

Medicaid Home and Community-Based Services Program in Vermont

Final Report

Site visit of August 21 through August 25, 2000

Submitted:

**Health Care Financing Administration
Project Officer**

Submitted by:

**The University of Minnesota Research and Training
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The Lewin Group

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INTRODUCTION

This report summarizes findings and observations of a site visit in Vermont to observe and discuss with key state officials, service providers, program participants and others the implementation, outcomes and challenges of Vermont's Medicaid Home and Community-Based Services ("waiver") program serving individuals with mental retardation and related conditions (MRIRC), hereafter referred to as "developmental disabilities" * in concordance with state program designations.

Authorization of the Medicaid Home and Community Based Services "waiver" program (HCBS) was contained in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), passed on August 13, 1981. It granted the Secretary of U.S. Department of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" services for Medicaid-eligible individuals. The HCBS program was designed to provide home and community-based services for people who are aged, blind, disabled, or who have mental retardation or a related condition, and who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid certified, institutional facility. Final HCBS regulations were published initially in March 1985. Since then a number of new rules and interpretations have been developed, including revised regulations published in July 1994, although these have not changed the fundamental premise of the program, which is to use home and community-based services and supports to reduce the need for institutional services.

The non-institutional services that can be provided in an HCBS program include case management, personal care services, adult day health services, habilitation services, respite care, or any other service that a state can establish in its application will lead to a decreased need for and costs of Medicaid funded long-term care. States are not allowed to use HCBS reimbursements to pay for room and board, but all states offering HCBS to persons with developmental disabilities (DD) do provide residential support services under the categories of personal care, habilitation, homemaker or other similar service types. HCBS recipients must use their own money, usually from cash assistance

* Vermont uses the term "developmental disabilities" to designate its HCBS eligible population, but operationally defines that group to include only persons with mental retardation and pervasive developmental disorders (i.e., infantile autism and closely associated syndromes with "autistic features" evident in childhood).

provided by other Social Security Act programs to fund room and board portion of residential services. In June 1999 about two-thirds (68.6 percent) of HCBS recipients in the 43 states reporting such data, received services in settings other than the home of natural or adoptive family members (Prouty & Lakin, 2000).

Given both its flexibility and its potential for promoting the individualization of services, the HCBS program is recognized in all states as a significant resource providing community services to persons with DD. Beginning in the early 1990s, administrative requirements that prevailed in the HCBS program's first decade that required that state applications to provide HCBS show reductions in projected ICF-MR residents and expenditures roughly equal to the projected increases in HCBS participants and expenditures were substantially relaxed, were then deleted in the 1994 revised regulations. As a result, there was dramatic growth in the number of HCBS participants and expenditures in the program's second decade, that is since 1992. On June 30, 1999 states provided HCBS to more than four times as many people with DD (261,930) as in June 1992 (62,429) and to more than twice as many HCBS recipients as to people residing in the Intermediate Care Facilities [for persons with] Mental Retardation (ICFs-MR) for which HCBS is the non-institutional alternative (117,900).

CASE STUDY OVERVIEW

Purpose.

All states have been expanding their services to individuals with DD and families through community services programs. States use a variety of mechanisms to fund these services, including their regular Medicaid program (e.g., home health and personal care), and DD targeted Medicaid Home and Community-Based Services (Section 1915[c] waivers), state-financed programs, and in some states small community ICFs-MR. By far the most significant and rapidly growing program for persons with DD has been the Medicaid HCBS program. While it is committed to non-institutional services, the Health Care Financing Administration (HCFA) has relatively little systematically gathered information about how states organize and deliver HCBS or about the effectiveness of services in contributing to the health and well being of those who receive them.

HCFA contracted with the Lewin Group to design and implement a study of the impact of Medicaid Home and Community Based Services (HCBS) programs on quality of life, quality of care, utilization and cost. The Lewin Group subcontracted with the Urban Institute, Mathematica Policy Research, Inc., the University of Minnesota and the MEDSTAT Group to assist in aspects of the study. One component of this study was site visits to 6 states to describe the financing, delivery and outcomes of Medicaid HCBS for people with DD and site visits to another six states to describe similar features of HCBS programs for older and younger people with physical disabilities.

The University of Minnesota conducted the state site visits related to HCBS administration and services delivery for people with DD. Site visits were conducted between February 2000 to August 2000. During these visits, site visitors conducted in-person interviews with state and substate region government officials who were associated with different aspects of the HCBS program, administrators of service agencies, case managers, direct care staff, advocates, and service recipients and their family members.

The case studies examined key program features, including (a) the context of the program, (b) the philosophy and goals, (c) coordination with the State Medicaid agency, (d) administration, (e) eligibility criteria, (f) financing, reimbursement and contracting for services, (g) quality assurance and monitoring, and (h) challenges for the future. This report is a summary of the case study of Vermont's Medicaid HCBS program. The Vermont site visit was conducted August 21 through August 25 by K. Charlie Lakin (report author) and Lori Sedlezky of the University of Minnesota.

Methodology

State Selection. States were selected for participation in this study based on a variety of features intended to represent HCBS programs that were relatively well-developed program as well as programs that were still developing. With the assistance of the Technical Advisory Group factors were identified to order states for sampling purposes including: the number of HCBS recipients as a proportion of all long-term care recipients with MR/RC, HCBS recipients per 100,000 of state population, HCBS expenditures as a percentage of all Medicaid long-term care expenditures for people with MR/RC, the proportion of all ICF-MR and HCBS recipients served in congregate housing, and the location of the state. Based on these factors an index ranking was created and states were

statistically ordered in a continuum from which they were selected. The states involved in this study held ranking of 1, 4, 9, 33, 44 and 51 on these indexes, reflecting the desired distribution from “well-developed” to “developing” that was desired for the study.

Site Visit Goals. The Vermont site visit, like the other HCBS site visits, was designed to be a “process evaluation.” Its primary focus was on the organizational aspects of delivering HCBS services and how key informants throughout Vermont viewed the effectiveness of the organizational structures created in achieving the objectives established for the program. Site visitors probed for the perceptions of different stakeholders about what was working well in Vermont's HCBS program and what might be improved and how. In all descriptions of the purpose of this study, site visitors always made it clear that they had no regulatory role in the Medicaid HCBS program and that the questions they asked were intended only to better understand the program. It was also explained to stakeholders that a second “outcome evaluation” stage of the study would focus directly on the effects of HCBS on the lives of a large sample of service recipients and on their satisfaction with the services received.

The site visit to Vermont attended to broad HCBS program design and implementation, including:

What principles, goals and objectives guide the state’s use of the Medicaid HCBS program, how were those principles, goals and objectives defined, and what is the nature, status and effects of the overall state effort to achieve them?

What are the origins, design, internal organization, financing and program relationships of the public and private agencies delivering HCBS? How and to what extent do they cooperate, coordinate and coinvolve with each other and with the state in pursuing the principles, goals and objectives established by the state for the HCBS program?

What is the nature and effectiveness of efforts within the state to define, monitor and improve the quality of services and consumer protections? How well do these achieve the minimum standards established by Congress and the specific principles, goals and objectives established by the state?

What are the primary accomplishments and challenges facing the state and its HCBS provider agencies and individuals in achieving state goals and objectives and the expectations of service

recipients; and what planning, staff recruitment and development, service delivery and service quality management practices are needed to maintain and enhance efforts to realize them?

CASE STUDY APPROACH

A primary approach used in the site visits was to interview representatives of major stakeholders and “implementers” of Vermont's HCBS program to describe the nature, quality, and outcomes of relationships among state and regional agencies, the agencies that provide and people who receive HCBS. Interviews were supplemented by a wide range of documents. In case studies it is typical to hear both consensus and differences in impressions about different aspects of programs, policies and agencies. The goal of the case study approach is to synthesize and summarize information from different sources to better understand the program and how policies, practices, and interpersonal factors have affected its development and challenges for the future. A range of information sources contributed to this summary.

Interviews. The primary methods of obtaining information in this case study was a series of interviews built around the general research goals identified above. Interview schedules were drafted by the project team. These were reviewed by members of the Technical Advisory Group and HCFA staff and were subsequently revised. The interview schedules were structured so that multi-level, multi-respondent corroborating interviews were generated in each of the research areas. For example, the interviews with state officials asked about the state’s objectives for HCBS. The interviews with service providers gathered corresponding information on how the state’s objectives were communicated, understood, and supported through policy, training, technical assistance and in other methods at the local levels.

Document review. In addition to interviews there was extensive use of document and data review in this case study. We gathered and examined the following types of documents: 1) the Vermont HCBS waiver application; 2) the Vermont Developmental Disabilities Act of 1996; 3) "Regulations Implementing the Developmental Disabilities Act of 1996;" 4) "Administrative Rules on Agency Designation;" 5) Annual Report 2000 of the Vermont Division of Developmental Services; 6) "the state System of Care Plan for Developmental Services, FY 2001 Update;" 7) "Guidelines for Quality Services" of the Division; 8) other relevant documents developed and disseminated by the Division,

other organizations (e.g., the Center on Human Policy, Syracuse University), and its contractors (e.g., University of Vermont satisfaction surveys); 9) reports and other documents of related public agencies, (e.g., Vermont Developmental Disabilities Law Project and Vermont Council of Developmental and Mental Health Services, Vermont Planning Council of Developmental Disabilities, Vermont Self-Determination Project); 10) documents developed by individual service provider agencies for external presentation of mission, programs, services, clientele, organizational challenges and future directions, and internal documents related to general operations, organizational development and provision of HCBS-financed community services; and 11) other state or provider agency materials and correspondence relevant to HCBS.

Cooperation of the Division on Developmental Disabilities and Others

We received very helpful and warm support from Theresa Wood, Director of the Vermont Division of Developmental Services, and from June Bascom and Muriel Morse, also of the Division, in preparing for this site visit. Their time and assistance in educating us about Vermont's system and connecting us to key personnel within the state agency related state agencies and within the broad community of service providers, advocates, service users and family was invaluable. We were also deeply appreciative of the involvement of key leaders and staff of state and local agencies with responsibility for advocacy, technical assistance and quality review. Vermont's service provider association and individual agency leaders and staff were extremely open and helpful in describing their experiences and challenges providing community services to persons with developmental disabilities. Finally, we are especially grateful for the opportunity to speak with individuals who receive HCBS services, their family members and the people who share their lives and homes with people with developmental disabilities, and to learn of their experiences, needs and hopes for the program.

Review of the Draft Report

The initial draft of this report was provided to select key Vermont state informants. They reviewed a draft of the report and provided corrections, criticisms, and questions to the site visit leader. Clarifications were accomplished through follow-up correspondence and telephone interviews. Appropriate corrections to the draft report were made.

Selection of Sites and Interviews

The selection of individuals and sites that were visited was carried out by the site visit coordinator, key contact, Theresa Wood, in consultation with the Lewin Group. As in other states, this visit was designed to include key staff members in the state's administration for developmental disabilities services/HCBS, including 1) key officials of the Vermont Division on Developmental Disabilities, 2) key leaders in state technical assistance and quality assurance roles, 3) representatives of key state advocacy and "provider" organizations, 4) service provider agency administrators, case managers, program directors and direct support staff, and individual developmental home "hosts" who were contracted by the HCBS service provider agencies; and 5) community service/HCBS recipients and their family members.

