 1,000 while the average number of deaths in ICFs-MR during those years was 10 per 1,000. As a pointed comparison during 1998 the average number of deaths in MN per 1,000 people was 8 and in the U.S. the total number of deaths per 1,000 people was 9 (Murphy, 2000).
- In almost all of the counties it was reported by waiver coordinators that when a report is made to the common entry point, it is almost immediately referred to the HCBS waiver coordinator and to the applicable case manager.
- HCBS waiver coordinators identified problems with the state's maltreatment reporting and investigation system and were generally dissatisfied with it.

DSS Maltreatment Reporting

- Ninety-nine percent of direct support staff members surveyed reported they knew how to report incidents of maltreatment. However, of those who actually reported maltreatment, only 63% said they received any feedback regarding what was done in response to the report they filed.
- Twenty-nine percent of DSS reported they were afraid they might lose their job if someone filed a complaint against them whether or not the report was true or substantiated. However, 95% reported they thought the maltreatment investigation system was fair to definitely fair.

- Twenty-six percent of all DSS reported they had observed an incident of abuse or neglect. Of those, 7% (2% of all DSS) said they were prevented or discouraged from reporting the incident by their supervisor and 2% by their co-workers. Only 63% of DSS who filed a report received any information regarding their report.

System Evaluations

- Providers said Minnesota's quality assurance (QA) system was good in several areas. The highest ratings were for state reviewers knowing the type of setting, and the quality of county licensing efforts. Service providers said technical assistance provided by the state was fair. Providers in greater Minnesota rural counties were more satisfied with QA efforts than those in other regions.
- While 84% of case managers reported that they should monitor service quality only 69% said they actually did. Similarly, while 91% of case managers thought the state QA system should gather information from and provide information to families, only 53% said the state QA system actually did so.
- Case managers rated six components of Minnesota's QA system good, and nine components only fair. The highest ratings were for assuring appropriate and regular health and physician services, and assuring that there is a system for consumer complaints and investigations about the quality of services. The lowest ratings were for recognizing exemplary performance, providing quality training to case managers, and assuring that consumers have access to QA information when selecting agencies to serve them.
- On average case managers rated Minnesota's system for assuring effective reporting and follow-up of incidents involving vulnerable adults as fair.
- Most county waiver coordinators reported that their system for monitoring quality was informal, usually occurring through unannounced visits to sites by case managers and through asking questions of recipients and family members at meetings. Two county HCBS waiver coordinators reported that they did not have an effective QA system within their counties.
- Most county waiver coordinators reported that families and consumers were not formally involved in monitoring and evaluating HCBS services.
- Primary strengths of HCBS QA according HCBS waiver coordinators included experienced, long-term case managers who know what is happening, an informal county system that makes people comfortable sharing information, random visits by case managers, good communication with service providers at the county level, building high expectations into contracts, and community members.
- The primary weakness of HCBS QA according HCBS waiver coordinators was the large caseloads of case managers that makes it difficult for them to conduct the amount of monitoring that is needed.
- County waiver coordinators observed that high turnover of staff and frequent reorganization at DHS-CSMD result in counties not getting answers to questions, having difficulty finding the right person to talk to, and getting mixed messages.
- Over half of the HCBS waiver coordinators reported that their Regional Resource Specialist (RRS) provided good supports and was helpful. However, many indicated that their RRS was stretched too thin and was not available as needed.

What's working?

Consumers and family members reported that the vast majority of HCBS recipients lived safely and without fear in their homes and in their neighborhoods. Service providers in rural counties are much more likely to be satisfied with a number of dimensions related to quality assurance and monitoring functions. Most direct support staff members reported that they knew how to report suspected maltreatment. Several HCBS coordinators reported their counties were conducting quality assurance and enhancement interventions. For example, one county had developed quality assurance teams that specifically included and paid family members and consumers in their quality assurance process.

Challenges and Concerns

Consumer-to-consumer violence should be of concern. Seven percent of HCBS recipients included in this survey reported they had been hurt by their roommate and 12% of families reporting that recipients were afraid someone would hurt them in their out-of-home residential placement. In other words an estimated 979 of HCBS service recipients are living in places where they are afraid of a roommate. Given the estimate that 37.9% of all HCBS recipients have moderate to very severe problems with temper outbursts, 31% engage in verbal or gestural aggression, and 28% engage in physical aggression, this is a widespread challenge (please note, this is a duplicate count estimate). Choice about where and with whom you live is a fundamental aspect of self-determination. Recognizing and responding to the fact that self-determined people rarely choose to live in places where they are afraid of the people with whom they live is an obvious aspect of promoting self-determination. A basic expectation of service providers, counties and the state should be that prevention and intervention to address issues regarding consumer to consumer violence or fear of violence occur and that no one who receives HCBS should be forced to live with people they fear.

The overwhelming majority of the crimes reported by providers for which HCBS recipients were victims were simple assault and larceny. The seriousness of consumer-to-consumer violence and reported and substantiated incidents of maltreatment by staff demand better understanding of how people's lives are truly affected by crime, violence and other aversive interpersonal circumstances and what and how should be the appropriate responses. The present maltreatment reporting system for vulnerable adults does adequately identify or respond to such issues.

Case managers and county waiver coordinators expressed significant concerns about Minnesota's quality assurance system. Some of their concerns may be related to a lack of common understanding between counties and the state about the role each plays in maltreatment investigations and in assuring overall quality in the HCBS waiver system. The issue is very complicated because so many different people have roles (e.g., state and county licensing staff, county MR/DD case managers, state maltreatment unit investigators, common entry point personnel, State Office of the Ombudsman). Establishing more effective communication between people in these various roles may help in both clearing up misunderstandings, and in finding ways to make the quality assurance system more effective. In addition to improving communication, a direct response to concerns expressed by stakeholders is needed.

Reports from common entry points that were determined not to be maltreatment by the DHS Investigations Unit (based on the definitions in the Vulnerable Adult Act or Maltreatment of Minors Act) were referred to many different agencies. Review of the logs regarding those referrals made it clear that some involved incidents (such as neglect or consumer-to-consumer violence) or injuries that likely warrant follow-up, licensing action, training interventions or other action by the state, the county and/or the service provider. Future efforts to examine Minnesota's quality assurance system should specifically review the mechanisms at the state and county level that ensure that incidents serious enough to be referred for further action are addressed, resolved and systemically tracked to identify important trends and issues.

Although almost all of direct support staff members report that they know how to file a vulnerable adult report, 27% of DSS stated they did not receive any feedback from their agency, the county common entry point or the state regarding what happened in response to a vulnerable adult report that they filed. All reporters of vulnerable adult maltreatment issues should receive accurate and timely feedback as to what happened with the report and what the outcomes of the situation are, even if the report was screened out. Currently, the legal requirements regarding feedback require DSSS to specifically ask for feedback from the county, and state regarding what happens with a specific maltreatment. This legal requirement needs to change to ensure that feedback and follow up to reporters occurs irrespective of if they ask for it. Of additional concern, 29% of DSS said they were afraid they'd lose their job if a maltreatment report was filed against them even if it wasn't substantiated. Lastly, though small in percentages, clearly a number of DSS reported that they had witnessed abuse or neglect and had been prevented by a co-worker or supervisor from reporting the incident. These are violations of the basic foundation of a successful maltreatment reporting system and need further investigation and intervention.

Although 83% of case managers said they should monitor consumer and family satisfaction of services, only 68% reported that they actually did so. This difference in expectation and reality seems related to average caseloads of Minnesota's case managers that considerably excess the national average. Other discrepancies were evident between what case managers thought should be a part of the quality monitoring activities within the HCBS program and what were actually components of that system. Only 52.7% of case managers reported that their county utilized a consumer advisory council and only 52.8% reported that quality monitoring activities gathered and provided information to families about the quality of HCBS services and service providers. Case managers reported that the overall quality assurance system (across 16 dimensions) only does a "fair" job at assuring the outcomes for which the state is responsible in administering its HCBS program.

HCBS Utilization and Costs

This section describes and analyzes HCBS costs and compares these costs to ICF/MR services and to averages in other states.

Key Findings.

- In FY 1998, expenditures for HCBS recipients averaged $52,961.06, and expenditures for ICF-MR recipients averaged $67,672.85.
- For the typical HCBS recipient, residential habilitation (SLS services) made up 69% of all health and social service expenditures in 1998.
- In FY 1999, Minnesota had average daily recipient expenditures for the combined ICF-MR and HCBS programs of $52,501 as compared with a national average of $47,985.
- Minnesota spent $113.88 per state resident on ICF-MR and HCBS services combined, compared to a national average of $65.53.
- Minnesota's relatively higher expenditures are associated with its overall high levels access to HCBS, its relatively high rate of supporting persons with severe disabilities in the HCBS program, and its proportionately greater use of small group living settings for HCBS recipients (used for 74% of HCBS recipients in Minnesota compared with 41% of HCBS recipients nationally).
- Counties authorize expenditures for children that are on average $6,885.73 more than they actually spend. They authorize expenditures for adults that are on average $3,843.73 more than they actually pay. Differences between children and adults are attributable to spending for SLS which predominately serves adults that is 98.3% of authorized levels as compared to much proportions of authorizations actually spent for services that predominately service children and families (e.g., statewide 70.6% of authorized expenditures for respite care were used). Factors contributing to these differences are explored in the technical report.

Average HCBS Costs in FY 1998

- In FY 1998, Metro counties were allowed an average of $149.71 per HCBS recipient and spent an average of $150.18. urban counties of greater Minnesota were allowed an average of $132.14 and spent an average of $125.61. Rural counties of greater Minnesota were allowed an average of $132.47 and spent an average of $115.62.
- In 1998, Metro counties served 3,078 HCBS recipients (45.2% of the total), urban counties of greater Minnesota served 1,322 recipients (19.4%) and rural counties served 2,409 recipients (35.4%).
- The highest cost HCBS services per recipient per year in 1998 were SLS services for children ($39,868 per recipient), SLS services for adults ($39,490), private duty nursing ($16, 734), day training and habilitation ($12,241), and personal care ($12,032).
- The average annual per person service expenditure was $51,494 in metro counties, $44,495 in urban counties of greater Minnesota, and $40,186 in rural counties of greater Minnesota.
- Average costs were lowest for children 0-10 years ($20,139), and highest for adults 41-50 years old ($53,030).
- Average annual costs were highest for persons in the Asian or Pacific Islander group ($50,689) and lowest for persons who were Hispanic ($39,927).
- Average annual costs were $40,394 for persons with mild mental retardation (MR), $40,999 for persons with moderate MR, $49,941 for persons with severe MR, and $64,006 for persons with profound MR. Average annual costs for persons with related conditions but with no MR were $36,232.
- Average annual costs for persons living in supported living services settings were $51,500 compared with $19,882 for persons living with their immediate or extended family. Costs for persons in other settings (foster family, own home) averaged $31,505.
- Minnesota's Waiver Allocation Structure (WAS) provides counties with different amounts of money to be placed into an allowed spending pool based on statistical assignment of consumers to one of four resource allocation levels. Average annual costs were highest for persons in the Level 1 WAS group (averaging $62,189 per year), and lowest for persons in the Level 4 WAS group (averaging $31,068).
- Average HCBS costs for children were predicted by level of support needed, use of an augmentative communication device, running away, using a wheelchair, needing frequent medical attention, needing mental health services, the WAS allocation level, and whether the child lived in a corporate foster care setting. Of those variables the most variability was accounted for by living in a corporate foster care setting (27.6%), and level of support needed (12.8%).
- For adults variations in HCBS costs were predicted by level of support needed, communication skills, all types of challenging behavior, using a wheelchair, level of medical support needs, use of mental health services, region of the state, and living in corporate foster care settings. As with children, the most variability was accounted for by living in a corporate foster care setting (12.9%), and level of support needed (13.2%).
- Most counties expressed a need and desire to increase the number of people served in the HCBS program in their counties.

- Most counties report using a master contract to identify agency responsibilities in providing HCBS services. The exact service and cost for each individual is identified through attachments and amendments.
- All of the counties used the state developed tracking system that incorporates MMIS data and produces monthly reports on authorized costs, average spending per recipient, and spending for the county as a whole.
- Only one county respondent reported that the state tracking system was effective. Several recurring complaints were mentioned about the tracking system relating to the timeliness and accuracy of information, and technical assistance available.

Impact of the Waiver Allocation Structure

- In 1995, a new methodology (the Waiver Allocation Structure) to establish the amount of money added to county funding pools for new HCBS recipients was implemented. After this new methodology was implemented, new HCBS recipients were slightly more likely to have profound mental retardation or related conditions and slightly less likely to have mild or moderate mental retardation.
- Actual expenditures for services to children are considerably less than (56.9% of) the resources allocated to counties for those same children through the allocation process.
- Actual expenditures for adults (18 and older receiving HCBS) are slightly higher (about $200) than allocations to counties when those adults entered the HCBS program.
- Although HCBS recipients enrolled before and after introduction of the WAS have similar current expenditures, the allocations to counties on their behalf in 1998 were very different (e.g. pre-WAS, $36,750 for children; post-WAS, $57,842).

What's working?

As the HCBS program in Minnesota has continued to expand, and as it has exceeded the size of the ICF-MR program, it continues to provide supports to individuals at a cost lower than that of the ICF-MR program ($52,961 versus $67,763 per year per person in 1998). The implementation of the Waiver Allocation Structure (WAS) was intended to provide appropriate levels of allowed spending to counties based on the specific supports needs of individuals entering the HCBS program. One of the primary reasons for doing so was to expand access to HCBS for persons with more substantial and costly support needs. The WAS has been associated with a modest increase in the proportion of individuals supported by the HCBS program who had profound mental retardation. The proportion of HCBS participants with profound mental retardation increased from 15.5% for persons entering the HCBS program prior to July 1995 to 18.3% for persons entering the program after that date.

Challenges and concerns.

Minnesota makes extensive use of corporate foster care in providing HCBS to Minnesota. It does so at an average cost (in 1998) of $54,733 annually as compared with $24,420 for all other HCBS funded services. While Minnesota provides HCBS at about 78% of the cost of ICF-MR service, in considering the differences two factors should be recognized. First, only 2.2% of ICF-MR residents are children and 11.8% of HCBS recipients are children. The average annual costs of HCBS in 1998 for children was about 55% of that for adults, so that the higher proportion of children receiving HCBS contributed substantially to the difference between HCBS and ICF-MR expenditures. Children's expenditures tend to be lower because their primary day activity is funded by their school districts and most live in the homes of family members who provide much of their care and supervision. Relatedly the 14% of HCBS recipients live with immediate or extended family members are major contributors to expenditure differences. In addition, ICF-MR residents are more likely than HCBS recipients to have severe or profound intellectual disabilities (59% and 36%, respectively). The average cost in 1998 of HCBS (excluding health services) for persons with mild and moderate mental retardation was only 72% of that for persons with severe and profound mental retardation ($40,660 and $56,234, respectively).

The 1996 Report to the Legislature from the Department of Human Services noted that there is general cost-effectiveness of the HCBS-financed "model" over the other ICF-MR alternative, but it also raised concern about over-reliance on small HCBS-financed group homes as primary approach to service delivery. The 1996 report recommended that Minnesota invest in training, technical assistance, increased flexibility and other forms of support to assist individuals, families and local governments to develop more personalized approaches to services. Still, there continues to be a heavy reliance on small group homes and day training and habilitation centers to support individuals with MR/RC in Minnesota.

In a time of great general difficulty in recruiting personnel, it appears that family-based services are receiving lower priority in staffing than SLS congregate care services where requirements and concern for safety requires that providers maintain a sufficient level of staffing and therefore billing. These differences in access to the services people are authorized to receive are affecting both children and adults living in their family home. For example, on average, respite care expenditures in 1998 were 70% of the authorized amounts; in-home family supports expenditures in 1998 were 82% of authorizations. Interviews with county waiver coordinators and service providers suggest that these problems are at least as serious in 2000 as they were in 1998 and in some areas in more so.

Irrespective of concerns about the fairness of such differences and the adequacy of the general commitment to families, the cost implications of failing to support people in their homes at relatively low cost at the risk of hastening out-of-home placement occurrences are impressive. Children living with their parents or extended family members had average HCBS expenditures that were 42% of the average HCBS expenditures for children living away from their family home ($18,262 and $43,064, respectively). Insufficient family support of children brings a substantial financial as well as psychological and social cost when it leads to out-of-home placement.

It is important to consider the effect of the current children who receive HCBS funding growing up. Although Minnesota has a relatively small proportion of children receiving HCBS (12%) as these children turn to adults, based on current expenditure patterns, the cost for their services will almost double. Considerable new financial commitments will need to be secured for their futures unless there is a substantial reduction in the use of SLS services and a greater use other alternatives to group residential settings, including "host family," extended family care and other much less costly models.

There are several longer-term implications of Minnesota's current cost allocation and expenditures practices. First, children make up a very small portion of Minnesota's HCBS population (about 10.6%), but the difference between their "allowed" funding (i.e. the amount added to the county-managed funding pool on their behalf) and the amounts actually spent on services for them keep the state system out of deficit. With almost half (45%) of the HCBS recipients who are 20 years or younger being between 16 years and 20 years old, the 83% higher costs on average for services to adults than children presents a fairly immediate threat to the current modest 4.1% difference between allowed and paid costs.

Counties have been providing services to adults and children who entered the HCBS program after 1995 at substantially less than their allowable costs. Even in the Twin Cities metro counties which in 1998 spent overall 4.8% more for their adult HCBS recipients than was provided by the state's allowed expenditures for those same adults, the post-WAS allowances for adults were 5.3% more than expenditures. Given the stability in expenditures for pre and post-WAS enrollees, the higher allowed costs derived from the WAS (on average $55,838 as compared with $44,497 for pre-WAS enrollees), has been extremely helpful to counties in managing the HCBS programs within budget. This assistance through the WAS has been all the more notable since persons who entered HCBS services after 1995 do not differ from those who entered earlier in levels or types of impairments. As results counties have to increase their pools of resources more rapidly than expenditures and make spending commitments to individuals whose services cost more than the amount allowed through the WAS.

Conclusion

While there certainly remain to be challenges and concerns regarding HCBS for Minnesotan with MR/RC the vast majority of interviewees, other key informants, data sets and other documents that informed this evaluation suggest that HCBS has supported people to having better integrated, more fulfilled lives. HCBS has enabled literally thousands of people to remain in or to be reconnected to their communities of choice as active citizens and has done so at lower cost than traditional congregate care through ICFs-MR and state institutions. Minnesota's HCBS program has been rapidly growing more than doubling in total recipients in just 6 years between 1993 and 1999. It now faces challenges in building an effective infrastructure under a program that has grown from the "alternative" to ICF-MR to Minnesota's primary program for people with MR/RC. Through focused and collaborative strategic change, the challenges facing HCBS in Minnesota can be addressed. Individuals who receive HCBS will benefit from this change by gaining greater choice, increased respect, greater self-determination, improved access, dependable and effective direct support, quality assurance that improves quality and other initiatives that will achieve the highest quality of community supports to Minnesotans with mental retardation and related conditions.

PART I: INTRODUCTION AND BACKGROUND

Evaluation Purpose

In April 1999, the Minnesota Department of Human Services, Division on Community Supports for Minnesotans with Disabilities (DHS-CSMD) entered into a contract agreement with the University of Minnesota's Research and Training Center on Community Living at the Institute on Community Integration (U of MN) to conduct an independent evaluation of Minnesota's MR/RC Home and Community Based Services (HCBS) Waiver Program. The last independent evaluation of Minnesota's MR/RC HCBS program was completed in 1992, also by the U of MN. The purpose of the present HCBS evaluation was to gather information on research questions raised by DHS-CSMD and the evaluation's Stakeholder Advisory Committee to identify progress and remaining challenges in the administration and design of the MR/RC HCBS program, and to assist in strategic planning for the future of the HCBS program.

This report describes key components of the evaluation of Minnesota's HCBS program. The methodology section describes the process used to develop instrumentation, obtain respondent samples, and code and analyze data. The results section summarizes and discusses findings in the context of state and national trends. The recommendations section summarizes recommendations to assist in strategic planning for the future of the HCBS program.

Overview of Medicaid Home and Community Based Services

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35), passed on August 13, 1981, granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" services for Medicaid-eligible individuals. The Medicaid Home and Community-Based Services "waiver" (HCBS) program was designed to provide home and community based services for people who are aged, blind, disabled, or who have mental retardation or a related condition (MR/RC) and who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid facility (i.e., an institution, Nursing Facility or an ICF-MR). Final regulations were published in March 1985. Since then several new regulations and interpretations have been developed, but none have changed the fundamental premise of the program to use home and community-based services and supports to reduce the need for institutional services.

Non-institutional services that can be provided under the HCBS program include case management, personal care services, adult day health services, habilitation services, respite care, or any other service that a state can convincingly argue will lead to decreased need for and costs of Medicaid funded long-term care. Although not allowed to use HCBS reimbursements to pay for room and board, all states offering HCBS to persons with MR/RC provide residential support services under the categories of personal care, habilitation, homemaker or other service categories. Cash assistance from other Social Security Act programs (S.S.I, S.S.D.I), state supplements and individuals' personal earnings are used to pay room and board costs. In 1998, about two-thirds (66.4%) of HCBS recipients in the 42 states reporting such data received services in settings other than the home of natural or adoptive family members (Prouty & Lakin, 1999).

Given both its flexibility and its potential for promoting individualization of services, the HCBS program is recognized in all states as a significant resource in the provision of community services as an alternative to institutional care. Since 1992, requirements that prevailed in the HCBS program's first 10 years that states demonstrate reductions in projected ICF-MR residents and expenditures roughly equal to the increases in HCBS participants and expenditures have been considerably relaxed. As a result, there has been recent dramatic growth in the number of HCBS participants, even as the number of ICF-MR participants has remained relatively stable. In June 1999, states provided HCBS to more than twice as many people with MR/RC (262,538) as resided in the ICFs-MR (117,764) (Prouty & Lakin, 2000).

Minnesota's HCBS Program

Overview

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 approved, and 278 Minnesotans with MR/RC were receiving HCBS by June 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 and to 7,102 by the end of state FY 1999 (Prouty & Lakin, 2000). In June 1999, Minnesota's HCBS program for persons with MR/RC (with 7,102 recipients) was the eleventh largest in the U.S.. Minnesota's utilization rate of 148.7 recipients per 100,000 of the state's population was the 14th largest, behind North Dakota (295.7), South Dakota (268.9), Vermont (259.3), Rhode Island (241.5), Wyoming (231.7) and nine other states (Prouty & Lakin, 2000). By comparison, in 1991, Minnesota's utilization rate for HCBS (57.6 per 100,000 state residents) was fourth largest in the nation.

In its original application Minnesota was authorized to provide HCBS participants with case management, habilitation, including residential habilitation (supported living services and in-home support services), day training and habilitation, homemaker/chore 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). Subsequent renewals and amendments have added crisis respite, 24-hour emergency assistance, adult-day care, supported employment, specialist services, caregiver training and education, housing access coordination, assistive technology, personal care attendant, personal support, transportation, consumer training and education and consumer-directed community supports. Minnesota's current menu of HCBS is among the most comprehensive and, at least by definition of available services, among the most person-centered and consumer-controllable of all state HCBS program service menus in the United States.

Administration of the HCBS 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 social 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 of Community Supports for Minnesotans with Disabilities (CSMD), with several other DHS divisions having specific responsibilities with respect the program's services (i.e., Licensing Division licenses and monitors provider agencies). At the county level, with cooperation and system support from the state DHS, county social service agencies act to plan, arrange or provide, and monitor HCBS for eligible persons within limits of budget and state and federal standards. Case management is provided by employees of the county social service agencies, or in a very limited number of cases, employees of contracted agencies.

Allocations of HCBS Waivers to individuals. The number of individuals allowed to receive HCBS services is managed by the state. 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 ICFs-MR, closing community ICFs-MR, preventing out-of-home placement of children, serving individuals with elderly parents), the number of persons requesting and eligible for HCBS, historical ICF-MR use, and county plans to develop new resources.

In recent years, in part because of how early MN began providing services and the size of the existing HCBS program, Minnesota's requested and realized growth, although substantial, has been considerably less than the national average. For example, between June 1992 and June 1999 Minnesota's number of HCBS recipients grew by 178% (from 2,551 to 7,102), but nationally the number of HCBS recipients grew by 320% (from 62,429 to 262,538 individuals)(Prouty & Lakin, 2000).

Management of allocated funds. Once individuals receive HCBS services they continue to receive such services so long as they remain eligible, HCBS services are judged to be adequate to meet their needs, and counties determine that they are able to do so within the allowed budgets passed on to counties to manage. Counties are authorized to serve an established number of people within a "unique allowable daily average". State allocations to county resource pools before 1996 were determined by various mechanisms based on the allowable daily reimbursement rate established for the county. Over time the state modified the amount added to county pools as individuals entered the HCBS program through the enhanced HCBS Waiver services fund, the family choice option demonstration, enriched funding, SILUN allocation, and crisis respite services. Since Fiscal Year 1996 state allocations to county resource pools have been adjusted by an "allocation structure" that provides four resource allocation categories (1-4) based on an assessment of the physical, functional, medical and behavioral support needs of newly enrolled individuals. Now "the calculation of each county's unique allowable daily average is based on the allowable average daily dollar amount associated with each person who enters the program after July 1, 1995 and the base dollar amount authorized for persons in service as of June 30, 1995" (DHS, 1996). These differential HCBS resource allocations are not provided directly to an individual as an individual budget, but are allocated to the individual's county to be managed as part of the counties overall pool of resources for serving all HCBS recipients within that county. So, for example, if the county is allocated $100 a day to serve an individual from DHS the county could select to spend $40 a day or $200 a day provided they stay within their total county HCBS allocation. The differential allocation of resources based on the assessed needs of individuals responded to tendencies in some countries to assure that they did not overspend their allocation by limiting HCBS access to persons whose services would cost more than the counties current unique allowable daily average.

Financing of HCBS

Although the state DHS establishes overall HCBS budget limits for counties, these limits are established as pooled budget 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 pool of funds for the county. This gives them the flexibility to allow for differences in the levels, types and costs of services needed by individuals. This also makes important for counties to attend to factors that may operate to push expenditures beyond available funding. For example, counties may find it relatively inexpensive to serve some children with HCBS because parents provided the bulk of personal support and schools provide the primary day activity. However, when these children become adults the costs of their HCBS services can increase dramatically as school programs are replaced by HCBS-funded employment and day services and the support provided by parents in their family homes is replaced with costly supervised residential arrangements. Because of the difficulties some counties have had in managing changing resource needs over time, the Department of Human Services has developed training programs and budget management and simulation software to assist counties in predicting the costs associated with changing needs of recipients and managing the finances of their HCBS programs.

Organizational Roles

County roles. County social service agencies play the key role in the implementation of Minnesota's HCBS Waiver program. Counties may act as direct providers of HCBS services; all counties provide case management, some provide homemaker and respite care services as well. County social services agencies also play the primary role in selecting individuals to receive HCBS and in purchasing services for them from state operated services or private for-profit or non-profit service providers. Some counties have a number of private service providers from which to choose while other, usually but not always rural, counties are dependent on one or two service provider agencies for most services.

Training and technical assistance. Minnesota's DHS provides training and technical assistance to county human services agencies, service providers, and others to maintain the quality of services and HCBS management. Periodic, statewide training is conducted by central office CSMD staff. A small network of regional CSMD staff (Regional Resource Specialists) is responsible for on-site training and technical assistance requested by counties and providers. Some counties also provide training and technical assistance, but for the most part private service providers and organizations of service providers carry out their own training activities and secure their own technical support with little formal assistance or involvement from state or local governments.

Quality standards and review. Monitoring the quality and appropriateness of services received by HCBS recipients is primarily the responsibility of the case managers of individual service recipients. Other targeted monitoring of service quality, as defined in formal licensing rules, is conducted by the Division of Licensing of the state DHS, with certain functions delegated 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. Many of the rules governing HCBS services in Minnesota are found in the "Consolidated Standards". In addition, "Rule 41" describes the funding and administration of HCBS, and specifies qualification requirements of providers. Other rules that pertain to the HCBS program include, "Rule 40" regarding the use of aversive and deprivation procedures, "Rule 10" regarding treatment of vulnerable adults, "Rule 11" regarding background investigations of care providers, and "Rule 206" regarding homemaker services. Additionally the "Consolidated Standards" provide standards regarding the staff who support HCBS recipients and the programming, habilitation and other supports that must occur within HCBS services.

Continuing oversight by the DHS Medicaid Surveillance, Utilization Review unit is among measures to assure appropriate use of federal and state funds for HCBS recipients. Several state and private oversight and advocacy organizations, including the office of the Ombudsman, the State Protection and Advocacy Agency ("The Disability Law Center"), the Governor's Planning Council on Developmental Disabilities and State and local chapters of the Arc, have ongoing responsibilities and interest in monitoring the quality and accessibility of the HCBS program.

Information systems. In addition to a fully computerized billings and payment system, Minnesota maintains an extensive system of computerized information on its HCBS program participants. This system provides current data on individual recipients and the services they receive; their physical, functional, medical, behavioral, sensory and other abilities and needs; their living circumstances and demographic and other information based on Screening Documents submitted to the state by county case managers. This state information system includes all persons with mental retardation or related conditions receiving or screened as eligible for but not receiving HCBS. It also includes individuals with MR/RC who are receiving other types of services. The state also maintains a database that summarizes the amount actually paid for each type of service received by each HCBS recipient, the amount of payment authorized by counties for each type of service for each HCBS recipient, and the amount of funding added to the county's overall resource pool when an individual is selected to receive HCBS services. The state provides periodic reports from these data bases to each county to assist local agencies in administering HCBS for those individuals for whom they are responsible within limits established for them.

PART II: RESEARCH DESIGN AND METHODOLOGY

Several different research methodologies were used in this study to maximize the validity and reliability of the findings. These methods included: 1) analyses of data from existing state data sets including information on HCBS recipients, expenditures and maltreatment reports; 2) direct interviews with individual recipients of HCBS; 3) written surveys of residential and vocational provider agencies, families, case managers and direct support staff; 4) telephone interviews with county MR/RC HCBS coordinators; 5) meetings with representatives of stakeholder groups (MHC, ARRM, MNDACA, Legal Aid, DHS-CSMD, Arc); and 6) document review. These methodologies along with the research questions, description of the sample, access to the sample members, instrumentation, data analyses, and the limitations of the study are reviewed in this section below.

RESEARCH QUESTIONS

This study examined several broad research questions developed for the proposal submitted to the DHS-CSMD and revised based on stakeholder advisory group input.

- What are the demographic characteristics of HCBS recipients and how do their characteristics differ from those of ICF-MR recipients?
- To what extent are basic health, monitoring and service needs of HCBS recipients met?
- Do recipients have adequate opportunities and quality of life?
- To what extent are providers of HCBS services providing high quality supports and services?
- What are the utilization and costs of specific HCBS and other Medicaid Services? How do they differ across recipient groups? How do they differ across time?
- How do the total service costs for HCBS recipients vary? How do costs for various categories of service for HCBS recipients vary?
- What are issues of concern with the HCBS program?

Stakeholder Advisory Committee

A Stakeholder Advisory Committee (SAC) was created to assure that the evaluation attended to the information needs, perspectives and concerns of the HCBS program's various constituents.   The SAC consisted of 39 individuals representing a variety of organizations, agencies and stakeholder groups including: DHS – CSMD; Governor's Planning Council on Developmental Disabilities; the Disability Law Center, the Arc, county social services, the Minnesota Ombudsman office, parents, consumers; the Association of Residential Resources in Minnesota (ARRM), Minnesota Habilitation Coalition (MHC), Minnesota Developmental Achievement Centers Association (MNDACA), the STAR Program, and other interested individuals. A complete listing of the Stakeholder Advisory Committee and their affiliations is located in the acknowledgements section of this report.

The Stakeholder Advisory Committee served four primary functions for this study; 1) identifying survey questions; 2) reviewing, editing and providing feedback on all instruments; 3) communicating to the stakeholder groups they represented about the purpose, design and outcomes of the evaluation, and 4) assisting in the interpretation of the results of the evaluation and in formulating recommendations based on these results.

Sample

Individual HCBS Recipients Sample

The sampling strategy used in this study was intended to yield a representative sample of 500 current HCBS waiver recipients. The first step in the sampling process was to identify a representative sample of counties. Minnesota's 87 counties were stratified into three categories: Twin Cities Metropolitan Area (7 counties), counties in greater Minnesota urban centers with populations of 50,000 or more residents (11 counties) and counties in greater Minnesota rural areas with populations of less than 50,000 residents (69 counties). From these groups, 24 counties were selected and invited to participate in the study. These include:

Four Twin Cities metropolitan area counties (Metro): Hennepin, Ramsey, Washington, Anoka;

Seven populous counties in greater Minnesota urban (GM Urban): Blue Earth, Clay, Crow Wing, Olmsted, Sherburne, Stearns, St. Louis;

And thirteen greater Minnesota rural counties (GM Rural): Becker, Carlton, Faribault, LeSueur, Mahnomen, Martin, Meeker, Norman, Redwood, Steele, Stevens, Wabasha, Wantonwan.

Once counties were identified a sampling ratio of all HCBS recipients in each county type was computed based on the proportion of all HCBS recipients in counties of each of the three county types. An earlier plan to sample 700 HCBS recipients was reduced to 500 to meet project timelines. A sample frame was then created to include all eligible HCBS recipients in the selected counties. HCBS recipients in the sample frame met following criteria: 1) their county of financial responsibility was one of the 24 counties in the sample, 2) their county of residence was one of the 24 counties included in the sample, 3) they were alive at the time the study sample was selected (screening document data includes people who might have received HCBS in 1998/99 but who subsequently died).

Table 1: Distribution of MN HCBS Waiver Participants in 1999 by County Type

County Type	Number of HCBS Waiver Participants	% of HCBS Waiver Participants	Number of People in Sample	% of People in Sample
Twin Cities	2,930	44.7%	204	43%
GM Urban	1,281	19.6%	84	18.6%
GM Rural	2,337	35.7%	182	38.4%
Total	6,548	100.0%	474	100%

Based on the sample frame membership and sampling rates, the sample distribution shown in Table 1 was obtained. An initial group of 665 people was randomly selected. To that random sample, a controlled over-sample of 35 people was selected from among racial or ethnic minority group members receiving HCBS. The additional selections from ethnic and racial minority groups were controlled to reflect the proportion of minority group members receiving HCBS recipients in each of the three county types. The over-sampling of HCBS recipients from ethnic and racial minority groups was done to ensure that a sufficient number of ethnic and minority group members would be included in the sample to allow reasonably reliable estimates of the experiences of HCBS recipients from Minnesota's ethnic and racial minorities.

The final HCBS sample size is presented by county of financial responsibility of those HCBS recipients included:

Table 2: County of Financial Responsibility for Sample Members

County	*N*	County	*N*
Metro		**GM Rural**	
Anoka	24	Becker	13
Hennepin	126	Carlton	19
Ramsey	44	Faribault	22
Washington	10	Le Sueur	26
GM Urban		Mahnomen	5
Blue Earth	1	Martin	20
Clay	13	Meeker	12
Crow Wing	10	Norman	3
Olmsted	13	Redwood	15
Sherburne	6	Stevens	6
Stearns	15	Steele	20
St. Louis	30	Wabasha	18
		Watonwan	3
Total			474

Informal Consent to Participate

Access to information about the services received by a sampled individual depended on that individual or his/her guardian providing informed consent to participate. Obtaining consent required the involvement of each sample members' county case manager. Until individuals provided consent to participate they remained anonymous to the interviewers. Case managers were asked to verify eligibility of sampled individuals, explain the study and its demands to them, and request consent to participate from HCBS recipients, family members or other legal representatives as appropriate. For individuals under state guardianship the case managers themselves exercised the power of consent. A total of 20 individuals in the initial sample were removed because they were ineligible based on the criteria noted earlier. For the others, once consent was obtained, case managers completed a "pre-interview form" which provided information about where the person lived, their service providers and as applicable their family member contact information.

Replacement of Sample Members Declining to Participate

When individuals or their legal guardians refused to participate, a replacement was randomly selected from the same county type and sampling group (general or the minority over-sample). Individuals who did not meet eligibility criteria were also replaced. Including replacements, requests for consent were sought from 801 eligible people of whom 192 declined to consent (24%). This resulted in a final sample of 608 individuals. From these 608 people informed consent forms and individual pre-interview forms were completed and returned by case managers on 474 individual HCBS recipients (78%). The guardianship status of individuals who were selected but who declined participation or who did not respond to the invitation is shown on Table 3.

Table 3. Number of People that Declined to Participate

Guardianship Status	Did not respond			Refused	Total
	Metro	GM urban	GM Rural		
Private guardian or conservator (adult)	37	20	22	109	188
Public guardian or conservator (adult)	23	6	2	18	49
No guardian needed (adult)	9	3	2	24	38
Parent is guardian (under 18)	6	8	3	33	50
Guardian ad litem (under 18)				1	1
County is legal representative (under 18)				1	1
Total	75	37	29	186	327

Final Sample Members

Table 4 provides a summary of individuals participating in the study by guardianship status. Participation rates (individuals participating divided by individuals participating plus individuals declining to participate) ranged from 52.2% for adults with private guardians and 54.5% for children with family members as guardians to 63.3% for persons who were their own guardian who were their own guardian and 76.8% for people who had public guardians.

Table 4: Guardianship Status of Consumers Who Consented to Participate

Guardianship Status	Metro	GM Urban	Rural	Total
Private guardian or conservator	81	35	89	205
Public guardian or conservator	77	29	56	162
No guardian needed	17	10	15	42
Parent is guardian under 18	28	12	20	60
County is legal rep. under 18	1		3	4
Guardian ad litem			1	1
Total	204	86	184	474

Table 5 compares selected characteristics of the 474 people who participated in the study with characteristics of all HCBS recipients in Minnesota. In general, the sample was statistically equal to the population. However, the sample included a higher proportion of females than the HCBS population as a whole (47.9% and 41.9%) respectively. Minority group members were over represented in the sample by design. (See Section B of this report for additional information on the characteristics of HCBS recipients and sample members).

Table 5: Selected Demographic Characteristics of Sample Members

Characteristic	HCBS Non-Sample		Sample		X^2/Sig.
	N	Percent	*N*	Percent	
Region					1.42
Metro	2,930	44.7%	204	43.0%	
GM Urban	1,281	19.6%	88	18.6%	
GM Rural	2,337	35.7%	182	38.4%	
Level of Mental Retardation					6.58
Related condition	213	3.3%	15	3.2%	
Mild	2,189	33.4%	141	29.7%	
Moderate	1,745	26.6%	141	29.7%	
Severe	1,318	20.1%	91	19.2%	
Profound	1,057	16.1%	86	18.1%	
MR - not specified	26	0.4%	0	0.0%	
Age group					5.5
0 to 5 years	43	0.7%	4	0.8%	
6 to 17 years	752	11.5%	64	13.5%	
18 to 39 years	3,012	46.0%	193	40.7%	
40 to 64 years	2,320	35.4%	179	37.8%	
65+ years	421	6.4%	34	7.2%	
Gender					
Male	3,804	58.1%	247	52.1%	6.49*
Female	2,744	41.9%	227	47.9%	
Race/Ethnicity					10.1*
Black non-Hispanic	157	2.4%	17	3.6%	
American Indian/Alaskan Native	92	1.4%	9	1.9%	
Asian/Pacific Islander	43	0.7%	8	1.7%	
Hispanic	36	0.6%	3	0.6%	
White	6,212	95.0%	437	92.2%	
White/Non-white					
Non-white	328	5.0%	37	7.8%	7.56*
White	6,212	95.0%	437	92.2%	

* $p < .05$, ** $p < .01$

Table 6 summarizes the average amounts allowed by the state for county expenditures for the HCBS sample and population, and the average of actual payments in 1998 for the HCBS sample and population. Again, none of these differences was statistically significant.

Table 6: Cost Comparison Sample vs. Non-Sample HCBS Recipients

	Non-Sample HCBS Recipients	Sample Recipients	*F*
Average Cost Allowable	$48,650.40	$47,460.70	1.14
Average Cost Paid	$46,778.72	$48,009.26	.94

Case Manager Sample

A sample of 75 case managers was randomly drawn from among all case managers of HCBS service recipients within the 24 sampled counties: 33 from metro counties, 15 from greater Minnesota urban counties and 27 from rural counties in greater Minnesota. Fifty-two case managers responded to the surveys. No attempts were made to replace case managers who did not return their surveys.

State Data Sets

The Department of Human Services Division of Community Supports for Minnesotans with Disabilities (CSMD) provided four existing data sets for this evaluation including:

Screening Document Files

The Minnesota screening document provided demographic, diagnostic, functional, behavioral, health and service need information on all 6,548 individuals with MR/RC receiving HCBS (including the 474 people in the sample). The files evaluated for this study contained the most recent screening available as of April 1999.

Administrative Reports

Information from the HCFA Form 372 and Form 64 cost reports were used to compare expenditures of HCBS and ICF-MR recipients, including expenditures for related Medicaid state plan services. Information from the October 1999 Report to the Legislature, "Home and Community Based Services for Persons with Mental Retardation and Related Conditions" provided background on the goals of DHS-CSMD for the HCBS programs, information on challenges faced in the programs and statistical trends in state and county service days, allowed expenditures, authorized expenditures and actual service payments by FY 1995 and FY 1999.

HCBS Payment Files

Department of Human Services payment files were used to analyze payments for fiscal years 1997 and 1998. These data sets included:

- Total costs of HCBS by county.
- Costs of HCBS by procedure code for each service recipient.
- Tables summarizing authorized and paid expenditures for each HCBS service provider.
- Total cost per recipient, including information conversion/diversion status and resource allocation grouping (1-4 or base for persons entering prior to FY 1996).
- Total cost per recipient by provider code and service procedure codes

Maltreatment Data

The Department of Human Services Licensing Division Investigations Unit provided 1995 – 1998 data logs which included information about maltreatment reports that were received by the investigations unit but after initial disposition were determined to not be maltreatment and either screened out or referred to another agency. This data was used to summarize the types of maltreatment reports that are screened out or referred to other agencies. Additional information obtained from a Department of Human Services report related to summary information on the number and outcomes of maltreatment reports that were referred for investigation and their final dispositions. DHS also provided information about the number of direct support staff members who applied to work in licensed programs who were disqualified based on background studies. Finally, another Department of Human Services report identified the number of maltreatment reports made to common entry points (at the county level) in Minnesota in 1998.

Other Reports

DHS Waiting list report. Information regarding waiting lists for HCBS services was obtained from a report called *Home and Community Based Services for persons with mental retardation and related conditions: A report to the Minnesota Legislature* (October, 1999).

Recent wage studies conducted by ARRM and the MnHAB/MnDACA taskforce were used in this study to compare DSS wage findings with other studies. These reports were entitled *Workforce crisis deepens: Caregivers need compensation increase* and *Minnesota Developmental Achievement Center Association and Minnesota Habilitation Coalition 1999 Salary Survey: Results Metro versus Non Metro.*

Instrumentation

Several survey instruments and interview protocols were developed as data collection tools for this study. (Copies are available upon request, they are not included in the Appendices due to their number and length).

Consumer Interview

The consumer interview protocol for the evaluation was specified by DHS-CSMD. The protocol was developed by the Human Services Research Institute and the National Association of State Directors of Developmental Disabilities Services for Core Indicators Project. The Core Indicators Consumer Interview Project was piloted by the Human Services Research Institute to establish the reliability and validity of the questions. Slight modifications to this protocol were made for the HCBS evaluation based on suggestions of the Stakeholder Advisory Committee (SAC), but consisted only the addition of questions to clarify the importance of certain items to individual HCBS recipients.

Additional survey instruments were developed by project staff in conjunction with the SAG. These included an individual case manager survey, a general case manager survey, residential and vocational provider surveys, family surveys (in-home and out-of-home), and residential and vocational direct support staff surveys. Instruments that had been used successfully in previous studies (e.g. 1992 HCBS Waiver evaluation, Performance Based Contracting project, Self-Determination Evaluation, the Minnesota Longitudinal Study and the Minnesota Longitudinal Study of Newly Hired Direct Support Staff Members) were used to identify established questions applicable to the HCBS evaluation. Sample questions were reviewed by SAG members in small work groups to identify topical areas and specific questions to include. Draft instruments were developed and then reviewed and edited by the SAG members, other researchers and project staff.

An interview protocol for county HCBS Waiver Coordinators was developed based on an instrument being used in a national evaluation of the Home and Community Based Services program. This interview protocol was reviewed by county SAG members and substantial revisions were made.

The Stakeholder group interview protocol also was developed by project staff based on an instrument that designed and piloted for the national evaluation of HCBS Program. This protocol was not reviewed by members of the SAG.

Data Collection and Response Rates

Several methods were used to collect data from study participants. These methods included face-to-face interviews, telephone interviews, group discussions and written surveys. Table 7 indicates the response rates for each data collection method.

Table 7: Response Rates

Surveys	Return	Rate
Declined to consent	186/801	23%
Did not respond to invitation	141/801	18%
Case manager returned pre-interview and consumer/guardian returned consent forms	474/801	59%
Individual Case Manager	468/474	99%
*Consumer Interviews	372/405	93%
Family	183/365	50%
Residential Site	184/309	60%
Vocational Site	82/163	50%
Residential DSS	151/618	24%
Vocational DSS	74/326	23%
General Case Manager	52/75	69%
County HCBS Waiver Coordinator Interviews	21/24	86%
Stakeholder Group		100%

* Consumer interviews not conducted for children under age 18

Interviews With Individual Recipients

Interviews were completed for 377 adult recipients of HCBS Waiver services of the 405 adults who consented to participate. This yields a response rate of 93%. These face-to-face interviews generally were conducted at the persons home or at an alternative location as requested by the individual. Interviews were conducted by volunteers of staff from local Arc chapters throughout the state who attended a training seminar on how to use the consumer interview protocol to conduct the interviews with HCBS Waiver recipients. Additional training was provided upon request to interviewers who needed additional information or needed additional support from U of MN project staff.

The interviews conducted with adult HCBS recipients included three sections. The first section was completed by the house coordinator, program manager or a family member where the person lived. This section contained background questions regarding personal, health, residence, and other supports. The second section was a direct interview with the adult HCBS recipient. If the adult recipient was unable to answer these questions, no proxy was used. This section asked about the person’s satisfaction with his/her work or day program, access to friends and family, home, and services/supports coordination. The third section could be completed by a direct interview with the recipient of services or with someone who knew him/her well. In most cases the individuals family member or case manager identified who the best proxy would be for the interview. This section obtained information about the individual’s inclusion in the community, choices, rights and access to services, supports and family/friends.

Written surveys

Written surveys were mailed or hand delivered to family members, provider agencies, case managers and direct support staff to obtain various perspectives on the type and quality of services and supports provided to Minnesotans with mental retardation and related conditions who receive HCBS Waiver services. The various survey instruments and response rates are described below (see Table 7 for an overview).

Family In- And Out-of-Home Surveys.

Surveys were mailed to the family members of participating sample members as identified by their case manager on the pre-interview form. A total of 365 family members of both adult and children who receive HCBS services were sent the mail survey to complete. Additional copies of surveys were sent to those families who had not responded by January 2000. A response rate of 50% was obtained. Of the families who responded to the survey, 75.6% of the responses were from natural or adoptive parents, 17.2% of the responses were from siblings or other relatives, and 7.2% were from others. Of the 183 surveys returned 34 were from families whose member lived in their home while 149 were from families whose member lived somewhere else. Families responded to questions about the quality of services their family member received including: in-home services, out-of-home residential services, employment/day services, county case management, transportation, specialized therapies, education, respite, crisis behavioral supports, home and environmental adaptations and assistive technology.

Provider agency surveys. Provider surveys were mailed to 309 residential and 163 vocational agencies that provided direct services to children and adults in the sample. These surveys collected information about the specific services provided at the site (e.g. group home, apartment building, DTH site). They were not intended to collect information about the entire agency. This design was requested by the Stakeholder Advisory Group so that individual outcomes could be linked to specific service sites. Information was collected regarding site characteristics, agency/organization characteristics, transportation, health & safety, staffing patterns, pay, paid leave and benefits, staff recruitment and retention, training practices, relationships with county and state, and general opinions about HCBS services.

Follow up phone calls were made by U of MN staff to each residential and vocational provider agency who was sent a survey but had not returned it by October 1999. Replacement surveys were mailed upon request. Additional calls and in-person contacts were made by U of MN staff to senior administrators in several of the larger residential and vocational agencies included in the sample to encourage these agencies to return surveys from the various sites from whom surveys had not been returned. In February 2000, DHS-CSMD called the 10 largest provider agencies in the survey that had multiple unreturned surveys. At this same time, the Institute on Community Integration modified the provider survey by substantially shortening its length because many of the providers had indicated that the length was the reason for not having completed the surveys. This shortened version was mailed to all providers who had not yet returned their surveys. These efforts to increase the response rates dramatically affected the number of surveys returned. In all, 182/309 residential surveys were returned (a response rate of 59%) along with 80/163 (49%) vocational surveys.

Direct support staff member surveys. Direct support staff member (DSS) surveys were hand delivered by the Arc consumer interviewer to the site where the consumer interview occurred. Surveys were mailed to other sites in which sample adults received services and to all service agencies in which sample children received services. Two DSS surveys were given to each site. The site supervisor was instructed to invite the longest tenured and the most newly hired direct support staff member at each site to participate. When more than one service recipient in the sample lived or received services at the same site, the supervisor was instructed to have the second longest term and second most newly hired DSS complete the survey and so on. The DSS survey collected information about the background and characteristics of the DSS, job characteristics, service quality, job related outcomes, training experiences and employment experiences. When follow up phone calls were made to the residential and vocational site, if applicable, the supervisor was also reminded that the DSS surveys from that site needed to be returned. When requested, additional copies of the DSS surveys were mailed to the sites. Of 618 DSS surveys provided to residential sites, a total of 157 were returned (25%) and of the 326 DSS surveys mailed to vocational sites, 71 were returned (22%). Because the “other” provider surveys were not included in the analyses for this evaluation project due to low response rates, the “other” DSS surveys were also excluded.

Individual case manager surveys. Written surveys were mailed to the individual case managers of every member in the sample. These surveys asked case managers about their relationship with recipient, what services the recipient was receiving, their opinions about the adequacy and quality of the services the recipient was receiving, the quantity and type of case management services provided, and general questions about the quality and future of HCBS services. Individual calls were made to all case managers when surveys had not been received by October 1999. Additionally, county MR/RC Waiver Coordinators were given several reports as to the response rates of the case managers within their counties and were asked to encourage case managers to return their individual case manager surveys. A total of 468 of 474 individual case manager surveys were returned for a response rate of 99%.

General case manager surveys. For a much smaller group of case managers, a general case manager written survey was mailed. This survey was longer than the individual case manager survey and asked questions related to the characteristics of people on the case managers caseload, the case managers experience/training, the criteria for receiving HCBS services in their county, issues around access and quality of services, limitations & barriers to effective HCBS services, direct support staffing issues, and opinions about quality assurance systems in Minnesota. A total of 52 general case manager surveys were returned out of a total of 75 (69%). Of those case managers, 45.1% were from Metro area counties, 21.6% were from Greater Minnesota Urban counties, and 33.3% were from Greater Minnesota Rural counties.

Interviews with County HCBS Waiver Coordinators

Telephone interviews were completed with county coordinators of HCBS programs for persons with MR/RC (responses were received from 21 of 24 counties, 87.5%). In some cases the MR/RC Waiver coordinators chose to also include county planners, supervisors, case managers or financial management staff in the interviews. The protocol developed for these interviews included questions related to the following topical areas: program enrollment, provision of services, financing & reimbursement, training and outreach, quality assurance, monitoring & evaluation, consumer choice, general opinions and future direction HCBS Waiver services in the county. Responses to the interview questions were transcribed.

Document Review

In addition to the many documents and data sources previously mentioned in this section, many county MR/RC Waiver Coordinators provided critical documents related to their interviews (e.g., policies, procedures, outreach materials). DHS-CSMD also provided documents for review in this project including:

- *October 1999 Report to the Minnesota Legislature*
- *Home and Community Based Services for Persons with Mental Retardation and Related Conditions,*
- *Comparison of Minnesota’s Home and Community Based Services Waivers,*
- *Bulletin 00-56-2: DHS Announces Training on Consumer-Directed Community Supports,*
- *Bulletin 00-56-3: Results of the MR/RC Case Management Survey for 2000.*
- *An Independent Assessment of Minnesota’s Medicaid Home and Community Based Services Waiver Program (1992),*
- *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1999 (2000).*

Stakeholder Group Meetings

Facilitated group discussions were conducted with key stakeholder groups including the Minnesota Habilitation Coalition (MHC), Association of Residential Resources in Minnesota (ARRM), Minnesota Developmental Achievement Center Association (MNDACA), Minnesota Legal Aid, Minnesota Department of Human Services - Community Supports for Minnesotans with Disabilities Division, and Arc MN. These facilitated discussions focused on topics related to HCBS administration and outcomes including eligibility for service access to service, types of services offered and received, quality assurance and monitoring, consumer direction, barriers to service delivery and recommended future directions of Minnesota’s HCBS program.

Data Analyses

Methods Used

Quantitative data were analyzed using SPSS statistical software package. The types of statistical methodologies and variables, including derived variables, used in each analysis is described with the relevant findings. The most common statistical analyses included: descriptive statistics (means, standard deviations), chi square, t-tests, one-way analysis of variance, correlations and multiple regression. Responses to open ended questions in the surveys and interviews were entered into data base software packages, coded and then analyzed to identify themes and patterns. MR/RC Waiver Coordinator responses were analyzed separately by two researchers. Independent summaries of outcomes were reviewed for common themes in an effort to ensure reliability of findings.

A Note for Non-Statisticians

Many of the results of this study were tested to find out if different groups (for example children vs. adults, or residential vs. vocational supports) had significantly different experiences in Minnesota’s HCBS program. Several different statistical tests were used to determine whether differences between the groups were larger than would be expected solely by chance. When you read the tables you will find the symbols “***F”*** or “X^2“ in some columns. The numbers under that heading tell the results of the statistical test. To understand those number, look for a “*”, “**”, or “***” after the number. If no star appears, the differences between the groups could have reasonably been explained by chance or random differences and the groups are not considered to be different. If “*” appears, the group scores are so different that the differences between them would have happened by chance only 5 times out of 100. If “**” appears, the groups are so different that those differences would have happened by chance only one time in 100. If “***” appears, the groups are so different that the differences would have been happened by chance only one time in one thousand. If “*”, “**”, or “***” appear, the text will describe that difference by reporting that the differences between groups are “statistically significant.” Also, under each table or within each table you will see an “N,” this indicates the total number of people answering a particular question. When a “mean” is listed it means average and when “range” is noted it means the variation in the reporting of that finding from the lowest number or percentage reported to the highest reported.

Strengths and Limitations of the Evaluation Design and Outcomes

Several strengths and limitations of the evaluation design, its implementation and outcomes should be noted.

Strengths

Among the strengths of this evaluation study are:

- The data sets used to identify recipient characteristics and costs and utilization of HCBS services include all people with MR/RC receiving HCBS services. These data sources have no sampling error or biases.
- The over-sampling of HCBS recipients from ethnic and racial minority groups permits analysis that would suffer from limited representation had "normal proportions" been sampled.
- The stratified random selection of sample members from different county types yielded a sample that was strikingly similar to the population of all HCBS waiver recipients.
- This study with 468 case managers, 372 consumers, 183 families, 184 residential site supervisors and 151 residential DSPs represents one of the largest studies of its kind ever conducted and provides a robust source of information about Minnesota's HCBS waiver program.
- Varied quantitative and qualitative research methods (extant data sets, written surveys, face-to-face interviews, telephone interviews, group interviews) increased the validity of findings by identifying issues concerns and trends with multiple methods and sources of information.
- Perspectives of varied and knowledgeable informants (HCBS recipients, family members, case managers, residential providers, vocational providers, direct support staff members, county HCBS Waiver Coordinators, and a wide array of stakeholder groups) provided comprehensive attention to important aspects of the HCBS program.
- The response rates for consumer interviews, individual case manager and general case managers surveys were sufficiently high to feel confident about the representativeness of the respondents.
- Key instruments in the evaluation have extensive tests for reliability and validity as part of the multi-state Core Indicators Project.
- DHS and CSMD provided access to a wealth of information about the HCBS system and its outcomes allowing a more comprehensive evaluation than has ever been conducted in Minnesota on this topic.

Limitations

Limitations and potential threats to the reliability and validity of the data collection include:

1. The response rates for certain surveys was not as high as was desired. The timelines on the project limited opportunities to conduct an adequate program of follow-up of late and non-respondents for certain surveys. Limited resources precluded providing incentives for completing the surveys and interviews. Among those notable affected were the provider, direct support staff and family surveys. The sample size for the general case manager survey is also somewhat smaller (52) than would be desired. Thus the reader should be cautioned that the returned surveys in certain categories may not be representative of the total populations being surveyed (especially providers, families receiving in-home supports or direct support staff members). This may limit the generalizability of some findings.
2. Because the sample members could only be approached through their county case managers, case managers who refused or made half-hearted attempts to recruit participants and to gain their consent (or that of their guardians and family members) affected the rate of participation and possibility the representatives of those who did participate.
3. Because of time constraints, some survey questions were not pilot tested prior to their use in the evaluation. Although efforts were made to develop questions that were valid and reliable, no formal testing of the psychometric properties was conducted for certain questions. Questions which were determined to be problematic, whether field-tested or not, were excluded in the analyses.

PART III: FINDINGS

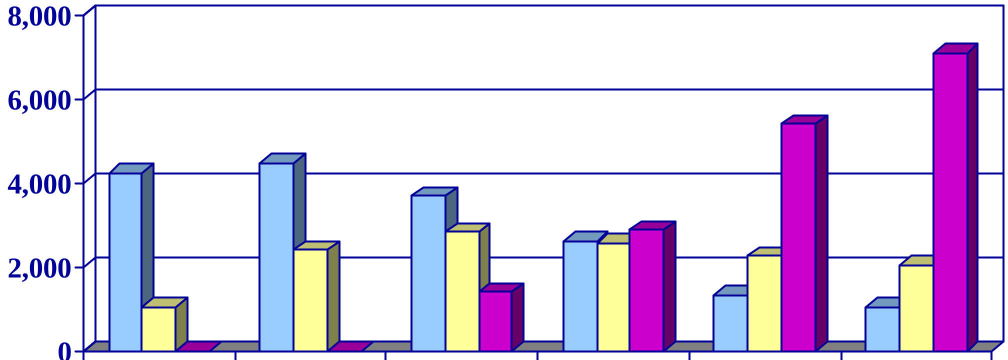
A. Home and Community Based Services Use and Expansion

Program Expansion in Minnesota

Today a large majority of Minnesotans with mental retardation and related conditions (MR/RC) who receive Medicaid-financed long-term care do so through the Medicaid Home and Community Based Services (HCBS) program. That has not long been the case. It was not until the mid-1990s that Minnesota's HCBS recipients equaled in number residents of ICFs-MR, and not until 1995 that it exceeded the number of people who received ICF-MR services.

Minnesota's commitment to maximizing Medicaid-financing. Prior to the creation of the HCBS program in 1981, and Minnesota's entry into the program in 1984, Minnesota had become more heavily invested in Medicaid ICF-MR financing than any other state relative to overall state population. That investment began in the early 1970's shortly after Congress enacted the Medicaid ICF-MR program in 1971. By June 1977, Minnesota had 154 ICF-MR certified facilities (including its 7 ICF-MR certified state institutions) with a total of 5,303 people receiving ICF-MR financed services. More than one in four of all ICFs-MR in the United States in June 1977 were in Minnesota. By June 1982, the number of ICFs-MR in Minnesota had again doubled (to 310 facilities) with a total of 6,899 ICF-MR residents. This concentration of ICFs-MR in Minnesota was part of a general effort to maximize Medicaid financing of all long-term care services for persons with MR/RC.

Figure A1: MN's Residential Service System 1977- 1999



	1977	1982	1987	1992	1997	1999
🟦 ICF-MR Large (16+)	4,251	4,487	3,702	2,618	1,331	1,056
🟨 ICF-MR Small (4-15)	1,052	2,412	2,847	2,584	2,273	2,045
🟪 HCBS Waiver	0	0	1,423	2,890	5,422	7,102

The Medicaid HCBS alternative to ICF-MR placement to persons with MR/RC was created by Congress in August 1981. In 1984, Minnesota began providing HCBS services. In the early development of HCBS services Minnesota was simultaneously increasing the number of small ICF-MR sites and downsizing or closing larger ICF-MR institutions. In the late 1980's, the Minnesota Legislature and Department of Human Services began to aggressively pursue the HCBS option as an alternative to ICFs-MR to finance newly developing community services. As a result, by June 1992, the total number of

ICF-MR residents had decreased to 5,202. For the first time in June 1992, the number of HCBS recipients in Minnesota (2,890) surpassed the number of people living in small (4-15 person) ICF-MR settings (2,584) (Prouty & Lakin, 2000).

Table A1: Medicaid Long-Term Care Program Use in Minnesota, June 1977- June 1999

Year	Small (4-15) ICF-MR	Large Private (16+) ICF-MR	Large State (16+) ICF-MR	HCBS Waiver	Total
1977	1,052	1,724	2,527	0	5,303
1982	2,412	2,070	2,417	0	6,899
1987	2,847	2,049	1,653	1,423	7,972
1992	2,584	1,585	1,033	2,890	8,092
1996	2,406	1,075	345	5,422	9,248
1999	2,045	984	72	7,102	10,203

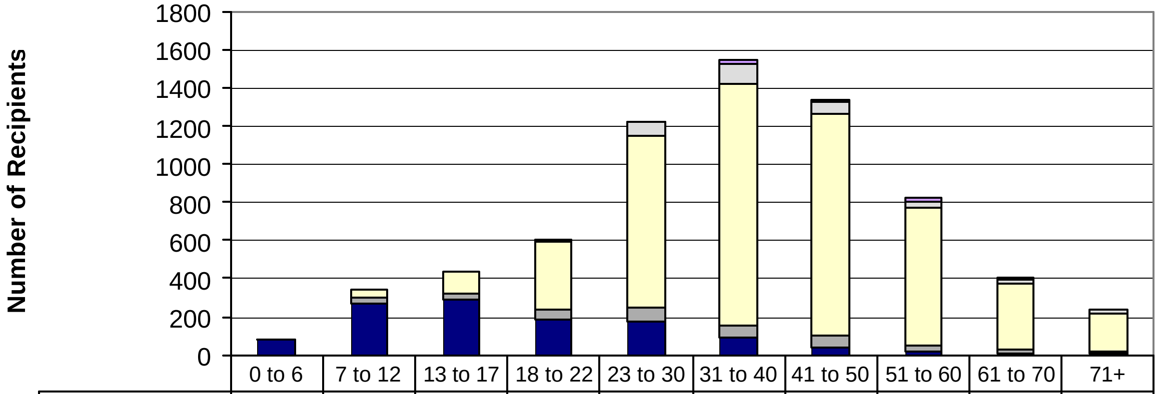
Since 1992, Minnesota's use of Medicaid programs to finance long-term care services has rapidly and substantially changed. In 1995, Minnesota passed the milestone of HCBS recipients (4,897) exceeding the total number of ICF-MR recipients (4,445). By June 1999, HCBS recipients had increased to 70% of the combined ICF-MR (3,101) and HCBS (7,102) recipients. Between 1992 and 1999, Minnesota not only dramatically decreased its numbers of individuals living in large ICFs-MR from 2,618 residents to 1,056 residents (a decline of 60%), it also decreased the number of residents of smaller ICFs-MR from 2,584 to 2,045 (a decline of 21%) (Prouty & Lakin, 2000).

Comparison of Residential Setting by Age for HCBS Recipients

The HCBS program in Minnesota is very different for young recipients than for adults. As Figure A2 shows, the majority of children live with family members and receive HCBS supports in their family homes. However, by the age of 18, the residential services shift from primarily family based services to primarily corporate foster care based services. For adults the vast majority of HCBS recipients receiving HCBS supports live in corporate foster care settings.

Figure A2 also shows the age distribution of HCBS participants. The vast majority of HCBS recipients are 23 to 60 years old. Children and young adults are the next largest group, with those 61 years and older comprising the smallest group of recipients.

Figure A2 HCBS Recipients in Various Residential Arrangements by Age



	0 to 6	7 to 12	13 to 17	18 to 22	23 to 30	31 to 40	41 to 50	51 to 60	61 to 70	71+
▪ Other/Unknown	0	0	1	1	6	19	14	16	5	1
▫ Own Home	0	0	0	7	71	106	63	35	21	12
▫ Corporate foster	1	43	123	360	892	1,270	1,167	720	344	201
▪ Family foster	3	26	32	53	82	62	56	36	24	17
■ Family home	78	271	285	180	170	89	39	12	6	2

Comparison of ICF-MR and HCBS Use with Other States

ICF-MR use. Compared with other states Minnesota began early and has remained a high user of Medicaid long-term care programs for persons with MR/RC. Although Minnesota reduced ICF-MR residents by 55% between June 1986 and June 1999 (from 6,852 to 3,101 residents), Minnesota remains a relatively high user of ICF-MR services. In June 1999, Minnesota's 42.8 residents of community ICF-MR per 100,000 of the state population was nearly three times the national average of 15.6 (Prouty & Lakin, 2000). In recent years Minnesota has, like the nation as a whole, begun to reduce its use of ICFs-MR to provide community residential services. In fact, Minnesota has done so at twice the rate as the U.S. as a whole. In the five years between June 1994 and June 1999, Minnesota reduced its number residents in small ICF-MR settings by 630 persons (23.6%). During those years, the number of residents of small ICF-MR nationally declined by 5,726 (11.8%). Despite its higher than average reductions, Minnesota remained in 1999 the fifth highest state (including the District of Columbia which was highest) user of ICF-MR financed community services.

