



Executive Summary

Report #55

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

November 2000

Research and Training Center on Community Living
Institute on Community Integration (UAP)
University of Minnesota



The College of Education
& Human Development

UNIVERSITY OF MINNESOTA



Minnesota Department of **Human Services**

Executive Summary

Report #55

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

November 2000

Research and Training Center on Community Living
Institute on Community Integration (UAP)
University of Minnesota



The College of Education
& Human Development

UNIVERSITY OF MINNESOTA



Minnesota Department of **Human Services**

Written by:

Amy Hewitt, Ph.D.
Sheryl A. Larson, Ph.D.
K. Charlie Lakin, Ph.D.

Contributions by:

John Sauer
Elizabeth Lightfoot
John Jendro
Nohoon Kwak
Lori Sedlezky
Jennifer Sandlin

This report was produced by the Research and Training Center on Community Living (RTC), Institute on Community Integration, University of Minnesota, with funding from the Minnesota Department of Human Services — Community Supports for Minnesotans with Disabilities through workforce agreement # 5402455T53.

This publication is available in alternative formats upon request. For more information about this evaluation, please visit the following Web sites or contact the addresses listed below —

Minnesota Department of Human Services
Community Supports for Minnesotans
with Disabilities
444 Lafayette Road
St. Paul, MN 55155-3854
651.582.1952
Joan.Warmington@state.mn.us
<http://www.dhs.state.mn.us>

Research and Training Center on Community Living
Institute on Community Integration
University of Minnesota
150 Pillsbury Dr. SE, 204 Pattee Hall
Minneapolis, MN 55455
612.624.6328
hewit005@umn.edu
<http://rtc.umn.edu>

The University of Minnesota is committed to the policy that all persons shall have equal access to its programs, facilities, and employment without regard to race, color, creed, religion, national origin, sex, age, marital status, disability, public assistance status, veteran status, or sexual orientation.

Contents

About This Report	1
Purpose of the Evaluation	1
What are HCBS?	1
Who Receives HCBS?	2
What are the Costs of HCBS?	3
How Have Minnesotans Benefited From HCBS?	3
2000 HCBS Recommendations	4
Quality of Services	4
Choice and Respect	4
Individualized Supports	5
Direct Support Staff (DSS) Crisis	5
Protection from Maltreatment	6
Access to HCBS	6
Affordable Housing	7
Project Methods	8
Strengths and Limitations	10
Results and Discussion	11
HCBS Use and Expansion	12
Access to Services	14
Satisfaction and Quality of Services	17
Choice and Respect	19
Supports for Families	22
HCBS Supports and Services	25
Health Supports	28
Figure 7: Availability and Quality of Health Care	28
Service Coordination/Case Management	31
Provider Agencies	35
Quality Assurance and Monitoring of Services	41
HCBS Utilization and Costs	48
Conclusion	55
References	56

Figures

Figure 1: Minnesota's Residential Service System 1982-1999	1
Figure 2: Source of Initial Information About HCBS for Families	15
Figure 3: Consumers did not Have Choices About	20
Figure 4: Staff are Understanding Most of the Time (Families)	22
Figure 5: Percent of Families Satisfied with Services Most of the Time	23
Figure 6: Where HCBS Recipients Work	25
Figure 7: Availability and Quality of Health Care	28
Figure 8: Percent Using Psychotropic Medications	29
Figure 9: Consumer Choose the Things in His/Her Individual Plan	31
Figure 10: Family Satisfied with Case Management Overall	32
Figure 11: Changes in DSS Wages 1995-1999	36
Figure 12: DSS Turnover Rates in 1999	37
Figure 13: Workforce Problems in Agencies	40
Figure 14: Consumer to Consumer Violence Problem: Provider Report	41
Figure 15: Fairness of Maltreatment System: DSS	44
Figure 16: QA System Assures Effective Reporting and Follow-up on VA Incidents: CM	45
Figure 17: HCBS Cost Per Recipient	50

Tables

Table 1: Characteristics of HCBS Program Participants in 1999	2
Table 2: Average Annual HCBS Costs	49