HCBS-financed services are provided throughout Vermont in each of the 10 designated regions. Because of the relatively small size of the state, the site visit team was able to visit agencies in designated regions from the northern to the southern parts of the state. In total, 4 of 10 regions and 5 of 16 certified provider agencies were visited. Individual "sites" were selected to include areas that represented relatively (for Vermont) urban and relatively "non-urban" catchment areas.

The site visit team interviewed over 60 key stakeholders in Vermont. HCBS recipients and family members were interviewed in a range of settings from their individual homes to conference rooms in the office of the service provider agencies. Everyone asked to participate agreed to be interviewed. All interviewees were extremely accommodating of the site visit team's requests and schedules. The week was structured so that evaluators had the opportunity to see and meet with a variety of recipients and other key stakeholders.

All respondents were promised anonymity. All interviews began with an explanation of the purpose of the site visit and assurances that the evaluators had no regulatory or enforcement roles in HCBS. We made it clear that we were not employees of the Health Care Financing Administration (HCFA) and the only influence that we could have would be if concerns were raised, and it were requested that we pass them on to appropriate public officials.

Major Areas of Inquiry

The major areas of inquiry described in this case study correspond to the primary topics from the interview protocol. Major areas of inquiry that are reflected in the outline of the report include: 1) context of the program, 2) philosophy and goals, 3) coordination with the State Medicaid agency, 4) administration, 5) eligibility criteria, 6) financing and reimbursement, and 7) quality assurance and monitoring. A final heading on “challenges in the future” captures issues that are subsumed under the general headings above, but which seemed to be particularly important to the people interviewed.

CONTEXT OF VERMONT'S HCBS PROGRAM

A Service System Without Institutions

Vermont operates a service system for persons with developmental disabilities (DD) that is totally comprised of community services. Vermont's only public institution for persons with DD was closed officially in November 1993. That closure was influenced by two major events. The first, the Brandon Judicial Review Law, established a legal process requiring the review of each resident's needs to determine if he or she could be served in a less restrictive community setting. The second event was the filing of a lawsuit on behalf of Robert Brace and five other residents who wanted to move into the community. The settlement in 1980 of this lawsuit, called the *Brace decree*, included a 10-year plan for developing community resources and moving most of the approximately 300 residents out of Brandon Training School.

The settlement did not specifically mandate the closure of Vermont's only state institution, but it was not unexpected that achieving the mandated outcomes might well make total closure the logical next step. Nearly 250 people moved into the community in 1979 and the early 1980s due to the state's successful use of the Medicaid Home and Community Based Services (HCBS) waiver, which allowed the state to develop services in the community, in many cases using employees who had been state employees at the Brandon Training School. Vermont was one of the earlier states to utilize the HCBS waiver to move people out of state institutions in a substantial concerted effort. But in the early 1980s depopulation of Brandon stagnated, with a population on June 1984 (202 people) that was not appreciably different than that of June 1989 (182 people).

In 1989, the Division of Mental Retardation (now "Developmental Services") drafted a plan that outlined a rationale and plan to close Brandon. The Division's plan was an effort to convince major constituencies, including the legislature, governor's office, families, institution employees and union of the economic and social benefits of closing Brandon and to elicit commitments to that end. A key aspect of the plan was expansion of the services provided to persons with DD by 10 community mental health organizations and 4 agencies serving only persons with DD. The infrastructure of regional community mental health and MR/DD agencies in Vermont were key to the ability to move nearly 200 people out of Brandon over a period of slightly more than 4 years. Between June 1988 and June 1993 the number of residents at Brandon decreased from 186 to 31 and the number of people living in community residential settings increased from 381 to 701 (an increase of 84%).

A key to Vermont's success in the rapid depopulation of Brandon was the capacity and commitment of its regional service providers. These agencies not only substantially expanded their services, but also accepted and developed the capacity to include Brandon residents with substantial intellectual and other impairments (85% of whom in 1989 had severe or profound intellectual disabilities and 51% of whom were reported to have "behavior disorders"). As part of the commitment to close Brandon over a four-year period the division began monthly meetings with regional agencies to plan for moving Brandon residents to the community. Individuals were identified and procedures set up to ensure the involvement of the residents, their parents or guardians, local agencies and state staff in all decisions regarding placement and transition. The staff of Brandon were also encouraged to be involved in the process. Together, the state and the mental retardation programs developed services and funding that were individualized. Some people moved in with existing families, often with former Brandon employees with whom they already had a relationship. Others found homes with nondisabled companions. Relatively few moved into group homes.

In June 1993 Vermont had 48 residents in 8 communities ICFs-MR of 6 residents each. It had 137 people living in 24 staffed group settings. But the substantial majority of residential service recipients were living in adult foster care settings ("developmental homes") or in their own homes, often with companion (housemate) support.

In June 1993 as Brandon was in the final stages of closure, Vermont had the nation's lowest average number of persons with DD per residential setting (1.7). In the years that have followed, it has retained that position by steadily lowering its average to 1.2. It has done so not only by completing the closure of Brandon, but by steadily reducing the numbers of people in-group settings in the community. In June 1999 only 7% (82) of Vermont's approximately 1,050 residential service recipients lived in settings of 4 or more people and none lived in settings with more than 6 residents. One state advocate observed that "We still have a lot to do, but one thing about Vermont is that we understand community and agree that it's important for everyone."

The Role of Medicaid HCBS

By many different standards Vermont is a national trendsetter in community services for persons with developmental disabilities. As just two examples, it has the highest percentage nationwide of residential service recipients living in settings of 3 or fewer residents (Prouty & Lakin, 2000); and it is ranked fourth nationally in the rate of supported employment of people with MR/DD per 1,000 of state population (Braddock et al., 2000). Vermont state agency, local agency leaders and advocates are aware and proud of Vermont's comparative excellence in the development of a community service system. They publicize their national standings in their annual reports and in presentations. But Vermont's leadership is not only evident in the shift from congregate care to individualized service models, it is also evident in the infrastructure created to support that transition. For example, Vermont's Crisis Intervention Network, established in 1991 to replace functions of Brandon Training School to support persons with challenging behavior through a comprehensive statewide program of training, consultation and crisis placements, has been a model for other states in developing an infrastructure to support community services for all persons with DD.

The Medicaid HCBS waiver is viewed as a primary instrument in major accomplishments of Vermont. Vermont made major commitments in the 1990s to maximize Medicaid participation in its services to persons with DD, especially through the Medicaid HCBS program. In Fiscal Year 1999 the state computes that 98.2% of all Division of Developmental Services expenditures for persons with DD were cost shared with Medicaid, 93.7% through the HCBS waiver and the remainder through ICF-MR, targeted case management, clinic and other services. The only "unmatched" state-only funding is

for a program called a "Flexible Family Funding," which provides 550 families with children or adult members with DD living at home with a small grant (usually about \$1,200 per year) to be used at the family's discretion to meet the needs of the family or the person with DD. Flexible Family Funding (FFF) makes up about 1.8% of the DDS budget, although supports about 20% of all support recipients.

Although Medicaid HCBS funding is dominant in Vermont's service system for persons with DD and has doubled from FY 1993 to 1999 (from \$28.6 million to \$54.5 million), Vermont is relatively conservative in its overall expenditures. It takes advantage of its federal Medicaid match of .62%, but is constrained by the economic realities that such a rate reflects. Among the notable accomplishments of Vermont in managing its HCBS waiver program has been an actual decrease in average per person HCBS expenditures between 1993 and 1999 from \$47,900 to \$36,000 (FY expenditures divided by end of year recipients). This has been accomplished primarily by increasing the use of less expensive services and decreasing the use of more expensive services, and by increasing support of people in their own homes. The results of this effort among residential service settings is shown in Table 1.

Table 1: Shifts Among Vermont's Residential Types, 1993 to 1999

Type of Residential Service	June 1999 Average Cost	Number of People Served		
		1993	1999	% Change
Supervised Apartment	\$12,550	140	183	+30.1%
Developmental Home	22,778	409	747	+82.6%
Group Home	49,421	119	80	-32.8%
Staffed Apartment	70,506	30	19	-36.7%
ICF-MR	133,533	54	12	-77.8%
Total	\$25,175	752	1041	+38.4%

Expansion of HCBS

Like most states, between 1993 and 1999 Vermont understood rapid expansion and "waiverizing" of its community services system. During the period between June 1993 and June 1999 Vermont rapidly expanded its HCBS recipients from 598 to 1,540 (158% growth), still substantially less than the national average growth of 202%. The primary factor in the different rate of growth in Vermont vs. other states was its earlier HCBS development, which caused it to have an HCBS use rate

of 101.9 recipients per 100,000 of state population by 1993 as compared with an average of 33.8 recipients per 100,000 nationally. In 1999 Vermont's HCBS use rate was the third highest in the United States. At 259.3 per 100,000, this far exceeded the national average of 96.1 per 100,000. As a result of Vermont's early and continued commitment to community service development and maximizing Medicaid federal participation (FFP) in its services, its commitment to the identification and expansion of cost-effective models of service, and its development and financing of family support, Vermont is able to maintain a system that has been generally able to respond to the demands for services placed on it. As a percentage of total DD agency budget Vermont's family support funding ranked ninth nationally and its family support spending per \$1,000 of the state's personal income ranked fifth nationally. These commitments to family support are viewed as an important ingredient to Vermont's ability to serve maximum numbers of people with the funding available from its legislature. One indicator of the general effectiveness of their commitment is that while Vermont ranks high nationally in its total Medicaid service utilization (HCBS and ICF-MR service recipients per 100,000) at 261.3 as compared with 139.3 nationally, its total residential service recipients are only 175.3 per 100,000 as compared with an average of 132.4 nationally.

PHILOSOPHY AND GOALS

Vermont's service system is based on and measures its success by clearly articulated sets of principles, goals and objectives for its services.

Vermont Developmental Disabilities Act

Services to persons with developmental disabilities in Vermont are authorized under and guided by the Developmental Disabilities Act of 1996 (DD Act of 1996). The DD Act of 1996 was characterized as a document integrating efforts to incorporate grassroots participation and consensus building of all stakeholders into a document to guide statewide services. The Act establishes that, "It is the policy of the State of Vermont that each citizen with a developmental disability shall have the following opportunities:

1. To live in a safe environment with respect and dignity.
2. To live with family or in a home of his or her choice.

3. To make choices which affect his or her life.
4. To attend neighborhood schools, be employed and participate in activities to the extent that this purpose is not construed to alter or extend rights or responsibility of federal laws relating to special education.
5. To have access to the community support and services that are available to other citizens.
(18 V.S.A. S 8721)

The DD Act of 1996 further stipulates 12 principles that will govern services provided to persons with developmental disabilities under the auspices of the Department of Developmental and Mental Health Services (DDMHS) and its Division of Developmental Services (DDS). These included:

1. "Children's services. Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment... Children with disabilities benefit by growing up in their own families; families benefit by staying together; and communities benefit from the diversity that is provided when people with varying abilities are included.
2. Adult services. Adults, regardless of severity of their disability, can make decisions for themselves, can live in typical homes and can contribute as citizens to the communities where they live.
3. Full Information. People with developmental disabilities and their families need complete information about the availability, choices and costs of services, how the decision making process works and how to participate in that process.
4. Individual Support. To be effective and efficient, services must be individualized to the capacities, needs and values of each individual.
5. Family Support. Effective family support services shall be designed and provided with respect and responsiveness to the unique needs, strengths and cultural values of each family and the family's expertise regarding its own needs.