HCBS use. Minnesota steadily increased the number and proportion of Medicaid long-term care recipients with MR/RC who receive HCBS funded supports. Nationally, the MR/RC HCBS program, which grew by an average of about 6,000 recipients per year in its first 10 years, grew by an average of nearly 29,000 recipients per year in the 7 years between 1992 and 1999. Minnesota's program growth between 1992 and 1999 was substantial (increasing from 2,890 to 7,102 recipients), but still substantially less than the national average (146% as compared with 321%). In June 1999, Minnesota ranked at the 75th percentile nationally in its number of HCBS recipients per 100,000 of state population. Its rate of HCBS participation (148.7 recipients per 100,000) was 54% above the national average (96.3), but was quite similar to the rates of neighboring upper Midwest states of similar size (Iowa, 143.5; Wisconsin, 159.5), and substantially less than its smaller neighbors (North Dakota, 295.7; and South Dakota, 268.9).

The types of places in which Minnesota's HCBS recipients live vary somewhat from the national tendencies (Prouty & Lakin, 2000). In June 1998, based on reports from 42 states, an estimated 41.2% of

HCBS recipients nationwide lived in residential settings that were owned, rented or managed by the agency that provided residential supports to the HCBS recipients. This compared with 73.6% in Minnesota (Prouty & Lakin, 2000). Nationwide, an estimated 33.6% of HCBS recipients lived with members of their own family, as compared with 15.4% in Minnesota (Prouty & Lakin, 2000). Minnesota ranked below the national average in the proportion of HCBS recipients living in homes that they themselves rented or owned in their own names (15.0% nationally, 4.9% in Minnesota) (Prouty & Lakin, 2000). Minnesota's use of family care in which people with MR/RC live in the home of the people who provide them direct support (i.e., in the manner of traditional "foster care") was similar to the national average (6.1% in Minnesota, 8.2% nationally).

Comparisons of Minnesota's ICF-MR and HCBS Users

The individual records in the Minnesota Screening Document File provide information on a range of characteristics of persons receiving Medicaid long-term care services in Minnesota. This section provides an overview of various characteristics of HCBS recipients and when possible compares these to ICFs/MR residents.

Proportion of all long-term care recipients in different settings. Table B2 presents the distribution of all Minnesota long-term care recipients, including ICF-MR, HCBS Supported Living Service (SLS) recipients, and non-SLS recipients by age, level of intellectual disability, race/ethnicity and presence of challenging behavior. SLS is a service that provides comprehensive set of residential supervision, training and other assistance (see definitions in Appendix B) and is almost always (about 87% of the time) provided in a group setting operated by an HCBS provider organization.

Table A2: Distribution of HCBS and ICF-MR Program Participants in 1999 by Type of Residence and Selected Characteristics

Type of Residence										
Characteristic	**ICF-MR**		**HCBS**						**ICFs-MR & HCBS Total**	
			SLS		**Non-SLS**		**HCBS Total**			
	N	**%**	***N***	**%**	***N***	**%**	***N***	**%**	***N***	**%**
Age										
Children (0-17 yrs.)	75	8.3%	207	22.9%	623	68.8%	830	91.7%	905	100.0%
Adults (18+ years)	3269	34.6%	5638	59.6%	554	5.9%	6192	65.4%	9461	100.0%
Total	3344	32.3%	5845	56.4%	1177	11.4%	7022	67.7%	10366	100.0%
Level of MR										
None (related condition)	29	18.5%	12	7.6%	116	73.9%	128	81.5%	157	100.0%
Mild	613	20.8%	2001	68.0%	329	11.2%	2330	79.2%	2943	100.0%
Moderate	720	27.6%	1500	57.6%	386	14.8%	1886	72.4%	2606	100.0%
Severe	865	38.0%	1190	52.3%	219	9.6%	1409	62.0%	2274	100.0%
Profound	1116	49.4%	1041	46.1%	102	4.5%	1143	50.6%	2259	100.0%
Unspecified	1	3.7%	1	3.7%	25	92.6%	26	96.3%	27	100.0%
Challenging Behavior										
Severe Property Destruction	304	29.3%	585	56.4%	148	14.3%	733	70.7%	1037	100.0%
Severe Physical Aggression	414	29.7%	778	55.8%	202	14.5%	980	70.3%	1394	100.0%
Race/Ethnicity										
White, Non-Hisp.	3204	32.5%	5589	56.7%	1060	10.8%	6649	67.5%	9853	100.0%
Black, Non-Hisp.	69	28.4%	117	48.1%	57	23.5%	174	71.6%	243	100.0%
Native American	36	26.3%	82	59.9%	19	13.9%	101	73.7%	137	100.0%
Asian/Pacific Isl.	17	25.0%	29	42.6%	22	32.4%	51	75.0%	68	100.0%
Hispanic	9	18.8%	26	54.2%	13	27.1%	39	81.2%	48	100.0%

Children are rarely placed in ICFs-MR. Only 8.3% of children (0-17 years) receiving long-term care services in Minnesota live in ICFs-MR. Only 24.9% of children receiving HCBS financed services live in supported living service settings. The remaining children receiving HCBS financed services live with their own or a foster family.

HCBS recipients, on average, have less serious intellectual disabilities than ICF-MR recipients. Of the 2,943 Minnesotans with mild mental retardation receiving either ICF-MR or HCBS funded supports (28.4% of all long-term care recipients), only 20.8% were ICF-MR residents; 79.2% were HCBS recipients. In contrast, of the 1,143 long-term care users (ICF-MR or HCBS) with profound mental retardation, 49.4% were in ICFs-MR and 50.6% received HCBS. Only 3.2% of HCBS recipients were screened as eligible based on a related condition alone.

Persons exhibiting severe challenging behavior were more likely to be HCBS recipients than ICF-MR residents. Minnesota's ICF-MR program supported 304 people who exhibited severe property destruction and 414 people who exhibited severe physical aggression. The HCBS program supported 733 persons who exhibited severe property destruction and 980 people who exhibited severe physical aggression (more than twice the number as the ICF-MR program). Furthermore, persons receiving HCBS funded supports were more likely to exhibit severe or very severe property destruction (10.4%) than were ICF-MR residents (9.1%). Likewise, persons receiving HCBS funded supports were more likely to exhibit severe or very severe physical aggression (14.0%) than were ICF-MR residents (12.4%).

White, non-Hispanic persons have higher levels of placement in ICFs-MR than members of other racial/ethnic groups. Nearly one-third (32.5%) of whites in combined ICFs-MR or HCBS programs in 1998 lived in ICFs-MR. This compared with 28.4% of black non-Hispanics, 26.3% of Native Americans, 25.0% of Asian-Americans and 18.8% of Hispanics. Members of non-white, non-Hispanic groups were particularly more likely to be served in HCBS settings other than SLS (10.8% of whites, 23.5% of Blacks, 27.1% of Hispanics, and 32.4% of Asians). Based on screening documents, the vast majority (70.9%) of non-SLS, HCBS-financed services are delivered in the individual's family home (parents or extended family).

Differences Between ICF-MR and HCBS Recipients

Health and Medical Status. While the majority of people with various health needs now receive supports funded by the HCBS program, there continue to be some differences in the profile of health characteristics for ICF-MR residents versus HCBS recipients (see Table B3). A higher proportion of ICF-MR residents require on-site medical attention or have current seizure activity (controlled or uncontrolled) than HCBS recipients. ICF-MR residents are more likely than HCBS recipients to have vision or hearing impairments, and to have motor impairments requiring assistance. Likewise, more ICF-MR residents are unable to walk than HCBS recipients. Finally, a higher proportion of ICF-MR residents than HCBS recipients are unable to speak and/or cannot comprehend spoken language, and a lower proportion of ICF-MR residents are capably of self-preservation.

Table A3: Health Characteristics of HCBS and ICF-MR Recipients (Screening Document)

Characteristic	ICF-MR	HCBS	Total
Total N	3,344	7,022	10,366
Medical Status			
Needs on-site medical attention	21.0	13.2	15.7
Current controlled or uncontrolled seizures	29.0	24.2	25.7
Sensory Impairments			
Vision impairment – not correctable	25.0	21.7	22.7
Hearing impairment – not correctable	6.2	4.5	5.0
Physical Impairments			
Cannot walk	19.6	13.9	84.2
Motor impairment requiring assistance	43.0	36.7	38.5
Communication			
No intelligible speech	47.7	32.3	37.0
Little or no comprehension of speech	26.8	18.7	21.1
Self-Preservation			
Not capable of self-preservation	59.3	47.8	51.4

Functional Limitations and Challenging Behavior. As was true for health limitations, while more people receiving supports funded by the HCBS program have limitations in various independent living skills, a higher proportion of ICF-MR residents have those needs (See Table B4). Specifically, a higher proportion of ICF-MR residents than HCBS recipients require assistance with self-care, leisure skills, household management, community living skills and money management.

Table A4: Support Needs for HCBS and ICF-MR Recipients (Screening Document)			
	ICF-MR	**HCBS**	**Total**
Number of people	3,344	7,022	10,366
Level of Support			
24 hour awake supervision	58.7	24.2	34.9
Independent Living Skills (Participates only with assistance/Unable to participate)			
Self-care	46.2	34.0	37.7
Leisure skills	52.9	40.1	44.1
Household management	57.9	45.2	49.2
Community living skills	71.7	58.3	62.5
Money management	83.7	73.5	76.8
Challenging Behavior (Severe or very severe)			
Temper outbursts	16.3	17.4	17.0
Physical aggression	12.8	14.0	13.6
Verbal/gestural aggression	11.9	13.5	13.0
Injurious to self	11.8	10.6	11.0
Property destruction	9.3	10.5	10.1
Other challenging behavior	9.9	9.5	9.7
Runs away	4.7	5.6	5.3
Inappropriate sexual behavior	4.9	5.2	5.2
Eats non-nutritive substances	4.6	3.5	3.8
Breaks laws	1.8	2.1	2.0

Interestingly, given the ongoing debate over the relative ability of the HCBS program to support persons with serious challenging behavior, people in the HCBS program are proportionately more likely than those living in ICFs-MR to engage in temper outbursts, physical aggression, verbal or gestural aggression, property destruction, “other” challenging behaviors, running away, inappropriate sexual behavior and law breaking behavior. While the HCBS program supports more individuals who engage in serious or very serious self-injurious behavior, and eating non-nutritive substances, a higher proportion of ICF-MR residents engage in these behaviors.

Service Access for Persons from Racial/Ethnic Groups

Access to Services Relative to Proportion of Population

Table B5 compares the proportions of racial/ethnic group members within the service recipient populations of the ICF-MR and HCBS programs with their proportions within the general population of Minnesota. It was estimated by the U.S. Census Bureau that white non-Hispanics make up an estimated 90.8% of Minnesota’s population in 1998 (Statistical Abstract of the United States, 1999). Their representation of 95.2% within the combined HCBS and ICF-MR populations (94.8% of HCBS, 96.1% of ICF-MR) was considerably greater than their expected level based on the general population in Minnesota. Put another way, based solely on proportion within the general population of Minnesota it would be expected that 9,415 white non-Hispanics would have been among the 10,366 HCBS and ICF-MR participants in the Screening Document file, but instead there were 9,853.

Table A5: Race/Ethnicity of Minnesota's Population and HCBS and ICF-MR Program Participants 1998

Distribution of Minnesota Citizens		White Non-Hispanic	Black Non-Hispanic	Hispanic	Asian/ Pacific Islander	Native Amer.	Total
HCBS Recipients	Number	6,649	174	39	51	101	7,014
	% of total	94.80%	2.48%	0.55%	0.73%	1.44%	100.00%
ICF-MR Residents	Number	3,204	69	9	17	36	3,335
	% of total	96.07%	2.07%	0.27%	0.51%	1.08%	100.00%
Total HCBS & ICF-MR	Number	9,853	243	48	68	137	10,349
	% of total	95.21%	2.35%	0.46%	0.66%	1.32%	100.00%
All Minnesotans	Number	4,387,000	152,000	95,000	135,000	61,000	4,830,000
	% of total	90.83%	3.15%	1.97%	2.80%	1.26%	100.00%

Source: Statistical Abstract of the United States, 1999 (1998 data) & Screening Documents

Native Americans were represented within the combined HCBS and ICF-MR populations at proportions expected from their presence in the general population (1.32% and 1.26%, respectively). Other racial/ethnic minorities were substantially underrepresented in both the HCBS and ICF-MR programs. Black, non-Hispanics made up an estimated 3.15% of Minnesota's population, but only 2.35% of people with MR/RC receiving long-term care services. Asians and Pacific Islanders made up an estimated 2.80% of Minnesota's population and only .66% of long-term care recipients and Hispanics made up 1.97% of Minnesota's population, but only .46% of HCBS/ICF-MR long-term care recipients. White non-Hispanics were the only group with higher proportional representation in ICF-MR than in HCBS populations. Some small part of these differences between white non-Hispanic and other Minnesotans in overall access to services and to use of institutional (ICF-MR) services may be attributable to the slightly higher proportion of adults among white, non-Hispanic as compared with minority populations of Minnesota and the great preponderance of adults (91%) among HCBS and ICF-MR recipients. However, the total difference is not explained by the disproportionate number of older people in HCBS and ICF-MR settings.

Changes in Service Access for Racial/Ethnic Minorities since 1990

At the time of Minnesota's last independent evaluation of its Medicaid HCBS program in 1991 (Lakin, Hayden, Burwell & Jackson, 1992), lower rates of HCBS participation among persons from racial/ethnic minorities were noted. It was recommended in that evaluation that more concerted outreach be undertaken to assure knowledge of and increased access to the HCBS program for Minnesotans from racial/ethnic minorities.

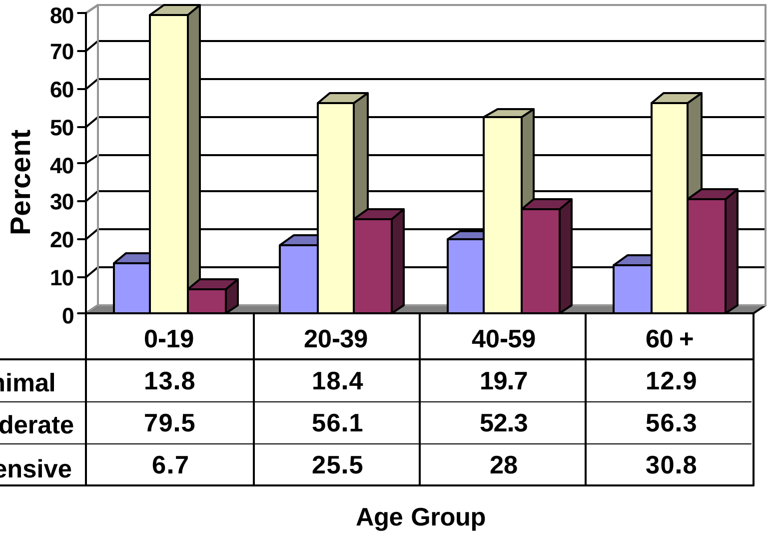
Table B6 presents a comparison of the proportion of Minnesota's total population made up of persons from different racial/ethnic groups in 1990 and 1999 and the proportions of HCBS recipients from the same groups. As shown between 1990 and 1999 Minnesota was successful in increasing the proportion of HCBS recipients from each of the majority racial/ethnic minority groups. Between 1990 and 1999, HCBS recipients from minority groups increased from 3.4% to 5.2% of all HCBS recipients. However, as this occurred persons from minority groups (other than white non-Hispanics) increased even more rapidly from 6.3% to 9.2% of Minnesota's population. The U.S. Bureau of Census projects that on July 1, 2005, persons from minority groups will make up 10.5% of Minnesota's populations (Statistical Abstract of the U.S., 1999).

Table A6: Proportion of All Minnesotans and HCBS Recipients By Race/ Ethnicity, 1990 and 1998						
	Year	**White Non-Hispanic**	**Black Non-Hispanic**	**Hispanic**	**Asian/ Pacific Isl.**	**Native Am./ Alaskan Native**
All Minnesotans	1990	93.7	2.2	1.2	1.8	1.1
	1998	90.8	3.1	2.0	2.8	1.3
HCBS Recipients	1990	96.6	1.6	0.4	0.5	0.9
	1998	94.8	2.5	0.5	0.7	1.4

Age Related Differences Among HCBS Recipients

Differences in support needs based on age. Participants in the HCBS program have a wide range of support needs. Several items on the screening document provide broad indicators of those support needs. One of those broad indicators is the DTH service level rating. Overall, 23.9% of HCBS participants are categorized as needing minimal supports, 58.5% are categorized as needing moderate supports, and 17.6% are classified as needing intensive supports. To be classified as needing intensive supports a person must require on a daily basis total care and monitoring or constant hand-over-hand physical guidance to successfully complete at least three of the following activities (toileting, communicating basic needs, eating or ambulating) or must assault others, be self-injurious or manifest severe dysfunctional behaviors at a documented level of frequency, intensity or duration requiring frequent daily ongoing intervention and monitoring as established in an approved behavior management program. As Figure B2 shows, the proportion of individuals who require more intensive supports increases with age. The proportion of HCBS recipients rated as needing intensive supports grew from 25.5% in ages 20-39 to 30.8% in ages 60+.

Figure A3 DTH Service Level by Age



	0-19	20-39	40-59	60 +
▨ Minimal	13.8	18.4	19.7	12.9
☐ Moderate	79.5	56.1	52.3	56.3
■ Intensive	6.7	25.5	28	30.8

Other indicators that support needs increase with age include the increasing proportion of HCBS recipients who need 24 hour awake support, and the increasing proportion of individuals who are unable to participate or who participate only with assistance in independent living skills. Among adults, people ages 60 and older are more likely to participate only with assistance or are unable to participate in various skills of independent living. Some stakeholder groups suggested that one of the biggest challenges they are facing is that HCBS recipients are aging and that their needs are increasing as a result. They report that funding levels for those individuals were established when they were younger and have not been adjusted to reflect their increased needs.

Table A7: Support Needs of HCBS Recipients of Different Ages (Screening Document)

Characteristic	**Age in Years**				
	0-19	**20-39**	**40-59**	**60 +**	**Total**
Number of people	1,076	2,992	2,250	704	7,022
Level of Support					
24 hour plan of care	86.1	79.2	68.6	68.2	75.7%
24 hour awake supervision	13.9	20.8	31.4	31.8	24.3%
Independent Living Skills (Participates only with Assistance/Unable to participate)					
Self-care	53.4	27.0	32.4	39.8	34.0%
Leisure skills	57.4	33.1	40.3	43.2	40.2%
Household management	67.6	36.2	44.3	53.0	45.2%
Community living skills	79.5	50.3	57.6	62.7	58.4%
Money management	85.9	66.7	74.9	79.1	73.5%

Differences in specific support needs of HCBS recipients based on age and race. Differences by age and race in the proportion of HCBS recipients with various support needs identified in their screening documents is shown on Table B8. Of the services needed as specified on the screening document, the most common needed services overall were transportation arranged by staff members (94%), specialized medical services (80% for recipients from racially or ethnically diverse groups, and 77% for white recipients), programs to address excess behavior (69% and 66%), and speech or communication training (65% and 57%). Fewer but still substantial proportion of recipients had service plans for occupational therapy (57% and 46%), mental health services (48% and 43%), and physical therapy (38% and 36%).

Table A8: Percent of HCBS Recipients with Specific Support Needs: Differences by Age and Race (Screening Document)

Services in the Service Plan	Age				
	0-19 yrs	20-39	40-59	60+	Total
Non-White *N*	119	168	67	11	365
Transportation arranged by staff	95.0	91.7	95.5	100.0	93.7
Specialized medical services	82.4	76.8	85.1	81.8	80.3
Program to address excess behavior	73.1	65.5	74.6	54.5	69.3
Speech or communication training	83.2	56.5	58.2	36.4	64.9
Occupational therapy	75.6	46.4	52.2	36.4	56.7
Mental health services	36.1	54.8	56.7	27.3	48.2
Physical therapy	49.6	32.1	35.8	27.3	38.4
Other support services	4.2	8.9	7.5	0.0	6.8
Early intervention services	11.8	0.6	0.0	0.0	4.1
White *N*	954	2,820	2,182	693	6,649
Transportation arranged by staff	96.0	93.1	94.3	95.4	94.1
Specialized medical services	86.4	73.0	77.5	82.0	77.3
Program to address excess behavior	70.9	64.8	66.6	61.8	65.9
Speech or communication training	86.2	52.7	55.3	43.4	57.4
Occupational therapy	75.7	39.9	42.5	37.2	45.6
Mental health services	33.1	44.5	45.6	40.5	42.8
Physical therapy	53.0	30.6	35.2	39.7	36.3
Other support services	5.2	4.5	6.5	4.6	5.3
Early intervention services	4.9	0.4	0.4	0.6	1.1

Across all of these services, recipients from racially or ethnically diverse groups were more likely to report needing the listed services than were white recipients. Significant exceptions were found among recipients ages birth to 19 years where white children were more likely to need specialized medical services, speech or communication training and physical therapy. Among people ages 20 to 39 years white young adults were more likely to need transportation services. Among adults 60 years and older, white recipients were more likely to need all of the services except transportation. However, since only 11 HCBS recipients over 60 years were from racially or ethnically diverse groups, differences lack practical significance in this age group.

Discussion

This section of the evaluation reviewed information to determine the use and growth of HCBS in Minnesota. It also made comparisons between ICF/MR and HCBS use in Minnesota and the United States as a whole.

Key findings

- In 1999, nationally, 41.2% of HCBS recipients lived in homes that were owned, rented or managed by an agency that provided residential supports compared with 73.6% of HCBS recipients in Minnesota.
- In 1999, more than twice as many Minnesotans received HCBS funded supports as lived in ICF-MR facilities (7,102 vs. 3,101).
- In 1999, 91% of all Minnesotans are members of white non-Hispanic racial or ethnic groups as compared with 96.6% of ICF-MR residents and 94.8% of HCBS recipients.

- Between 1992 and 1999 the proportion of Minnesotans from non-white, non-Hispanic racial or ethnic groups grew faster than the proportion of ICF-MR residents and HCBS recipients in those groups.
- Between 1992 and 1999, Minnesota reduced the number of people in state operated large ICF-MR settings from 1,033 to 72.
- Of the 3,101 ICF-MR residents in 1999, 34% lived with 16 or more other people.
- Of the 3,101 ICF-MR residents and the 7,102 HCBS recipients in 1999, 79.2% of persons with mild intellectual disabilities received HCBS as compared with 50.6% of persons with profound intellectual disabilities.
- While more people with various health-related and other support needs now receive HCBS funded supports than live in ICF-MR settings, ICF-MR residents have proportionately greater health-related and other support needs.
- The HCBS program in Minnesota now supports more people with serious or very serious challenging behavior and a higher proportion of such individuals than the ICF-MR program.
- Child HCBS recipients were most likely to report needing assistance with independent living skills.
- Adult HCBS recipients have greater overall needs than children who were HCBS recipients.
- Among adult HCBS recipients, older adults were proportionately more likely than younger adults to report needing assistance with independent living skills.
- HCBS recipients from non-white racial and ethnic groups were more likely to report needing various specialized services such as specialized medical services, programs to address challenging behavior, and speech or communication training.

What's working?

Continued expansion of HCBS has supported the downsizing and closure of many ICFs-MR and state institutions since HCBS began in 1984, but especially between 1992 and 1999. In 1995, Minnesota passed the milestone of HCBS recipients (4,897) exceeding the total number of ICF-MR recipients (4,445). By June 1997, HCBS recipients made up 63% of the combined total ICF-MR residents (3,604) and HCBS recipients (6,097). By June 1999, HCBS recipients had increased to 70% of the ICF-MR (3,101) and HCBS (7,102) recipients. As Minnesota developed its HCBS program, it was able to decrease the number of people living in large (16 or more people) ICFs-MR from 2,618 people to 1,056 people (60% decline). It was also able to decrease the number of people living in small (4-15 people) ICFs-MR from 2,584 to 2,045 (21% decline). Today, the HCBS program serves more people with severe challenging behavior, more children, more adults, more people with the most severe intellectual impairments (profound mental retardation), more people with significant support needs, more people with significant medical needs, and a higher proportion of people from racially diverse groups than the ICF-MR program.

Challenges and concerns

Despite its notable successes Minnesota exhibits unusually high reliance on congregate care as its method of community service delivery when compared with the U.S. as a whole. In June 1998, based on reports from 42 states, nationwide an estimated 41.2% of HCBS recipients lived in residential settings that were owned, rented or managed by the agency that provided residential supports to HCBS recipients. In MN this average is 73.6%. Likewise nationwide estimates of HCBS recipients who live with family members is 33.6% compared to 15.4% in Minnesota. Additionally, nationally an estimated 15% of HCBS recipients rent or own their own home/apartment as compared to only 4.9% in Minnesota.

Clearly the current pace and productivity of outreach, identification and enrollment of people from ethnic and racial minority groups, will not close the gap between majority and minority populations having access to HCBS in Minnesota. Even though the number of people from racial and ethnic minority groups who are receiving HCBS increased between 1992 and 1999, with the exception of Native Americans racial and ethnic minorities were substantially less represented in the HCBS program than would be expected based their presence in the general population in Minnesota.

In Minnesota, the HCBS program serves more people at each level of intellectual disability than the ICF-MR program. However, people with more severe intellectual disabilities are less likely to have access to HCBS than are people with less severe intellectual disabilities. Possible reasons for this include concern about the higher expense of supporting individuals with more extensive support needs while maintaining the total cost of services under a county's allowable total expenditures. An effort was made to address this concern in 1995 with the implementation of the Waiver Allocation Structure which added more resources to a county's allowable expenditures for persons with more extensive support needs. Arguably this has contributed to there now being more persons with severe or profound intellectual disabilities receiving HCBS than living in ICF-MR settings. Five years after this change, however, persons with severe or profound intellectual disabilities are still proportionally less likely to receive HCBS funded supports (rather than ICF-MR services) than are persons with mild or moderate intellectual disabilities.

B. Access to Services

The utilization and costs of HCBS services section of this report (Section J) provides information about access to the HCBS Waiver program statewide and describes differences in access by region, personal characteristics and service type. This section describes issues related to waiting lists and access to services and supports for current HCBS recipients.

Waiting lists

Who is waiting for HCBS services and supports? In October 1999, DHS-CSMD authored a report to the legislature that included information about people in Minnesota who were waiting for HCBS Waiver services (DSH-CSMD, 1999). That document included information about the total number of people waiting for HCBS services, the ages and current residences of those waiting, the urgency of need for Waiver funded services, and what services people were waiting for. A total of 4,321 individuals were waiting for HCBS services at the time of the report. The vast majority of individuals waiting for HCBS services are currently living in their family home (N = 2,766). Other large groups waiting for HCBS services are persons living in ICF-MR settings (N = 727), and individuals living in family foster care (N = 318). Overall, 2,482 children and young adults ages 0-22 years, 1,119 people ages 23 to 39, 589 people ages 40 to 59 years, and 131 people 60 or older are waiting for HCBS Waiver funded services.

How urgent is the need for Waiver funded services? Beginning on April 1, 1999, the DHS-CSMD began collecting information about how soon HCBS services were needed for those individuals who were on the waiting list for HCBS services. Of 1,340 people who had been screened by October 29, 1999, 57% were requesting or needing services within the next 12 months, 25% within 13 to 36 months, and 18% after more than 36 months. Those who needed services within the next 12 months included 537 living with their families, 119 living in ICF-MR settings, 42 living in family foster care, and 67 people living in other types of settings.

What services are needed? People are currently waiting for a variety of services. Not surprisingly, given that most of those waiting are children living with their families, in-home family support (2,149 are waiting) and respite care (1,989) are the most common supports needed. However, many were waiting for supported living services (1,840). More than 500 people were waiting for environmental adaptations (1,572), assistive technology (935), specialist services (829), caregiver training and education (748), personal support (580), or crisis respite services (514). The report noted that the state had responded to the number of people reportedly waiting for assistive devices by informing county staff about other funding mechanisms that could be used to pay for assistive technology (e.g., augmentative and alternative communication devices can be purchased directly through MA state plan services). A variety of other administrative actions were taken to address waiting list issues. Three actions were authorized by the legislature in 1999 to address the waiting lists:

- Increased diversion allocations to be distributed by 100 per year.
- Create additional HCBS Waiver allocations within the current budget if ICF-MR closure activity is lower than projected.
- Developing criteria by which county agencies may receive MA administrative reimbursement for identified activities.

The DHS-CSMD added consumer-directed community support services (CDCS) as an optional HCBS funded service. Seven counties have memorandums of understanding to provide this service. While access to CDCS is very limited, the Department reports that it is providing technical assistance on how services can be shaped to meet personal needs and preferences, support natural relationships, create longstanding community infrastructures, and avoid use of institutional care in the first five counties to offer this service.

HCBS Waiver Coordinator Perspectives on Access to the HCBS Program

Selecting HCBS participants. Overwhelmingly counties report a “priority based” system for selecting new HCBS participants meaning that they give priority to certain individuals on the waiting list based on certain circumstances. However, the counties varied regarding which people were considered a “priority”. Depending on the county, any of the following characteristics or circumstances could make an individual a priority**:**

- Children
- The person’s immediate needs
- Health & safety issues
- Needs cannot be met with other Medical Assistance programs or with county funded programs
- Combined assessment of the adequacy of the person’s support network, immediacy of the person’s need and the level of support needed.
- How long the person was on the waiting list
- Individuals who will have a change in their circumstances soon (e.g. transition from school to work and community living; people who are aging)
- The amount of money the county will receive based on the person’s screening and the amount of money the person will actually cost the county
- Children/adults who could be maintained in their family home if given HCBS funding
- At risk of losing current residential placement (family home, ICF-MR)
- At risk of being sent to an ICF-MR

- Person is affected by a county project such as closing or downsizing an ICF-MR program
- How well the person might "match or fit in" with people who are currently served in a HCBS Waiver funded home

Four counties reported that they used the state criteria identified in Bulletin #98-56-***XX.*** Three counties reported that they had no formal criteria.

Counties vary in who makes the final decisions regarding who is served by HCBS. To some degree this is based on the size of the county and how large the HCBS program is within that county. However, in all counties the case manager played a critical role in determining the circumstances a person was in and in advocating the need for the person to receive HCBS. Without strong support and advocacy on the part of a case manager it seems unlikely in any of the counties that a person would be seriously considered to receive HCBS.

Screenings practices when HCBS services are currently unavailable. Counties reported different screening practices for people who are considered for HCBS services. Some counties screen everyone who comes into the county requesting any type of service, others screen new applicants plus all people who currently receive any type of service. In one county, there is a policy to screen every new child that is requesting services. However, screenings may or may not occur for all new adults requesting services. Four counties indicated that they annually screen all ICF-MR recipients and in one county they have a practice of annually screening people in Class A ICF-MRs but not in Class B unless requested by the person. Many counties indicated that they would only complete a screening if specifically requested by a person who was seeking new services or by a person who was currently receiving some other type of service. Two counties reported that they screen whenever they feel the person is appropriate for HCBS services.

County initiatives to respond to people with MR/RC waiting for HCBS services. All counties reported having waiting lists. Most reported knowing if the HCBS waiting list included all people that could benefit from the HCBS, only people known to want HCBS services, or only those determined to be priority. Many reported their waiting lists would be considerably longer if all people who could benefit from HCBS services were included. All counties reported that families on the waiting list currently received case management services. Most counties reported asking families on the waiting list exactly what services they want and need. Based on that assessment, they reported trying to find needed services for the family using other funding streams (e.g. PCA, respite, DTH, in-home, ICF-MR).

One county reported strategically using case managers to connect people to community services offered in after-school programs, community centers and the like. Another county reported supporting families in developing a five-year plan looking at the residential, employment and recreational needs of their family member with a disability. Once these needs were identified, the case manager helped the family to meet as many of these needs as possible through alternative funding streams. Another county reported that when a person was in crisis and was high priority to receive HCBS services but a "slot" was not available they submitted a special request to their County for special funding until the county received a new "slot."

County outreach efforts. Several counties reported they try not to "over-publicize" or "over-offer" the HCBS Waiver as an option because of the long waiting lists. They purposefully try to get families to talk about what they need rather than asking for a funding source or specific program such as the HCBS Waiver. Many counties thought families saw the HCBS Waiver as an entitlement and as the "ultimate service" or the "pot of gold." They reported that this, in part, could be because of a recent Arc campaign to address the HCBS Waiver waiting list. Several counties described processes to move case managers and intake workers away from specifically talking about certain program types and toward emphasizing the person's needs and how services could developed to meet those needs – irrespective of the funding source. One county said, "we have such a long waiting list, it doesn't seem right to recruit people for the HCBS Waiver if these services are not available."

Counties used several strategies to reach people with disabilities who need services. A few counties, in collaboration with their local Arc chapters, developed "Transition Road Maps" to help families whose children are transitioning from school to employment and community residential and recreational alternatives. Additionally, several counties participate in transition fairs sponsored by local school districts and local Arc chapters for individuals transitioning from school to the community. One county was developing a WWW site describing the availability of HCBS services. Another county learned that informing families about service options during intake and screening processes is confusing to families who are just beginning to ask for and receive services. In response, case managers are encouraged to talk to individuals and families annually about all of their options. In addition, the county developed informational seminars about the range of service options and specific informational sessions about HCBS services.

Community outreach plans to encourage enrollment in the HCBS program by individuals from racial and ethnic minority groups. Only two counties (both metro counties) reported having specific outreach plans to get information about HCBS and other related services to individuals from racial and ethnic minority groups. Those counties had specialized support methods for individuals and families from minority groups who inquire about services. One county employs Spanish speaking, Hmong and African American case managers specifically to respond to requests from families who desire a case manager from their own ethnic or racial minority group. The other county has a non-developmental disability specific outreach plan to get information about services to minority communities and has hired specialized service coordinators to assist the county in making services more accessible. Both counties reported having increased the number of providers who specialize in supporting individuals with developmental disabilities from racial or ethnic minority groups.

Several counties reported that they often learn about Native American children who need services through participation in schools and connections to public health services. One county reported, however, that it is almost impossible to get services provided on a Native American Reservation because existing providers are not willing to drive to the Reservation and the people who live on the Reservation who need services are not willing to move to a town or city to receive services. The inability to reimburse for transportation is seen as the largest barrier in this situation. This county is hoping that the consumer directed supports option will create more options for people to receive services on their Reservation. Several counties reported that they often receive referrals from local Head Start programs and that often these referrals are for families from ethnic and racial minority groups. Also, several counties used the HCBS Waiver brochure developed by DHS (although this brochure is somewhat outdated and needs revision). Others developed brochures specifically for their county in both English and Spanish. Many counties provide translation services to families if requested.

Most counties reported that they would not treat a family from a racial or ethnic minority group any differently than any other family. They assumed that people from these communities learned about service options in the same way other people learned about them. However several county HCBS Waiver Coordinators indicated that their counties had increasing numbers of immigrants and they were not seeing any requests for services from individuals and families within these immigrant communities.

Case Manager Perspectives on People Waiting for HCBS Waiver Funded Services

Information about access to services and waiting lists provided by county DD Waiver coordinators was supplemented by several questions asked on the general case manager survey. Case managers for each of the study participants also provided information about access to services.

Selecting HCBS recipients. All of the case managers reported that their county maintained a waiting list for HCBS Waiver-funded supports on the general case manager survey. Eighty-one percent reported that their county had a written policy for prioritizing persons on the waiting list, and 37% said that a waiting list policy was available to persons waiting or to members of the general public. One case manager from a rural county reported that their county sometimes defers screenings for people that are potentially appropriate for the HCBS Waiver until an allocation "slot" is available for that person.

Case managers reported their counties used a variety of different criteria for selecting HCBS participants from the waiting list (See Table B3). Among the most frequently selected are people who require emergency or crisis supports, people with the greatest impairments, and families who are struggling to provide day-to-day support. In metro counties, a greater proportion of new HCBS allocations were given on the basis of emergency or crisis needs, and for people who have "connections" (i.e., people with connections or who are exceptionally effective and demanding advocates or who have other advocates working on their behalf) than in rural counties.

Table B1: General Case Managers Report How HCBS Recipients Are Chosen From The Waiting List (Percentage of HCBS Waiver Slots Allocated By Each Criteria)

Selection Criteria	**Region**			
	Metro	**GM Urban**	**Rural**	**Total**
Emergency or crisis *	33.6	27.7	12.9	25.1
Other reasons	6.7	1.7	36.1	22.4
Greatest impairments	15.9	25.0	24.3	21.6
Family difficulties managing	14.2	19.1	14.5	15.6
Waiting the longest	10.4	18.5	12.7	13.6
Relatively lower costs	8.9	5.1	19.9	12.1
Children and youth	11.5	10.0	11.9	11.3
People with connections*	13.0	3.1	0.0	5.7
Special allocation or priority for members of specific minority groups	11.7	0.0	0.0	4.2

*Emergency or crisis was significantly more likely to be the reason in metro counties than in rural counties (F = 4.40, $p < .05$). Having connections was significantly more likely to be the reason in metro than in rural counties (F = 3.76, $p < .05$). Numbers do not sum to 100 because sample sizes varied from response category to response category. ***N*** = 52

Almost all of the surveyed case managers (96%) reported that their counties had a brochure or other written information on HCBS services. Of the 25 case managers who knew if their county had a brochure available in languages other than English, 36% said they did. More than 50% of case managers in metro and GM urban counties reported that a brochure was available in other languages compared with only 10% in rural counties.

Who gets HCBS allocations (By Prior Residence)? The individual case manager surveys asked case managers to describe where the individuals in the study had lived prior to their current home (See Table B4). The proportion of sample members who had lived in various settings varied significantly by county. Metro area sample members were more likely to have been living in RTCs, while GM urban and GM rural sample members were more likely to have been living with family members. Rural sample members more likely to have been living in small ICF-MR or SOCs settings and less likely to have lived in RTC or psychiatric settings.

Table B2: Previous Residence of Sampled HCBS Participants				
Previous Residence	**Region**			**Total**
	Metro	**GM Urban**	**Rural**	
Family home	22.8%	32.1%	31.4%	27.9%
RTC or psychiatric unit	23.4%	21.0%	13.4%	19.0%
Small ICF-MR or SOCS	11.4%	12.3%	29.1%	18.5%
Large ICF-MR or nursing home	26.1%	13.6%	9.3%	17.2%
Foster home	4.3%	6.2%	5.2%	5.0%
Own home	3.3%	3.7%	4.7%	3.9%
Other	8.7%	11.1%	7.0%	8.5%

(N=468)

The county-to-county differences may be explained in a variety of ways. One possible explanation is that metro area counties may have been able to get relatively more conversion HCBS Waiver slots than diversions compared to GM urban and rural counties. It may also be the case that consumers living with family members in the metro counties were a relatively lower priority for HCBS slots than those living with family members in the other types of counties. These findings suggest that access to HCBS funded supports may differ depending on where one lives within the state. Alternatively, it may just be that some regions were heavier users of RTC or large ICF-MR services than others. Variations in previous residence may also be due to variations in county emphases regarding downsizing ICF-MR settings.

Parental reasons for selecting HCBS funded supports. Case managers for the 474 sampled HCBS recipients were asked whether they thought parents understood that ICF-MR services were an alternative service available to them (See Table B2). Overall, case managers reported that 95% of the families understood the ICF-MR alternative. Metro area case managers reported that significantly fewer families understood the ICF-MR option than case managers in rural communities. When asked to identify their understanding of why families choose HCBS funded services, case managers reported that the most common reasons were a desire for flexibility (76%) smaller homes (72%), and having services in their home communities (64%). Case managers in rural areas were significantly less likely to report that families chose HCBS funded services because they accommodated the needs and desires of the families (54%), than were case managers in GM urban (78%), or metro counties (64%).

Table B3: Parental Access: Why Parents Choose the HCBS Waiver (Case Manager Individual)					
Factor	**Metro**	**GM Urban**	**Rural**	**Total**	***F***
Parents understand that ICF-MR is an option	92%	96%	99%	95%	6.05**
Reasons for selecting the HCBS Waiver:					
Wanted greater flexibility	75%	79%	77%	76%	0.28
Wanted a smaller residence	73%	62%	75%	72%	2.19
Wanted services in home community	60%	68%	66%	64%	1.06
Accommodated needs and desires of family	64%	78%	54%	63%	6.75***
Other reason	15%	7%	18%	15%	2.17
Only available option	10%	3%	4%	6%	2.91

* $p < .05$, ** $p<.01$, *** $p<.001$

Possible reasons for differences across county type in whether parents understood ICF-MR alternatives include potential differences in case manager behavior, differences in the sophistication of families in understanding options, or possibly ethnic differences. Further research would be needed to test these possible explanations.

Access To Services For Current HCBS Recipients (County Perspectives)

This evaluation asked current participants, case managers and families about their experiences related to access to HCBS funded services.

Availability of specific types of HCBS funded supports. Case managers were asked on the general case manager survey about the availability of services for HCBS Waiver recipients. Overall, case management, interdisciplinary planning, day training and habilitation, and health care/physician services were reported by case managers as most likely to be available to *all* HCBS recipients who needed them (see Table B3). The services least likely to be available to HCBS recipients who needed them were transportation, regular respite care, assistance to families or consumers on how to manage their own services, information on "cutting edge" innovations, and crisis respite or emergency care. Case managers in GM urban counties reported that dental care was more difficult to find than case managers in rural or metro counties. Case managers in rural counties reported that general community services such as parks and YMCA's were more difficult to find than in metro counties reported. Case managers also differed in their ratings of the accessibility of case management or service coordination. However, because the sample was small (only 48 case managers) the source of those differences could not be pinpointed. As Table B3 shows, case managers in metro counties seemed to report less access to case management and service coordinators than those in GM urban or rural counties.

Table B4: Availability of HCBS Services for County Residents (General Case Manager)

Service	**Region**			**Total**	***F***
	Metro	**GM Urban**	**GM Rural**		
Case management/Service Coordination	3.43	3.82	3.88	3.67	3.21*
Interdisciplinary planning/assessment	3.17	3.64	3.63	3.43	2.20
Day training and Habilitation	3.30	3.36	3.53	3.40	0.37
Health care/physician services	3.13	3.60	3.47	3.34	1.70
Info on local community services	2.87	3.40	3.35	3.14	2.73
Supported community employment	2.80	2.64	2.76	2.75	0.13
Person-centered lifestyle planning	2.74	2.55	2.76	2.71	0.17
Recreation/leisure activities	2.78	2.60	2.65	2.70	0.22
Facility based residential	2.59	2.36	2.88	2.64	0.97
In-home residential	2.64	2.40	2.71	2.61	0.38
Assistive technology/Housing modifications	2.65	3.00	2.13	2.56	3.07
Dental/Dentist services	2.83	1.73	2.59	2.51	4.42*
Generic community services	2.87	2.64	1.94	2.51	4.71*
Transportation	2.35	2.18	2.29	2.29	0.10
Regular respite care	2.17	2.18	2.12	2.16	0.02
Assistance on how to manage own services	2.04	2.18	2.18	2.12	0.09
Info on "cutting edge" innovations	2.32	1.70	1.76	2.00	2.32
Crisis respite/emergency	2.17	2.00	1.71	1.98	0.88

0 = not available, 4 = available to all who need it; * $p < .05$, $N = 48$

Difficulty finding providers or needed services. On the individual case manager survey, 23% of case managers reported having trouble finding one or more needed provider to meet the support needs of the sampled HCBS participants. Table B4 shows the total number of case managers who reported having difficulty finding various types of support services, the proportion of case managers reporting such difficulties, including the proportion that had some difficulty and the percentage that had much difficulty or could not find a provider at all. The most difficult services to find for HCBS participants were dental services (problematic for 11.5% of participants), non-health specialists such as physical, occupational or speech therapy or behavior management specialists (11.0%), supported living services (10.2%) and transportation (9.2%). Case managers reported difficulties in more than 5% of the cases in finding providers for in-home supports, respite, health and physician services, DTH, emergency or crisis supports and supported employment. In the majority of cases, case managers reported “some” difficulty finding providers. However, case managers reported having much difficulty or not being able to find supported living services for 3.9% of sample members, in-home supports (3.3%), health and physician services (3.0%) and dental services (2.9%). There were no regional differences in whether case managers reported difficulties obtaining needed services for sample members.

Table B5: Difficulty Obtaining Needed Services For Study Participants (Individual Case Manager)

Service	***N* with Difficulty**	**% with Difficulty**	**Amount of Difficulty**	
			Some	**Much/None found**
Dental Services	51	11.5%	8.6%	2.9%
Non-health specialists	48	11.0%	8.5%	2.5%
Supported living	44	10.2%	6.3%	3.9%
Transportation	40	9.2%	8.1%	1.2%
In-home supports	33	8.4%	5.1%	3.3%
Respite	33	8.4%	5.6%	2.8%
Health and physician services	35	8.0%	5.0%	3.0%
DTH	30	7.3%	4.6%	2.7%
Emergency or crisis supports	29	7.2%	5.0%	2.2%
Assistive Technology	23	5.8%	5.0%	0.8%
Supported employment	21	5.5%	3.4%	2.1%
Nursing or Home Health Aides	18	4.7%	3.6%	1.0%
Home modifications	16	3.9%	3.7%	0.2%
Consumer education	13	3.5%	2.4%	1.1%
Family foster care	11	2.9%	1.3%	1.6%

N = 456

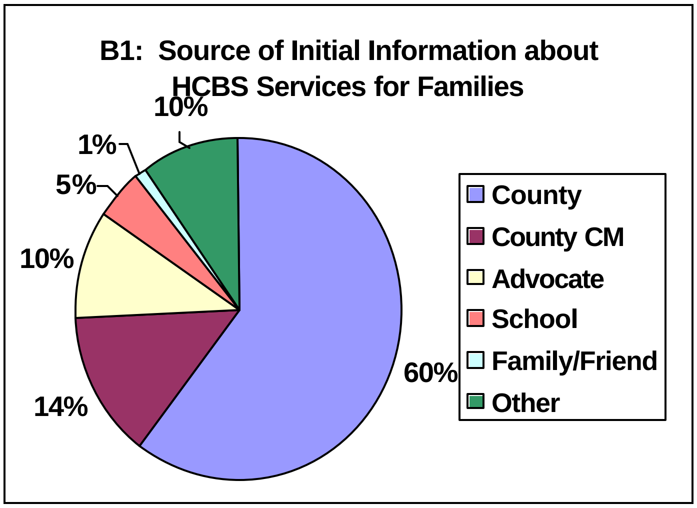
Access To Services For Current HCBS Recipients (Family Perspectives)

Source of initial information about the HCBS. Families responded to set of questions about where they first heard that a service was available (See Table B5; Figure B1). Parents heard about most types of services from either the county welfare or social services agency or from their county MR/RC case manager. A substantial minority of parents heard about educational services, employment services, county case management, adaptive equipment and specialist services from someone in the school system. Advocates from an Arc or other agency were the first source of information about in-home services (11.6%) and HCBS services (10.2%). They were also the first source of information for between 5 and 10% of families for the other types of services. Family members or friends were rarely the first source of information. There were no differences in source of information across regions or ethnicity with one exception. In rural areas the schools were the first source of information about specialized therapy (OT, PT, ST, Counseling) more often than in metro or GM urban regions.

Table B6: Percent of Families who First Learned of Services From Various Sources

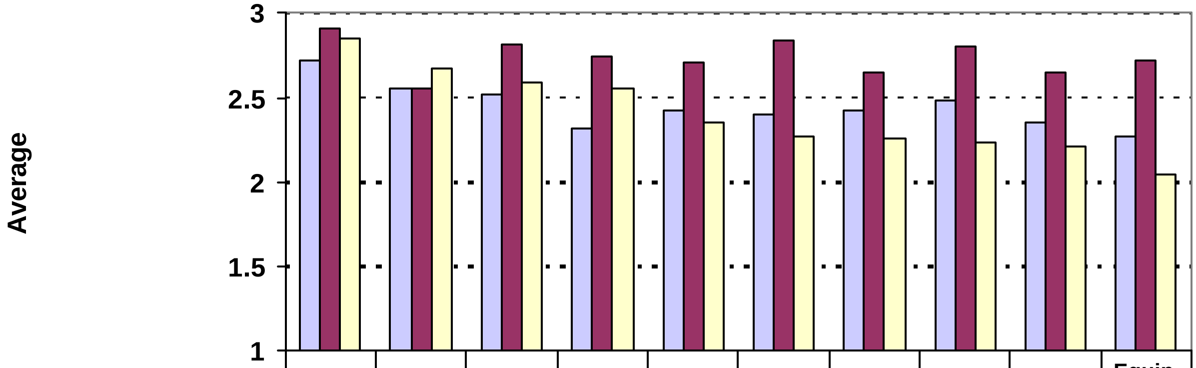
Service	*N*	County Welfare/ Social Services	MR/RC Case Manager	Advocate (Arc/ Other)	School Teacher/ Counselor	Friend/ Family Member	Other
Crisis behavioral services	48	60.4	18.8	8.3	2.1	2.1	8.3
HCBS services	166	60.2	13.9	10.2	4.8	1.2	9.6
Residential out-of-home	134	59.0	14.2	8.2	5.2	0.7	12.7
County services/Case mgmt.	168	53.0	5.4	8.9	14.9	6.5	11.3
In-home services	34	47.1	26.5	11.8	0	0	14.7
Specialized therapy (OT, PT) *	95	45.3	15.8	6.3	12.6	2.1	17.9
Transportation	120	43.3	19.2	5.8	11.7	0.8	19.2
Employment	123	43.1	16.3	8.9	19.5	0	12.2
Education	56	37.5	7.1	5.4	32.1	1.8	16.1
Adaptive equipment/ Environmental Modifications	61	32.8	18.0	9.8	13.1	1.6	24.6

*Rural families more likely to hear through school, metro families more likely to hear from MR/RC case manager or other ($X^2 = 18.77$, $p < .05$)


B1: Source of Initial Information about HCBS Services for Families

Family access to information about specific services. Families provided extensive information about their ability to access information about the services they received (See Figure B2). Across all service types, the vast majority of parents said that information they received was easy to understand. There were differences across service types, however, in terms of the availability of information (both timeliness and ease of access). In general parents were most satisfied with their access to information about employment services, transportation services and county case management services. Fewer parents reported that they got timely information most of the time about respite services, in-home supports, and adaptive equipment or environmental modifications. Furthermore fewer parents reported that it was easy to access information about services most of the time for adaptive equipment and environmental modifications, in-home supports, out-of-home residential supports, crisis respite services, and school services.

Figure B2: Family Access to Information About Services Recieved



	Employ ment	Transpo rtation	County CM	Respite	Therapy	School	Crisis	SLS	In-Home	Equip-ment/ Mods.
☐ Got Timely Info	2.72	2.55	2.52	2.32	2.43	2.4	2.42	2.48	2.36	2.27
■ Info Understandable	2.91	2.55	2.81	2.75	2.71	2.84	2.65	2.8	2.65	2.72
☐ Easy Access to Info	2.85	2.67	2.59	2.56	2.35	2.27	2.26	2.23	2.21	2.04

3=Most of the time, 2 = Sometimes 1 = Rarely

Family access to needed services. Families evaluated their access to services on four different criteria for ten different service types (See Table B6). For each question, families reported whether the criterion was met most of the time, some of the time or rarely.

Table B7: Family Access To Services: Percent Saying Statement Is True "Most of The Time"

Service	***N***	**Supports Meet Needs**	**Get Needed Supports / Auth Hours**	**Supports Available when Needed**	**Supports Available in a Crisis**
Respite services	28	53.6%	46.2%	46.4%	50.0%
In-home services	33	69.7%		55.6%	46.4%
Specialized therapy (OT,PT, ST, Counseling)	83			59.0%	65.7%
Education	46			63.0%	66.7%
Crisis behavioral services	34				67.6%
Adaptive equipment/ Environ. Mods.	43				74.4%
County services/ Case Management	158	72.6%	65.6%	76.6%	76.0%
Residential out-of-home	119				80.7%
Employment services	94			81.9%	86.3%
Transportation	107	82.2%		86.0%	

Of the 10 services rated, families of current HCBS recipients reported poorest access to respite services. Only 53.6% of families said that respite services met their family members needs most of the time (35.7% said respite services met their needs some of the time and 10.7% said respite services rarely met their needs). Only 46.2% of families reported getting the respite hours they were authorized most of the time while 27% reported getting their authorized hours rarely and 27% reported getting their authorized hours some of the time. Only 46.4% of families reported that respite services were available when needed most of the time (35.7% reported they were available when needed some of the time and

17.9% reported they were rarely available when needed). Furthermore, only 50% of families reported that crisis respite supports were available when they needed them most of the time (21% reported they were rarely available when needed).

A similar pattern was identified for in-home supports. While 69.7% of families said in-home supports met their family members need most of the time, only 55.6% said that in-home supports were available when needed most of the time. Furthermore, only 46.4% of families said that most of the time in-home supports were available in a crisis (18% said they were rarely available in a crisis). Parents were a little more likely to report that specialized therapy (OT, PT, ST, Counseling) were available when needed most of the time (59%). However 11% reported that specialized therapy were rarely available when needed. Similar proportions reported that specialized therapy services were available in a crisis (66% said most of the time while 13% said rarely). About two-thirds of families (63%) of school age children reported that educational supports were available when needed most of the time. About three fourths of families (74.4%) reported that in a crisis, they could get timely repairs of equipment or devices.

Access to case management services was better than for some of the other services. Sixty-five percent of families reported they received needed case management and other county services most of the time. However, 12% of families said their family rarely received needed county case management services. Case management supports met the needs of the person/family most of the time for 73% of families and were available when needed most of the time for 76.6% of families. A similar proportion of families (76.0%) said in a crisis, county case management supports were available in a timely manner most of the time.

The vast majority of families (80.7%) who used Supported Living Services said that in a crisis those services were available most of the time. A similar proportion of families reported that employment services were available when their family member wants and needs them most of the time (81.9%), and that in a crisis employment supports are available in a timely manner most of the time (86.3%). Finally, 86.0% of families said that transportation supports are available when their family member wants and needs them most of the time, and 82.2% of families receiving transportation services said that the transportation supports offered meet their family member's needs most of the time.

Families waiting for needed services. Twelve families of current HCBS recipients (7.5%) reported that they were currently on a waiting list or were waiting for one or more services funded by HCBS. Services for which more than one family was waiting included: in-home supports, semi-independent living services, adaptive aids, supported employment, enclave or work crew, or day training and habilitation.

Unmet needs reported by consumers. Consumers (or proxies when applicable) were asked whether there were services they needed but did not get in the previous 12 months. Overall 22.7% of consumers surveyed reported that there were services they needed but were not getting. This included 28.3% of consumers in metro area counties, 29.1% of GM urban counties, and 14.5% of consumers in rural counties.

Discussion

This part of the evaluation gathered and reviewed information about how people get HCBS in Minnesota and the issues they face in gaining access to the program's services. Also, issues related to the state's waiting list for HCBS were explored.

Key Findings

- There was a waiting list of 4,321 individuals with MR/RC for HCBS in October 1999. Many of these persons (1,687) were children living with their families, needing in-home and respite care. Of those waiting, 1,151 were adults living alone or with their families who were not currently receiving long-term care services.

- County practices varied a great deal with respect to the criteria for who gets HCBS.
- All counties reported maintaining waiting lists for HCBS services. Most counties reported trying to find alternative ways to meet current needs of individuals waiting for HCBS services.
- While 81% of case managers reported that their county has a written policy for prioritizing persons on the waiting list, only 37% said that copies of the policy were available to parents or other members of the general public.
- Although HCBS supports are intended to meet individual needs, some counties reported selecting new HCBS participants based at least partly on how well the person might match or "fit in" with people currently supported in an SLS setting.
- Only two counties (both in the metro area) reported having specific outreach plans to communicate about service options for individuals from racial and ethnic minority groups.
- Many counties only complete HCBS waiver screenings if specifically requested. One case manager reported their county defers screenings until a "waiver slot" is available.
- Over one-quarter (25.9%) of families receiving HCBS reported that they first heard about HCBS from someone other than county.
- Overall, case managers reported the most common reasons for awarding a new HCBS "slot" were a) emergency or crisis situations or b) people having the greatest impairments of all those waiting.
- Among the 468 sample members, almost 30% were living with their families prior to entering the HCBS program. The metro area had substantially higher proportions entering the HCBS program from large ICFs-MR or nursing homes (26.1%).
- Families receiving HCBS supports reported significant difficulty accessing respite services, crisis respite supports, and in-home family supports (either they did not meet their needs or they were not available).
- When asked about access to services for HCBS recipients in general, case managers reported that the most difficult services to access were crisis/respite, information on cutting edge innovations, assistance on how to manage own services, regular respite care, and transportation.
- Case managers for more than 23% of individual study participants reported having difficulty finding a provider for one or more needed services. The most difficult services to find were dental services, non-health specialists, and supported living services.
- Dental services were reportedly most difficult to access in greater Minnesota urban counties, and generic community services were most difficult to access in greater Minnesota rural counties.
- Parents reported relatively greater difficulty getting information about adaptive equipment or environmental modifications, in-home supports, out-of-home residential supports and crisis respite services than for other types of services.

What's Working?

Minnesota has an effective data system for documenting the extent of its waiting list, and the characteristics and needs of the people waiting, so that it can understand the meaning and implications of this waiting list. Establishing a baseline of who is waiting for supports and goals to reduce this list are necessary prerequisites to achieving the desired outcomes of providing supports to all who need them. Almost all Minnesotans waiting for HCBS services receive case management services and other services (e.g., school or day program supports, Medicaid state plan services for which they are eligible). Although available supports may not meet all of their needs, Minnesota has made an exemplary commitment to assuring that all eligible individuals and families have basic support even as they wait for the more comprehensive services available through the HCBS program.

Challenges and Concerns

The findings regarding access to services raise several concerns. Despite Minnesotans substantial growth in its HCBS program in recent years, there are still 4,321 Minnesotan's waiting for HCBS services. Second, while the state's waiting list report provides good information about people waiting for HCBS services, it does not contain all of the information needed to fully describe the extent of unmet needs of people with MR/RC in Minnesota.

For example, virtually all people waiting for HCBS are receiving some support services from minimum entitlements to case management, personal care and/or school services, but the extent to which those are meeting individual needs or would need to be augmented to do so is not available in the waiting list data. This evaluation also suggests that access issues are a significant issue for people even once they begin receiving HCBS services. Many families reported that respite and in-home supports did not meet their needs or were not available when they were needed. One reason for this difficulty is likely the shortage and turnover of direct support staff. Minnesota is therefore challenged to increase access to services both for people who currently receive HCBS supports and for those on waiting lists.

Case managers identified crisis respite, information on options and innovations, for creative use of HCBS assistance on how to manage one's own services (e.g., consumer directed consumer supports), and regular respite to be the services most difficult access in their counties. Their insights on the status of the service system suggest a need to enhance outreach, technical assistance and training to counties to increase the availability and effective use of HCBS supports.

C. Quality of Services

Many different quality indicators were included to evaluate the quality HCBS services in MN. This section includes information from different groups about their perceptions of the quality of outcomes for persons receiving HCBS Waiver funded supports.

Satisfaction with Services

Individual recipient. In the consumer interview, adults who could respond for themselves evaluated the quality of their vocational and residential services (See Table C1). Consumers who attended a site based day program reported they liked the program (81.8%), that it was a good place to go (82.5%), that the staff were nice and polite (85.8%), and that staff help them fix their problems (88.2%).

Table C1: Quality of Services (Consumer Interview)				
		Percent		
Component	***N***	**Yes**	**In-Between**	**No**
Day program				
Do you like it there?	209	81.8	11.0	7.2
Is it a good place to go?	200	82.5	10.5	7.0
Are the staff nice and polite?	204	85.8	12.3	2.0
Is this a bad place to go?	200	6.0	14.0	80.0
Do staff help fix problems you have?	195	88.2	5.1	6.7
Community Job				
Do you like your job?	130	89.2	5.4	5.4
Is this a good place to work?	128	79.7	13.3	7.0
Are the staff nice and polite?	124	94.4	3.2	2.4
Do you work enough hours?	120	58.3	3.3	38.3
Is this a bad place to work?	128	4.7	11.7	83.6
Are you satisfied with your earnings?	89	77.5		22.5
Home				
Do you like the people you live with?	351	84.6	13.1	2.3
Do you like where you live?	256	84.4	9.4	6.3
Is this a good place to live?	251	83.7	11.2	5.2
Are the staff nice and polite?	252	94.8	4.4	0.8
Is this a bad place to live?	248	5.2	11.7	83.1

Consumers working in community jobs were even more likely to say they liked their job (89.2%). The proportion who said the community job was a good place to work was similar to that for center-based settings (79.7%). Those in community job sites were more likely to report that staff members are nice and polite (94.4%). However, only 58.3% of consumers with jobs said they worked enough hours and only 77.5% were satisfied with their earnings. More than 83% of consumer rated the place they lived positively. Almost all consumers (94.8%) reported that the staff members at their home are nice and polite.

There were no significant differences between consumers based on race for any of the day program (responded to by 11 non-white participants) or home outcomes (responded to by 15 non-white participants). Individuals from non-white racial or ethnic groups were significantly less likely to like the community based job they held, but only 7 such individuals were interviewed so the results should be viewed with extreme caution as they may not be representative (1.43 vs. 1.86; ***F*** (1,128) = 5.24; ***p*** < .05).

Family. Families reported their satisfaction with the services they received, and whether they felt that their family member was happy (See Table C2). Families were most satisfied with transportation services (90.8% were satisfied most of the time), out-of-home residential services (86.8%) and case management services (86.0%). They were much less satisfied with environmental modifications or adaptive equipment (54.7% were satisfied most of the time), education services (67.3%), in-home supports (71.0%), and respite services (71.4%). Families receiving specialized therapies reported the family member improved as a result most of the time (63.4%), some of the time (29.3%) or rarely (7.3%).

Table C2: Parent/Family Member Satisfaction With Services (Family Survey)							
Type of Service	***N***	**Consumer/Family Happy**			**Family satisfied with service**		
		Most of the time	**Some of the time**	**Rarely**	**Most of the time**	**Some of the time**	**Rarely**
Transportation	109	90.8	7.3	1.8	91.2	5.3	3.5
Out-of-home residential	130	87.7	10.8	1.5	86.8	13.2	0.0
Case management	141	92.9	5.0	2.1	86.0	10.5	3.5
Employment supports	107	85.0	13.1	1.9	75.0	25.0	0.0
Specialized therapies	72	83.3	13.9	2.8	73.3	23.3	3.5
Respite services	27	86.4	13.6	0.0	71.4	14.3	14.3
In-home supports	31	100	0	0	71.0	22.6	6.5
Education	44	86.4	13.6	0.0	67.3	28.6	4.1
Environmental adaptations/ Adaptive Equipment	53				54.7	22.6	22.6

Blanks indicate that family members were not asked about that service.

All families receiving in-home supports said their family member was happy most of the time. Families reported that consumers were happy when receiving transportation services (90.8%), and case management services (92.9%) most of the time. Between 85% and 97% of consumers were happy most of the time in out-of-home residential services, employment supports, respite services and education.

Families rated how often staff members from various types of services were understanding, respectful and caring. More than 87% of families reported that staff members in each of the service categories were understanding "most of the time" (See Table C3). Families said staff were most understanding in respite services, case management, employment services and specialized therapies. Lowest ratings were for in-home supports and crisis behavior supports.

Table C3: Staff Level of Understanding (Family Surveys)				
Staff are understanding, respectful, professional and caring	***N***	**Most of the time/ Yes**	**Some of the time**	**Rarely/ No**
Respite services	27	96.3	3.7	0.0
Case management	175	94.9	4.0	1.1
Employment services	110	94.5	5.5	0.0
Specialized therapy services	87	94.3	3.4	2.3
Residential out of home	134	91.8	7.5	0.7
Education	50	90.0	8.0	2.0
Crisis Behavioral (agency)	39	89.7	10.3	0.0
In-home supports	33	87.9	12.1	0.0

(Agency) Most questions ask if staff members are understanding but for crisis behavioral services the question asks if the agency as a whole is understanding.

Provider Responsiveness

Resolving problems. Families reported their satisfaction with three components of problem resolution practices (getting competent and timely answers to questions, feeling comfortable voicing complaints, and satisfactory resolution of complaints; See Table C4). The sample size reflects the number of families who reported receiving the service and who responded to the question. More than 85% of families reported that their questions were answered in a timely and competent manner by employment services (89.7%), residential out-of-home providers (86.8%), case managers (86.0%) and transportation providers (85.4%). However, fewer than 65% said their questions were answered in a timely and competent manner by agencies providing home modifications and adaptive equipment (62.3%) or respite services (64.3%).

Similarly more than 85% of families reported being comfortable voicing complaints to transportation providers, employment services, case managers and residential out-of-home providers. However, fewer than 80% of families reported being comfortable voicing complaints to respite providers (70.4%), schools (78.0%), and in-home support providers (78.8%).

Table C4: Satisfaction With Process To Resolve Problems (Family Surveys)

Indicator	*N*	Most of the time (Yes)	Some of the time	Rarely (No)
Questions are answered competently in a reasonable amount of time				
Employment services	116	89.7	6.9	3.4
Residential out of home	136	86.8	9.6	3.7
Case management	171	86.0	9.9	4.1
Transportation	103	85.4	8.7	5.8
In-home supports	33	78.8	18.2	3.0
Crisis Behavioral (agency)	40	77.5	17.5	5.0
Specialized therapy services	90	76.7	15.6	7.8
Education	48	75.0	22.9	2.1
Respite services	28	64.3	32.1	3.6
Home and Environmental modifications (agency)	53	62.3	20.8	17.0
Feel comfortable voicing complaints				
Transportation	104	90.4	7.7	1.9
Employment services	117	88.9	4.3	6.8
Case management	170	87.1	10.0	2.9
Residential out of home	134	85.1	10.4	4.5
Home and Environmental modifications (agency)	58	84.5	10.3	5.2
Specialized therapy services	89	83.1	14.6	2.2
Crisis Behavioral	41	80.5	12.2	7.3
In-home supports	33	78.8	12.1	9.1
Education	50	78.0	14.0	8.0
Respite services	27	70.4	29.6	0.0
Complaints are resolved to your satisfaction				
Transportation	96	83.3	14.6	2.1
Employment services	112	82.1	17.0	0.9
Case management	160	79.4	15.6	5.0
Residential out of home	134	78.4	20.1	1.5
Specialized therapy services	86	70.9	25.6	3.5
Home and Environmental modifications (agency)	55	69.1	21.8	9.1
Education	49	65.3	30.6	4.1
In-home supports	32	62.5	34.4	3.1
Crisis Behavioral	40	62.5	30.0	7.5
Respite services	26	57.7	34.6	7.7

(Agency) For these items parents were rating the agency rather than particular staff members.