Stakeholder Advisory Committee

Steve Anderson, Mount Olivet Rolling Acres
Mary O'Hara Anderson, STAR Program
Mary Jean Babcock, Arc Suburban
Alexandra Bartolic, Hennepin County
Pat Boyer, Clay County Social Services
Bob Brick, Arc Minnesota
Lori Dablow, Department of Human Services (DHS)
Kathy Dohmeier, Office of Ombudsman
Ella Gross, Institute for Minority Development
Judy Hauschild, DHS-Community Supports for Minnesotans with Disabilities (CSMD)
Ann Henry, Minnesota Disability Law Center
Mary Hinze, Parent
Claudia Johnson, Parent
Kristin Johnson, DHS-CSMD
Kathy Kelly, DHS-CSMD
Steve Larson, DHS-CSMD
Sharon Laures, Olmsted County
Liz Lightfoot, University of Minnesota School of Social Work
Ronna Linroth, STAR Program
Bob Meyer, DHS-CSMD
Denise Miller , REM-Waivered Services, Inc.
Lynn Noren, Minnesota Habilitative Coalition (MHC)/RISE, Inc.
Donna Olson, Mains'l Services, Inc.
Richard Oni, Progressive Services, Inc.
Carol Pankow, Minnesota Developmental Achievement Center Association
Cliff Poetz, Consumer
Bud Rosenfield, Minnesota Disability Law Center
Michael Sarafolean, MHC/Community Involvement Program
Bud Seltzer, Parent
Orapat Sivantonpisit, Parent
Jill Slakieu, DHS-CSMD
Susan Shogren, Smith, Governor's Council on Developmental Disabilities (GCDD)
Becky Smith, MHC/NE Contemporary Services
Sharon Staton, Access, Inc.
Pat Tietz, GCDD
Brenda Walton Jenkins, Perspectives Inc.
Janet Wassman , Parent
Debra Zahn, Riesco, Inc.

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.

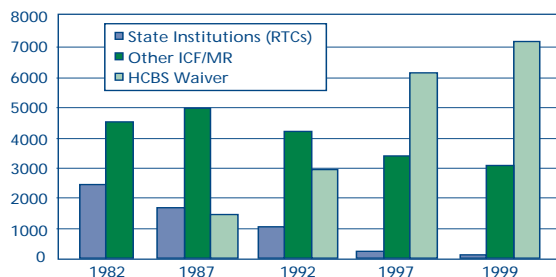
Purpose of the Evaluation

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?

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

Figure 1: Minnesota's Residential Service System 1982-1999



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?

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.

Table 1: Characteristics of HCBS Program Participants in 1999

Characteristic	%	N
<i>Age</i>		
Children (0-17 yrs.)	11.8%	830
Adults (18+ years)	88.2%	6,192
<i>Level of MR</i>		
None (related condition)	1.8%	128
Mild	33.7%	2,330
Moderate	27.2%	1,886
Severe	20.4%	1,409
Profound	16.5%	1,143
Unspecified	0.4%	26
<i>Race/Ethnicity</i>		
White, Non-Hispanic	94.8%	6,649
Black, Non-Hispanic	2.5%	174
Native American	1.4%	101
Asian/Pacific Islander	0.7%	51
Hispanic	0.6%	39

What are the Costs of HCBS?

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?

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.

Counties included in this study:

Metropolitan Twin Cities Area:
Hennepin, Ramsey, Washington, Anoka

Greater Minnesota Urban: *Blue Earth, Clay, Crow Wing, Olmsted, Sherburne, Stearns, St. Louis*

Greater Minnesota Rural:
Becker, Carlton, Faribault, LeSueur, Mahnomon, Martin, Meeker, Norman, Redwood, Steele, Stevens, Wabasha, Wagonwan.

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

Research Questions

- *What are the demographic characteristics of HCBS recipients and how do their characteristics differ from those of ICF-MR recipients?*
- *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?*
- *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?*
- *How do the total costs of various services 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?*

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.