6. Meaningful choices. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values and needs and assure that each recipient is directly involved in decisions that affect that person's life.
7. Community participation. When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community.
8. Employment. The goal of job support is to obtain and maintain paid employment in regular employment settings.
9. Accessibility. Services must be geographically available so that people with developmental disabilities and their families are not required to move to gain access to needed services...
10. Health and Safety. The safety and health of people with developmental disabilities is of paramount concern.
11. Trained staff. All individuals who provide services to people with developmental disabilities and their families must receive training...
12. Fiscal integrity. The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities." (18 V.S.A. S 8724)

Beyond its contributions in law, state officials and advocates also agree the Legislature has been supportive of the development of community services for persons with DD. They note that such services have been able to grow at a rate that has substantially outpaced that of other programs in the Agency of Human Services. They further observe that because these services are contracted to local agencies for their delivery, their support has been advocated effectively with legislators within local communities by the local agencies that provide the services.

State Commitment to Community Services Access

Vermont's commitment to people with developmental disabilities having access to services in the community is strong and comprehensive in scope. It not only has eliminated the use of congregate care settings for persons with DD with more than 6 residents and substantially reduced the number of people in facilities of 3-6 residents, it attends carefully to people with DD in other types of institutions.

Vermont has over the past decade reduced patient days of persons with DD in the Vermont State (Psychiatric) Hospital from an average 3,113 in 1989-1990 to an average of 1,095 in 1998-1999. A major factor in this accomplishment was the establishment of the Vermont Crisis Intervention Network in 1991 (to be described later).

Vermont has also accomplished a steady decline in the number of persons with DD residing in nursing facilities. State reports of nursing facility residents show a decrease from 100 to 56 in the decade between June 1989 to June 1999 and a further reduction to 50 by the end of 1999. This decrease is attributed to pre-admission screening and diversion implemented as part of the state PASAAR program and to the capacity to develop and support more individualized community settings. Vermont's placements in Medicaid certified nursing facilities in June 1999 equaled 3.5% of all Medicaid long-term care placements of persons with DD. This compared with a national average of 6.5%.

Vermont even monitors the number of persons with DD who are incarcerated in correctional settings. In September 1998 the state identified 6 inmates meeting its definition of DD in state correctional facilities, which state officials suggest compares favorably (i.e., is much lower) of national estimates of 4% and higher. The difference was attributed to overall low crime and incarceration rates in Vermont and to a mandated diversion program which places in custody of the Department persons viewed as a danger to others but not competent to stand trial. Recently there have been approximately 10-15 people in that status.

STATE ADMINISTRATION OF HCBS

As noted there is essentially no distinction between services for persons with DD in Vermont and the services financed by Medicaid. The Agency of Human Services is Vermont's single state agency for Medicaid programs. The Department of Developmental and Mental Health Services and specifically the Department's Division of Developmental Services manages all operational aspects of the

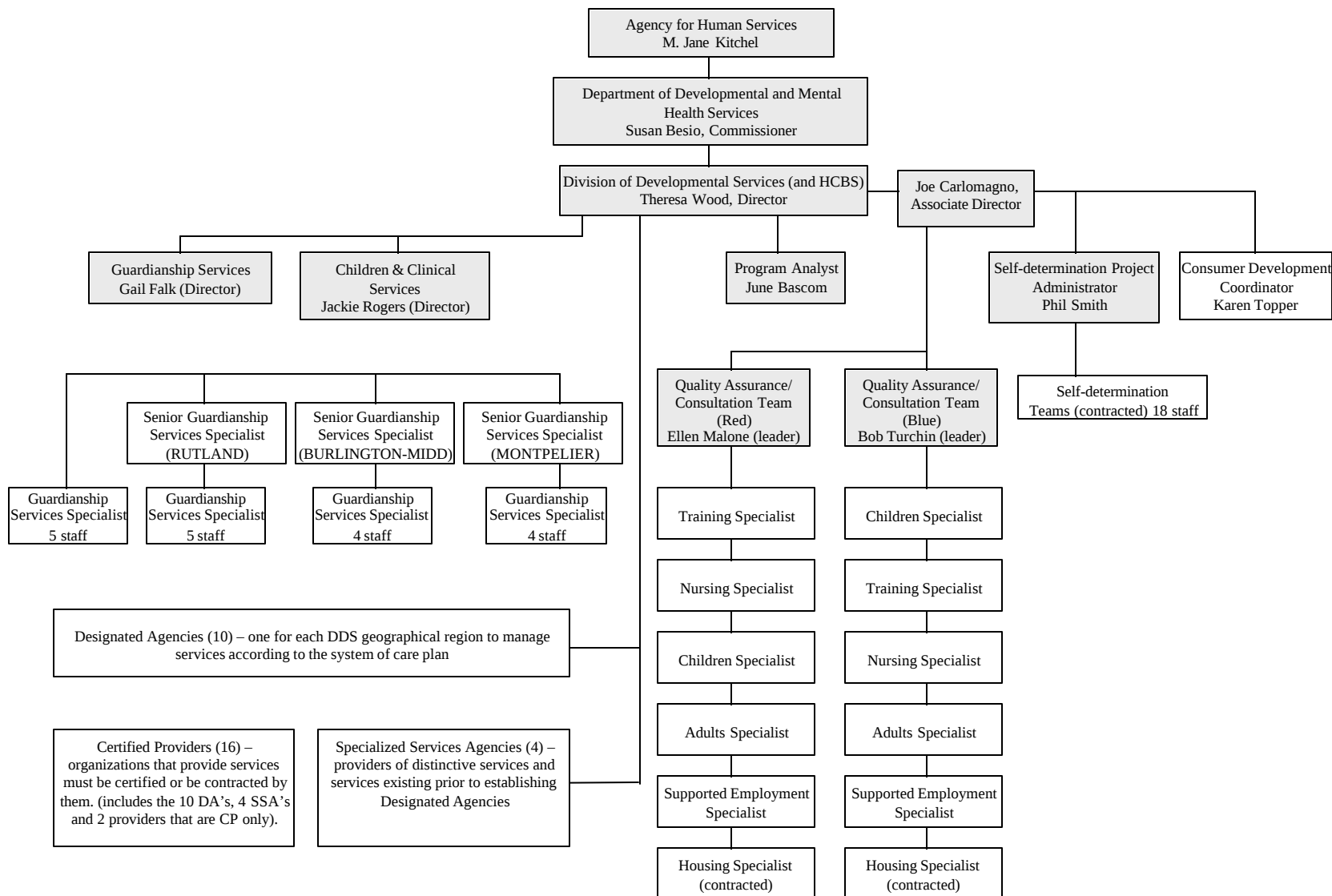
HCBS program, including developing rules and regulations and establishing and operating payments within guidelines established by the DD Act of 1996 and federal rules. Certain investigative roles fall within the scope of agencies such as the Attorney General, but for the most part the Division manages the HCBS program, including the interactions with the HCFA Regional Office officials independently, as the programmatically responsible component of the Department of Developmental and Mental Health Services.

State officials indicate that they have a very positive relationship with the Regional Office and have found staff in the Regional Office very helpful and supportive of innovations pursued by Vermont. They indicate that there seems to be a shared sense of pride in what Vermont and other states in the Region have accomplished and in the role of the Medicaid HCBS program in those accomplishments.

Organizational Chart of the State HCBS Administration

The organizational chart in Figure 1 shows the organization of Vermont's HCBS program administration. It is the same as would be shown for any DDS services, since with the exception of state financed "Flexible Family Funding" (the state Family Subsidy program), 2 small ICFs-MR, and targeted case management, Vermont's services for persons with DD are financed as HCBS.

Figure 1: Vermont HCBS Organizational Chart



Lead HCBS Agency: Division of Developmental Services (DDS)

Vermont's Division of Developmental Services has responsibility for planning, administering, monitoring and evaluating all HCBS for persons with DD. It provides guardianship services for individuals under court-ordered protective services, from 8 regional offices with 21 guardianship specialists. It selects, reviews and reapproves the 10 non-profit entities with which it contracts to administer the DDS program on a regional basis.

The Developmental Disabilities Act of 1996, within the funding allocated and priorities established in collaboration with the "State Standing Committee" requires DDS to:

1. Promote the principles of. . . the DD Act. . . collaborating and consulting with people, their families, guardians, service providers and others.
2. Develop and maintain an equitable and efficiently allocated statewide system of community-based services that reflect the choices and needs of people.
3. Acquire and administer funding for these services and identify needed resources and legislation.
4. Establish a statewide procedure for applying for services.
5. Facilitate or provide pre-service training and technical assistance to service providers consistent with the system of care plan.
6. Provide quality assessment and quality improvement support for services provided throughout the state.
7. Encourage the establishment and development of locally administered and controlled non-profit services based on the specific needs of individuals and their families.
8. Promote and facilitate participation by people and their families in activities and choices that affect their lives and in designing services that reflect their unique needs, strengths and cultural values.
9. Promote positive images and public awareness of people and their families.

10. Certify services that are paid for by the Department.
11. Establish a procedure for investigation and resolution of complaints regarding the availability, quality and responsiveness of services provided.

In specifically defining its administrative responsibilities, the DDS has sought to reduce the overall administrative expenditures incurred in delivering HCBS. It points with pride to an overall reduction of 26% in the proportion of total expenditures for persons with DD that are incurred as administrative expenditures (from 11.7% to 8.6%). It notes that the primary factor in this accomplishment was the limited growth in administrative expenditures as total service expenditures grew by 90%. State officials and local agency directors point specifically to successful efforts on the part of agencies to control administrative expenditures, including 3 separate agencies that created an entity to consolidate and manage their individual business functions.

In carrying the programmatic and administrative responsibilities of HCBS, DDS depends on a highly decentralized network of non-profit regional entities with which it contracts for major administrative roles. It maintains a relatively small central office staff (even for a small state). A substantial majority of the state employees are engaged in implementing the HCBS program and its goals in roles that fall into one of two categories: 1) Guardianship Service Specialists (GSS) and 2) Community Alternatives Specialists (CAS). In addition to their specific roles, team leaders of the GSS and CAS cadres are also part of the DDS leadership team, bringing street level realities to the weekly administrative meetings.

Guardianship Services. In Vermont 21 Guardianship Services Specialists (GSS) are assigned to approximately 550 individuals who are under court-ordered protective services. The majority of the individuals under public guardianship are adults who were once residents of the Brandon Training School and include about half of Vermont's residential service recipients. Typically the recipients of guardianship have limited involvement of family members in their lives. The role of the guardians is to assure ongoing monitoring of the well-being of individuals including personal home visits at least monthly. Guardians participate in the development of individual support plans, advocate for needed services, address issues related to quality of life and assure that the rights granted in the DD Act of 1996 are respected by the individuals and agencies providing services. These rights include that people will 1) be

free from aversive procedures and treatments; 2) have their right to privacy, dignity, confidentiality and humane care; 3) to be able to associate with people of both genders; 4) to have privacy in and access to one's primary mode and language of communication; and, 5) to be free of retaliation for exercised rights.