Fewer than 85% of families reported that their complaints were resolved to their satisfaction by any of the assessed provider types. In fact, fewer than 70% of families said their complaints were resolved to their satisfaction for respite services (57.7%), crisis behavioral service (62.5%), in-home supports (62.5%), educational services (65.3%), and home modifications and adaptive equipment (69.1%). Overall, transportation, employment services, residential out-of-home services, and case managers were best at resolving problems and concerns. Providers of respite services, crisis behavioral services, in-home supports, education, and environmental adaptations and adaptive equipment were worst at resolving problems and concerns. These later provider types were not surprisingly, also lowest in overall family satisfaction (as reported on Table C4).

Planning. There were dramatic variations among provider types in the extent to which they involved family members in planning for the future (See Table C5). In general, the traditional service providers (residential out-of-home, case managers, employment services and education) worked with families to plan their future more often than the other types of providers. Only about half of all families indicated that respite service providers, providers of environmental modifications or adaptive equipment, and specialized therapy providers involved the family in planning for the future most of the time. Furthermore, only 53% of families reported that in-home support providers worked with them most of the time to plan current services and only 66.7% of families said they worked with them most of the time to plan future services.

Table C5: Involving Families In Planning For The Future (Family Surveys)

Indicator of Planning	***N***	**Most of the time**	**Some of the time**	**Rarely**
Work with family to plan for the future				
Residential out of home	130	81.5	15.4	3.1
Case management	168	79.2	14.3	6.5
Employment services	110	77.3	18.2	4.5
Education	46	76.1	15.2	8.7
Crisis Behavioral (agency)	39	69.2	20.5	10.3
In-home supports	33	66.7	15.2	18.2
Respite services	24	58.3	16.7	25.0
Home and Environmental modifications (agency)	59	57.6	23.7	18.6
Specialized therapy services	87	51.7	21.8	26.4
Work with family to plan current services				
In-home supports	32	53.1	28.1	18.8

Flexibility. The final aspect of provider responsiveness rated by families was whether services were flexible and adaptable to meet family member needs (See Table C6). As with other areas of responsiveness, the provider types that were most flexible and adaptable were employment services (87.3% were flexible most of the time), case management (85.2%), and residential out-of-home services (84.0%). Oddly, the services rated by families as being least flexible were those that are looked to because of their potential for flexibility (respite services and in-home supports). Only 70.4% of families said that respite providers were flexible most of the time, and only 71.9% of families said that in-home support providers were flexible most of the time. Perceived flexibility of those services is probably related to and reduced by the difficulties providing access to the quantity of services in Individual Service Plans due to staffing shortages. This raises serious questions about whether the full potential of the HCBS program is being used in terms of offering flexibility to families.

Table C6: Flexibility of Services (Family Survey)				
Services are flexible and adaptable to meet family member needs	***N***	**Most of the time**	**Some of the time**	**Rarely**
Employment services	110	87.3	11.8	0.9
Case management	162	85.2	13.6	1.2
Residential out of home	131	84.0	13.0	3.1
Crisis Behavioral (agency)	37	78.4	16.2	5.4
Specialized therapy services	84	75.0	21.4	0.4
Education	47	72.3	25.5	2.1
In-home supports	32	71.9	15.6	12.5
Respite services	27	70.4	11.1	18.5

Choice/Respect and Self-Determination

Guardianship status. Any discussion of choice and self-determination for individuals with cognitive disabilities must begin with a discussion of the basic right to make choices guaranteed by the Constitution of the United States to all adults. While Minnesota has been working for almost two decades to reduce the number of people with mental retardation and related conditions whose choices are made for them by a state designated decision maker, there are still more than 2,000 adults in the HCBS program who are wards of the Commissioner in the HCBS program alone (See Table C7).

Table C7: Guardianship Status of Adults with Mental Retardation or Related Conditions in MN								
Guardianship status	**Nursing home**		**ICF-MR**		**HCBS**		**Other/NA**	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**	***N***	**Percent**
Private guardian/conservator	248	42.2%	1,607	52.8%	3,362	54.0%	1,625	41.9%
Public guardian/conservator	212	36.1%	1,257	41.3%	2,040	32.8%	380	7.9%
No guardian needed	126	21.5%	179	5.9%	819	13.2%	1,874	48.3%
Needs guardian	1	0.2%	0	0%	0	0%	2	0.1%

In comparison to the ICF-MR program, adults receiving HCBS services are more likely to be their own guardian and thus, less likely to have a public guardian or conservator. The question remains, however, as to how many others with public or private guardians could succeed with either a less restrictive guardianship status or with no guardian at all. Additional questions include whether efforts could be made to modify appointed legal representation to a non-public entity.

Consumer choice making opportunities. Choice and self-determination is important in daily life. Table C8 shows the types of choices available to persons who are receiving HCBS-funded supports. The table presents information about choices in order from the lowest percentage of consumers who don't participate in the decision at all, the highest. Adult HCBS recipients were most likely to have choices about what to do for fun and what to buy with their spending money. While many consumers can choose either with or without assistance when they get their money, when they eat, and when they go to bed, nearly a quarter of these adults do not even participate in these basic decisions. Individuals living in corporate foster care settings were significantly less likely to participate in making decisions about when to eat/go to bed at all (73.8% vs. 81.7%; $X^2 = 9.82$; $p < .01$) or to participate in decisions about what to do for fun unassisted (36.0% vs. 55.9%; $X^2 = 9.64$; $p < .05$) than individuals living in family homes, family foster settings or their own home. Those groups did not differ regarding other choices about daily life.

Table C8: Consumer Choice Making Opportunities (Percents) Consumer Interview				
Choice	***N***	**Yes (Unassisted)**	**Yes (With Assistance)**	**No**
Choices about Daily Life				
Chose things you do for fun	362	39.2	50.8	9.9
Chose things to buy with spending money	361	22.4	65.4	12.2
Can get your money whenever you want	357	33.1	43.1	23.8
Decides when to eat/go to bed	354	34.2	41.0	24.9
Decisions about Work				
Chose job (for those who have a job)	160	13.8	45.6	40.6
Chose to attend day program	253	3.2	32.8	56.9
Chose the staff who help at job	296	5.1	14.9	80.1
Decisions about Home				
Chose the place you live	342	7.3	44.2	48.5
Chose the people you live with	323	4.6	23.5	71.8
Chose the staff who help at home	348	4.0	20.7	75.3
Other				
Ever participated in a self-advocacy meeting	330	27.0		73.0
Chose case manager	343	4.1	6.1	89.8

At the next level, of the 160 consumers who had a community job, 13.8% choose they job without assistance, 45.6% participated in choosing the job, and 40.6% did not participate in the decision about where they work. This finding only refers to people who are actually working in a community job. This finding does not include people who would like a job but who currently do not have the choice to do so.

The next three questions get to the heart of the HCBS program in terms of true choice (choosing where to live, where to receive day supports, and with whom to live). A "no" response to these questions indicates that not only did the individual not make the final decision, they also did not provide any input into the decision making process. Overall, 48.5% of adults had no input into decisions about where they would live, 56.9% had no input into what day program they would attend, and an incredible 71.8% did not have any input into whom they would live with. Individuals living in corporate foster care settings were significantly less likely to report participating in the decision about where to live (48.6% vs. 69.6%, $X^2 = 9.39$, $p < .01$) or who their roommate would be (26.0% vs. 47.1%; $X^2 = 16.28$, $p < .001$) than were individuals living in their family home, a foster home, or their own home.

One encouraging finding is that fully 27% of adult HCBS participants reported that they had attended at least one self-advocacy meeting. There were no differences between recipients living in corporate foster care settings and those living in other settings in whether they had attended a self-advocacy group meeting.

The last three questions about choice focus on participation in choosing who will provide direct supports (including intimate personal care for those who need it). Fewer than one in four consumers reported any involvement in the process to select people who will support them at home. Only one in five participate in the process to select people who will support them at work, and only one in ten had any say in who their case manager would be.

Questions about choice making opportunities were responded to by 22 individuals from non-white racial or ethnic groups. There were no significant differences in choice making opportunities for individuals in different racial or ethnic groups.

Family choice. Choice making opportunities are important not only for the people who receive supports, but also for their families. In assessing family choice, information was gathered from both case managers and from families about the types of choices they had made. One of the most important choices for HCBS participants is where to live. While consumers reported they had little involvement in deciding where they would live, case managers reported (on the individual case manager survey) that 81.6% of consumers were living in the place the families preferred.

Families may make several choices regarding the services they and their family member would receive. Table C9 summarizes the extent to which families had a) a range of options to choose from, b) a choice of which services they would receive, c) a choice of which agency would provide the service, d) choices about the person or agency that would provide the support and e) a chance to participate in other important decisions daily life (e.g., roommates, medications).

Families were most likely to report that they had a range choices regarding educational supports (70.6% reported having a range of options “most of the time”) and general services brokered by the case manager (67.1%). Families were least likely to report they had a range of options regarding out-of-home residential supports (32.1% reported having a range of options “most of the time”), home and environmental modifications (53.6%), and specialized therapy services (58.4%).

Families were asked if they had a choice of which services they would receive. Families were most likely to report they had a choice about which in-home supports they would receive (78.8% reported having a choice “most of the time”). They were least likely to choose case managers (5.2% chose their case manager), transportation services (33.7%), and types of vocational supports their family member would receive (45.3% said they chose the types of vocational supports “most of the time”). Of the 58 families who reported that they were rarely involved in decisions about the types of vocational supports their family member would receive, 44 (75.9%) were the legal guardian for the person.

Additional investigation is needed to identify the factors that prevent legal guardians from choosing the type of vocational supports (not the agencies but the actual types of supports) their family member will receive. A lack of choice about this basic issue suggests a need for ongoing systems change efforts so that it becomes more responsive to the desires of the people it serves. There were no regional or racial/ethnic differences in whether families have a choice about the types of vocational supports. Of the people for whom the families reported rarely participating in decisions about employment supports, 42.6% work at least some of the time in supported employment, 44% work at least some of the time in work crews or enclaves, 63% work at least some of the time in center based work activity, and 21% spend at least part of their time in non-vocational day settings.

Table C9: Family Choices (Family Survey)

Indicator of Choice	*N*	Most of the time (Yes)	Some of the time	Rarely (No)
Range of options offered to meet needs				
Education	34	70.6	14.7	14.7
Services brokered by the case manager	167	67.1	18.6	14.4
Employment services	110	64.5	25.5	10.0
Crisis Behavioral	34	64.1		35.9
Respite services	25	64.0	24.0	12.0
Transportation	109	63.3	18.3	18.3
Specialized therapy services	89	58.4	15.7	25.8
Home and Environmental modifications	58	53.4		46.6
Residential out of home	109	32.1		67.9
Choose which services you receive				
In-home supports	33	78.8	18.2	3.0
Education	46	63.0	17.4	19.6
Residential out of home	121	58.7	28.9	12.4
Specialized therapy services	84	57.1	21.4	21.4
Employment services	106	45.3	21.7	33.0
Transportation	104	33.7	18.3	48.1
Case management	172	5.2		94.8
Chose the agency providing the supports				
Home and Environmental modifications	58	67.2		32.8
Crisis Behavioral	41	58.5		41.5
Out-of-home residential	113	49.6		50.4
Choose the staff person who provides supports				
Respite services	28	78.6	14.3	7.1
In-home supports	30	70.0	20.0	10.0
Crisis Behavioral	38	39.5	18.4	42.1
Education	50	34.0	20.0	46.0
Employment services	97	25.8	14.4	59.8
Specialized therapy services	85	23.5	30.6	45.9
Residential out of home	112	20.5	15.2	64.3
Involvement in important decisions (roommates, medical decisions)				
Residential out-of-home	136	81.6	10.3	8.1
Crisis behavioral supports	37	70.3	10.8	18.9

The number of respondents varies because families only answered questions related to services they or their family member actually received.

Families were asked whether they chose the agency they would receive support from for three service types. A total of 67.2% of families said they chose which agency or vendor would provide environmental modifications or adaptive equipment, 58.5% said they chose which agency would provide crisis behavioral supports, and 49.6% said they chose which agency would provide residential supports. Fewer than half of parents had a choice of residential agencies. Families in the metro counties were significantly more likely to have a choice of vendor for residential services than in the other regions (59% vs. 37%; $X^2 = 4.86$, $p < .05$). This suggests that a continued need to find ways to expand the pool of residential providers in greater Minnesota.

The next two sets of findings focus on choices families make once a provider agency has been selected. One question was whether families choose the particular staff member(s) who would be supporting their family member. Most families reported that they chose the staff member who provided respite supports (78.6% choose the person most of the time), and in-home supports 70%). Only one in four families, however had a choice most of the time about the person who would provide employment services (25.8%) and even fewer had a choice about who would provide specialized therapy services (23.5%) or out-of-home residential supports (20.5%).

The final type of choice was involvement in important decisions about things like medical, dental, safety, house location, and roommates or housemates. The majority of families reported they were involved in these decisions most of the time (81.6% for out-of-home residential settings and 70.3% for crisis behavior supports). A small minority of families reported never being involved in those decisions (8.1% for out-of-home residential settings; 18.9% for crisis behavioral supports). One concern about this finding is that follow-up analysis reveals that 45% of families who said they were rarely involved in those decisions were actually the person's legal guardian or conservator. While that was only 5 people (of 11), that the legal guardian is not involved in important decisions regarding out-of-home residential services is a concern. This is an even bigger issue for crisis behavioral services where 5 of 7 families (71%) who said they were rarely involved in important decisions regarding those services were legal guardians. While a lack of resources could explain lack of involvement in selecting providers, it does not explain lack of involvement in personal decisions about a person with a legal guardian.

County Perspectives on Choice in the Wavier program (HCBS Waiver Coordinator Interviews)

Formal county position regarding consumer control of services and supports. Two counties within the sample have participated in the self-determination pilot project or other initiatives and this has helped them begin to offer consumer directed supports. One county who also participated in the self-determination project has moved toward consumer-controlled supports by offering this option in their county respite programs. They currently do not offer it under their HCBS funded programs although they plan to move ahead in this direction. Seven counties fully support the concept of consumer-controlled supports and are planning to move in that direction within the next year or so. Two counties support the concept but experienced barriers such as lack of county board support that halted their movement in this direction. Seven counties reported that they had taken no formal position regarding consumer directed supports and that they currently had no plans to move in this direction. In many counties, the respondents indicated that they felt that consumers and their family members already had control over their services through the ISP and opportunities to choose provider organizations.

County role in promoting consumer control of services and support. The overwhelming majority of counties indicated that their support for consumer directed supports is evidenced through case manager involvement with every person who receives HCBS services. The ability of case managers to integrate consumer direction and control into their annual ISP planning, person centered planning options and through building alliances and partnerships with families were identified as specific strategies to promote consumer control by offering choices and encouraging families to take more control. The three counties in the sample that participated in the self-determination project all indicated that these grant dollars were instrumental in allowing counties to have targeted staff who could promote the necessary change and move in the direction of consumer controlled supports and services.

Use of standards, expectations, recognition of excellence and other strategies to encourage inclusion in community programs and activities. A few counties reported they engaged in county initiated activities to set standards and expectations and to recognize excellence in the inclusion of people with developmental disabilities and related conditions into the community. These activities included:

- Encouraging case managers to set expectations for community inclusion in their ISP planning and through participation of all team members
- Setting expectations for community inclusion in contracts with provider organizations to ensure that people who receive services are active in their communities
- Arranging for a work group to look for best practices within the county
- Training provider organizations and case managers to encourage best practices

- Hosting county sponsored recognition events for foster care providers
- Developing and disseminating a newsletter that includes illustrations of excellence

Eight counties saw community inclusion primarily as a provider responsibility and noted that their county does little if anything to set expectations or recognize excellence related to community inclusion.

Choices for HCBS recipients in selecting agencies to provide their HCBS services. Most counties try to honor family requests for certain provider agencies to provide supports to their family member and encourage families to pursue options. Several mechanisms were used by counties to support this choice. Many counties included:

- Developing and disseminating booklets to families that identify all potential provider agencies and provides information on the types of services each provider offers,
- Hosting selection meetings and provider fairs, and
- Having case managers encourage families to visit and interview a number of provider organizations.

Many counties also reported that the "reality" in their counties is that families often have little choice in who provides them with supports. This limited choice is a result of a limited number of providers within the county and/or limited responses by providers to Requests for Proposals (RFPs). In addition, if a family wants a provider that is far more expensive than other providers they may be denied a choice due to cost.

Respect

Respecting choices made by consumers and families. One measure of respect is whether people are afforded choices. Another measure is whether the choices made are honored. Table C10 summarizes family reports of whether their choices and preferences are honored, and about whether consumer choices and preferences are honored by various types of service providers. All of the families who received respite services reported that their providers respected family choices and preferences most of the time. Family choices and preferences were respected most of the time for 87.9% of families receiving in-home supports, 87.0% of families regarding their case manager, 86.2% of families for residential out-of-home supports and 81.7% of families receiving employment services. Of families with children still in school only 66.7% reported that the educational system respected their choices and preferences "most of the time".

Table C10: Providers Respect Family And Consumer Choices (Family Surveys)				
Indicator of Choice	***N***	**Most of the time**	**Some of the time**	**Rarely**
Providers respect family choices and preferences				
Respite services	26	100.0	0.0	0.0
In-home supports	33	87.9	12.0	0.0
Case management	169	87.0	11.8	1.2
Residential out of home	130	86.2	10.8	3.1
Employment services	109	81.7	13.8	4.6
Crisis Behavioral (agency)	36	77.8	13.9	8.3
Specialized therapy services	85	74.1	14.1	11.8
Education	48	66.7	18.8	14.6
Providers respect consumer choices and preferences				
Respite services	26	100.0	0.0	0.0
Case management	141	97.9	0.0	2.1
In-home supports	33	87.9	12.1	0.0
Employment services	102	86.3	10.8	2.9
Residential out of home	121	83.5	13.2	3.3
Specialized therapy services	73	82.2	12.3	5.5
Crisis Behavioral	33	75.8	18.1	6.1
Education	42	71.4	11.9	16.7

In regard to respect for consumer choices and preferences, all of the families reported that respite services respected their family members choices and preferences most of the time and 97.9% reported that case managers did so. On the other end of the spectrum, only 71.4% of families reported that educational programs respected their family members choices and preferences most of the time. Similarly, only 75.8% of families reported that crisis behavioral services respected consumer choices and preferences, most of the time.

Respecting the personhood of people who receive HCBS supports. The consumer interview included several questions about how people are treated within their homes (See Table C11). Most individuals reported that they could spend time alone with guests if they wished (74.1%) and that they could be alone when they wished (86.7%). However, 54% of consumers would like to have more time to be alone. There were no differences between setting types. One in four consumers reported that people who do not live in the house enter the house without knocking first. Individuals in corporate foster care settings were significantly more likely to report that people entered the home without knocking than were people in other types of homes (25.1% vs. 11.9%; $X^2 = 4.87$; $p < .05$). One in ten reported that people enter their bedrooms without knocking first. There were no differences between setting types on this indicator. Almost 20% of consumers who were capable of using a telephone reported that their use of the telephone was restricted. Individuals in corporate foster care settings were significantly more likely to report restrictions on phone use than individuals in other types of settings (20.5% vs. 6.4%; $X^2 = 5.25$; $p < .05$). More than 10% of consumers reported that someone else opens their mail without asking for permission. Individuals in corporate foster care settings were significantly more likely to have someone sometimes or always open their mail without their permission than individuals in other types of settings (36.5% vs. 21.3%; $X^2 = 5.22$; $p < .05$).

Questions about respect were responded to by 22 individuals from non-white racial or ethnic groups. There were no significant differences reported on any of these outcomes depending on racial or ethnic group.

Table C11: Respect for Consumers (Consumer Interview)				
Indicator	***N***	**Yes**	**Sometimes**	**No**
Has privacy with guests	347	74.1%	15.7%	10.2%
Can be alone with I want	214	86.7%		13.3%
Would like more time alone	200	54.1%		45.9%
Someone else opens my mail	349	13.6%	19.4%	67.0%
People enter house w/o knocking	354	22.8%		77.2%
Restrictions on using phone	271[1]	19.3%		81.7%
People enter bedroom w/o knocking	344	10.3%		89.7%

[1] Excludes 89 people who cannot use the phone or who do not have a phone.

Cultural sensitivity. Families reported the extent to which supports and services were culturally sensitive and the extent to which staff communicated with them in their preferred language (See Table C12). More than 95% of families reported that case management, specialized therapy, employment, education, respite and out-of-home residential services were culturally appropriate most of the time. Overall 93% of families reported that in-home supports were culturally appropriate most of the time. However, two of five non-white respondents (40%) indicated that in-home supports were culturally appropriate only some of the time. Crisis behavioral supports were considered culturally appropriate most of the time by 84% of families, some of the time by 9% of families, and rarely by 6% of families. Because so few families from racial and ethnic minority groups responded to these questions it is difficult to generalize these findings to all non-white HCBS recipients.

Table C12: Cultural Sensitivity of Providers (Family Surveys)						
Service Type	**Services are culturally appropriate**			**Staff communicates in your preferred language**		
	Most of the time	**Some of the time**	**Rarely**	**Most of the time**	**Some of the time**	**Rarely**
Case management	99.3%	0.7%	0%	98.6%	0.7%	0.7%
Specialized services	98.6%	1.4%	0%			
Employment services	97.9%	2.1%	0%	90.8%	4.1%	5.1%
Education	97.9%	2.1%	0%	85.4%	12.2%	2.4%
Respite services	96.0%	4.0%	0%	100%	0%	0%
Residential out of home	95.9%	2.5%	1.7%	97.4%	1.7%	0.9%
In-home supports*	93.1%	6.9%	0%	94.6%	1.4%	4.1%
Crisis Behavioral	84.4%	9.4%	6.3%	82.4%	8.8%	8.8%

Two of five (40%) respondents from racially or ethnically diverse groups reported services were culturally appropriate only some of the time.

All of the families receiving respite services reported that staff communicate in their preferred language all of the time. More than 94% of families receiving case management, out-of-home residential, and in-home supports reported that staff members communicate in their preferred language most of the time. The services least likely to communicate in the families' preferred language most of the time were employment services (90.8% did so most of the time), education (85.4%), and crisis behavioral supports (82.4%).

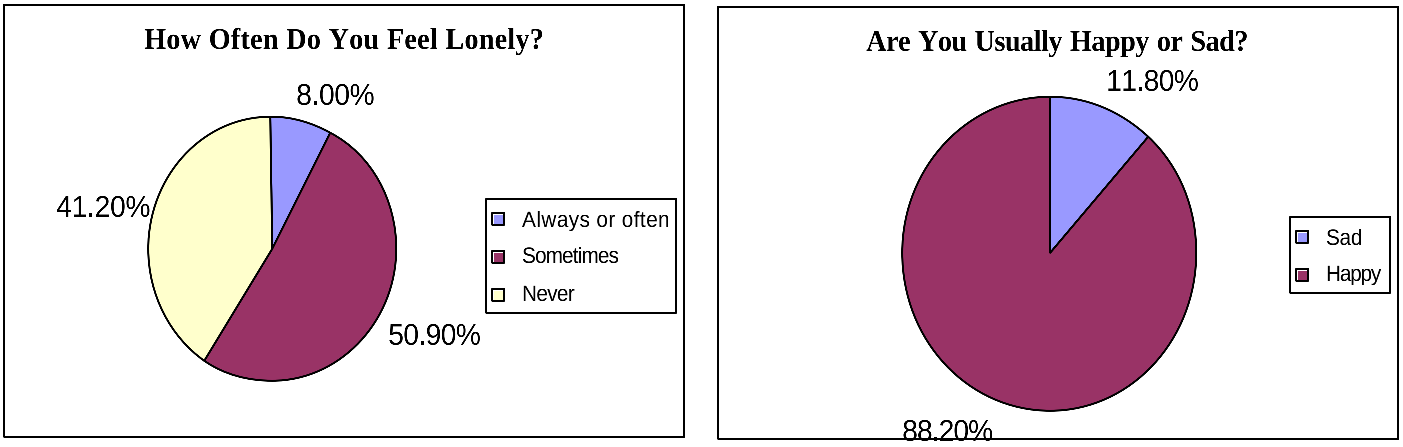
Community Inclusion and Participation

Social opportunities. The consumer interviews assessed several dimensions of community inclusion and participation. One section asked individuals about their social networks (See Table C13). A total of 71.4% of respondents indicated that friendship was important to them. A similar percentage of people reported having friends to talk to or do things with (75.8%), having a best friend (75.4%), and seeing friends when they want to (73.6%). Almost all consumers surveyed (94.4%) reported that they saw their families at least occasionally. About three fourths (75.8%) reported seeing their family when they wanted to.

Table C13: Friends And Families: Social Opportunities (Consumer Interview)				
Social Opportunity	***N***	**Yes**	**Some**	**No**
Have friends to talk to or do things with	244	75.8	18.9	5.3
Have any best friends	232	75.4		24.6
See friends when you want to	235	73.6	22.1	4.3
Friendship is important to me	220	71.4	22.7	5.9
Ever see family	252	94.4		5.6
See family when you want to	223	75.8	20.2	4.0

When asked about social belonging, 8.0% of individuals interviewed reported that they were always or often lonely, and 50.9% reported that they were sometimes lonely. Most (88.2%) reported that they were usually happy. Fifteen individuals from non-white racial or ethnic groups responded to questions about social opportunities. There were no differences between the groups on most items. The exception was that adults from non-white racial or ethnic groups were significantly less likely to ever see their family members than other adults (80.0% vs. 95.4%; ***F*** (1,250) = 6.45; ***p*** < .05).

Figure C1: Emotional Well-Being/Social Connectedness (Consumer Survey)



Community activities. Of the 374 consumers interviewed, 61.8% reported living in a place that was centrally located in a city or town, 26.5% reported being within walking distance of a city or town, and 11.8% reported living in a physically remote location (See Table C14). More than 90% of consumers reported at least sometimes going out on errands (97.5%), going shopping (96.2%), going out to eat (95.9%), or going out for entertainment (92.1%). Three fourths (74.7%) reported going out for exercise or sports. While going to religious services was really or somewhat important to 71.6% of consumers, only 54.6% reported that they go to religious services. There were no differences between persons in corporate foster care settings and other settings in whether they participated in these activities.

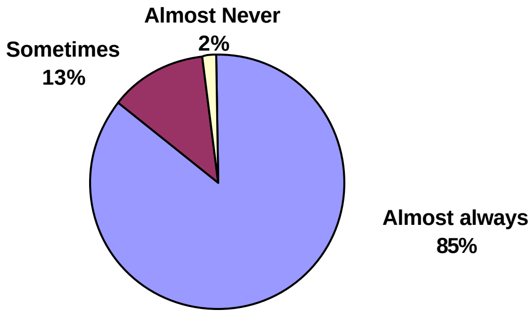
Table C14: Participation In Community Activities (Consumer Interview)					
Activity	***N***	**Participates**	**Level of Importance**		
			Really	**Somewhat**	**Not**
Go out on errands	361	97.5%			
Shopping	366	96.2%	61.8%	27.8%	10.5%
Go out to eat	364	95.9%			
Go out for entertainment	365	92.1%	62.0%	29.2%	8.8%
Go out for exercise or sports	364	74.7%			
Go to religious services	359	54.6%	46.4%	25.2%	28.5%

Families reported the extent to which consumers participated in community activities while receiving supports from various types of providers. Fewer than 60% of families reported that family members spent most of their time in community activities with any service type. Overall, 55.6% of families reported that consumers were involved in community activities most of the time when served by out-of-home residential providers, while 43.8% reported the same for employment services, and 38.6% did so for education settings. Of the parents whose child was in school 28.2% reported that their child spent most of their time in activities with peers without disabilities at school, 35.9% reported that their child spent some of their time with non-disabled peers, and 35.9% reported that their child rarely spent time in activities with peers who did not have disabilities. Most parents (63.6%) who received in-home supports reported that their family member spent some of the time involved in community activities while those supports were being provided.

Table C15: Family Member Is Involved In Community Activities When Served By This Provider (Family Survey)				
Family member is involved in community activities	***N***	**Most of the time**	**Some of the time**	**Rarely**
Residential out of home	133	55.6	34.6	9.8
Employment services	89	43.8	34.8	21.3
Education	44	38.6	43.2	18.2
Involved in activities with peers without disabilities at school	39	28.2	35.9	35.9
In-home supports	33	12.1	63.6	24.2

An important factor in whether individuals will be able to participate in community events and activities is whether they have transportation to get to those events and activities. Overall, 85.6% of consumers reported that the almost always could get to the places they wanted to go, 12.5% reported they sometimes could, and 1.9% reported the almost never had transportation to desired events or activities (See Figure C2). There were no significant regional differences in access to transportation.

Figure C2. Do you have a way to get to places you want to go? (Consumer Interview) (N = 361)



Provider linkages to community supports (family surveys). Finally, families reported the extent to which various types of providers helped them link to various community supports, and the extent to which those providers assisted their family members to build social connections with families, friends or neighbors (See Table C16). Residential out-of-home providers facilitated community connections most of the time for 92.9% of all families. Case managers, transportation providers and respite services helped families make get other supports from the community most of the time for just over 70% of families receiving those types of services. For more than half of families who got in-home supports, those providers rarely helped them get other supports from the community.

Table C16: Assistance Provided To Families By Various Provider Types To Make Community Connections (Family Survey)

Assistance getting needed supports	*N*	Most of the time (Yes)	Some of the time	Rarely (No)
Provider helps you to get other supports from the community				
Residential out of home	127	92.9		7.1
Case management	151	74.8		25.2
Transportation	41	73.2		26.8
Respite services	21	71.4	14.3	14.3
Employment services	92	68.5		31.5
Crisis Behavioral (agency)	22	63.6	22.7	13.6
In-home supports	25	20.0	24.0	56.0
Provider helps your family member find families, friends or neighbors to provide supports needed				
Residential out of home	97	75.3		24.7
In-home supports	25	68.0	12.0	20.0
Employment services	77	57.1		42.9
Transportation (providers & cm help find it)	72	56.9	8.3	34.7
Case management	113	45.1	11.5	43.4
Crisis Behavioral	22	40.9	9.1	50.0
Education	40	35.0		65.0
Specialized therapy services	58	32.8	20.7	44.8
Respite services	21	14.3	4.8	81.0

Residential out-of-home providers were most likely to assist consumers make community connections (75.3% of families reported they do so most of the time). However, even for this service, almost 25% of families said residential out-of-home providers rarely assisted their family members to find families, friends or neighbors to add to their support networks. Twenty percent of families said in-home support providers rarely assisted family members to add people to their support networks, and 42.9% of families said vocational providers rarely do so.

Provider Perspective Regarding Barriers to Community Inclusion

The provider survey included ten questions about factors that limited or restricted access to community supports. A total of 235 providers responded to these questions. None of the listed factors were barriers for more than half of the provider (See Table C17). The most common barriers reported were: too few staff scheduled (reported by 43% of all provider respondents), behavioral needs of consumers (43%), and lack of consumer interest in community activities (40%). There were significant differences by provider type, region or both for three of the ten factors. Vocational providers reported significantly more difficulty with transportation than did residential providers. Furthermore, for both residential and vocational providers, transportation was an issue for substantially more of the metro area providers that for providers in the other regions. Lack of program money was significantly more likely to be reported as a barrier for vocational programs than for residential programs. Finally, metro area providers were significantly more likely to report "other" barriers than were providers in other regions.

Table C17: Factors That Restrict Requested Community Activities (Provider Survey)

Factor	Vocational			Residential			Total	*F*	Diff
	Metro	GM urban	Rural	Metro	GM urban	Rural			
Too few staff scheduled	40%	43%	55%	40%	47%	43%	43%	0.34	
Behavioral needs	49%	57%	65%	32%	47%	36%	43%	2.19	
Lack of consumer interest	20%	38%	35%	42%	47%	48%	40%	1.62	
Lack of personal $	46%	38%	35%	33%	26%	43%	36%	0.94	
Position vacancies	46%	24%	1%	35%	28%	32%	31%	1.77	
Medical needs	40%	38%	35%	22%	16%	23%	26%	1.78	
Lack of Transportation	54%	19%	25%	28%	9%	9%	24%	6.46***	P, R[1]
Lack of program $	31%	29%	40%	11%	7%	23%	20%	3.66**	P
Other	34%	14%	10%	17%	9%	11%	16%	2.34*	R
Staff breaks/ schedules	11%	10%	1%	3%	7%	16%	9%	1.35	

N = 235. An overall multivariate analysis of variance showed significant differences by region and by type of provider in barriers to community activities.
Group differences P = Provider type, R = Region. * p < .05, ** *p*<.01, *** *p*<.001;
[1] Metro providers reported significantly more difficulties with transportation than providers in other regions.

Continuity of Services

One of the more basic indicators of quality is whether people in the HCBS program receive stable supports over time. On the consumer interview, the vast majority of adults surveyed reported they had lived in the same location for at least one year (88.9%). The proportion living in two or more places during the year was highest in GM rural counties (13.8%), and lowest in GM urban counties (4.5%). A total of 11.2% of metro area consumers had lived in two or more places during the year.

Providers also reported on the rate at which individuals moved in and out of their programs in the previous year (See Table C18). In the year prior to the survey, 34.1% of residential sites added a new consumer to the site and 22.2% had one or more consumer leave. The most common reason consumers left a site was because they died (11.3% of sites reported one or more consumer death in one year). Other reasons consumers left were to move to another site within the same agency (9.0% of sites had one or more person move), to move to a different agency (5.9% of sites), to obtain a different type of residential support (5.8% of sites), and other reasons (1.8% of sites). There were no regional differences in the proportion of sites that added a new consumer or had a consumer leave.

Table C18: Percent of Residential Sites with Changes in Consumers in 1 Year (Provider Survey)				
Indicator	***N* of Sites**	**Percent w/1 or more change**	**Number of Consumers**	
			Range	**Mean**
Added new consumers	82	34.1	0-8	0.59
<u>Consumer Left (Reason)</u>				
Died	71	11.3	0-2	0.13
Moved to another site	67	9.0	0-6	0.18
For another agency	68	5.9	0-2	0.07
For a different service type	69	5.8	0-1	0.06
Left for other reasons	56	1.8	0-2	0.04
Total	74	22.2	0-6	0.35

Several possible conclusions could be drawn from these findings. One is that a considerable number of consumers in SLS settings experience changes in housemates in a one-year period. More than one-third have a new housemate while almost one-quarter have one or more housemates leave. More than 10% of SLS sites had one or more consumer death in a year. Another possible conclusion, if people are moving because of poor initial matching in where and with whom individuals will live, would that poor planning and possibly of lack of choices may be involved. If people are moving because of lease or other housing issues, this may suggest a management or resource issue. However, if people who initially chose their current location are moving because they want to live elsewhere or with different people, turnover of consumers could reflect that providers are respectful and accommodating of individual choices.

Quality of HCBS versus ICF-MR Services

Case manager perspective. In the general case manager survey, case managers compared the outcomes of HCBS Waiver services to outcomes in ICF-MR services (See Table C19). They rated outcomes in 20 areas, and in seventeen of those 20 areas outcomes were considered better for people receiving HCBS. Case managers considered HCBS to be superior in terms of having choices in what to do in free time, having privacy, living in places that feel "like home," participating in the community, picking where and with whom a person will live, and growth in independence. ICF-MR services were not rated as significantly superior in any of the rated areas. In most cases there were no differences by region. The exception was for staff training where case managers in metro area counties felt ICF-MR staff were better trained but case managers in GM urban counties felt HCBS staff were better trained.

Table C19: Case Manager Comparison of Quality In Community ICF-MR Versus HCBS Funded Settings (General Case Manager Survey)

Point of comparison	Comparative Quality	*t*
People have more choices in what they do with their free time	1.25	10.34***
People have privacy	1.15	11.11***
People live in places that feel like home to them	1.10	9.68***
People participate more in the community	.98	7.09***
People pick where and with whom they want to live	.96	8.62***
People grow in independence	.82	7.57***
People are happy with their lifestyles	.77	7.12***
People have more relationships with friends	.75	5.31***
People set their own goals	.73	7.15***
People are happy with the services they receive	.67	5.04***
Families are happy with the services their family member receives	.65	6.38***
People get more respect	.40	3.59***
Families feel secure about their family members' future	.40	3.16**
Services are a better value for the dollars spent	.35	2.45*
People pick their direct support staff	.34	3.89***
People are safe from abuse and injury by housemates	.31	3.92***
Staff are better trained[a]	-.08	-.73
People are safe from abuse and exploitation by outsiders	-.11	-.93
People have access to the health services they need	-.17	-1.66

****p*<.001, ***p*<.01, **p*<.05 Note: A significant *t* indicates that HCBS settings were rated as significantly better. Items that were not significant indicate case managers rated HCBS settings and ICF-MR settings as of equal quality.

[a] In the metro area case managers feel ICF-MRs are superior while in GM Urban counties case managers felt HCBS providers are superior (F = 4.62, p < .05; N = 48).

HCBS Waiver Coordinator Perspective. Almost all of the Waiver Coordinators interviewed described similar differences between ICF-MR and HCBS SLS services. In their opinion, HCBS SLS services were smaller in size, provide for more individualized programs and increase community integration and have more staff members per recipient. Additionally, in HCBS SLS settings, people were more likely to have their own bedrooms, had more privacy, had fewer difficulties with roommates and had greater flexibility in the way the house was decorated. HCBS SLS recipients were considered to have more involvement in simple daily decisions about the meals they eat, where and when they shop and what they do for fun. Finally, most Waiver Coordinators reported that people in HCBS SLS settings had more flexibility to move to different homes or apartments when desired.

Quality of HCBS and Related Services

General case manager survey. The general case manager survey asked for ratings of the quality of specific HCBS supports ranging from "4" indicating excellent quality to "0" indicating poor quality. Of the 18 rated services, case managers reported that the highest quality services were case management (Mean = 3.24), interdisciplinary planning and assessment services (3.19), facility-based residential services (3.06), and health care or physician services (3.06). The lowest quality services were information on cutting edge innovations (Mean = 1.98), assistance to individuals or families on how to manage their own services (2.30), transportation (2.48) crisis respite or emergency care (2.48) and person-centered lifestyle planning (2.55). There were no regional differences except that case managers in rural areas were much less satisfied with the quality of information on cutting edge innovations than were case managers from the Twin Cities metropolitan area, though even case managers in the Twin Cities ranked this as the lowest quality component. Many of the lower quality services newer and were reported to be difficult to access.

Table C20: Quality of HCBS Funded Supports (General Case Manager Survey)

Service	Region			Total	*F*
	Metro	GM urban	Rural		
Case management/service coordination	3.14	3.45	3.25	3.24	0.77
Interdisciplinary planning/assessment	3.00	2.55	3.20	3.19	2.47
Facility based residential services	2.82	3.36	3.19	3.06	2.91
Health care/physician services	2.95	3.33	3.06	3.06	0.72
Info on local community services	2.95	3.10	3.00	3.00	0.14
Day training and habilitation	2.90	3.10	2.94	2.96	0.30
Dentist/dental services	2.77	2.82	3.00	2.86	0.34
Regular respite care	2.52	2.82	3.00	2.75	1.55
Recreation/leisure activities	2.59	2.90	2.87	2.74	0.57
In-home residential supports	2.50	3.10	2.69	2.69	2.16
General community services	2.68	3.00	2.47	2.69	1.33
Supported community employment	2.75	2.64	2.63	2.68	0.15
Assistive technology/ housing modifications	2.64	3.09	2.31	2.65	2.03
Person-centered lifestyle planning	2.57	2.60	2.50	2.55	0.39
Crisis respite/emergency care	2.48	2.73	2.29	2.48	0.32
Transportation	2.48	2.45	2.50	2.48	0.01
Assistance for individuals on managing own services	2.38	2.30	2.19	2.30	0.15
Info on cutting edge innovations	2.32	2.11	1.47	1.98	3.23*
Average	2.72	2.93	2.71	2.76	0.61

0 = poor or no quality, 4 = excellent quality * $p < .05$; $N = 48$

Case manager ratings of HCBS quality. Case managers of 468 sample members rated the quality of HCBS services on a variety of dimensions (See Table C21). The highest rated HCBS services overall were residential or in-home services (41.6% of case managers reported quality to be excellent), protection of basic rights and dignity (34.7%), freedom from abuse and neglect (34.7%) and day training or habilitation services (37.0%). However, only 15% of case managers said the system was excellent at sharing the results of quality assurance and other reviews with families, case managers, and others involved in service planning. Other concerns were direct support staff member (DSS) skills (26.1% rated these components as poor or only adequate), access to sufficient numbers of DSS (26.2% poor or adequate), and quality of dental care (16.3% poor or adequate).

Table C21: Quality And Quality Assurance Practices (Individual Case Manger Survey)

Service	*N*	Poor	Adequate	Good	Excellent	Mean	*F*	Dif
Residential or in-home services	461	0.9%	7.2%	50.3%	41.6%	3.36	1.03	
Basic rights and dignity are protected	445	1.3%	6.8%	57.1%	34.7%	3.26	0.82	
Free from abuse and neglect	455	1.3%	6.6%	57.1%	34.7%	3.25	0.41	
DTH or work	384	0.8%	14.3%	47.9%	37.0%	3.20	0.52	
Appropriate attention to personal safety						3.14	0.59	
Health and physician quality	457	1.5%	9.8%	62.4%	26.3%	3.11	1.62	
Authorized services are received	451	0.9%	11.1%	63.6%	24.4%	3.11	1.34	
Privacy is respected	445	1.1%	11.2%	64.9%	22.7%	3.09	0.82	
Free from physical harm	456	1.8%	11.4%	63.2%	23.7%	3.07	2.22*	
Quality of life for individual	440	1.4%	12.5%	64.5%	21.5%	3.07	2.34*	C,I
Freedom from medication errors	436	2.1%	7.6%	70.9%	19.5%	3.07	0.85	
Quality of dental care	453	2.4%	13.9%	62.9%	20.8%	2.99	3.59***	S,L
Sufficient numbers of DSS	451	4.0%	22.2%	55.7%	18.2%	2.92	1.32	
DSS have sufficient skills	452	3.1%	23.0%	56.2%	17.7%	2.91	1.36	
Quality assurance results are shared	393	6.6%	17.6%	60.6%	15.0%	2.83	2.57*	R[1]

* $p < .05$, ** $p < .05$, *** $p < .05$; R = region; S = consumer support needs, L = Living in corporate foster care or other setting (family home, family foster care, own home), C = Cost, A = age, I = interaction between region and type of residence.

[1] Case managers in metro counties rated sharing of QA results higher than those in GM urban counties.

Each quality indicator was tested to see whether quality was related to region of the state, receiving corporate foster care supports, intensity of consumer support needs, total costs paid for services to the person, age of the consumer, and interactions between region and type of residence. For most indicators, these factors were not related to quality as reported by case managers. There were differences in whether case managers felt the person had a high quality of life as defined by the interests, desires and needs of the individuals. Specifically, case managers reported that persons whose total costs were lower had a higher quality of life. There were also differences by region and type of residence. Specifically, in metro counties, case managers reported that individuals in corporate foster care settings had higher quality of life than those living elsewhere (Mean = 3.17 for corporate foster care and 2.83 for other settings). Conversely, case managers rated quality of life higher in other settings (family homes, own home, family foster care) than in corporate foster care settings in GM urban counties (Mean = 3.08 vs. 2.93) and in GM rural counties (Mean = 3.14 vs. 3.03).

There were also differences in rated quality of dental services (persons with higher needs were getting lower quality care, and people living in corporate foster settings getting higher quality of care). Finally, case managers in metro counties were more likely to say the system was excellent at sharing the results of quality assurance and other reviews with families, case managers, and others involved in service planning than were case managers in GM urban counties.

Case manager reports of quality: Differences by Race. The individual case manager survey provided the best opportunity in this project to compare outcomes for individuals from various racial and ethnic groups. Individual case manager surveys were returned for 36 individuals from non-white racial or ethnic groups. Of the 15 quality indicators described on Table C21, the only one that differed significantly by race the quality of dental services. On that indicator HCBS recipients from non-white racial or ethnic groups received poorer quality dental services than other HCBS recipients (2.81 vs. 3.04; F (1,451) = 4.07; $p < .05$).

Provider and DSS rating of overall service quality. Both supervisors and direct support staff members rated the quality of services provided in specific sites on general maintenance and upkeep, overall quality of services, and frequency of consumer or family satisfaction surveys (See Table C22). Supervisors rated general maintenance and upkeep as 3.35 on a scale of one to four with four meaning excellent. Vocational providers in the metro counties rated maintenance better than those in GM rural areas but residential providers in the metro and GM urban counties rated their maintenance worse than those in GM rural areas. Average scores for overall quality of services and supports were 3.48 and did not differ by region or by provider type. Overall, 83.7% of providers said they surveyed consumers or families at least annually about the quality of services provided. Providers in GM urban areas were less likely to survey families annually than were providers in other regions.

Table C22. Quality of Services Provided (Provider Survey; DSS Survey)

Perspective/Factor	**Vocational**			**Residential**			**Total**	***F***	**Diff**
	Metro	**GM Urban**	**GM Rural**	**Metro**	**GM Urban**	**GM Rural**			
Supervisor (N=261)									
Maintenance of equipment and physical plant	3.42	3.30	3.14	3.31	3.24	3.61	3.35	2.62*	I
Overall quality of site services and supports	3.53	3.50	3.32	3.44	3.41	3.65	3.48	1.47	
Survey consumers or families about satisfaction annually	91.2%	79.2%	86.4%	84.9%	68.8%	93.3%	83.7%	2.66*	R[1]
DSS (N=220)									
Maintenance of equipment and physical plant	2.92	2.93	2.81	3.06	3.21	3.24	3.08	1.74	
Overall quality of site services and supports	3.26	3.00	3.24	3.39	3.47	3.61	3.39	3.12*	P
Survey consumers or families about satisfaction annually	92.0%	100%	55.6%	80.8%	82.7%	52.9%	78.4%	2.98*	R[2]
Survey DSS annually	70.4%	63.6%	43.8%	65.7%	56.1%	59.3%	61.3%		

(1 = poor, 4 = excellent) * $p < .05$, ** $p < .01$, *** $p < .001$; I = Interaction between provider type and region. R = regional differences are significant, P = differences between providers are significant.

[1] GM urban regions were less likely to survey consumers or families at least annually than were providers in the other region types.

[2] DSSs in rural areas said their agencies were less likely to survey consumers or families than in the other region types.

Direct support staff members rated general maintenance and upkeep lower than supervisors (3.08 vs. 3.35). Ratings of maintenance did not vary by region or by provider type. There were however, differences for overall quality of supports and services. Residential DSS reported overall quality significantly higher than vocational DSS. Overall quality ratings by DSS were lower than those by providers. Overall 78.4% of DSS reported that their agency survey consumers or families at least annually. DSS in GM rural areas were less likely to report that their agencies surveyed consumers or families annually than were DSS in other regions. Finally, 61% of DSS reported that their provider conducts surveys of staff satisfaction at least annually. There were no significant differences by provider type or region.

Discussion

The evaluation gathered information from HCBS recipients, families and case managers about quality and satisfaction of services. Also, information regarding community inclusion, choices and delivery of services in a respectful manner is included.

Key findings

- Adult HCBS recipients liked where they live (82%) and work (89%). They had friends (76%) and could see them when they wanted to (74%).
- Most people who receive HCBS (85%) reported almost always having a way to get to places they wanted to go.
- HCBS recipients with community jobs did not feel they worked enough hours and 22.5% were not satisfied with their earnings.
- Families were most satisfied with transportation, out-of-home residential services and case management. They were least satisfied with environmental adaptations and adaptive equipment, educational services, in-home supports, and respite services.
- While families were mostly satisfied with complaint resolution practices, providers of respite services, crisis behavioral services, in-home supports and educational services were rated lower than other types of services in satisfactorily resolving complaints.
- Families were less satisfied with planning for specialized therapy services, home and environmental adaptation agencies, respite services and in-home supports.
- Twenty-five percent of families reported that residential out-of-home providers rarely assisted their family members to find friends, family members or neighbors to add to their support networks.
- Providers reported that the most common barriers to accessing community supports were too few staff members (43%), behavioral needs (43%), and lack of consumer interest (40%).
- Providers reported that in the year prior to the survey, 34% of residential sites added a new consumer, and 22% had one or more consumer leave.
- Almost 90% of interviewed adult waiver recipients had lived in the same place for more than one year.
- Case managers and county waiver coordinators overwhelmingly rated HCBS services as superior to ICF-MR services. HCBS were considered to be superior in terms of having choices in what to do with free time, having privacy, living in places that feel like home, participating in community activities, choices in location and roommates, and growth in independence.
- The general case manager survey indicated that the highest quality HCBS services were case management, interdisciplinary planning and assessment and residential services. The lowest rated services were information on cutting edge innovations, assistance to families and individuals on managing their own services, transportation, crisis respite or emergency care, and person-centered lifestyle planning.
- Case managers of 468 sample members rated residential and in-home services highest in overall quality. The lowest quality components of the HCBS system were sharing quality assurance results, skills of DSS, number of available direct support staff (DSS), and quality of dental care.
- Case manager ratings of quality of life were higher for individuals with lower costs, metro area residents living in corporate foster care, and Greater Minnesota HCBS recipients living in family homes, own homes or family foster care settings.
- In general there were very few differences in outcomes for individuals by race or ethnicity. The most prominent difference was that case managers reported that individuals from non-white racial or ethnic groups received poorer quality dental services.

What's working?

Many of the stakeholders involved in this evaluation reported overall satisfaction with HCBS services. Consumers generally liked the places they lived and worked. Most families were satisfied with transportation, residential services and case management services. Families reported that most of the time and in most settings staff members were understanding, respectful, professional and caring. Case mangers and county waiver coordinators reported that when compared to ICF-MR services, HCBS services were superior with regard to people having choices, privacy, feeling at "home," participating in their community, picking where and with whom they live, small size of home, and staffing ratios. Eighty percent of case mangers rated HCBS supports as good or excellent.

Adults receiving HCBS services had stable living environments (10% had moved in the last year). Almost three-fourths of adults reported having friends and being able to see them when they wanted to. Furthermore, 94% of HCBS recipients who receive Supported Living Services (SLS) (typically in "corporate foster care settings") had on-going contact with their families. Almost all of the HCBS recipients participated in common community activities such as running errands, going shopping, going out to eat and going out for entertainment. More than half of the adult HCBS recipients in the sample had attended a self-advocacy meeting.

Challenges and concerns

Families report that approximately one-quarter of HCBS recipients do not receive support from formal service providers in finding and using natural supports such as friends, family members, neighbors or community groups. Achieving meaningful community inclusion usually requires both natural and paid supports in people's lives. Shortages of direct support staff, available staff working excessive overtime hours to respond to shortages, high turnover of experienced staff and limited staff development are also having effects on people's opportunities.

Several findings suggest that improvements should be made in facilitating community inclusion for HCBS recipients. For example, 25% of families reported that residential out-of-home providers rarely assisted their family members to find friends, family members or neighbors to add to their support networks. While 41% of the adult respondents reported that they were never lonely, 8% said they were always or often lonely and 51% indicated that they were sometimes lonely. Providers reported that the most common barriers to accessing community supports were too few staff members (43%), behavioral needs of the people receiving services (43%), and lack of consumer interest (40%). Increased efforts to support HCBS recipients in making friends, building support networks and becoming fully participating citizens in their communities of choice are needed to reduce the loneliness experienced by HCBS recipients.

Cultural and ethnic factors associated with perceived quality of services and community inclusion could not be adequately addressed by this study because of the practical limits on sampling respondents from ethnic and racial minority groups. However, very few outcomes were statistically different for sample members from ethnic and racial minorities. Among important statistically significant differences were that case managers reported that persons with racially or ethnically diverse backgrounds experienced significantly lower quality of dental services. Further investigation is needed to understand the quality and outcomes of services for HCBS participants and individuals waiting for HCBS supports who are from ethnically and culturally diverse backgrounds.

Choice and Respect

This part of the evaluation gathered and reviewed information reflecting the extent to which HCBS recipients and their families experienced choice, respect and sensitive support within the HCBS program.

Key Findings

- Adults reported having friends and being able to see them when they wanted. Almost all had at least some contact with their families.
- Case managers reported that 81.6% of HCBS recipients were living in the place their family preferred.
- Many adults who receive services reported that direct support staff (DSS) and other non-residents of their home entered without knocking first (25%), that there were restrictions on phone use where they live (19%) or that people opened their mail without permission (33%).
- Large proportions of adults reported having no input in major life decisions about where they would live (49%), work (57%), or with whom they would live (72%).
- Families reported that 17% of HCBS recipients were afraid of someone in their residential or work setting.
- Families reported they had the least amount of choice in selecting a case manager (95% rarely/never).
- People living in corporate foster care settings had significantly fewer choices and experienced significantly more forms of disrespect or insensitivity (e.g., people entering the home without knocking) than adults living in family homes, family foster care settings or their own homes.
- Almost 20% of consumers who were capable of using a telephone reported that their telephone use was restricted. This was more likely to be true in corporate foster care settings. Thirty-three percent reported that someone sometimes or always opened their mail without permission. Again this was more likely to be true in corporate foster care settings.
- While going to religious services was really or somewhat important to 72% of consumers, only 55% reported going to religious services.
- Families reported having the greatest degree of choice about in-home supports and the least choice about who their case manager was, transportation services, and types of vocational supports. Only 31.5% of families reported having a range of options regarding out-of-home residential supports, and only 49.6% reported choosing which agency provided out-of-home residential supports. Families in metro counties were significantly more likely to report having a choice of vendor for residential services than those in other counties.
- While most family members reported being involved in decisions about medical, dental, safety issues, house location, and roommates, some reported never being involved in these decisions (including some who were the legal guardian for their family member).
- Many county HCBS Waiver coordinators indicated that they felt that consumers and their family members already have control over their services through the individual support plan (ISP) and opportunities to choose provider organizations. However, many counties reported that the reality in their counties is that families often have little choice in who provides them with supports.
- Most parents reported that providers respected family choices and preferences. However, educational providers, specialized therapy services and crisis behavioral services were rated as relatively less likely to respect family choices and preferences. Similarly, while most families reported that most providers respected consumer choices and preferences, educational providers and crisis behavioral services were relatively less likely to respect consumer choices and preferences.

What's working?

The ability to seek and maintain social development and relationships is instrumental to human development and satisfaction. The majority of adult HCBS recipients reported that they had friends and could see them when desired and almost all had desired contact with their families. Minnesota HCBS recipients reported that they felt supported in developing and maintaining relationships. A majority of families reported being involved in making important decisions regarding the health, safety and well-being of HCBS recipients. Parents reported that most service providers respected their choices and preferences and that satisfactory complaint resolution occurs when there are differences.

Challenges and concerns

Adult HCBS recipients deserve to be treated with respect. Reports from 25% of sample members who said people came into their homes without knocking, 10% who said people came into their bedroom without knocking and 20% who said that although they are capable of using their phone they are restricted in when and how they can do so should be of concern. Many of the adults interviewed said that attending religious services or events was really or somewhat important to them, but they never attended religious services or events. People living in corporate foster care settings reported significantly more indications of disrespect (e.g., people entering the home without knocking) than adults living in family homes, family foster care settings or their own homes. Increased awareness, training and expectations must be made to improve the respect people with MR/RC who receive HCBS get.

A pervasive lack of choice was also evident in the experiences of consumers and family members in the HCBS program. Few consumers had choices about where and with whom they would live, where they work, how many hours they would work, how they spend their days or who would provide personal supports to them. Furthermore, many recipients are excluded from basic daily decision making about meals, bedtimes, and privacy. For example, 54% wanted more time alone. Improving sensitivities outcomes in this area should be a priority.

The lack of choice was not limited to people who receive HCBS. Only 31.5% of families reported having a range of options regarding out-of-home residential supports, and only 49.6% reported choosing which agency provided out-of-home residential supports. Families also reported having little choice among agencies for case management, transportation, and vocational supports.

Supports for families

This part of the evaluation gathered and reviewed information from family members of HCBS recipients to assess the extent to which they as family members well supported by the program's services.

Key findings

- Families reported that most of the time and in most settings staff were understanding, respectful, professional and caring.
- Families were generally satisfied with the extent to which out-of-home residential services worked with the family in planning for the future.
- While generally satisfied with the flexibility of employment, case management and out-of-home residential services, families were less satisfied with the flexibility of respite services, in-home supports, and educational services.
- In 1999 Minnesota had a combined total of more than 200 children and youth 17 years or younger living in group homes funded by HCBS of ICF-MR programs.

What's working?

Being treated with respect and dignity is a critical component of service delivery and customer service. High proportions of family members surveyed reported that in most settings staff were understanding, respectful, professional and caring. Their testimony confirms that in general Minnesota's service provider organizations and personnel are dedicated to supporting and enhancing the lives of people with disabilities and their families. Families also reported general satisfaction with the flexibility offered in employment, case management and out of home residential service.

Challenges and concerns

Although substantial majorities of families reported satisfaction with their services, more than 25% of families were not satisfied with in-home supports, respite services, specialized therapies, environmental adaptations, adaptive equipment and education. These families reported that in-home and respite supports were the least likely to be flexible enough to meet their needs as a family and the needs of their family member with MR/RC. This is somewhat ironic given that in-home and respite services are designed to be highly flexible and responsive to the specific needs of families and individuals and shows how failure to be so leads to consumer dissatisfaction. The perceived lack of flexibility is undoubtedly attributed to the general shortage of qualified staff to meet the needs of respite and in-home recipients. Because of that shortage families often get fewer hours than they have been authorized and are often "forced to take what they can get," the antitheses of the flexibility these services are expected to exhibit.

Families receiving respite or in-home family supports also report less support from case managers and service providers in helping them to plan for their future needs. Although 79% of families reported that most of the time case mangers helped them plan for the future, 21% of families reported that this occurred only some of the time or rarely. Continued efforts are needed to ensure that service providers and case managers are attending to and supporting families in planning for their future needs.

While the majority of families usually choose the respite provider they use, 21% reported never or only sometimes having a choice. Similarly, while most families choose the person who will come into their home to provide in-home supports, 10% rarely or never do, and 20% choose only some of the time. Given the intrusive nature of having a person provide supports in the family home, assuring such choice should be a priority. One such strategy is to increase the opportunities for families and individuals to participate in consumer directed community support options where they are given the opportunity to choose who provides them with supports.

There were differences between case manager assessments of HCBS services and the family reports of satisfaction. Case managers reported that case management services were the most likely to be of excellent quality while families reported greater satisfaction with out-of-home residential supports and transportation than with case management. Conversely case managers rated transportation services as one of the lowest quality services while families receiving transportation services rated it as the service with which they were most often satisfied. This apparent discrepancy may be related to an access issue. That is, low case management ratings may reflect relative difficulty in accessing transportation services while parent satisfaction ratings are for those who actually get transportation services. Environmental adaptations, assistive technology and adaptive equipment were rated near the bottom of the list for both families and case managers. In-home and respite services ranked in a middle range by case managers and near the bottom for families.

Minnesota should make a special commitment to assure that all possible family support and substitute family alternatives options have been exhausted before children are placed in non-family congregate settings. A formal commitment to the philosophy and goals of "permanency planning" as has been made in states like Michigan should substantially lower the number of children in Minnesota deprived of the developmental benefits of family life.

D. HCBS Supports and Services Provided

Supports and Services Received

The screening document offers an opportunity to examine differences in service use patterns by age, race and ethnicity. The services used by HCBS recipients varied considerably depending on age and on whether the recipient was white or from racially or ethnically diverse groups (See Table D3). To understand the patterns of service use by age and racial group, the following differences must be considered. HCBS recipients from diverse racial and cultural backgrounds were considerably younger than HCBS recipients who were white. Among recipients from diverse racial and cultural backgrounds, 32.6% were ages birth to 19 years, 46% were 20 to 39 years, 18.4% were 40-59 years, and only 3% were 60 years or older. In contrast, among HCBS recipients who were white, only 14.3% were ages birth to 19 years, while 42.4% were 20 to 39 years, 32.8% were 40 to 59 years, and 10.4% were 60 years or older.

Table D1: Percent of HCBS Recipients Getting Various Supports and Services: Differences by Age and Race (Screening Document)

Supports/Services	Non-White					White					Grand Total
	0-19 yrs	20-39	40-59	60+	Total	0-19 yrs	20-39	40-59	60+	Total	
Number of People	119	168	67	11	365	954	2,820	2,182	693	6,649	7,022
% in each age group	32.6%	46.0%	18.4%	3.0%		14.3%	42.4%	32.8%	10.4%		
Current Residence											
Lives in foster care shift staff	27.7	62.5	80.6	81.8	55.1	24.5	66.3	79.3	80.7	66.1	65.4%
Lives with immediate family	58.8	16.7	4.5	0.0	27.7	66.4	10.9	2.3	0.9	15.0	15.6%
Lives with live in foster care giver	0.8	6.0	6.0	9.1	4.4	1.7	10.1	7.9	5.9	7.7	7.5%
Lives with foster family	10.9	7.1	4.5	9.1	7.9	6.5	5.9	4.3	6.3	5.5	5.6%
Own home with Lt 24 hr support	0.0	4.8	3.0	0.0	2.7	0.0	5.1	4.4	4.8	4.1	4.0%
Other residence	0.0	1.2	1.5	0.0	0.8	0.2	0.9	1.3	1.2	0.9	0.9%
Own home w/ 24 hr support	0.0	1.2	0.0	0.0	0.5	0.0	0.7	0.4	0.4	0.5	0.5%
Lives with extended family	2.5	0.6	0.0	0.0	1.1	1.0	0.3	0.2	0.3	0.4	0.4%
Education/Training											
In school	95.0	13.1	0.0	0.0	37.0	93.6	7.4	0.0	0.0	16.6	17.6%
Jobs and training (non-DTH)	0.0	8.9	7.5	0.0	5.5	1.3	12.5	9.9	6.6	9.4	9.2%
Non-HCBS funded DTH	0.0	1.8	4.5	9.1	1.9	0.6	1.7	1.0	1.4	1.3	1.3%
Adult education	0.0	1.8	0.0	0.0	0.8	0.1	0.3	0.2	0.0	0.2	0.2%
HCBS Waiver Funded Services											
SLS	37.8	81.0	94.0	90.9	69.6	31.3	88.5	97.1	97.4	84.1	83.2%
DTH	0.8	75.0	86.6	72.7	52.9	1.8	77.5	84.6	75.3	68.7	67.8%
Home modifications	47.1	37.5	37.5	45.5	40.8	47.7	35.6	41.1	46.3	40.3	40.2%
Respite services	58.0	13.4	3.0	9.1	26.3	63.0	13.3	4.4	4.8	16.6	17.1%
In-home family support	52.9	14.3	4.5	0.0	24.7	57.2	9.5	2.2	1.0	13.1	13.6%
Specialist services	26.1	14.3	10.4	0.0	17.0	24.5	13.0	10.2	7.1	13.1	13.2%
Crisis respite	20.2	19.6	10.4	18.2	18.1	15.6	13.7	10.1	6.6	12.0	12.3%
Assistive technology	23.5	4.2	3.0	0.0	10.1	23.7	6.4	5.0	4.2	8.2	8.3%
Personal support	12.6	2.4	0.0	0.0	5.2	10.6	5.6	3.0	2.7	5.2	5.2%
Care giver training	16.8	1.2	1.5	0.0	6.3	19.0	1.3	0.8	0.4	3.6	3.7%
Homemaker services	3.4	0.6	0.0	0.0	1.4	9.0	1.1	0.5	1.7	2.1	2.1%
Supported employment	0.0	0.6	0.0	0.0	0.3	0.1	1.4	1.2	0.3	1.0	1.0%
24 hour emergency assistance	0.8	1.2	0.0	0.0	0.8	1.0	0.9	0.7	0.7	0.8	0.8%
Adult day care	0.0	0.0	0.0	0.0	0.0	0.0	0.4	0.2	3.6	0.6	0.6%
Foster care - primary care giver	0.8	0.6	0.0	0.0	0.5	0.2	00.3	0.1	0.1	0.2	0.2%
Alternative day services	0.0	0.6	0.0	0.0	0.3	0.0	0.1	0.4	0.7	0.2	0.2%
Housing access	0.0	0.0	0.0	0.0	0.0	0.4	0.1	0.1	0.0	0.2	0.1%

Current residence. The most common living arrangement for HCBS recipients is homes with foster care shift staff (65.4% of recipients of all ages and more than 80% of adults 40 years and older). Other common living arrangements include living with the immediate family (15.6%), living with live-in foster caregivers (7.5%), living with a foster family (5.6%) or living in a person's own home with less than 24-hour support (4.0%). Very few HCBS recipients live with extended family members (0.4%), in their own home with 24-hour support (0.5%) or in some other type of residence (0.9%).