Study Strengths:

- *Use of extent data sets represent 100% HCBS recipients,*
- *Random sample, including over- sample of people from racial and ethnic minority groups,*
- *Use of multiple research methods,*
- *Multiple stakeholder group perspectives,*
- *Representative sample, and*
- *Use of reliable instruments.*

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.

Study Limitations:

- *Low response rates from some respondent groups,*
- *Access to study participants via case managers, and*
- *Limited piloting of instruments.*

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.

“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].”

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.

HCBS 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

“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.”

“I was thrilled to receive a Waiver for my child. But, I can’t find any staff. Just this week three PCAs quit.”

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

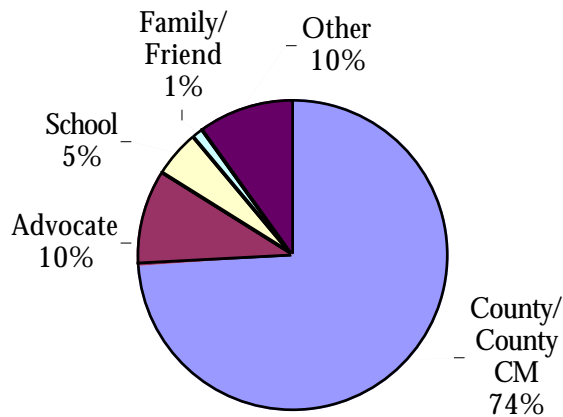
- There was a waiting list of 4,321 individuals with MR/RC for HCBS in October 1999. Many of these persons (1,687) were children living with their families, needing in-home and respite care. Of those waiting, 1,151 were adults living alone or with their families who were not currently receiving long-term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

Most common barriers to HCBS Access

- *Too few direct support staff,*
- *Challenging behavior of people who seek services, and*
- *Lack of consumer interest.*

Figure 2: Source of Initial Information About HCBS for Families



- 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.

“A family has five children, four of whom 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”

- 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 Minnesotans 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.

“Since moving to Minnesota 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. Her social worker is fabulous and her new home setting is very caring and supportive. We feel so lucky!”

“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.”

“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”.

“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 her and always take the time to talk with her. She does not talk but it is wonderful to see the interaction between her and the other people at the food shelf.”

“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.”

- 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 managers 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 managers 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.

"A person I support was always being picked on (hit and slapped constantly) by another client in her previous placement. She had to move from her previous placement to here – not the person who was hitting her."

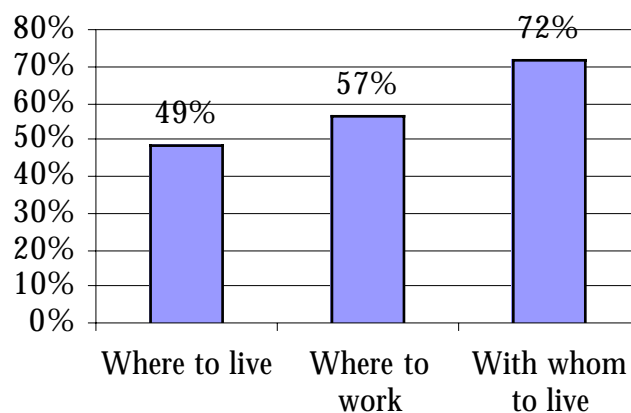
“A consumer is communicating that she doesn’t want to leave her house to attend day programming. Meetings have been held, a few different approaches have been tried and she is still coming to day program. She is still very unhappy about coming to day program. So there has not been an outcome and the consumer’s needs are still not being met.”

“A 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.”

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.

Figure 3: Consumers did not Have Choices About



- 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.

