

# Vermont Olmstead Plan

Prepared by the  
*Vermont Olmstead Commission*

**for submission to  
Governor James Douglas  
and  
the Vermont General Assembly**

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Vermont Olmstead Legislation

Olmstead Commission Members, Ad Hoc Members, and Staff

## Preface

Vermont's Olmstead Commission is a group of individuals representing consumers, family members, state government, advocacy organizations, and providers, created by the Vermont Legislature in 2002 in response to the United States Supreme Court ruling in *Olmstead v. L.C.*, June 1999. In that case, the Court was asked by two women from Georgia who had spent years in institutions whether the anti-discrimination provision in the Americans with Disabilities Act of 1990 (ADA) requires a state to discharge people with disabilities to community settings once their treatment providers determine community placement is appropriate.<sup>1</sup>

The Court's answer was a qualified "yes". The Court ruled that "undue institutionalization qualifies as discrimination "by reason of...disability", and that the ADA requires community placement when:

- The "State's treatment professionals have determined that community placement is appropriate," and
- The community placement is not "opposed by the affected individual," and
- The "placement can be reasonably accommodated taking into account the resources available to the State and the needs of others with mental disabilities."<sup>2</sup>

The Court found that a state has a responsibility to maintain a range of facilities and administer services with an even hand. The Court suggested that one way states could comply with this ruling would be to have a "comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace...".

On February 1, 2001 President Bush announced the creation of The New Freedom Initiative followed by an Executive Order on June 18, 2001. The order instructed the Federal Government to assist States and localities to swiftly implement the Olmstead decision. The Order asked the U.S. Attorney General, the Secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the Commissioner of the Social Security Administration to "provide technical assistance and work cooperatively with States to achieve the goals of Title II of the ADA, particularly

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<sup>1</sup> The Americans with Disabilities Act (ADA) found at 42 U.S.C. §§ 12101 et seq. 42 U.S.C. subchapter II Public Services § 12132 states "no qualified individual with a disability shall, by reason of such disability, be excluded from participating in, or be denied the benefits of, a public entity's services, programs, or activities." One of the regulations implementing this provision of the ADA is known as the "integration regulation" and is found at 28 CFR § 35.130(d) it requires "public entities (to) administer...programs...in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

<sup>2</sup> *Olmstead v. L.C.*, 527 U.S. 581 (1999)

where States have chosen to develop comprehensive, effectively working plans to provide services to qualified individuals with disabilities in the most integrated settings.”

Vermont, like forty-two other states and the District of Columbia, created an Olmstead-related commission or task force. Many, but not all, are developing or have developed comprehensive plans.<sup>3</sup> Appendix A contains the legislation that created the Vermont Olmstead Commission. The statute requires the commission membership to include: three members appointed by the secretary of human services; a member selected by the commissioner of the department of education; a member selected by the secretary of transportation, four members appointed by the governor from a list of individuals recommended by the Vermont Center for Independent Living (VCIL); a member selected by the commissioner of the department of corrections; the executive director of the state housing authority or his designee; and two nongovernmental provider members appointed by the governor from a list supplied by the secretary of human services.<sup>4</sup> The statute instructs this commission to develop a comprehensive plan by undertaking the following activities:

- To meet, gather testimony from consumers, advocates, providers, other state advisory bodies, and interested others, and hold public hearings to identify barriers that prevent people with disabilities from living in the most integrated settings;
- Determine whether any existing state or federal administrative policies, rules, and organizational structures constitute barriers that prevent people with disabilities from living in the most integrated settings;
- Examine the current allocation of resources and identify what additional resources are needed to ensure that Vermont’s comprehensive plan is effective.
- Propose to the general assembly, in consultation with the secretary of human services, a long-term financial plan supporting implementation of the comprehensive plan that includes anticipated revenues and expenditures, and any other information needed to insure financial sustainability.

