



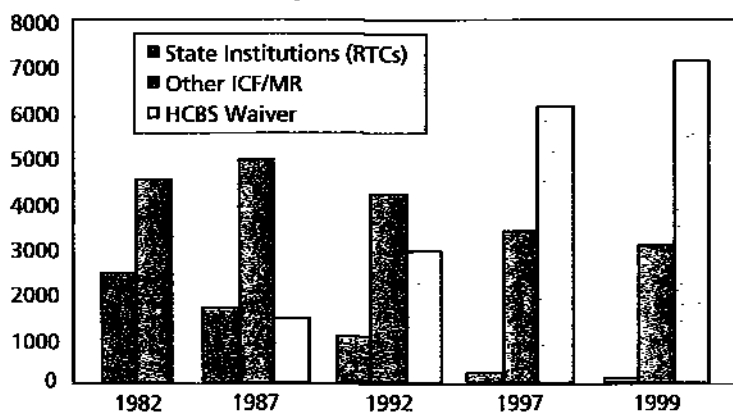
## Home and Community Based Services (HCBS)

### What are HCBS?

Medicaid HCBS were designed 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. Minnesota has been authorized to provide HCBS to people with MR/RC since 1984 through a wide range of services, including 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

**Figure1: Minnesota's Residential Service System 1977-1999**



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. The waiver reduced residents of 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 ICF-MR residents is among the most notable in the United States,

### Who Receives HCBS?

Approximately 8,000 Minnesotans benefit from HCBS and 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 challenging behavior and/or serious medical and health needs have also received HCBS to keep them out of institutions.

### 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 Centers was \$197,465. Average annual HCBS expenditures vary according to a number of factors. The most significant is where a recipient lives. The average cost for people who live in their own homes (\$21,454) or with their families (\$19,568) is much less than the annual cost for people who live with foster families (\$31,518) or in small group homes or "corporate foster care" (\$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.

### About This Report

This report is considered the Brief Summary of a lengthy technical report which includes all of the detailed findings from this evaluation effort. The most important key findings, issues and recommendations are summarized in this brief. Readers are encouraged to secure a copy of the technical report (or its executive summary) to obtain more detailed results.

**Table 1: Characteristics of HCBS Program Participants in 1999**

Characteristic	%	N
<b>Age</b>		
Children (0-17 yrs.)	11.8%	830
Adults (18+ years)	88.2%	6,192
<b>Level of MR</b>		
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
<b>Race/Ethnicity</b>		
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

# Qualify of Services

## Key Findings/Critical Issues

- Adult HCBS recipients liked where they lived (82%) and worked (89%). They had friends (76%) and could see them when they wanted (74%).
- Almost all HCBS recipients saw a doctor annually and a dentist semi-annually for medical and dental care.
- Overall, 43% of adults reported receiving medication for mood, anxiety or behavior problems. Providers reported that 34% of all individuals they supported were taking psychotropic medications.
- More people with challenging behaviors were served in HCBS than ICFs-MR. The HCBS program supported 733 people who exhibited severe property destruction and 980 people who exhibited severe aggression. This was more than twice the number of individuals with such characteristics living in ICF-MR settings.
- Service providers reported they occasionally used crisis-intervention techniques, including sending a person to an off-site crisis program (18%), calling the police (11%), or overnight stays in hospital psychiatric wards (16%).
- The majority of adult recipients (75%) said they could talk to their case manager (CM) whenever they wanted to, that their CM helped them with their needs (85%), and that it was easy to contact their CM (67%). Almost all HCBS recipients (84%) had at least one visit from their CM in the previous 6

months and 90% had some form of contact. Slightly less than half (48%) of HCBS recipients had unscheduled visits from a CM in the past year.

- Case managers were identified as a critical link in assuring quality services by counties, yet the average caseload for a HCBS case manager was 53.
- Focus groups of stakeholders concluded that the quality assurance and monitoring system was not as responsive as it should be and needed improvement to monitor individual outcomes and health and safety issues.

## Recommendations

- 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 ongoing 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 individu-

alized service outcomes, smaller average "caseloads," greater amounts and better quality of interactions with HCBS recipients and families.