The primary difference between recipients who are white and those from other racial or culture groups is that recipients who are white are more likely to live in homes with foster care shift staff (66.1% vs. 55.1%) or with a live-in foster caregiver (7.7% vs. 4.4%) and less likely to live with their immediate families (15.0% vs. 27.7%) or with a foster family (5.5% vs. 7.9%). These differences are generally true for all age groups. Exceptions are that children from racial or ethnically diverse groups are more likely to live with a foster family or extended family members and less likely to live with their immediate family than children who are white. Among young adults ages 20 to 39 years, those from racial or ethnic minority groups are less likely than young adults who are white to live in foster care with shift staff or with a live in foster care giver, and more likely to live with their immediate family or with a foster family. Among adults ages 40 to 59 years, persons from racial or ethnically diverse groups are more likely than persons who are white to be living with their immediate families or with a foster family and less likely to be living with a live in foster care giver or in their own home with less than 24 hour support.

Overall, two age related trends can be observed with respect to where HCBS recipients live. First, the proportion of HCBS recipients living in foster homes with shift staffing patterns increases dramatically between childhood and adulthood and continues to increase as people get older. Second, and correspondingly, the proportion of HCBS recipients who live with immediate family or live-in foster caregivers declines sharply when recipients become adults and continues to decline as people get older.

Education and training. Overall, 17.6% of HCBS recipients are currently in school. Another 9.2% are receiving supports from a jobs-and-training provider, 1.3% receive DTH services funded by a source other than the HCBS Waiver, and 0.2% are in adult education programs. Since substantially more HCBS recipients who are from racially or ethnically diverse groups are children, those individuals are also more likely to be in school.

Comparing individuals of similar ages, several differences emerge. Among HCBS recipients who are 20 to 39 years old, persons from racially or ethnically diverse groups are more likely to be in school or in adult education, and are less likely to be receiving jobs and training services (Extended employment services including work activity, long term employment and supported employment or competitive employment not provided by a DTH provider). Among Waver recipients who are 40 years or older, persons from racially or ethnically diverse groups are less likely to be receiving non-DTH jobs and training supports and are dramatically more likely to be in DTH programs funded by sources other than the HCBS Waiver.

The only notable trend in education and training across ages generally is that the proportion of HCBS recipients in jobs and training programs declines steadily throughout adulthood

HCBS Waiver funded services (from Screening Document). Overall, the most common HCBS funded services are supported living services (83.2% of recipients), day training and habilitation (67.8%) and home modifications (40.2%). Other HCBS funded services received by between 10 and 20 percent of HCBS recipients are in home family support, specialist services, crisis respite and assistive technology.

Several differences in service utilization emerge for individuals with different racial or ethnic backgrounds. Many of those differences are likely associated with age differences between the two groups compared. Persons from racially or ethnically diverse groups are less likely than HCBS recipients who are white overall to receive SLS or DTH services. They are more likely overall to receive respite services, in-home family supports, specialist services, crisis respite, caregiver training, and assistive technology.

The pattern of service use varies by both age and ethnicity. Among children, HCBS recipients from racially or ethnically diverse groups are more likely than recipients who are white to receive supported living services, less likely to receive respite services, in-home supports, caregiver training or homemaker services. Children from racially or ethnically diverse groups are more likely to receive specialist services, crisis respite and personal support services.

Among adults ages 20 to 39 years, HCBS recipients from racially or ethnically diverse groups are less likely than recipients who are white to receive supported living services, DTH services, assistive technology, personal support, homemaker services, or supported employment services. They are more likely to receive home modifications, in-home family support, crisis respite, and 24-hour emergency assistance.

Among adults ages 40 to 59 years, HCBS recipients from racially or ethnically diverse groups are less likely than recipients who are white to receive supported living services, home modifications, respite services, personal support, or supported employment services. They are more likely to receive day training and habilitation services, in-home family support, and caregiver training. The small numbers of HCBS recipients from racially or ethnically diverse groups over 60 years old make comparisons for that group not meaningful.

Other services. Overall, 7.4% of HCBS recipients received home care services funded by a source other than the HCBS program. This included 12.1% of recipients from racially or culturally diverse groups and 7.2% of recipients who were white. Those services were most commonly used for children (used by 23.5% of children from racially or ethnically diverse groups and 25.1% of white children).

Specific Vocational Services

While the screening document data provides a wealth of information about services received by HCBS recipients, it does not include certain details that are important to further refining our understanding of the HCBS program. Therefore, this evaluation gathered information about services from several other sources. One source of additional information about services was the consumer interview. While the screening document recorded only a handful of HCBS recipients whose supported employment services were specifically paid for as a distinct HCBS service, many more recipients received supported employment and other types of services from day training and habilitation providers. Table D2 summarizes the various types of vocational supports provided to adults who were receiving HCBS services and were interviewed for this study.

Table D2: Type of Vocational Supports Received by Adult Sample Members (Consumer Interview)

Vocational Supports	**Region**			**Total**	X^2
	Metro ***N* = 138**	**GM Urban** ***N* = 68**	**Rural** ***N* = 147**		
Facility based work	49.3%	54.4%	71.4%	59.5%	15.40***
Supported employment	45.4%	40.0%	23.3%	35.8%	14.97***
Enclave or work crew	26.5%	46.2%	29.2%	31.5%	8.30*
Non-vocational day program	29.9%	8.1%	23.0%	23.0%	11.37**

Note: One person could receive more than one type of vocational service or support
p < .05, ** *p* <.01, *** *p* < .001

Overall, 59.4% of all adults interviewed reported they were paid to work in a center or facility-based program. A total of 35.8% of adults reported engaging in supported employment in community settings (full or part time), 31.5% reported working in enclaves or work crews, and 23.0% reported receiving non-vocational day training and habilitation supports. (Note: The totals add up to more than 100% since a particular individual could receive more than one type of support). Overall, 26.8% of adults worked in supported employment or work crew or enclave settings exclusively, 27.4% worked in both supported employment or work crew/enclave and facility based employment, 29.5% worked but only in a center based program, and 16.3% were reported to only work in a non-vocational day program setting.

There were significant regional differences in the proportion of HCBS recipients who received the vocational supports listed on Table D4. HCBS recipients in rural communities were significantly more likely to participate in facility-based work but were significantly less likely to participate in supported employment. Enclave and work crew support models were significantly more common for adults in GM urban counties than in metro or rural counties whereas center based non-work was significantly less common in the GM urban counties.

The finding that so many of the HCBS participants receive community based employment supports is a bit surprising and merits further investigation. One possible method to verify this finding would be for the items on the screening document that describe current and planned services be further subdivided so that the types of DT&H services each person receives is specifically coded. The form already lists out the service types, it just does not ask the screening team to specify them on the data submitted to the state. This minor change would provide a population-based estimate of the number of recipients of supported employment, community enclaves, competitive employment and so on.

Behavioral Supports

A variety of behavioral supports were provided to HCBS recipients. To understand the use of those supports, the behavioral characteristics of HCBS recipients are described below and are followed by a description of the services used to meet those supports.

Behavioral characteristics of HCBS recipients. Overall the most common behaviors defined as moderate to very severe problems for HCBS recipients were temper outbursts (37.9%), physical aggression (27.6%), verbal or gestural aggression (31.0%), self-injurious behavior (23.3%), and property destruction (21.8%). In addition, slightly more than 10% of all HCBS recipients engaged in inappropriate sexual behavior (defined as the person expressing himself/herself in a sexual manner that is socially unacceptable or offensive or injurious to self or others). Although not common, 4.1% of all HCBS recipients (287 people) have ever broken laws (defined as being arrested and convicted of breaking a law or laws which demonstrates that the person had intent and knowledge). For the sake of comparison, 4.3% of the general U.S. population was arrested for a crime in 1997 (U.S. Bureau of the Census, 1999).

The behavior characteristics identified in the screening document for HCBS participants were most common in children or youth. All but two of the behavioral characteristics declined steadily with age. The exceptions were inappropriate sexual behavior which was as common among HCBS participants between 20 and 39 years as among children and youth, and verbal or gestural aggression which dropped among young adults (ages 20 to 39) but then increased again among persons 40 to 59 years and persons 60+ years.

Table D3: Behavioral Characteristics of Current HCBS Recipients (Screening Document)					
Percent With Moderate To Very Severe Challenging Behavior	**Age in Years**				**Total**
	0 –19	**20-39**	**40-59**	**60+**	
Temper outbursts	52.0	36.6	35.2	31.1	37.9
Aggressive, Verbal/Gestural	34.9	29.4	30.9	32.1	31.0
Aggressive, Physical	44.9	26.5	23.8	17.6	27.6
Injurious to self	32.0	23.0	22.6	13.4	23.3
Property destruction	34.8	21.8	18.5	12.8	21.8
Inappropriate sexual behavior	14.4	14.2	11.2	6.5	12.5
Runs away	21.6	8.9	7.8	3.1	9.9
Eating non-nutritive substances	15.8	4.3	6.2	3.0	6.6
Breaks laws	4.5	5.1	3.4	1.6	4.1
Other	20.9	17.8	18.9	15.2	18.4

N = 7,022

Crisis Supports. Agencies that support individuals receiving HCBS funded services use a variety of strategies to address challenging behavior among the people they support. While more than 60% of HCBS recipients have behavioral supports in their service plans, an unknown but presumably smaller proportion of those individuals engage in behaviors that sometimes exceed the internal expertise of provider agencies. When that happens, several options are available to providers. Table D4 shows information from the provider surveys about specific types of intervention strategies used by residential and vocational provider agencies.

Table D4: Crisis Supports Used by Providers in the Previous 12 Months (Provider survey)						
Type of support in last 12 months (Number of times used in 12 months)	**Vocational**		**Residential**		**Total**	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**
Number of Providers Responding	56		130		186	
Consulted Crisis Team	36	64.3%	34	26.2%	70	37.6%
1 time	31	55.4%	26	20.0%	57	30.6%
2 –30 times	5	8.9%	8	6.2%	13	7.0%
On-site intervention by crisis team	24	43.6%	15	12.3%	39	22.0%
1 time	21	38.2%	11	9.0%	32	18.1%
2-5 times	3	5.4%	4	3.3%	7	4.0%
Person sent to off-site crisis program (1x)	11	19.6%	9	7.4%	20	11.2%
Police called to assist with behavioral crisis	9	16.1%	24	19.0%	33	18.1%
1 time	8	14.3%	16	12.7%	24	13.2%
2 or 3 times	1	1.8%	8	6.4%	9	4.9%
Ambulance/police transport to psychiatric ward	5	8.9%	19	15.4%	24	13.4%
1 time	5	8.9%	18	14.6%	23	12.8%
2 times	0	0.0%	1	0.8%	1	0.6%
Overnight stay in hospital psychiatric ward	9	16.3%	19	15.4%	28	15.7%
1 time	8	14.5%	17	13.8%	25	14.0%
2 – 9 times	1	1.8%	2	1.6%	3	1.7%
Suspension or demission from program	12	21.8%	5	4.1%	17	9.7%
1 time	11	20.0%	4	3.3%	15	8.5%
2 or 3 times	1	1.8%	1	0.8%	2	1.2%
Temporary RTC placement (or METO*)*	8	14.5%	5	4.1%	13	7.4%
1 time	8	14.5%	4	3.3%	12	6.8%
3 times	0	0.0%	1	0.8%	1	0.6%

Note: Number of times refers to the number of times in the last year an agency reported using a crisis support strategy.

In recent years, the supports available to agencies providing services and supports to individuals with mental retardation or related conditions in Minnesota have expanded tremendously. Major efforts have been made to establish regional crisis prevention and intervention services throughout the state. The emphasis of those services is to support families and service providers to prevent the need for invasive and disruptive forms of crisis intervention such as police involvement, ambulance transport to psychiatric units, overnight stays in psychiatric units, suspension or demission from programs and regional treatment center placement. This study provides a brief look at the overall successes and continuing challenges to be overcome by the statewide crisis intervention and prevention system for HCBS recipients.

A variety of forms of extra assistance were used by provider agencies in the previous 12 months. Many of the providers surveyed reported using the new crisis prevention and intervention system at their sites: consulting with regional crisis teams was used by 37.6% of all sites, and on-site intervention by crisis team members was used by 22.0% of all sites. However, despite these efforts, some of the sites continued to use more invasive crisis intervention techniques including sending a person to an off-site crisis program (used by 11.2% of sites), calling police to assist with a behavioral crisis (18.1%), using an ambulance or police to transport a person to a psychiatric ward of a general hospital (13.4%), overnight stays in a hospital psychiatric ward (15.7%), suspension or demission from the program (9.7%) and temporary placement in a regional treatment center (including the Minnesota Extended Treatment Options program at Cambridge) (7.4%).

The proportion of vocational sites that used these strategies was higher than the proportion of residential sites in all cases except for calling the police to assist, and ambulance or police transport to a hospital psychiatric ward. The use of the more invasive interventions was limited to one occasion per year per site in the vast majority of sites. On the other hand, a few sites used consultations with or on-site interventions by crisis team members more frequently. Participating sites reported demitting or suspending 20 people in the previous 12 months.

There were no statistically significant differences across regions in the use of crisis services. The only notable regional finding was that none of the temporary RTC placements were reported from metro area sites. All were either GM urban or rural.

Outcomes of crisis support services. Families of twenty-six individuals who used crisis behavioral supports from a regional crisis team reported whether the initiation of those supports was associated with changes in the use of medications for mood, anxiety or behavior. In 13 cases (50%), the use of medications for behavior increased after crisis behavior services started. In 9 cases (36%), the use of medications for behavior decreased and in 4 cases behavior medications remained the same. Families of 29 other individuals who had received crisis behavioral supports reported that the questions about medications were not applicable or that they didn't know whether medication use had changed. Other outcomes and satisfaction ratings regarding crisis support services can be found in Section C of this report.

Use of controlled behavioral interventions. Another indicator of the success of providers in supporting individuals with challenging behavior is the extent to which providers used procedures that are controlled under Rule 40. Table D7 shows the extent to which physical restraints and other controlled procedures are used in residential and vocational sites supporting HCBS recipients. Overall, 9.3% of all surveyed sites reported planned use of physical restraints in the last year and 11.2% reported the use of physical restraints on an emergency basis (in the absence of an ongoing plan). Other controlled procedures such as time out programs or restitution programs were used on a planned basis in 5.6% of all surveyed sites, and on an emergency basis in 2.2% of surveyed sites.

Table D5: Use of Procedures Controlled by Rule 40 by Providers (Provider Survey)						
Type of support in last 12 months (Number of people at site used for)	**Vocational**		**Residential**		**Total**	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**
Number of Providers Responding	71		166		237	
Planned use of physical restraint	13	18.3%	9	5.4%	22	9.3%
1 person	7	9.9%	8	4.8%	15	6.3%
2 to 10 people	6	8.5%	1	0.6%	7	3.0%
Emergency use of physical restraint	18	25.0%	8	5.1%	26	11.2%
1 person	10	13.9%	6	3.8%	16	6.9%
2 to 20 people	9	12.5%	2	1.3%	11	4.7%
Planned use of other Rule 40 procedure	9	13.0%	4	2.5%	13	5.6%
1 person	6	8.7%	4	2.5%	10	4.4%
2 to 8 people	3	4.3%	0	0.0%	3	1.3%
Emergency use of other Rule 40 procedure	3	4.3%	4	2.5%	5	2.2%
1 person	2	2.9%	3	1.9%	5	2.2%
2 or 3 people	1	1.4$	1	0.6%	2	0.8%

1 person – one person at the site receives the intervention

Planned physical restraints were used by 4.8% of residential sites for one person and in 0.6% of residential sites for 2 or more people. Emergency physical restraints were used by 3.8% of residential sites for one person, and by 1.3% of residential sites for two or more people. Other planned controlled behavioral interventions were used by 2.5% of residential sites for one person at the site. Other emergency controlled behavioral interventions were used by 1.9% of residential sites for one person and by 0.6% of sites for 2 or three people.

A higher proportion of vocational sites reported that they used controlled behavioral interventions for at least one person during the last year (probably because they served more people per site). Overall 18.3% of vocational sites used planned physical restraint procedures for at least one person, 25.0% used emergency physical restraint for at least one person, 13.0% used another type of planned controlled behavioral intervention for at least one person, and 4.3% reported using another type of emergency controlled behavioral intervention for at least one person.

HCBS Waiver Coordinator Perspectives on Crisis Prevention and Intervention. Most of the Waiver Coordinators interviewed reported that their primary intervention and option for crisis supports for people with challenging behavior in HCBS services was proactive prevention. Almost all of the counties used components of the crisis support system funded by the state that uses various regional teams to provide training, one-to-one consultation with agency staff and families and program development. These regional teams also provide crisis respite and crisis “beds” when it is no longer an option for the person to remain in their home. All but two of the counties reported that this system is currently working for them. One reported that they had heard from providers that the prevention and response services were “not good.” Another reported that although preventative services were good, it seemed that when the person needed to be removed from their current setting, the crisis team was unclear about their responsibilities and that a “bed” was not always available when needed. In addition to the regional crisis response services, most counties also reported relying on mental health units for temporary alternative housing and crisis services.

Specialist Services

Specialized therapy. Earlier the proportion of HCBS recipients using various HCBS Specialist Services was reported. Here results from the family surveys comparing the use of various specialized therapies (OT, PT, ST, Counseling) for persons living with their families are compared to the use of those therapies among persons living in other types of settings. Table D8 shows the proportion of HCBS recipients whose family responded to the survey receive various types of specialized therapies.

Overall, 54.6% of families reported that their family member received one or more form of specialized therapy. Therapies received included occupational therapy (41.0%), speech therapy (41.0%), mental health counseling (36%), physical therapy (35%), behavioral therapy (28%) and other therapies (14.0%). Among families whose family member with mental retardation/related condition lived with them, 70.6% reported receiving one or more type of specialized therapy. The most common forms of therapy for those individuals were occupational therapy (62.5%), speech therapy (58.3%) and physical therapy (50.0%). Among families whose family member lived elsewhere, 51.0% reported the family member received specialized therapies. All of the identified types of therapy were used by between 30% and 41% of the family members living elsewhere. The most common forms of therapy for those individuals were mental health counseling (40.8%) and behavior therapy (36.8%). Since people living with their families tended to be younger, the differences in the rates of therapy use may be related to age as much as to where the individuals live. Further analysis would be needed to test whether that is true in this case.

Table D6: Types of Specialized Therapy Services Used (Family Survey)

Specialized Therapy	**In-Home**		**Out of Home**		**Total**	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**
Any type of Specialized Therapy	24	70.6	76	51.0	100	54.6
Occupational Therapy	15	62.5	26	34.2	41	41.0
Speech Therapy	14	58.3	27	35.5	41	41.0
Mental health counseling	5	20.8	31	40.8	36	36.0
Physical Therapy	12	50.0	23	30.3	35	35.0
Behavior Therapy	0	0.0	28	36.8	28	28.0
Other	4	16.7	10	13.2	14	14.0

N = 183

Adaptive equipment. The screening document indicates which HCBS recipients received some form of environmental adaptations or assistive technology, but did not specify exactly which type or types of adaptations or technologies were used. The family surveys asked more specifically what types of adaptation or technology were used by families whose family member lived with them or in some other setting. Overall, 33.3% of families reported that their family member used some form of assistive technology. A total of 21.3% reported that their family member used environmental adaptations or modifications (See Table D7). Of the people who used assistive technology, the devices used included wheelchairs for personal mobility vehicles (68.9% of assistive technology users), adaptive equipment such as feeding equipment, positioning devices, switches or computers (41.0%), augmentative or alternative communication devices (37.7%), prostheses (14.8%) and other assistive technology (21.3%). Persons living with their families were more likely to use these types of devices. A slightly higher proportion of persons living in other settings (e.g., SLS, foster care) used wheelchairs, and a higher proportion of assistive technology users living with their family members used adaptive equipment or other assistive technology.

Table D7: Types of Environmental Adaptations and Assistive Technology Used (Family Survey)						
Type of Adaptation/Technology	**In-Home**		**Out of Home**		**Total**	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**
Types of Assistive Technology	16	47.1%	45	24.6%	61	33.3%
Wheelchair/personal mobility vehicle	10	62.5%	32	71.1%	42	68.9%
Adaptive equipment (e.g., feeding equipment, positioning devices, switches, computer)	8	50.0%	17	37.8%	25	41.0%
Augmentative/ Alternative Communication device	6	37.5%	17	37.8%	23	37.7%
Other assistive technology	5	31.3%	8	17.8%	13	21.3%
Prosthesis	4	25.0%	5	11.1%	9	14.8%
Types of Environmental Adaptations/Modifications	12	35.3%	37	24.8%	49	26.8%
Bathroom modifications (e.g., grab bars, accessible sinks, chairs/lifts for bathing)	7	58.3%	26	70.3%	33	67.3%
Ramps	4	33.3%	24	64.9%	28	57.1%
Vehicle lift/roof extensions	5	41.7%	19	51.4%	24	49.0%
Other	4	33.3%	9	24.3%	13	26.5%
Lifts to assist with transferring	1	8.3%	11	29.7%	12	24.5%
Stairway lift	0	0.0%	2	5.4%	2	4.1%

N = 183

Overall 21.3% of study participants not living with their family members used environmental adaptations or modifications. Among participants who used environmental adaptations, 67.3% had bathroom modifications, 57.1% had ramps installed, 49.0% had a vehicle lift or roof extension, 24% had lifts to assist with transferring, 4.1% had stairway lifts, and 26.5% had other environmental adaptations.

Transportation. Information regarding the use of various forms of transportation is not recorded on the screening document and therefore cannot be discussed for all HCBS recipients. However, the provider and family surveys did include questions about transportation. Table D8 summarizes family reports about who provides transportation needed by sample members. Overall 73.8% of families reported that their family member received some form of transportation service. Transportation services were provided by employment or day programs (for 72.6% of sample members), residential providers (57.0%), family members (44.4%), independent providers (e.g., Metro Mobility, 20.7%), public transportation (21.5%) and other providers (14.8%). Where the HCBS recipient lived with his/her family members, the most common form of transportation was family provided (50.0%). Day programs, public transportation systems and other vendors provided transportation to 25% of family members getting transportation services. For families whose member was living elsewhere, 82.6% reported the family member got transportation services. The most common forms of transportation assistance for those family members were employment providers, residential providers and family members.

Table D8: Who Provides Needed Transportation (Family Survey)

Transportation Provider	In-Home		Out of Home		Total	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**
N receiving Transportation services	12	35.3%	123	82.6%	135	73.8%
Employment Day program	3	25.0%	95	77.2%	98	72.6%
Residential Provider	2	16.7%	75	61.0%	77	57.0%
Family	6	50.0%	54	43.9%	60	44.4%
Independent (e.g., Metro Mobility)	2	16.7%	26	21.1%	28	20.7%
Public Transportation (e.g., Bus)	3	25.0%	26	21.1%	29	21.5%
Other	3	25.0%	17	13.8%	20	14.8%

N = 183

A total of 158 provider sites reported on their use of various modes of transportation (See Table D9). Overall, 49.1% of all travel by HCBS recipients was provided in site vehicles and 24.5% was provided in staff vehicles. Less than 10% of travel was completed using fixed route public transportation, door-to-door public transportation, door-to-door private transportation or other modes of transportation. Vocational agencies were more likely to report travel occurred in site owned vehicles, and residential agencies were more likely to report travel occurred in staff vehicles.

The total number of vehicles assigned to the responding sites was 4.3 for vocational providers and 1.0 for residential sites. The total passenger capacity for vocational vehicles was 40.5 with 33.9 consumers using those vehicles, and was 5.8 for residential site vehicles with 4.1 consumers using those vehicles. No significant differences were found in transportation arrangements for consumers in different regions. However, vocational providers had more agency vehicles per site than residential providers even when the number served was taken into account.

Table D9: Transportation Arrangements used by Providers (Provider Survey)

Arrangement	**Vocational**	**Residential**	**Total**	***F*/Sig.**
<u>Percent of Consumers Using</u>	***N*** = 76	***N*** = 82		
Site vehicle	65.0%	47.9%	49.1%	
Staff vehicle	14.0%	25.3%	24.5%	
Fixed route public transportation	3.7%	8.8%	8.4%	
Door-to-door public transportation (e.g., Metro mobility)	3.5%	8.3%	7.9%	
Other	1.3%	5.9%	5.6%	
Door-to-door private transportation (e.g. taxi)	12.5%	2.4%	3.1%	
<u>Agency Vehicles</u>	***N*** = 56	***N*** = 81		
N vehicles assigned to site	4.3	1.0	3.4	16.43***
Passenger capacity	40.5	5.8	20.0	17.50***
N consumers using	33.9	4.1	16.3	17.86***

*** ***p*** <.001.

Discussion

The supports and services section of this report includes key findings and issues related to the types of supports and services HCBS recipients receive.

Key Findings

- Eighty-three percent of HCBS recipients receive SLS services and most (65.4%) live in corporate foster care settings.

- Overall, 26.8% of adult HCBS recipients interviewed worked in supported employment or work crew or community group work settings exclusively, 27.4% worked in both supported employment, work crew, or community group work and facility based employment, but 29.5% worked but only in a center based program, and 16.3% were reported to receive only non-vocational day program services.
- Although only 15.6% of all HCBS recipients lived with their immediate family, more than 73% of children did.
- HCBS recipients from diverse racial and cultural backgrounds were substantially younger, on average than other HCBS recipients (32.6% were birth through 19 years compared with 14.3% of other HCBS recipients)
- HCBS recipients from diverse racial and cultural backgrounds were less likely to live in corporate foster care settings (55.1% vs. 66.1%) or to live with a live-in foster caregiver (4.4% vs. 7.7%), but more likely to live with their immediate family (27.7% vs. 15.0%) or with a foster family (7.9% vs. 5.5%). Most of these differences are attributable to their younger age.
- HCBS recipients in greater Minnesota urban counties were significantly less likely to be in non-vocational day programs (8.1%).
- More than 60% of HCBS participants were indicated to have had a behavioral support plan. Prevalence for moderate to very severe challenging behaviors included: temper outbursts (37.9%), physical aggression (27.6%), verbal or gestural aggression (31.0%), self-injurious behavior (23.3%), and property destruction (21.8%). Moderate to very severe challenging behaviors were more common among children receiving HCBS than adults.
- Sixty-four percent of vocational sites and 26% of residential sites reported consulting with a regional crisis team in the last 12 months. Twenty percent of vocational sites and 7% of residential sites supported a person who had been sent to an off-site crisis program in the last 12 months.
- During the previous year HCBS residential and vocational providers reported resorting to crisis interventions for one or more service recipients, including calling police to assist with a behavioral crisis (18.1% of sites), using an ambulance or police to transport a person to a psychiatric ward or a general hospital (13.4%), overnight stays in a hospital psychiatric ward (15.7%), suspension or demission from the program (9.7%) and temporary placement in a regional treatment center or the Minnesota Extended Treatment Options program (METO) (7.4%).
- While fewer than 6% of residential sites reported using any type of restriction or punishment controlled by Minnesota’s Rule 40, 18% of vocational sites used planned physical restraints (this difference is likely explained by the fact that vocational sites on average supported larger numbers of people at any given site).
- All but two of the 21 HCBS waiver coordinators interviewed reported that the crisis prevention and intervention system was working well for their counties. One county reported hearing from providers that the prevention and response services were “not good”. One county said that the crisis team was unclear about their responsibilities and that a “bed” was not always available when needed.
- Overall, 54.6% of families reported that their family member received one or more form of specialized therapy. Therapies received included occupational therapy (41.0%), speech therapy (41.0%), mental health counseling (36%), physical therapy (35%), behavioral therapy (28%) and other therapies (14.0%).

- Overall, 33.3% of families reported that their family member used some form of assistive technology. A total of 21.3% reported that their family member used environmental adaptations or modifications.
- Overall, 49.1% of all travel by HCBS recipients was provided in site vehicles and 24.5% was provided in staff vehicles. Less than 10% of travel was completed using fixed route public transportation, door-to-door public transportation, door-to-door private transportation or other modes of transportation.

What's working?

Most adults in the sample reported working in community settings at least part of the time. Overall, 26.8% of adult HCBS recipients interviewed worked in supported employment or group work crews exclusively, 27.4% worked in both supported employment or work crew and facility based employment, 29.5% worked but only in a center based program, and 16.3% were reported to only receive non-vocational day program services.

At the time of Minnesota's last HCBS evaluation in 1991-1992, the state still had over 1,100 people in large state institutions. One barrier to moving those individuals to community homes was the lack of an adequate crisis prevention and intervention system for community services. Since that time, Minnesota has developed a crisis prevention and intervention system using a mix of private and public specialists to assist families and provider agencies in supporting individuals with challenging behavior. This evaluation found that in 1999, providers not only reported access to the crisis prevention and intervention system, almost half (42.3%) of all providers in the study reported using this system in the last 12 months (37.6% reported consulting with regional crisis services, and 22% reported using on-site intervention by crisis team members).

The HCBS program is supporting in the community people who would have once been institutionalized and is doing so without state institutions as a "safety net." In 1999 the extent of challenging behavior among HCBS recipients exceeds that of ICF-MR residents and include people who have significant challenging behaviors including temper outbursts (37.9%), aggressive-verbal/gestural behavior (31%), physical aggression (27.6%), self-injury (23.3%), property destruction (21.8%), inappropriate sexual behavior (12.5%), running away (9.9%), eating non-food substances (6.6%), and breaking laws (4.1%). Over 60% of HCBS recipients now have behavioral support plans, but very few people are reported to present behavior challenges that exceed the expertise within their provider agencies.

Challenges and Concerns

The most common living arrangement for HCBS recipients is a "corporate foster care" home with shift staff (65.4% of all recipients). This is also the most costly type of service. To assure resources to reduce waiting lists and to serve those children who are currently receiving HCBS in their family when they become adults and seek to move to their own homes, service initiatives should focus alternatives to corporate foster care as the predominant mode of support.

Children who receive HCBS and are from racially and ethnically diverse groups are more likely than children who are white to receive out-of-home supported living services. Investigation of this difference may help in better understanding the reasons and perhaps assist with developing outreach strategies to diverse racial and ethnic communities to increase the proportion of people from these communities who receive HCBS.

The majority of HCBS recipients still receive facility based work or non-vocational services (59.5%), in Greater Minnesota rural counties this percentage is significantly higher (71.4%). Additionally, many individuals reported that they wanted to work in a community job but did not. Greater emphasis on increasing supported, community and competitive work/day opportunities is needed.

Although most of the providers surveyed indicated that they could internally meet the behavior support needs of the people they served, 28% used other crisis intervention techniques in the 12 months before the survey. For example, 11.2% sent people to an off-site crisis program, 18.1% called police to assist with a crisis, 13.4% used overnight stays in a hospital psychiatric ward, 9.7% suspended or demitted a person from a program and 7.4% temporarily placed a person in a state operated crisis center, a psychiatric unit or Minnesota Extended Treatment Options (METO).

E. Health Supports

Health Status of HCBS Participants

Individual interview. Adult HCBS participants interviewed reported being sick 0.64 days in the month prior to the interview. There were no differences in the number of sick days a person reported in the previous 30 days by region, provider type, age or "medical status" (as measured on the screening document).

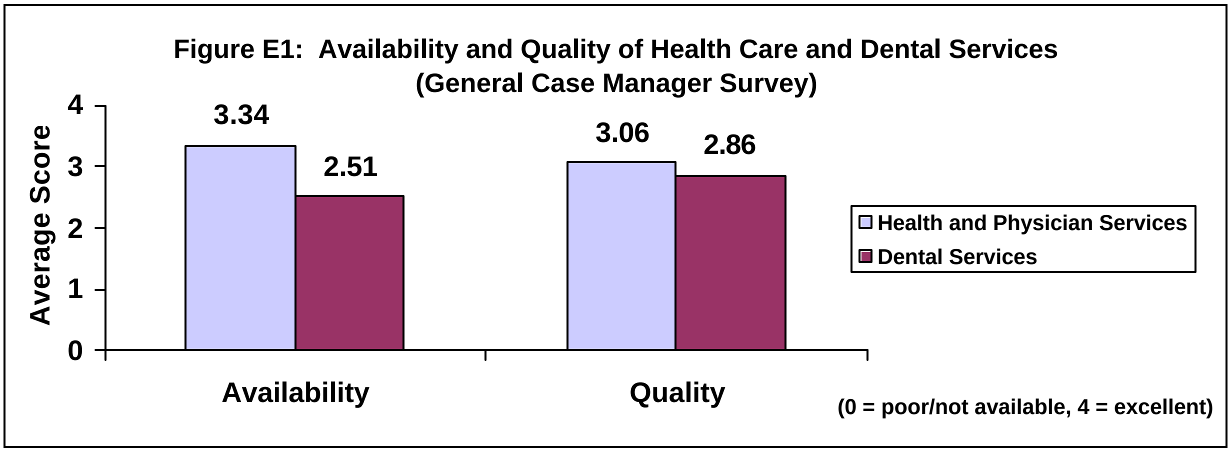
Family perspective. The majority of families surveyed reported that their family member was healthy most of the time. For the 138 families whose family member receives out-of-home supports, 89.9% said their family was healthy most of the time, 8.7% said some of the time and 1.4% said rarely. For 33 families receiving in-home supports, 78.8% reported their family member with MR/RC was healthy most of the time and the rest reported their family member was healthy some of the time (21.2%).

Quality of Health Care for HCBS Recipients

Individual case manager perspective. Case managers reported that the average quality of health care available to Minnesota HCBS recipients was good (Mean 3.06; 0 = poor, 4 = excellent; $N = 449$) with no significant differences between case managers from various regions. The rated quality of health care and physician services for individual HCBS recipients varied by the level of medical supports needed (based on the screening document), and the type of residential setting ($F = 2.59$, $p < .001$) once level of mental retardation, ethnicity, whether the person had special medical needs, whether the person walked, and region were taken into account ($R^2 = 0.91$, Adjusted $R^2 = .055$, $N = 449$). Specifically, case managers reported that people with more medical support needs received higher quality health services. Although overall tests of differences by type of home were significant, follow-up tests did not specify which type of home had better outcomes.

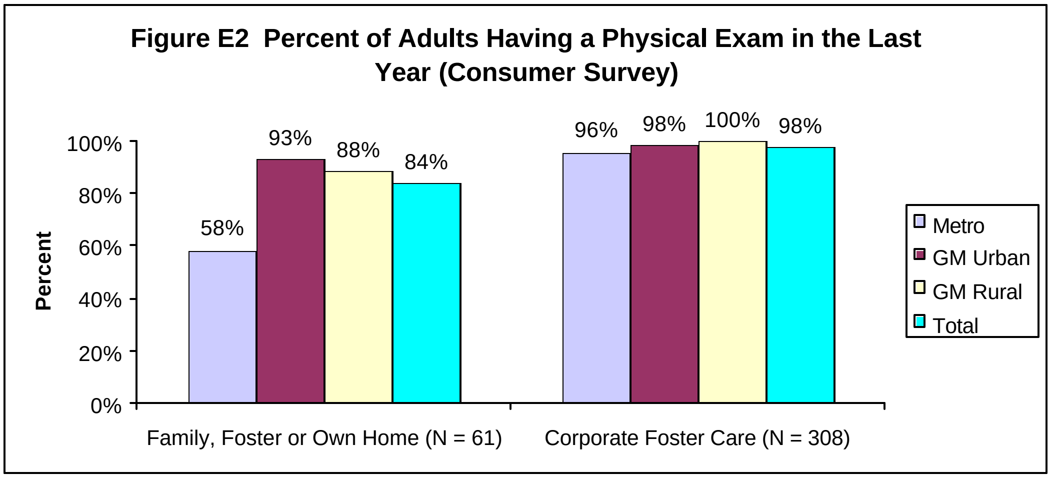
Case manager assessments of the quality of dental care for individual sample members averaged between fair and good (Mean = 2.86; $N = 446$). Case manager assessments of the quality of dental care were lower for people living with a family member, lower for people who used a wheelchair, higher for people who are white, and higher for people who needed on-call medical services ($R^2 = .136$, Adjusted $R^2 = .102$, $N = 446$). Quality of dental care did not vary by age, level of mental retardation, level of challenging behavior, or region.

Access and quality of medical services (General Case Manager). Fifty-two randomly selected case managers rated the quality and availability of health care or physician services on the general case manager survey. Overall, case managers said health and physician services were easier to access than dental services (3.34 vs. 2.51; See Figure E1). Their ratings of quality averaged 3.06 for health and physician services and 2.86 for dental services. They reported that dental services were significantly less available in GM urban counties (Mean = 1.73) than in metro or GM rural counties (Means = 2.83, 2.59; $F = 4.42$, $p < .05$).



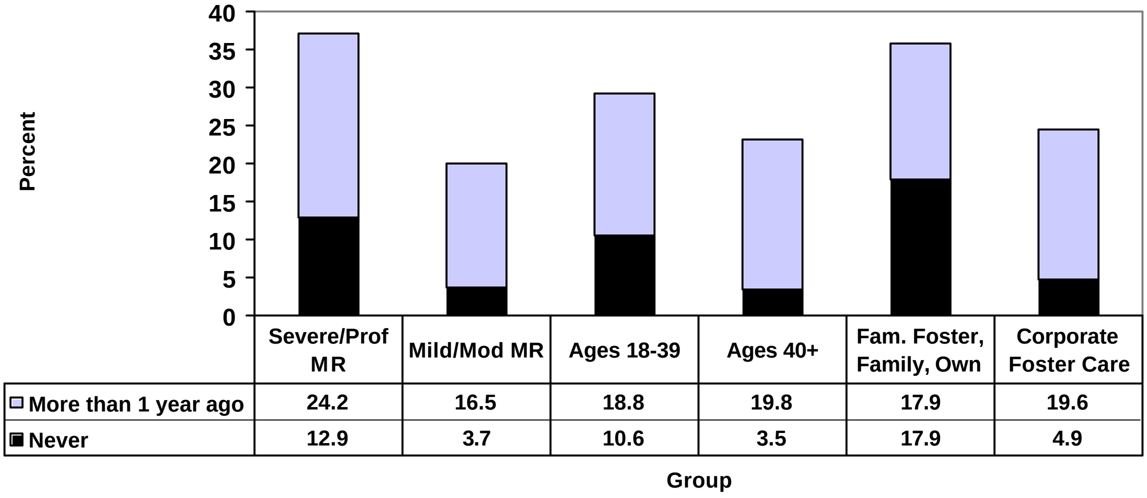
Access To Selected Medical Services

Physical exams. Overall, 91.7% of adults had had a physical exam within the past year. Several factors were tested to see if there were differences in medical and dental services based on region, type of residence, whether the person was white or from racially or ethnically diverse groups, age, level of mental retardation, whether the person walked or used a wheelchair and whether the person had specialized medical needs. Statistical analysis revealed a significant difference in the time of the last physical exam ($F = 6.51$, $p < .001$; See Figure E2). Factors explaining variability in the timing of the most recent physical included: where the person lives, region of the state, interaction of home type and region, and age. Adults who were older were more likely to have had a physical exam while people in the metro area were less likely to have had an exam. People living in metro counties in corporate foster care settings were more likely than other people in metro counties to have had a physical exam. Level of challenging behavior, level of mental retardation, race, and the number of sick days did not predict the timing of the most recent physical exam.



Gynecological exams. Overall, 73.7% of adult women sampled had received a gynecological exam in the past year (7.0% had never had one). Timing of the last gynecological exams varied by age, level of mental retardation and type of residence (See Figure E3). Specifically, older women with less severe mental retardation living in corporate foster care settings were more likely to have had a gynecological exam in the last year. Timing did not vary by race, number of sick days, level of challenging behavior, or region ($N = 137$ $R^2 = .129$; Adjusted $R^2 = .073$).

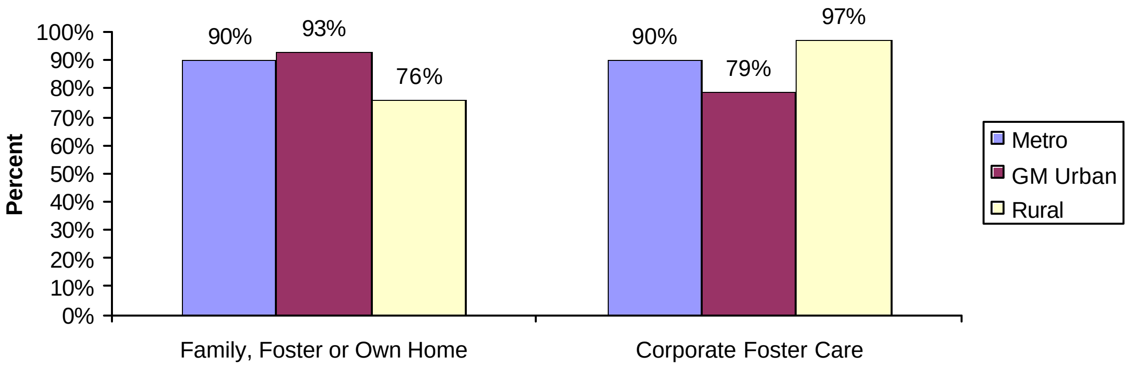
Figure E3: Timing of Last Exam for Adult Women Who had not had an OB/GYN Exam in the last 12 months: Consumer Survey



	Severe/Prof MR	Mild/Mod MR	Ages 18-39	Ages 40+	Fam. Foster, Family, Own	Corporate Foster Care
□ More than 1 year ago	24.2	16.5	18.8	19.8	17.9	19.6
■ Never	12.9	3.7	10.6	3.5	17.9	4.9

Dental exams. Overall 89.4% of adults sampled had been to the dentist within the previous 6 months. The percent of HCBS recipients who had seen a dentist in the previous six months varied significantly by level of mental retardation, seriousness of challenging behavior, and the interaction between region and type of residential setting. Specifically, people with less severe mental retardation and less challenging behavior were more likely to have seen the dentist in the prior six months. Furthermore, there were regional differences depending on provider type (See Figure E4). In the metro area, type of residence did not matter. However, HCBS recipients in GM urban counties were more likely to have seen the dentist in the previous six months if they were living with their families, a foster family or on their own. HCBS recipients in the rural areas were much more likely to have seen the dentist if they were in a corporate foster care setting. Overall, 7% of the difference in access to dental services could be explained by these factors. The proportion of individuals who saw a dentist recently did not vary by race or age (*N*=303 R^2 = .129; Adjusted R^2 = .073).

Figure E4: Percent of Adults Seeing a Dentist in the Previous Six Months by Region and Type of Residences: Consumer Interview



Medication Use

Consumer Interview. Overall, 43% of adult HCBS recipients who were interviewed for this evaluation reported receiving medication for mood, anxiety or behavior problems, 29% for epilepsy or seizures, and 56% for some other health problem. Of the individuals taking medications for epilepsy or seizures, 9.3% had no history or evidence of seizures and 21.5% had a history of seizures but had not had any recently. Presumably some of those individuals were taking seizure medication for behavioral or other reasons besides seizure activity.

Whether a person received medication for mood, anxiety or behavior was not associated with type of residence, age, ability to walk, race or region but variability was explained by level of mental retardation and level of challenging behavior. People with less severe mental retardation and/or more severe challenging behavior were more likely to be taking medication for mood, anxiety or challenging behavior. Overall, 17% of the differences in the use of medication for mood, anxiety or behavior could be explained by level of challenging behavior and level of mental retardation ($R^2 = .196$, Adjusted $R^2 = .173$, $N = 362$).

Provider Survey. When providers were asked about the types of medications people took, overall, 33.9% of the individuals supported by the 235 reporting providers were taking psychotropic medications. There were no differences in the proportion of individuals taking psychotropic medication between residential and vocational providers, nor were there differences by region, number of individuals served or intensity of consumer support needs. The proportion of individuals taking psychotropic medications in this study was higher than the 22.8% of all persons in ICF-MR settings in Minnesota in the 1992 On-Line Survey Certification and Reporting System (Larson & Lakin, 1995).

Discussion

The evaluation gathered and reviewed information regarding the health status of HCBS recipients and access to various health care services.

Key findings

- Overall, 98% of adults living in corporate foster care settings, and 84% of adults living in family foster care, with their families or on their own had had a physical exam in the last year.
- Overall, 89% of adults had been to the dentist within the previous 6 months. People with less severe mental retardation and less challenging behavior were more likely to have been to the dentist.
- Overall, 74% of adult women had received a gynecological exam in the past year. Older women, women with mild or moderate mental retardation, and women living in corporate foster care settings were more likely to have had a gynecological exam in the last year.
- Case managers reported the overall quality of health care supports for individuals in the HCBS program was good. They reported that people with special medical needs experienced higher quality health care supports.
- Overall, 43% of adults interviewed reported receiving medication for mood, anxiety or behavior problems. Providers reported that 34% of all individuals they supported were receiving psychotropic medications.
- Case managers reported that the overall quality of dental care was between fair and good. Case manager assessments of quality of dental care were lower for people living with family members, lower for non-ambulatory people, higher for people who were white, and higher for people who needed more intense medical supervision.

- Case managers reported that dental care was more difficult to access than health care and physician services. They also reported that dental services were less available to persons in Greater Minnesota urban counties than in the other county types.
- Families whose family member with MR/RC lived with them were less likely to report that their family member was healthy than families whose member lived elsewhere (79% vs. 90%).

What's Working?

The majority of families reported that their family member was usually healthy and case managers reported that the overall quality of health care available to HCBS recipients was above average (mean 3.06; 0=poor, 4=excellent). Almost 92% of adult HCBS recipients had a physical exam within the past year, and 89% had been to the dentist. As a point of comparison the National Health Interview Survey, Disability Supplement found that a total of 60% of all non-institutionalized people with mental retardation or developmental disabilities in the U.S. had seen a general practitioner in the previous 12 months, 36% had seen a specialist physician and 89.7% had seen one or the other or both.

Challenges and Concerns

Across indicators, health care access and quality were reported to be better for HCBS participants living in corporate foster care settings than those living in other types of settings. Access to dental care was reported to be worse for people with severe or profound mental retardation, people with more serious challenging behaviors, and people in urban counties of Greater Minnesota. The quality of dental care was reported to be better for people in corporate foster care settings, people who were ambulatory, people who were white, and people who required more medical supervision. Quality of medical care was reported to be better for individuals with special medical needs. Efforts should be made to more fully evaluate access to medical and dental care (including gynecological care) across the state, especially for persons with more severe intellectual and behavioral disabilities. Access to gynecological care for younger women, women with severe or profound mental retardation, and women not living in corporate foster care settings may also need improvement.

The final concern is the high use of medications for mood, anxiety or behavior for persons in HCBS settings. Both providers and individual consumers (and their proxies) reported high rates of psychotropic medication use (33% and 43% respectively). In 1999, ICF-MR providers reported 34.4% of 2,945 Minnesotans living in ICF-MR settings received "drugs to control behavior" (Karon & Beutel, 2000). In the National Health Interview Survey Supplement on Disability sample, 10.5% of people with MR/DD were taking prescription medication for an ongoing mental or emotional condition. Since the screening document does not ask about the use of psychotropic medication, however, further analysis is beyond the scope of this study. Further research is required to examine changes in patterns of medication use over time. Also an effort to better understand the specific types and classes of mood altering drugs that are being used and for what reason they are prescribed. It is important to determine whether the mood altering drugs (psychotropic medications) that are being prescribed to HCBS recipients today have high rates of extra-pyramidal side effects (e.g., tardive dyskenisia) or whether they are the newer anti-depressant, anti-anxiety or anti-psychotic medications whose side effect profiles are much less severe. Further examination of this issue should also consider the extent to which psychotropic medications are being used without a mental health diagnosis, and to what extent they are prescribed by general practitioners as opposed to psychiatrists, neurologists or other specialists.

F. Service Coordination/Case Management

This evaluation obtained information regarding service coordination (case management) from a number of different perspectives. Individual consumers, their families and their staff were asked a variety of questions about the quality of their case management services. Provider organizations and stakeholder groups were asked their opinions about case management services. Additionally, case managers themselves were asked to describe the services they provide to individual HCBS recipients.

Case Manager Access and Support for Individuals

Access to case managers. Self-responding HCBS recipients reported whether they could talk to their case managers when they wanted to, if it was easy to contact their case manager and if their case manager helped them with their needs (See Table F1).

Table F1: Case Manager Access and Support (Consumer Interviews)

Case Manager Issue	Yes	Sometimes/ Somewhat	No	*N*
I can talk to my CM whenever I want to	75%	13%	12%	222
Not important to be able to talk to my CM	55%	16%	29%	31
Somewhat important to be able to talk to my CM	77%	18%	5%	66
Really important to be able to talk to my CM	82%	11%	7%	105
It is important to be able to talk to my CM	50%	33%	17%	216
CM helps me with my needs	85%	-	15%	210
It is easy to contact case manager	67%	-	33%	208

Seventy-six percent of interviewed HCBS recipients said they could talk to their case manager whenever they wanted to, 18% said they could sometimes talk to their case manager when they wanted to and 9 % said they could not talk to their case manager when they wanted to. Of these individuals who said it was really important for them to be able to talk to their case manager when they wanted to, 82% reported that they were able to do so. Seven percent of the people who said it was really important to them were not able to talk to their case manager when they wanted to. Sixty-seven percent of respondents reported that it was easy to contact their case manager, 33% said it was not. Eighty-five percent of respondents said their case manager helps them with their needs; 15% said they did not.

Individual planning meetings. Eighty-seven percent of HCBS recipients reported having a planning meeting within the last year and 97% of those who had meetings reported that they went to their meetings at least sometimes (see Table F2). Of those individuals who said it was really important or somewhat to them to attend their own meetings, 3% reported that they did not attend their meetings. Individuals living with their family, in their own home, or in a foster family home were significantly more likely to report that they had had a planning meeting in the last year than were individuals in corporate foster care settings (97.9% vs. 85.0%; $X^2 = 5.75$, $p < .05$).

Table F2 Individual Planning Meetings (Consumer Survey)

Planning meeting issue	Yes		Sometimes/ Maybe		No		Total
	N	%	*N*	%	*N*	%	*N*
Had a planning meeting this year	207	87	0	0	30	13	237
Have an advocate or guardian to help make decisions at meetings	182	81	9	4	35	16	226
I chose the things in my plan	83	44	70	37	34	18	187
I picked who came to my meeting	41	21	6	34	86	45	193
I went to my planning meeting							
Attending my meeting is really important to me	137	91	8	5	5	3	150
Attending my meeting is somewhat important to me	32	87	4	11	1	3	37
Attending my meeting is not important to me	8	80	2	20	0	0	10
Total	177	90	14	7	6	3	197

Eighty-one percent of those interviewed reported that an advocate or guardian helped them make decisions at their meetings. Fifty-five percent of the individuals reported independently choosing the people who attended their meetings, (21%) or helping to pick (34%) the people who came to their meetings. Forty-four percent of respondents reported that they chose the things they worked on in their individual plans and 37% reported that they sometimes did. Eighteen percent of self-reported sample members reported that they did not participate in choosing the things that were including in their individualized plan.

Satisfaction with Case Management

Table F3 summarizes family reports of their experiences with various aspects of case management services. Using 3-point scale (3 = most of the time, 2 = some of the time, and 1 = rarely) families reported that most of the time case managers provided culturally appropriate service (2.93), delivered satisfactory outcomes (2.86), and were responsive to the family needs (2.78). Families were less satisfied that their case managers knew about availability of services (2.67), supported what the family wanted or needed (2.65) and provided information in a manner that was easy to understand (2.58).

Table F3: Family Satisfaction with Case Management Services (Family Survey)

	White		Non-White		Total		
Service Component	***N***	**Mean**	***N***	**Mean**	***N***	**Mean**	***F*/Sig.**
CM provides services that are culturally appropriate	159	2.95	15	2.77	174	2.93	10.43**
Family is satisfied with CM services/supports	161	2.87	15	2.70	176	2.86	3.42
CM is responsive to family needs	158	2.79	12	2.67	170	2.78	.99
Overall family satisfaction with CM	163	2.75	15	2.60	178	2.71	.12
CM knows about availability of services	151	2.68	13	2.58	164	2.67	.45
CM supports what family wants	157	2.66	15	2.53	172	2.65	1.02
Information from CM easy to access and understand	157	2.58	13	2.62	170	2.58	.05

3= most of the time, 2= some of the time and 1= rarely **p* <.05; ***p* <.01

Importantly, families of HCBS recipients who were non-white reported significantly less satisfaction with the extent to which case management services were delivered in a culturally appropriate manner. However, only 15 (8.6%) of the family satisfaction responses were from family members of non-white sample members.

Service Provider Satisfaction with Case Management

Table F4 summarizes provider satisfaction with service coordination. Vocational and residential providers reported that case management services were “good” overall (3.02 on a 4-point scale) with no significant differences among county types. With respect to satisfaction with resolution of conflicts (e.g. issues with case managers, new service development, ISP development or modification) residential providers were less satisfied than were vocational providers.

Table F4: Provider Satisfaction with Service Coordination (Provider Survey)

	Vocational				Residential				Total					
Service Coordination Issue	**Metro**	**GM Urban**	**GM Rural**	**Total**	**Metro**	**GM Urban**	**GM Rural**	**Total**	**Metro**	**GM Urban**	**GM Rural**	**Total**	**Overall *F*/Sig.**	**Diff**
Overall quality of case management services	2.85	3.17	3.1	3.01	2.95	2.96	3.17	3.02	2.92	3.03	3.15	3.02	1.44	
Satisfaction with how conflict with the county is resolved	3.04	3.14	2.95	3.04*	2.78	2.7	3.05	2.84*	2.87	2.84	3.02	2.91	2.28*	P
Provider agency is supportive of creative ideas	3.60	3.33	3.32	3.44	3.31	3.35	3.60	3.41	3.4	3.35	3.51	3.42	1.85	
Parents are supportive of creative ideas	3.31	3.12	3.18	3.22	3.01	3.06	3.29	3.11	3.11	3.08	3.26	3.14	2.32*	I
Case manager is supportive of creative ideas	3.11	3.12	3.09	3.11	2.96	3.06	3.27	3.08	3.01	3.08	3.22	3.09	1.54	

1 = poor, 4 = excellent, **N** =259 *p < .05 Diff: P = Provider, I = Interaction between provider type and region.

Providers rated themselves considerably higher than case managers (3.42 and 3.09, respectively) at supporting and implementing creative or innovative ideas. They rated parents and case managers similarly in being “good” at supporting creative and innovative ideas (3.14 and 3.09, respectively).

Case Management Services

Case managers of sample members were asked to report the number of visits they made to the recipients home and day program within the last six months and the number of other types of contact (e.g., phone calls and letter writing) they had with the individual HCBS recipient within the last six months (See Table F5). Of 459 case managers, 72 (15.7%) had not visited the home within the past six months; 189 (41.2%) had visited the person in their home one time; 100 (21.8%) had visited the person within their home twice; 53 (11.5%) had visited the person within their home three times and 98 (19.4)% had visited the person in their home more than three times. The overwhelming majority of case management visits (86%) last from 30 minutes to more than an hour. Of all reported visits, 44.7% (191) lasted an average of more than an hour; 41.5% (177) lasted 30-60 minutes, 9.6% (41) lasted 15-30 minutes and 4.2% (18) lasted 15 minutes or less.

Table F5: Number of Case Manager Visits and Contacts Within the Last 6 Months

	Visits to the Home		Contacts		Visits to the Day Program	
***N* of Visits/ Contacts**	***N***	**%**	***N***	**%**	***N***	**%**
0	72	15.7	44	9.9	17	7
1	189	41.2	86	19.4	72	29.6
2	100	21.8	92	20.7	64	26.3
3	53	11.5	70	15.7	38	15.6
4	25	5.4	44	9.9	20	8.2
5	4	0.9	22	4.9	5	2.1
6	8	1.7	36	8.2	12	4.9
7-9	1	0.2	17	3.9	2	0.8
10-19	7	1.5	22	4.9	8	3.3
20-60+	0	0	11	2.4	5	2.0
Total	459	99.9	444	99.9	243	99.8

Numbers total to less than 100 due to rounding

Case managers were asked to describe the types of services they provided to the individual HCBS recipient within the last 12 months (See Table F6). Almost all of the case managers surveyed had participated in the development of the HCBS recipient’s individual support plan and that they had assessed the person’s progress in meeting their goals.

Table F6: Percent of Case Management Services Provided Within Last 12 Months: Differences By Region and Race/Ethnicity (Individual Case Manager Survey)

	Region				Ethnicity			
Service provided	**Metro *N*=192**	**GM Urban *N*=86**	**GM Rural *N*=181**	***F*/Sig**	**White *N*=424**	**Non-White *N*=36**	***F*/Sig**	**Total**
Participated in ISP development	93%	94%	95%	.48	94%	91%	.40	94%
Assessed person's progress in meeting goals	85%	89%	87%	.40	86%	89%	.18	86%
Supported family, staff, adm. to meet needs	77%	83%	79%	.55	79%	81%	.05	79%
Determined eligibility	75%	68%	83%	4.36*	77%	71%	.64	77%
Reviewed health, safety or person in context	72%	68%	80%	2.51	75%	63%	2.57	74%
ID problems with staff, family, other recipients	69%	59%	59%	2.57	63%	60%	.13	63%
Developed a HCBS budget	38%	47%	78%	36.13**	56%	49%	.73	56%
Presented options for new services or providers	58%	49%	44%	3.70*	50%	58%	.97	50%
Nonscheduled visit to home	48%	41%	51%	1.12	48%	51%	.16	48%
Nonscheduled visits to day program	40%	43%	64%	4.56**	51%	34%	3.76	50%
Identified responses to problems	48%	45%	38%	2.27	43%	46%	.08	43%
Assisted with forms/paperwork	45%	41%	41%	.31	42%	56%	2.56	43%
Participated in and/or arranged PCP meeting	34%	43%	45%	2.72	40%	36%	24	40%
Arranged for new/different services	37%	36%	29%	1.20	33%	43%	1.42	34%
Took action to protect rights	37%	26%	26%	3.26*	31%	31%	.01	31%
Received and reviewed VA reports	36%	15%	21%	8.73**	36%	31%	.54	26%
Arranged diagnostic essentials	27%	20%	21%	1.41	22%	37%	40*	23%
Responded to issue in VA on incident report	31%	17%	13%	9.89**	21%	26%	.44	21%
Assisted with crisis	23%	24%	12%	4.80**	18%	29%	2.4	19%
Visited potential new providers with recipient	20%	20%	16%	5.63	17%	26%	1.51	18%
Number of contacts within last 6 months	1.65	1.72	1.82	3.09*	3.76	6.73	8.52**	3.99

p < .05, ** *p*<.01, *** *p*<.001;

More than half of the case managers had completed the following tasks: a) supported the family, staff or agency administration how to meet the person's goals, b) determined eligibility for HCBS services, c) reviewed health, safety of the individual, d) identified problems with families, staff and other recipients, and e) developed a HCBS budget. Less than half of the case managers reported that they a) presented options for new services or new providers to individual recipients and their families, b) participated in a nonscheduled visit to the person's home, c) identified responses to identified problems, d) assisted in completed forms and paperwork for the person served, e) participated in a person centered planning meeting, f) arranged for new or different services, g) took action to protect the rights of the individual served, h) received and reviewed a Vulnerable Adult report, i) arranged for diagnostic reports, j) responded to an issue in a Vulnerable Adult or incident report, k) assisted with a crisis, and l) visited with a potential new provider with the recipient. Although 63% of case managers reported that they assisted in identifying problems with staff, family and other recipients, only 43% reported that they assisted with solving these problems. Almost all of case managers (93%) participated in developing an individual support plan for sample members and 40% reported having participated in or arranging a person centered planning meeting for sample members.

There were several differences in the types of services case managers delivered by county type, race and ethnicity and residential setting type. Case managers in rural area counties were more likely to have assisted in determining eligibility and developing a HCBS budget than were case managers in Greater Minnesota urban or metro counties. Greater Minnesota rural case managers were also more likely to have made a nonscheduled visit to a day program to see a person they served. They also made more frequent contacts (e.g. phone, letters, meeting attendance) with the individuals they served then did case managers in other county types. Case managers in the metro area were significantly more likely to have presented families and individuals with options for new services (58% vs. 47%). They were also more likely to report having taken action to protect the rights of a person they served (33.7% vs. 26%), and to have received, reviewed and responded to vulnerable adult reports (36% vs. 19%). Case managers in Metro and GM urban counties were significantly more likely to have assisted with a crisis situation then were case managers in the rural counties.

Only two significant differences were noted in comparing white and non-white service recipients. Case managers were significantly more likely to have arranged for diagnostic assessments and to have made individual contact with recipients who were non-white.

Case management services provided in the last twelve months also varied for individuals living in different types of settings (See Table F6). For individuals in corporate foster care, case managers were significantly more likely to have reviewed health and safety issues related to the person in the context of their environment. For individuals living in their family home, case managers were significantly more likely have developed a HCBS budget, presented options for new services or arranged for new service providers, assisted with completing forms or required paperwork, and assisted in a crisis within the past twelve months. Case managers were more likely to have made contacts with individuals in foster family settings than those living in other residential settings.

Table F7: Percent of Case Management Services Provided Within Last 12 Months: Differences by Residential Setting (Individual Case Manager Survey)

	Residential Setting					
Service provided	**Foster Family (*N*=23)**	**Corp. Foster (*N*=346)**	**Own home (*N*=27)**	**Family home (*N*=63)**	***F*/Sig**	**Total**
Participated in ISP development	100	94	92	94	.55	94
Assessed person's progress in meeting goals	87	86	88	87	.06	86
Supported family, staff or admin. on how to meet needs	74	79	85	78	.31	79
Determined eligibility	96	75	73	82	2.17	77
Reviewed health, safety or individual within context	70	78	73	57	3.86*	74
Identified problems with staff, family, other recipients	65	64	65	57	.32	63
Developed a HCBS budget	61	50	65	79	6.63**	56
Presented options for new services or providers	52	47	42	75	6.02**	50
Nonscheduled visit to home	35	50	50	39	1.43	48
Identified responses to problems	35	39	42	48	.69	43
Assisted with forms/paperwork	17	40	58	63	6.86**	43
Participated in PCP meeting	35	39	42	48	.69	40
Arranged for new/different services	22	31	31	53	4.46**	34
Took action to protect rights	30	32	31	25	.44	31
Received and reviewed VA reports	22	27	27	21	.40	26
Arranged diagnostic essentials	13	22	23	34	2.04	23
Responded to issue in VA on incident report	9	24	23	10	2.89*	21
Assisted with crisis	0	19	15	28	2.99*	19
Visited potential new providers with recipient	17	17	12	30	2.25	18
Visited day program non scheduled	57	50	65	40	1.71	50
Number contacts within last 6 months	2.7	1.7	1.4	1.6	4.14**	1.8

$p < .05$, ** $p<.01$

Table F7 presents information about caseloads in terms of the number and characteristics of individuals, types of services or supports received and whether case managers are aware of a process within their county to determine case manager caseload size. Over half of case managers served individuals with psychiatric disabilities (53%); 41% served individuals with “other” disabilities. Eighteen percent served individuals who were elderly and 18% were case mangers for children in the child protection system. There were significant regional differences in caseload characteristics. Metro area case managers were more likely have a caseload of only people with developmental disabilities (90%) than were GM urban (82%) or rural case managers (50%). On average, 38% of their caseload received HCBS services, 27% had severe or profound mental retardation, 33 % were individuals under age 21, and 30% lived with family members.

Table F8: Caseload Characteristics (General Case Manager)

	Total			Metro		GM Urban		Rural		*F*/Sig
Caseload (CL) Characteristics	***N***	**Mean**	**Range**	**Mean**	**Range**	**Mean**	**Range**	**Mean**	**Range**	
Only MR/RC	49	67		90		82		50		5.25*
Includes mental health	17	53		50		83		33		1.89
Includes other disabilities	17	41		50		33		44		0.11
Includes elderly (non-MR/RC)	17	18		0		17		22		0.24
Includes child protection cases	17	18		50		33		0		2.43
% on HCBS	48	38	(0-100)	38	(3-100)	43	(0-100)	34	(10-00)	0.30
% under age 21	48	33	(0-100)	39		29		27		0.53
% living w/family	47	30	(0-100)	40		30		20		1.87
% w/severe or profound MR	48	27	(0-100)	31		14		31		2.15
County process to determine CL size	51	39		43		55		24		1.51
Number HCBS recipients	48	20	(0-57)	21	(1-57)	21	(0-45)	18	(5-51)	0.17
Number MR/RC other	47	20	(0-51)	23	(2-45)	17	(0-51)	19	(0-37)	0.88
Number ICF-MR recipients	49	6	(0-30)	6	(0-22)	3	(0-9)	9	(0-30)	2.58
Number SILS recipients	49	4	(0-24)	2	(0-7)	6	(0-24)	4	(0-10)	2.95
Number non-MR/RC	40	6	(0-62)	2	(0-27)	16	(0-62)	4	(0-32)	3.53*
Number people on CL	49	53	(22-87)	51	(22-75)	56	(43-89)	53	(33-85)	0.52

* $p < .05$, ** $p<.01$, *** $p<.001$; scale 1=yes, 2=no

Case managers reported average caseloads of 52.9 people, with a range of 22 to 89 people. The average caseload included 20 HCBS recipients, 6 ICF-MR recipients, 3.7 people who receive SILS, and 5.9 individuals who did not mental retardation or related conditions. The only differences by region was that case managers in GM urban counties reported more individuals without MR/RC on their caseloads. Only 51% of the case managers surveyed reported that they perceived their county had a process in place to determine case manager caseload size.

Case Manager Characteristics

Tables F8 and F9 present findings with respect to the experience and education of case managers. On average, case managers had been a developmental disabilities case manager for 100 months (range 1-365 months) and had served individuals receiving HCBS funded supports for 76 months (range 1-180 months). Most case managers (56) held other MR/RC positions prior to becoming case managers, which they had held for 1 to 31 years. About 62% of case managers had a professional license (typically in social work) and 2% were currently in school.