Conversations with service providers, guardians and state personnel working at the community level indicated that there is considerable acceptance and confidence in the guardianship specialists. The relatively modest “caseloads” of 30 (although of concern for their size in Vermont) permit serious attention to the responsibilities given. Among people interviewed there was a sense that the GSS were strongly committed, knowledgeable and demanding of appropriate person-centered service provision. Their employment by the state was not generally viewed as a conflict of interest since services are provided through a network of non-profit organizations. It was further suggested that there are benefits to the guardians being state employees because of the perception (and the reality) of communication between guardians and state employees who operate more directly in regulatory areas. Of the people interviewed guardians seemed most likely to express concerns about the extent to which services were able to be developed and support providers found that could adequately meet the specific needs and desires of people and the hopes that their guardians had for them. In Vermont there is a feeling that for the approximately 550 people under public guardianship, guardians play an important role in quality assurance and service development. It was also observed that their presence within the operations of agencies influences services more broadly than for just those persons under the guardianship.

Community Alternatives Specialist (CAS). Vermont employs individuals and contracts with others to carry out the roles of Community Alternative Specialists (CAS). These individuals are divided into 2 “teams” (“Blue” and “Red”), each with a team leader. Each team shares a common role within different regions of the state assigned to it. That role entails both quality assurance review and ongoing training and technical assistance in essential areas of HCBS performance. Each team has a specialist in: a) adult services, b) services to children, c) training, d) nursing, e) employment and f) housing (a contracted position shared between the two teams). In addition to roles in various quality assurance functions, providing technical assistance to agencies and in providing state personnel training of direct support staff each CAS serves as a direct liaison between the state and one or more designated

agencies and certified service providers in Vermont. The CAS personnel have demanding roles of central importance within the system. Persons fulfilling this role seemed highly skilled, committed and were held in positive regard by members of the organizations to which they are assigned. CASs have substantial practical experience in the field broadly and within their own specialty areas. It is notable that CASs are selected for competence rather than credentials, with some members substituting extensive successful experience in service provision and applied training for college degrees in related fields.

State Program Standing Committee

Vermont's administrative rules for the DDMHS require a "State Program Standing Committee" for each of the three primary populations served by the Department of Developmental and Mental Health Services, including "developmental disabilities." With the issuance of these rules in September 1998 the previously existing Developmental Disabilities Advisory Board undertook the responsibilities of the State Program Standing Committee (SPSC) for DDS programs. The SPSC is by rule made up of a majority of persons with developmental disabilities and family members appointed by the Governor. Its functions are primarily advisory, but include: a) providing input to the Commissioner of DDMHS on the appointment and performance of the Director of DDS, b) reviewing the various sources of information on the performance of the systems of services for people with DD and providing recommendations based on that information; c) participating in the development of an annual State System of Care Plan update and triennial new System of Care Plan; d) reviewing the use of resources and service delivery within the state in relationship to the State System Plan of Care and the principles, goals and objectives articulated for services to persons with MR/RC.

State System of Care Plan

The State System of Care Plan (SSCP) is updated annually by the DDS to guide administrators on the state and regional level in the use of existing and new financial resources. The SSPC is developed by the Division with advice from the State Standing Committee guided by review of local System of Care Plans developed by regional administrative and service providing agencies and local standing committees. The SSCP development is also informed by open public forums. The System of Care Plan is rewritten every three years with annual review and updates. It provides both general rules

to govern continuity of services and to establish priorities for the development of new services and enrollment of new service providers. Among examples of general rules established in the current SSPC are that:

1. “All State Plan Medicaid Services must be explored and accessed before providing funding with a Medicaid Waiver ...,”
2. “All relevant generic and community resources are evaluated prior to using new or existing caseload (DDS) dollars for waiver services;”
3. “Payments to spouses, parents, step-parents and guardians are not allowed under the Medicaid Waiver. Payments to other family members are allowed;”
4. “The minimum age requirement for individuals paid with waiver funds is 18, unless there are extenuating circumstances....” And
5. Infrastructure costs for services such as psychiatric and facilitated communication are charged to the individuals who use these services. Costs for broader-based services such as crisis, respite beds, or the Vermont Crisis Intervention Network (VCIN) are spread overall consumers’ waivers.” The State Plan also provides non-funding recommendations for agencies regarding desired directions in Vermont’s evolution of service delivery.

The most important role of the State System of Care Plan is to establish criteria for the use of previously available and newly appropriated public funds. In fiscal year 2001, all DDMHS received an increase of over 10 million dollars or 9.5% of the previous year’s budget. Of this, 2.6 million dollars was earmarked by the Legislature as a 5.7% cost of living increase for direct support professionals. Of the new funds available for persons entering the service system, the SSPC established “caseload” priorities for: a) preventing abuse, neglect or exploitation, b) preventing mental or physical regression, c) keeping a child in the family home, d) supporting people who have lost primary support through death or illness, e) preventing homelessness, f) preventing job loss, f) preventing or ending institutional placements, g) allowing people to become independent of DDS within 2 years, and h) supporting for whom the Department has specific legal responsibility (i.e., offenders with mental retardation and PASARR referrals). Persons categorically eligible for services (based on diagnoses of mental

retardation or pervasive developmental disorder), but not meeting the caseload priorities are not served until those who do meet the priorities have been (i.e., given insufficient resources to serve all eligible people, they are placed on waiting lists of indefinite duration).

Designated Agencies

One of the most important roles in the delivery of services in Vermont is that of the “Designated Agency.” In Vermont the DDMHS/DDS is responsible for the “designation” of a non-profit agency to administer services in each of 10 geographic regions. Agencies are “designated” for a period of up to 4 years according to a process and criteria established in the State’s “Administrative Rules on Agency Designation” (effective September 1998). The role of the designated agency is to receive and manage financial resources for the individuals eligible for services in its regional catchment area and to insure that needed services are available and provided according to the state’s regulations, established principles, goals and objectives, and in congruence with the priorities in the state System of Care Plan.

The Designated Agencies in Vermont are relatively large and long-standing service providers (most are the designated agency for at least one other DDMHS target population as well). Technically the process and criteria of designating an agency as the management entity for a region and certifying agencies as service providers are separate processes. But, in addition to their service management roles, designated agencies provide direct services to the vast majority of HCBS recipients in Vermont and they are the largest service providers in their respective regions.

The procedures and criteria for agency designation are new in Vermont with the first formal “redesignation reviews” to occur shortly. Observers are positive about the implementation of formal reviews of the traditional, established service providers that were selected to operate as designated agencies. While stakeholders express a variety of opinions about the relative capacity and commitment of the different DAs to deliver on the principles, goals and objectives established for services in Vermont, there seems little expectation that the process will lead to any current DAs being replaced. But there is also a sense that in creating standards for the designated agencies for the administration of services, the state has achieved important specifications of the roles, responsibilities, organization and oversight of the DAs that can serve as a foundation to quality control and enhancement.

It was noted by two designated agency administrators that they were in favor of the process as it makes the expectations of state clearer so that administrators can feel more confident that their practices are in alignment with state expectations and standards. There seems to be substantial agreement, including among DA executives, that “designation” should not be assumed, is not deserved simply because the agency has “always been there,” and that the redesignation process was in part motivated by perceived problems in administration and/or service quality. A state-level advocate summarized the value of the designation process as follows: “There is a lot of variability between [among] designated agencies because they existed before there was any template for what they were supposed to do. There are still differences, but now they know what they are supposed to do and that someone will check to see if they are doing it.”

Roles and Responsibilities. The Designated Agencies have a number of roles and responsibilities. These include:

1. assuring consumer and family involvement through representation in management and advisory roles, monitoring of satisfaction with services, providing for participation with services, providing for participation in activities related to service quality and guaranteeing participation in individual service planning;
2. gathering and managing data that related to and measure the outcomes of services provided by or contracted by the designated agency and that account for billings and expenditures for those services;
3. assuring that a full range of services is available within the designated region including information and referral, eligibility determination, plan of care development, development of needed services and provision of services requested;
4. assessing and improving the quality of the services provided by the designated agency and its contractors, including formal quality assessment procedures, staff recruitment and training processes, and safety protections; and
5. serving as a quasi-state entity with established roles in the state management of services, including development of a “Local System of Care Plan” to inform the State System of Care

Plan, administering contracts with, “non-designated” service providers, to work with CASs and other state officials to identify system needs for new or improved services or service supports.

Organizational Management. Vermont’s Designated Agencies (DA) are traditional grassroots, non-profit community service agencies that served their current catchment areas prior to the implementation of the HCBS program. Catchment areas served include one to three counties. Most DAs were originally community mental health programs that absorbed community services for persons with DD as alternatives to institutional care were established. Today services for persons with DD constitute over half the total budgets of DAs, although not necessarily half their total clientele. As non-profit organizations DAs are governed by a Board of Directors and managed by an Executive Director. The responsibilities of the Board, in addition to those related to its non-profit role, are specified in regulations to include among other things to a) assure the DA is successful in its responsibility in developing sufficient service capacity in the region; b) oversee the DA’s commitment to assessing and improving the quality of services in the region; and c) successfully carrying out the fiscal management roles given the DA by the state. It should be noted that the Boards serve as directors of organizations that serve as a DAs for more than one population. For example, 9 of the 10 DAs for services to persons with DD also serve as DAs for adult and children’s mental health services. By state statute, Boards of Directors are required to maintain a majority membership of people eligible for services and their families. Organizations report that when they also serve as DAs for services to other populations, program functions within the organization are operationally discrete. But the fact that Boards must nonetheless attend to programs across multiple population groups led to imposition in the administrative and planning role focused specifically on developmental disabilities (see “Program Standing Committees below).

Agency Program Standing Committee. In addition to a Board of Directors DAs also have an “Agency Program Standing Committee.” Advocates and state officials involved in developing the DD Act of 1996 and the resulting regulations considered it important that evaluation and planning of regional policy and services should be guided by an administrative entity that had majority membership of persons with DD or their family members. Because DA’s are typically community organizations that serve the DA function with more than one of the DDMHS populations, obviously majority membership

of representatives of any one population is not attainable. The Agency Program Standing Committee was required in regulation to assure “majority representation” on a policy and planning committee intended to guide the administration, priorities and quality of services in each region.

The Agency Program Standing Committee is required in regulation to a) advise on program management, b) evaluate service quality and consumer complaints, c) review resource allocation, service development and operation, d) review and recommend agency policy and e) participate (with the Board of Directors) in the developmental and implementation of the Local System of Care Plan.

The role and responsibilities of the Agency Program Standing Committee and its overlap with traditional as well as regulatory Board of Director functions is a source of both confusion and concern among DA Executive Directors and certain state staff members. In some regions Standing Committees have yet to identify specific activities and roles for members. One Agency Program Standing Committee member noted, that his particular Committee has yet to have sufficient attendance at a meeting to establish a quorum whereby official decisions about such activities and roles could be undertaken. A DA executive director summarized the present situation as, “We are still figuring out what it is and how it works, but we’ve got to get it together soon to develop a three-year plan.” A state official agreed, observing that, “Standing Committees are struggling. We are currently reexamining the role of local standing committees. We have found that most have yet to make the connections with consumers and families that was expected.”