To show compliance with the Olmstead decision and potentially avoid legal ramifications, most states have developed very specific Olmstead Plans that identify the resources and timeframes needed to move individuals from institutions. This was also the genesis behind the fourth directive of the Vermont Olmstead legislation. However, as is noted by the first two sections of the Vermont legislation (See Appendix A), Vermont has been a national leader in enabling people to live in settings they prefer and ensure they are not confined unnecessarily in institutional settings. Because of this, the Vermont legislation broadened the focus of the Olmstead Commission beyond those residing in institutions to include all people with disabilities and elders who are at

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<sup>3</sup> Folkemer, Donna, Fox-Gage, Wendy, and Lewis, Jordan, The States’ Response to the Olmstead Decision: How are States Complying?, 2003. Prepared for the National Conference of State Legislatures.

<sup>4</sup> A list of past and current members of the Olmstead Commission can be found in Appendix B.

risk of institutionalization and, even more broadly, people at risk of not receiving services and supports in the most integrated settings. (It is important to note that for people who are deaf or hard of hearing, the term “integrated” is more accurately described as respecting and providing access to deaf culture and supporting accessible communication.)

Given the above, the approach that Vermont has taken in the development of an Olmstead Plan is largely different than other states. To meet the more expansive objectives, the Vermont Olmstead Commission examined a number of broader issues related to community integration and developed a catalogue of needs related to these areas. As such, the Vermont Olmstead Plan does not provide a long-term financial plan to reduce waiting lists for community services. Instead, the Vermont Olmstead Plan provides a tool for planning and prioritization of state resources to support its citizens with disabilities and those who are elders to have access to the same community options and opportunities afforded to all Vermonters.

To complete its work, Vermont’s multi-stakeholder Olmstead Commission has met six to seven times a year since October 2002. Commission members have conducted focus groups and public hearings; received reports and presentations from state agencies and offices and written topic briefs, all of which were analyzed by the Commission to develop this Comprehensive Plan.

## I. Introduction

In the U.S. Census, about 9.4 percent (or about 57,200 individuals) of the Vermont population were persons with disabilities aged between 21 and 64. Approximately 17 percent of Vermonters were aged 60 or more; this number is expected to grow to approximately 25 percent by 2020.

Vermont has consistently been a national leader for integrating citizens with disabilities<sup>5</sup> in their communities.<sup>6</sup> Policymakers, providers, consumers, and family members have worked hard and continue to work hard to ensure that Vermonters are not unnecessarily confined to institutions. For more than ten years Vermont has implemented policies and programs to promote consumer choice, independence and self-determination. In fact, one of the ten Outcomes of Well-being for Vermonters, as identified in state statute<sup>7</sup>, is specifically directed towards elders and people with disabilities (Outcome 9):

Outcome 1: Families, Youth, and Individuals are engaged in their community's decisions and activities

Outcome 2: Pregnant Women and Young Children Thrive

Outcome 3: Children are Ready for School

Outcome 4: Children Succeed in School

Outcome 5: Children Live in Stable Supported Families

Outcome 6: Youth Choose Healthy Behaviors

Outcome 7: Youth Successfully Transition to Adulthood

Outcome 8: Adults Lead Healthy and Productive Lives

**Outcome 9: Elders and People with Disabilities Live with Dignity and Independence in Settings They Prefer**

Outcome 10: Communities Provide Safety and Support to Families and Individuals

The legislature asked Vermont's Olmstead Commission to build on all of this work and develop a comprehensive plan that specifically takes into account the following core populations and gaps:

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<sup>5</sup> The term "disability" in this report will have the same definition given to it in the ADA and its implementing regulations. The ADA definition of 'disability' is an individual who has "(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (c) being regarded as having such an impairment." (42 U.S.C. § 12102). "The phrase physical or mental impairment includes but is not limited to ...orthopedic, visual, speech and hearing impairments, cerebral palsy, epilepsy, muscular dystrophy, multiple sclerosis, cancer, heart disease, diabetes, mental retardation, emotional illness, specific learning disabilities, HIV disease, tuberculosis, drug addiction, and alcoholism...The phrase major life activities means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working." (28 CFR § 35.104.)

<sup>6</sup> For people who are deaf or hard of hearing, the term "integrated" may be more accurately described as "communicatively accessible."