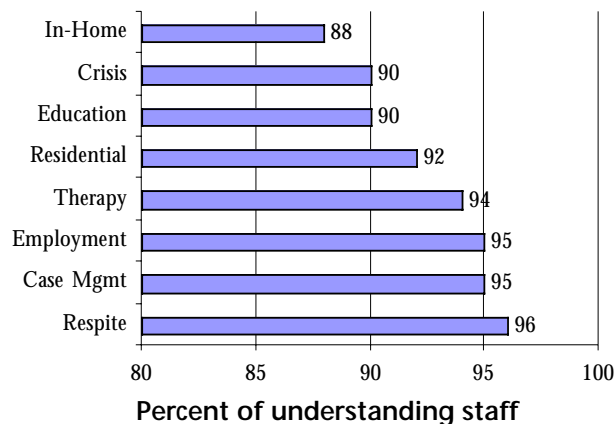
A pervasive lack of choice was also evident in the experiences of consumers and family members in the HCBS program. Few consumers had choices about where and with whom they would live, where they work, how many hours they would work, how they spend their days or who would provide personal supports to 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.

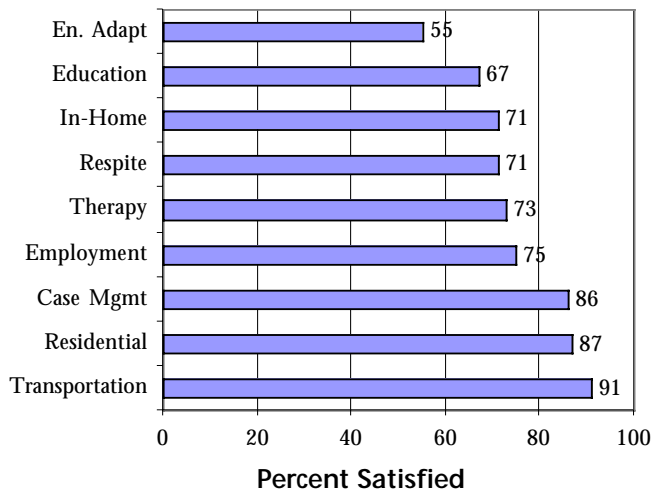
Figure 4: Staff Are Understanding Most of the Time (Families)



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.

Figure 5: Percent of Families Satisfied with Services Most of the Time



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

“The assistive technology our son received through the Waiver has opened up many possibilities for his life.”

“Our family was able to attend a Sotos Syndrome conference in Seattle, WA where we were able to become better educated on this syndrome.”

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 managers 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 “perma-

nency 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.

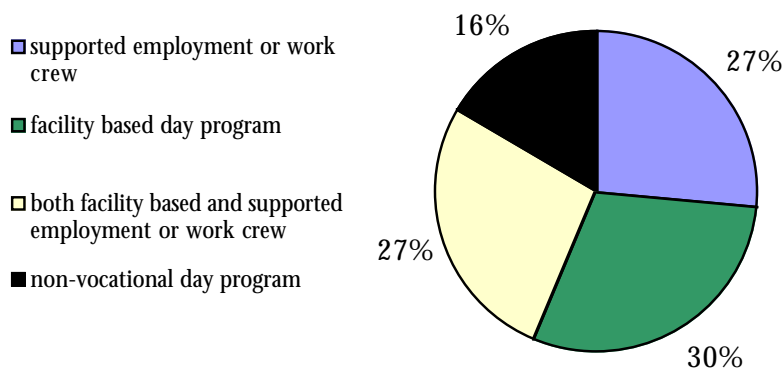
HCBS Supports and Services

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.

Figure 6: Where HCBS Recipients Work



- 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.

“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.”

- 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.

"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."

“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].”

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).