Local System Plan of Care. One of the responsibilities of the Designated Agencies is to develop a plan that identifies needs and proposes means to address gaps and inadequacies of services in the region served. These plans must be newly developed every three years, but are required to be updated annually. Areas addressed include quality and comprehensiveness of local services, local needs, gaps between needs and available services, training needs, related issues of relevance to achieving the state’s goals and objectives for services to persons with DD in the region. Copies of Local System of Care Plans are submitted to the state both to document local planning and as a means of informing the developing and updating of the State System of Care Plan. Regulations specify that local System of Care Plans must be based on information obtained from consumers, family members, guardians and other relevant private and governmental organizations in their region.

Local system of care planning remains an evolving process in Vermont. There remain questions about the specific roles of different entities in the process especially between the DA's Board of Directors and Local Steering Committee, but also with regard to other issues such as the use of the plans submitted by the independent "Specialized Service Agencies" as they bear on planning within the region they serve. Designated Agency executives also note that they are unaware of how Local System of Care Plan findings are integrated into the State System of Care Plan. Finally, after reviewing a number of systems of care plans it is not clear how and to what extent procedures have been implemented to assure that plans are "based on information obtained consumers, families and guardians and other relevant... organizations." The expectations in this regard do not seem clear given the wide range of state level interviews and questionnaires and data collection involving these groups, and given that the state requested that agency-wide consumer satisfaction surveys be suspended in favor of a statewide efforts to measure satisfaction.

It should be noted that in addition to their role as "designated agencies" the local entities serving as DAs in their region are also the primary service providers. That particular role and its relationship with the DA will be presented subsequently.

SERVICE ELIGIBILITY, PRIORITIES AND FUNDING

With the passage of Vermont's Developmental Disabilities Act of 1996, the "Division of Mental Retardation" was formally redesignated as the "Division of Developmental Services" and its target was redesignated as persons with "developmental disability." In reality, however, the interest among advocates that the members and range of disabilities of persons eligible for services be substantially altered as part of this redesignation was only partially realized due to resistance in the Governor's office to changes in operational definitions with potentially significant implications for service demand and expenditures.

Eligibility Standard. Vermont's operational definition of "developmental disability" is substantially more restrictive and condition-based than the federal government's definition of developmental disabilities (or even for that matter the condition lists typically associated with "related conditions"). Specifically in Vermont's DD Act of 1996 "developmental disability means mental retardation, autism or pervasive developmental disorder"(PDD) with onset before age 18 and resulting

in “severe deficits in adaptive behavior.” (Regulations substitute “substantial” for “severe” in the specification of required level of deficit in adaptive behavior as in accepted clinical definitions of mental retardation.) Infantile autism is by far the most common differential diagnoses under the PDD category. In the DSM III the differentiation between “infantile autism” and “pervasive developmental disorder, childhood onset” was eliminated, so that in common usage Vermont’s DDS program serves persons with mental retardation and autism (albeit with the slightly broader categorization autistic features subsumed under PDD). Although the prevalence of PDD is lower than that of mental retardation, as in other states, Vermont’s identified prevalence of PDD has been increasing steadily, and as a result the expansion of eligibility to people with PDD in 1997 presented Vermont with greater than anticipated demand for service. The state has committed a substantial share of its recent funding increases to meeting the needs of people entering the system because of the PDD target group expansion with earmarked dollars, although by most estimates a substantial majority of persons meeting the criteria of PDD also meet the diagnostic criteria of mental retardation.

“Regulations Implementing the Developmental Disabilities Act of 1996” issued in July 1998 specify separate criteria for establishing a diagnostic determination of conditions constituting “developmental disabilities” for young children and for school age children/adults. These criteria include diagnosis by licensed psychologists or psychiatrists whether qualifying by mental retardation or PDD. School age children and adults must also be determined to have adaptive behavior limitations two or more standard deviations below a normalative sample of age peers.

Absence of Entitlement. The DD Act of 1996 was clear that Vermont “does not provide an entitlement to services” based solely on eligibility. It explains that, “The law does not guarantee support or services to all people who want or need them. Resources are limited to the funding provided each year by the Legislature. Each year the System of Care Plan will describe what funding and services will get state support.” Although each regional Designated Agency maintains a waiting list of people determined to be eligible for and desirous of HCBS services, unless individuals meet the specific caseload priorities established in the State System of Care Plan access to services will be denied. It should be that state Medicaid plan services, targeted case management and information and referral services are generally available to persons who meet HCBS eligibility, but not funding priorities. In

addition to their role in HCBS, the DAs typically serve as coordinator of these services (e.g., personal care for children) and as a source of connection, advice, planning and monitoring of changing individual circumstances and system priorities that may make people eligible for HCBS.

Caseload Priorities. As identified in the current State System of Care Plan (effective for FY 2001) the HCBS-eligible people who will receive priority for new resource allocations (i.e., the people who will be permitted to enter the HCBS program) are:

- adults for whom HCBS can prevent abuse, neglect or exploitation or jeopardy of health and/or safety
- children or adults for whom HCBS can prevent mental or physical regression
- children for whom HCBS can prevent an out-of-home placement
- adults for whom HCBS can prevent homelessness
- adults who have experienced death or loss of primary caregivers
- young adults aging out of Social and Rehabilitation who need ongoing services
- individuals who need assistance to maintain a job
- children or adults for whom HCBS can prevent or end institutionalization in psychiatric, nursing or out-of-state residential facilities
- adults for whom HCBS can yield a move to independence or minimal support from DDS-financed services within two years
- adults who are committed to the custody of the DDMHS Commissioner under the state's commitment statute for offenders with mental retardation
- children and adults who need services as required in OBRA's 87 nursing facility reforms

Each year DDS goes through the process of reassessing priorities as it updates the State System of Care Plan. Designated Agencies are also responsible for monitoring changes in priorities to assure that people currently on waiting lists, but who may be included in new priorities are provided access to HCBS.

The priority setting mechanism is intended to insure that within the foundation “given,” the prior authorization of total spending by the Legislature, rational and objective decisions can be made about which HCBS eligible persons will and which will not be served. One state advocate observed, “This is a crisis system. People don’t get in because they are eligible or because they need help. They get in when something bad will happen to them if they don’t get in.” In this regard the site visit team could not help being impressed with the number of adults they met during the visit who showed the remarkable effects of high quality, committed support through HCBS (and who were presumably chosen because they exemplified those remarkable effects), who would not have had access to those services if they needed to reapply under the eligibility standards and caseload priorities that currently exist.

Funding Approach

Virtually all funding for HCBS (i.e., community services) in Vermont is managed within capped annual budgets provided to Designated Agencies for the purposes of providing services to persons with DD within the regions for which they are responsible (and to a much smaller extent 4 Specialized Service Agencies which existed prior to the creation of regulations governing DAs). The base amount available for serving “current caseload” is based on the previous year allocation plus any designated adjustments, including notably for FY 2001 a 5.7% cost of living increase designated by the Legislature to go primarily to the individuals providing direct support. In addition to the adjusted funding for existing HCBS recipients, the state provides additional funding for persons recommended for entry into the program by DAs based on eligibility for HCBS, meeting of current priorities and the insufficiency of Medicaid state plan or other support systems to offer the needed types and/or levels of support.

The actual funding allocated by the state for new service recipients is added to the existing budget of the Designated Agency. The amount provided is determined by the estimated cost of providing the needed services through the development and pricing of an individual draft budget. The draft budgets are approved at the Designated Agency level by a local funding committee that is made up of agency staff and management, and depending on the DA, sometimes family members and outside community members. The draft budgets for individuals are then translated into one of 10 flat rates (i.e., the one closest to the draft budget amount) that range from \$7,191 per year to \$71,376 per year. In

necessary circumstances higher rates are based on unique individual needs. These rates are then added to the overall budgets of the DAs for the provision and/or purchase of service.

Individual budgets are used to establish rates, and annually service providers are allocated a capped level of funding equal to the total of all individual budgets for their service recipients. At least once each year, Designated Agencies review all individual budgets in comparison to the periodic needs assessment and make changes in the budget based on changes in individual needs. Based on this assessment some individual budgets increased from the previous year, and some decreased. The Designated Agencies (DA) also have the flexibility during the fiscal year to make adjustments to the budgets, in consultation with the individual families and guardians affected as changes occur. The state has maintained this as an expectation within the State System of Care Plan with local management of funding so that all current resources are used for the increased needs of existing service recipients, prior to accessing new caseload funds. The state requires that each DA and SSA submit a revised HCBS waiver spreadsheet monthly, outlining changes to individual budgets. The state then approves corresponding changes to the billing rates. State and DA officials consider this approach to offer beneficial flexibility in the use of resources to purchase of services and supports.

This approach is not without questions however. There are questions raised about whether there is consistency in the budgets developed by the local budget committees of DAs region to region. Some members have requested that the state association of service provider organizations identify ways that this issue could be studied. There were also concerns articulated about whether the local budget committees are relatively more generous in drafting budgets for people who are to be served by the DA than they are for persons who are to be served by non-DA agencies or by people who which to self-manage their services. One non-DA agency director observed that she feels there is considerable “tension” around the budget setting process and that for her “an objective rate determination process” (involving objective assessment of people’s skills and needs in physical, functional, behavioral and health areas and their circumstances with respect to available support and other needs)... “would really be appealing.”

SERVICE PROVIDERS AND SERVICES

One of the most salient characteristics of the Vermont service system is its regionalization of service delivery resources and responsibilities. Most services in Vermont are provided by service “arms” of the organizations that also serve as designated agencies, including their “developmental home” contractors. A small number of other agencies also serve people with DD in Vermont. In all there are 16 certified HCBS (community service) providers in Vermont. Ten of the organizations also serve as DAs, 4 are recognized as “Specialized Service Agencies” (which operate with direct state funding) and 2 are certified agencies from which DAs purchase services for members of their “caseload.” Each of these agencies must be certified as a service provider to provide DDS-financial services.

Certified Service Providers

The Developmental Disabilities Act of 1996 required that the DDMHS services establish standards and processes for the certification of different programs of support provided by agencies receiving funding through the state’s HCBS program. The certification of services is a process different from the “designation” of an agency as the quasi-public administrative entity for a region of Vermont. All designated agencies are, however, certified as service providers for persons with DD and in each region and the state as a whole are by far the primary providers of HCBS.

One or more certifications are available to agencies in the areas of: 1) homes supports, 2) community/social supports, 3) work supports, 4) support coordination, 5) family support and 6) crisis support.

Certifications are issued for periods of one to three years. Longer certifications are provided to agencies viewed as outstanding in their achievement of certification standards and responsiveness to the correction of deficiencies and attention to recommendations. Probationary certifications can be given to new providers or to agencies viewed as falling substantially short of certification criteria. Decertification is also provided should agencies show inadequate attention to standards or insufficient efforts to make expected improvements. Decertification is also a possibility if agencies knowingly endanger people’s health or safety, violate their rights or engage in fallacious financial or other reporting. (The content of the annual review is described under Quality Assurance.)

Designated Agencies as Service Providers. As noted in addition to their quasi-public management of resources allocated for services in their respective regions, the designated agencies (under the official DA name or another name given the service program) are the primary service providers in Vermont. For the most part in this role they operate in a traditional manner established before the development of the HCBS program.