Table F9: Case Manager Characteristics (General Case Manager)							
	Metro		GM Urban		GM Rural		
Characteristic	Mean	Range	Mean	Range	Mean	Range	F/Sig.
Total months as MR/RC CM	116.0	(12-365)	88.0	(12-264)	84.0	(1-240)	0.75
Total months as HCBS CM	76.0	(2-180)	74.0	(12-141)	78.0	(1-168)	0.02
Held other MR/RC position	48%		82%		50%		1.95
Years in other MR/RC position	7.5	(1-31)	7.9	(1-18)	6.0	(1-16)	0.17
CM hold professional license	57%		73%		56%		0.46

*p <.05; N=52;

All case managers in the sample had at least a Bachelor's degree and 24% held a Master's degree (See Table F9). Most held degrees in social work (55%) or psychology (20%). Ten percent of case managers reported that their college education was "very useful" in preparing them to be a case manager; 50% reported their education as "useful." Forty percent reported that their education had "limited usefulness" (34%) or was "not at all useful" (6%) in preparing them as case managers.

Table F10: General Case Manager Education by Region								
	Metro		GM Urban		Rural		Total	
Level and Type of Education	N	%	N	%	N	%	N	%
Educational degree								
BA/BSW	15	65%	7	64%	16	100%	38	76%
MA/MSW	8	35%	4	36%	0	0%	12	24%
Educational field								
Social work	15	65%	5	46%	7	47%	27	55%
Psychology	2	9%	4	36%	4	27%	10	20%
Other	3	13%	1	9%	4	26%	8	16%
More than one	3	13%	1	9%			4	8%
College prepared for MR/RC								
Very useful	4	18%			1	6%	5	10%
Useful	11	50%	9	82%	5	29%	25	50%
Limited usefulness	6	27%	2	18%	9	53%	17	34%
Not at all useful	1	5%			2	12%	3	6%

*p <.05; **p <.01; N=52

Discussion

The service coordinator/case management component of the evaluation gathered and analyzed in formation on case management services to identify aspects of their quality and availability. The roles and functions that case managers play in the lives of HCBS recipients were also studied.

Key Findings.

- Eighty-four percent of HCBS recipients had at least one visit from their case manager in their home in the previous 6 months and 93% had at least one visit in their work setting.
- About half of HCBS recipients had one or more nonscheduled visits from their case manager to their home (48%) or to their day program (50%) in the last six months.

- Overall, 75% of consumers said they could talk to their case manager whenever they wanted to, 85% said their case manager helps them with their needs and 67% said it is easy to contact their case manager.
- Eighty-seven percent of consumers reported they had a planning meeting in the last year. Of those, 90% attended the meeting, 44% reported choosing the things in their plan, and 21% chose who came to the meeting.
- Almost all of the case managers had developed an ISP for the recipient in the last 12 months (94%) and assessed the person's progress (86%). About three fourths had supported family, staff and administrators to meet needs (79%), had determined eligibility for services (77%), or had reviewed the health or safety of the person in context (74%).
- Case managers reported average caseloads of 53 people, with a range of 22 to 89 people. The average caseload included HCBS recipients, ICF-MR recipients, people who receive SILS, and individuals who did not have mental retardation or related conditions.
- The typical case manager had supported individuals with MR/RC for 100 months, and supported persons receiving HCBS funded supports for 76 months.
- Families reported that most of the time case managers provided culturally appropriate service (2.93 out of 3), delivered satisfactory outcomes (2.86), and were responsive to the family needs (2.78). However, families of HCBS recipients who were non-white reported significantly less satisfaction with the extent to which case management services were delivered in a culturally appropriate manner.
- Families were less satisfied that their case managers knew about the availability of services, supported what the family wanted or needed or provided information in a manner that was easy to understand.
- While both residential and vocational providers rated case management services as good overall, residential providers were significantly less satisfied than vocational providers with conflict resolution involving case managers.
- Case managers in rural counties were more likely to have assisted in determining eligibility, developed a HCBS budget, made a nonscheduled visit to a day program, and made more frequent contacts (e.g. phone, letters, meeting attendance) than case managers from other types of counties.
- Case managers in metro counties were significantly more likely to have presented families and individuals with options for new services, taken action to protect the rights of a person they served, and to have received, reviewed and responded to vulnerable adult reports.
- Case managers in metro and greater Minnesota urban counties were significantly more likely to have assisted with a crisis situation than case managers in the rural counties.
- Case managers were more likely to have arranged diagnostic assessments and to have made individual contact with HCBS recipients from diverse racial or ethnic groups than with other HCBS recipients.
- Case managers were more likely have developed a HCBS budget, presented options for new services or arranged for new service providers, assisted with completing forms or required paperwork, and assisted in a crisis for individuals living in their family homes.
- Metro area case managers were more likely to have a caseload of only people with developmental disabilities (90%) than were case managers of urban counties of greater Minnesota (82%) or of rural counties (50%).

What's working?

Despite the caseload size and demands on case managers, families, providers and individual recipients all report general satisfaction with case management services (on average "good," but rarely "excellent"). Most families are satisfied with case manager services and supports most of the time and find their case manager responsive to family needs most of the time. Case mangers are reported generally to be able to find opportunities to visit HCBS recipients in their homes (84% of sample members were visited in the previous 6 months), and 50% of sample members were visited more than twice. About 45% of case manger visits lasted an hour or longer.

Challenges and Concerns

Case managers for individuals living with their families were more likely to develop budgets, help fill out forms and paperwork, present options for new service providers, arrange for new services and assist with crises. Individuals who receive services in the family home were least likely to satisfied with their services. This raises questions about the function of case management with respect to people who receive in-home supports and the extent to which the supports provided by case managers respond to special circumstances and needs of families.

Clearly, case manager roles varied significantly by type of county region. This variation likely creates different experiences, expectations and outcomes for service recipients and their family members. But stakeholder group interviews and surveys indicate that across the state case managers have a great deal of responsibility. They are a viewed as having an essential role in assuring quality and outcomes for HCBS recipients. Many counties report that their case managers make decisions about who is the greatest priority to receive HCBS services. They are the county's link with service recipients and with the service providers with which the county contracts.

Given significant role of case managers in developing and following up on the implementation of individual support plans as well as in ensuring quality of services the average Minnesota caseload is high (average of 53 with a range of 22-89). In a 1996 survey of states by the National Association of State Directors of Developmental Disabilities Services only 12 of 42 reporting states had average caseloads greater than 53 including 5 that were slightly higher (53.3 to 55.5) (Cooper & Smith, 1996). Stakeholders perceive caseloads as too high. High caseloads are reflected in the finding that 33% of HCBS recipients report that it is not easy to contact their case manager.

Not only are caseload sizes high, there is great diversity in the people on those caseloads. But only 51% of case managers report that their county has a process to determine appropriate caseload size. Variations in service recipient needs also require case managers to have eclectic skills and a great deal of knowledge. In that regard, it is notable that 40% of case managers reported that they found their education to be of limited or no use in preparing them for their current roles.

Although satisfaction with case management is generally "good," it was rarely rated as excellent. Obviously meeting people's expectations for individualized case manager support while maintaining caseloads that average more than 50 people is difficult regardless of individual skills, knowledge and commitments. Among the areas which case management services tended to be rated less positively were those related to receiving information from case managers that is easy to access and understand (lowest in family satisfaction), support for creative ideas (lowest in provider satisfaction), presenting options for new services and/or providers (provided to only 50% of sample members in the year prior to the survey), or visiting new potential service sites with HCBS recipients (provided to only 18% of sample members in the previous year). These are areas of essential performance in increasing consumer control and implementing the Consumer Directed Community Supports HCBS service option. Of related concern was that 45% of HCBS recipients interviewed reported that they were not involved at all in choosing who attended their planning meetings. Only 18% of the people interviewed reported that they have a role in changing the goals in their individualized plan. Obviously attention to the knowledge, attitudes, skills and working conditions of case managers will need to be part of any state effort to fulfill the state's commitment to person-centered HCBS.

G. Provider Agencies

Agency Characteristics

Survey respondents. Provider surveys were returned by 183 residential sites and 82 vocational sites. While some of those sites completed the long form of the survey (84 residential and 14 vocational), most completed the short form (N = 167). The long and short form differed in length and in the level of detail about each question. For this section when sample sizes are below 100 it is generally indicative that the question was only asked on the long form. Most of the people who responded to the provider surveys were supervisors (33.2%), managers (27.9%) or administrators (25.3%; See Table G1).

Table G1: Provider Agencies Respondents (Provider Survey)

Job Title	**Residential**		**Vocational**		**Total**	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**
Number of Sites Responding	183		82		265	
Front line Supervisor	68	37.2%	20	24.4%	88	33.2%
Other supervisor manager	53	29.0%	21	25.6%	74	27.9%
Administrator	29	15.8%	38	46.3%	67	25.3%
Direct support worker	13	7.1%	0	0%	13	4.9%
Degreed Professional	9	4.9%	0	0%	9	3.4%
Trainer	1	0.5%	0	0%	1	0.4%
Other	10	5.5%	3	3.7%	13	4.9%

Agency size and type. The typical residential site surveyed for this study opened in 1992 (range 1970 to 1999). Overall, 27% of residential sites were part of an agency that supported individuals in more than one state (See Table G2). Overall, 62% of residential sites were operated by private for profit agencies, 28.4% were operated by private non-profit agencies, 3.8% were state operated, and 3.8% were operated by a family as an unincorporated business. The typical vocational program site surveyed opened in 1986 (range 1960 to 1999). Only 7% of vocational sites were operated by a multi-state agency. The vast majority of vocational sites were operated by private non-profit agencies (78%) and only a handful of vocational sites were state operated (15%), private for profit (4%) or county operated (2%).

Table G2: Characteristics of Provider Agencies and Respondents (Provider Survey)

Characteristic	**Residential**		**Vocational**		**Total**	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**
Number of Sites Responding	183		82		265	
% sites part of multi-state agency	84	27%	14	7.1%	98	24%
Type of agency						
Private for profit	113	61.7%	3	3.7%	116	43.8%
Private non-profit	52	28.4%	64	78.0%	116	43.8%
State	7	3.8%	12	14.6%	19	7.2%
Individual/Family home owner	7	3.8%	1	1.2%	8	3.0%
County	1	0.5%	2	2.4%	3	1.1%
Other	3	1.6%	0	0%	3	1.1%

Staff characteristics (agency perspective). Based on the provider surveys, the typical HCBS licensed residential site employed 6.5 direct support staff, just under one supervisor, and three direct support staff who did not have regularly scheduled hours but worked "on-call" (See Table G3). Overall, 44 (24.2%) of the residential sites supported 1 to 3 people, 125 (68.7%) supported 4 people, and 13 (7.1%) sites or buildings supported between 5 and 23 HCBS recipients. Sites where more than 4 people were supported were almost all apartment buildings with more than one HCBS license. The average number of direct support staff members per consumer in residential sites was 1.8.

Table G3: Staffing Characteristics of Provider Agencies (Provider Survey)

Characteristic	**Residential**	**Vocational**	**Total**	F/X^2
Number of Sites Responding	183	82	265	
Number of consumers per site[1]	5.45	28.75	13.0	21.99***
Number of Staff				
DSS	6.47	11.56	8.07	51.71***
FLS	0.95	1.58	1.15	18.31***
On-Call DSS	3.01	1.31	2.45	0.98
DSS per consumer	1.79	0.44	1.36	141.52***
Education of DSS (Average Percent)				
Less than GED	1.8	0.0	1.5	0.74
HS or GED	69.8	54.1	67.4	2.62
2 year degree	12.5	13.6	12.6	0.04
4 year degree	19.8	41.9	22.9	6.67*
Percent of current staff who are female	79.0%	80.9%	79.6%	0.38

* $p < .05$, ** $p<.01$, *** $p<.001$

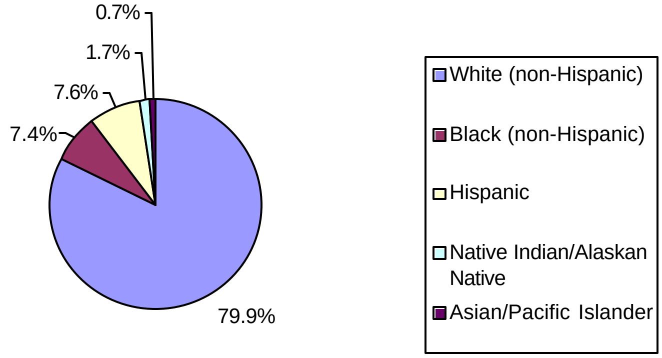
[1] Some sites provided SILS or SLS services to more than 4 people in one apartment building increasing the average number of consumers to above 4. 92.9% of residential sites served 4 or fewer people.

The typical vocational site served 29 consumers with 11.6 direct support staff members, and 1.6 front line supervisors. The typical vocational site had 1.3 "on-call" staff members. There were four direct support staff members for every ten consumers in vocational service settings. The total number of individuals served, direct support staff members and front line supervisors was significantly higher in vocational settings than in residential settings. Similarly the number of direct support staff members per consumer was significantly higher in residential settings.

The typical direct support staff member in residential and vocational settings was female (79.6%) and had a high school diploma or a general equivalency diploma. A few staff had two year degrees (12.6%). The proportion of direct support staff members who had four-year degrees was significantly higher in vocational sites (41.9%) than in residential sites (19.8%).

A total of 75 residential respondents who completed the long-form of the survey indicated the ethnicity of direct support staff members. Of the 542 direct support staff members in those homes, 79.9% were to be white and non-Hispanic, 7.4% were black and non-Hispanic, 7.6% were Hispanic, 1.7% were Native Indian or Alaskan natives, and 0.7% were Asian or Pacific Islander. Interestingly, the proportion of DSS from diverse racial or ethnic groups was substantially higher than the proportion of HCBS recipients in those groups (20.1% vs. 6.2%).

Figure G1: Race/Ethnicity of Direct Support Staff in Residential Sites (Provider Survey)



Wages. In recent legislative sessions, considerable attention has been given to the wages paid to direct support staff members in community human service settings. This study asked providers to report starting, average and highest wages for both direct support staff members (DSS) and for front line supervisors (FLS). Wages for DSS were different depending on the whether the provider was state operated or not, the type of provider (residential or vocational), and the region of the state (metro, GM urban or rural) (See Table G4). Overall, DSS in vocational programs had higher starting, average and highest wages than direct support staff members in residential programs. DSS in state operated programs had higher starting, average and highest wages than those in non-state programs. Finally, DSS starting, average and highest wages were higher for metro area providers, than for staff in GM urban or rural areas.

Table G4: Staff Wages (Provider Survey)

	Residential				**Vocational**				***F***	***N***
Outcome	**Metro**	**GM Urban**	**Rural**	**Ave.**	**Metro**	**GM Urban**	**Rural**	**Ave.**		
DSP Wages										
Non-State										
Ave. Starting	$8.81	7.44	7.67	8.11	9.93	7.45	7.67	8.70	24.72***[1]	226
Ave. Mean	9.41	8.12	8.60	8.81	10.72	9.13	9.04	9.80	33.44***[2]	194
Ave. Highest	10.40	9.55	9.83	10.02	13.18	11.86	11.29	12.35	24.2***[3]	221
State										
Ave. Starting		-	8.91	9.27	10.00	9.84	10.07	9.92		15
Ave. Mean		-	-	-	13.54	14.04	14.67	14.06		11
Ave. Highest		15.96	12.69	14.65	16.84	16.01	16.00	16.22		17
FLS Salaries										
Non-State										
Ave. Starting				22,534				24,548	4.73*	58
Ave. Mean				25,308				27,201	3.74	43
Ave. Highest				27,897				29,143	1.01	49
State										
Ave. Starting				22,050				-		5
Ave. Highest				32,428				-		5

- Only one site provided this information. * $p < .05$, ** $p < .01$, $p < .001$

[1] State v. Non-State $F = 35.55$***, Provider type $F = 6.36$ ***, Region $F = 53.88$***, Interaction $F = 3.39$*.

[2] State v. Non-State $F = 95.31$***, Provider type $F = 15.59$ ***, Region $F = 17.51$***, Interaction $F = 0.98$.

[3] State v. Non-State $F = 53.88$***, Provider type $F = 40.53$ ***, Region $F = 6.34$***, Interaction $F = 0.28$.

Table G4 also shows the average starting mean and highest salaries for front line supervisors in residential and vocational settings. A test of the differences between residential and vocational salaries showed that vocational starting salaries were higher and the range of salaries was greater than starting salaries for front line supervisors in residential settings. Differences in average and highest salaries for front line supervisors were not statistically significant.

Because of the importance of reporting accurate wage information, wage data collected for this project was compared to two recent provider industry studies of the same group of workers. The starting wages reported here for residential direct support staff are within a penny per hour of the estimate given by ARRM based on their recent membership ($8.13 in this report, $8.14 in the ARRM report)(ARRM, 1999). MnHab and MNDACA survey data indicated a statewide average wage of $9.77 and a statewide starting wage of $7.63 based on a survey of 151 providers as of January 1999. The average wage for non-state vocational direct support staff in this study was very similar to the MnHab/MnDACA provider survey but the starting salaries are slightly higher.

Wage changes over time. The average starting wage for residential direct support staff members working in HCBS funded settings in January 2000 was $8.13 ($16,910 per year for a full-time worker, $12,615 for the typical worker at 30 hrs/week). By comparison, a 1995 statewide study of direct support staff wages in residential settings reported an average starting wage of $7.07 per hour (Larson, Lakin & Bruininks, 1998). Starting wages for residential DSS have increased 15% in five years (See Figure G2). However, the increase in average highest wage paid was less. In 1995, the average highest wage was $9.27 and in 2000 it was $10.16. That is an increase of only 9.6% over five years. Basically, incentives for people to stay in DSS positions have decreased because long-term DSS salaries have increased more slowly than salaries for new DSS.

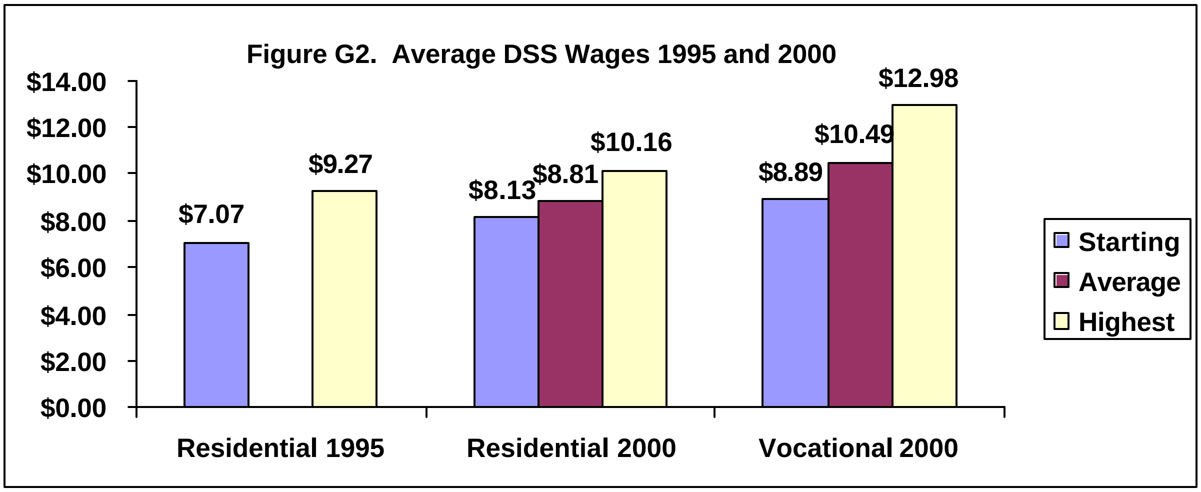


Figure G2. Average DSS Wages 1995 and 2000

Employee benefits. Overall, DSS had to work an average of 36.8 hours per week to be considered by their employer to be full-time (See Table G5). They had to work an average of 24.4 hours per week to be eligible for paid time off, and they had to work 29.0 hours per week to be eligible for benefits such as health insurance or retirement. There were no differences between residential and vocational providers on these items. There were, however, differences in the proportion of all DSS who were considered full-time workers between different types of providers. Overall 49.3% of residential DSS were considered full-time compared with 71.9% of vocational DSS. The proportion of residential DSS considered full-time in January 2000 is higher than it was in 1994 when only 43% of residential DSS were considered to be full-time (Larson, Lakin & Bruininks, 1998).

Table G5: DSS Benefits (Provider Survey)

Benefits	*N*	Residential	Vocational	Total	*F*
N hours to be Full-time	101	36.7	37.5	36.8	0.47
Hours to work for eligibility for paid time off	82	24.0	26.4	24.4	0.36
Hours to work for eligibility for benefits	92	28.7	30.7	29.0	0.67
% Full-time	267	49.3%	71.9%	56.1%	44.64***
% Eligible for Paid Time off	95	67.1%	79.2%	68.7%	1.13
% Eligible for Benefits	94	64.2%	83.4%	67.1%	4.85*

* $p < .05$, ** $p<.01$, *** $p<.001$

Overall 68.7% of DSS workers were eligible for paid time off (sick, vacation or holiday). The differences between residential and vocational agencies in eligibility for paid time off were not statistically significant. The proportion of residential DSS eligible for paid time off in January 2000 was somewhat lower than it was in 1994 (67% vs. 72%). Similarly, 67.1% of DSS were eligible for benefits. The proportion of residential DSS eligible for benefits (64.2%) was significantly lower than the proportion of vocational DSS eligible for benefits (83.4%). The proportion of residential DSS eligible for benefits in January 2000 was higher than for DSS in 1994 (64% vs. 59%).

Direct Support Staff Member Characteristics (DSS Survey)

Demographic characteristics. The newest DSS and the most senior DSS at each site were asked to complete a DSS survey. A total of 116 senior DSS and 93 newly hired DSS returned surveys. The demographic characteristics of the DSS who returned surveys are summarized on Table G6. The majority of respondents were female (83.1%) and white (95.1%). Half of the respondents were in their first position with the agency, 25% were in their second position, and 22% were in their third or subsequent position. Respondents had worked with persons with mental retardation or related conditions for an average of 8.5 years and had worked at their current site for 5.6 years. A total of 78.1% of respondents were eligible for paid time off and 78.7% were eligible for benefits. The proportion eligible for benefits was significantly higher for DSS in vocational settings than for those in residential settings. Overall, 41.5% of respondents had a high school education or less, 54.5% had at least some college, and 4% had attended graduate school. Overall 13.3% of the respondents were currently students, including 16.6% of residential DSS and 6.8% of vocational DSS. Almost half (47.5%) of the respondents had taken a college or technical school course on mental retardation or developmental disabilities.

Table G6: DSS Survey: Characteristics of DSS Respondents (Percentages)

Characteristic	**Residential**	**Vocational**	**Total**	***F/ X^2***
% Female	83.4	82.4	83.1	0.04
Ethnicity				
White	94.7	95.9	95.1	2.28
Black	2.6	4.1	3.1	
Hispanic	0.7	0.0	0.4	
Asian/Pacific Islander	0.7	0.0	0.4	
American Indian	0.7	0.0	0.4	
Other	0.7	0.0	0.4	
Number of positions in agency				
1	51.6	56.8	53.4	1.94
2	23.5	28.4	25.1	
3 or more	24.8	14.9	21.5	
Months working in DD	89.9	127.1	102.0	
Months at this site	60.4	82.2	67.6	
Eligible for paid time off	77.0	80.3	78.1	0.30
Eligible for benefits	71.8	93.1	78.7	13.08***
Education				
HS or less	43.0	38.4	41.5	2.24
1-4 years college	53.6	56.2	54.5	
5+ years college	3.3	5.4	4.0	
Currently a student	16.6	6.8	13.3	4.13*
Plan to stay after school	53.7	42.9	52.1	0.28
Had course on MR/DD	43.0	56.9	47.5	3.78

N = 74 vocational; 151 residential * $p < .05$, ** $p<.01$, *** $p<.001$

DSS respondents described various characteristics of their jobs (See Table G7). The number of individual HCBS recipients supported by DSS differed significantly, ranging from 5.26 to 5.65 for residential DSS (some worked at more than one licensed site) and from 20.0 to 32.71 for vocational DSS. Average hours worked per week also varied significantly with DSS working an average of 32.3 to 35.2 hours per week in residential settings and between 36.5 and 38.2 hours per week in vocational settings. Overall, DSS intended to continue working for their current employer for an average of 7.6 years. Metro area DSS said they planned to stay for significantly fewer years than rural DSS.

Overall, 13% of DSS said they were current students. Thirty-two percent said their employer provided at least some form of tuition reimbursement. The proportion of DSS eligible for tuition reimbursement varied by region and provider type. More vocational DSS were eligible for tuition reimbursement than residential DSS. In addition, DSS working in metro area agencies were more likely to be eligible for tuition reimbursement than those working in GM urban agencies. While a substantial minority of DSS were eligible for tuition reimbursement, very few received reimbursement in the previous year (6%).

Table G7: Direct Support Staff Job Characteristics (DSS Survey)

Characteristic	***N***	**Residential**			**Vocational**			**Total**	**Overall *F***	**Diff**
		Metro	**GM Urban**	**Rural**	**Metro**	**GM Urban**	**Rural**			
N consumers supported	210	5.26	5.65	5.39	31.97	32.71	20.0	13.00	22.0***	P
Hours worked per week	211	35.2	32.3	35.0	37.8	38.2	36.5	35.2	3.29**	P
Years plan to stay	197	4.9	6.7	10.4	7.1	8.5	10.7	7.6	3.56**	R[1]
Years of education	214	13.9	13.5	12.9	14.2	13.9	13.0	13.6	10.5	R[1]
Currently a student	215	14%	20%	14%	13%	0%	0%	13%	1.61	
Eligible for tuition reimbursement	195	34%	11%	27%	54%	29%	56%	32%	5.56	P, R[2]
Received tuition reimbursement	119	3%	4%	12%	4%	0%	15%	6%	0.88	

* p < .05, ** *p*<.01, *** *p*<.001;R = Region, P = Provider type (residential vs. vocational) I = Interaction of R and P; Covariates: DS = DSS Starting Wage, ***N*** = Total number of DSS; [1]Metro less than rural [2]Metro more than GM urban

One hundred three DSS who were eligible for tuition reimbursement were asked why they did not take advantage of the opportunity. The most common reasons for not taking advantage of tuition benefits were family or personal reasons (40% of eligible DSS), seeing no advantage to taking classes (29%), and lack of interest in classes (26%). A small proportion of DSS reported that they didn't know how to find relevant courses (7%) or that they couldn't take classes because they couldn't get off work (7%) and 20% reported they did not take advantage of tuition benefits for some other reason.

The most common form of supports provided by surveyed DSS were transportation, corporate foster care, consumer training and education, and center based work (See Table G8). The most common supports provided by residential DSS included corporate foster care (61.2%), transportation (54.7%), and homemaker or chore services (41.7%). For vocational settings, the most common forms of support provided by DSS included center based work (86.3%), transportation (67.1%), and supported or competitive employment (60.3%). Since the DSS survey described these services by category only, the DSS who responded may not have had the technical "HCBS program" definitions in mind when they answered the questions. Their responses are included to document the diversity in job responsibilities of DSS in Minnesota.

Table G8: DSS Survey: Types of Supports Provided by the DSS (Percentages)

Setting Type	Vocational	Residential	Average
Transportation	67.1	54.7	60
Corporate foster care	1.4	61.2	41
Consumer training and education	45.2	29.5	36
Center based work program	86.3	7.2	34
Homemaker/chore services	2.7	41.7	29
Supported or competitive employment	60.3	5.8	23
Semi-independent living services	2.7	31.7	22
Crisis supports	9.6	17.3	14
In-home family/individual supports	1.4	16.5	12
Center based non-work program	23.3	5.0	11
Respite care out-of-home	1.4	5.8	3

N = 202

Recruitment and Hiring Problems

This evaluation includes information about staffing patterns, challenges and outcomes. It also examines the extent and seriousness of specific staffing problems, including recruitment, retention and training for direct support staff members. This information is important because problems with staffing have been identified as one of the most pressing issues facing providers of HCBS funded supports both in Minnesota and throughout North America. This section summarizes the extent to which providers, case managers, HCBS Waiver Coordinators and other stakeholder groups found staff recruitment, retention and training issues to be a problem in Minnesota.

Provider reports of staffing difficulties. Overall, 75% of all providers reported that finding qualified applicants for direct support positions was a challenge (See Table G9). This proportion is much higher than the 57% of 110 residential site supervisors who reported recruitment to be a major problem in a 1995 statewide study (Larson, Lakin & Bruininks, 1998). This entrenched problem will not soon be solved because the number of people in the US who are between 18 and 44 years of age (the age of most direct support staff members) will decline another 1.3% between 2000 and 2005 before starting to grow again (U.S. Bureau of the Census, 1999).

Table G9: Percent of Sites Reporting Problems (Provider Survey)

Problem	*N*	Residential			Vocational			Total	*F*	Diff.
		Metro	GM Urban	Rural	Metro	GM Urban	Rural			
Finding qualified applicants	138	74%	83%	62%	87%	78%	53%	75%	1.96	
DSS Turnover	138	39%	53%	49%	65%	33%	33%	46%	1.50	
DSS Training	138	31%	30%	14%	17%	39%	53%	28%	2.31*	I

* $p < .05$; R = Region, P = Provider type (residential vs. vocational), I = Interaction of R and P

Direct support staff turnover was reported as a problem by 46% of respondents. There were no significant differences in the extent to which either recruitment or turnover were problems by region or by provider type. There were, however, differences in the proportion of providers who reported problems with training direct support staff members. Overall, 28% of providers reported training of direct support staff was a problem for them. Among residential providers rural agencies were less likely to report problems with training (14%) than metro or GM urban providers (31% and 30% respectively). Among vocational providers, rural providers were most likely to report training challenges (53%) while metro area vocational providers least likely to.

Case manager reports of staffing difficulties. Case managers were asked several questions regarding the seriousness of problems in recruiting, training, monitoring, supporting and retaining qualified staff members. Overall, case managers reported that the most serious staff related problems affecting HCBS funded supports were the high number of direct support staff members in the lives of consumers (Mean score 3.31), difficulty recruiting family foster providers (3.21) and difficulty recruiting residential and in-home staff (3.18; See Table G10). Scores above 3.0 indicated the average case manager saw the problem as being between extremely serious (4) and serious (3). Staffing problems considered to be moderately serious (2) to serious (3) included recruiting and training vocational staff (2.63), the ability of new staff to fulfill their job responsibilities (2.56), problems with families being unable to find people to hire to work in their homes (2.56), monitoring safety because of staffing shortages and turnover (2.53), families not getting authorized or needed services (2.47) and quality of training for DSS (2.09).

Table G10: General Case Manager Opinions About The Seriousness of Staffing Problems

		Region				
Problem Area	***N***	**Metro**	**GM Urban**	**Rural**	**Total**	***F***
Number of DSS in lives of consumers (turnover)	51	3.57	3.27	3.00	3.31	3.46*
Recruiting family foster providers	48	3.48	2.82	3.13	3.21	2.42
Recruiting residential and in-home staff	51	3.52	3.18	2.71	3.18	8.26***
Recruiting and retaining vocational staff	49	2.90	3.00	2.06	2.63	8.73***
Ability of new staff to fulfill responsibilities	50	2.91	2.55	2.55	2.56	1.08
Families can't find people to hire	36	2.88	2.40	2.20	2.56	2.62
Monitoring safety due to staffing shortages and turnover	47	3.00	2.20	2.00	2.53	10.29***
Families not getting authorized or needed services	47	2.82	2.18	2.14	2.47	4.54*
Quality of training for DSS	47	2.45	2.00	1.60	2.09	7.63***
Level of respect by DSS	49	2.13	1.73	1.93	1.98	0.91
DSS have limited English proficiency	46	2.74	1.18	1.25	1.98	21.77***
Supervisors limited ability to train DSS	48	2.52	1.64	1.29	1.96	19.39***
Average	51	2.90	2.34	2.19	2.54	14.0***

* p < .05, ** *p*<.01, *** *p*<.001; 4 = Extremely serious; 1 = No problem
All significant differences were metro versus the other regions except recruiting and DSS training (metro was more than rural).

Regional differences were noted for all but three of the problems. In most cases, case managers in metro area counties were significantly more concerned about staffing issues than case managers in the other regions. In the case of quality of training for DSS, case managers in metro areas thought it was more of a problem than case managers from rural counties but there were no differences between metro and GM urban case managers.

Provider perspective. Provider surveys were completed by people in a variety of job roles including direct support staff (DSS), front line supervisors, other supervisors or managers, administrators and others. Table G11 examines whether residential respondents had different hiring and orientation responsibilities depending on their job role. DSS were most likely to report being involved in providing house orientation (81.8%) and providing ongoing training to other DSS (81.8%). Of the DSS respondents, 54.5% reported being responsible for performance evaluations, and 36.4% reported being involved in responding to inquiries about posted positions. More than 90% of front line supervisor respondents reported being involved in house orientations, providing ongoing training and conducting performance evaluations. Other common tasks for front line supervisors included firing employees (82.4%), interviewing applicants (79.4%), and hiring new employees (76.5%). The most common roles for managers included conducting performance evaluations (93.3%), interviewing applicants (86.7%), hiring new employees (80%), providing ongoing training (80%) and firing employees (80%). The most common tasks performed by administrators were conducting ongoing training (100%), conducting performance reviews (100%), and firing employees (88.9%).

Table G11: Hiring Practices In Residential Sites: Who Does It?

Task	**DSS**	**FLS**	**Other Supervisor**	**Administrator**	**Other**
Number responding	11	34	15	9	13
Advertises job openings	18.2%	44.1%	66.7%	66.7%	38.5%
Respond to inquiries	36.4%	61.8%	66.7%	77.8%	76.9%
Screens applicants	18.2%	52.9%	73.3%	66.7%	69.2%
Interviews applicants	27.3%	79.4%	86.7%	77.8%	61.5%
Hires new employees	18.2%	76.5%	80.0%	66.7%	53.8%
Provides agency orientation	9.1%	55.9%	73.3%	77.8%	76.9%
Provides house orientation	81.8%	94.1%	60.0%	66.7%	61.5%
Provides ongoing training	81.8%	91.2%	80.0%	100%	84.6%
Conducts performance evaluations	54.5%	97.1%	93.3%	100%	92.3%
Fires employees	9.1%	82.4%	80.0%	88.9%	46.2%

DSS Direct support staff; FLS Front Line Supervisor; Other = Trainer, Degreed Professional, Other

Providers reported a variety of recruitment challenges for their sites (See Table G12). Overall, they reported paying for 46.1 hours of overtime per site in the month prior to the survey. Residential sites paid for significantly more hours of overtime than vocational sites. The total cost of overtime for one month averaged $334 per site. The total cost for advertising averaged $249.63 per site. Vocational providers reported spending an average of $805 per site in the previous month on advertising while residential providers reported spending an average of $51.29 per site on advertising. The survey did not ask how much residential agencies spend on advertising through regional or corporate offices so the amount reported was the amount spent directly by the site. Differences between residential and vocational settings are explained, at least in part, by the significant difference in the average number of direct support staff members employed at each site.

Table G12: Vacancy Rates and Hiring Challenges (Provider Survey)

Outcome	***N***	**Vocational**	**Residential**	**Total**	F/X^2
T hours of overtime in 1 month	52	21.1	51.2	46.1	5.4*
$ on overtime in 1 month	45	$25.72	$422.24	$334.12	1.91
$ on advertising for new hires 1 month	38	$805.00	$51.29	$249.63	11.82***
Used staff from a temporary agency	88	43%	4%	10%	24.17***
Pay per hour for temp employees	16	$11.83	$10.65	$11.24	0.27
Ave. number of weeks a DSS position is vacant	77	4.4	4.3	4.3	0.00
Ave. number of weeks a FLS position is vacant	59	0.7	1.2	1.1	0.57
% of new hires with prior experience	81	70.0	46.9	49.8	7.01**

* $p < .05$, ** $p<.01$, *** $p<.001$

There were significant differences between residential and vocational providers in the use of employees from temporary agencies. Overall, 43% of vocational providers reported they used temporary agency employees while only 4% of residential provider sites did. Readers are cautioned to remember that only fourteen vocational providers answered the questions about vacancy rates and hiring challenges. Therefore, these findings should be considered preliminary. For the sites that reported using temporary agency employees, the average cost per hour for those employees was $11.24 (paid to the temporary agency).

The extent of recruitment challenges faced by providers can also understood in terms of the time it takes to replace a direct support staff member who leaves. It now takes over one month to replace each leaving worker. This leaves a vacancy that must be filled using overtime, supervisors, temp workers, or which is simply left unfilled. The proportion of new hires that had previously worked with persons with developmental disabilities was 70% for vocational providers and 47% for residential providers. Most new recruits read at the 12th grade level (63.2%), 28.7% read at a college level, and 8.0% read at an 8th grade level or below.

Table G13 describes the extent of recruitment challenges in further detail. Overall, the number of DSS whose first language was not English was 6 people per 10 sites (0.6 per site). The number of DSS who are immigrants to the United States was just under 4 DSS per 10 sites (0.4 per site). The number of immigrants differed by the total number of workers a site employed, by provider type (with more immigrants working in residential sites), and by region. More metro providers employed immigrant workers than GM urban or rural providers.

Table G13: Absences, Vacancies And Recruitment Challenges (Provider Survey)

Outcome	*N*	Residential			Vocational			Total	Overall *F*	Diff.
		Metro	GM Urban	Rural	Metro	GM Urban	Rural			
N DSS whose first language is not English	154	0.71	0.43	0.68	0.64	0.00	1.12	0.60	0.85	
N DSS who are immigrants	154	0.86	0.07	0.13	0.63	0.00	0.00	0.38	8.70***	R[1],P, N
% of DSS positions vacant	152	13.9%	6.0%	8.4%	7.9%	1.1%	1.8%	8.2%	3.65**	R[2], P
N of applicants for open DSS position	86	2.5	4.1	3.0	4.8	8.1	5.4	4.2	6.72***	R[3],P,DS
% DSS scheduled hours not worked	124	3.1%	3.3%	4.5%	10.4%	2.7%	3.5%	4.5%	1.29	
% DSS hours not filled due to absences	144	0.6%	1.7%	1.4%	2.9%	1.5%	5.3%	1.9%	2.01	
% DSS hours not filled due to vacancies	184	3.9%	1.7%	3.6%	8.1%	13.0%	2.6%	4.6%	1.20	

* p < .05, ** *p*<.01, *** *p*<.001; R = Region, P = Provider type (residential vs. vocational) I = Interaction of R and P; Covariates: DS – DSS Starting Wage, ***N*** **=** Total number of DSS

[1]Metro different than the other two regions; [2]Metro more than GM urban; [3]Metro had fewer than GM urban.

The overall vacancy rate for DSS positions in January 2000 was 8.2%. Vacancy rates were higher in metro provider agencies than in GM urban agencies, and were higher in residential sites than in vocational sites. Overall, 4.2 people applied for each vacant direct support staff position. Providers who paid higher starting wages had significantly more applicants for positions than providers who paid lower starting wages. The number of applicants per opening also varied by region with fewer applicants applying for metro area openings than for GM urban openings, and by provider type, with vocational providers receiving significantly more applications for each position than residential providers.

The impact of recruitment challenges is demonstrated in that 4.5% of all direct support hours went unfilled in the week prior to the survey. Overall, 1.9% of hours that were scheduled were not filled because a direct support staff member was absent, and 4.6% of scheduled hours went unfilled because of open positions. These numbers do not sum to the total percent of unfilled shifts because different numbers of providers answered various parts of this question.

DSS perspective. One factor influencing whether a newly hired direct support staff member will stay in their position for at least six months after hire is whether they had realistic expectations about what the job would be like when they decided to take the job (Larson, Lakin & Bruininks, 1997). With this in mind, the DSS survey asked participants about the extent to which their jobs met their expectations. Overall, 40.2% of all current DSS said their job responsibilities and working conditions definitely turned out to be what they expected and 44.6% reported that they somewhat turned out to be what they expected (9.8% reported that they did not turn out to be what they expected; See Table G14). Current DSS in residential settings were significantly more likely than DSS in vocational settings to report that the job responsibilities and working conditions turned out to be what they expected.

Table G14: Met Expectations for DSS Respondents (Percentages, DSS Survey)

Expectation	**Residential**	**Vocational**	**Total**	X^2
Job responsibilities and working conditions turned out to be what was expected				
Definitely yes	43.5	29.7	40.2	7.31**
Somewhat yes	43.3	47.3	44.6	
Neither yes or no	4.0	8.1	5.4	
Somewhat no	6.7	13.5	8.9	
Definitely no	0.7	1.4	0.9	
Overall this job meets my expectations				
Definitely yes	46.0	34.2	42.2	8.36**
Somewhat yes	47.3	45.2	46.6	
Neither yes or no	2.7	8.2	4.5	
Somewhat no	3.3	11.0	5.8	
Definitely no	0.7	1.4	0.9	

* $p < .05$, ** $p<.01$, *** $p<.001$

Overall, 42.2% of current DSS reported that their job definitely meets their original expectations about it, and 46.6% reported that is somewhat meets their expectations. DSS in residential settings were more likely that DSS in vocational settings to say that the job met their original expectations.

Turnover and Tenure

Provider perspective. Providers reported several different outcomes related to turnover and tenure (See Table G15). DSS turnover for 1999 averaged 44% in residential settings and 23% in vocational settings. Turnover was significantly higher for providers offering lower average wages, serving individuals with more intense support needs, and in metro counties compared to rural counties. Direct support staff turnover was not related to staff ratios. Overall, 11.7% of all leavers in residential settings were fired and 2.8% of all leavers in vocational settings were fired. The average tenure of a leaver in a residential setting was 13.7 months, and in a vocational setting was 26.7 months.

Table G15: Staff Turnover and Tenure (Provider Survey)

Outcome	***N***	**Residential**				**Vocational**				***F***
		Metro	**GM Urban**	**GM Rural**	**Total**	**Metro**	**GM Urban**	**GM Rural**	**Total**	
Turnover										
DSS	218	42.7%	52.4%	37.7%	43.9%	43.7%	28.0%	22.8%	33.1%	3.63***[1]
FLS	132	29.6%	10.0%	35.4%	27.6%	17.5%	16.2%	13.4%	15.8%	1.11
Months Tenure for Current DSS										
0-6	182	23.9	31.2	18.6	24.8	21.2	16.5	18.3	19.3	
7-12	181	16.4	13.8	18.2	16.1	20.0	13.9	9.1	15.8	
13+	182	59.7	55.0	63.2	59.1	58.8	78.0	72.6	64.9	

[1] R^2 = .158, Adj. R^2= .114; * $p < .05$, ** $p< .01$, *** $p< .001$; Significant predictors of turnover were average DSS wage, intensity of consumer support needs, and region (with turnover significantly higher in metro than in rural counties).

Among current residential direct support staff, 59.1% had been in the home for more than a year, 16.1% had been in the home for 7 to 12 months, and 24.8% had been in the home for less than 6 months.

Among current vocational direct support staff, 64.9% had been at the site for more than a year, 15.8% had been there for 7 to 12 months, and 19.3% had been there for less than 6 months.

Family perspective. Thirty-one family respondents noted how many different direct support staff had been to their homes to provide supports in the previous 3 months. Overall, families reported that they had 3.3 different people come to their home in the past 3 months. Families also reported on the number of different case managers they had had over the last three years. Overall, of the 168 families who reported this information, the average family had had 1.6 different case managers in three years.

Families also shared their opinions about whether staff turnover was a problem for them and their family member for each type of support they received (See Table G16). Overall, the proportion of families who thought turnover was a problem was highest for out-of-home residential services (50% of families whose member received this service thought staff turnover was a problem), in-home supports (48%), and respite services (35%). For families in metro counties, the services in which turnover was most likely to be considered a problem were in-home supports (50%), out-of-home residential supports (49%), respite services (42%), and educational services (39%). For GM urban counties turnover was considered a problem for 71% of families receiving out-of-home residential supports, 63% of families receiving vocational services, and 50% of families receiving respite services. In rural counties, turnover was considered a problem for 50% of families receiving in-home supports and 39% of families receiving out-of-home residential supports.

Table G16: Is Staff Turnover A Problem? (Family Surveys)

Type of Support	**Metro**		**GM Urban**		**Rural**		**Total**	
	N	**Percent**	***N***	**Percent**	***N***	**Percent**	***N***	**Percent**
Supported Living Services	49	49%	24	71%	46	39%	119	50%
In home supports	14	50%	7	43%	10	50%	31	48%
Respite Services	12	42%	8	50%	6	0%	26	35%
Vocational services	41	17%	16	63%	36	28%	93	29%
Educational Settings	17	39%	10	20%	13	15%	40	23%
Case management	74	8%	35	14%	56	9%	165	10%

DSS Staff Training

The quality and availability of training opportunities for direct support staff members was addressed on both the provider surveys and the direct support staff surveys.

Provider perspective. Providers reviewed a list of training topics for direct support staff members and reported the total number of hours of training provided on each topic in a year, the number of weeks after a new person started that they were first trained on the topic, and the number of months after the initial training that a refresher course was offered (See Table G17). Some providers did not specify the number of hours by topic and instead reported a total annual number of hours of training. In those cases, the hours are listed under the "other" category.

Residential providers offered an average of between 1.4 hours and 9.0 hours of training to their direct support staff members each year on each of the assessed topics. The largest number of hours of training provided per year for direct support staff members in residential settings were for crisis intervention and behavioral supports (average of 9.0 hours per year), medication administration (7.4 hours), agency policies and procedures (5.99 hours), health (5.4 hours), CPR (5.2 hours), and assessing medical conditions (4.6 hours). Providers reported that 71% of all direct support staff members were actually certified to distribute medications.

Vocational providers offered between 1.2 hours and 6.5 hours of training annually to direct support staff members on the assessed topics. The largest number of hours of training provided to direct support staff members in vocational settings were CPR (6.5 hours per year), organizational participation

(5.95 hours), facilitation of services (5.25 hours), vocational, educational and career supports (4.9 hours), and crisis intervention and behavioral supports (4.7 hours).

Table G17: DSS Training Provided (Provider Survey)

Training topic	**Hours per Year**		**Weeks after start**	**N Months til refresher**
	Residential (*N*=121)	**Vocational (*N*=67)**	**Residential (*N*=56)**	**Residential (*N*=46)**
Crisis intervention, behavioral supports	9.00	4.71	3.61	9.00
Medication Administration	7.44	3.49	3.41	12.28
Agency policies and procedures	5.99	3.36	2.14	10.90
Health	5.37	2.05	2.04	10.17
CPR	5.23	6.49	6.61	15.30
Assessing Medical Conditions	4.60	2.09	2.45	12.30
DSS Education, training and self development	4.57	3.59	4.31	9.08
Documentation	4.49	3.06	2.21	10.12
First Aid	4.31	4.16	5.73	11.48
Communication (staff, consumers, families)	4.20	2.55	2.28	8.25
Organizational participation	4.01	5.95	8.87	8.90
Teamwork	3.99	3.40	4.26	8.64
Community living skills and support	3.32	3.27	2.58	8.76
Formal and informal assessment of needs, desires and interests of participants	3.21	2.92	2.90	8.82
Facilitation of services (program implement.)	3.13	5.25	3.22	8.97
Consumer safety (safe environments)	3.09	2.52	1.98	11.90
Rights of people with disabilities	2.94	2.31	1.76	8.39
Blood Borne pathogens	2.80	1.57	2.77	8.96
Respecting people with disabilities	2.21	1.17	1.82	9.32
Community services and networking	1.91	2.74	3.72	8.59
Empowerment and self-determination	1.87	2.00	3.84	8.00
Advocating for people with disabilities	1.74	2.16	3.29	8.54
Vocational, educational and career supports	1.37	4.86	3.09	9.23
Other (or didn't divide hours by topic)	11.92	5.78	3.00	6.55
Total Hours Per Staff Member Per Year	102.71	81.45		

Note: The number of respondents indicating that particular topics were offered during orientation, as needed or on an ongoing basis instead of specifying the number of hours for each topic varied from 3 to 7.

Providers who completed the long form of the provider survey indicated how soon a new staff person received initial training on various topics. Topics typically covered within the first two weeks of employment included rights of people with disabilities, respecting people with disabilities, and consumer safety (safe environments). Topics typically covered between two and three weeks after hire included health, agency policies and procedures, documentation, communication with staff, consumers and families, community living skills and supports, formal and informal assessments of needs, desires and interests of consumers, and blood borne pathogens. Most of the remaining topics were covered between three and four weeks after hire (exceptions were First Aid (5.7 weeks), CPR (6.6 weeks), and organizational participation 8.9 weeks). Providers offered refreshers for the topics every 8 to 12 months on average. Providers reported that 71% of all direct support members were certified to distribute medications.

DSS perspective. Overall, between 56% and 100% of direct support staff members surveyed reported that they had received training on the identified topics from their current employer (See Table G18). More than 90% of all DSS reported receiving training on abuse and neglect (99%), agency policies and procedures (98%), rights of people with disabilities (98%), consumer safety (97%), documentation (97%), First Aid (97%), respecting people with disabilities (96%), CPR (95%), blood borne pathogens (94%), health (94%) and medication administration (85%). Fewer than 80% of DSS reported receiving training on advocating for persons with disabilities (78%), facilitation of services (78%), staff education, training and self-development (74%), community services and networking (71%), vocational, educational and career supports (60%), or organizational participation (56%).

For most topics there were not differences by type of provider or by region. However, for medication administration, nearly all of the residential DSS reported receiving training but fewer than 87% of vocational DSS did. There were also regional differences, especially for vocational DSS. While 87% of metro area and 85% of rural area DSS in vocational settings reported receiving training on medication administration, only 55% of DSS in GM urban vocational settings reported receiving that training. As might be expected, DSS in residential settings were more likely to report receiving training on community living skills and support while DSS in vocational settings were more likely to have received training on vocational, educational or career supports.

Direct support staff members also rated their knowledge of various training topics. Their skills were rated in one of four levels:

1. Introductory – I have little or no knowledge about this topic
2. Practice – I have some knowledge about this topic. The strategies I use may not be the most effective but they do not harm the people I support.
3. Proficient – I have good knowledge about this topic. I usually use skills effectively with participants at this site but may not know how or be able to use them with participants at other sites or in other situations.
4. Advanced – I have superior knowledge of this topic. I always or almost always use this skill effectively with participants at this site, and I could use this skill effectively with other participants at other sites or in other situations.

Overall, DSS reported they were most knowledgeable about respecting people with disabilities (Average = 3.69), rights of people with disabilities (3.59), abuse and neglect (3.56), and consumer safety (3.50). On the other hand, more than 20% of DSS reported they had only introductory or practice level knowledge about organizational participation (30%), vocational, educational and career supports (30%), advocating for people with disabilities (25%), community services and networking (23%), empowerment and self-determination (21%), facilitating services (including person centered planning and program implementation)(21%), assessing medical conditions (21%), and staff education, training and self-development (20%).

Table G18: Direct Support Staff Training: Percent Trained On Each Topic By Their Current Employer (DSS Survey)

Characteristic	**Residential**			**Vocational**			**Average**	***F***	**Diff**
	Metro	**GM Urban**	**GM Rural**	**Metro**	**GM Urban**	**GM Rural**			
Abuse and neglect	99	98	100	97	100	100	99	0.59	
Agency policies and procedures	95	98	97	100	100	100	98	0.56	
Rights of people with disabilities	95	100	100	94	100	100	98	1.38	
Consumer safety	95	98	100	94	100	100	97	0.89	
Documentation	99	95	97	100	91	95	97	0.56	
First Aid	100	96	95	94	100	100	97	0.82	
Respecting people with disabilities	93	96	97	94	100	100	96	0.57	
CPR	95	94	95	94	100	100	95	0.37	
Blood Borne pathogens	98	97	100	91	100	100	94	2.45*	
Health	88	96	97	94	100	90	94	0.97	
Med. Administration	98	96	95	87	55	85	91	5.51***	P,R,I
Crisis intervention, behavioral supports	81	87	97	91	82	85	88	1.17	
Teamwork	74	87	95	91	91	90	87	1.77	
Communication	91	73	95	74	87	92	86	1.93	
Assessing Medical Conditions	86	79	87	81	91	85	84	0.39	
Formal and informal assessment	77	87	95	87	73	70	84	1.93	
Community living skills and support	81	92	92	75	64	65	83	3.02*	P
Empowerment and self-determination	86	85	85	81	64	75	82	0.82	
Advocating for people w/ disabilities	72	75	85	87	73	70	78	0.93	
Facilitation of services	91	82	60	77	73	85	78	1.76	
Staff education, training/development	63	75	77	78	82	80	74	0.98	
Community services and networking	63	75	79	72	55	65	71	0.98	
Vocational, educ. and career supports	40	54	62	84	82	65	60	4.00**	P
Organizational participation	51	58	67	56	45	45	56	0.74	

N **=** 197; * $p < .05$, ** $p < .01$, *** $p < .001$

In the overall multivariate analysis of variance, there were significant differences in the proportion receiving training from their current employer by provider type (F = 4.07, $p < .001$) and an interaction between provider type and region (F = 1.46, $p < .05$). The overall F column on this table refers to the follow up tests for each training topic. R = Region, P = Provider type (residential vs. vocational) I = Interaction of R and P; [1]Metro less than rural; [2]Metro more than GM urban.

Table G19: DSS Knowledge of Training Topics (DSS Survey)

Characteristic	Total	% less than Proficient
Respecting people with disabilities	3.69	2.3%
Rights of people with disabilities	3.59	2.3%
Abuse and neglect	3.56	4.6%
Consumer safety (safe environments)	3.50	5.0%
Documentation	3.45	5.4%
Medication Administration	3.41	7.3%
CPR	3.39	7.8%
Agency policies and procedures	3.37	8.2%
First Aid	3.36	6.9%
Blood Borne pathogens	3.35	12.4%
Health	3.32	6.9%
Teamwork	3.32	8.3%
Community living skills and support	3.26	12.4%
Communication (staff, consumers, families)	3.24	11.5%
Formal and informal assessment of needs, desires and interests of participants	3.16	13.8%
Empowerment and self-determination	3.12	20.6%
Crisis intervention, positive behavioral supports	3.07	17.9%
Facilitation of services (person centered planning, program implementation)	3.07	20.6%
Advocating for people with disabilities	3.01	24.8%
Assessing Medical Conditions	2.96	20.6%
Community services and networking (community access, facilitating friendships)	2.93	22.9%
Education, training and self development for staff	2.91	20.2%
Vocational, educational and career supports	2.77	30.3%
Organizational participation (quality assurance, budgets, committees)	2.62	30.3%

N = 135; There were no differences by region or provider type on a multivariate analysis of variance.

Direct support respondents evaluated the overall quality of the training they had received from their providers (See Table G20). In general DSS, agreed or strongly agreed that the orientation and training they had received helped them to complete most of their specific job responsibilities (93.4%), that the training assisted them to develop interaction skills with the people they support (88.8%), and helped them to improve the quality of life of the people they support (88.0%). However, 20.3% of DSS reported that the training they had received missed important information needed to perform their job. While most DSS would recommend the training they had received to new employees (73.2%), 35.3% said the agency should improve its current training program and 21.5% said the agency should develop a new training program. Just over half of the DSS reported that their agency's training program was excellent (51.5%).

Table G20: DSS Rating of Training Provided by Their Current Employer (DSS Survey)			
Characteristics	Mean	% Agree	% Strongly Agree
The orientation and training I have received so far has:			
Prepared me to complete most of my specific job responsibilities	4.30	52.0%	39.7%
Assisted me to develop my interaction skills with people I support	4.21	47.0%	39.3%
Helped me to improve quality of life for the people I support	4.20	48.3%	37.2%
Been worthwhile	4.10	41.0%	37.2%
Missed important information I need to perform my job	2.28	13.2%	8.1%
Not sparked my interest	2.09	11.5%	3.8%
Recommendations and Overall Ratings:			
I would recommend the training I have received to new employees	4.08	41.5%	36.3%
This agency should improve its current training program	3.03	24.4%	12.4%
This agency should develop a new training program	2.64	13.2%	9.8%
Overall, this organization's orientation and training program is excellent.	3.64	35.5%	23.9%

N = 274; There were no differences by region or provider type on a multivariate analysis of variance.
1 = Strongly disagree; 5 = Strongly Agree (SA)

County perspective. In general, counties do not train providers on strategies to meet the needs of persons with extensive physical, behavioral or health support needs. Almost all of the counties reported that they did not see that as their role. A few of the counties reported that they try to facilitate providers sharing resources and networking to create efficiency and availability of training opportunities to more providers. A number of counties also reported that they have in the past held provider meetings on certain topics. Almost all of the counties indicated that the staff from the regional crisis response teams provided a significant amount of training on supporting individuals with challenging behavioral support needs. One county reported that they co-sponsored annual training in conjunction with their Community Transition Education Council (CTEC) and another county reported that the specialist staff from their schools often are hired to provide training to the families of HCBS service recipients.

Staff Satisfaction

The final set of questions on the direct support staff survey provided information about staff satisfaction with various components of their jobs (See Table G21). Overall, DSS were most satisfied with their relationships with their co-workers (3.42), the availability of their supervisor (3.35), and the attitudes of consumers about their agency (3.30). They were least satisfied with their pay (2.26), the support they received from administrators or managers (2.85), the support they received from case managers (2.85), the benefits they received (2.90), and the morale in their office or program (2.90). There were no differences between DSS in residential versus vocational programs. There were three cases in which satisfaction varied by region. DSS in metro counties were significantly less satisfied with their pay than DSS in rural counties. DSS in rural counties were significantly more satisfied with morale and opportunities to share ideas about improving services than DSS in metro or GM urban counties.

Table G21: Staff Satisfaction (DSS Survey)

Outcome	Region			Average	*F*
	Metro	GM Urban	GM Rural		
Orientation and Training					
Clear job description available	3.21	3.20	3.42	3.26	0.98
Expectations about job performance communicated	3.23	3.11	3.47	3.26	1.94
Complete and timely agency and site orientation	3.10	3.07	3.26	3.13	0.74
Sufficient training materials and opportunities	2.92	3.23	3.34	3.13	2.79
Supervision					
Supervisor availability	3.44	3.27	3.32	3.35	1.84
Fairness in supervision and employment opportunities	3.21	3.09	3.16	3.16	2.57
Feedback and evaluation of performance	3.02	3.02	3.32	3.10	0.96
Recognition For Accomplishments	3.15	2.91	3.16	3.08	3.05
Compensation and Benefits					
Paid time off received (PTO, sick, vacation, holiday)	2.92	2.98	3.34	3.06	1.94
Eligibility for benefits	3.08	2.80	3.16	3.01	0.63
Eligibility for paid time off	2.90	2.93	3.21	2.99	1.18
Benefits received (health and dental, retirement)	3.00	2.70	2.97	2.90	0.45
Rate of pay for work	1.98	2.39	2.58	2.26	3.17*
Other Aspects of Job					
Relationship with co-workers	3.45	3.30	3.50	3.42	1.53
Attitude of your customers toward this agency	3.32	3.25	3.32	3.30	0.49
Schedule and flexibility	3.02	3.39	3.50	3.26	4.36*
Access to internal job postings	3.13	3.39	3.29	3.25	0.87
Relationship with supervisor's manager	3.19	3.27	3.29	3.24	0.26
Opportunities to share ideas about improving services	3.19	3.09	3.34	3.20	3.06*
Degree to which your skills are used	3.11	3.07	3.29	3.15	1.24
Opportunities for ongoing development	2.87	3.09	3.08	2.99	0.50
Morale in your office or program	2.82	2.86	3.05	2.90	1.32
Level of Support Provided					
By supervisor	3.34	3.14	3.26	3.26	2.54
By families of the people you work with	2.92	2.93	3.29	3.02	2.24
By administrators/managers	2.65	3.00	3.03	2.85	1.30
By Case Managers	2.71	2.80	3.16	2.85	2.99

N = 144. The overall multivariate analysis of variance showed no significant differences between provider types but did show significant differences regionally ($F = 1.71$, $p < .01$). * $p < .05$.
1 = poor, 2 = fair, 3 = good, 4 = excellent

HCBS Waiver Coordinator Perspectives About Providers

HCBS Services provided by the county (not through purchasing of services agreements). In almost all of the counties included in this study case management is the only service that is paid for by HCBS Waiver dollars and actually delivered and managed by county employees. However, there are some exceptions. One metro county provides a day program (DTH) that is partially funded by HCBS dollars. Five of the counties included in this sample reported that they serve as contractors for individuals who want to deliver respite services and one county provide nursing to HCBS recipients through their public health departments.

In almost all of the counties a variety of types of agencies provided various HCBS services. These providers were large for profit corporations, small family run businesses and both large and small non-profit organizations. Perhaps the biggest determinant to the number of agencies available in any of the counties was the size of the county and the geographic location. Small and more rural counties reported that they have fewer providers.

How agencies are selected to serve an individual HCBS recipient? With few exceptions counties considered individual recipient and family opinion when selecting provider agencies for HCBS recipients. This was particularly true for in-home services, respite and other more individualized services. More variation exists in the extent to which individuals and family opinion was considered when SLS services are selected. A few examples are described below:

- Some counties get input from individuals and families with respect to the service providers they are interested in and then submit a Request Response for Proposals from only those provider agencies in which there was interest. Then the county or the county and families interview the providers and make a selection based on the needs of the people who will live in the home and the ability of the provider to meet these needs.
- Some counties leave the decision up to the individual and families with support provided from the county in terms of identifying all possible providers and assisting with scheduling interviews and other activities – this practice was more common in larger counties.
- Some counties reported that although in some circumstances they might use an RFP process, many times they just make the selection based on the reputation of the provider agency.
- In many counties there is an RFP process that includes sending requests out to all providers that currently provide services in the county and then the county case managers and other personnel with some input from the families and individuals make the decision based on the provider responses to the RFP.
- In a few GM rural counties, the selection process is limited because there might be as few as one SLS provider in the county.

Inability of existing providers to meet the amount or type of HCBS service demand. Almost all counties reported substantial difficulty finding existing providers to meet the amount and type of service demand for HCBS services. One county said, “That would be YES in capital letters.” Another indicated, “we are lucky to just keep what we already have open.”

The primary barrier identified by counties in meeting demands for HCBS services is the severe workforce crisis. Almost all counties have noticed a decline in the quality and quantity of staff being hired in all types of HCBS services and across all service providers. Counties reported serious declines in the number of people willing to do this kind of work and in the quality and skills of the people who are willing to work in direct support. Additionally, several counties noted that the quality of the supervision provided to direct support staff has decreased.

Several counties reported an increase in incident and maltreatment reports as a result of labor shortages and now field more complaints from case managers and families about staffing related issues (e.g. quality, shortages, lack of needs being met). One county, scheduled to open three new SLS programs on April 1, 2000, reported that by late March the providers had yet been able to hire one staff member (direct care or supervisors). Wage was identified as the most common reason for these difficulties along with poor supervision, low unemployment, a lack of understanding about the type of work people are being asked to do, and increased competition with other human service agencies and other industries.

Many counties reported capacity issues related to a lack of providers qualified to meet the needs of people with high medical and/or behavioral support needs. Severe nursing shortages were reported by one county and have resulted in people within the county advocating for more ICF-MR beds because there does not seem to be such a severe shortage of nurses in these programs.

Other reported barriers included severe housing shortages, a lack of and a decrease in room and board funding options, and an inability to get service providers to meet the needs of people who live in extremely rural areas. One county reported that this serves as a primary barrier to meeting the needs of individuals who live on a Native American reservation in their county because existing providers are not willing to travel to the reservation to deliver services because of the distance involved. In this county, people who needed HCBS Waiver services had to move or travel 60- 100 miles to receive services. Other counties also reported difficulty in finding provider agencies who could meet the needs of people from different cultural backgrounds. Lastly the ability to find new DTH service providers was reported by several counties.

Several counties had already implemented strategies designed to address the above mentioned problems. Of the 21 counties interviewed only one indicated that they felt it was a “provider problem” and therefore they did not see that they had any responsibility to work toward change. Among the strategies counties had employed are:

- Supporting job fairs with county jobs and training agencies and in conjunction with post secondary educational institutions.
- Placing emphasis on increasing the use of community support options under the HCBS so that individuals can receive services from people who are not licensed providers.
- Supporting new providers by linking them with existing providers who can provide mentoring or can actually complete the administrative functions (e.g. billing) of service provision.
- Organizing meetings with key legislators from their communities.
- Conducting a pilot study to determine if increased wages actually decreases turnover and improves retention.
- Coordinating a county wide working group to network, identify solutions and share resources related to recruitment, retention and training of direct support staff.
- Working with county planners to address issues of lack of affordable housing.

Discussion

The evaluation gathered and analyzed information from provider agencies at the service site level to identify the nature and scope of services provided, and the demographics and characteristics of direct support staff who provide HCBS services.

Key findings

Provider agency size/scope

- Sixty-nine percent of residential Supported Living Services (SLS) sites supported four people. The typical site employed 6.5 direct support staff (DSS), one supervisor, and three on-call DSS.
- The typical vocational site supported 29 people and employed 11.6 DSS, one supervisor and 2.5 on-call DSS.
- With few exceptions county waiver coordinators and case managers reported that they considered individual recipient and family opinion when selecting provider agencies for HCBS recipients. This was particularly true for in-home services, respite and other more individualized services. More variation exists in the extent to which individuals and family opinion was considered when SLS services are selected.
- Almost all HCBS waiver coordinators reported substantial difficulty finding existing providers to meet the amount and type of demand for HCBS services.
- Many county waiver coordinators noted particular difficulty in finding providers qualified to address the needs of people with high medical and/or behavioral support needs.
- Some counties reported difficulty in finding providers to support individuals in very rural areas and on American Indian reservations.