<sup>7</sup> Language was initially established in 1998 by Act 47, Sec. 100a. It was then codified in 2001 as 3 V.S.A. § 3026.

Core Vermont Olmstead Populations in 3 V.S.A § 3096	Number Served by State-Funded Programs on July 1, 2005	Number Waiting for Community-based Services on July 1, 2005 (A) =Actual (E) = Estimated
<p>People with developmental disabilities living in nursing homes, group homes, and intermediate care facilities for persons with mental retardation (ICF/MRs).</p> <p><i>(Note: both the federal and state definition of institution does not include small group living e.g., group homes)</i></p>	<p>Nursing Facilities = 27 ICF/MR = 6 Group Homes = 76</p> <p><i>Note: these are individuals known to the DS system, and does not include other people whose services are paid from other sources.</i></p>	<p>Waiting list = 0</p>
<p>Elders and others with physical or cognitive disabilities living in nursing homes and residential care homes.</p> <p>Elders</p> <p>Younger adults with physical or cognitive disabilities</p>	<p>Elders ( 65+) = 2,928 Others (Under 65) = 220</p> <p><i>Note: Nursing home residents have to meet Nursing Facility Level of Care Guidelines to be clinically eligible.</i></p>	<p>Waiting list = 0</p> <p><i>Elders and younger adults with physical disabilities in Nursing Facilities are provided community services if they want them and meet Medicaid LTC financial eligibility.</i></p>
<p>Persons (all ages) with psychiatric disabilities confined to institutions or at risk of institutionalization or involuntary treatment.</p> <p>In institutions</p> <p>At risk of institutionalization or involuntary treatment</p>	<p>Approx. 25 people aged 18+ at VSH over 90 days</p> <p>44 youth aged 17 committed for emergency exam in '05</p> <p>324 people admitted to Designated Hospitals on involuntary emergency exam status in '05</p>	<p>7 people at VSH are awaiting community placement in supervised (sub-acute) residential; the VSH Futures plan for sub-acute capacity development will address this need.</p>
<p>Persons (all ages) with psychiatric or developmental disabilities at risk of placement in correctional facilities.</p> <p>Psychiatric disabilities</p> <p>Developmental disabilities</p>	<p>Average of 29 patients at VSH on forensic legal status, some of whom have psychiatric disabilities and are at risk</p> <p>8–10 people with DD at risk of incarceration or in jail (e)</p>	<p>Number not available</p>
<p>Other persons with disabilities who are at risk of not receiving services or supports in the most integrated settings (The Olmstead Commission has identified the following populations under this category):</p> <p>Children in state-placed residential schools</p> <p>Children under 18 with developmental disabilities who are not in one of the other categories</p> <p>People with developmental disabilities who have aging caregivers</p> <p>People with traumatic brain injuries (TBI)</p> <p>People who are deaf or hard of hearing who also have another disability</p> <p>Elders and people with physical disabilities at risk of institutionalization</p>	<p>Number not available</p> <p>208</p> <p>252 (e)</p> <p>TBI Waiver = 51 91 (e)</p> <p>Home Based (HB) Waiver = 1092 Enhanced Residential Care (ERC) Waiver = 169 Attendant Services Program (ASP) = 300</p>	<p>Number not available</p> <p>Waiting list = 72 (e)</p> <p>Waiting list= 0</p> <p>Waiting list = 6 (a) Waiting list = 0</p> <p>HB Waiver Waiting list = 92 ERC Aged and Disabled Waiver Waiting list = 48 ASP Waiting list = 61</p>



## **The Olmstead Commission's Activities**

Many of the members of Vermont's Olmstead Commission are leaders in our state's efforts at community integration and providing real choices for Vermonters with disabilities. The Commission composed its vision statement to reflect their goals and values as well as the goals of the ADA and the Olmstead decision.

### ***Vision Statement***

*Affirming that all Vermonters have the right to live, learn and work in the most integrated setting of their choice, it is our vision that people with disabilities and their families have access to the same community options and opportunities afforded to all Vermonters.*

The work of the Commission was guided by both the knowledge of Commission members and by the disability policy framework prepared by Robert (Bobby) Silverstein, Director of the Center for the Study and Advancement of Disability Policy (CSADP) in Washington, D.C.<sup>8</sup> Based on these foundations, the Commission agreed that the goals of disability policy must be:

- Equality of opportunity and full access to services in the most integrated settings
- Full participation
- Independent living, and
- Economic self-sufficiency.