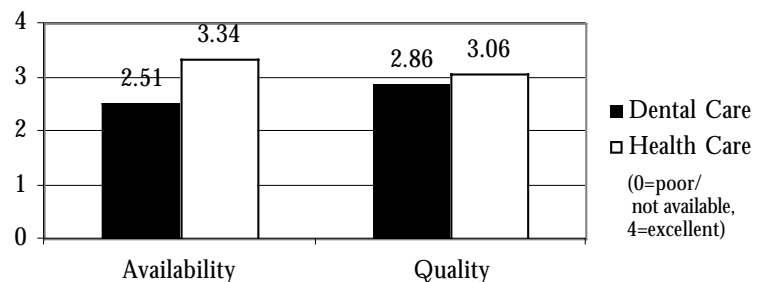
Health Supports

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

Key Findings

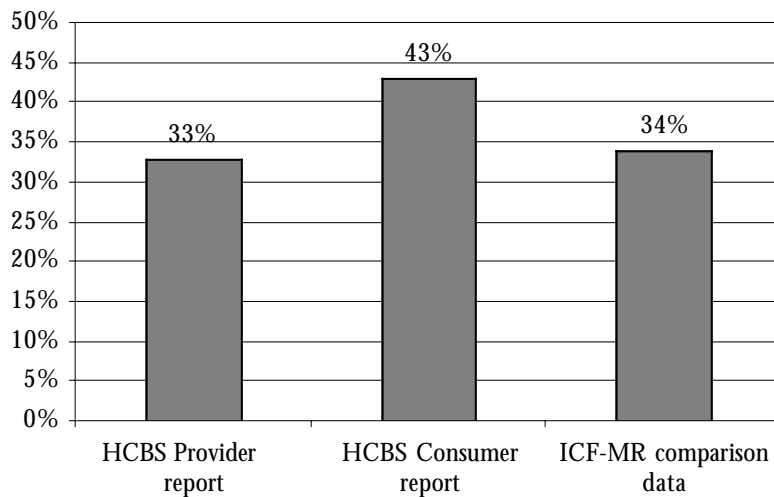
- Overall, 98% of adults living in corporate foster care settings, and 84% of adults living in family foster care, with their families or on their own had had a physical exam in the last year.
- Overall, 89% of adults had been to the dentist within the previous 6 months. People with less severe mental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

Figure 7: Availability and Quality of Health Care



- 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.
- 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.

Figure 8: Percent Using Psychotropic Medications



- 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 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%).

“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”

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 dyskinesia) 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.

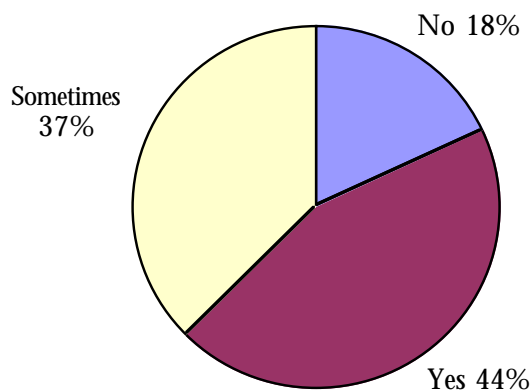
Service Coordination/Case Management

The service coordinator/case management component of the evaluation gathered and analyzed information 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.

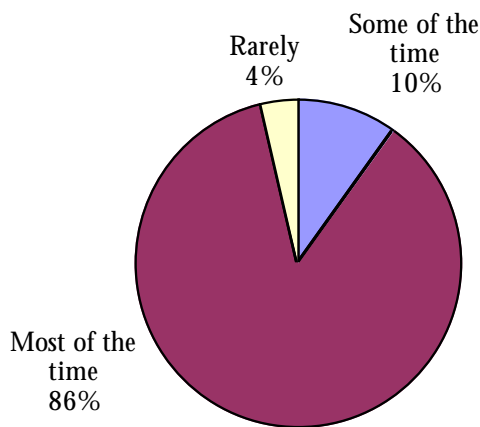
Figure 9: Consumer Choose the Things in His/Her Individual Plan



“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.”

- 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.

Figure 10: Family Satisfied with Case Management Overall



- 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%).

“I found out that in a 3-month period the county had been paid about \$1,000 for the case manager assigned to my child. I was shocked because the case manager really had done nothing for our family yet in terms of finding and accessing needed services. My estimate was that we had actuality received only about \$30 worth of case management services.”

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 managers 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 manager 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 be 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 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.

"I requested a specific county case manager because that person knew my daughter. This request was denied by the county because there had been no previous complaints about the exiting case manager assigned to my daughter."

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).