Among the responsibilities of the DA is to assist people in understanding options available to them, including their choices of service providers. The DA must also assure that at least one service provider (including itself) is available to provide services needed by each individual receiving services in the region. Because often DAs are both the unit responsible for explaining to people their options and choices and an agency with substantial interest in the choice, there is expressed concern about the independence of the information people receive and the support they receive to make non-traditional demands. Also because the DA is often the only certified provider for an individual service or total service “package” in parts of Vermont, the extent to which sufficient choice can be said to exist is also questioned. In parts of Vermont where only one agency exists, choice was often expressed as something different than choice of provider. It is often thought of as choice from among the different staff and developmental home contractors within the service boundary of the only available agency. Under these circumstances it was not surprising to find advocates who felt that “monopoly by providers is a major challenge.” The challenge was most often expressed as a lack of incentive to be responsive to changing times in general or to individual desires. One advocate explained that “the system is still controlled by agencies founded a long time ago on an “expert model.” It’s hard to promote change among agencies that have never thought that way or they have no need to think differently. Another respondent noted that “sometimes people feel fear of retaliation if they are criticized since there really is no where else to go and if there was, the DA decides who would talk with you.”

Contracted services. In addition to services provided by their own staff, DA’s also contract services. In fact, most residential services in Vermont are services that are contracted independent “developmental home” providers. Contracted service providers are not themselves certified but operate under the certification and associated rules of the certified entity. By contracting with independent

residential service providers outside the agency, the DA is able to offer some level of choice in their direct service providers.

Specialized Service Agencies. In addition to the 10 Designated Agencies that also function as service providers, Vermont has 4 additional agencies that have been given the status of Specialized Services Agency (SSA). SSAs are agencies that can be designated as such either because of its specific services or because they pre-dated the shift to the designated agencies as regional administrative entities. SSAs retain autonomy from the DA entity with the funding and oversight coming directly from the DDS. Like the service providing components of the DAs the SSAs must also be certified.

Other Certified Agencies. Vermont has two certified agencies that are neither DAs or SSA. The independent service providers receive their clientele and their funding in contracts from the DAs. It is an expressed interest of certain state officials and advocates that the number of non-DA certified agencies will grow in Vermont to offer greater choice and variety in the types and quality of available service. There is, however, concern that for these new agencies to develop, DAs must support them through purchase of service. There are advocates who doubt that all DAs will willingly nurture their own competition.

Self-Determination/Self Advocacy

Consumer/Family Service Management. In addition to agency delivered and contracted services, Vermonters also have an option of recruiting their own support providers and managing their own services and budgets. To assist in that process an Intermediary Service Organization (ISO) has been available to support individuals/families selecting the option since July 1999. Information sessions/training has been provided around the state to inform service recipients of the option. In Vermont “self-directed service options” appear to be imbedded in a comprehensive focus on self-determination that also includes a) promoting, training and support of self-advocacy, b) increasing consumer understanding and active engagement in service planning and development of “Individual Support Agreements” (ISA) and c) promotion of a culture of self-determination in publications and presentations for consumers and in goals and objectives for agency reviews. In interviews service users described a number of activities that were added to their lives as a result of being encouraged to use the

ISA as a process to make their life the way they wanted it (e.g., by replacing a diet with a membership in a health club).

Vermont Peer Support Network.

Vermont has made both a philosophical and financial commitment to increasing self-determination through both individual and collective empowerment. Activities have been supported by a Robert Wood Johnson Self-Determination Project Grant but have extended beyond the specific project with support of consumer empowerment evident in other state and local initiatives. Advocates and family members were very supportive of efforts to better inform parents and consumers of their options and encouraged continued development of them. As one advocate observed, “Agencies do have different incentives than families when it comes to changing the way things are done. I don’t mean to be critical of providers, but it is important to be realistic. Providers have good reasons not to stress the self-determination options.” Although not technically a service, the Vermont Peer Support Network is a partially state funded and state supported program to promote a culture of self-determination and consumer involvement in the evolution of services in Vermont. The state DDS, advocacy organizations, service providers and others have made a substantial commitment to building an organized self-advocacy movement in Vermont. The statewide Vermont Peer Support Network is a key component of this initiative. By the relative standards of other states it has a remarkable number of members, equal to about one-sixth of all DDS service recipients. Its program includes a grants program for local development and individual opportunity, quarterly ITV meetings, statewide meeting, leadership development and organized commitment to political advocacy on behalf of persons with disabilities and issues of importance to them. Throughout the state, state officials, advocates, service providers and others noted the important roles that self-advocates played in the previous legislative session advocating on behalf of direct support personnel and the needs to make a supplemental budgetary commitment to achieve needed cost of living increments in their pay. Self-advocates spoke with awareness and pride of their role and success.

HCBS Services

As noted previously, the state office of the Division of Developmental Disabilities maintains responsibilities for overall system design, service and definitions and establishment and maintenance of

quality standards and monitoring. In establishing service categories to be included in its HCBS program (which other than state-funded family cash subsidies, two community ICFs-MR and limited state Medicaid plan services constitute all state services for persons with DD), Vermont has received approval for a remarkably streamlined set of three HCBS services. These include: 1) service coordination, 2) flexible supports (habilitation) and 3) work supports.

Service Coordination. Service coordination is defined as a support that assists individuals and families in gaining access to needed services irrespective of their funding source and that monitors the ongoing provision of services in the persons plan of care. In Vermont service coordinators usually work within the same agency that provides the residential, day and/or family supports received by the individual. There are, of course, critics of a system in which most people receive all services, including service coordination from the same agency. They note the lack of exposure to other systems or services when coordinating is “inside” the organization (Limited Version). But the site visit team also heard stories of remarkable levels of dedication on the part of service coordinators to assist people through difficult periods of their life and also of major organizational efforts on behalf of people that were motivated by the efforts and commitments of individual service coordinators.

Given the organization of service coordination in Vermont it is hard to imagine that there are not proponents of increased independence of service coordination. Proponents of independent service coordination note that there is growing interest, but little development in this area. But proponents also recognize that the integrated, agency-based role affords people with one of the lowest consumer-to-service coordinator ratios in the United States (about 12:1), and the flexibility for service coordinators to fill necessary roles in people’s lives (from substitute respite care provider to counselor), and the integration to advocate within the agency on behalf of the individual. It is also observed that by having service coordinators integrated into large agencies serving multiple populations, service coordinators often have access to mental health services or services for aging individuals that would be much harder for independent service coordinators to access. Vermont also has a targeted case management program for people not meeting the state’s priorities for HCBS. In June 1999 there were 38 HCBS eligible, but non-priority (waiting list) recipients of targeted case management.

Flexible Supports. Flexible supports is a broad service category approved by HCFA in 1998 to encompass a wide range of possible supports for HCBS recipients, including personal support in the home and community, transportation, therapies, crisis services, environmental modifications and equipment and any other support other than service coordination and supported employment included in the individuals plan of care. Flexible supports are provided through certified agencies with certification in areas including: 1) home supports, 2) community/social supports, 3) work supports, 4) support coordination, 5) family supports, and 6) crisis support. Within these general certification categories a number of service models are available to individuals.

HCBS residential supports. Under its HCBS flexible supports, Vermont provides a range of highly individualized residential options that make Vermont's ratio of service recipients to residential service setting the lowest of all states. In June 30, 1999 Vermont had 1.2 residential service recipients (excluding people living within their families' homes) per setting. Looking at residential providers with 19 or more recipients, this ranged from a low of 1.06 to a high of 1.34 people per home.

Developmental homes (DH) are the primary service "model" for Vermont's residential supports. Developmental homes began as a pilot program in 1984 to provide homes for children who were living at the Brandon Training School (the state's former institution for people with mental retardation). DHs have since grown in number steadily to the point at which almost three-quarters (73%) of residential service recipients are served in DHs today, with the vast majority of residents now being adults. Developmental homes are homes in which people typically live in a pre-existing household in which they receive the support they need. Some "developmental homes" are companion arrangements where people with disabilities live with roommates able to provide the needed support, often in the home rented or owned by the person with a disability. Developmental homes are viewed as "foster homes" for tax purposes so that a major benefit of the model is that reimbursements of "difficulty of care" payments are treated as tax-free incomes substantially increasing the value of the payment to individual providers. Another benefit is the greater stability in care providers than is evident in staffed programs. Observers noted that residents benefit from the social networks of the individuals and families with whom they live, although some observers noted that people sometimes have a hard time creating their

own networks for friends and activities as they are absorbed into the social lives and routines of the families with whom they live.

Supervised residences. Supervised residences are the second most common residential support financed by HCBS. Supervise residences are designed for people who need assistance with activities, but do not need full-time staff support. Because support is limited, costs of HCBS provided to persons living in supervised residences cost on average only about \$12,600 per year.

Group homes. Vermont has about 80 people in group homes. Typically group homes belong to agencies and provide full-time staffing. Group homes in Vermont average less than 5 residents each and cost about \$50,000 per year.

Staffed residences. Staffed residences are specialized settings for one or two individuals needing intensive supervision and specialized support. Only 19 people (in 13 homes) receive this specialized support at an average cost of just over \$70,000 per year.

Family Support

Also included under flexible supports are support services (other than service coordination and supported employment) provided to people in their family home. In June 1999, 274 people were receiving HCBS funded supports in their family home, 61% of whom (166) were children and youth under 22 years. Family support services include both in-home support and respite care options. In addition to the HCBS funded family supports about 550 families (over 80% with children as the eligible individual) received Vermont's family cash subsidy ("Flexible Family Funding") in amounts that were typically \$1,122 per year, but in some cases as much as \$3,000. In addition to the cash payments family subsidy recipients are connected to DAs to help them meet other needs they may have.

Crisis Support

The Vermont Crisis Intervention Network (VCIN) was established in 1991 as part of Vermont's plan to end institutional services. The VCIN provides training, assessment, consultation, emergency support and short-term crisis residential support. The VCIN was intended to eliminate the need for an institutional "safety net" to respond to particularly difficult patterns or episodes of challenging behavior that had previously been relegated to the Brandon Training School and Vermont State

Hospital. Since the creation of VCIN in 1991 not only was Brandon State School Closed, but the number of “patient days” for persons served by Division of Developmental Services programs has decreased from an average of about 3,000 per year to an average of 66 in 1998 and 1999.

The VCIN is obviously not solely responsibility for such success. Observers view these changes a result of a number of interacting factors including increased focus on crisis prevention through skill development within regions, development of regional crisis capacity, stronger commitments by providers to supporting individuals in their communities, reduction in congregate care placements, and stronger focus and skills in arranging with individuals, satisfying living arrangements. In some areas of the state it was reported that the reach of VCIN was quite limited.

The VCIN is funded through HCBS as a managed insurance policy, that is, the service is paid for prospectively at a single per recipient cost and is available on an as needed basis to any HCBS recipient. For the fee, agencies and recipients have access to three levels of service. Level I or Clinical Network focuses on developing the skills of lead staff in the various agencies to respond to behavioral and psychological challenges they presently face or may anticipate. Level II or On-Site Consultation brings VCIN staff or consultants to a specific agency to respond to general or specific problems. Level II focuses on both skill development among agency staff and plan development for specific individuals and/or organizational needs. It can include psychiatric as well as psychological consultation. Level III or Crisis Residential Services are intended as a last resort option. When determined that individuals need to leave their home for a safe setting for evaluation and treatment of a behavioral or psychiatric crisis the VCIN provides such a placement. To reduce pressure of VCIN staff to solve problems through admitting people to a crisis home, staff of the Vermont DDS actually control admissions to crisis beds. Despite substantial growth in the number of people eligible for VCIN Services through DDS/HCBS eligibility, the number of Level III placements and placement days has decreased steadily since the closure of Brandon Training School. In 1993 there were 15 individuals who required a total of 816 days of Level III services as compared with 12 individuals requiring 255 days of Level III service in 1999. Fiscal year 2000, however, has seen substantially more activity. In 1993 there were 44 Level II on-site consultations as compared with 63 in 1999.