The Commission identified the following areas that impact the lives of all people with disabilities and their ability to be full participants in their communities:<sup>9</sup>

- Information, Referral and Assistance
- Housing
- Transportation
- Healthcare
- Employment
- Education and Learning
- Family Supports
- The Legal System and Protections
- Voting and Citizenship

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<sup>8</sup> Silverstein, Robert, *Using the Emerging Disability Policy Framework to Craft a Comprehensive Effectively Working Olmstead Plan*. Center for the Study and Advancement of Disability Policy (CSADP).

<sup>9</sup> Commission members wrote Topic Briefs for most of these areas, which informed the contents of this Plan. These Briefs delineated the current laws, policies, regulations, funding sources and services that advance the goals of disability policy, the Olmstead decision and the ADA; whether there are laws, policies, and regulations that present barriers to these goals; and waiting lists for these programs and services and how the lists are maintained.

The Commission also identified the following specific service systems dedicated to people with particular types of disabilities that also needed to be a focus of the Plan:

- Services for people with Mental Health Disorders
- Services for people with Developmental Disabilities
- Services for Elders and People with Physical Disabilities

Chapter III of this Plan provides a description of each of these topics, as well as Challenges related to community integration for each of these areas.

A major part of the Commission's work was to gather the stories, experiences, and recommendations from people with disabilities, their families, and their providers and caregivers. The commission accomplished this through five statewide public hearings; focus groups designed for individuals unlikely to attend a public hearing; and by inviting written testimony. These stories are essential to the Commission, and Vermont state government, in order to understand how the current system is experienced by those it is designed to assist. Making changes to the system that will really improve lives and promote independence will succeed only if the voices of people with disabilities, their family members, and providers are heard.

This Plan provides highlights of the testimony from the public; describes the current status of Vermont's institutions and community-based services, including information from the topic briefs; identifies challenges to full community integration and the fiscal and non-fiscal implications associated with these challenges.

## **Context of the Olmstead Plan**

### ***Medicaid Crisis***

Medicare and Medicaid are essential health insurance programs for individuals with disabilities. However, economic downturns have led both employers and government programs to reduce their costs through expanded use of premiums and co-pays and by offering more limited benefit coverage for health care and disability related services. For example, Tennessee recently chose to eliminate community Medicaid coverage for respirator dependent individuals, (and for 300,000 other individuals, particularly those with high health care costs due to disability or illnesses like cancer). Other states have taken similar actions over the past year, representing a threatening national trend against coverage of disability service - one Vermont is doing everything it can to avoid. For individuals with disabilities who depend on public or private insurance for things like medical devices such as wheelchairs, medical supplies, hearing aids, and pharmacy coverage, the reduction of state and employer costs often represents greater out of pocket expenses or going without needed services.

Vermont has done more than many states to increase access to medical care and supports for people with disabilities through Medicaid. The state of Vermont has been a national leader in making affordable health coverage available to low income children and adults. Vermont was among the first states to expand health coverage for children and pregnant women, through implementation of the state-funded ***Dr. Dynasaur program*** in 1989. The Dr. Dynasaur program subsequently became part of the state-

federal Medicaid program in 1992. In 1995, Vermont implemented a section 1115a Demonstration waiver program known as the **Vermont Health Access Plan (VHAP)**. The program's primary goal was to expand access to comprehensive health coverage for uninsured adults with household incomes below 150 percent of FPL (later raised to 185 percent) through enrollment in managed care. VHAP also included a prescription drug benefit for low-income Medicare beneficiaries who did not otherwise qualify for Medicaid. When the federal government introduced the **State Children's Health Insurance Program (SCHIP)** in 1997, Vermont took full advantage by extending coverage to uninsured and underinsured children living in households with incomes up to 300 percent of the Federal Poverty Level (FPL).