DSS recruitment and vacancy

- In this study, 75% of all providers reported finding qualified applicants for DSS positions was a challenge compared to 57% of residential providers in 1995.
- Despite families reporting serious problems getting in-home supports, case managers said families not getting authorized or needed services, and families not finding people to hire was a moderately serious to serious problem.
- Providers reported paying for an average of 46.1 hours of overtime per site in the month prior to the survey. Overtime hours constituted substantially higher proportion of total hours paid in residential site than in vocational settings.
- Average costs for recruitment of a new DSS included $334 per month per site for overtime and $250 per month for local advertising (excluding advertising costs paid by parent agencies).
- While 43% of vocational providers reported using temporary agency employees, only 4% of residential providers did.
- Residential provider vacancy rates were 13.9% in metro counties, 6.0% in urban counties of greater Minnesota, and 8.4% in rural counties. About 4.5% of all DSS hours went unfilled (due to vacancies or staff absences) in the week prior to the survey.
- Residential providers received 2.5 applicants per position in metro counties, 4.1 applicants per position in urban counties of greater Minnesota, and 3.0 applicants per position in rural counties.
- The number of applicants per opening was higher in vocational agencies, and agencies that paid higher DSS starting wages.

DSS wage and benefits

- Starting wages for residential DSS averaged $8.13 and mean wages of all staff averaged $8.81.
- Starting wages for vocational DSS averaged $8.89 and mean wages of all staff averaged $10.49.
- Starting wages in residential settings grew 15% between 1995 and 2000; average "top wages" rose only 9.6% during those years. According to the Minnesota Department of Economic Security, the average wage for all Minnesotans increased by 22.4% between 1995 and 1999.
- Overall, 64% of residential DSS and 83% of vocational DSS were eligible for benefits.
- Thirteen percent of DSS were currently students. While 32% said their employers offered tuition reimbursement, only 6% actually received tuition reimbursement in the previous year.
- Metro area DSS were significantly less satisfied with their pay than DSS in greater Minnesota.

DSS retention

- Forty-six percent of providers said DSS turnover was a problem, and 28% reported DSS training was a problem for them.
- Case managers reported that the high number of different DSS in the lives of consumers, recruiting family foster providers, and recruiting residential and in-home staff were serious to extremely serious problems facing the HCBS program.
- While 40% of DSS said their job responsibilities and working conditions turned out to be what they expected, 45% said they were only somewhat as expected, and 10% said they definitely were not as expected.
- DSS turnover for 1999 averaged 44% in residential settings and 23% in vocational settings.

- Turnover was significantly higher in sites offering lower average wages, serving people with more intense support needs, and in metro counties.
- Forty percent of all residential DSS and 35% of vocational DSS had been in their jobs for less than one year.
- Many families reported turnover was a problem including 50% of families whose family member received out-of-home residential services, 48% of families receiving in-home supports, and 35% of families receiving respite services. Families in urban counties of greater Minnesota were more likely to say that turnover was a problem.
- DSS were most satisfied with their relationships with their co-workers, the availability of their direct supervisor, and the attitudes of consumers about their agency. They were least satisfied with their pay, the support they received from agency administrators and managers, the support they received from case managers, the benefits they received, and the morale in their office or program.

DSS demographics

- DSS in vocational settings were more likely to have a four-year degree than DSS in residential settings (42% vs. 20%).
- Twenty percent of DSS were from non-white racial or ethnic groups.
- Overall, 49% of residential DSS, and 72% of vocational DSS were full-time employees.

DSS training and education

- Seventy-one percent of all DSS were certified to administer medications.
- Residential providers offered more than five hours per year of training on crisis intervention and behavioral supports, medication administration, agency policies and procedures, health and CPR. They offered fewer than 2.5 hours of training per year on respecting people with disabilities, community services and networking, empowerment and self-determination, and advocating for people with disabilities.
- Vocational providers offered more than five hours of training per year on CPR, organizational participation, and program implementation. They offered fewer than 2.5 hours of training per year on respecting people with disabilities, blood borne pathogens, health, assessing medical conditions, rights of individuals with disabilities, and advocating for people with disabilities.
- DSS reported they were most knowledgeable about respecting people with disabilities (average rating 3.69 out of 4 with indicating “advanced” knowledge), abuse and neglect (3.56), and consumer safety (3.50).
- Direct support staff reported that they feel least knowledgeable about organizational participation (2.62), vocational, educational and career supports for people who receive support services (2.77), education, training and self-development for staff (2.91), community services and networking (2.93), and assessing medical conditions (2.96).
- Fifty-nine percent of DSS agreed or strongly agreed that their organization’s orientation and training program is excellent. However, 35% said the agency should improve its current training program and 22% said the agency should develop a new training program.

Other

- Case managers in metro area counties were more concerned about staffing issues (e.g., recruitment, retention, training) than case managers in other regions.

- Almost all county waiver coordinators reported a decline in the quality and quantity of staff being hired. Several noted that the quality of supervision provided to DSS has declined.

What's working?

Both residential and vocational service providers reported that they delivered a large number of hours of training to DSS. On average, each residential site offered 103 hours of training per year and each vocational site offered 81 hours of training per year on a variety of topics. In general, DSS reported that the orientation and training they had received helped them to complete most of their specific job responsibilities, develop interaction skills with the people who support and improve the quality of life of the people they support. About half of the DSS rated their agency's training program as excellent. Direct support staff also report that their supervision, benefits, co-workers and supervisor relationships, schedule and flexibility, opportunities for on-going development, morale, and support from supervisors and families are "good."

Challenges and Concerns

All of the stakeholders who participated in this evaluation reported concerns about the severity and effects of direct support staff vacancies, turnover, and difficulties in recruiting needed staff members. Direct support staff turnover was reported to be 44% in residential settings statewide, and vacancy rates for metro area residential providers exceeded 13%. Many families reported turnover was a problem, including 50% of families whose member received out-of-home residential services, 48% of families receiving in-home supports, and 35% of families receiving respite services. The turnover rates were higher in the urban counties of greater Minnesota.

Seventy-five percent of providers reported difficulty finding qualified applicants for DSS positions. Many counties reported an inability to develop new services and supports or significant delays in doing so because of difficulties in finding qualified staff. All county waiver coordinators interviewed reported that they had seen a decrease in the quality of HCBS because the quality of both direct support staff and supervisors is steadily declining. In addition to DSS shortages, county waiver coordinators reported nursing shortages, severe housing shortages, and difficulty finding providers qualified to address the needs of people with high medical or behavioral needs. Stakeholders perceived staffing issues as one of the greatest barriers to growth and sustainability of the HCBS program. Significant coordinated statewide efforts are needed to address the workforce crisis to ensure that the HCBS program can be sustained.

While DSS receive substantial amounts of training, relatively little of it is reported to focus on essential DSS skills such as formal and informal assessment, advocating for people with disabilities, community services and networking, and empowerment and self-determination. Over one-third of DSS said training should be improved and 22% said their employer's training program should be replaced. Today DSS are expected to assure that individuals are respected, become full citizens within their communities and are supported in achieving their desired life goals. To fulfill such expectations, DSS need skills beyond medication administration, positioning lifting and transferring. DSS need skills in advocating for people they support, and in networking within communities to assist people in developing natural supports, relationships and friendships. They need to understand principles such as self-determination and must be able to take concrete daily action to foster the self-determination of the people they support. DSS must learn to work cohesively with their peers and supervisors to get their jobs done. Efforts are needed to continually share and/or develop tools and resources for agency trainers and DSS to narrow these gaps and assure effective competency-based training for all.

There were significant differences noted in staffing outcomes (turnover, recruitment, satisfaction, training) between agencies that pay higher wages and relatedly between vocational and residential providers, and between private and public providers. These differences suggest a need for attention in policy on wage equity between service types. Additionally, while many of the people who left positions left within the first six months of employment, 59.1% had been in their positions more than a year. The average high wage for long term DSS in service sites increased only 9.6% between 1995 and 2000 an average increase in starting DSS wages of 15%. Salary compression is an important issue for retaining experienced DSS. Wage compensation also appears to be a major challenge to maintaining a skilled workforce. Systemic attention to the important challenges of worker compensation should include incentives for workers to stay in their existing positions.

H. Quality Assurance and Monitoring of Services

Minnesota uses a wide array of the quality assurance and monitoring activities to improve its HCBS program. This evaluation examined those activities from the perspective of families, individual HCBS recipients, providers, stakeholder groups and county HCBS coordinators. Issues addressed include health and safety; abuse, neglect and exploitation; and quality assurance and monitoring.

HCBS Recipient Safety

Adults who receive HCBS and their families were interviewed about how safe they felt in their current service environments and fears they had about being hurt.

Injury caused by people at home. Of the 237 adult sample members who were interviewed (and who did not require a proxy respondent), 85% reported that nobody hurt them (See Table H1). For those who said someone had hurt them, most reported they were hurt by a roommate (7%). Six people (3%) reported being hurt by a staff member and two people reported they had been hurt family members (1%). Individuals in corporate foster care settings were significantly more likely to report that someone where they live hurts them than were individuals in the other types of settings (20.0% vs. 4.3%; $X^2 = 6.47$, $p < .05$).

Table H1: Consumer Report on Who Hurts Them (Consumer Survey)

Type of Home	Roommate	Staff	Family	Other/ Unknown	No one	*N*
Family home	0%	0%	0%	0%	100%	11
Family foster care	0%	0%	0%	0%	100%	11
Own home	4%	4%	0%	0%	91%	23
Corporate foster care	8%	3%	1%	5%	83%	192
Total	7%	3%	1%	4%	85%	237

N=237; Note: Numbers may not total exactly to 100 due to rounding.

Fear. Family members also reported whether or not their family member was afraid of anyone and if so who they were afraid of (see Table H2). Overall, 16.7% of 114 families reported that their family members were afraid of someone in their out-of-home residential placement (10.8% were afraid of a roommate, 2.7% were afraid of a staff person and 1.8% were afraid of someone else). Families of 85 HCBS recipients reported that 11.8% of HCBS recipients were afraid of someone at work. For individuals who received crisis behavioral supports, 21.4% of 28 families reported HCBS recipients fear that someone would hurt them (15.4% feared a roommate, 7.7% were afraid of staff members and 3.8% were afraid of someone else).

Table H2: Family Report on Recipients Fear of Others (Family Survey)		
Where/Whom	**% Afraid**	***N* Afraid**
Afraid of Someone in out-of-home placement (*N*=114)	**16.7**	**19**
Roommate	10.8	12
Staff	2.7	3
Family member	0	0
Someone else	1.8	2
Afraid of someone at work (*N*=85)	**11.8**	**10**
Co-worker	8.3	7
Staff	0.0	0
Strangers	2.3	2
Someone else	0.0	0
Afraid of someone at crisis behavioral environment (*N*=28)	**21.4**	**6**
Roommate/housemate	15.4	4
Staff	7.7	2
Family member	0.0	0
Someone else	3.8	1

Note: Percentages do not add to 100 due to rounding. Families could identify more than one type of person their family member was afraid of.

Sense of Safety

HCBS recipients. HCBS recipients were asked how safe they felt in their home and in their neighborhood. Of 250 individuals interviewed, 90% reported that they felt safe where they live, 6% report feeling in-between safe and not safe and 4% reported not feeling safe at home. Of 242 individuals reporting, 76% reported that they felt safe in their neighborhoods, 13.2% reported feeling between safe and unsafe, and 11.2% reported they did not feel safe in their neighborhood. There were no significant differences by region or setting type on these questions.

Family Members. Family members reported how they perceived their family members safety in a variety of settings (see Table H3). Almost all of families reported that most of the time their family member felt safe while being transported (98%), in their employment/day program (97%), in an out-of-home residential setting (95%) and at school (96%). In contrast, only 83% of families who had used a crisis or behavioral support setting said their family member felt safe in that setting most of the time (14% said their family member sometimes felt safe and 3% said their family member rarely felt safe).

Table H3: Percentage of Individuals Who Feel Safe in Different Settings (Family Survey)				
Setting	**Mostly**	**Sometimes**	**Rarely**	**N**
Transportation	98%	2%	0%	111
Employment/Day Program	97%	3%	0%	112
School	96%	4%	0%	45
Supported Living Services	95%	4%	1%	136
Crisis Behavioral Support Setting	86%	14%	3%	35

Injuries occurring in service settings. Providers reported the number of serious injuries requiring professional medical attention that occurred to the people they support at any given site over the past year. For vocational settings, on average, about one (.99) serious injury requiring professional medical treatment occurred within the past year per site. For residential programs the average number of serious injuries was .41 per year per site. The combined average number of serious injuries per site for

HCBS recipients was .58. Differences in the number of serious injuries between vocational and residential settings were not statistically different once the number of people served per site was considered. No significant differences were detected by region or level of mental retardation.

Victimization. Table H4 presents information from providers regarding the number of individuals at a site that were victims of crimes that were serious enough to be reported to law enforcement. Providers reported that 55 out of 3,912 consumers (1.4%) were alleged victims of crimes reported to law enforcement within the last year (17 of 3,301 individuals served in surveyed vocational sites; 38 of 611 individuals served in residential sites). Of these 32 alleged crimes, (58%) were simple assault; 10 (18%) were larceny; 6 (11%) household burglary; 2 (.04%) were forcible rape, 2 (.04%) criminal sexual assault, and 2 (.04%) were aggravated assault. No information was collected about the identity of the alleged perpetrator for this evaluation.

Table H4: Total Number of HCBS Recipients Who Allegedly Were Victims of Various Crimes in Surveyed Sites (Provider Survey)

Crime	**Allegations in HCBS Settings**		**1997 MN Convictions**
	Residential	**Vocational**	
Victims of Alleged Crimes (Reported to Law Enforcement)			
Simple assault	22	10	22,991
Larceny theft (taking property from owner)	6	4	27,364
Household burglary	6	0	4,212
Forcible rape (rape and attempts to commit rape)	1	1	956
Criminal sexual assault	1	1	1,129
Aggravated assaulted (Using dangerous weapon, feet, fists)	1	1	4,545
Other	1	0	
Personal robbery (using a weapon or force)	0	0	1,478
Arson	0	0	208
Total	38	17	62,983
Number of sites reporting	161	71	
Number of individuals in reporting sites	611	3,301	4,725,419
Allegations/Convictions per person	0.062	0.005	0.013

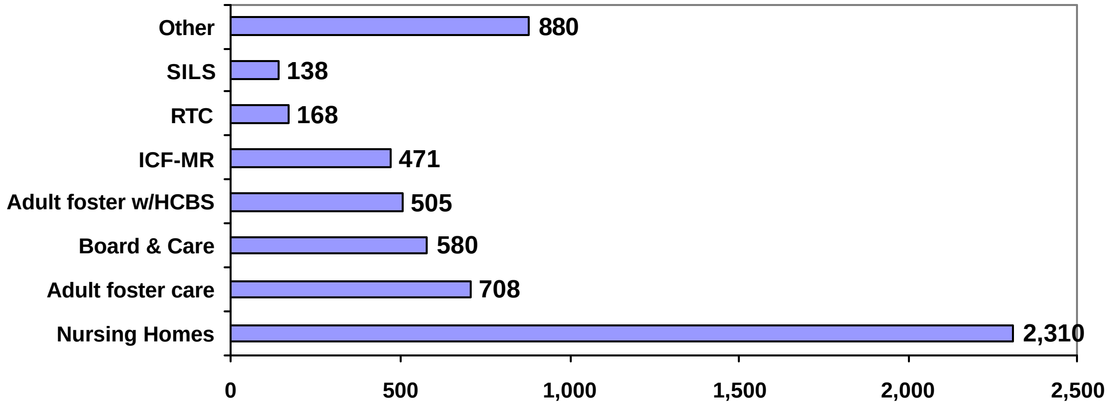
As a point of comparison, about 31% of Minnesotans who were surveyed by Minnesota Planning and the Department of Public Safety reported that they were victims of crime in 1992. About three out of every 10 respondents reported that they were victims of property crime and one out of every 10 was a victim of violent crime (Minnesota Criminal Justice Statistical Analysis Center at Minnesota Planning, 1994).

Another report provided information about actual criminal convictions in Minnesota in 1997 (See Table H4). In that report, there were 22,991 simple assaults, 27,364 larceny thefts, 4,212 household burglaries, 956 forcible rapes, 1,478 personal robbery and 208 arson convictions in 1997 (a rate of 13 convictions per 1,000 Minnesotans). It is difficult to compare the actual 1997 crime statistics to the HCBS reports because one reports actual convictions while the other reports allegations. However, while the most common cause for a conviction in Minnesota was larceny theft, simple assault was the most common type of allegation for persons in residential or vocational settings. In terms of self-reported crimes, persons in HCBS residential settings or vocational settings were much less likely than the population as a whole to report being a victim of a crime (62 per 1,000 for residential settings, 5 per 1,000 for vocational settings versus 300 per 1,000 for the general population). Further investigation may be helpful to determine whether consumers and family member reports would match the provider reports regarding the number of alleged crimes encountered.

Abuse, Neglect And Exploitation

Figure H1 shows the number of alleged maltreatment incidents in 1998 by type of facility as reported in August 1999 by the Department of Human Services Aging and Adult Services Division. This figure reflects reports received by common entry points at the county level.

Figure H1: Number of Maltreatment Reports Submitted to Common Entry Points (Regardless of Disposition) in 1998



Source: DHS (August 1999). Report of vulnerable adult allegations 1998 statewide results

In 1998, there were 505 reports of alleged maltreatment in adult foster care with HCBS services. In comparison there were 708 in adult foster care settings that did not provide HCBS services, 138 in semi-independent living services, 471 in ICF-MR, 580 in Board and Care Facilities, 2,310 in nursing homes, 168 in state regional treatment centers and 880 in other DHS or Minnesota Department of Health licensed settings. In 1998, 5,190 people lived in HCBS funded adult foster care settings, 4,787 adults in adult foster care funded by another source, 1,484 people in SILS settings, 3,804 in ICF-MR settings, 3,014 people in certified or non-certified boarding homes, and 44,303 people in nursing homes (Chen, 1998, DHS, 2000; Prouty, Lakin & Anderson, 2000).

Table H5 reports the number of maltreatment of minors and vulnerable adult reports received by the Department of Human Services Licensing Division in 1998. This table provides information about the number of people who received each type of service in a given year and the rate of reports per consumer that were received (sent by common entry point to DHS Licensing Division Investigations Unit), screened out (in initial disposition determined not to be maltreatment and not requiring further follow-up), referred (does not meet the legal definition of maltreatment but referred to another agency such as police, Minnesota Department of Health, or County licensing units for further follow up and possible action) or assigned (determined that it could possibly be maltreatment and assigned to a state investigations unit staff person for further investigation). This table also includes information on services other than HCBS for a point of comparison.

Table H5: Number of MOMA or VA Reports by Service Type for 1998			
Service Type/ Disposition	**N Consumers**	**% of Reports Received**	**Rate per Consumer**
HCBS (Not Adult Foster Care)	**1,321**		
Received	68		0.051
Screened out	19	27.9%	0.014
Referred	34	50.0%	0.026
Assigned	15	22.1%	0.011
HCBS (Adult Foster Care)	**5,190**		
Received	508		0.098
Screened out	3	0.6%	0.001
Referred	426	83.9%	0.082
Assigned	79	15.6%	0.015
Semi-Independent Living	**1,484**		
Received	17		0.011
Screened out	6	35.3%	0.004
Referred	8	47.1%	0.005
Assigned	3	17.6%	0.002
ICF-MR	**3,804**		
Received	467		0.123
Screened out	304	65.1%	0.080
Referred	84	18.0%	0.022
Assigned	79	16.9%	0.021
DTH	**10,447**		
Received	305		0.029
Screened out	123	40.3%	0.012
Referred	133	43.6%	0.013
Assigned	49	16.1%	0.005

Source: May 2000: MN Review and Analysis of trends in Agency Maltreatment Reports- DRAFT

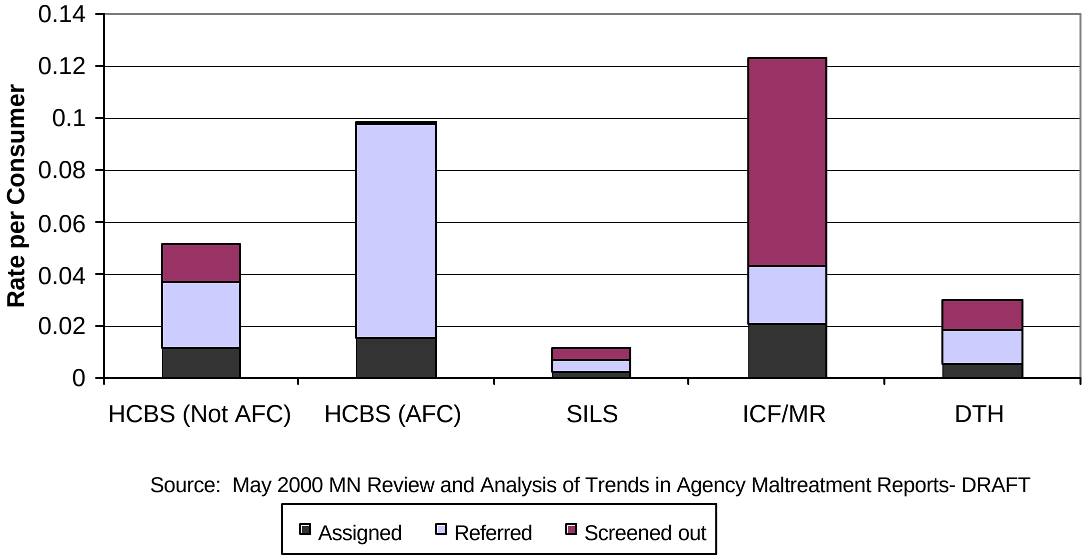
MOMA = Maltreatment of Minors Act; VA = Vulnerable Adults Act

In 1998, 68 maltreatment reports were received by DHS Licensing for HCBS services not provided in adult foster care settings. Of those, 19 (28%) were screened out, 34 (50%) were referred and 15 (22%) were assigned to an investigator. For HCBS services provided in Adult Foster Care settings, 508 reports were received. Of these 3 (.6%) were screened out, 426 (84%) were referred, and 79 (16%) were assigned. A total of 17 reports were received for persons in SILS settings, 467 for persons in ICF-MR settings, and 305 for persons in DTH settings. Because this table does not describe whether allegations were substantiated or not, it should not be used to assess which type of setting is safer. It only indicates the rate of reporting potential maltreatment and the system response to those reports.

Figure H2 presents the number of report received per consumer in MR/RC programs in1998. In 1998, the number of reports received per consumer was highest in ICF-MR programs and lowest in SILS programs. The process used for handling cases that were not considered to meet the legal standard for maltreatment (those that are referred or screened out) varied for different programs. Specifically, for reports related to Adult Foster Care settings, almost all reports that were not considered to be maltreatment were referred to another agency. This occurs because counties license Adult Foster Care settings and all reports that are not maltreatment are referred back to the county for further consideration. This means that a comprehensive evaluation of critical incidents in HCBS funded adult foster care settings (e.g., incidents that do not meet the criteria for maltreatment but which were not screened out) would require an examination of what happens to those reports once they are referred back to the county. Reports not considered maltreatment related to persons in ICF-MR or DTH settings are more likely to be screened out with no further action being taken.

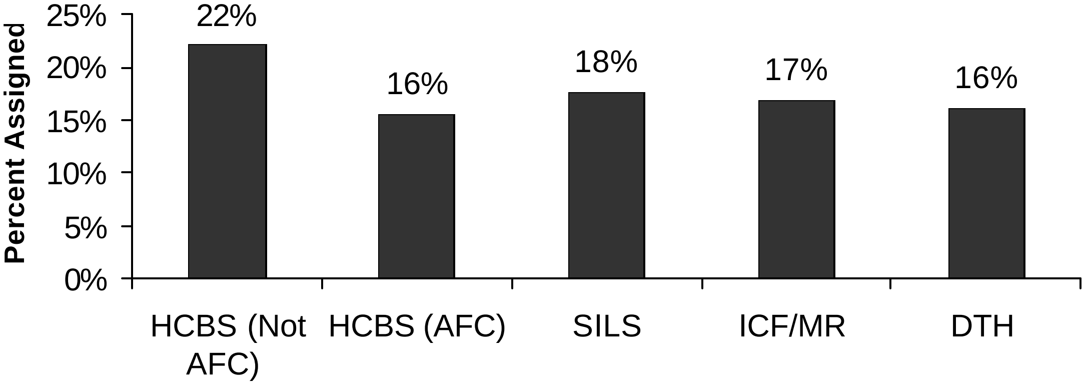
Figure H3 shows the proportion of all reports received that were assigned for further investigation by DHS Licensing. Reports related HCBS services not provided in Adult Foster care settings were slightly more likely to have been assigned for investigation in 1998 than reports received regarding other types of services (22% vs. 16% to 18%).

Figure H2: Number of MOMA or VA Reports Per Consumer in 1998



Source: May 2000 MN Review and Analysis of Trends in Agency Maltreatment Reports- DRAFT

Figure H3: Percent of Reports Assigned for DHS Investigation in 1998



Source: May 2000 MN Review and Analysis of Trends in Agency Maltreatment Reports (DRAFT)

Data from the Department of Human Services Licensing Division Investigations Unit regarding allegations that were determined not to be maltreatment were reviewed for this evaluation. Word-processed logs of maltreatment reports that were received by the DHS Licensing Unit, reviewed by senior investigations unit staff and determined to not be cases of maltreatment and therefore not requiring further investigation as maltreatment were reviewed. These logs described the incident and provided general information about action taken by the investigations unit staff with respect to making referrals or screening out. A total of 1,856 logged reports referred to the DHS Licensing Division investigations unit in 1998 and determined not to be incidents of maltreatment as defined by the Vulnerable Adults Act or the Maltreatment of Minor Act were reviewed. Researchers at the University of MN coded each of these incidents into one of 11 descriptive categories: allegations of sexual abuse, physical assault, emotional/verbal abuse, neglect, financial exploitation, use of aversive or deprivation procedures, self-abuse, client-to-client abuse, unexplained injury, needed more information, or multiple incident types.

Table H6: 1998 MR/RC Reports Not Investigated: Initial Disposition -- Not Maltreatment

	Allegation Type											
DHS Action	**Neglect**	**Unexplained-Injury**	**Physical Abuse**	**Emotional/ Verbal Abuse**	**Client to Client**	**Financial Exploitation**	**Sexual Abuse**	**Aversive Deprivation**	**Self-Abuse**	**More info Needed**	**Multiple Incidents**	**Total**
Screened Out	170	134	42	21	58	12	18	1	4	39	2	493
Referred to												
County Adult Foster Care	389	53	57	45	29	25	22	10	5	36	0	643
DHS MR/RC Unit	250	19	41	58	23	39	11	19	1	23	1	480
Office of Health Facilities Complaints	34	10	13	6	4	6	6	2	0	18	1	98
Adult Protection	27	3	13	3	3	5	14	0	1	15	2	80
County (Unspecified)	1	0	3	0	1	0	1	0	0	5	0	11
Police	0	0	0	1	1	2	5	0	0	2	0	10
Ombudsman	2	0	0	0	0	0	0	0	0	6	0	7
Child Protection	2	0	3	0	0	0	1	0	0	0	0	6
DHS MH/CD	1	0	1	0	0	2	0	0	1	0	0	5
Other	5	1	2	1	1	0	1	0	0	2	0	13
Unknown	0	0	0	0	0	0	0	0	0	10	0	10
Total	881	220	175	135	120	91	79	32	12	156	6	1,856

Source – Data provided by the MDH-Licensing Division's Investigation Unit regarding referrals/reports initially disposed as a non-maltreatment case and are screened out or referred to a more appropriate agency.

As Table H6 shows, of 1,856 reports determined not to be maltreatment as defined by Minnesota's Vulnerable Adult Act or Maltreatment of Minors Act, 493 were screened out and the remaining 1,363 were referred to other related agencies. The majority of the incidents were referred to adult foster care units at the county level and to the DHS MR/RC unit. The most common type of report screened out or referred to another jurisdiction was alleged neglect (881 reports). Allegations related to unexplained injuries (220), physical assault (175), emotional/verbal assault (135) and client-to-client aggression were also common. Based on the information included in the investigation unit logs, it was not possible to code the type of incident for 156 reported incidents. No information was reviewed about what happened to reports once they were referred to another unit or agency for further processing.

Table H7 provides an overview of the final dispositions for maltreatment reports that were assigned to an investigation's unit staff person for a full investigation for 1998. Once assigned and when an investigation has been completed there are four possible outcomes: substantiated, inconclusive, false or other. A disposition of "other" means that either no determination will be made or that the investigations unit had no jurisdiction in that particular case. Of all investigations in 1998, 28.9% were substantiated, 29.8% were inconclusive, 40.4% were false, and 0.9% had another disposition. The total number of substantiated maltreatment reports was 62 (.010 per consumer) in HCBS settings, 32 (0.008) in ICF-MR settings, 7 (.001) in DTH, and 0 in SILS. Overall, 29.1% of investigations in HCBS, 36.4% in ICF-MR, 15.2% in DTH, and 0% in SILS were substantiated.

Table H7: Disposition of Assigned and Further Investigated Maltreatment Reports for 1998

Service Type/ Disposition	N Reports	% of Reports	Rate Per Consumer
HCBS (N = 6511)			
Substantiated	62	29.1%	0.010
Inconclusive	66	31.0	0.010
False	85	39.9	0.013
Other	0	0.0	0.000
Total	213	100	0.033
ICF-MR (N = 3,804)			
Substantiated	32	36.4	0.008
Inconclusive	23	26.1	0.006
False	32	36.4	0.008
Other	1	1.1	0.000
Total	88	100	0.023
DTH (N = 10,447)			
Substantiated	7	15.2	0.001
Inconclusive	14	30.4	0.001
False	24	52.2	0.002
Other	1	2.2	0.000
Total	146	100	0.004
Semi-Independent Living (N = 1,484)			
Substantiated	0	0	0.000
Inconclusive	1	100	0.001
False	0	0	0.000
Other	0	0	0.000
Total	1	100	0.001
Total MR/RC			
Substantiated	101	28.9	
Inconclusive	104	29.8	
False	141	40.4	
Other	3	0.9	
Total	349	100	

The answer to the question, is one type of service more dangerous than another, is complex. This data suggests that the difference between HCBS and ICF-MR settings in the rate of substantiated maltreatment is small for the year 1998 (8 per 1,000 vs. 10 per 1,000 consumers). However, this analysis does not take into account risks other than substantiated maltreatment. For example, it does not compare the rate of injuries caused by the violence of a roommate. An analysis of that type of risk would require follow-up on incidents of consumer-to-consumer violence that were referred to find out which of the alleged incidents occurred, and what types of settings were involved. This analysis also excludes most maltreatment that occurred in a family home because that type of maltreatment is investigated at the county level rather than at the state level.

Another important question is whether differences in the rate of substantiated maltreatment varied over time. Between 1995 and 1998, there were a total of 5 cases of substantiated maltreatment in SILS settings (a rate of 0.001 per year per consumer). Between 1993 and 1998, there were 380 substantiated cases of maltreatment in ICF-MR settings (a rate of 0.015 per year per consumer). Between 1996 and 1998, there were 145 substantiated cases of maltreatment in adult foster care settings that were also licensed under Rule 42 (a rate of 0.010 per year per consumer). Finally, between 1993 and 1998, there were 27 substantiated cases of maltreatment in settings licensed under Rule 42 but not licensed as adult foster care (a rate of 0.004 per year per consumer). Over a three to six year time frame, the rate of substantiated maltreatment per consumer in HCBS settings was slightly lower than the rate per consumer in ICF-MR settings.

Table H8 presents information on the types of substantiated maltreatment in HCBS, ICF-MR and DTH for years 1993 to 1997 (1998 data were not available). This table excludes at least 84 cases of substantiated maltreatment that occurred in 1996 and 1997 in settings dually licensed as adult foster care and Rule 42 (HCBS) services. Of the cases examined on Table H8, in HCBS services 50.5% of all substantiated maltreatment cases were neglect; 15.6% were physical abuse and 3.9% were sexual abuse. The DHS licensing unit classified the other 29.8% of cases as something other than neglect, physical abuse or sexual abuse. The percent substantiated neglect and "other" substantiated maltreatment were very similar for HCBS and ICF-MR settings. The percent of physical abuse was slightly higher in ICF-MR and the percent of sexual abuse was slightly higher in HCBS.

Table H8: Types of Substantiated Maltreatment in DHS Licensed MR/RC Services 1993-1997

	Number of Substantiated Cases					**Percent of Substantiated Cases**				
Year	**Physical**	**Sexual**	**Neglect**	**Other**	**Total**	**Physical**	**Sexual**	**Neglect**	**Other**	**Total**
ICF-MR										
1993	9	4	26	19	58	15.5%	6.9%	44.8%	32.8%	100.0%
1994	16	3	55	37	111	14.4%	2.7%	49.5%	33.3%	100.0%
1995	17	2	45	22	86	19.8%	2.3%	52.3%	25.6%	100.0%
1996	11	2	25	20	58	19.0%	3.4%	43.1%	34.5%	100.0%
1997	6	0	12	12	30	20.0%	0.0%	40.0%	40.0%	100.0%
Total	59	11	163	110	343	17.2%	3.2%	47.5%	32.1%	100.0%
DTH										
1993	4	2	5	2	13	30.8%	15.4%	38.5%	15.4%	100.0%
1994	6	2	30	14	52	11.5%	3.8%	57.7%	26.9%	100.0%
1995	0	0	15	6	21	0.0%	0.0%	71.4%	28.6%	100.0%
1996	2	1	14	1	18	11.1%	5.6%	77.8%	5.6%	100.0%
1997	4	0	7	2	13	30.8%	0.0%	53.8%	15.4%	100.0%
Total	16	5	71	25	117	13.7%	4.3%	60.7%	21.4%	100.0%
HCBS										
1993	0	1	1	0	2	0.0%	50.0%	50.0%	0.0%	100.0%
1994	1	0	5	6	12	8.3%	0.0%	41.7%	50.0%	100.0%
1995	0	1	3	3	7	0.0%	14.3%	42.9%	42.9%	100.0%
1996	0	0	1	1	2	0.0%	0.0%	50.0%	50.0%	100.0%
1997	0	1	2	0	3	0.0%	33.3%	66.7%	0.0%	100.0%
Total	1	3	12	10	26	3.8%	11.5%	46.2%	38.5%	100.0%
TOTAL	76	19	246	145	486	15.6%	3.9%	50.5%	29.8%	100.0%

Total is less than 100% due to rounding

Source: May 2000: MN Review and Analysis of trends in Agency Maltreatment Reports- DRAFT

Questionable Death Investigations

Data from the DHS Licensing Division's Investigation Unit indicates that between 1995 and 1999, eight deaths of persons served in HCBS adult foster care settings were investigated. Of those, four deaths involved substantiated maltreatment (1.03 per 1000 individuals served) (see Table H9). Ten questionable deaths involving persons in adult foster care (some of which involved persons with MR/RC and others of which involved other groups) were investigated four of which involved (but may or may not have been caused directly by) substantiated maltreatment (.66 per 1000 individuals served). This compares to 6 investigated questionable deaths between 1995 and 1999 in ICFs-MR, of which 4 involved but may or may not have been caused by substantiated maltreatment (.93 per 1000 people served).

Only four deaths between 1995 and 1999 were actually determined to be the direct result of maltreatment (one in 1996, two in 1997 and one in 1998). All four involved persons with MR/RC. Three occurred in programs licensed as Adult Foster Care settings that provided HCBS services. The fourth also occurred in a licensed Adult Foster Care setting, but HCBS services were not provided to that person. In two cases the death was due to lack of supervision, one was due to failure to provide needed health care and one involved both a lack of supervision and a failure to provide needed health care. As a point of comparison the average death rate in MN for 1998 was 7.87 per 1,000 residents and in the U.S. it was 8.65 per 1,000 residents (Murphy, 2000).

Table H9: Five Year (1993-1998) Rates of Deaths Investigated/Substantiated per 1,000 Consumers with MR/RC Served

Service Type	Investigated Deaths	Average *N* Consumers	Investigated Rate	*N* Substantiated	Substantiated Rate
SILS	1	1,410	0.71	0	0.00
ICF-MR	6	4,284	1.40	4	0.93
HCBS Adult Foster Care	8	3,892	2.06	4	1.03
Adult Foster Care (HCBS or other)	10	6,085	1.64	4	0.66

May 2000: MN Review and Analysis of trends in Agency Maltreatment Reports- DRAFT

Direct Support Staff Reporting of Maltreatment

Direct support staff members in residential and vocational programs serving people with MR/RC have responsibility to report observed maltreatment. Almost all direct support staff surveyed for this evaluation (99%) reported that they knew how to report an incident of maltreatment. Only 63% reported that they received *any* feedback regarding what was done in response to the report they had filed.

Twenty-nine percent of the DSS respondents reported that they were afraid they might lose their job if someone filed a vulnerable adult report against them whether or not the report was true or substantiated. When asked about the fairness of the maltreatment investigations system in Minnesota 95% of the DSS respondents reported that they thought it was fair and 5% reported that it was not fair (see Table H10).

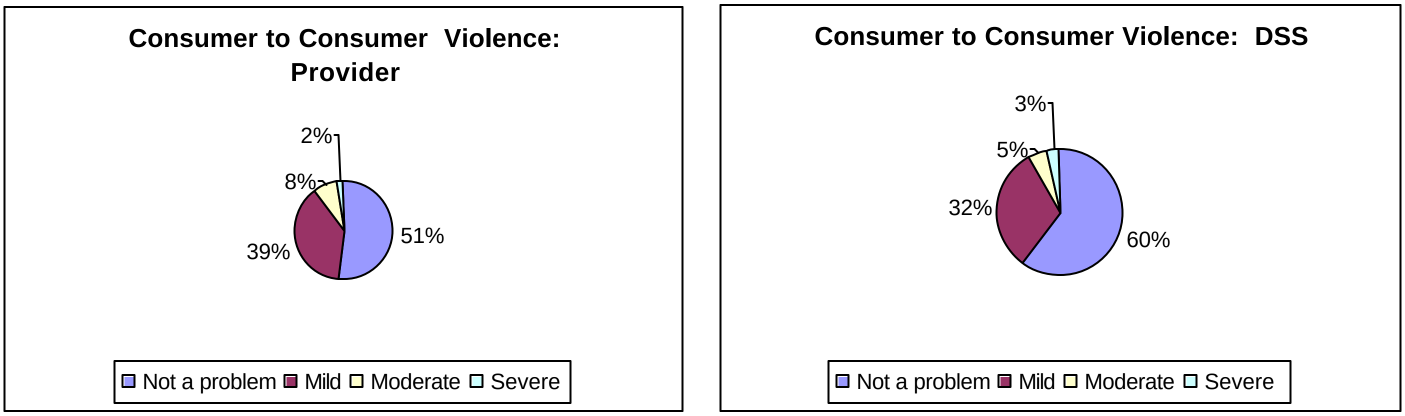
Table H10: Direct Support Staff Experiences Regarding VA Maltreatment Report (*N*=226)	
Experience or Perception	**Total**
Know how to report VA	99%
Afraid of job loss if someone reports VA (whether true or not)	29%
Did not get adequate feedback regarding VA report made	27%
Observed another person commit maltreatment	26%
Discouraged or prevented from reporting:	
Possible maltreatment (by Sup=7%, by co-worker 2%)	9%
Staff misconduct	10%
Medication error	7%
Client to client violence	6%
Consumer injury	3%
Theft of consumer belongings	3%
Client to client sexual acting out	2%
Theft of agency belongings	2%
Fairness of the maltreatment investigation system	
Definitely not fair	2%
Mostly unfair	3%
Mostly fair	36%
Definitely fair	59%

Of the direct support staff respondents, 26% reported that they had observed an incident of abuse, neglect or exploitation and of these 9% reported that they had been discouraged or prevented from reporting the incident by co-workers (2%) or supervisors (7%). Direct support staff provided information on the types of incidents for which they were discouraged or prevented from filing a vulnerable adult maltreatment report. These included incidents related to staff misconduct (10%), medication errors (7%), consumer to consumer violence (6%), injury to client (3%), theft of consumer property or belongings (3%), client-to-client sexual incidents (2%), and theft by an agency staff (2%).

Consumer-to-Consumer Violence

Direct support staff and providers were asked about the seriousness of consumer-to-consumer violence. Both groups reported that this was a problem. A total of 40% direct support staff and 49% of the providers reporting that consumer-to-consumer violence was a mild to severe problem.

Figure H4: DSS Provider/Opinions Seriousness of Consumer-to-Consumer Violence and Provider Type (DSS Survey)



Consumer to Consumer Violence: Provider

Consumer to Consumer Violence: DSS

Quality Assurance Monitoring

Providers, case managers and HCBS Waiver Coordinators reported their opinions regarding the quality assurance and monitoring system for HCBS services in Minnesota. Specifically providers were asked to rate on a scale of one to four (one being poor and four being excellent) the quality of their interactions with county staff, county and state licensing, standard relevance, helpfulness of licensing reviews, expectations from the state, focus of monitoring activities on individual recipients, available technical assistance in response to activities, health and safety issues, general knowledge of licensors about the service type and how well conflict with the state is managed.

Table H11 presents provider opinions across these dimensions. Overall, providers were most satisfied with state reviewers knowing about their setting, the quality of county licensing and the quality of interactions with county staff. They were least satisfied with technical assistance on quality assurance provided by the state, the extent to which efforts focus on interviews with consumers and the helpfulness of state technical assistance regarding quality assurance.

Table H11: Mean Satisfaction with Quality Assurance Monitoring by Region (Provider Survey)

Component of Satisfaction	Metro *N*=36	GM Urban *N*=35	GM Rural *N*=24	*F*/Sig.	Total
State reviewers know this type of home	3.04	3.07	3.53	3.55*	3.18
Quality of county licensing	3.00	3.09	3.33	1.12	3.13
Quality of interactions with county staff	2.97	2.97	3.42	4.10*	3.08
Quality of state licensing	2.89	2.91	3.47	5.62**	3.04
Clear expectations from state	2.85	2.77	3.32	3.53*	2.93
State identifies health and safety problems	2.73	2.87	3.16	2.24	2.89
State standard relevance	2.68	2.71	3.44	7.77**	2.87
Conflict with state resolved well	2.40	2.80	3.21	6.14**	2.80
Helpful of state license reviews	2.46	2.63	3.32	7.72**	2.74
State focuses on interviews for consumers	2.44	2.68	3.21	5.80**	2.73
State technical assistance	2.16	2.54	2.74	2.18	2.46

*p <.05, **p <.01; 1 = Poor, 2 = Fair, 3 = Good 4 = Excellent

Significant regional differences were found with providers in GM rural counties being significantly more satisfied then in GM urban and metro counties across the following dimensions: quality of interactions with the county, quality of state licensing, relevance of state standards, helpfulness of state licensing reviews, clear expectations form the state, focus of quality assurance on interviews with consumers, knowledge of the state regarding the type of service provided and how well conflict is resolve with the state.

Case managers also provided their opinions regarding county involvement in quality assurance and monitoring. Table H12 presents information regarding case manager opinions about what quality assurance and monitoring activities their county "should" be involved with and those that their county "is" involved with. Case managers reported that counties "should" survey families regarding satisfaction with services 91.7% of the time and 56.1% reported that their county "does" survey families. Similarly 100% of case managers reported that counties "should" expect providers to survey counties. In 85% of the counties case managers expected providers to survey families.

Table H12: County Involvement in Quality Monitoring (General Case Manager Survey)

	Strongly Disagree	Disagree	Agree	Strongly Agree
County "should" survey families	0%	8.3%	64.6%	27.1%
County "does" survey families	4.9%	39.0%	29.3%	26.8%
County "should" expect providers to survey families	0%	0%	67.3%	32.7%
County "does" expect providers to survey families	2.5%	22.5%	62.5%	12.5%
Case manager "should" monitor satisfaction	2.0%	5.0%	63.3%	20.4%
Case manager "does" monitor satisfaction	2.1%	29.2%	52.1%	16.7%
County "should" have a consumer advisory council	0%	11.6%	76.7%	11.6%
County "does" have a consumer advisory council	5.7%	37.1%	42.9%	14.3%
State QA system "should" gather from and provide information to families	0%	8.7%	73.9%	17.4%
State QA system "does" gather from and provide information to families	11.%	36.1%	52.8%	0%

N=51

A total of 83.7% of case managers reported that they themselves "should" monitor quality but only 68.8% of these individuals reported that they did monitor quality. With respect to consumer advisory councils 88.3% of the case managers surveyed reported that they felt counties "should" have councils yet only 52.7% reported that the county in which they worked actually did have a consumer advisory council. Lastly, case managers reported strongly that the state quality assurance monitoring activities "should" gather information from and provide information to families regarding quality (91.3%) however, only 52.8% of case managers reported that the state's system did this.

Table H13: Outcomes of Minnesota's Quality Assurance System (General Case Manager)

Quality Assurance for HCBS Services	Metro	GM Urban	GM Rural	*F*/Sig.	Total
Assures health and physician services	2.63	3.00	3.18	3.05	2.88
Has a system for consumer complaints	2.58	2.44	3.18	3.32*	2.72
Assures basic rights and dignity	2.60	2.67	2.82	0.31	2.68
Assures appropriate dental care	2.58	2.40	3.00	1.66	2.65
Assures physical safety	2.33	3.00	2.92	4.04*	2.64
Assures medication safety	2.26	3.00	2.83	5.89**	2.60
Assures effective reporting and follows up on incidents involving VA	2.15	2.67	2.91	3.28*	2.48
Assures people get needed services	2.32	2.44	2.55	0.46	2.41
Has adequate background checks for staff	2.25	2.67	2.42	0.91	2.39
Assures proper staff training	2.05	2.67	2.42	1.93	2.29
Assures people get what is paid for	2.16	2.44	2.36	0.63	2.28
Uses information obtained through QA activities to improve services	2.06	2.25	2.36	0.57	2.19
Gives consumers access to QA information	1.94	2.11	2.20	0.49	2.06
Provides quality training to case managers	1.99	2.49	1.84	1.87	2.03
Recognizes exemplary performance	2.00	2.13	1.91	0.17	2.00
Average quality of services to individuals	2.72	2.93	2.71	0.61	2.76

N=51; 1 = Poor, 2 = Fair, 3 = Good, 4 = Excellent

Case managers were asked to report on the outcomes of Minnesota's quality assurance and monitoring system for HCBS services (See Table H13). Across the quality assurance outcomes measured none were considered by case managers to be excellent. Six were rated good (i.e., 2.5 to 3.5) and nine were rated fair (1.5 to 2.5). Statewide, the lowest ratings were for recognition of exemplary performance (2.00), provision of quality training for case managers (2.03), giving consumers access to quality assurance information (2.06), and using information obtained through quality assurance activities to improve services (2.16). Significant regional differences were found. Case managers in metro counties were significantly less likely to report that Minnesota's quality assurance system assures physical and medication safety. Case managers who worked in GM rural counties were more likely to report that Minnesota's quality assurance and monitoring system follows up on vulnerable adult reports and provides a mechanism for consumer complaints.

County HCBS Waiver Coordinators Perspective

County review state licensing reports on HCBS providers. In every county there is at least one designated person that reviews licensing reports. These reports almost always eventually get forwarded to the case managers responsible for the site on which the report was developed. Generally case managers are responsible for follow up. However, in many counties, the HCBS Waiver Coordinator and/or the person who develops the contracts with agencies might also be involved. HCBS Coordinators had differing opinions regarding the timeliness in which they receive licensing reports from the state DHS Licensing Division. Some counties reported that they never get the reports, others reported that they get them months after the review has been completed and by the time they contact the provider the problem has been resolved. Yet others reported that they received reports in a timely manner.

County quality assurance monitoring. Every county in the sample indicated that case managers play a vital role in monitoring the quality of services and supports received by HCBS recipients. It was reported that this monitoring often occurs through unannounced visits to the sites and through asking questions of the recipient and his/her family at annual and semi-annual meetings. Most counties reported that these processes were informal and that in many cases they are most effective when the case manager's has a good relationship with the family members and the individual receiving services.

Most counties reported that their monitoring processes were informal and two counties reported that, in their opinion, they did not have an effective quality assurance system within their county. One county developed quality assurance teams made up of people who work and know the individual consumers of HCBS Waiver services. County personnel are involved on these teams and their time is paid for their participation. Consumers and family members are also paid stipends for their participation in these formal monitoring teams.

One quality monitoring strategy reported by a county was that they purposefully have more than one case manager who has individuals on their caseload living at any given site. Another reported that their best strategy was their competitive multi-provider approach to services that, they reported, increased competition and increased quality. One county is trying to develop a "best practices report," which would include stories and strategies regarding how providers can do things well.

Significant differences in HCBS quality assurance mechanisms and those of the ICF-MR program. Most counties reported very similar quality assurance mechanisms for ICF-MR and HCBS Waiver services, especially the mechanism employed at the county level. However there were some noted differences reported by the counties interviewed including:

- The State is more involved in monitoring ICF-MR and the county has more control over HCBS.
- For HCBS services, counties often use their contracts with providers as a means to ensure quality.

Mechanism for gathering and using reports of injuries, abuse, risk exposure and/or consumer complaints about services and providers. All counties reported that reports of abuse and neglect and other related incidents are reported to case managers and generally go to county common entry points as well. Almost all of the counties reported that when a report is made to the common entry point it is almost immediately referred to the HCBS Waiver Coordinator and to the applicable individual case manager. These referrals are made even if a decision is made to refer it to the state Licensing Division Investigations Unit. In some cases, the counties require through their provider contracts that reports also be made directly to case manager and to families.

In every county there were different reporting mechanisms between adult and children who receive services. Adult reports of maltreatment are reported to adult protection services and child maltreatment reports are brought to the attention of child protection services. To varied degrees case managers and HCBS Waiver staff reported being invited to participate in county Foster Care Licensing Investigations. Generally, HCBS Waiver Coordinators reported problems with and dissatisfaction with the state's maltreatment reporting and investigation system. Several direct comments illustrate their concerns and frustrations.

> *"We get little to no follow up from the state regarding VA issues. We eventually hear back but it takes awhile and we often have to make many phone calls."*
>
> *"We are not happy with the state system. We have had instances where we think the state should do something and they don't. They screen it out or whatever [referral]. I think we are better off when we just handle them locally."*
>
> *"We just sit back and wait until we hear from the state as to whether it is substantiated. Sometimes we never hear and if we do it takes forever."*
>
> *"We have had situations where we pass it along to the state and we feel it is a BIG issue and the state refuses to investigate."*
>
> *"Screening out of the [maltreatment] reports does occur at the county level."*
>
> *"Case managers would say the system does not work."*

> *"I might not even know an incident happened until I get a notice of investigation from the state. There is a lag time of 2-3 months to get information back after I have been notified."*
>
> *"If case managers have questions, they ask a supervisor if not they do the follow up and handle the situation. Almost always the people get fired. Rarely do we wait for the [state licensing division maltreatment] investigation to occur."*
>
> *"We get copies [of dispositions] but it has no meaning for any practical purposes because it is so delayed."*
>
> *"We need authority to act quickly at the county level."*
>
> *"If it looks serious case managers will follow up on it."*
>
> *"I don't think the State investigates as much as the county does."*

Methods used by counties to ensure that HCBS recipients are protected from neglect, physical and sexual abuse, and exploitation. Most counties reported that risk management plans helped to ensure that HCBS recipients were protected from harm and exploitation. They also reported that their case managers were involved in the planning and monitoring of services and this helped to assure that adequate steps were being taken by providers to protect people from harm and exploitation. One county reported that they ensure that the budgets that are developed for individual services have sufficient staffing patterns.

County efforts to use consumers of HCBS services as part of the system of monitoring or evaluating HCBS services. Almost all counties reported that they did not have any existing quality assurance mechanisms that formally included family members and consumers as a part of the system of monitoring and evaluating HCBS services. However most did indicate that through case managers, individuals and family members are asked if they are pleased with their services and have input into quality through this mechanism. A few counties surveyed individuals and families to determine their satisfaction with services.

Several counties reported that they would like to develop more effective quality assurance mechanisms and that in so doing they would like to involve families and consumers in the process. Yet others indicated that they did not have the time to develop such a system. Two counties had taken action in this area. One included consumers and family members in a quality assurance oversight group as well as when conducting community forums. Another county had developed quality assurance teams who go out and complete interviews with individual recipients and consumers and family members are paid a stipend for their participation on these teams.

Primary strength of the overall HCBS quality assurance program for people who receive HCBS services. Counties reported that the strengths of the HCBS quality assurance program included:

- Experienced long term case managers who are out there and listening and watching what is happening.
- The informality of the quality assurance system at the county level makes people feel comfortable in sharing information.
- Random visits by case managers.
- At the county level we have good communication between the providers and the county.
- The community is the primary strength, not the government. Parents, family members, neighbors they know what is going on.
- Having high expectations for providers and building these into our contracts.

Primary weakness of the overall HCBS quality assurance program for people who receive HCBS services. The most common weakness in quality assurance cited by county HCBS Waiver Coordinators was that high caseloads for case managers make it difficult to conduct the amount of monitoring that should occur. Additional comments are summarized below.

- It may be the case that because at the county level we know the providers so well it is harder to be objective.
- Our system relies on consumers and families to report problems but they often have nothing to compare their experiences with.
- No mechanisms to detect the issues that fall through the cracks or which we never hear about.
- The quality assurance system is so entrenched in the institutional mindset.
- The quality assurance doesn't focus much on individual outcomes.

Balancing opportunities for HCBS recipients to take reasonable risks in their everyday lives with the county's need to provide reasonable protections of health and safety. All of the counties reported that balancing risk and protection is a great challenge and results in a lot of discussion and difficult decision-making at the individual case manager and support team level. Almost all counties reported the use of the Risk Management Plan as a primary tool to assist teams and case managers in assessing risks. In general, counties reported that they try to provide training and support to case managers to encourage individuals to take normal risks associated with everyday life. One county reported that they rely on the legal guardians and would not stand in the way of a guardian's decision. Another county indicated that they try very hard to focus on the individual and what he/she wants vs. focusing on the county's liability regarding the situation.

Training and Outreach

Training and technical assistance provided by DSH CSMD. A significant number of counties reported that there seemed to be a high turnover of staff and frequent reorganization within the DHS-CSMD division. They reported that this often results in counties not getting answers to questions, having difficulty finding the right person to talk to and often getting mixed messages and conflicting information from DHS staff. Also, many counties reported that it did not seem like the various divisions within DHS communicated with each other. This resulted in counties getting conflicting answers to their questions. For several counties, inconsistency in the information they receive from the Department of Human Services results makes them hesitant to move forward on certain issues because of a fear that the next week or month they'll hear something different that will result in them having to change everything they started. Several counties reported that bulletins often are not timely.

Counties reported that they wanted to get a current updated list of who within DHS is responsible for what information and that they wanted to receive responses to their questions in a more timely and accurate manner. Several counties reported needing additional training and support regarding the Waiver Allocation Tracking System.

Contact with and assistance from CSMD Regional Resource Specialists. Counties reported mixed experiences with respect to the role and assistance provided by the RRS in their counties. Well over half of the HCBS Waiver Coordinators indicated that the RRS that served their county generally provided good support and was helpful. However many of these same Coordinators indicated that their RRS was "stretched too thin" and was not available enough to their county staff. A little less than half of the Coordinators interviewed indicated that their RRS was generally not that helpful. One county stated that their RRS was patronizing and several reported that there seemed to be an adversarial relationship vs. a partnership or sense of a team effort.

County Board knowledge of and support of the HCBS program. Almost all county Boards were described as being aware of HCBS Waiver services and "superficially" approving contracts. Many counties reported that Board members knew providers in the community and that they occasionally presented information about new developments or special projects to the Board members. Many county Board members were reportedly in favor of HCBS growth because they understood enough to know that it saved the county money. In one county, the MR/RC service division and the Board organized an event every few years that brought together service providers, consumers and their family members and Board members**.**

Consumer controlled budgeting options. Many counties reported that they wished the state was more forthcoming with their expectations and with some training with respect to the consumer directed supports option amendment to the HCBS program. They are hesitant to take a "leap of faith" only to get started and then to be told they are expected to do it differently or to learn that there are parameters.

For the counties that had provided this option or who had taken initial steps to explore this option a number of issues were identified including:

1. Difficulty matching needs with dollars in an equitable way.
2. People need to know the parameters and counties need to establish these parameters to reduce unrealistic expectations.
3. Biggest successes have been when families are not already ingrained in the system and connected to providers. One county reported that when families are adamant about having a certain provider the providers often hold out and say they have to have more money then the families come back and can be angry and demanding more money.
4. Family and county fear that they are dumping all responsibility onto the family and figuring out the role of the county in supporting families to direct their own supports.
5. County Board refused to allow the concept of giving families checkbooks and allowing them to spend money using the checkbooks. As an alternative have secured an agency who is willing to be an employer of record.

Identified barriers included:

1. One county HCBS Waiver Coordinator said that their county will never pay parents or family members to "parent" or to "provide supports" and if the state moves in that direction they will no longer provide HCBS services in that county.
2. Fear of what taxpayer expectations and parameters are with respect to how far consumer directed services can go. What are their limits on what is acceptable to taxpayers and therefore County Board Members?
3. Fear that "families will take the money and run" without ever providing the service.

Discussion

This section reviews key findings and issues in the area of quality assurance. Topics include fear, safety, victimization and injuries, deaths, maltreatment reporting and the performance of the quality assurance and monitoring system for HCBS.

Key findings

Fear and Safety

- Forty percent of DSS and 49% of provider agencies (residential and vocational) reported that consumer-to-consumer violence was a problem (8% and 10% respectively said it was a moderate or severe problem).
- When asked, "Does anybody where you live hurt you," 85% of consumers said nobody hurt them, 7% said a roommate had, 3% said staff, and 5% said someone else had.

- Families reported that 17% of individuals in out-of-home residential settings were afraid of someone (including 11% who were afraid of their roommates) and 12% of individuals were afraid of someone at work (including 8% who were afraid of a co-worker).
- Ninety percent of all consumers felt safe where they live, and 76% reported feeling safe in their neighborhoods (11% said they felt unsafe in their neighborhood).
- Twenty-one percent of families who had a family member who received crisis behavioral supports reported that their family member was afraid of someone in their crisis behavioral service setting.
- Almost all family members reported that their family member felt safe most of the time while receiving transportation supports, in their employment or day program, in out-of-home residential settings, and at school.

Victimization and Injuries

- Sampled vocational service providers reported that 17 of 3,301 individuals (0.5%) in their programs had been victims of crimes serious enough for them to report it to law enforcement in the previous year. Residential providers reported that 38 of 611 individuals (6.2%) were victims of crimes reported to law enforcement. By comparison, 31% of Minnesotans reported they were a victim of a crime in 1992.
- The most common cause for a criminal conviction in Minnesota was for larceny theft. In both residential and vocational settings the most commonly reported crime was simple assault.
- Several county waiver coordinators attributed an increase in incident and maltreatment reports to labor shortages.

Processed Maltreatment Reports

- In 1998, 508 vulnerable adult (VA) or maltreatment of minor (MOMA) reports were processed for persons in HCBS funded adult foster care settings (including "corporate foster care") and 68 were processed for HCBS recipients living in other types of settings).
- In 1998, between 16% and 18% of VA or MOMA reports processed by DHS for day program, ICF-MR, SILS, and HCBS adult foster care settings were assigned for detailed investigation as compared with 22% of DHS processed reports for other HCBS recipients.
- Reports determined not to involve maltreatment as defined by VA or MOMA statutes could either be screened out (no further action needed), or referred by the DHS investigations unit to another state unit or county agency for further action. Most reports that did not involve maltreatment for ICF-MR settings were screened out rather than referred, but almost all reports involving HCBS adult foster care settings that did not involve maltreatment were referred to county licensing units or other agencies for further action.
- In 1998, 1,856 reports reviewed by DHS and determined not to involve maltreatment were logged. Of those, 493 were screened out and 1,363 were referred to other agencies. The most common type of complaint referred to other agencies involved allegations of neglect, unexplained injuries, physical abuse, emotional/verbal abuse, or client-to-client abuse. The majority of those complaints were referred to county adult foster care or the DHS CSMD unit for further action.
- In 1998, 62 cases of maltreatment were substantiated for HCBS settings, 32 cases were substantiated for ICFs-MR, 7 were substantiated for day program settings, and none were substantiated in SILS settings.
- The rate of substantiated maltreatment per consumer was 8 per 1,000 for ICF-MR settings and 10 per 1,000 for HCBS settings in 1998. The rate of substantiated maltreatment per consumer per year

averaged 15 per 1,000 in ICF-MR settings between 1993 and 1998; 10 per 1,000 in HCBS adult foster care settings between 1996 and 1998; and 4 per 1,000 in HCBS settings not also licensed as adult foster care settings between 1993 and 1998.

- In 1998, 51% of all substantiated maltreatment cases involved neglect, 16% involved physical abuse, 4% involved sexual abuse and 30% involved some other kind of maltreatment.
- Case managers for 26% of HCBS recipients reported receiving and reviewing a vulnerable adult report on that person in the last 12 months, and 21% responded to an issue raised in those reports.

Deaths

- Between 1995-98, four deaths involving people with MR/RC who received HCBS services were judged to have occurred as a result of maltreatment. The total number of HCBS recipients who died between 1995-1998 was 74.
- The average number of deaths per 1000 service recipients in HCBS between 1995 and 1998 was 3 per 1,000 while the average number of deaths in ICFs-MR during those years was 10 per 1,000. As a point of comparison during 1998 the average number of deaths in MN per 1,000 people was 8 and in the U.S. the total number of deaths per 1,000 people was 9 (Murphy, 2000).
- In almost all of the counties it was reported by waiver coordinators that when a report is made to the common entry point, it is almost immediately referred to the HCBS waiver coordinator and to the applicable case manager.
- HCBS waiver coordinators identified problems with the state's maltreatment reporting and investigation system and were generally dissatisfied with it.

DSS Maltreatment Reporting

- Ninety-nine percent of direct support staff members surveyed reported they knew how to report incidents of maltreatment. However, of those who actually reported maltreatment, only 63% said they received any feedback regarding what was done in response to the report they filed.
- Twenty-nine percent of DSS reported they were afraid they might lose their job if someone filed a complaint against them whether or not the report was true or substantiated. However, 95% reported they thought the maltreatment investigation system was fair to definitely fair.
- Twenty-six percent of all DSS reported they had observed an incident of abuse or neglect. Of those, 7% (2% of all DSS) said they were prevented or discouraged from reporting the incident by their supervisor and 2% by their co-workers. Only 63% of DSS who filed a report received any information regarding their report.

System Evaluations

- Providers said Minnesota's quality assurance (QA) system was good in several areas. The highest ratings were for state reviewers knowing the type of setting, and the quality of county licensing efforts. Service providers said technical assistance provided by the state was fair. Providers in greater Minnesota rural counties were more satisfied with QA efforts than those in other regions.
- While 84% of case managers reported that they should monitor service quality only 69% said they actually did. Similarly, while 91% of case managers thought the state QA system should gather information from and provide information to families, only 53% said the state QA system actually did so.
- Case managers rated six components of Minnesota's QA system good, and nine components only fair. The highest ratings were for assuring appropriate and regular health and physician services,

and assuring that there is a system for consumer complaints and investigations about the quality of services. The lowest ratings were for recognizing exemplary performance, providing quality training to case managers, and assuring that consumers have access to QA information when selecting agencies to serve them.

- On average case managers rated Minnesota's system for assuring effective reporting and follow-up of incidents involving vulnerable adults as fair.
- Most county waiver coordinators reported that their system for monitoring quality was informal, usually occurring through unannounced visits to sites by case managers and through asking questions of recipients and family members at meetings. Two county HCBS waiver coordinators reported that they did not have an effective QA system within their counties.
- Most county waiver coordinators reported that families and consumers were not formally involved in monitoring and evaluating HCBS services.
- Primary strengths of HCBS QA according HCBS waiver coordinators included experienced, long-term case managers who know what is happening, an informal county system that makes people comfortable sharing information, random visits by case managers, good communication with service providers at the county level, building high expectations into contracts, and community members.
- The primary weakness of HCBS QA according HCBS waiver coordinators was the large caseloads of case managers that makes it difficult for them to conduct the amount of monitoring that is needed.
- County waiver coordinators observed that high turnover of staff and frequent reorganization at DHS-CSMD result in counties not getting answers to questions, having difficulty finding the right person to talk to, and getting mixed messages.
- Over half of the HCBS waiver coordinators reported that their Regional Resource Specialist (RRS) provided good supports and was helpful. However, many indicated that their RRS was stretched too thin and was not available as needed.

What's working?

Consumers and family members reported that the vast majority of HCBS recipients lived safely and without fear in their homes and in their neighborhoods. Service providers in rural counties are much more likely to be satisfied with a number of dimensions related to quality assurance and monitoring functions. Most direct support staff members reported that they knew how to report suspected maltreatment. Several HCBS coordinators reported their counties were conducting quality assurance and enhancement interventions. For example, one county had developed quality assurance teams that specifically included and paid family members and consumers in their quality assurance process.

Challenges and Concerns

Consumer-to-consumer violence should be of concern. Seven percent of HCBS recipients included in this study reported they had been hurt by their roommate and 12% of families reporting that recipients were afraid someone would hurt them in their out-of-home residential placement. In other words an estimated 979 of HCBS service recipients are living in places where they are afraid of a roommate. Given the estimate that 37.9% of all HCBS recipients have moderate to very severe problems with temper outbursts, 31% engage in verbal or gestural aggression, and 28% engage in physical aggression, this is a widespread challenge (please note, this is a duplicate count estimate). Choice about where and with whom you live is a fundamental aspect of self-determination. Recognizing and responding to the fact that self-determined people rarely choose to live in places where they are afraid of the people with whom they live is an obvious aspect of promoting self-determination. A basic expectation of service providers, counties and the state should be that prevention and intervention to address issues regarding consumer to consumer violence or fear of violence occur and that no one who receives HCBS should be forced to live with people they fear.