# Choice/Respect

## Key Findings/Critical Issues

- A majority of families reported that most of the time providers respected family and consumer choices and preferences.
- Many adults who received services reported that direct support staff (DSS) and other non-residents of their homes entered without knocking first (25%), that there were restrictions on phone use where they lived (19%) or that people opened their mail without permission (33%).
- Most 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).

## Recommendations

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

## Individualized Supports

### Key Findings/Critical Issues

- HCBS recipients in Minnesota were much more likely to live in small group homes that were owned, rented or managed by a provider agency (74%) than the national average (41%) for HCBS recipients.
- For the typical HCBS recipient, residential habilitation made up 69% of all health and social expenditures,
- Seventy-eight percent of adults lived in corporate foster care (small group home) settings, which are the most expensive type of HCBS-financed residential care.
- Only a few counties offered the consumer-directed community supports (CDCS). Many stakeholders reported that there was demand in counties that do not offer this option.
- Counties authorized expenditures for children that were on average \$6,886 (21%) more than they actually paid; for adults they authorized \$3,844 (7%) more than they pay.

- In 1998, 16% of all HCBS recipients lived with members of their own family, but 73% of children lived with family members (an additional 7% of children lived with foster families).
- Over half of the families reported difficulty in finding people to deliver in-home or respite supports when needed.
- Although most families reported satisfaction with most services, more than 25% were rarely or only sometimes satisfied with respite services, in-home supports, school services, and adaptive equipment or environmental modifications.

### Recommendations

- 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 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.

## Direct Support Staff (DSS) Crisis

### Key Findings/Critical Issues

- Most families and almost all consumers reported that DSS were nice, understanding, respectful, professional, and caring.
- Direct support staff turnover in 1999 was 44% in residential settings and 23% in vocational settings and was significantly lower in sites offering higher wages.
- For residential DSS, average hourly wages were \$8.81; average starting wages were \$8.13. For vocational DSS, average wages were \$10.49; average starting wages were \$8.89. Residential starting wages grew 15% between 1995 and 2000, but average top wages grew only about 9.6%.
- Nearly half of families, service providers, and counties reported turnover of DSS was a significant problem,
- All counties reported difficulty in getting agencies to develop new services because of the difficulty in recruiting and retaining DSS and a decline in the quality and quantity of effective staff! Three-quarters of service providers said DSS recruitment was a serious problem.

## Recommendations

- 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

### Key Findings/Critical Issues

- Recipients of residential (.5%) and vocational (6.2%) supports were reported to be victims of serious crime at rates much lower than the general population (31%).
- When asked "Does anybody where you live hurt you", 85% of HCBS consumers said nobody hurt them, 7% said a roommate had, 3% said staff had, and 5% said someone else had. Still 40% of DSS and 49% of providers said they considered consumer-to-consumer violence to be a problem.
- Ninety-nine percent of DSS said they knew how to report abuse and neglect.
- Twenty-six percent of 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 by their supervisor and 2% by their coworkers. Only 63% of DSS who filed a report received any information regarding their report.
- Between 1995-98, four deaths involving people with MR/RC who received HCBS services occurred as a result of maltreatment. The total number of HCBS recipients who died between 1995-1998 was 74.
- Most stakeholder groups reported dissatisfaction with the maltreatment reporting and follow-up system in Minnesota.

### Recommendations

- 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.

## Access to HCBS

### Key Findings/Critical Issues

- Despite progress since 1992, there are still fewer HCBS recipients from racial and ethnic minority groups than would be expected, and there continues to be limited outreach by counties to minority communities,
- There was a waiting list of 4,321 individuals with MR/RC for HCBS in October 1999. Many (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 tremendously on the criteria for who gets HCBS.

### Recommendations

- 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.

- Consistency and fairness should be increased in the county processes and priorities for decisions about HCBS access.

## Affordable Housing

### Key Findings/Critical Issues

- Most HCBS recipients lived in small group homes where they received group residential housing (GRH) payments to assist providers to pay for their living expenses, but adequate state subsidies were not available to people in non-licensed settings.
- The lack of affordable housing was identified as a significant barrier to people's ability to use HCBS to achieve the lives they would like.

## Recommendations

- 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.



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Minnesota Department of Human Services

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 report is available in alternate formats upon request. To obtain copies of the complete technical report or for more information about this evaluation, please visit the following Web sites or contact the addresses listed below —

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