

## **Chapter 2: Service Gaps by Program and Consumer Perspectives**

In each service area where a site visit was conducted by PHPG a number of agency staff, as well as consumers and family members, identified several gaps in terms of available and/or accessible services. In some cases a service may actually be technically “available” through the agency, but cannot be “accessed” by a given individual due to funding limitations and/or their not meeting the funding priority for the program. Similarly, in meetings with various groups and in the public forums held in September, participants raised issues related to the range of services available in their communities and the needs that sometimes go unmet. Some individuals indicated they had moved to another area of the State where more services were available.

The community-based system of services provided through the Designated and Specialized Service Agencies is designed to reduce the need for more costly inpatient and residential services that require much more in the way of “bricks and mortar” and 24-hour staffing. As more and more care has been shifted to the community-based system, other institutional systems have shrunk (Vermont State Hospital), closed (Brandon Training School), or have not had to expand or be newly created. It is always difficult to quantify avoided costs and no attempt is made in this report to do so; however, in general there is consensus among providers and policymakers alike that, on a per person served basis, community-based care is less expensive overall than care provided in an institutional or congregate living facility.

Many of the gaps in services, where they exist, are reported by the Designated Agencies as being primarily the result of a lack of funding to develop or expand services. However, some services (such as child and adolescent psychiatry) are impacted by a general shortage of providers and exacerbated by the relatively low rates of reimbursement provided by the state. The shortage of psychiatrists who will accept Medicaid is an issue in a number of states.

The service gaps identified across the five major program areas are briefly described below. Readers of this report may also refer to the Local and State System of Care plans for more detail on the service needs of the major population groups.

### **Developmental Services**

In general, consumers expressed general dissatisfaction that only roughly 25 percent of those who are eligible for developmental services are actually receiving services, with the remaining three-quarters of those in need not being served because they do not meet the program’s funding priorities. There is the perception that the funding priorities are becoming increasingly restrictive as the budget constraints become more severe. Following are the highlights of the service gaps identified within the developmental services program.

Respite Services – There is a significant need for additional respite providers. This service was identified as being particularly critical for aging caregivers who are struggling to continue to care for their adult children at home. Currently in Vermont 22

percent of developmentally disabled persons live with unpaid caregivers (usually parents) who are age 60 years or older.

“June Graduates” – Services for individuals graduating from the state’s special education programs are not adequate in all areas, particularly employment and supportive services. Developmentally disabled adults emerging from the state’s special education system need continuing services if they are going to remain active participants in community life. For many this includes job training and employment opportunities. It also includes activities within the community that replace those lost when school-based activities are no longer accessible. The High School Graduate Fund includes funding to serve approximately 19 individuals, but the number of graduates is significantly greater (approximately 75 in FY2004). When targeted graduate funding is insufficient for individuals who otherwise meet the funding priorities for developmental services, New Caseload funds or the Equity Fund can be accessed. However, these funds are limited as well.

Transition Planning – Many aging parents need prospective assistance in planning for the transition that must occur when they are no longer able to care for their developmentally disabled adult children. These parents need information on resources and the alternatives available and assistance in preparing for the transfer of caregiver responsibilities.

There are also some concerns about the ability of the DAs to continue to recruit and maintain adequate numbers of developmental homes and shared living providers and to replace those who are exiting the system as time goes by. Some of the former Brandon Training School employees who became home-based providers after the school’s closure are beginning to withdraw from the program as they become older and are no longer able to provide appropriate assistance to these clients. Like the aging parent issue, the loss of these providers will place increased demands on the system in the coming decade.

### **Adult Mental Health Services (Outpatient and CRT)**

State and federal expenditures through the DAs for adult outpatient mental health services are relatively low (\$3.2 million in FY2004), although they have grown during the period between FY1998 and FY2004. However, with expenses increasing, the DAs have actually reduced the total number of clients served by approximately 1.6 percent during this time period.

On the other hand, expenditures for the CRT program, which serves the seriously mentally ill, have increased significantly during the period from FY1998 to FY2004.<sup>10</sup> By 2004 state expenditures for the CRT program reached \$29.2 million. The level of increases also reflect an expansion in the intensity of services required by some individuals in the CRT population, including clients who may pose a risk to public safety. This includes people being discharged from the Vermont State Hospital and the Department of Corrections. However, not all of these individuals meet the criteria for the CRT program but do require outpatient mental health services and/or treatment for substance abuse. This in turn increases the pressure on the DAs to provide more of those

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<sup>10</sup> A portion of the cost increase for CRT includes some funds shifted from emergency services to the CRT budget.

services or to increase the intensity of services. There was also almost no growth in the CRT caseload (less than one-third of one percent) between FY1998 and FY2004.