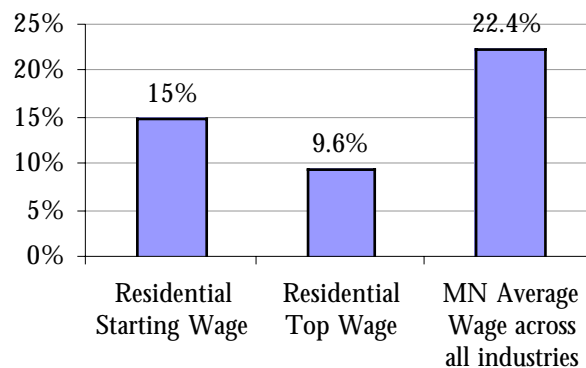
“As a single mom I have lost three jobs due to missing hours of work because I cannot find PCA care or they call in sick or simply don’t show up.”

- 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.

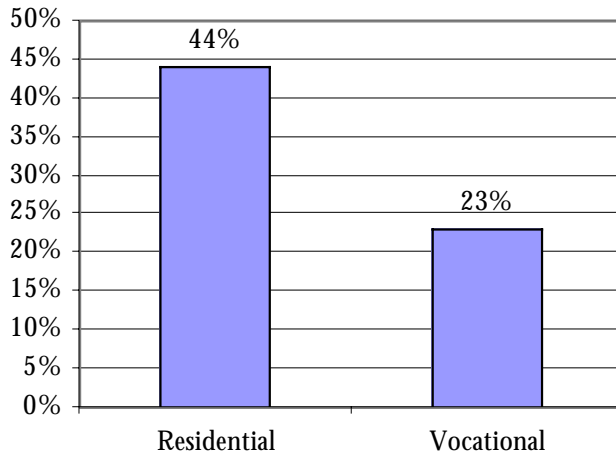
Figure 11: Changes in DSS Wages 1995-1999



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.

Figure 12: DSS Turnover Rates in 1999



- 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.

“I think the biggest problem in this whole field are the low wages [of 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!”

“My daughter has consistently only received about 50% of the in-home and PCA hours she is authorized.”

- 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).

“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.”

- 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."

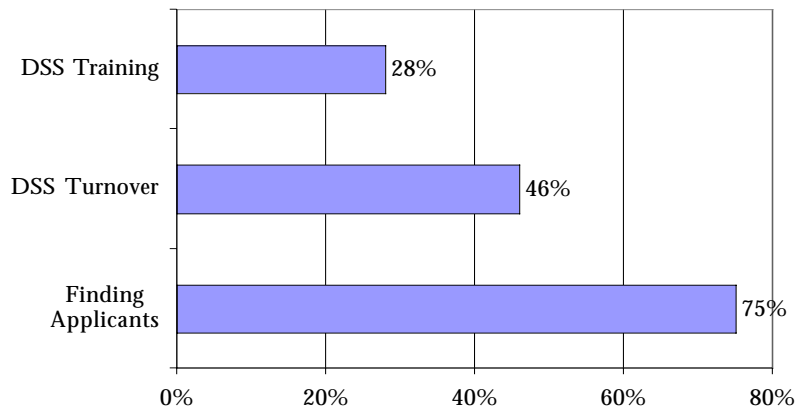
Challenges and Concerns

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

"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."

Figure 13: Workforce Problems in Agencies



“My son was badly burned in a group home because there was not enough staff.”

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

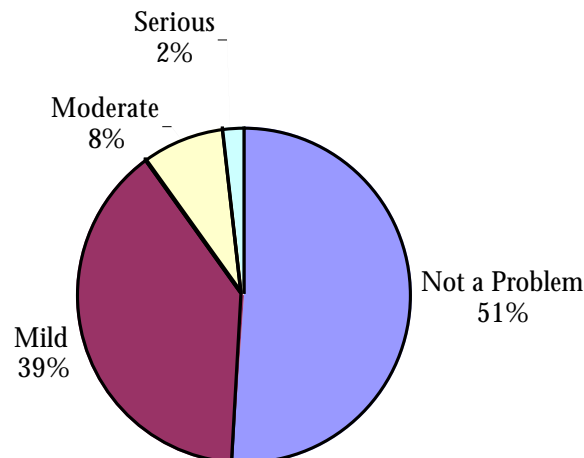
This section reviews key findings and issues in the area of quality assurance. Topics include fear, safety, victimization and injuries, deaths, maltreatment reporting and the performance of the quality assurance and monitoring system for HCBS.