The overwhelming majority of the crimes reported by providers for which HCBS recipients were victims were simple assault and larceny. The seriousness of consumer-to-consumer violence and reported and substantiated incidents of maltreatment by staff demand better understanding of how people's lives are truly affected by crime, violence and other aversive interpersonal circumstances and what and how should be the appropriate responses. The present maltreatment reporting system for vulnerable adults does adequately identify or respond to such issues.

Case managers and county waiver coordinators expressed significant concerns about Minnesota's quality assurance system. Some of their concerns may be related to a lack of common understanding between counties and the state about the role each plays in maltreatment investigations and in assuring overall quality in the HCBS waiver system. The issue is very complicated because so many different people have roles (e.g., state and county licensing staff, county MR/DD case managers, state maltreatment unit investigators, common entry point personnel, State Office of the Ombudsman). Establishing more effective communication between people in these various roles may help in both clearing up misunderstandings, and in finding ways to make the quality assurance system more effective. In addition to improving communication, a direct response to concerns expressed by stakeholders is needed.

Reports from common entry points that were determined not to be maltreatment by the DHS Investigations Unit (based on the definitions in the Vulnerable Adult Act or Maltreatment of Minors Act) were referred to many different agencies. Review of the logs regarding those referrals made it clear that some involved incidents (such as neglect or consumer-to-consumer violence) or injuries that likely warrant follow-up, licensing action, training interventions or other action by the state, the county and/or the service provider. Future efforts to examine Minnesota's quality assurance system should specifically review the mechanisms at the state and county level that ensure that incidents serious enough to be referred for further action are addressed, resolved and systemically tracked to identify important trends and issues.

Although almost all of direct support staff members report that they know how to file a vulnerable adult report, 27% of DSS stated they did not receive any feedback from their agency, the county common entry point or the state regarding what happened in response to a vulnerable adult report that they filed. All reporters of vulnerable adult maltreatment issues should receive accurate and timely feedback as to what happened with the report and what the outcomes of the situation are, even if the report was screened out. Currently, the legal requirements regarding feedback require DSSS to specifically ask for feedback from the county, and state regarding what happens with a specific maltreatment report. This legal requirement needs to change to ensure that feedback and follow up to reporters occurs irrespective of if they ask for it. Of additional concern, 29% of DSS said they were afraid they'd lose their job if a maltreatment report was filed against them even if it wasn't substantiated. Lastly, though small in percentages, clearly a number of DSS reported that they had witnessed abuse or neglect and had been prevented by a co-worker or supervisor from reporting the incident. These are violations of the basic foundation of a successful maltreatment reporting system and need further investigation and intervention.

Although 83% of case managers said they should monitor consumer and family satisfaction of services, only 68% reported that they actually did so. This difference in expectation and reality seems related to average caseloads of Minnesota's case managers that considerably excess the national average. Other discrepancies were evident between what case managers thought should be a part of the quality monitoring activities within the HCBS program and what were actually components of that system. Only 52.7% of case managers reported that their county utilized a consumer advisory council and only 52.8% reported that quality monitoring activities gathered and provided information to families about the quality of HCBS services and service providers. Case managers reported that the overall quality assurance system (across 16 dimensions) only does a “fair” job at assuring the outcomes for which the state is responsible in administering its HCBS program.

I. Utilization and Costs of Home and Community Based Services

This section examines HCBS expenditures generally and for various individual services. It provides summaries of expenditures for different groups of service users and for different county types. This section includes information on all HCBS recipients in MN for fiscal year 1998. In reading this section it is important for the reader to understand what is meant by the terms “allowable,” “authorized,” and “paid.” These terms are defined below to help clarify the remaining parts of this section.

Allowable – The amount of money the DHS-CSMD puts into the county pool of HCBS waiver funds based on the characteristics of individuals as identified in their screening document.

Authorized – The amount of money authorized by the county to be spent on certain services for the individual. This is identified in the individual service plan.

Paid – The amount of money that is actually paid out to service providers for the hours/units of service for which they billed DHS for the people to whom they provide services and supports.

HCBS vs. ICF-MR Expenditures

Table I1 uses Minnesota reports to the Health Care Financing Administration, including the “Form 372” report on HCBS expenditures (which differ slightly from Medicaid payment files) and “Form 64” reports on ICF-MR billings, to compare total Medicaid payments for HCBS, ICF-MR and other Medicaid state plan health services for HCBS and ICF-MR recipients. In Fiscal Year 1998, the average annual cost of HCBS services for each HCBS recipient was estimated to be $47,786. ICF-MR average annual expenditures reported in HCFA Form 64 reports were $63,744. In addition to the HCBS and ICF-MR expenditures, the state estimated additional $5,474.60 per person expenditures for state plan health services for HCBS recipients and an additional $4,018.85 in expenditures for state plan services for ICF-MR recipients. The primary difference in health services costs was reported in the “other” category. Among the “other” services is personal care, widely used by HCBS recipients. For the average Minnesota HCBS recipient, residential habilitation or Supported Living Services (SLS) made up 69.0% of all health and social services expenditures for the year.

Table I1: Average Annual Expenditures for Medicaid Services for HCBS and ICF-MR Recipients Adjusted for Average Days of Enrollment with Comparisons to ICF-MR, 1998		
Type of Service	**ICF-MR**	**HCBS***
Social Services		
Case Management		1,416.49
Adult Day Care/Day Training and Habilitation		8,367.37
Supported Employment		9.78
Assistive Technology		4.08
Caregiver Training and Education		1.48
Consumer Directed Community Support		6.77
Environmental Modifications		204.93
Residential Habilitation (SLS)		36,548.58
Homemaker		24.21
Personal Support		104.67
Respite Care (including crisis)		1,018.75
Specialist Services		75.93
Transportation		00.24
24 hour Emergency Assistance		3.18
Total Social Services	$63,744.00**	$47,786.46*
Health Services		
Inpatient Hospital	249.98	655.74
Physician Services	255.81	326.38
Outpatient Hospital Clinic	168.68	180.62
Laboratory and X-Ray Service	42.52	46.39
Prescribed Drug	1,607.81	1,583.95
Other Acute Care	1,628.73	2,681.52
Total Health Services	4,018.85*	5,474.60*
Total Social And Health Service	$67,762.85	$52,961.06

Sources of Expenditure Data: * Minnesota's HCFA 374; ** HCFA 64

Note: Average annual cost for each HCBS recipient by individual services cost was adjusted for average annual days of HCBS enrollment (344). The unadjusted total (i.e., total expenditures divided by unduplicated recipient counts) was $45,037. HCFA 64 expenditures were divided by the average daily ICF-MR recipients as computed by mid-point between first and last day ICF-MR residents in FY 1998.

Comparative Expenditures in Minnesota and U.S.

In 1999, Minnesota's combined ICF-MR and HCBS utilization rate of 213.6 per 100,000 was 53% more than the national average of 139.5 per 100,000 (Prouty & Lakin, 2000). Because of Minnesota's relatively high utilization rate, it tends to have higher overall expenditures for ICF-MR and HCBS than do other states. In FY 1999, Minnesota spent 543.89 million state and federal Medicaid dollars on ICF-MR and HCBS. This compares with expenditures of 17.87 billion dollars nationwide. Minnesota's expenditures equaled $113.88 per state resident as compared with the national average of $65.53. Although Minnesota's overall expenditures were relatively high, its average expenditures for each service recipient was considerably nearer to the national average. In Fiscal Year 1999, Minnesota had average daily recipient expenditures for the combined ICF-MR and HCBS programs of $53,501, as compared with $47,985 nationwide (Prouty & Lakin, 2000).

Further examination of Minnesota's ICF-MR and HCBS expenditures reveals substantially different pattern than the nation as a whole. Minnesota's average annual expenditure per average daily ICF-MR resident ($60,600) was substantially less than the national average ($81,830). This is likely related to Minnesota's elimination of state operated institutional ICF-MRs, the most expensive form of

ICF-MR by far. On the other hand, national HCBS expenditures in Fiscal Year 1999 were $32,750 per average daily recipient, while Minnesota expenditures per average daily recipient were $51,545.

Factors associated with Minnesota expenditures. Two major factors contribute to the relatively low ICF-MR expenditures in Minnesota. First, Minnesota's substantial reduction and near elimination of its state institution programs accounts in large measure for relatively lower per ICF-MR resident expenditures. On June 30, 1999, nationally 41% of ICF-MR recipients were housed in state institutions, which had an average national cost of $107,550 (Prouty & Lakin, 2000). By the end of FY 1999 Minnesota's dwindling number of state institution residents made up only 2.3% of ICF-MR recipients, albeit a costly 2.3% at an annual average expenditure of $224,500 per person.

Another factor accounting for Minnesota's relatively low cost of ICF-MR care is its relatively less impaired populations residing in ICFs-MR. This phenomenon is largely attributable to Minnesota's use of ICF-MR in the mid-1970s to mid-1980s to finance community services and the parallel tendency during those years first to move relatively less severely impaired people out of institutions, and into these newly developed community ICFs-MR. This effect was shown in a 1995 analysis of the Health Care Financing Administration Online Survey Certification and Reporting System (Larson & Lakin, 1995) which showed that 37.2% of Minnesota's ICF-MR population was made up of persons with mild, moderate or no mental retardation as compared with 26.6% in ICFs-MR nationally. Among Minnesota's ICF-MR population only 35.1% were persons with profound mental retardation as compared with 50.7% nationally. (As shown in Table 10 Minnesota's ICF-MR population in 1999 with 40.7% of residents indicated to have mild or moderate mental retardation was even slightly less impaired than the 37.2% reported in the 1995 report.)

Two other, but not unrelated, factors contribute to the relatively high expenditures for HCBS in Minnesota when compared with the U.S. as a whole. The first relates to the movement in relatively recent years of people with severe disabilities out of Minnesota's institutions into community service settings financed by the HCBS program, and the related low rates of placement into state institutions and other ICFs-MR of persons with severe disabilities who are entering the service system. As Minnesota state institution populations decreased from over 1,033 residents in June 1992 to 72 residents in June 1999, the HCBS program was the primary means of financing community services for people who often needed rather high levels of support.

A second factor in Minnesota's relatively high HCBS costs relates to the statistics above that showed that relatively few of Minnesota's HCBS recipients are served in their family homes (15% as compared with 34% nationally in 1998), and conversely that 74% of Minnesota's HCBS recipients are served in small group residential settings as compared with 41% nationwide. Although no national data are available on cost implications of these differences, they are clearly significant. In Minnesota, for example, the average annual expenditure in 1998 for persons living in their family home was $19,881.69 as compared with $50,209.76 for persons living outside the family home. The average annual cost for persons living in small group, "corporate foster care" housing was $54,733 as compared to $24,420 for persons living in all other HCBS-financed settings.

Relative Cost-Effectiveness of HCBS and ICF-MR

In 1995, the Minnesota Legislature requested that the Department of Human Services complete an analysis and report of a "cost-effective model" ... "for the purposes of serving high level care clients who are discharged from regional treatment centers." The study developed in response to this request examined expenditures, staffing and outcomes of services to determine the relative cost-effectiveness of ICF-MR and HCBS financed community services for 116 adults with severe and profound mental retardation who had recently moved from state institutions to various community living arrangements, as well as 71 matched comparison group members who remained in state institutions. This study is important because it is the last study comparing services and outcomes in Minnesota's large state institutions to services and outcomes for those same people after they moved to community HCBS and

ICF-MR settings. Analysis of covariance techniques were used in all analyses to adjust for potentially significant pre-existing differences among the groups, however statistical tests showed the community ICF-MR, HCBS and the state institutions groups to be statistically equivalent in almost all demographic functional and behavioral dimensions. The outcome or independent variables studied included community access, social activities, community inclusion, family relationships, and choice. The dependent variables included HCBS and ICF-MR financing, state institution and community service setting, 2-4, 5-6 or 7-15 resident home, and state or private operation. Among the conclusion of these comparisons (Stancliffe & Lakin, 1996, 1998) were:

- *Community service settings in general delivered considerably more favorable outcomes at substantial less cost than state institutions*. Individual outcomes were substantially better for persons who left the institution and moved to community settings than they were for those who stayed in the institutions. Combining costs of room and board, residential support and day program, revealed average costs for state institution residents of $315 per day as compared with $230 for the recently discharged community residents, despite the statistical equality of the groups in disability characteristics, age and years institutionalized.
- *The least expensive models of community care were small private settings of 2-4 residents with HCBS financing or larger established ICF-MR group homes with 7-15 residents.* The combined room and board, residential services and day program costs for newly developed services were lowest for 2-4 person HCBS settings, averaging $218.50 per person per day in those settings. Existing private ICF-MR group homes with 7-15 residents had lower nominal costs ($193 per person per day) when people moved into openings in existing facilities, but the differences were not statistically significant. The nominal cost difference was attributable to a) lower housing costs because the facilities were purchased over a decade earlier, and b) lower ratios of staff to residents.
- *While larger group homes had lower nominal costs, individual outcomes and staffing ratios were better in HCBS-financed homes*. Although individuals who moved to ICFs-MR with 7-15 residents had nominally lower expenditures than the residents of HCBS-financed homes of 2-4 residents, people in the ICF-MR group homes enjoyed less personal integration in the community, less choice in their leisure activities and less favorable levels of staff support. On a typical weekday evening the ICF-MR group homes of 7-15 residents had an average of 6.0 residents per staff member as compared with 3.05 in the HCBS-financed settings.
- *Differences in expenditures were much more determined by placement type than by people's relative need for resources and support*. When expenditures for individuals were averaged for groupings based on resource and support needs, there was remarkable lack of variation. Specifically, within the relatively narrow ranges of resource and support needs for former state institution residents (averaging 27.4 years of institutionalization), with an average age of 47 and with severe or profound mental retardation, people differentiated as having "substantial" or "moderate" resource and support needs, had between group differences in residential, day program and total expenditures that hardly varied at all. People with "substantial" support needs and people with "moderate" support needs who lived in HCBS-financed places with 2-4 residents varied in total service costs by only 1% ($220 vs. $217 per day). People in ICFs-MR of 5-6 residents varied even less ($267 vs. $265). Paradoxically, for people moved to the pre-existing ICF-MR group homes of 7-15 residents, those with "moderate" resource/support needs had costs that were actually higher than those of people with "substantial" resource/support needs ($197 vs. $174).

Expenditure Patterns for HCBS

Allowable, Authorized and Paid Expenditures

In 1992, the Minnesota Legislature required the Department of Human Services to develop plans for implementation of a system of rate setting that "bases funding on assessed needs of persons with mental retardation or related conditions." In May 1995, the Legislature formally authorized the Department's plan for implementing the "Waiver Allocation Structure" (WAS). This methodology was used to establish the funds made available to serve new HCBS recipients beginning in Fiscal Year 1996 (beginning July 1995). Prior to implementation of this methodology, the state added the same amount to the counties pool of resources for most persons entering the state's HCBS program irrespective of individuals need. Prior to the newly developed WAS, in order to overcome the disincentives for counties to serve persons with more substantial support needs and to promote its deinstitutionalization objectives, DHS had created special higher HCBS allocations to county pools for persons leaving public and in some cases private institutions. This system of "enhanced and enriched" funding was based on the placements from which people entered the community rather than what they needed once they were there and was the source of considerable criticism.

The purposes of the Waiver Allocation Structure included: 1) to enhance access to appropriate services for eligible persons by increasing the correlation between the needs of persons to be served and the distribution of resources; 2) to continue ICF-MR downsizing initiatives through an ability to serve a greater percentage of recipients with significant needs; 3) to place decision making authority at the local level closest to the individual; and 4) to streamline administrative procedures and reduce layers of governmental management (DHS, 1996). By design, the state allocates funds to counties, not to individuals. Within a pool of funds established by individual allocations, a county exercises its own discretion in making resources available to individuals without necessary regard to the funds allocated to the county on behalf of the individual. Importantly, the pool of resources managed by counties for persons receiving HCBS prior to state Fiscal Year 1996 were not recomputed. Amounts added to county pools are determined by data on new HCBS enrollees' screening document. In general terms (the actual operational definitions are confidential), the levels are: Level 1: "Very high self-care needs or mental illness and destructive behavior; Level 2: High self-care needs or aggressive/destructive behavior; Level 3: Limited self-care needs, but no major behavior problems or limited self-care needs but aggressive/destructive behavior; Level 4: Limited self-care needs and no major behavior problems. Counties receive a "base" state allocation to their HCBS pool for individuals who entered the HCBS program prior to the 1995.

HCBS Services Authorized and Paid

Table I2 presents a summary of the average amounts of funding authorized by counties for various HCBS services in 1998 and the average amounts actually paid for those services. The data are further broken down for children (0-17 years) and adults (18 years and older). For each of Minnesota's 23 HCBS services, the table presents for children and adults: a) the average amount of expenditure authorized by counties for HCBS services; b) the average amount paid for each HCBS service; c) the total amount paid for each service in 1998; and d) the average per person difference between the amount allocated and the amount paid.

Differences between authorized and paid costs are related to at least three different factors. First, in attempting to maximize their use of HCBS Waiver resources, some counties intentionally authorize more expenditures than will be used. This is done in part to maximize administrative efficiencies by reducing the need to change authorization amounts for small adjustments made throughout the year. Over-authorizing is also done because over time counties have realized that they have "practiced" over-authorized and they continue to do so as a means of managing their waiver funds. Another factor explaining these differences is that different types of supports have been in the state plan for HCBS for different time periods. Those services that have been used for longer periods of time have produced payment histories that counties can use to predict how much to authorize in order to spend their allowable pool of resources. Newer services do not have those histories, and may, therefore, have greater discrepancies until a stable payment history for that service is established. A third factor is that for some types of services (e.g., respite care), counties may authorize expenditures for an individual at several different providers for the same hours. In this case the authorization allows families more flexibility in where they get respite services with the understanding that the number of total hours may not be exceeded. Another factor influencing these differences is that there is, in fact, under-spending in some service types due to lack of providers or lack of staff to provide the service.

Authorized expenditures. On average in 1998, service plans for HCBS recipients authorized a total average expenditure of $33,380.44 for 720 children and $52,300.79 for 6,089 adults. By far the highest average authorized expenditures were for Supported Living Services (SLS) (87.2% of persons receiving SLS in “corporate foster” settings.) The average annual SLS authorization for the 191 children with SLS authorizations was $43,282.30. The average annual authorization for SLS for adults was $40,094.56. Case Management was a nearly universally authorized service (it is a required service for HCBS participants). Among children, 717 of 720 individuals (99.6%) were authorized to receive HCBS-financed case management (at an average authorized cost of $2,878.32). Among adults 6,084 of 6,089 (99.9%) of those with authorized services were authorized to receive HCBS-financed case management (at an average authorized cost of $2,641.30 per year).

Table I2: County Authorized and Total Paid Costs for Each HCBS by Age in Fiscal Year 1998

HCBS Services	Average County Authorized Costs				Average Paid Costs				Total Paid		Average Per Person Difference, Authorized vs. Paid	
	0-17 yrs.	*N*	18+ yrs.	*N*	0-17 yrs.	*N*	18+ yrs.	*N*	0-17 yrs.	18+ yrs.	0-17 yrs.	18+ yrs.
Home Care Assess.	0.00 **	0	0.00 **	0	145.52	66	125.76	65	9604.32	8174.4	-145.52	-125.76
Assistive Tech.	677.06	42	561.52	28	610.13	34	289.69	20	20744.42	5793.8	66.93	271.83
Caregiver Training and Education	335.47	32	468.42	10	394.60	14	515.61	8	5524.4	4124.88	-59.13	-47.19
Case Management	2,878.32	717	2,641.30	6084	1,693.69	699	1,337.56	5981	1183889.31	7999946.36	1,184.63	1,303.74
Consumer Directed	7,299.75	5	7,200.21	12	2,330.44	4	3,477.40	10	9321.76	34774	4,969.31	3,722.81
Crisis Respite	10,495.14	78	7,321.03	441	8,880.81	73	5,921.17	397	648299.13	2350704.49	1,614.33	1,399.86
Adult Day Care	0.00	0	7,428.48	52	0.00	0	6,147.76	50	0	307388	0.00	1,280.72
DTH	0.00	0	13,396.53	4478	0.00	0	12,241.33	4419	0	54094437.27	0.00	1,155.20
24-Hour Emergency	12,300.00	1	1,761.95	5	12,255.00	1	1,695.90	5	12255	8479.50	45.00	66.05
Ext. Transportation	0.00	0	220.00	1	0.00	0	160.00	1		160.00		40.00
Home Health Aide	2,942.20	10	5,921.30	25	2,535.73	8	5,495.44	22	20285.84	120899.68	406.47	425.86
Homemaker	2,352.50	55	2,576.63	39	1,815.61	47	1,903.06	38	85333.67	72316.28	536.89	673.57
Housing Access Coord.	0.00	0	55.00	1	0.00	0	0.00	1	0	0	0.00	55.00
In-Home	14,146.53	446	12,334.39	542	11,557.01	429	10,114.60	498	4957957.29	5037230.16	2,589.52	2,219.88
Live in Caregiver	0.00	0	0.00	0	0.00	0	0.00	0	0	0	0.00	0.00
Environ. Mods.	2,526.65	153	2,170.20	477	2,692.43	121	2,577.24	388	325784.03	999969.12	-165.78	-407.04
Personal Care	14,911.49	190	20,541.23	132	9,720.27	184	15,382.45	127	1788529.68	1953571.15	5,191.22	5,158.78
Private Duty Nurse	22,404.65	8	5,568.19	3	19,861.11	7	5,789.35	2	139027.77	11578.7	2,543.54	-221.16
Personal Support	11,206.87	32	3,359.65	174	9,531.83	27	2,846.35	149	257359.41	424106.15	1,675.04	513.30
Respite Care	4,946.13	471	4,661.28	582	3,491.03	414	3,278.16	500	1445286.42	1639080	1,455.10	1,383.12
Supported Living-Child*	43,282.30	191	*	*	42,755.20	187	*	*	7995222.4	*	527.10	*
Supported Living-Adult*	*	*	40,094.56	5584	*	*	39,395.31	5572	*	219510667.3	*	699.25
Skilled Nursing	1,247.38	33	1,213.30	80	869.01	28	884.44	70	24332.28	61910.8	378.37	328.86
Specialist Service	2,731.32	89	2,012.62	277	1,992.35	70	1,438.93	240	139464.5	345343.2	738.97	573.69
Supported Emp.	0.00	0	4,436.46	18	0.00	0	4,549.37	14	0	63691.18	0.00	-112.91
AVERAGE	33,380.44	720	52,300.79	6089	26,494.71	720	48,456.92	6089	19,058,617.31	295,046,012.04	6,885.73	3843.87

*Expenditures are for an entire year. Age is the individual HCBS recipient age on July 1, 1998. As a result individuals receive both supported living as a child and adult. These amounts have been combined into the category congruent with the age groupings. ** No authorization required.

Average paid costs. Altogether, in 1998, average paid costs for children receiving HCBS were $26,494.71 per person. For adults, average paid costs were $48,456.92 (about 83% more than for children). Children's expenditures are, of course typically lower than those of adults because they do not need HCBS-financed day services when they are in school, and because 68.6% of children receiving HCBS live with family members who share in their care.

The most costly service for both children and adults was Supported Living Services ($42,755.20 and $39,395.31, respectively). The most common service for which payments were made was case management (97.1% of children received paid case management, 98.2% of adults). The second most common paid service for children was in-home family support (59.6%) with average annual payments of $11,557.01. Respite care services were received by 57.5% of children at an average annual cost of $3,491.03. The second most common service for adults was Supported Living Services (91.5%) at an average annual cost of $39,395.31. Day training and habilitation service (DTH) was received by 72.6% of adult HCBS recipients and another 50 people (or 0.8%) received day program services through a licensed Adult Day Care program. The average annual payments for DTH was $12,241.33 and for Adult Day Care, $6,147.76.

Differences between county authorized and paid expenditures. Notable differences were found between authorized and provided ("paid") HCBS expenditures. Not only do adults have higher service authorizations and expenditures than children, they have service expenditures that are much nearer their authorized levels than do children. Specifically, in 1998, adult HCBS recipients received paid services that were on average $3,843.87 less than their average authorized expenditures of $52,300.79, or in other words had paid services that equaled 92.7% of authorizations. Expenditures for children's services fell on average $6,885.73 below authorization, only 79.3% of the authorized level of expenditures.

In large measure, the differences between adults and children in authorized spending, actual spending and the differences between authorized and actual spending are attributable to patterns in the use of the SLS service. SLS is by far the most costly HCBS services and its users are overwhelmingly adults (96.7% of all 5,775 SLS recipients were adults). A notably greater proportion of the authorized spending for SLS was actually spent for services than was the case for other types of HCBS. SLS providers were paid 98.3% of the authorized amounts for their services, while services more typically provided to children showed the greatest differences between authorized and reimbursed service costs. For example, average respite care payments for children were 70.6% or the authorized amounts. In home family support for children payments were 81.7% of authorized amounts. Payments for personal care for children were 65.2% of authorized expenditures.

Authorized and paid costs by age groupings. Further examination of the differences in the proportions of authorized expenditures actually paid for HCBS recipients in more specific age categories was complete. Table I3 shows, in specific detail that children were receiving proportionally less of authorized services than was the case for adults. Differences between county authorized expenses and actual payments increased as age decreased. HCBS recipients between the ages of 40-70 had actual expenditures equal to 94.1% of the authorized costs. Children 10 and younger had actual expenditures equal to 72.1% of authorized expenditures.

Table I3: Comparison of Average Costs Authorized and Costs Paid for HCBS Recipients of Different Ages

Age Group	*N*	Cost Authorized	Costs Paid	% of Authorized Costs Paid
0-5 years	34	23,029	14,509	63.0%
6-10 years	209	28,599	21,055	73.6%
11-15 years	337	36,088	29,563	81.9%
16-20 years	469	38,600	31,991	82.9%
21-25 years	670	47,161	42,872	90.9%
26-30 years	770	51,940	47,653	91.7%
31-35 years	722	54,154	49,897	92.1%
36-40 years	770	54,756	51,090	93.3%
41-50 years	1,319	56,421	53,030	94.0%
51-60 years	828	54,646	51,539	94.3%
61-70 years	420	50,007	47,091	94.2%
71+ years	260	45,751	42,530	93.0%
TOTAL	6,808	$50,300	$46,135	91.7%

A Measure of Effects of the WAS on Access

One way to examine effects of the allocation structure on access to HCBS is to compare enrollees in the system prior to and subsequent to the implementation of the WAS on a relatively stable measure of substantial general association with severity of overall impairment. Table I4 does so using level of intellectual impairment.

Table I4: Level of Mental Retardation of HCBS Recipients Enrolled Before and After to Implementation of the Waiver Allocation Structure (WAS) by County Type

	Metro Area		**GM Urban**		**GM Rural**		**Total**	
Level of MR	**Before**	**After**	**Before**	**After**	**Before**	**After**	**Before**	**After**
Mild	33.5%	32.0%	32.3%	34.5%	34.7%	34.4%	33.7%	32.2%
Moderate	27.9%	22.8%	28.0%	28.1%	26.2%	24.9%	27.3%	24.3%
Severe	21.3%	18.3%	20.9%	18.7%	20.9%	18.4%	21.1%	18.4%
Profound	14.9%	21.5%	17.6%	13.5%	15.0%	15.9%	15.5%	18.3%
Related Conditions	2.4%	4.4%	1.2%	4.7%	3.2%	5.7%	2.5%	4.9%
Not Specified	0.0%	1.1%	0.0%	0.6%	0.0%	0.7%	0.0%	0.9%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
(individuals)	(2,006)	(1,072)	(980)	(342)	(1,669)	(738)	(4,655)	(2,152)

Assuming that level of mental retardation is sufficiently stable as an indicator of degree of impairment, there was not a great difference between the level of impairment of people enrolled in HCBS prior and subsequent to implementation of the waiver allocation structure (WAS). The proportion of persons with mild intellectual disability did decrease slightly from 33.7% of prior enrollees to 32.2% of people enrolled after July 1, 1995, and the combined enrollments of persons with mild and moderate mental retardation decreased from 61.0% of persons enrolled before WAS implementation to 56.5% for those enrolled after. Conversely the proportion of persons with profound mental retardation enrolled after July 1, 1995 was somewhat higher than among those enrolled previously, an increase of 18.3% from 15.5%. By far the largest proportional change was among persons indicated to have a related condition, but not mental retardation, from 2.5% of HCBS recipients enrolled before WAS implementation to 4.9% of those enrolled after.

Associations Between WAS Allocations and Spending

A goal of the waiver allocation structure (WAS) was to provide to counties resources for individuals that were reasonably reflective of the needed expenditures to adequately serve them. Table I5 presents summary statistics on the allocations to the counties and actual expenditures by the counties for services to people with MR/RC by age. It provides breakdowns by WAS groups and by persons enrolled prior to and after the WAS was implemented.

Table I5: Cost Allocations and Expenditures for HCBS Recipients by Allowable, Age, and County Type

WAS Group	**Children**			**Adults**			**Total**		
	Allowable	**Spent**	**(*N*)**	**Allowable**	**Spent**	**(*N*)**	**Allowable**	**Spent**	**(*N*)**
Metro									
1	79,376	36,615	(36)	73,307	70,235	(219)	74,164	65,488	(255)
2	59,909	35,831	(70)	64,151	60,977	(248)	63,217	55,442	(318)
3	46,744	15,025	(52)	49,632	48,309	(319)	49,227	43,644	(371)
4	47,859	13,005	(6)	37,650	31,400	(122)	38,129	30,538	(128)
Pre-WAS	39,070	28,286	(150)	48,662	53,786	(1,856)	47,944	51,879	(2,006)
Post-WAS	59,567	28,571	(164)	57,968	54,785	(908)	57,984	50,775	(1,072)
Total	49,775	28,435	(314)	51,630	54,114	(2,764)	51,441	51,494	(3,078)
GM Urban									
1	76,052	42,782	(10)	69,487	51,160	(24)	71,418	48,696	(34)
2	49,622	19,810	(26)	63,395	52,099	(102)	60,597	45,540	(128)
3	58,963	26,557	(12)	45,727	39,563	(119)	46,940	38,371	(131)
4	38,329	18,513	(5)	43,107	36,926	(44)	42,620	35,047	(49)
Pre-WAS	33,578	28,510	(71)	43,968	46,831	(909)	43,215	45,504	(980)
Post-WAS	55,658	25,549	(53)	53,537	44,549	(289)	53,863	41,605	(342)
Total	43,015	27,244	(124)	46,276	46,281	(1,198)	45,970	44,495	(1,322)
GM Rural									
1	70,189	27,086	(31)	74,717	59,990	(61)	73,191	48,903	(92)
2	57,266	22,656	(52)	63,007	50,354	(181)	61,780	44,172	(233)
3	44,458	16,648	(30)	48,824	38,828	(247)	48,351	36,425	(277)
4	38,093	5,264	(6)	37,178	30,318	(130)	37,218	29,212	(136)
Pre-WAS	35,997	25,893	(163)	41,660	42,248	(1,506)	41,107	40,651	(1,669)
Post-WAS	56,437	21,419	(119)	53,097	42,496	(619)	53,636	39,097	(738)
Total	44,622	24,005	(282)	45,005	42,331	(2,127)	44,960	40,186	(2,409)
Grand Total	$46,593	$26,495	(720)	$48,262	$48,457	(6,089)	$48,086	$46,135	(6,809)
Pre-WAS Total	36,750	27,312	(384)	45,194	48,237	(4,271)	44,497	46,511	(4,655)
Post-Was Total	57,842	25,561	(336)	55,467	48,967	(1,819)	55,838	45,313	(2,152)

Table I5 stimulates a number of observations; including: 1) actual expenditures for services to children are considerably less than (56.9% of) the resources allocated to counties when those same children entered the HCBS program; 2) actual expenditures in adults (18 and older receiving HCBS) are slightly higher (about $200) than allocations to counties when those adults entered the HCBS program; 3) although expenditures of HCBS recipients enrolled before and after introduction of the WAS have expenditures that are similar, the allocations on their behalf are very different (e.g. pre-WAS, $36,750 for children; post-WAS, $57,842); 4) services for HCBS recipients enrolled pre-WAS cost about 104.5% of the base allocation provided to counties when they entered the program (74.3% for children, 106.7% for adults), while services for HCBS recipients enrolled post-WAS recipients cost considerably less (81.2%) than the allocation provided to counties when they entered the program (44.2% for children; 88.3% for adults) (this is an expected finding since the allocations made under the WAS structure were intended to assist counties by providing resources for their overall pool that could be used to fund services for persons whose daily costs of services was higher than the amount the county pool received for those individuals) and; 5) Patterns noted above were consistent across county types with the exception of rural counties in which pre-WAS allocations were sufficient to cover the expenditures for pre-WAS HCBS recipients (expenditures were 98.9% of allocations).

Because resources are now allocated to counties based on individual characteristics of new HCBS recipients and because prior to the implementation allocation structure a number of other special allocation procedures provided different funding to counties for people from circumstances (e.g., leaving institutions, closing facilities), counties differ considerably in the amounts of funding they are allowed to spend for the HCBS recipients. Table I6 presents descriptive statistics on the county average variability in a) the average per person per day amount of funding provided by the state for counties to provide services for individuals authorized to receive HCBS, b) the average per person amount of funding authorized for HCBS recipients, c) and the actual per person expenditures for HCBS in FY 1998. In addition Table I6 provides the number of service days that were divided into total allowable, authorized and paid expenditures to compute daily per person average. This table also provides an index to compare percentage differences between a) allowable and authorized expenditures (allowable minus authorized expenditures divided by allowable); b) allowable and paid expenditures (allowable minus paid expenditures divided by allowable); and authorized and paid expenditures (authorized minus paid expenditures divided by paid). These statistics are further broken down by county type. In Table I6 statistics for each Twin Cities Metropolitan and GM urban Counties are presented, but for the sake of brevity the 69 “rural area” counties have been combined. Remarkable variables are evident among county types and individual counties in the per person amounts of funding in the allowable, authorized and paid categories, and in the ratios between the categories.

Table I6: Comparisons of Difference Between Allowable Authorized and Paid Service Expenditures by County within County Types, FY 1998

			Average Dollars Per Day			% Differences Between*:		
County	Type	HCBS Days	Allowable	Authorized	Paid	Allow-Auth.	Allow - Paid	Auth – Paid
Anoka	T.C. Metro	65,493	150.43	153.40	142.40	-2.0%	5.3%	7.2%
Carver	T.C. Metro	19,932	116.94	116.34	104.61	0.5%	10.5%	10.1%
Dakota	T.C. Metro	102,336	141.41	158.64	141.57	-12.9%	-0.1%	10.8%
Hennepin	T.C. Metro	476,627	162.94	176.79	160.69	-8.5%	1.4%	9.1%
Ramsey	T.C. Metro	295,698	146.28	156.21	155.44	-6.8%	-1.9%	6.2%
Washington	T.C. Metro	59,595	134.03	145.56	132.72	-8.6%	1.0%	8.8%
Scott	T.C. Metro	24,900	137.13	137.55	120.90	-0.3%	11.8%	12.1%
Total		1,044,581	149.71	163.85	150.18	-9.4%	-0.3%	8.3%
Blue Earth	GM Urban	23,656	133.50	131.35	117.59	1.6%	11.9%	10.5%
Clay	GM Urban	28,337	134.35	133.82	128.52	0.4%	4.3%	4.0%
Crow Wing	GM Urban	22,907	140.17	131.85	125.03	5.9%	10.8%	5.2%
Olmstead	GM Urban	65,485	140.53	150.11	142.65	-6.8%	-1.5%	5.0%
Otter Tail	GM Urban	27,435	128.38	120.14	115.14	6.4%	10.3%	4.2%
Rice	GM Urban	28,499	145.75	139.42	125.57	4.3%	13.8%	9.9%
Sherburne	GM Urban	20,520	115.97	117.94	106.56	-1.7%	8.1%	9.6%
Stearns	GM Urban	61,141	126.46	129.15	127.10	-2.1%	-0.5%	1.6%
St. Louis	GM Urban	115,298	133.54	134.48	123.20	-0.7%	7.8%	8.4%
Winona	GM Urban	33,393	120.82	146.04	131.44	-20.9%	-8.8%	-10.0%
Wright	GM Urban	36,374	126.19	124.79	116.73	1.1%	7.5%	6.5%
Total		463,045	132.14	134.45	125.61	-1.7%	4.9%	6.6%
69 "Rural" Counties	GM Rural	822,642	132.47	127.00	115.62	4.1%	12.7%	9.0%
All 87 Counties	Statewide	2,330,268	140.16	144.77	132.97	-3.3%	5.1%	8.2%
Statewide (less Hennepin, Ramsey, Dakota)	Statewide	1,467,081	131.44	131.09	120.54	0.3%	8.3%	8.1%

***** Percentage (%) differences between "allowable - authorized," "allowable - paid" and "authorized - paid" are computed by subtracting the second of the pair from the first and dividing the difference by the first. A negative number indicates second of the pair is larger than the first.

Twin Cities metro area. In FY 1998, Twin Cities metropolitan counties were allowed an average of $149.71 per HCBS recipient and they spent on average $150.18. In other words, Twin Cities metro counties spent all the funds that were made available to them for HCBS. It was notable, however, that these counties had actually authorized ISPs for individuals that were 9.0% higher than the amount of money available to them to manage in providing HCBS. In the end, then, the Twin Cities metropolitan counties were able to stay within their allocated budgets by spending 8.2% less than the individual service plans authorized. This "average" outcome does, however, mask considerable variation among the counties in a number of categories. The variations among counties were least in the authorization of service expenditures that were 8.3% (plus or minus 4%) of the amounts eventually spent. Variations were most notable in differences between funding allocated by the state and actual service payments. Counties ranged from spending 1.9% more than allowed to spending 11.8% less. Large metro counties were much more likely to expend all that they were allowed than were the smaller counties in the metro area (See Table M6).

Greater Minnesota urban counties. Unlike the metropolitan counties in which expenditures were nearly equal to the allocation of state and federal funding, GM urban counties significantly under spent the money they were allowed (by 4.9%). In FY 1998 with per person average allowable of $132.14 the GM urban counties spent on average $125.61. Authorized services, if delivered, would have been 1.7% more costly than the funding allocated to the county, but the actual expenditures were 6.6% less than the amounts authorized. Olmstead and Winona counties stood out among GM Urban counties in authorizing 6.8% and 20.9% more in expenditures than their state allocation and in actually spending 1.5% and 8.8% more. Blue Earth, Crow Wing, Otter Tail and Rice counties spent more than 10% less for HCBS than they could have under the state allocation.

Greater Minnesota rural counties. GM rural area counties actually authorized 3.3% less in expenditures for HCBS than they were allowed by the state and spent 12.7% less than allowed. On average the 69 GM rural counties were allowed $132.47 per person, authorized expenditures of $127.00 and actually spent $115.62. In other words, almost $14 million dollars of allowed expenditures in rural area counties went unspent in FY 1998. These summary statistics as well as the wide variability among individual rural area counties are part of a pattern in which larger counties tend to be considerably more able (or committed) to manage their HCBS expenditures close to their HCBS allocation (See Table I6).

Statewide averages. Statewide, counties were allowed on average $140.16 per person for HCBS. They authorized an average $144.77 per person in services and spent an average of $132.97 per HCBS recipient. On average allowed expenditures were 3.3% less than what the counties authorized, but they were 5.1% greater than counties actually spend as counties authorized 8.2% more in expenditures than they spent.

Statewide minus the three largest metro counties. Twin Cities metro area counties accounted for 3 of 8 (37.4%) of all HCBS service days in FY 1998. Because of their program size they have substantial effects on statewide summary statistics. Removing Hennepin, Ramsey and Dakota counties from statewide calculations, in Fiscal Year 1998, 84 counties were allowed average daily expenditures of $131.44 per person. They authorized average expenditures of $131.09 per HCBS recipient, or 0.3% less than they were on average allowed. These 84 counties spent 8.3% less on services than they were allowed and 8.1% less than they authorized (See Table I6).

Patterns among the three large metropolitan counties were considerably different than the rest of the state. Their average allowed funding was on average considerably higher than the state average ($154.70 and $131.44 respectively) and they spent nearly all that they were allowed (all but 0.6%). Their authorizations were 8.3% greater than what they were allowed, but their actual expenditures were 8.1% less than they authorized.

HCBS Expenditures by County Type

Table I7 presents the distribution of paid HCBS service expenditures by type of county: Twin Cities Metro (Hennepin, Ramsey, Dakota, Washington, Carver, Anoka, Scott), Greater Minnesota urban (Blue Earth, Clay, Crow Wing, Olmsted, Otter Tail, Rice, Sherburne, Stearns, St. Louis, Winona, Wright), and GM rural area counties (all others). In 1998, HCBS payments were made for 3,078 metropolitan county HCBS recipients (45.2% of the total), 1,322 GM urban county recipients of HCBS (19.4% of the total) and 2,409 GM rural area recipients (35.4% of the total).

Table I7: Average Annual Costs Per HCBS Recipient Per Service By County Type, 1998								
	Metropolitan		GM Urban		Rural Area		Statewide	
Service	$ Annual	*N*	$ Annual	*N*	$ Annual	*N*	$ Annual	*N*
Assessment for Home Care	$136	49	$151	21	$131	61	$136	131
Assistive Technology	$516	17	$355	11	$533	26	$491	54
Caregiver Training and Ed.	$380	7	$809	5	$294	10	$439	22
Case Management	$1,401	2,974	$1,369	1,316	$1,346	2,390	$1,375	6,680
Consumer Directed Supp.	$3,330	13	$800	1	$0	0	$3,150	14
Crisis Respite	$5,680	245	$10,280	93	$4,934	132	$6,381	470
Day Training/Adult Day	$8,189	21	$4,808	14	$4,541	15	$6,148	50
Day Training & Hab.	$13,420	2,179	$11,638	827	$10,777	1,413	$12,241	4,419
24 Emergency Service	$7,650	1	$0	0	$2,617	5	$3,456	6
Environmental Mods	$3,267	261	$1,374	75	$214	173	$2,605	509
Extended Transportation								
Home Health Aide	$6,169	3	$3,765	6	$4,766	21	$4,706	30
Homemaker	$2,222	15	$1,796	25	$1,765	45	$1,855	85
Housing Access Coord.	$0	0	$0	0	$0	0	$0	0
In-Home Family Supp.	$11,196	437	$11,856	158	$9,727	332	$10,782	927
Live in Caregiver	0	0	0	0	0	0	0	0
Personal Care	$12,648	160	$10,431	38	$11,699	113	$12,032	311
Private Duty Nurse	$17,292	3	$11,557	2	$18,904	4	$16,734	9
Personal Support	$2,861	72	$9,058	32	$2,577	72	$3,872	176
Respite Care	$3,922	363	$2,653	160	$3,161	391	$3,375	914
Support Living Child	$44,256	78	$34,167	48	$39,097	89	$39,868	215
Support Living Adult	$43,672	2,524	$37,283	1,109	$35,248	1,911	$39,490	5,544
Skilled Nursing	$866	27	$962	15	$865	56	$880	98
Specialist Service	$1,806	123	$1,630	111	$1,122	80	$1,569	314
Supported Employment	$10,019	3	$919	1	$3,272	10	$4,549	14
Average Payments	$51,494	3,078	$44,495	1,322	$40,186	2,409	$46,135	6,809

Expenditure differences. Substantial differences in expenditures for HCBS were noted across the county types. The average annual per person service expenditure was $51,494 in metropolitan counties, $44,495 in GM urban counties, and $40,186 in GM rural counties. In other words average expenditures for HCBS services in the metropolitan counties were on average 28.1% higher than in the rural area counties, and 15.7% higher than in the large GM counties (See Table I7).

Contributing factors. Differences in expenditures were driven primarily by the differences in the payments for adults receiving SLS (23.9% higher in the metro area than in the GM rural area counties; 17.1% higher than in the GM urban counties). Day Training and Habilitation expenditures also contributed to the differences, being 15.3% higher in the metropolitan area than in the GM urban counties and 24.5% higher in the metropolitan area than in GM rural area counties. Although case management was the most commonly used service, it contributed very little to expenditure difference because of similarities across the county types in both the proportions of persons receiving case management and the average per person case management expenditures. The counties averaged $1,374.83 per HCBS recipient, with the average case manager expenditure rates being within 4% of one another across the county types. The proportion of HCBS recipients receiving case management paid for by HCBS ranged from 96.6% in the metropolitan counties to 99.5% in the rural area counties.

Costs by Recipient Ages and County Types

The distribution of expenditures for HCBS recipients of different ages in the metropolitan, GM urban and GM rural area counties are presented in Table I8. Patterns showing service expenditures to be highest in the metropolitan area and lowest in the GM rural area counties are maintained in almost every age grouping. The only exceptions were among children 10 and younger and adults 61-70 years. Although the highest average expenditures for children 10 years and younger were in the GM urban counties, low proportions of all HCBS recipients were found in that age group (2.3% in GM urban counties, 3.5% in the metropolitan area and 4.4% in the GM rural area counties).

Table I8: Distribution of Paid Costs for HCBS Recipients by Age Groups and Type of County

	Type of County							
	Metropolitan		**GM Urban**		**GM Rural**		**Total**	
Age	**$ Paid**	***N***	**$ Paid**	***N***	**$ Paid**	***N***	**$ Paid**	***N***
0-10 years	$20,578	108	$25,586	30	$18,131	105	$20,139	243
11-15 years	$32,440	148	$28,408	64	$26,747	125	$29,563	337
16-20 years	$34,385	191	$32,435	100	$29,189	179	$31,991	470
21-25 years	$46,876	306	$43,990	136	$36,830	228	$42,872	670
26-30 years	$54,220	342	$46,405	173	$39,692	255	$47,653	770
31-35 years	$55,090	343	$47,983	141	$43,547	238	$49,897	722
36-40 years	$55,739	398	$48,638	138	$44,627	234	$51,090	770
41-50 years	$59,563	629	$49,917	253	$45,428	437	$53,030	1,319
51-60 years	$58,711	349	$46,928	142	$46,055	337	$51,539	828
61-70 years	$53,084	150	$42,820	93	$44,256	177	$47,091	420
71+ years	$44,066	114	$42,883	52	$40,473	94	$42,530	260
TOTAL	$51,494	3,078	$44,495	1,322	$40,186	2,409	$46,135	6,809

Expenditures by Race/Ethnicity and County Type

Table I9 presents the distribution of expenditures for HCBS recipients of different racial/ethnic groups in the metropolitan, GM urban and GM rural counties. These expenditures tend not to fall into consistent patterns, except for white non-Hispanics who make up 95% of all HCBS recipients. The variability among the minority groups is driven by relatively few individuals from racial/ethnic minorities in certain county types. As a group only Hispanics deviated by more than 10% from the statewide average, receiving services that cost 86.5% of the average for all HCBS recipients. This difference is attributable to metropolitan area Hispanics having paid costs that were 67.3% of all average for the metropolitan area HCBS recipients because of the high proportion of children.

Table I9: Distribution of Paid Costs for HCBS Recipients of Different Racial/Ethnic Groups by Type of County, FY 1998								
	Type of County							
Racial/ Ethnic Group	**Metropolitan**		**GM Urban**		**GM Rural**		**Total**	
	$ Paid	***N***	**$ Paid**	***N***	**$ Paid**	***N***	**$ Paid**	***N***
White, Non-Hispanic	$51,902	2,841	$44,483	1,297	$40,130	2,328	$46,176	6,466
Black, Non-Hispanic	$46,312	151	$35,595	8	$27,503	3	$45,435	162
Native American	$50,001	37	$53,254	7	$42,414	56	$45,980	100
Asian/Pacific Islander	$52,769	30	$57,169	5	$37,147	7	$50,689	42
Hispanic	$34,678	17	$37,014	5	$47,912	13	$39,927	35
TOTAL	$51,494	3,076	$44,495	1,322	$40,185	2,407	$46,1357	6,805

Expenditures by Age and Level of Intellectual Disability

Table I10 presents average HCBS expenditures for individuals by age and level of intellectual disability. This data shows a consistent pattern of increased expenditures in all age categories for persons with relatively greater impairments. It is notable that while expenditures for persons with mild mental retardation were consistently less than those for persons with moderate mental retardation the amount of the difference was very small (about 1.5% in average difference). Costs for persons with severe and profound mental retardation differed considerably from those of persons with mild and moderate mental retardation. Expenditures for persons with severe mental retardation were 21.8% higher than for persons with moderate mental retardation. Average expenditures for persons with profound mental retardation were 28.2% higher than for persons with severe mental retardation and 56.1% higher than for persons with moderate mental retardation.

Table I10: Expenditures for HCBS Services by Age and Level of Intellectual Disability										
	Level of Intellectual Disability									
	Mild		**Moderate**		**Severe**		**Profound**		**Rel. Condition**	
Age Group	**$ Paid**	***N***	**$ Paid**	***N***	**$ Paid**	***N***	**$ Paid**	***N***	**$ Paid**	***N***
0-10 years	$16,940	50	$20,581	53	$19,500	43	$31,800	18	$22,311	60
11-15 years	$20,530	80	$27,185	107	$33,748	626	$38,386	44	$37,047	44
16-20 years	$28,076	129	$29,746	161	$33,925	95	$45,673	56	$29,116	29
21-25 years	$35,889	205	$38,782	250	$54,096	109	$56,088	79	$49,774	27
26-30 years	$42,196	327	$45,295	203	$53,851	133	$63,336	94	$44,917	13
31-35 years	$43,303	280	$45,991	204	$57,746	129	$65,956	100	$52,539	9
36-40 years	$43,325	279	$45,271	194	$55,570	134	$69,309	150	$48,152	13
41-50 years	$45,083	448	$45,677	285	$53,478	270	$71,487	301	$51,621	15
51-60 years	$43,286	237	$43,811	190	$54,210	215	$67,647	180	$43,357	6
61-70 years	$42,086	157	$43,994	92	$48,377	109	$63,638	60	$15,926	2
71+ years	$40,419	92	$42,122	56	$42,220	78	$50,288	33	$27,869	1
TOTAL	$40,394	2,284	$40,999	1,795	$49,941	1,377	$64,006	1,115	$36,232	219

Expenditure information for persons with related conditions (cerebral palsy, spina bifida, autism, etc.) who did not also have mental retardation was highly variable by age grouping. This reflects both the significant differences in support needs associated with different types and degrees of impairment and the relatively low number of people who have only related conditions within Minnesota's adult HCBS population. Indeed it is notable that 61% of all HCBS recipients who had only related conditions were 20 years or younger, while persons 20 years and younger on a whole made up only 15% of all HCBS recipients.

Expenditures by Residential Program

Residential services costs are the primary factor driving expenditures for HCBS. This section provides summary statistics on HCBS expenditures by residential program type.

Supported Living Service and family support. Table I11 presents the average annual expenditures for HCBS recipients in receiving HCBS in different residential settings, including Supported Living (87.2% of which are provided in "corporate foster" or small group homes), in-home family supports (in the immediate or extended family home), and "other" residential arrangements. The patterns in this table show a) much higher average costs of SLS as compared with in-family support ($51,501 and $18,882) and, b) consistency of expenditures for SLS and in-family supports across the categories of children and adults. People receiving HCBS in non-SLS licensed out-of-home settings were relatively few in number (380), but had relatively modest service costs for both children and adults.

Table I11: Average Annual Paid Costs for HCBS Services By Type of Living Arrangement and Level of Intellectual Disability

Level of Intellectual Disability	HCBS Residential Support Services							
	Supported Living Service		Family (extended or immediate)		Other		Total HCBS $ Paid	
	$ Paid	*N*	$ Paid	*N*	$ Paid	*N*	$ Paid	*N*
Children (0-17 yrs)								
No MR/Related Condition	$60,282.40	20	$20,671.79	80	$20,602.65	12	$27,737.64	112
Mild MR	$47,296.97	35	$14,784.67	112	$11,006.12	17	$21,185.95	164
Moderate MR	$47,930.46	55	$17,678.47	147	$18,216.50	11	$25,517.80	213
Severe MR	$51,047.80	37	$21,568.96	93	$14,497.00	7	$29,169.06	137
Profound MR	$55,824.06	34	$21,016.28	34	$31,537.88	7	$37,777.82	75
Unspecified MR	N/A	0	$10,330.13	15	$12,863.42	4	$10,863.46	19
Total	$51,292.80	181	$18,261.50	481	$17,386.48	58	$26,494.71	720
Adults (18+ years)								
No MR/Related Condition	$46,828.28	84	$34,375.59	15	$47,379.91	8	$45,123.80	107
Mild MR	$44,742.84	1,837	$17,869.67	140	$28,448.93	143	$41,869.12	2,120
Moderate MR	$46,340.16	1,361	$19,877.72	156	$30,573.60	65	$43,082.91	1,582
Severe MR	$55,244.13	1,090	$23,396.59	83	$39,020.21	67	$52,235.78	1,240
Profound MR	$68,374.45	952	$31,156.69	49	$49,095.64	39	$65,897.97	1,040
Unspecified MR	N/A	0	N/A	0	N/A	0	N/A	0
Total	$51,559.67	5,324	$21,640.87	443	$34,048.46	322	$48,456.92	6,089
All Ages								
No MR/Related Condition	$49,415.54	104	$22,835.55	95	$31,313.55	20	$36,232.25	219
Mild MR	$44,790.59	1,872	$16,498.56	252	$26,595.63	160	$40,394.45	2,282
Moderate MR	$46,401.93	1,416	$18,810.76	303	$28,785.07	76	$40,998.58	1,795
Severe MR	$55,106.36	1,127	$22,430.85	176	$36,700.46	74	$49,940.84	1,377
Profound MR	$67,941.68	986	$27,002.79	83	$46,423.81	46	$64,006.48	1,115
Unspecified MR	N/A	0	$10,330.13	15	$12,863.42	4	$10,863.46	19
Total	$51,500.90	5,505	$19,881.69	924	$31,505.31	380	$46,134.59	6,809

Expenditures by Place of Residence

A breakdown of HCBS expenditures for children and adults according to specific types of residential placement as recorded on their screening document at the time of the last screening is summarized in Table I12. The settings are defined as follows: 1) "Foster family" refers to people who are living in the home of people who are not immediate or extended family members who are providing services and support to them; 2) "Corporate foster care" is a home of 4 or fewer people in which services are provided by paid staff in a setting that is under the control of a provider agency (note: occasionally corporate foster care settings are leased from the individual or family); 3) "Own home" refers to a place that is owned or rented by a service recipient or by a service recipient's family to serve as the home for HCBS recipient; and 4) "Family home" refers to a place in which an HCBS lives with members of the immediate or extended family. People living in corporate foster care, 71.5% of Minnesota HCBS recipients, have by far the most costly HCBS services, both for children and adults. Both children and adults living in their own home and their family home have the least expensive services ($21,454 and $19,568, respectively). While foster family care is considerably less expensive to the state than corporate foster care ($31,518 and $54,733 per year respectively), foster family home residents made up only 5.4% of HCBS recipients in 1998.

Table I12: HCBS Expenditures by Residential Situation and Age Group

	Foster Family		Corporate Foster		Own Home		Family Home		Other/No record	
Age Group	Average $ Cost	Recipients	Average $ Cost	Recipients	Average $ Cost	Recipients	Average $ Cost	Recipients	Average $ Cost	Recipients
Children (0-17 yrs.)	$29,375	7.1%	$57,510	19.0%	$7,389	0.1%	$17,912	69.2%	$20,490	4.5%
Adults (18+ yrs.)	$31,861	5.2%	$54,653	77.7%	$21,499	5.2%	$21,329	7.7%	$36,997	4.1%
Total	$31,518	5.4%	$54,733	71.5%	$21,454	4.7%	$19,568	14.2%	$35,085	4.2%

Expenditures by Type of Residence and Level of Service Needs

Table I13 presents a breakdown of expenditures for persons in different categories of the waiver allocation structure (WAS) living in different types of settings. Among foster family, corporate foster and own family homes average expenditures are consistently associated with the WAS groupings. Within the family foster care settings persons with "Level 1" profiles had services that are 56.2% more expensive than those with "Level 4" profiles. Among people living in their family homes those with "Level 1" profiles had services that cost on average 75.6% more than those with "Level 4" profiles. The smallest range in average expenditures between people with "Level 1" and "Level 4" profiles was with the corporate foster care settings, with only a 32.0% difference. Presumably the differences reflect the relative limited flexibility in providing staffed group housing. In that regard, it is notable that people with highest needs living in foster families had total expenditures that were only 78.4% of the total expenditures for people with lowest needs in corporate foster settings. Too few HCBS recipients with "Level 1" and "Level 2" profiles were living in their own homes (5), for analysis of people living in their own homes across all profile levels to be statistically significant, but there were consistent differences between persons at levels 3 (moderate needs) and 4 (lowest needs). It is notable that expenditures for "Pre-WAS enrollees" are quite similar on average to those who entered the program subsequently in each residential arrangement, as is the distribution within the different arrangements. For example, 71.6% of pre-WAS recipients lived in corporate foster settings as did 74.7% post-WAS recipients. Pre-WAS HCBS recipients were also slightly more likely to be in foster family homes (6.2% and 4.4%, respectively), and to live their own home (5.7% and 3.0%, respectively). They were less likely to live in their family home (13.4% and 17.9%, respectively), which reflects their slightly older age.

Table I13: HCBS Expenditures by Residential Situation and Allocation Profile Level of Service Need

	Type of Residence									
	Foster Family		Corporate Foster		Own Home		Family Home		Total	
Waiver Allocation Group	**Average $**	***N***	**Average $**	***N***	**Average $**	***N***	**Average $**	***N***	**Average $**	***N***
Level 1 (highest needs)	$30,665	11	$72,224	271	$7,389	1	$21,521	57	$62,189	340
Level 2 (high needs)	$28,301	32	$60,554	489	$16,846	5	$18,655	129	$50,393	655
Level 3 (moderate needs)	$26,939	34	$48,238	567	$24,053	24	$14,460	126	$40,834	751
Level 4 (lowest needs)	$19,626	14	$39,121	205	$14,785	31	$12,812	54	$31,068	304
Pre-WAS (enrolled before FY 96)	$33,076	279	$54,523	3,338	$22,160	257	$21,259	600	$46,865	4,474
Total*	$31,518	370	$54,733	4,870	$21,454	318	$19,568	966	$46,588	6,524

* A total of 275 people lived in settings that were “unrecorded” in the data or “other” than those indicated in Table A4.
Note: Service levels are determined from the individual’s profile on the “Screening Document.” Service levels include: Level 1, “Very high self-care needs or mental illness and obstructive behavior”; Level 2, “High self-care needs or aggressive/destructive behavior;” Level 3, “Limited self-care needs, but no major behavior problems;” Level 4, “Limited self-care needs and no major behavior problems.” Prior enrollees are people who were enrolled in HCBS prior to FY 1996 and were not profiled for resource allocations.

Accounting for Cost Variations

Table I14 presents findings from three multiple regression analyses to identify factors accounting for the variability in total service costs for HCBS recipients in Fiscal Year 1998. The groups identified for these analyses were a) all adult HCBS recipients, b) all adult HCBS recipients who entered the HCBS program after July 1, 1995, i.e., who went through the “Waiver Allocation Structure (WAS) profiling process, and c) all children. Efforts to account for variations in HCBS expenditures were carried out by entering specified blocks of variables into the multiple regression formula.

The first block entered was comprised of Individual Characteristics:

a) level of mental retardation with 5 continuous levels: normal, mild, moderate, severe, profound;
b) level of support needed with 4 continuous levels: accesses own support, requires less than 24 hour support, needs 24 hour plan of care, needs 24 hour awake supervision;
c) communication, including: uses speech to communicate (yes/no) and uses augmentative communication (yes/no);
d) behavior disorder, including severe or very severe self injury (yes/no), property destruction (yes/no), aggression toward others (yes/no), inappropriate sexual behavior (yes/no), running away (yes/no),
e) physical impairment, including needs help walking (yes/no) and uses wheelchair independently (yes/no);
f) medical conditions: none (yes/no), needs frequent, but not on-call medical attention (yes/no), needs on-call medical staff (yes/no), needs on-site medical staff (yes/no),
g) mental health service need (yes/no) and
h) WAS profile rating from 1 to 4 for children and for adults entering the HCBS program after July 1, 1995.

The second block of variables was county type: metropolitan Twin Cities county (yes/no) and GM urban counties (yes/no). The final block of variables was type of living arrangement: Corporate foster care (yes/no), living in one’s own home (yes/no), and living with immediate or extended family members (yes/no).

As indicated by the “R-square” statistic, the predictor variables used in the three regression equations accounted for 45.4% of the variation in individual HCBS expenditures for all adults, 41.8% for those adults who began HCBS after the introduction of the WAS and 55.4% for children. The block of individual characteristics was very similar in prediction of costs for both the all adult group and the post-WAS group, affected, of course, by 31.6% of the all adult group being made up of the post-WAS group members. For the all adult and post-WAS adult group individual characteristics accounted for 30.5% and 30.0% of cost variations. When the WAS profile score was added to the equation following the block of individual characteristics, it accounted for only another 1.0% in cost variation among post-WAS adults.

The type of county in which HCBS recipients lived, controlling for individual characteristics, contributed relatively little to accounting for cost variations. Among the all adult group members, entering county type into the regression equation accounted for only another 1.6% of variation in cost and among the post-WAS adults, county type accounted for only another 0.6% of cost differences. After controlling for individual characteristics and county type, type of living arrangement remained a substantial predictor of variability in living arrangement. Residence in a corporate foster care setting as a yes/no dummy variable accounted for another 12.9% in cost variations for all adults and 10.0% for post-WAS adults.

Among children, controlling for individual and geographic differences, living in a corporate foster care setting, was a highly predictive of cost. Approximately 27.6% of the variability in costs for children was predicted by the corporate foster variable. In contrasting cost predictors for children and adults, among adults intellectual impairments and level of support were substantially more predictive of cost differences than among children (R-squares of .338 for all adults, .339 for post-WAS adults and .158 for children).

Table I14: Variable Accounting for Differences in Costs of Services for Adults and Children Receiving HCBS in 1998

	All Adults		Adults (w/ Profile only)		Children	
Variable	R^2	R^2 Change	R^2	R^2 Change	R^2	R^2 Change
Intellectual (Level of MR)	0.103		0.107		0.015	
Level of Support	0.235	.132***	0.232	.125***	0.143	.128***
Communication						
Non-verbal	0.238	.003***	0.235	.003*	0.145	0.001
Augmentative device	0.239	0.000	0.235	0.000	0.159	.014*
Behavioral Disorder						
Injure self	0.249	.011***	0.252	.017***	0.165	0.006
Destroy property	0.265	.015***	0.260	.009***	0.167	0.002
Aggressive to others	0.270	.006***	0.263	.002*	0.171	0.003
Inappropriate sexual beh.	0.272	.002***	0.264	0.001	0.171	0.000
Runs away	0.274	.002***	0.267	.003*	0.183	.012*
Physical Impairment						
Needs help walking	0.280	.006***	0.284	.018***	0.192	0.008
Uses wheelchair	0.282	.002***	0.288	.004**	0.203	.012*
Medical Conditions						
None	0.287	.005***	0.290	0.001	0.209	0.006
Needs frequent attention	0.289	.001***	0.293	.003**	0.231	.023**
Needs on-call medical	0.289	0.000	0.293	0.000	0.235	0.004
Needs on-site medical	0.291	.002***	0.295	.002*	0.236	0.001
MH Service	0.305	.013***	0.300	.005***	0.256	.020**
Allocation Profile Level			0.310	.010***	0.267	.011*
Region						
Metro Twin Cities	0.319	.014***	0.316	.006***	0.276	0.008
GM Metro	0.321	.002***	0.316	0.000	0.277	0.001
Living Arrangements						
Corporate foster	0.450	.129***	0.417	.100***	0.553	.276***
Own home	0.450	0.000	0.417	0.001	0.554	0.001
With family	0.454	.004*	0.418	0.001	0.554	0.001

*: $p \leq .05$, **: $p \leq .01$, ***: $p \leq .001$

County Perspectives on Financing and Reimbursement

In the interviews with MR/RC Waiver Coordinators (and in some cases their financial managers an/or planners) several questions were asked regarding costs, expenditures and managing their allowed county waiver costs. The narrative below summarizes their opinions and experiences.

County goals for the HCBS program related to cost and utilization. Most counties reported that they wanted to increase the number of people served on the HCBS program in their counties. This expansion in some cases included increasing their use of consumer support and consumer direct options; developing collaborations with other counties to utilize efficiency waivers; and developing new SLS sites. Three counties reported goals of getting their expenditures more inline with their allocations and five reported that they had no goals or strategic directions.

Established reimbursement rates for each unit of service provided under HCBS. In general, counties reported that the rates for each type of service for the people who receive HCBS services vary by the individual based on their needs and the type of services they receive. DTH services were reported to be standard rates based on the agency with some variation depending on the type of employment service the person is receiving and whether or not they go to a DTH program. In some cases, counties reported that they had set rates for in-home, PCA and/or respite services and often within a county there were established rates for specific types of services that had been negotiated between the provider agency and the county.

Contracting with providers of HCBS services. The overwhelming majority of counties have a Master contract that they use with provider agencies that identifies the agency's responsibilities in providing HCBS services. Then through attachments and amendments each individual service agreement is identified which indicates the amount of payment for each type of services. If a new person is served by the organization an amendment is attached regarding that individual's service agreement. Two counties reported that they have a master contract for the agency and then site agreements for each location. Two counties reported that they do not use Master contracts, one of them has a different contract for each site and the other has a separate contract for each individual served. One county reported that they use a different contract for each type of service delivered (e.g. supported employment, foster care, SLS) even if the same agency provides multiple services. One county who uses a Master contract reported that this process has limited the number of new providers with whom they contract because it is easier to go with existing corporate providers then to "mess with" developing a new Master contract for a new provider.

Total annualized county expenditures for HCBS exceeded the allowable limits. Several counties reported overspending in the early years of the HCBS program. A few of the counties interviewed had experienced recent problems with overspending. In response to this overspending, these counties are seeking to bring new people into HCBS services who cost less, are not giving providers increases in their rates and in a few cases have actually decreased rates.