As such, Vermont has made enormous progress over the past fifteen years in reducing the number of **uninsured** in the state. Vermont's average uninsurance rate is second lowest in the nation. In State Fiscal Year 2004, approximately 36,000 persons were enrolled in the VHAP managed care and prescription benefit programs and another 95,000 were traditional Medicaid beneficiaries. Today nearly one-in-four Vermonters receive some coverage through the public Medicaid health insurance program.

The state also is implementing a new **Vermont pharmacy program** to provide wraparound coverage to those affected by the new Medicare Part D Pharmacy Program. Given that approximately 2/3 of individuals with disabilities take three or more prescriptions a day, this new wraparound significantly enhances the affordability of pharmacy benefits for many Vermonters. The legislature also has put together a study committee to look at restoring Medicaid coverage for eyeglasses and dentures, key needs for individuals with disabilities.

Under Federal Medicaid law there are a range of services that are available to adults and children eligible for Medicaid. Some of these services are mandatory and all states participating in the Medicaid program must provide these services to all Medicaid eligible individuals. In addition to the mandatory services, there are 23 optional services. Each state can choose to offer one or more of the optional services to adult beneficiaries. However, with respect to children, all of the optional services covered in the Federal law, must be made available to children under 21 if that service is "medically necessary." This is referred to as the **Early Periodic Screening, Evaluation, and Planning and Treatment (EPSDT) program**. The EPSDT program is designed to provide children with periodic early identification and treatment of the acute and long term health care conditions. Among the optional services are personal care services, skilled nursing services, rehabilitation and case management services. These services are extremely important to children and young adults with disabilities.

Vermont has been very aggressive in pursuing and receiving federal **Medicaid Waivers** to assist people with disabilities to remain in their homes and communities and avoid institutional care. Vermont currently has federal waivers for adults with severe and persistent mental illnesses (CRT) program), children with severe emotional disturbances, elders and people with disabilities who need personal care services and supports, people with traumatic brain disorders and people with developmental disabilities. In addition, a new Long-term Care 1115 Demonstration Waiver began on October 1, 2005 (see section on Services for Elders and People with Disabilities).

Vermont's achievements in providing broad access to health care and disability supports have been substantial, but they are now being **jeopardized** by the ever escalating cost of health care and pharmacy costs, changes in the rates of matching funds by the federal government for this program, and dependence on state revenue sources that do not grow at the rate of medical inflation. The Vermont Medicaid program today faces the prospect of large and deepening annual deficits. Without program changes in fiscal year 2006, the state share of the Medicaid deficit will be approximately \$60 million and the cumulative deficit over the upcoming five fiscal years, if unaddressed, will be approximately \$370 million.<sup>10</sup> Given that many of the services and supports available for people with disabilities rely on Medicaid funding, this crisis may have a dramatic impact on their well-being.

To help address this Medicaid crisis, as of October 1 Vermont entered into a new five year comprehensive 1115 federal Medicaid demonstration waiver called **Global Commitment to Health**. The goals of the Global Commitment to Health waiver are to provide the state with financial and programmatic flexibility to help Vermont maintain, and possibly extend, its broad public health care coverage.

This waiver includes all Medicaid services in the state, with the exception of the new Long-term Care Demonstration Waiver, SCHIP and Disproportionate Share payments to hospitals. The Global Commitment to Health Waiver does include all other traditional Medicaid services, the existing VHAP programs, and all other waivers mentioned above. This waiver caps overall federal contributions for these services over the next five years and, in return, provides program flexibility to enable the state to restructure the Medicaid program and address future needs in a holistic, global manner.

Under the Global Commitment to Health waiver, the Office of Vermont Health Access (OVHA), the state's Medicaid organization, is now a public Managed Care Organization (MCO), which can invest any savings in preventive services that are currently state funded. This will enable Vermont to bring in an estimated \$150 million in new federal funds without the need for new state funds – thereby reducing the projected five year deficit. However, the restriction in federal contribution also means that the state must manage under a growth trend, and continued deficits and any downturn in the state economy could affect the state's capacity to maintain current benefits.