Total DA state-funded revenues for adult mental health services increased an average of five percent per year from FY1998 to FY2004. During that time the Consumer Price Index (CPI) hovered around 2.5 percent, so roughly half of the increase was consumed by general inflationary effects. However, the total dollar increase for mental health services was largely allocated to the CRT program. Consumers and staff members from the DAs reported some erosion in available services and limited resources in several areas:

Outpatient Services – There has been erosion in this area due to funding constraints, and some adults who need outpatient mental health services cannot be served by the Designated Agencies.

Residential Services – There are limited resources for individuals who need to transition from the Vermont State Hospital to independent living arrangements. The agencies must prioritize clients for these services, sometimes substituting more in-home supports for the seriously mentally ill population served through the CRT program.

Partial Hospitalization – This resource is not currently available in all areas of the state.

The provision of mental health services also impacts other state program costs, among them the cost of the correctional system. An analysis conducted by DDMHS as a part of its Mental Health Performance Indicator Project shows a direct correlation between the utilization of mental health services and incarceration rates in the states. Of the 14 states included in the study, Vermont had the highest mental health utilization rate and the lowest incarceration rate (See Figure 5.22 in Chapter 5). At the opposite end of the spectrum was the State of Texas, with the lowest utilization of mental health services and highest rate of incarceration.

## **Children's Services**

Revenues to the Designated Agencies for children's mental health services have increased significantly since FY1998, rising from \$27.8 million to \$70 million in FY2004. Much of this growth was comprised of new federal matching funds for services financed by Medicaid and purchased through other state agencies, including the school districts and the child welfare departments within AHS. Caseload increased by more than 40 percent over the seven year period. By 2004, the average DA expenses per client served were approximately \$6,750, including the services provided through the schools. However, even with significant growth in total expenditures for children's services, parents and caregivers reported some service gaps. In particular, parents and staff focused on the impact of the mid-year reductions made to the initial appropriation for children's services in FY2001. Economic and budget issues during that time resulted in a reduction in the level of funding originally provided for in the FY2001 appropriation from the legislature.

Following are the primary service gaps identified by DA staff and parents:

Respite Services – Families with children with serious emotional disturbances often need some respite care to avoid a crisis situation which could result in the need for an out-of-home placement for their child. These services are not always available.

Wraparound Services – Targeted case management and other waiver services are not available to all families who need them. Personal care services provided through the Medicaid and SCHIP program to eligible and enrolled children are not as comprehensive as waiver services, but funding limitations have capped enrollment in waiver programs.

Individual Counseling – DA staff and consumers tend to believe that individual counseling is the most effective model for families and children, but the agencies struggle to provide individual therapy services in lieu of group therapy due to the increased cost.

Child and Adolescent Psychiatry – The availability of psychiatrists who specialize in the treatment of children and adolescents is limited in some areas. Even where providers are located in the community they are often unwilling to provide services for the reimbursement rates available through public funds.

## **Substance Abuse Treatment**

In general Vermont has historically spent more on substance abuse treatment than most other states. A comprehensive study conducted by the National Association of State Alcohol/Drug Abuse Directors includes state level expenditure data for fiscal year 1999. Vermont ranked seventh highest among the 46 states providing data. That year, Vermont spent \$19.93 per capita for substance abuse services, versus a national average of \$16.32.

Spending for substance abuse treatment through the DA system does not represent the entirety of state spending for these services, but it comprises a significant proportion of the total. In FY2004 the State of Vermont expended \$3.85 million within the DA system for substance abuse treatment (state and federal.) This is a moderate increase over the level expended just six years ago (approximately 4.7% per year increase between 1998 and 2004). However, consumers and providers continue to identify a number of gaps in the array of treatment options available and accessible in the state. Part of the issue is that substance abuse treatment is not a service the DAs are mandated to provide. Accordingly, there is great variability within the state with respect to the availability of services. Identified service gaps include:

Residential Treatment – There is a shortage of residential treatment options, both short and long term, for persons with addiction problems.

Outpatient Services – There is sometimes a waiting list to get into a treatment program, which is particularly problematic for those referred by the judicial/correctional system.

Educational/Rehabilitation Programs – Consumers expressed a need for assistance in understanding how to “clean up the wreckage” many experience as a result of their addictions (e.g., bad credit, homelessness, child in foster care system, unemployed, etc).