Total annualized county expenditures for HCBS were significantly below allowable amounts. Most counties reported that they had been under-spent at some point in time and many of these counties indicated that they have consistently "under-spent." The amount ranged from 2-3% to as much as 20-30%. One county expressed that it seemed odd to get pressure to spend more because advocates were unhappy about waiting lists when their county had managed the HCBS Waiver well and met the needs of everyone on the HCBS Waiver using the least amount of HCBS Waiver dollars needed to do so. For this reason, this county was pleased with the option to partner with four other counties and to use the unspent money to serve additional people through efficiency waivers.

Managing expenditures to assure they do not exceed allowable levels. All of the counties interviewed rely in some way on the state developed and implemented tracking system that incorporates MMIS data and produces monthly reports on authorization, average spending per recipient and for the county HCBS program as a whole. Only one county reported that they found this system to be effective. Even that county reported that they felt the state needed to designate a person they can rely on for troubleshooting. In general, smaller counties reported having an easier time managing their expenditures and staying within their allowable allocations. There were many recurring complaints about the ineffective of this system and several recommendations were suggested for its improvement.

Reported WAS tracking system problems:

- The data only provides information received and entered by DHS up to a certain day and the data is often delivered late to the counties. One county reported that they had not received a disk from DHS in over 8 months. Many reported that they receive them inconsistently and late.
- The numbers that are in the system seem to be inaccurate and usually don't match the county numbers regarding, allocations and expenditures.
- There is a great time delays in adding new information (such as a new person) into the system – one county reported that it can take as long as 6 months to get a new person entered into the DHS system.
- The system relies on billing to have occurred and many providers don't bill frequently enough to know how much of the authorized services are actually being delivered. This problem is greatly enhanced by the staffing shortages where we might authorize a number of PCA services or respite services but the staff aren't there to provide them. It is difficult to project because we don't know how much if any service the provider has billed.
- It is very difficult to find a person at DHS with whom county staff can talk to about the issues they are having trouble identifying who within the Department has answers to their questions.

County Recommendations for improvement of the WAS Tracking System:

- Additional DHS staff members are needed to support the system and ensure that data input occurs in a timely fashion and that troubleshooting is available for the counties who rely on the system to manage their spending.
- The system needs to be networked ("live" or "real time") to allow continuous access to the data from counties and to allow counties to enter in their own authorizations vs. depending on MMIS system staff to do this when they seems to be so back logged. Several suggestions included getting the system up and running on a WWW site.
- The Tracking System needs to provide information about whether or not the provider has billed for the authorized services and/or an indication of the period through which payment has been made.

Discussion

This section describes and analyzes HCBS costs and compares these costs to ICF/MR services and to averages in other states.

Key Findings.

- In FY 1998, expenditures for HCBS recipients averaged $52,961.06, and expenditures for ICF-MR recipients averaged $67,672.85.
- For the typical HCBS recipient, residential habilitation (SLS services) made up 69% of all health and social service expenditures in 1998.

- In FY 1999, Minnesota had average daily recipient expenditures for the combined ICF-MR and HCBS programs of $52,501 as compared with a national average of $47,985.
- Minnesota spent $113.88 per state resident on ICF-MR and HCBS services combined, compared to a national average of $65.53.
- Minnesota's relatively higher expenditures are associated with its overall high levels access to HCBS, its relatively high rate of supporting persons with severe disabilities in the HCBS program, and its proportionately greater use of small group living settings for HCBS recipients (used for 74% of HCBS recipients in Minnesota compared with 41% of HCBS recipients nationally).
- Counties authorize expenditures for children that are on average $6,885.73 more than they actually spend. They authorize expenditures for adults that are on average $3,843.73 more than they actually pay. Differences between children and adults are attributable to spending for SLS which predominately serves adults that is 98.3% of authorized levels as compared to much proportions of authorizations actually spent for services that predominately service children and families (e.g., statewide 70.6% of authorized expenditures for respite care were used). Factors contributing to these differences are explored in the technical report.

Average HCBS Costs in FY 1998

- In FY 1998, Metro counties were allowed an average of $149.71 per HCBS recipient and spent an average of $150.18. urban counties of greater Minnesota were allowed an average of $132.14 and spent an average of $125.61. Rural counties of greater Minnesota were allowed an average of $132.47 and spent an average of $115.62.
- In 1998, Metro counties served 3,078 HCBS recipients (45.2% of the total), urban counties of greater Minnesota served 1,322 recipients (19.4%) and rural counties served 2,409 recipients (35.4%).
- The highest cost HCBS services per recipient per year in 1998 were SLS services for children ($39,868 per recipient), SLS services for adults ($39,490), private duty nursing ($16, 734), day training and habilitation ($12,241), and personal care ($12,032).
- The average annual per person service expenditure was $51,494 in metro counties, $44,495 in urban counties of greater Minnesota, and $40,186 in rural counties of greater Minnesota.
- Average costs were lowest for children 0-10 years ($20,139), and highest for adults 41-50 years old ($53,030).
- Average annual costs were highest for persons in the Asian or Pacific Islander group ($50,689) and lowest for persons who were Hispanic ($39,927).
- Average annual costs were $40,394 for persons with mild mental retardation (MR), $40,999 for persons with moderate MR, $49,941 for persons with severe MR, and $64,006 for persons with profound MR. Average annual costs for persons with related conditions but with no MR were $36,232.
- Average annual costs for persons living in supported living services settings were $51,500 compared with $19,882 for persons living with their immediate or extended family. Costs for persons in other settings (foster family, own home) averaged $31,505.
- Minnesota's Waiver Allocation Structure (WAS) provides counties with different amounts of money to be placed into an allowed spending pool based on statistical assignment of consumers to one of four resource allocation levels. Average annual costs were highest for persons in the Level 1 WAS group (averaging $62,189 per year), and lowest for persons in the Level 4 WAS group (averaging $31,068).
- Average HCBS costs for children were predicted by level of support needed, use of an augmentative communication device, running away, using a wheelchair, needing frequent medical attention, needing

mental health services, the WAS allocation level, and whether the child lived in a corporate foster care setting. Of those variables the most variability was accounted for by living in a corporate foster care setting (27.6%), and level of support needed (12.8%).

- For adults variations in HCBS costs were predicted by level of support needed, communication skills, all types of challenging behavior, using a wheelchair, level of medical support needs, use of mental health services, region of the state, and living in corporate foster care settings. As with children, the most variability was accounted for by living in a corporate foster care setting (12.9%), and level of support needed (13.2%).
- Most counties expressed a need and desire to increase the number of people served in the HCBS program in their counties.
- Most counties report using a master contract to identify agency responsibilities in providing HCBS services. The exact service and cost for each individual is identified through attachments and amendments.
- All of the counties used the state developed tracking system that incorporates MMIS data and produces monthly reports on authorized costs, average spending per recipient, and spending for the county as a whole.
- Only one county respondent reported that the state tracking system was effective. Several recurring complaints were mentioned about the tracking system relating to the timeliness and accuracy of information, and technical assistance available.

Impact of the Waiver Allocation Structure

- In 1995, a new methodology (the Waiver Allocation Structure) to establish the amount of money added to county funding pools for new HCBS recipients was implemented. After this new methodology was implemented, new HCBS recipients were slightly more likely to have profound mental retardation or related conditions and slightly less likely to have mild or moderate mental retardation.
- Actual expenditures for services to children are considerably less than (56.9% of) the resources allocated to counties for those same children through the allocation process.
- Actual expenditures for adults (18 and older receiving HCBS) are slightly higher (about $200) than allocations to counties when those adults entered the HCBS program.
- Although HCBS recipients enrolled before and after introduction of the WAS have similar current expenditures, the allocations to counties on their behalf in 1998 were very different (e.g. pre-WAS, $36,750 for children; post-WAS, $57,842).

What's working?

As the HCBS program in Minnesota has continued to expand, and as it has exceeded the size of the ICF-MR program, it continues to provide supports to individuals at a cost lower than that of the ICF-MR program ($52,961 versus $67,763 per year per person in 1998). The implementation of the Waiver Allocation Structure (WAS) was intended to provide appropriate levels of allowed spending to counties based on the specific supports needs of individuals entering the HCBS program. One of the primary reasons for doing so was to expand access to HCBS for persons with more substantial and costly support needs. The WAS has been associated with a modest increase in the proportion of individuals supported by the HCBS program who had profound mental retardation. The proportion of HCBS participants with profound mental retardation increased from 15.5% for persons entering the HCBS program prior to July 1995 to 18.3% for persons entering the program after that date.

Challenges and concerns.

Minnesota makes extensive use of corporate foster care in providing HCBS to Minnesota. It does so at an average cost (in 1998) of $54,733 annually as compared with $24,420 for all other HCBS funded services. While Minnesota provides HCBS at about 78% of the cost of ICF-MR service, in considering the differences two factors should be recognized. First, only 2.2% of ICF-MR residents are children and 11.8% of HCBS recipients are children. The average annual costs of HCBS in 1998 for children was about 55% of that for adults, so that the higher proportion of children receiving HCBS contributed substantially to the difference between HCBS and ICF-MR expenditures. Children's expenditures tend to be lower because their primary day activity is funded by their school districts and most live in the homes of family members who provide much of their care and supervision. Relatedly the 14% of HCBS recipients live with immediate or extended family members are major contributors to expenditure differences. In addition, ICF-MR residents are more likely than HCBS recipients to have severe or profound intellectual disabilities (59% and 36%, respectively). The average cost in 1998 of HCBS (excluding health services) for persons with mild and moderate mental retardation was only 72% of that for persons with severe and profound mental retardation ($40,660 and $56,234, respectively).

The 1996 Report to the Legislature from the Department of Human Services noted that there is general cost-effectiveness of the HCBS-financed "model" over the other ICF-MR alternative, but it also raised concern about over-reliance on small HCBS-financed group homes as primary approach to service delivery. The 1996 report recommended that Minnesota invest in training, technical assistance, increased flexibility and other forms of support to assist individuals, families and local governments to develop more personalized approaches to services. Still, there continues to be a heavy reliance on small group homes and day training and habilitation centers to support individuals with MR/RC in Minnesota.

In a time of great general difficulty in recruiting personnel, it appears that family-based services are receiving lower priority in staffing than SLS congregate care services where requirements and concern for safety requires that providers maintain a sufficient level of staffing and therefore billing. These differences in access to the services people are authorized to receive are affecting both children and adults living in their family home. For example, on average, respite care expenditures in 1998 were 70% of the authorized amounts; in-home family supports expenditures in 1998 were 82% of authorizations. Interviews with county waiver coordinators and service providers suggest that these problems are at least as serious in 2000 as they were in 1998 and in some areas in more so.

Irrespective of concerns about the fairness of such differences and the adequacy of the general commitment to families, the cost implications of failing to support people in their homes at relatively low cost at the risk of hastening out-of-home placement occurrences are impressive. Children living with their parents or extended family members had average HCBS expenditures that were 42% of the average HCBS expenditures for children living away from their family home ($18,262 and $43,064, respectively). Insufficient family support of children brings a substantial financial as well as psychological and social cost when it leads to out-of-home placement.

It is important to consider the effect of the current children who receive HCBS funding growing up. Although Minnesota has a relatively small proportion of children receiving HCBS (12%) as these children turn to adults, based on current expenditure patterns, the cost for their services will almost double. Considerable new financial commitments will need to be secured for their futures unless there is a substantial reduction in the use of SLS services and a greater use other alternatives to group residential settings, including "host family," extended family care and other much less costly models.

There are several longer-term implications of Minnesota's current cost allocation and expenditures practices. First, children make up a very small portion of Minnesota's HCBS population (about 10.6%), but the difference between their "allowed" funding (i.e. the amount added to the county-managed funding pool on their behalf) and the amounts actually spent on services for them keep the state system out of deficit. With almost half (45%) of the HCBS recipients who are 20 years or younger being between 16 years and 20 years old, the 83% higher costs on average for services to adults than children presents a fairly immediate threat to the current modest 4.1% difference between allowed and paid costs.

Counties have been providing services to adults and children who entered the HCBS program after 1995 at substantially less than their allowable costs. Even in the Twin Cities metro counties which in 1998 spent overall 4.8% more for their adult HCBS recipients than was provided by the state's allowed expenditures for those same adults, the post-WAS allowances for adults were 5.3% more than expenditures. Given the stability in expenditures for pre and post-WAS enrollees, the higher allowed costs derived from the WAS (on average $55,838 as compared with $44,497 for pre-WAS enrollees), has been extremely helpful to counties in managing the HCBS programs within budget. This assistance through the WAS has been all the more notable since persons who entered HCBS services after 1995 do not differ from those who entered earlier in levels or types of impairments. As results counties have to increase their pools of resources more rapidly than expenditures and make spending commitments to individuals whose services cost more than the amount allowed through the WAS.

K. Personal Stories and County Best Practices

One way to understand how HCBS effect the lives of people with mental retardation and related conditions and their families in Minnesota is to identify what is working well and to hear stories from the various people involved in the delivery and receipt of HCBS. This section identifies personal stories and county best practices as reported by various stakeholders through focus groups, interviews and open-ended questions on written surveys.

Family Member Personal Stories

One strategy used in this evaluation to learn about HCBS was to ask families to share their experiences with respect to the HCBS their family member recieves. This section of the evaluation summary shows some of these stories that illustrate what is working well and what are continued issues or concerns.

What's working?

- A parent whose child had been receiving HCBS through a provider agency was tired of staff turnover so she became a licensed provider under another agency and serves as her child's own provider and will be paid for it.
- The assistive technology our son received through the Waiver has opened up many possibilities for his life.
- Since moving to MN in 1996, the services available to our daughter have been wonderful. School, in-home assistance and now out of home placement and her new work environment. The transition stage was gradual with lots of support and that support has been ongoing. Tricia's social worker is fabulous and her new home setting is very caring and supportive. We feel so lucky!
- Michael lives in a group home with 2 other young men. His physical condition is deteriorating every day. His staff puts forth extra effort to see that he works out and swims at the YMCA four times a week – the support of his case manager and group home staff was needed to get him enrolled [at the YMCA].
- My daughter had a physically abusive roommate, but the problem was resolved in a timely manner and she was able to move into her own apartment. The intervention was immediate – staff listened and acted.
- Our family was able to attend a Sotos Syndrome conference in Seattle, WA where we were able to become better educated on this syndrome.
- Our provider agency has a staff and family picnic where staff and families of the entire organization get together to informally network in an informal, relaxed atmosphere.
- Our child has had the same staff person for the past two years. This counselor has helped her grow, develop, become more social, understand cause and effect such as consequences to her behavior. She has taught her to think about how things could happen and to make better choices.
- Jim was in two ICF-MR facilities from the time he was 18 to 37. Few community-based options were available for our family because we live 2.5 hours from any urban area. For 15 years my parents saw him on holidays or when they were able to manage the 5-hour trip. HCBS services have allowed us to have him 5 minutes away and the past three years has been a dream come true.
- Kris lives with her boyfriend of 8 years in a group home provided for the two of them. They hope to be married and this has been their wish for many years. I hope it will happen within a year. Family who worked

in the field told us of this option for Kris and her boyfriend and then her Dad and I had to advocate for it. The case manager helped to coordinate services once we informed her of what our choice was.

Challenges and issues.

- Michael's first three months at the group home was devastating. The live-in staff emotionally abused him. If house staff and his case manager would have listened to him and me when we tried to tell them what was happening it could have been resolved sooner and would not have lasted for three entire months.
- A fellow housemate of my daughter's bit her in the back.
- As a single mom I have lost three jobs due to missing hours of work because I cannot find PCA care or they call in sick or simply don't show up.
- My son was badly burned in a group home because there was not enough staff.
- One parent said she found out that in a 3-month period the county had been paid about $1,000 for the case manager assigned to her child's case. She was shocked because the case manager really had done nothing for the family yet in terms of finding and accessing needed services. Her estimate was that they had in actuality received about $30 worth of case management services.
- A former child molester worked in a group home where my son lived – we are unsure if he perpetrated our son but a female resident was victimized. Was a criminal check done by the provider for his background? They did respond and terminate the staff person once it was known.
- Finding residential services and day training has been very easy. However, finding other special services has been very difficult. Speech/communication services are available if we make a 120 mile round trip. Physical and occupational therapy has been equally troubling. Local people seem very reluctant to work with people with disabilities…some have directly stated to us that they believe physical therapy is a "waste of taxpayer dollars." Much education needs to be done with the medical professionals.
- It was very frustrating to have been on a waiting list for HCBS for 13 years. We thought we only needed to wait patiently and then our turn would come up. As we inquired more deeply we learned that the criteria for [who gets] a waiver is vague and that your family needed to go into crisis for you to rise to the top.
- One parent requested a specific county case manager because that person knew her daughter. This request was denied by the county because there had been no previous complaints about the exiting case manager that was assigned to her daughter's case.
- My daughter has consistently only received about 50% of the in-home and PCA hours she is authorized.
- I was thrilled to receive a Waiver for my child. But, I can't find any staff. Just this week three PCAs quit.

Provider Personal Stories

Provider agencies shared stories about HCBS in Minnesota. This section identifies some of these stories and what providers think is working well and what their challenges are.

What's working?

- Conversion and downsizing of an ICF-MR with 15 people allowed individuals to receive HCBS services. Everyone who moved to homes for 3-4 people is visibly happier, more independent, and experienced reduced behavior problems. They interact more normally. They have pride in "their homes." I have heard them now refer to going to their parents as going to their "parents home" [instead of saying I am going home (to my house) when visiting parents].
- We have worked out an arrangement with a residential provider that they can have the people who live in their program conduct interviews with potential new staff here at the day program site in our conference room. This is a win win situation because it offers the person the chance to interview potential new staff but also doesn't require that the person miss their own work in order to conduct an interview with a potential new

direct support person. It is great to see the people we support having the chance to choose who will provide supports to them.

- We provide supports to a man who for years turned down several supported employment opportunities. We continued to pursue and offer chances for this person to work in the community. At the last meeting he and his brother agreed that he'd give it a try. He got a job at Burger King and he loved it! They started an employee of the month award and he was the first recipient of the award. When they asked him what he wanted as an incentive or reward he said a Burger King jacket. They got him one. Now, you couldn't get him to leave Burger King for anything.

Challenges and issues.

- We were asked [by the county] to develop services for two individuals in four weeks. This was poor planning. We were not able to sufficiently meet the needs. We did not have good, full referral information. Aggressive behavior escalated, the individual was demitted, and the family was angry with the provider.
- We often don't get current up to date ISPs from case managers and when we do it seems they just change the date and nothing else. In fact I was working for a provider once that changed the name of their company and two to three years later we still were getting ISPs that had the old company's name on them.
- Sometimes the direct support staff (and in some cases the companies they work for) lack the dedication to putting the individuals desires and needs first. For example I knew of a case where there was a staff person in one home who was having a personal relationship with a staff person in another home and so those two homes always did things together even though the people who lived in them really didn't want to do things together. The activities were done for the preferences and convenience of staff.

Direct Support Staff Personal Stories

Direct support staff have the opportunity to observe what HCBS are really about. They are the people on the front lines who actually deliver the support. An important aspect of this evaluation was to seek their input and to hear about their observations. This section includes a number of their personal stories about what is working in HCBS and what are existing challenges.

What's working?

- I take a consumer I work with to a food shelf to volunteer 2 days a month. The people who come to the food shelf have gotten to know Debbie and always take the time to talk with her. Debbie does not talk but it is wonderful to see the interaction between her and the other people at the food shelf.
- I support a young man with autism in going to folk dance classes. Although at first he was excited and scared of the crowds I helped him with the dance steps and now he laughs and seems to really like the classes.
- A person began living here about three years ago. When she first moved in she had a lengthy list of inappropriate behaviors. She had had episodes of cutting her wrists, daily verbal abuse toward others, property destruction, stealing etc… She presented us with a lot of challenges and had never been able to live in any other community setting for more than a year. Over the past three years she has made remarkable progress. Her behaviors are almost extinct with the exception of some verbal abuse every once in awhile. This is the most gratifying experience to see an individual grow and learn and is a reminder that people with DD are capable of improving their lives.
- A man I support called his mother on the phone for years and would always listen to her but he would never talk to her. Staff got a picture of her out one time when he was on the phone with her and he said, "mamma." His mother was so happy she was crying.

- When we moved in we had a house warming party and were welcomed by about eight of our neighbors who came to the party or sent flowers or cookies. We have a good relationship with our neighbors and have a neighborhood party each year to keep everyone in touch with one another.
- I was able to take a consumer to her Aunt's church for Sunday morning service. She was very excited about being able to go and enjoyed all of the new sounds she heard [she is blind]. She is also African American and I felt it was really positive for her to be able to go to a church with her family and one that was culturally relevant to her. The staff hope to continue to support her attendance at this church whenever possible – hopefully twice a month.

Challenges and issues.

- A consumer is communicating that she doesn't want to leave her house to attend day programming. Meetings have been held, a few different approaches have been tried and she is still coming to day program. She is still very unhappy about coming to day program. So there has not been an outcome and the consumer's needs are still not being met.
- A person who receives HCBS was given medication by staff to control behavior (Ativan) for use only when the consumer was very anxious. This went on for several weeks before it was discovered that there had been an obvious misuse of the medication and a disregard for the consumer's well-being. The staff person who was giving out the medication left the company. This staff person was a menace to the staff and the consumers; it was very stressful. Bad staff are the number one worst problem of our field.
- I think the biggest problem in this whole field are the low wages [direct support staff] which lead to burnout, frustration and high turnover. I love my job but I am only making $10.25 an hour as a live in coordinator with a BA degree and many years of experience. This needs to change!
- One of the people we support got burned with hot water. He ended up in the hospital for ten days with 1st – 3rd degree burns. He has scars that will be with him for the rest of his life and it has taken him a long time to trust the water again.
- A person I support consistently has new bruises on her body each time I work with her. I reported these incidents to my supervisor and I filled out all of the necessary paperwork. My supervisor reported it to her case manager. The consumer is obviously being abused. The case manager and the government still insist that she continue to live in this environment where she is obviously being abused. Nothing has been done to help her and it is out of my hands and the agency's hands to do anything more.
- A person I support began taking new medication for some of her problem behavior. The staff felt she was overmedicated because her behavior became very bizarre after she started on the new medication. Staff reported it to the nurse and the administration but we were largely ignored. This made staff burn out and angry.
- A person I support was always being picked on (hit and slapped constantly) by another client in her previous placement. She had to move form her previous placement to here – not the person who was hitting her.
- It was my day off and I was at a department store with my family. I saw the company van parked in the parking lot and noticed there was a client left alone in the van [was not supposed to be left unsupervised]. Shortly afterwards two staff returned to the van and drove off. I went to another store and spotted the same van and the client was left alone again while the staff went into the store. My supervisor told me the situation had been taken care of but the staff involved still work here.
- The budget situation is the worst thing. There is never enough money to train direct support staff. The rent people have to pay here is just short of exploitation, and we have to pay for all repairs. The clients suffer because they have to cut the food budget, activities, training, safety etc…
- I worked with a staff member who was stealing form the clients and who was also not completing self-care and taking people out into the community when they were supposed to.
- We support a person who has a gastrostomy tube that needs to be replaced frequently. Because we have no nursing staff on site we have to make frequent trips to the hospital to have the tube replaced. The staff at the hospital get quite mad at the Waiver staff because we couldn't replace the tube ourselves and they said it was

a waste of taxpayer money having us go to the hospital each time it needed to be replaced. They stated it was "easy" but we couldn't [replace the tube] due to the limitations placed on us by our company as direct care staff.

Case manager's Personal Stories

Case managers also have a unique opportunity to observe what happens in the lives of many HCBS recipients across varied service types and provider agencies. A few of the stories they shared express what is working well and what challenges still exist in MN HCBS are below.

What's working?

- Our county was able to bring [a person with] very significant medical needs and challenging behavior out of the regional center. He was a very sick man who was dying. A competent provider stepped up to the plate and said they would work with him. They have an excellent nurse who can support his Tardive Dyskinesia, diabetes, catheter, limited water intake, chronic constipation, and verbal and physical aggression. He lives in the country, in a two-person SLS. He has a deck he sits on with a dog, has a whirlpool tub to use and can ride his bike. He is very happy and staff members love him and enjoy him.
- A family has five children four of which have been diagnosed with Fragile X. All children are 10 and under. Three of the children now receive in-home HCBS services. It has kept the family together. Five young children would be stressful for any family, but when they are special needs it is even more stressful.

Challenges and Issues.

- The company did not have the skills to provide services for a person with high behavioral needs (the person exhibited sexual, physical and verbal aggression). They hired young, untrained men (more for muscle than brain) who hung out in lawn chairs in the front yard 8-10 hours a day and smoked cigarettes. Client scared the community by visiting their homes unannounced, touching their children, running outside naked, setting fire to neighbor's yard, and going into neighbor's bedroom when the woman came out of the shower. My supervisor (at the county) took him out and drove him to the RTC.

County Best Practices

County HCBS Waiver Coordinators commented on the services offered in their county that they considered exemplary or that they did very well. They also reported innovative things they had done to improve services in their counties. Their comments are summarized below.

Exemplary features of services offered.

Counties identified several "exemplary services" offered in their counties through the HCBS program. Their self-identified exemplary services include:

- Proactive and careful planning before a new service is provided for an individual HCBS recipient to ensure that they are receiving support from staff who are well trained and can support their individual needs.
- Involving consumers and parents on the interview team to help select the agency and staff that will be supporting them. An emphasis is placed on finding an agency that will partner with the family and that shares similar philosophies and beliefs.
- The opportunity for people to receive consumer directed supports for which they determine how and on what supports the money they are given is spent.

- Case managers who are effective, long-term employees and who have built relationships with provider organizations, families and the individuals they support. Because of this they are able to serve as strong advocates.
- A multi-county consumer directed alliance in which a joint administrative effort is underway to serve more individuals through the HCBS program by releasing encumbered dollars.
- Encouraging a diverse network of provider organizations within the county so that families and individuals who receive services actually have a choice of provider organizations.
- Bringing people out of RTCs and being able through effective public relations that the people who moved from the RTCs can effectively be supported in their home communities.
- An effort to continually challenge the county to provide families with choices and control by asking them what they need and then within fiscal limitations being flexible enough to reasonably offer them what they want.
- Allowing families the option to receive part-time foster care services for their children, thus successfully preventing full-time out of home placement.

Innovations made to improve the HCBS program.

Counties also reported a number of creative an innovative actions they have taken to improve the HCBS supports they offer to families. Among the reported innovations are:

- Developed an alliance with the County Community Action Program (the county agency responsible for developing HUD homes/programs). This alliance has enabled us to have this agency actual develop the residential homes for new services and supports and then the county facilitates provider organizations working through HUD to find housing for HCBS recipients.
- Worked to bring new residential and/or vocational providers into the county so that competition exists and families have a choice.
- Established standards that are built into the contracts between the county and the provider agency and require that progress reports be provided to the county on how well the provider organization is meeting these standards.
- When developing a service package with families an attempt is made to utilize all of the applicable HCBS services such as adaptive equipment, home modifications, specialist services and supported employment.
- Participation in the self-determination demonstration project.
- Ability to reach out and meet the needs of a number of diverse populations through hiring case managers who speak a variety of languages and through other outreach activities.
- Development and implementation of "client surveys" in which information is sought regarding satisfaction with services.
- Providing families with their own individual budgets and allowing them to choose how the money is spent.

L. Barriers/Issues Identified by Stakeholders

Several different stakeholder groups identified significant barriers to delivering high quality HCBS now and in the future through interviews and focus groups. Their barriers and issues are summarized in this section of the report.

Direct Support Staff Survey

In 1998, the University worked with the State of Minnesota to conduct a series of focus groups with direct support staff members, front line supervisors, and administrators from around the state to identify competencies and training needs for front line supervisors. Those focus groups spent time discussing the state's vision for community-based services and the barriers that were getting in the way of accomplishing that vision. For this evaluation, we included the list of barriers identified by state and non-state staff in the survey of direct support staff members. Table L1 shows the responses of 218 direct support staff members from around the state regarding the extent to which various issues are barriers. Scores ranged from 1 (strongly disagree) to 7 (strongly agree) that the item is a barrier. A score above 4.0 indicates that, on average, direct support staff members felt the item represented a barrier to providing high quality supports where they worked. The only area that the direct support members consistently reported that barriers existed was regarding staffing issues. Within that area the most pressing barriers, according to direct support staff members, are wages for direct support staff members (some live below the poverty line), a lack of rewards or incentives for exemplary staff, lack of qualified and interested new direct support staff members, high turnover for direct support staff members and front line supervisors, and many staff vacancies.

Table L1: Barriers To Implementing Community Support Services That Help People Live As Valued, Contributing And Self-Determined Members Of Their Community (DSS Survey)

Characteristic	**Mean**
Systemic and Regulatory Barriers	
DSS who know people best have no input into licensing or QA	3.73
Rules and regulations prevent creativity, risk taking and choice making	3.32
Agency Barriers	
Vocational agencies don't have enough work or do not support people in desired jobs.	3.50
Paperwork limits time to connect to communities	3.33
Programs and supports are designed by people who know individuals least well	3.28
Reactionary policy making	3.27
Supervisors are spread too thin. Little support is available to DSS.	3.24
Agencies don't support choice making or risk taking for fear of retaliation or liability	3.19
Creativity is not rewarded or valued	3.11
Agency or licensing rules limit choices for consumers	2.91
Agency growth exceeds capacity to attend to needs	2.87
Resource Barriers	
People with MR/RC limited income limits preferred community activities	3.70
Not enough program $ for new or existing treatment plans	3.36
Too few staff members are scheduled to provide needed supports	3.35
Transportation is not available for community events	2.40
DSS not reimbursed for costs of community activities	2.32
Staffing Barriers	
DSS do not earn livable wages/ some live below poverty line	4.55
No rewards or incentives for exemplary staff	4.45
Not enough qualified and interested new DSS	4.29
Turnover is high for DSS and FLS	4.19
Many staff vacancies	4.01
Lack of FT positions and benefits impedes recruitment and retention	3.83
Staff are unhappy, disgruntled or burned out	3.68
Staff try to control consumers and situations	3.24
DSS do not take initiative to try new things	3.04
DSS do not know how to work as team players	3.04
Staff training is unavailable or difficult to access esp. for community inclusion	2.99
Staff refuse to honor the requests of consumers	2.18
Training	
DSS do not know about available community resources	2.84
Orientation for DSS is ineffective	2.75
Supervisors are not trained to be supervisors	2.64
DSS do not understand basic job duties yet work alone and make decisions without support	2.51
Community Barriers	
Community members are not connected with people with MR/RC due to fear, ignorance or lack of opportunities	3.73
People with MR/RC are not valued and accepted by our communities	3.21
Media reports focus on negative situations and issues related to community supports	2.99
Community resources are not physically accessible	2.53
Needed support services are not available	2.20
Family or Team Barriers	
Parent or guardian wishes often conflict with individuals with MR/RC	3.26
Legal guardians/conservators place unnecessary restrictions on choices by consumers	3.24
Vocational and residential providers approach providing supports inconsistently.	3.13
Lack of trust between families and provider agencies	2.88
Individual Consumer Barriers	
Differences in consumer support needs make it difficult to honor everyone's requests and desires	3.95
Difficult to discern what activities or events are of interest to consumers especially those who do not communicate verbally	3.75
If one person is having a bad day, no one else gets to go anywhere due to limited staff availability.	3.72
Some individuals have significant challenging behavior and pose a real risk to community members	3.53

N **=** 218

1 = Strongly disagree, 7 = strongly agree

Case manager survey

The general case manager survey also asked what factors limited opportunities for HCBS recipients to have homes of their own (i.e., homes they select, rent or own in their own names, control, and that they live in alone or with people they select). In every case, case managers reported that the identified factors were sometimes to often a barrier limiting access to consumer controlled housing. Of the eleven factors listed, the most frequent limitations were difficulty staffing personal housing within available budgets, few models of successful consumer controlled homes in the county, a shortage of accessible housing, difficulty in obtaining Section 8 housing subsidies, and a shortage of affordable housing in safe neighborhoods. In general the issues were the same across regions. The exception was that case managers in rural areas were significantly less likely to report difficulty in obtaining Section 8 housing subsidies (Mean = 2.00) than case managers in metro (Mean = 2.67) or GM urban counties (Mean = 2.65).

On the individual case manager survey, 13.7% of case managers reported that the person had difficulty accessing community resources and places because of negative community attitudes.

Table L2: Factors Limiting Opportunities For HCBS Participants To Have Homes Of Their Own (Case Manager Survey)

Factor	Extent of limitation
Difficult to staff personal housing within available budgets	2.59
Few models of successful consumer controlled homes in this county	2.57
Shortage of accessible housing	2.53
Difficult to obtain HUD Section 8 housing subsidies*	2.52
Shortage of affordable housing in safe neighborhoods	2.50
Group residential housing subsidies limited to agency controlled houses	2.40
Lack of assistance in planning and finding personal housing	2.36
People don't know it is possible to have a home of their own	2.12
Difficulty finding agencies open to supporting people in their own homes	2.08

3 = Often a problem, 1 = hardly ever a problem *problem is bigger in rural counties ($F = 3.56$, $p < .05$)

Advocacy organization group interviews (Arc MN and Disability Law Center)

- There seems to be a lack of criteria for who gets a "Waiver slot" and who goes on a waiting list. It seems that the "squeaky wheel" is the one who actually gets the "slot" in the end. Practices vary by county and they seem to be arbitrary.
- Once people are receiving HCBS it is difficult to get an increase in their allocation based on their needs. This is especially true for people who are aging and have been receiving HCBS for quite some time.
- Families often do not get the amount of hours [PCA and in-home] they are authorized.
- Many parents report that they are not satisfied with case management services and that they do not get enough service for what is being paid for case management.
- Lack of choice with respect to who is your case manager or service coordinator. Also, there is no known process in place to change case managers if one is not satisfied.
- Often there is no ISP in place for HCBS recipients.
- Direct support staff training is lacking. There is still little portability of training to meet requirements of the Consolidated Rule. This is especially a problem for PCA and Home Care agencies who do not have to meet the requirements of the Consolidated Rule.
- Many families experience barriers related to access to home modifications and adaptive equipment. Providers are not always reimbursed even when they submit bids and issues arise related to the monitoring and maintenance of equipment once it is purchased. Additionally, counties seem to have different practices related to what are "approved" adaptive equipment and home modification expenditures.

- Lack of availability of consumer directed support options for families who want it. Currently only available in four counties.
- Direct support staff are not paid nearly enough for the work they do.
- There is a severe staffing crisis and without staff there is no quality of life for the people who receive HCBS or their families.
- New providers are reimbursed at higher rates then long-term existing providers. This pits long term providers against new providers and existing consumers against new consumers.
- It seems that people who have active and involved families get higher quality services. We have to figure out a way to get similar quality for people with and without family.
- Licensing, BCA checks and regulations are not quality assurance. We truly do not have a quality assurance system for HCBS in Minnesota.
- The number of licensing staff members have been consistently cut over time. We now get little out of licensure in Minnesota because the enforcement piece is simply not in place.
- Need to figure out how counties can work together to optimize use of efficiency Waivers.
- The federal Health Care Financing Administration policies are squarely in the way of moving toward true consumer directed support options and giving families the money to decide how they want to spend it.
- Interpretive services are not funded by HCBS.

Provider organization group interviews (Association of Residential Resources in Minnesota (ARRM), Minnesota Habilitation Coalition (MHC), Minnesota Developmental Achievement Center Association (MNDACA))

- There is limited access to HCBS and families who are trying to plan for the future get put on a waiting list but what does that get them? If you don't have a crisis, especially in smaller counties who get fewer "slots," then you don't get HCBS.
- Often providers are not allowed to be involved in the screening process and yet they report that they have very good insight into the person's abilities and skills and also understand the importance of filling out the screening document accurately. Families don't always understand the implications of the screening document and also like to identify the positive skills their children have. Depending on the case manager providers may be completely left out of the screening process or may be involved.
- How a person receives or is "awarded" a "Waiver slot" is not clear. This is an internal process within the county system and there is no standardization across counties. This creates confusion for consumers and their families. Inconsistency in case manager approach to who gets HCBS. If your case manager is assertive and a good advocate you are more likely to be consider "a priority" for HCBS.
- There is tremendous demand for services as is evidenced by the HCBS waiting lists and there are providers out there who want to deliver services but as suppliers of the services they are constrained by limited availability of resources.
- HCBS have no built in annual inflationary adjustments to allow for increased housing, employee benefits and wages.
- The room and board component (GRH) is under-funded.
- The severe staffing shortages and low pay make it difficult to find new people who are willing to do this kind of work. As we continue to increase the expectations we have of direct support staff (e.g. community and social networking, self-determination, building natural supports) this challenge will only worsen.
- There are good case managers and there are case managers that are not so good. It is difficult when you have to work with a case manager that does not advocate for the persons needs or is not informed and is rigid. There are a lot of case managers out there like this.
- It is a conflict of interest when the case manager represents the interests of an individual who is under public guardianship. It seems like dollars talk versus the persons needs and the case manager has all of the power then.

- A number of case managers do not develop and give providers copies of ISPs. Yet providers are held accountable by licensing to have these and to develop all programming and support around the ISP.
- Case managers have too large of caseloads to really give time and support to the people who are on their caseloads.
- Families are not given choices related to case managers. Even in some of the self-determination projects choice is not provided in the area if service coordination. There is no 360 degree feedback loop on how well case managers are doing and on what consumers and families should expect of their case managers.
- It is an inherent conflict of interest when case managers work for the funding agency and are also expected to advocate on behalf of the people who need services but also who authorize those services within the limitations placed on them by the funding agency.
- The DTH single rate for all individuals served is a barrier to providing individualized supports to HCBS recipients. Irrespective of needs or issues people pay the same rate.
- Transportation costs for DTH have increased since people have moved into smaller homes from large ICF-MR or institutions. Now providers sometimes have to go and pick people up all over town and yet transportation rates for some provider have never increased.
- Is there a Waiver [HCBS] quality assurance program? If so, what is it? There is licensing but that's it and that doesn't seem to be quality assurance.
- People who receive HCBS sometimes get little choice about where and with whom they live. Often it seems there is an open bed and a person who needs services so they get placed in that particular HCBS SLS home irrespective of their needs, interests or compatibility with the other people who live in that home. When people want to move to another home or to another county they often cannot.
- People often only have the "choice" to live in a four person SLS even when they don't want to.

County MR/RC HCBS Coordinator Interviews

- Lack of available direct support staff to provide the support and poor wages for direct support staff.
- Limited number of available "slots" for people who need services but cannot get them - need to move away from slots and if counties are efficient with the money they get they should be able to add additional people onto the HCBS Waiver – this shouldn't be limited by the number of slots available.
- Lack of available affordable housing.
- Administrative complexities in managing the HCBS Waiver (e.g. keeping track of expenditures, multiple types of waivers and within each waiver multiple types of available services). It is hard for counties to understand let alone families and consumers.
- No accessible transportation.
- Need to be able to get people into situations where they don't have to live with 2 or 3 other people but the HCBS Waiver is predicated on 4 person SLS programs that are the most expensive
- Many people are at the base rate and their needs are changing so dramatically and in order to keep within our average we are not going to be able to continue to meet the needs of people who have high support needs.

When asked what the biggest barriers were that counties faced with respect to continuation of existing services and development of new services and supports for HCBS Waiver recipients the overwhelmingly and biggest reported barrier was the staffing crisis that providers are facing. Most counties reported that the direct support staff are underpaid, poorly trained and that providers simply cannot recruit enough staff to support the existing HCBS programs in their communities. This problem is exacerbated when considering new development. Another commonly reported barrier was a lack of affordable housing for people with MR/RC who receive HCBS services. Other reported barriers included:

- High case manager caseloads which limit the ability of case managers to effectively monitor services,

- Ability of case managers, provider organizations and others to effectively nurture the development of natural supports,
- Difficulty in figuring out whether HCBS service costs are related to the actual person who is receiving services or to the provider organization's need to keep a house (program) up and running,
- Ability to find provider organizations (particularly in more rural areas) that can provide support to people with high medical needs,
- Difficulty in controlling certain costs such as DT&H because these rates are pre-established, and
- Lack of supported employment options for people who receive HCBS supports.

DHS Community Supports for Minnesotans with Disabilities

- There is a labor shortage affecting the ability to recruit direct support as well as professional level staff.
- Counties need additional training on new HCBS options including the consumer directed support option and supported employment.
- There is a need to look at and better understand how technology can assist in providing supports to people and reduce the need for 24 hour staffing support.
- Providers are not ready and available to deliver services on the service start date.
- There is a need to be able to figure out how to pay for DTH services based on a person's need (i.e. part-time).
- There is a need to look at options to address issues related to GRH funding.
- There is a need to identify and get information out to counties and the provider community on best practices regarding consumer directed support options and self-determination.
- Case management caseloads have not gone down in proportion with increased spending in this service area.
- There is an underutilization of HCBS environmental modification, assistive technology, housing access and parent training and education.

PART IV: RECOMMENDATIONS

Status of Recommendations from the 1992 HCBS Evaluation

In 1992, Minnesota submitted to the health care Financing Administration its final required independent assessment of it Medicaid Home and community based Services (waiver) program (Lakin, Burwell, Hayden & Jackson, 1992). The federal requirement for independent assessments of state HCBS programs for “access”, “cost-effectiveness” and “quality” of services has since been rescinded, but the Minnesota department of Human services requested reexamination in this evaluation of progress toward the 1992 recommendations. This is done below in three categories: 1) recommendations that continue to require attention; 2) recommendations in which the identified problems were largely overcome; and 3) recommendations that are no longer relevant.

Recommendations That Remain a Challenge

1) ***“The state should work to establish more consistent and systematic policies among counties in the prioritization of individuals to receive HCBS”***

At the time of the earlier evaluation there was considerable concern about several counties systematically excluding from consideration for HCBS persons whose level of need and potential HCBS costs would substantially exceed the single per person “average cost” allowed to counties for serving each new HCBS recipient. The state’s efforts in assisting counties to serve a wider range of HCBS recipients without a sense of jeopardizing their ability to remain under their allowable pool of federal-state HCBS funds has been impressive. It includes developing the Waiver Allocation Structure to provide states with new funding for new service recipients that varies according to a general level of anticipated expenditures required to meet the individual’s needs, and a wide range and continuously improving technical assistance and budget management software to assist counties in managing their total resource pool for all HCBS recipients so that concerns about the impact of new recipients and changing needs among current recipients and the associated high expenditures can be projected without blanket exclusions of potentially high cost recipients. Another beneficial initiatives has been the promotion of partnerships among smaller counties so that the potential impact of higher than anticipated expenditures for one or more of relatively few HCBS recipients can be shared across a larger pool of resources. While these efforts have provided substantial assistance for supporting equal access to the HCBS program for all eligible service recipients, the methods by which priorities are established for HCBS access in the individual counties does still vary by individual county practice.

2) ***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”***

There was considerable progress in responding to this recommendation. The enrollment of minority group members increased substantially. Minority group leadership is evident in both service provision and outreach. The state has promoted recognition of county responsibility to reach out in culturally appropriate ways to minority communities in Minnesota. However, although Minnesota minority enrollments have achieved the levels recommended in 1992, minority group representation in Minnesota’s population continued to grow. The moving target of general minority group growth, the growth in the diversity among those in Minnesota’s non-white, non-Hispanic population requires continuous attention to the need to reach out in culturally appropriate ways, establish priorities for service based on established need, increase the range of service and resource use options to assure match between the needs of individuals and the possibilities of meeting those needs in ways that are culturally as well as personally responsive.

3) ***“The Department of Human Services should work with counties and with other Departments to improve access to needed HCBS and related services,” including especially respite care, employment***

services, speech and communication, psychological services, non-formal supports and to do so in part through promotion of new service providers.

Since 1992, Minnesota's menu of available services and flexibilities in using those services has expanded dramatically to authorize many new services and more flexible approaches of providing HCBS-financed supports. The expansion of options available under Minnesota's HCBS program has not yet caught on in ways that have substantially expanded people's use of those options. Many of Minnesota "new services go essentially, if not totally, unused and the vast majority of HCBS recipients continue to receive the standard packages of small group home (corporate foster care) and day training and habilitation services. Although respite care and other in-home options have been expanded, new concerns arise about families receiving many fewer hours of those services than they are now authorized and that they feel they need.

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

Although the Department of Human Services has expanded the menu of services that would allow people to experience lifestyles that involve other than living in small group homes, the residential reality for the majority of HCBS recipients, and the vast majority of adult HCBS recipients, is still group home living. The proportion of HCBS recipients living in small group homes has not changed significantly since 1991, with the growth in the total number of HCBS recipients has come substantial growth in the numbers living in homes of their own. In recent years, several counties have begun initiatives to increase only numerical growth in people using more personalized residential options, but to achieve proportional growth as well.

5) ***"The state should develop a concerted effort with counties to increase the pool of potential service providers"***

The scope of this evaluation did not permit firm conclusions to be drawn with respect to progress in this area. Data was not made available to the evaluation team to determine growth in the number or providers. Anecdotally many county DD Waiver Coordinators did report that they had recently expanded the number of providers in their county.

6) ***"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"***

Limited progress was made in responding to this recommendation. Responses of case managers, county officials, family members and stakeholders to surveys, interviews and focus groups, suggest that the recommendation is even more relevant today than it was a decade ago. Compared to a decade ago, Minnesota's HCBS program is much larger and more dispersed than the program that generated the above recommendations. Efforts at the state level to authorize a wide range of options for people have produced limited success in their use. Access to information is consistently viewed as the least successful component of the HCBS service program in Minnesota. The lessons of the decade may be that the visions of system change at the state level in Minnesota are more about education and changing expectations than they are about changing rules and expanding options.

Recommendations That Have Been Responded to With Significant Success

1) ***"The state should implement strategies to improve awareness of certain requirements of the HCBS program regarding access and enrollment"***

Two concerns in the earlier evaluation led to the above recommendation: 1) evidence that HCBS recipients/family members did not know of their right to choose institutional services (ICF-MR) instead of HCBS, and 2) people's eligibility determination for HCBS frequently was being "deferred" when services were unlikely to be available to them for some time. Although instances were found of families not remembering that they had an option for ICF-MR instead of HCBS and that they retained that option over time, efforts to integrate presentation and recording of that information into the screening process have been generally successful in communicating people's rights under the federal legislation. The practice of "deferred screenings" has largely been eliminated. This has not only resulted in adherence to people's basic program rights, it has improved Minnesota's information on people waiting for services which in turn has contributed to Department and advocacy group initiatives to achieve substantial program expansion.

2) ***"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 Minnesota Department of Human Services has made substantial, successful effort to obtain federal Medicaid cost-share of services under HCBS that were previously state financed. The leveraged dollars have contributed significantly to Minnesota's ability to expand HCBS options for Minnesotans with mental retardation and related conditions.

Recommendations That are No Longer Relevant

1) ***"The state should communicate about and solicit input from counties into the process of requesting and negotiating allocation and distribution of allocations for diversion and conversion enrollees."***

Prior to 1992, the Health Care Financing Administration required states to demonstrate that the number of people who would be receiving HCBS was roughly equal to the reduction in the number of ICF-MR "beds" allowed by people moving into settings with HCBS-financing (conversions) and the reduction in projected ICF-MR "beds" that would otherwise be needed if people did not have access to HCBS-financed services (diversions). At the time of the earlier evaluation there was concern that Department of Human Service commitments to deinstitutionalization of Regional Treatment Centers (i.e., conversions) was affecting access to services for people living in and or desiring to leave their family homes. Counties wanted to have greater input into the relative balance of conversion initiatives and the "diversion" needs of their county residents. Two factors have obviously and significantly intervened to eliminate the concern evident in 1991. First, Minnesota's Regional Treatment Centers have been essentially closed so that the desired discussion is now moot. Second, under the Clinton Administration linkages of HCBS access to ICF-MR reductions have been substantially altered in content and spirit so that states' numbers of allowed diversions are essentially determined by the amount of funding made available for "diversions" by state legislatures. Minnesota retains distinctions between conversions and diversions, but for the most part conversions are available at any time support an effort to reduce or eliminate beds of an ICF-MR, provided, of course, the alternative service can be provided the funding made available from the Waiver Allocation Structure.

Stakeholder Recommendations

Individuals who participated in this evaluation study through written surveys and group or individual interviews identified a number of recommendations related to the future of HCBS in Minnesota. These recommendations are summarized in this section of the report.

Case Manager Recommendations

The case managers for individual HCBS participants rated the importance of seven specific types of interventions for improving services. By a large margin, the recommendations most commonly made were to reduce staff turnover (65% reported this was badly needed or that it would help), and to reduce caseloads for case managers (60% reported this was badly needed or that it would help). For the other recommendations, the proportion of case managers who said it was either badly needed or it would help were: improving staff training (52.5%), better quality assurance efforts (37.1%), more or better choices of providers (29.1%), provide better information about service options (27.2%), and increase consumer control (23.4%).

Advocacy Organization Recommendations

- Consumers, families and case managers all need better and more accurate information about what types of services are available under the HCBS program.
- Consumers and families need direct control of the money.
- More flexibility in how to access services and supports. Should not have to go through a county case manager to access services. Need to develop alternative service coordination options for families and individuals with MR/RC.
- Access to HCBS needs to be fair and equitable irrespective of where you live in the state.
- No waiting list for access to HCBS.
- The HCBS waivers in Minnesota (CAC, CADI, MR/RC, TBI) need to become less categorical. Also we need to figure out a way to support people with mental illness who have similar support needs.

Provider recommendations

- The eligibility criteria and categorization needs to be opened up so that HCBS are not based primarily on diagnostic categories (e.g. MR/RC, TBI, aging) and so that the types of supports offered to people are equal and based on their needs.
- Use HCBS more flexibly and based on individual needs and preferences, not on available beds or the WAS allocation. There needs to be a better process of matching people with others that they want to live with instead of filling open beds. There also needs to be a better way of providing services and supports people need versus those that are available.

County HCBS Waiver Coordinator Recommendations

- Counties should be provided with greater flexibility in the number of people they serve through HCBS funding. Instead of the State allocating slots they should allocate a certain amount of money with a parameter related to the minimum number of people that should be served on the HCBS Waiver in that county. This would afford counties the flexibility to maximize the use of HCBS dollars and more efficiently serve people with MR/RC.
- The Waiver Tracking System needs to be improved so that it is more accurate and reflects true expenditures. Additionally counties need more technical support available from DHS CSMD personnel on how to effectively manage the system.
- An effort needs to be made to ensure that when a person is re-screened and their profile changes that their allocation also changes to correspond with their needs. This is particularly true for the many people who receive allocations based on the base rate and yet their needs have substantially changed over the years.
- Technical assistance should be provided to counties to promote the newer options that are available under the HCBS Waiver such as consumer directed supports.
- Counties need to know who is responsible for what components of the HCBS Waiver and who they can call to get answers to their questions. Additionally, they need more timely written information.

- An effort needs to be made to make it easier for people to become providers of services. The current system is so complex that is serves as a deterrent for new people who want to become providers. The system as it is almost dictates the use of larger corporations.
- Consideration needs to be given to having a funding safety net for counties who have people with extremely high needs (e.g. people coming out of METO with significant behavior support needs) being served under their HCBS programs.
- The HCBS Waiver needs to be re-written to reflect where we are today. Minnesota is no longer in an era of deinstitutionalization, community based services our are new era and we need to maximize flexibility and outcomes.

2000 Recommendations

This executive summary includes all of the recommendations made by the research team and stakeholder advisory group after receiving the overall findings of this evaluation. These recommendations appeared to center around several broad themes including: quality of services; choice and respect; individualized supports; direct support staff crisis; protection from maltreatment; access to HCBS and affordable housing. Please review the large technical report for this information regarding the extent to which the recommendations made in 1992 had been attended to and improvements made and specific recommendations made by various stakeholder groups as identified in focus groups.

Quality of Services

- Stakeholders argue that quality assurance/enhancement activities for HCBS should be improved. A new system is recommended in which families and consumers are active participants in the development, implementation and on going review of a redesigned quality assurance program that integrates health and safety monitoring, quality of life assessment, and quality improvement assistance.
- The state should institute a program to share public information regarding service quality, outcomes and issues (e.g., licensing citations, substantiated maltreatment reports, employment outcomes, choice making, respect and satisfaction data) so that individuals and families can make informed decisions about service options and providers of services.
- Case managers need to be better able to contribute to the quality of life of HCBS recipients through improved training on options and creative ways to use them, greater commitments and higher expectations for individualized service outcomes, smaller average “caseloads,” greater amounts and better quality of interactions with HCBS recipients and families.

Choice and Respect

- People who receive HCBS should have choice in where and with whom they live, where they work and who provides their support.
- DSS must be better trained to respect the people they support and to exhibit this respect in assuring control over homes, their daily lives and basic choices.
- Support options that promote choice and respect must be expanded (e.g., consumer directed support options, consumer-controlled housing).
- Choice and respect are primary service outcomes that need to be systematically monitored in all quality assurance programs and publicly reported to assist in choosing service providers.
- Choice of case managers should be treated with the same respect for individuals choice as other HCBS.

Individualized Supports

- Minnesota needs to promote a greater array of individualized HCBS options (e.g., host families, consumer controlled housing, consumer directed service options, development and management). This will require eliminating systemic barriers that perpetuate the use of group home models (e.g., lack of GRH-like subsidies for individuals, dependency on shift staff models).

- Consumer-directed community supports (CDCS) should be available to all HCBS recipients. The state should provide technical assistance and training to counties to enable them to offer CDCS to all HCBS recipients who want this service option. Additional efforts to provide information and training to individuals and families about CDCS are needed.
- Families need substantially improved access to high quality in-home respite and personal care supports. If the present system cannot provide families with those services it recognizes as needed, families should be empowered and supported to use their authorized resources to meet their own needs.
- A mechanism is needed to adequately support people whose needs change over time due to their age and/or disability. This mechanism should not solely rely on counties to provide increased support to people with changing needs by giving people with lower support needs access to HCBS "slots" or by "forcing" people to move to a new provider in order to get an increase in services. A method should be developed to periodically re-determine a person's needs and adjust the amount allowable resources to the counties based on this re-determination.
- The state should develop a system for accurately identifying and tracking the amount, type and costs of service needed by and promised to individuals and their families versus the actual amount and costs of the services received. The state should use the system to monitor and provide trend analyses regarding this important issue.

Direct Support Staff (DSS) Crisis

- Given the pervasive, long-term and detrimental effects of the direct support staffing crisis on individuals, families and the ability of counties to develop new services, the state should make it a priority to create a coordinated workforce development system with resources to significantly increase DSS and frontline supervisor wages, reduce turnover, improve recruitment, and support and train DSS and their supervisors.

Protection from Maltreatment

- Minnesota's maltreatment reporting system needs improved communication between agencies and individuals in the system (e.g., DHS Licensing and Investigations units, State Ombudsman Office, county MR/RC services, common entry points, county foster care licensing units, provider agencies, case managers, direct support staff, and the individuals and families who receive supports).
- The maltreatment reporting system should be designed to systematically respond to concerns voiced by stakeholders regarding maltreatment reporting and follow-up.
- A statewide method for tracking and conducting trend analyses of all incidents reported, irrespective of whether they involve substantiated maltreatment or whether they are investigated further by the investigations unit should be developed.
- Consumer-to-consumer violence must be reduced. Most people do not choose to live with people who hurt them. All people should be given the freedom to choose with whom they live, but the right must begin with victims of current household violence.
- Further investigation should occur to better understand the proportion of individuals with certain characteristics that are prescribed psychotropic and other mood altering medications, why these medications are being prescribed and the extent to which the use of these medications increases, decreases or remains the same over time for HCBS recipients. Consideration should be made for adding fields to the screening document that would enable this information to be systemically tracked.

Access to HCBS

- Access to individualized HCBS supports that meet the needs of citizens with MR/RC from ethnic, racial and cultural minority groups should keep pace with the numeric growth of these groups in the general population.
- The state should develop a specific initiative to address the issue of access for minority groups and should provide information and technical assistance to counties on specific outreach and support methods designed to increase information for and access to individuals and families from ethnic and racial minority groups.
- This initiative should specifically investigate these issues as they relate to people from minority groups who currently receive HCBS services as well as people from these groups who are not receiving HCBS.
- Efforts should be made to better understand why HCBS is under-utilized by these groups, and modifications to current services should be made so that HCBS can be individualized to meet the needs of people from minority groups.
- Systematic efforts are needed to better understand the specific needs of the people who are waiting for HCBS, and to identify people who may need HCBS but are not yet recognized as waiting. Minnesota should respond to the reasonable desires of large numbers of people currently living in ICFs/MR who seek HCBS.
- The state should develop a process that would increase the consistency and fairness throughout the state in decisions about who and how people get access to HCBS are made.
- Substantial efforts are needed to increase the availability of supported employment opportunities (e.g., community group work, individual community work) to all HCBS recipients who want to work. Additionally the state should systematically code and use data collected on the screening documents to measure progress in this area.
- Continued efforts are needed to increase the availability and access to dental services, specialized medical and specialized therapies (e.g., speech therapy, occupational therapy, counseling, behavioral therapy) for all HCBS recipients, especially those with significant challenging behavior.
- The tracking system developed by the state to provide counties feedback regarding authorized and paid expenditures should be improved so that more accurate and timely information is provided in a manner useful to counties. The state should increase the amount of DHS staff support and technical assistance provided to counties and should improve the system to coordinate and provide this support. The state should also explore the possibility of making this a Web based system.

Affordable Housing

- Consistency and fairness should be increased in the county processes and priorities for decisions about HCBS access.
- Minnesota needs to increase access to affordable housing options for HCBS recipients who desire to own or rent their own homes through expanded access to housing subsidies such as Section 8 and GRH-like assistance for non-licensed homes.

Appendix A: HCBS Waiver Service Descriptions

(Budget categories included in each service type for the cost report)

Adult Day Care: Adult day care programs provide integrated supervision, care, assistance, training and activities that are age appropriate to help a person to be as involved in the community as possible and have meaningful social experiences with non-disabled peers. Meals and transportation are covered by this service. Specialized therapies and adaptive equipment may also be provided. It is intended to help the person maintain skills, and to prevent or delay the use of institutional services. A person can choose adult day care services instead of DT& H services when it has been decided that DTH services are no longer appropriate to meet the person's needs. (DTH, Adult Day Care)

Assistive Technology: Assistive technology refers to devices, equipment, or a combination of these which improve a person's ability to perform activities of daily living, control or access the environment, or communicate. This service may include evaluation for an assistive device, equipment rental during a trial period, obtaining and customizing devices, as well as training and technical assistance to the person, caregivers, and staff to teach the person how to best use the device or equipment. This service will also cover the cost of maintenance and repair of devices, and rental of equipment while a device is being repaired. (Assistive Technology)

Caregiver Living Expenses: This service provides payment for the rent and food that may be reasonably attributed to a live-in personal caregiver. The live-in personal caregiver also provides one of the following Waivered services: residential habilitative services; personal support services; extended personal care attendant services; or consumer-directed community supports. (Included in in-home family support for cost analysis purposes)

Caregiver Training and Education: This service provides training for a person who is a primary caregiver, such as a parent, on a variety of topics such as developmental disabilities, community integration, parent skills, family dynamics, stress management, intervention and mental health. The training is provided by individuals, agencies, and educational facilities. The service allows for the cost of enrollment fees, materials, mileage, hotel and meal expenses to be paid so that a parent or primary caregiver can attend the training sessions. (Caregiver Training & Education)

Case Management: This service is available to al persons with mental retardation or a related condition. The purpose of this service is to help locate, coordinate and monitor social and daily living activities, medical, and other services needed to meet the specific needs of a person and his or her family. (Case Management Access, Case Management).

Chore: This service supports or assists a person or his/her primary caregiver to keep their home clean and safe. Examples include, washing floors, windows and walls; basic home maintenance; or moving heavy items of furniture to provide safe entry and exit. Chore services are provided when the person who is regularly responsible for these activities is temporarily absent or is unable to mange the home and care for themselves or others in the home. (Chore Service).

Consumer Training and Education: This service provides training and education to person to strengthen their self-advocacy skills, to learn how to better exercise their civil rights, and/or to acquire skills that strengthen their ability to exercise control and responsibility over the services and supports they receive. The training is provided by individuals, agencies, and education facilities. The service allows for the cost of enrollment fees, materials, mileage, hotel and meal expenses to be paid. (Consumer Ed and Training)

Consumer-Directed Community Supports: Consumer-directed community supports are services which provide support, care and assistance to a person, prevent the persons' institutionalization and allow the person to live an inclusive community life. Consumer-directed community supports are designed to build, strengthen or maintain informal networks of community support for the person. Consumer-directed community support services are available when local agencies have memorandums of understanding with DHS to demonstrate the feasibility and effectiveness of consumer-directed community supports. (Consumer Directed Community Support)

Crisis Respite: Crisis-respite services are specialized services which provide short-term care and intervention to a person. Crisis-respite services give needed relief and support to the caregiver and protect the person or others living with them. Crisis-respite services include activities: assessment; development of a provider intervention plan; consultation and training to the providers and/or caregivers; development and implementation of a transition plan if out of home crisis-respite was provided; on-going technical assistance to the caregiver or provider; and recommendations for revisions to the Individual Service Plan (ISP). (Respite crisis)

Day Training and Habilitation: Day training and habilitation (DTH) provides training, supervision, and assistance to help a person develop and maintain vocational and daily life skills and become more involved in the community. These services are coordinated with residential services. (DTH pilot – rate A-D, Day Training and Habilitation, DTH waiver job coach)

Environmental Modifications: Environmental modifications are equipment and physical adaptations to a person's home and/or vehicle necessary to help the person have greater independence. This service includes only modifications to the home or vehicle which are of direct and specific benefit to the person due to his or her disability. (Environmental modifications)

Extended Personal Care Attendant: This service provides a continuation of personal care assistant services when the need for service exceeds the scope and duration of service available through the state plan service option. (RN supervision – personal care, Personal care 1 to 2 ratio, Personal care 1 to 3 ratio, Personal care – independent PCA, RN supervision – independent PCA, Personal Care)

Homemaker Services: General household activities are provided through this service by a trained homemaker when the person who is regularly responsible for these activities is temporarily absent or is unable to manage the home and care for themselves or others in the home. (Homemaker)

Housing Access Coordination: The purpose of the service is to help a person make choices about where to live, the type of home the person wishes to have, and who will be a roommate(s), if any. This service helps the person to identify affordable, accessible housing and assures that housing needs are provided for separately from other service needs. It may also include assistance in identifying options and making choices, planning for on-going maintenance and/or repair of the home, and identification of financial resources such as eligibility for housing subsidies and other benefits. (Housing Access Coordination)

In-Home Family Support: This service provides training and support to a person and his or her family, including extended family, in the family home and in the community. It is designed to increase the family's ability to care for and support the person in the family home. (In-home family support, Live in caregiver, Extended personal care, Extended transportation)

Personal Support: This service helps a person increase independence, productivity, and involvement in the community. Personal support services provide more flexible and less formal, or less intensive support than supportive living services. It includes supervision and assistance to help a person find and use community services and to participate in community activities. This service may be provided in a person's home or in the community. (Personal support)

Respite Care: This service provides short-term care to a person when the family member(s) or primary caregiver cannot be there or needs a rest from his or her responsibilities. Respite care may be provided in the person's home or in a different home or residential setting which has been approved by the county. Respite care may include day and overnight services. (Respite care – in home, respite care – out of home)

Specialist Services: Specialist services include services which are not available through regular Medical Assistance (MA). These are specific services to meet the unique needs of the person which provide assessment, program development, training and supervision of staff and caregivers, monitoring of how programs are provided, and evaluation of service outcomes to assure that staff and caregivers are able to meet the needs of the person. (Specialist Service)

Supported Employment Services: This service is available to a person who lived in an ICF-MR any time before receiving HCBS Waivered services. Supported Employment services provide ongoing training and support to the person while he or she is a paid employee at an existing business or industry in the community. This provides the opportunity to work with people who do not have disability and who are not paid caregivers or service providers. (Supported Employment, Business Supported Employment)

Supportive Living Services (SLS): The purpose of this service is to teach specific skills to a person who requires daily intervention. Daily intervention means providing on-going supervision, training or assistance to help the person reach his or her individual goals in the following areas: self-care, sensory/motor development, interpersonal skills, communication, reduction and/or elimination of challenging behaviors, community living, mobility, health care, leisure and recreation, money management and household chores. (Supported Living – Child, Supported Living – Adult)

24-Hour Emergency Assistance: This service provides on-call counseling and problem solving and/or immediate response for assistance at the person's home due to a health or personal emergency. Electronic personal emergency response system may be provided. 24-hour emergency assistance is available to people who live in their own home or with their primary caregiver and do not receive 24-hour supervision. (24 hour emergency service).

Transportation: This service provides transportation that allows an individual with a disability to gain access to community services, resources, and activities. This service is offered in accordance with the needs and preferences identified in the person's plan of care. (Included with in-home services for the cost analysis)

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Appendix C: Abbreviations Used (alphabetical order)

ARRM - Association of Residential Resources in Minnesota
CSMD – Community Supports for Minnesotans with Disabilities
CTEC –
DHS – Minnesota Department of Human Services
DSS – Direct support staff
DTH – Day training and habilitation
FLS – Frontline Supervisor
GM – Greater Minnesota
GMR – Greater Minnesota Rural counties
GMU – Greater Minnesota Urban counties
HCBS – Home and Community Based Services
ICF-MR – Intermediate Care Facility for the Mentally Retarded
MHC - Minnesota Habilitation Coalition
MNDACA - Minnesota Developmental Achievement Center Association
MR/RC – Mental retardation and related conditions
OT – Occupational Therapy
PCA – Personal care attendant
PT – Physical Therapy
RFP – Request for proposal
SLS – Supported Living Services
ST – Speech Therapy
WAS – Waiver Allocation Structure