Staffing and Staff Development

Recruitment and Retention. Service providers in Vermont observe that they are facing the most serious general problem in staffing community services in their experience. As one agency director noted, “Staffing is still going down hill and we are operating in a crisis mode.” Directors from other agencies shared the sentiment, but also sympathy for those in the workforce.

- “Staffing is our big issue. People do very hard work and sometimes don’t feel a lot of support.”
- “Everybody seems to be having great difficulty hiring new staff. We are fortunate that our turnover rate is relatively low.”

A number of factors contribute to the problem in recruiting and retaining direct support workers. First, as one direct support provider noted, “The pay scale is the real problem. I feel valued and listened to. It’s just hard to get by [on the pay].” A cost of living adjustment of 5.7% to the budgets of DAs and SSAs in FY 2001 primarily to increase direct support worker compensation was significant, but with statewide unemployment at about 2% administrators expect the challenges to continue.

Agency directors note that the crisis in recruitment is causing them to focus greater attention on the staff they already have. One Executive Director observed that such a focus was long overdue: “our staff have a lot of sensitivity, people depend on them and they would be very hard to replace.” Another said that her agency is reexamining its relationship with direct support staff: “We are trying to connect people with the agency so that they feel part of it and appreciated by it.”

Agency administrators also note becoming much more attentive to the importance of effective recruitment. Individual agencies note that for the first time they are beginning to identify their most productive sources of recruitment. Others note that because old methods are insufficient to address the growing challenge, they have turned to new approaches. For example, one reported success in moving from print media to radio and website. Agency strategic plans attend to a wide range of issues and responses; including building a human resource capacity in areas of professional development; employee assistance and training; developing recognition programs; using creative scheduling to increase the number of full-time benefit-eligible positions; increasing alternative benefits such as tuition credits and child care; position sharing with school districts; and developing merit pay approaches.

The challenges of recruiting and retaining support staff appear also to be affecting developmental home providers. Two of the interviewed home-based service providers noted growing difficulty in finding respite care for themselves and complain that their DAs do not appreciate the effects this lack of support has on developmental home providers and their ability to sustain themselves in the role. One begged that some of the state's cost savings derived from developmental homes be invested in assistance in recruiting, training and assisting with the growing costs of paying for respite care.

Training. Vermont requires “pre-service” and “introductory” in-service for all support personnel. Pre-service training is required before staff begin to work directly with individuals and covers basic issues of principles, rights, confidentiality, prohibited and restricted procedures, abuse and neglect. This training provides general orientation to the role of direct support, the relationship with individuals being supported and to the values, mission and expectations of the individual agency with which they are working. Pre-service orientation is often done on an individual one-to-one basis because of the necessity of completing it before working with consumers.

“Introductory training” provides a more comprehensive overview of the service system and the roles, responsibilities and skills required of support staff in it. Training topics include a system overview, considerations of a “quality life,” understanding behavior, teaching functional skills, health and safety monitoring and promotion. The state has developed a manual to guide the training and state CAS trainers are available to provide the training over the course of about 5 weeks. The training must be completed within 6 months of employment.

In addition to the specified training modules for new staff, Vermont DDS develops and disseminates a directory of training events of relevance among Vermont disability and other community agencies, as well as outside the state. Training topics addressed in the in-state training of July and August and September of 2000 included job coaching, sexuality, communication strategies, sexual abuse and sex offenders, crisis intervention and prevention. The extent to which organizations tap this training resource is dependent on the accessibility, relevancy of training topic to providers, training costs, and associated costs of sending staff to off-site training. The state maintains a “state training pool” for this specialized training that may go beyond the regular training budgets of agencies, though this does not seem to meet the needs of all providers.

Some agency administrators and case managers observed that training events conducted or sponsored by the state or conducted by other organizations and promoted by the state were reported to not adequately to meet the needs of the provider organizations their staff and developmental home providers. They observed that the topics of available training seemed to be driven by the training opportunities made available by other community organizations and by public interest in “trendy” therapies and practices than by systematically identified needs of the direct support providers and/or provider organizations. Administrators also noted that often times the same topics are presented each year and as a result, direct support staff and case managers who have worked in the field for a number of years and who might be most likely to benefit from specialized training can “outgrow” the training the state provides. In addition, material presented is not specific enough to the needs of the service providers and their staff members. They observed the information presented in the available training is often interesting and informative, but “competency-based” view of the direct support or case manager role, and seldom has a follow-up component that allows opportunity to practice the application of skills to the workplace. Higher skill level training for longer-tenured direct support staff and case managers seems like an important component of staff retention, and an area in which additional attention by the state might yield benefits improvement as identified earlier in this report.

Vermont has purposely developed a training system that is not highly structured and regulated in order to maintain flexibility and allow support to be provided in a way that is most meaningful. This approach avoids irrelevant, cumbersome and duplicative training requirements. On the other hand, the effectiveness of such an approach depends on a rich selection of opportunities so that service providers can find and use training opportunities that meet their specific needs. These opportunities are not viewed as widely available as desired. Furthermore, case managers note that in their responsibility to assure that developmental home providers receive the training and support they need, they find it difficult to find training on the breadth of topics they need to train and support the developmental home providers and the diverse needs of their residents. Obviously, maintaining a system that is flexible and not highly bureaucratic while still being demanding, responsive and comprehensive enough to assure that the training needs of direct support staff and developmental home providers are being met is a substantial but important challenge for Vermont.

QUALITY ASSURANCE

A primary function of the CAS teams is to evaluate annually the performance of service provider agencies according to Vermont's "Guidelines for Quality Services." The Guidelines are built around 10 "goals and outcomes" which define the quality of services expected, the activities of the monitoring system and the areas in which agencies will be asked to attend to improve the quantity and quality of services.

Goals and Objectives

The goals and sample outcomes from Vermont's Guidelines for Quality Service include the following:

Goal 1: People...are treated with respect and dignity.

- Environments and services allow for personal privacy
- Services and environments are respectful of individual differences and are physically, culturally and linguistically accessible

Goal 2: People are supported in their own families,...homes, ... neighborhoods and communities

- People have a sense of belonging, inclusion and membership in their communities
- No people are admitted to institutional settings in or out of state

Goal 3: People and their families and guardians have opportunities to make meaningful choices...

- People and their families participate in the development of services
- People make choices regarding their daily lives and future planning

Goal 4: Services foster the development of personal relationships

- Opportunities are presented and support is provided for people to develop and maintain relationships outside the home.

Goal 5: Services support people in regular jobs and/or activities of their choice

- Employment is actively pursued for people who want jobs

Goal 6: Services foster the development of practical life skills

- Skills are taught which benefit the individual promote independence, interdependence and offer personal challenges

Goal 7: Services are supported and managed in a manner which ensures fiscal stability of the system

- Generic services and resources are not duplicated
- Annual fiscal audits support stable financial management

Goal 8: Services...enhance varying abilities of people to communicate and are responsive to their needs

- People have access to the necessary technologies to enhance their communication

- People with whom the person communicates most frequently have the ability to understand, interpret and respond using the modality chosen by the person

Goal 9: People providing services are properly trained to perform their work competently

- People providing services demonstrate their ability to perform their job...

Goal 10: The health and safety of people are valued and promoted

- People live in homes which meet applicable standards for fire safety and accessibility
- People receive medical and dental services in a manner consistent with those available to all community members

In the annual agency reviews the CAS review team focuses on services of a sample of recipients, ranging from about 20% in the larger agencies to greater proportions (up to 50%) in smaller agencies. Members of these samples are controlled so as to include the people newly served by the agency since the last review or who are receiving new services from it, as well as people for whom there is a record of concern or special interest. Other sample members up to the established number of selection are chosen randomly from lists of service recipients.

Structure of the Review

In all, there are 39 objectives after specifying achievement in the 10 global areas. Reviewing achievement of each objective by the sample members in its final report the CAS provides a summary table that contains the percentage of sample members who a) “exceeded the outcome” b) “met the outcomes” and c) “did not meet the outcome.” The report also identifies with respect to these findings a) “examples of positive practices,” b) “recommendations,” and c) “necessary changes.”

Reviews include brief file reviews for all sample members and about 20% of these reviews include a detailed assessment of the quality of documentation and accuracy of records. All reviews evaluate the extent to which services and activities contained in the individual plan of care (or program plan) are carried out. Each of the sample members receiving residential and vocational/day services are visited at their service sites. Attention to and achievement of the goals and outcomes of the “Guidelines

for Quality Services” is monitored through interviews with service recipients, family guardians, support staff and other involved individuals and through direct observations of the individual HCBS recipients.

In addition to quality of life services monitoring, specific attention is provided by the team and particularly its member nurse, to the agency’s adherence to the detailed specifications of the Division’s Medical Guidelines for HCBS recipients living in staffed residential settings and developmental homes. These guidelines cover rules for incident reporting, immunization, physical and dental health and exam results, medication prescriptions, histories and efforts and other medically relevant physical, mental and dental health information.

Vermont’s Quality Assurance System is very demanding on service providers, but almost all provider agency leaders also described it as very thorough. Agency reviews were also commonly described as “very comprehensive” and “intensive.” For the larger agencies, reviews last about 2 weeks. The director of one such agency wondered why if CARF could accredit the agency after 3 days, the state team needed two weeks. Still, provider agency administrators acknowledge the efforts on the part of state staff and Department officials to make the review process a collegial process attending to widely valued goals and outcomes. Opinions are expressed however, that the agency process when combined with required “standing committee” reviews, satisfaction surveys, and other required reviews “can be a bit much.”

Immediately following the site visits, an exit interview is conducted with agencies to identify topics and causes that were particularly notable to the review team. These are discussed with agency administrators to lay the foundation for a report or review funding that describes agency performance with respect to the goals and objectives of the “Guidelines” and required actions on the part of the agency in response. Service providers note the importance of the exit interview process and its structuring of a discussion between review team members and the agency about areas of priority action to improve the agencies services.

Based on the agreed areas of focus, the agency then provides the state with a) a plan of correction for immediate necessary changes, and b) a plan for improvement to address each of priority areas identified in the review. Ongoing reports of progress on each priority area improvement plan are

submitted to and monitored by the CAS teams. As part of the improvement plan the agency can include technical assistance and training from the CAS team.

Other Areas of Quality Assessment

In addition to annual CAS reviews using the Guidelines for Quality Services, there are a number of other quality assessment and review activities in Vermont.

Satisfaction surveys. Each year for the past 4 years Vermont has implemented a satisfaction interview with a quarter of adult HCBS recipients. In 1998 and 1999 it also mailed to families of persons receiving HCBS a Family Satisfaction Questionnaire. The consumer interview satisfaction survey was carried out by teams organized by staff of the University of Vermont, specifically including team members with disabilities. The mailed family questionnaire was carried out by Division staff.