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).

Figure 14: Consumer to Consumer Violence Problem: Provider Report



“A fellow housemate of my daughter’s bit her in the back.”

- 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 Minnesota 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.

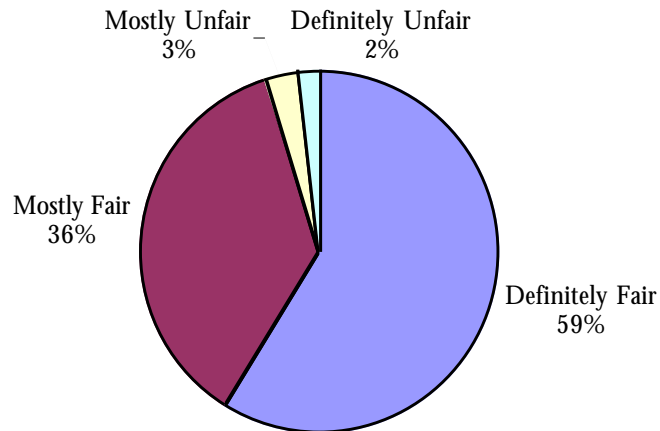
“We were asked [by the county] to develop services for two individuals in four weeks. This was poor planning. We were not able to sufficiently meet the needs. We did not have good, full referral information. Aggressive behavior escalated, the individual was demitted, and the family was angry with the provider.”

“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.”

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.

Figure 15: Fairness of Maltreatment System:DSS



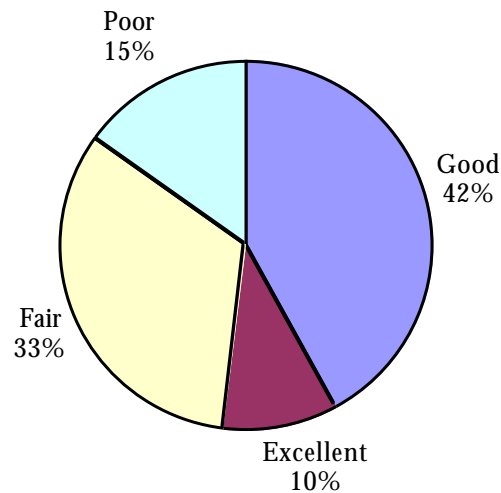
- Twenty-nine percent of DSS reported they were afraid they might lose their job if someone filed a complaint against them whether or not the report was true or substantiated. However, 95% reported they thought the maltreatment investigation system was fair to definitely fair.
- Twenty-six percent of 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.

Figure 16: QA System Assures Effective Reporting and Follow-up on VA Incidents: CM



- 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 DSS 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.

“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...”

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 exceed 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

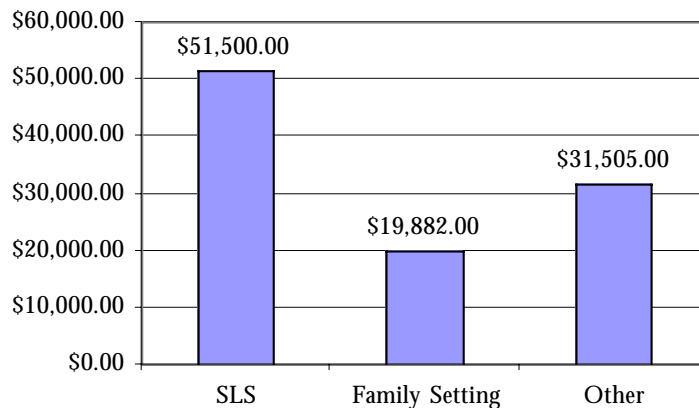
- In FY 1998, Metro counties were allowed an average of \$149.71 per HCBS recipient and spent an average of \$150.18. urban counties of greater Minnesota were allowed an average of \$132.14 and spent an average of \$125.61. Rural counties of greater Minnesota were allowed an average of \$132.47 and spent 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%).