Halfway Houses/Sober Houses – Consumers also expressed a need for housing options where drug and alcohol use is prohibited.

Methadone Maintenance – There are not an adequate number of geographically dispersed methadone providers available to persons with opiate addictions.

Alternatives to Methadone – There is not adequate access in all regions of the state to an alternative to Methadone – Buprenorphine (BUP).

Adolescent Programs – There are no residential substance abuse treatment programs specifically geared to adolescents in the state.

### **Emergency/Crisis Services**

The issues related to provision of emergency and crisis response services are primarily tied to a reduction in funding. Since 1998 Emergency and Crisis Intervention funding has declined by 10.5 percent. Some of those funds were transferred to the CRT program, which provides emergency services to its enrolled population. By FY2004 expenditures for emergency and crisis services for non-CRT clients had fallen to \$1.4 million (state and federal.) That amount is not deemed adequate to maintain a comprehensive mobile emergency response system as required by the State. Since 1998 the DAs report cumulative losses of \$5.7 million in providing emergency services.

Consumers who are in need of services, but are not receiving services for whatever reason, are prone to crises that require an emergent response. In general, the DA staff feel that the need for emergency response could be lessened by more proactive treatment of those with mental health and/or substance abuse problems.

### **Other**

A general gap in services that affects many program areas is psychiatry. While the shortage of psychiatric services may be more acute for children and adolescents, adult services are also in short supply. The relatively low level of reimbursement available through publicly funded programs has contributed significantly to the shortage of psychiatrists. Other factors were identified as isolation and risk. In addition, the public nature of the DAs system and its funding mechanisms (which are unique within the health care system) makes the integration of its services with the rest of the health care community more complex.

### **Consumer Perspectives and Concerns about the Future**

In conducting this study, PHPG held a series of meetings with consumers and family members at five Designated Agencies around the state (Rutland Mental Health Services, Upper Valley Services, Clara Martin Center, United Counseling Service, and Washington County Mental Health). In addition, two public forums were held and each was well-attended by people using the services of the DAs/SSAs. Consumers of all types of

developmental and mental health and substance abuse treatment services attended. The discussion included consumer and family perspectives on:

- ✓ the range of services being used
- ✓ their satisfaction with the choices available within the DA system
- ✓ gaps in services
- ✓ needed services which are not available or are inadequate
- ✓ the effectiveness of the agencies in meeting consumer needs
- ✓ the impact of staff turnover
- ✓ their concerns about the future

In general, consumers and family members reported a high level of satisfaction with the services they are receiving through the DAs and SSAs. The regionalized, non-competitive nature of the system was not a concern among the vast majority of individuals who provided input to the study team. Most felt that the agencies worked hard to provide the best array of services possible in their communities. Where gaps exist there appeared to be an understanding of both the funding constraints the agencies are experiencing and the rising demand for services.

Many consumers and family members spoke of the critical role those services play in their lives and in their ability to maintain their independence and function as contributing members of their communities. Many of those receiving developmental services were formerly residents for some period of time at the Brandon Training School. Many of the individuals receiving mental health services have also been cared for at various times in their life at the Vermont State Hospital. The vast majority indicated their preference for a non-institutional, community-based living environment.

Consumers and family members expressed the opinion that the agencies operated efficiently, although they believed that many programs are understaffed. Many consumers indicated that the agencies were meeting a portion, if not all, of their needs. However, some consumers did identify a number of issues, including gaps in available services, impacting their ability to access the services and/or treatment they need. For example, parents with adult developmentally disabled children reported a lack of access to needed respite services. Appendix 7 to this report includes a matrix summarizing the results of the DA site visits, including those areas addressed by consumers and family members.

The major concern expressed by consumers and family members with respect to the future was the commitment of state policymakers to continue the existing model of service delivery. They greatly favor the community-based system and are concerned that budgetary constraints will lead some to conclude that Vermont cannot afford the current system. They feel that this will lead to a retrenchment in both the volume and type of services, returning them to an environment where the available alternatives are not desirable and that some needy individuals will simply do without. Many are truly concerned that the progress they have made and the quality of life they have been able to obtain will be set back, perhaps dramatically. They fear that the values that led Vermont's policymakers to adopt the Developmental Disabilities Act of 1996, along with other steps taken to create the system that exists today, will be relegated to secondary

status behind the fiscal realities of competing budget priorities. They fear that the voices of the disabled will be lost in the debate.