The waiver also provides the state with the ability to be more flexible in the way it uses its Medicaid resources. Examples of this flexibility include utilization of creative payment mechanisms (e.g., case rates, capitation) rather than fee-for-service to pay for services not traditionally reimbursable through Medicaid (e.g., consultation for pediatricians by psychiatrists regarding mental health issues) and investment in innovative programmatic initiatives (e.g., the Chronic Care Initiative and prevention programs). It is hoped that these types of flexibilities will enable the State to implement programs and reimbursement mechanisms in the first few years of the program that will curb the health care inflation experienced within the state and thereby reduce even more of the projected five year deficit.

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<sup>10</sup> Deficit figures taken from September 30, 2005 Joint Fiscal Office memo to the Joint Fiscal Committee based on the consensus five-year Medicaid forecast with newly revised FMAP projections for FY07.

The waiver was based on the following key concepts and legislative priorities that will guide future program decisions:

- High quality health care should be accessible to all Vermonters
- The health of the state's children should be promoted through broad availability of well child services, prevention efforts and education activities
- Appropriate prescription drugs should be available at a reasonable cost
- Health care coverage for the state's most vulnerable populations, including people living in poverty and people with disabilities, should be protected
- Elders and people with disabilities should be assisted in remaining as independent as possible in their homes and communities

Advocates have expressed fears and concerns about the new waiver, given that many of the services and supports available for people with disabilities are dependent on Medicaid funding. Primary concerns include the fear that the cap on federal funding will limit the State's ability to receive federal participation if expenditures go beyond the cap; the ability of the state to make programmatic changes without federal approval; and potential cuts in optional services and populations in the future.

The federal approval of the waiver is very explicit that all mandatory populations and mandatory benefits cannot be changed under the new waiver, and, with very limited exceptions, any other changes in program eligibility or benefits will require state legislation and federal review before implementation. It is true that the Vermont legislature retains the ability to reduce eligibility or benefits if needed to address budget constraints in future years, but this is no different than the legislative authority under the Vermont Medicaid waiver in existence prior to Global Commitment. While this waiver does contain some risks for the State, the legislature approved entering into the waiver agreement because of the potential financial and programmatic benefits for Vermont.<sup>11</sup>

Even with the financial benefits of the new waiver, given the enormity of the state's predicted Medicaid budget crisis, difficult discussions and decisions will need to occur over the coming five years if Vermont is to continue to provide the broad-based health care currently offered through its Medicaid program. Without adequate access to needed health, support and preventive services, Vermonters with disabilities are less likely to experience successful employment, sustain their independence, and participate fully in society and benefit from the equal opportunity protections promised by the ADA. The social and economic costs to individuals, families and society are significant.

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<sup>11</sup> The Legislative Joint Fiscal Committee unanimously granted approval for the Global Commitment to Health Demonstration Waiver Program to begin on October 1, 2005, contingent on the following being provided by November 17, 2005: 1) a more thorough explanation of waiver provisions; 2) final information about premium rates and methodologies; 3) a list of criteria and MCO targeted health care investments; and 4) review by the Attorney General.

## ***Re-organization of the Vermont Agency of Human Services***

This Olmstead Plan also has been developed in the context of a recent re-organization of the Vermont Agency of Human Services. In July, 2004 AHS realigned its programs and established the new Department for Children and Families; new Department of Disabilities, Aging and Independent Living; and Department of Health to include Mental Health; and established the Office of Vermont Health Access as a separate entity. AHS also created a new Field Services Division within the Department for Children and Families to provide a strong agency presence in each region to focus on issues of access, service coordination, and the overall effectiveness of service delivery in the region. Through the re-organization, AHS also appointed an AHS Director for Housing and Transportation, and hired new specialists for autism; deaf and hearing-impaired services; and trauma.