Table 2: Average Annual HCBS Costs

<i>County Type</i>	\$
Metro	51,494
GM urban	44,495
GM rural	40,186
<i>Level of MR</i>	
mild	40,394
moderate	40,999
severe	49,941
profound	64,006
<i>Service type</i>	
SLS	51,500
in-home	19,882
other (e.g., foster family, own home)	31,505

- 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.

“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.”

Figure 17: HCBS Costs Per Recipient

- 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).

“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.”

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 Minnesotans 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 the 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.

References

- Association of Residential Resources in Minnesota (October, 1999). *Workforce crisis deepens: Caregivers need compensation increase*. Legislative Fact Sheet. St. Paul: Author.
- Cooper, R., & Smith, G. (1996). *Medicaid and case management for people with developmental disabilities: Options, practices and issues*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services.
- Department of Human Services. Comparison of Minnesota's Home and Community Based Waiver. St. Paul: Author.
- Lakin, Hayden, Burwell & Jackson (1992). An Independent Assessment of Minnesota's Home and Community Based Services Waiver Program. Minneapolis: Research and Training Center on Community Living, University of Minnesota.
- Larson, S.A., & Lakin, K.C. (1995). *Status and changes in Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) program: Results from analysis of the Online Survey Certification and Reporting System (OSCAR)*. Minneapolis: University of Minnesota, Research and Training Center on Community Living.
- Larson, S.A., Lakin, K.C., & Bruininks, R.H. (1998). *Staff recruitment and retention: Study results and intervention strategies*. Washington DC: American Association on Mental Retardation.
- Larson, S., Hewitt, A., Anderson, L., Sauer, J. & O'Neil, S. (2000). *Minnesota Review and Analysis of Trends in Agency Maltreatment Reports*. Research and Training Center on Community Living, University of Minnesota: Minneapolis, MN.
- MN Department of Human Services. Bulletin 00-56-2: DHS Announces Training on Consumer-Directed County Supports. St. Paul, Author.
- MN Department of Human Services: Bulletin 00-56-3: Results of the MR/RC Case Management Survey for 2000.
- MN Department of Human Services (CSMD, 1999). Home and Community Based Services for Persons with Mental Retardation and Related Conditions. St. Paul: Author.
- MN Department of Human Services (CSMD, 1996). *Summary report: The HCBS Waiver allocation structure*. St. Paul: Author.
- Minnesota Department of Human Services (1999). *Report of Vulnerable Adult Maltreatment Allegations: 1998 Statewide Results*. St. Paul, Minnesota.
- MN Planning, 1994. *Troubling Perceptions: 1993 Minnesota Crime Survey*. Criminal Justice Statistical Analysis Center, MN Planning: St. Paul, Minnesota.

- Murphy, K.A. (1999). *Minnesota Developmental Achievement Center Association and Minnesota Habilitation Coalition 1999 Salary Survey: Results Metro versus Non Metro*. Data as of January 1999. St. Paul: Murphy Management Consultants.
- Murphy, S.L. (2000). *Final deaths for 1998. National Vital Statistics Reports 48* (11). Hyattsville, MD: National Center for Health Statistics.
- Prouty, Lakin & Anderson (2000). *Residential Services for Persons with Developmental Disabilities: Status and Trends through 1999*. Minneapolis: Research and Training Center on Community Living, University of Minnesota.
- Stancliffe, R., & Lakin, K.C. (1996). *Cost effectiveness for people with severe/profound mental retardation*. Report to the legislature.
- State of Minnesota, 1998. *Arrests and Apprehensions in the State of Minnesota*. <http://www.mnplan.state.mn.us/cgi-bin/datanetweb/justice?prototype=1&year=97&topic=P&area=S>
- U.S. Bureau of the Census (1999). *Statistical abstract of the United States: The National Data Book 1999*. 119th Edition. Washington DC: Author.