The Consumer Satisfaction Interviews were carried out with persons determined to be able to self-respond reliably with or without visual response aids. No proxy respondents were used. For the most part the quarter of HCBS interviewed in the summer of 1999 reported general satisfaction with their lives. For example, 82% reported being “happy” with where they lived and 16% said they wanted to live somewhere else. However, in areas of choice and individual control, only 53% indicated that they felt they had complete or some choice in where they lived, while 47% reported they felt they had no choice.

In addition to providing state summaries of each annual survey, the survey results are broken down by individual agency. Agencies report that they could use assistance in understanding how to use the satisfaction survey results. One problem in interpretation they note is that with the exception of only a few items, their sample in any one-year provides too few negative responses to individual items to be useful in planning. Second, those persons who do provide negative responses cannot be identified because of anonymity so that they find themselves with one person who seems unhappy about something, but they do not know who or why. Finally, they note because only a quarter of service recipients who are able to respond for themselves are surveyed each year, for smaller agencies the sample sizes are often too small to be useful (e.g., 4 total respondents). One agency director summed up the experience saying: “We were pleased with the results, but don’t know how accurate or useful the

results are for us.” The DDS has decided to take a one year hiatus on the consumer satisfaction interviews while it considers the potential future uses of the survey and ways it may contribute to the quality of services and lives of service recipients within the context of other information gathering efforts.

The family Satisfaction mail survey asks family members of people with developmental disabilities living with them to rate questions on a 5 point rating scale, with opportunities for open-ended responses. In 1999, the survey was mailed to 957 families, with 523 responses (58%). The majority of respondents (65%) reported they were satisfied overall with the services and supports currently received by their family member, while 26% said they were sometimes satisfied with services overall. Over 50% reported supports are available when their family needs them, with 35% saying supports are sometimes available, and 12% saying supports are not available when needed. A majority of people (53%) indicated emergency or crisis supports had not been, or only sometimes been, provided right away when requested. Respondents indicated they choose staff who worked with them (38%) or sometimes had been able to do so (25%). One out of five respondents found frequent changes in staff to be a problem for their family, with it being sometimes a problem for another 32%.

A majority (52%) of respondents also indicated that they had “no” or only “sometimes” had control or input over hiring and managing staff. Despite the limited choice families overwhelmingly indicated “yes” that staff respect their choices and opinions (77%) and are generally respectful, courteous and knowledgeable (86%).

As with the consumer interviews, there is a sense from providers that help is needed in understanding how to use the family surveys. The Division might, for example, discern that there is a need to work on providing families with choice of service providers or support staff, yet agencies themselves say they feel uncertain what the data means and how to use the information from the surveys.

Incident reports and reporting. Vermont requires both internal and external reporting of “critical incidents” and provides a standard form for such reports. Documentation is required for a) medical incidents (hospitalizations, medication errors, “significant injuries” and the use of medications for behavior control), b) restrictive procedures (use of restraints; seclusion locked doors; medications), and c) crucial incidents (deaths and major injuries); alleged or suspected criminal acts, abuse, neglect and

exploitation by or against service recipients; missing persons; losses from intentional or destruction of property).

Medical incidents must be reported internally and reviewed according to an internal agency review plan for such incidents. Restrictive procedures are defined in Vermont as “actions which intrude into an individual’s autonomy in ways which adult Vermonters would generally find unacceptable or against the law...Our goal is to eliminate altogether the need for restrictive procedures...[but] certain restrictive procedures are permitted in extraordinary circumstances where the stakes are high (most commonly where personal safety is at risk) and where non-restrictive responses have failed. Restrictive procedures may not be used for the purpose of training or changing behavior.” When restrictive procedures are used in response to an emergency circumstance, reporting is required to both the individual’s guardian and to agency administration. Use of restrictive procedures more than once in a month requires review by the individual’s Individual Program Planning (IPP) team to identify appropriate alternative responses and/or environments.

Vermont specifically prohibits corporal punishment, non-emergency, non-temporary seclusion and isolation, psychological or verbal abuse, restrictions of contact with others for the purpose of controlling/changing behavior, denial or limitations on basic physical or health needs, and withholding personal resources. While less severe restrictions are permitted on a “time limited basis in rare instances in the presence of documented evidence that less intrusive attempts to control behavior have failed, such procedures may be used in a planned program of “Restrictive Procedures for Addressing Safety.” The use of non-prohibited procedures (i.e., mechanical, chemical physical restraints, emergency seclusion, locked exits and other non-prohibited restrictions and emergency procedures) is allowed when necessary to protect an individual if approved by the individual or guardian, the individual’s team and an agency’s “Professional Review Committee based on a individual functional assessment of the target behavior(s), full description of the procedure to be used, its purpose, means of assessing benefit, plan for decreased or discontinued use and procedures for ongoing monitoring of individual safety. Planned uses of restrictive interventions must also be reviewed by Human Rights Committees made up of persons with disabilities, family members and professionals familiar with non-aversive behavioral procedures. These committees review planned procedures for the quality and necessity of the

procedures and their monitoring and make periodic reports to the Division regarding the use of restrictive procedures and recommended policy and training.

By law known, suspected or reported incidents of abuse, neglect and exploitation must be formally reported to the Department of Aging and Disabilities in Vermont within two days occurrence. The Department is required to investigate such reports and to issue findings of substantiated or unsubstantiated. Substantiated findings may be pursued in criminal proceedings, but at a minimum findings are provided to the employing agency if any and entered into a state registry of substantiated reports that potential employers can access when screening potential employees.

Vermont's pre-service training curriculum provides substantial attention to the topics of preventing and recognizing abuse and neglect, abuse reporting requirements, individual rights and prohibitions and requirements around restrictive procedures.

Other monitoring activities. In addition to the above, Vermont requires reviews of residential and day service settings for safety and accessibility compliance. Residential settings are reviewed prior to people moving in. Day service settings are reviewed annually, with separate reviews conducted of supported employment projects. The state also conducts annual fiscal audits of contracted agencies for all Medicaid services.

CHALLENGES FOR VERMONT

Vermont like all states faces significant challenges as it maintains and expands its programs of service for persons with developmental disabilities (DD). At the same time Vermont is in the position of having successfully accomplished much of what most states have left to address, especially in terms of closing larger institutions and reducing the use of community congregate care. Vermont's Developmental Disabilities Act of 1996 lays a remarkable foundation of principles, goals and objectives for its programs of service. The administrative requirements and procedures that have been derived from the Act, which have been in effect for only two years have broad acceptance, but their implementation is still in a developmental stage. They do, however, offer much promise to guide a program of service that will continue the inclusion and empowerment of Vermonters with DD.

At the local level, organizations are struggling with the requirements and expectations of the requirements being implemented. This was especially notable in the expectations for Agency Standing Committees. Agencies voiced desire for assistance in clarifying and implementing the roles, structure and operation of these committees for and their role vis-à-vis the responsibilities of the agencies' Boards of Directors. There were concerns about access to the financial and staff resources needed to support the voluntary activities of the committees which are made up primarily of persons with DD and family members. This concern was raised in light of recent efforts to reduce the amounts of agency budgets dedicated to non-service operations and the potential for inefficiency in overlapping or redundant expectations for Standing Committees and Boards of Directors. There is substantial interest at the local level in receiving guidance and training and entering into discussions and renegotiations about ways to efficiently and productively design and implement a role for Standing Committees.

Vermont has developed a comprehensive, multi-faceted and generally well regarded approach to quality assurance. Integration of the Community Alternative Specialists into quality monitoring, technical assistance, staff training and agency liaison roles, and the selection of effective and experienced people for those roles, is a notable accomplishment. It contributes to Vermont's ability to integrate quality assurance and quality improvement into a single "program" in a way that is rare in most states. There is, however, a sense among service providers of growing and sometimes redundant burden of a growing number of requirements related to quality assessments. There appears to be interest in an assessment of the various designation, certification and accreditation reviews and the different consumer satisfaction interviews, family surveys, standing committee data collection, etc. being conducted at both the agency and state level and how these can be integrated into a coordinated, efficient program of quality monitoring and improvement.

As in other states there is considerable concern about economic pressures of Vermont's program of services for persons with DD. Resources to recruit and retain direct support staff is a challenge expressed throughout the state. But people throughout the state also speak with enthusiasm of how concerted lobbying by service users, family members, advocates and agencies brought substantial attention and legislative attention to the needs of direct support staff (and a 5.7% cost-of-living funding increase for FY 2001).

Challenges in staff recruitment, training and retention will be ongoing. But people throughout Vermont expressed a desire to make these not simply challenges to be faced independently by each agency, but the focus of a concerted statewide initiative. Goals of such would include more effective recruitment of people into the pool of potential workers and ongoing focus on retention through concentration on wages and other forms of compensation, public recognition of staff, a unified curriculum to allow portable training across agencies and other initiatives to make direct support work more attractive, rewarding and valued. Concerns about resources extend beyond the needs to provide stable support for people presently being served. There is great concern about the limited access to services, the need to create priorities and the fate of people who are eligible for service, but do not meet the state's priorities.

Choice is an ongoing challenge in Vermont. Much of the challenge derives from community agencies that have traditionally been responsible for defined catchment areas. The challenge of nurturing choice would appear to be to balance the value of Vermont's existing grassroots community organizations with the rights and potential benefits of people to know and exercise options. Vermont has made a commitment to creating a culture of self-determination through its Self-Determination Project and its support of the Vermont Peer Support Network. It has opportunities to continue this commitment through expanded efforts to disseminate information about the options available to people, continuing to support self-management of services, supporting the development of independent service coordination, nurturing the development of new service providers and other such initiatives. Offering new options to expand choice would not diminish the importance, contributions or success of Vermont's grassroots community service agencies; it would simply recognize that no one organization can ever be what everyone wants and needs.

SUMMARY

Vermont operates a system of services for persons with DD that is totally comprised of community services. It closed its state institution of persons with DD in 1993 and has steadily reduced its use of all congregate care settings. Today its largest residential settings are its last 2 ICF's – MR, each with 6 residents.

By almost any quantitative standard, Vermont is a national leader in the development of community services. Its average of 1.2 people per residential setting, its rapid and continuing development of supported employment, its high ranking in relative financial commitment to spending for family and community support, all show Vermont to be consistently among the 5 most community-oriented service systems in the U.S., and together make it the national leader. Such statistics do not surprise Vermonters. They monitor and take pride in both the haste and the extent of their efforts to make community life a reality for all state residents with DD.

Vermont's services system is governed by state law and rules that are based on a foundation of clear principles, goals and objectives that recognize the rights of persons with DD and families to live lives of dignity in the community, to participate in one's neighborhood, to enjoy family and friends, to be healthy and safe and free from fear, abuse, neglect and exploitation and to exercise control over their own lives and services. At times Vermont's service system and the organizations which are called on to implement such ideas struggle with the demands such ideals place on them. But the commitment to these ideas and to evidence of them in the lives of people with DD prevails throughout the state. It seems in many ways that what has been accomplished in Vermont is easier and more natural given the state's traditional orientation to community, equality and individual rights, and perhaps it is. But seeing these accomplishments makes them seem no less exceptional.

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