As part of re-organization, AHS also adopted the following principles as standards to guide its work, which are very relevant to the work of the Olmstead Commission <sup>12</sup>

### *WHEN WE ENGAGE WITH INDIVIDUALS AND FAMILIES WE WILL...*

- ❖ *HONOR THEIR EXPERTISE and right to make choices that they know to be in their own best interest*
- ❖ *RESPECT AND ACCEPT THEIR VALUES that are based in personal preferences, cultural beliefs and life-ways*
- ❖ *SUPPORT INDIVIDUAL AND FAMILY RELATIONSHIPS that are safe, stable and long lasting*
- ❖ *FOCUS ON THE ENTIRE FAMILY as it is defined by the family*
- ❖ *PROMOTE FLEXIBLE SERVICE AND FUNDING supporting individual and family control over who, what, when, where and how supports are provided*
- ❖ *AFFIRM LIFESPAN PLANNING AND SELF-DETERMINATION that encourages decision-making and planning for independence beginning within the family when children are young, following the individual throughout their life and including aging issues*
- ❖ *ASSURE PARTNERSHIPS WHICH ACTIVELY INCLUDE INDIVIDUALS AND FAMILIES in planning, development, implementation and evaluation of policies, practices and personal programs*
- ❖ *PRACTICE OPEN COMMUNICATION promoting a clear understanding of all aspects of systems policy, procedure, practice and all other information regarding them*
- ❖ *RECOGNIZE THE IMPORTANCE OF THE COMMUNITY, where individuals and their families belong and realize their full potential*

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<sup>12</sup> The National Center for Family Support, Human Services Research Institute (HSRI) promotes these as model principles for national use; they were developed by the Oklahoma Family Council based on the University of Vermont curriculum, *Family Support, Self-Determination and Disability*.

## II. Public Hearings and Focus Groups

In the summer and fall of 2004 the Olmstead Commission conducted public hearings and focus groups across the state. Hearings were held in Springfield, Montpelier, Rutland, St. Johnsbury and Burlington. Focus groups were conducted in Montpelier, for people with disabilities unlikely to attend a public hearing; at the Vermont State Hospital, for people with mental illness currently confined to an institution; and at a Bennington nursing home, to hear directly from elders and adults with disabilities currently living in a nursing facility. Participants were given information about the commission's mandate and a handout to stimulate testimony. The handout included questions such as, "Are there services and supports that you do not have now that would help you be even more independent?" and "Are there services and supports that are lacking that make it more likely that you might need to move to a less independent housing or care situation?" Those individuals attending the hearings and others, who could not attend but submitted written testimony, provided the commission with vital information on which to base many findings and recommendations. Following is a thematic summary of their comments.

➤ ***Strict Eligibility Guidelines can leave out people with a great deal of functional Impairment***

"People fall through the cracks because they just miss qualifying for services. For example, someone can max out of SRS (and have) a 70 IQ and not get picked up by developmental services or mental health." (*case manager attending a focus group*).

"It was difficult to hook him up with services once he turned 18. He wanted to work but could never find a job. We don't serve adults and adolescents in the same program but if it's not working in child/adolescent services anymore there's no place to go." (*Mother, who is a psychiatric nurse, talking about the gap between children and adult services they encountered once their son, with schizophrenia, turned 18.*)

"Deaf folks often don't fit into DD/MH criteria for services and yet definitely need case managers especially regarding finances, parenting support, and domestic violence (education)." (*A man, who is deaf and visually impaired.*)

"There are all these agencies whose intent is to support people but because of a diagnosis you're not eligible for a lot." (*Woman whose son has athetoid palsy, a disability that results in numerous physical and medical problems but does not cause him to have any intellectual impairment.*)

"One very big concern several parents have is the almost total lack of services for high IQ/low functioning adults. Also there seems to be no community support for these individuals. What are these adults doing?" (*Written testimony from a woman living with a child with autism and founder of a parent support group.*)

➤ ***Access to Information regarding Supports and Services is hard to find and is not integrated***

“As a disabled person I’ve found that if you don’t know the right questions to ask you don’t get any answers.” (*A man with multiple disabilities at a public hearing.*)

“There isn’t one place that you can go to get all the information and to find out about your rights, it is very fractured. Things are out there for the elderly and the handicapped and yet no one knows about it, so what good is it?” (*A resident at the Crescent Manor Nursing Home.*)

“There are a lot of agencies out there but none of them talk to each other so you are forced to become the expert. The state should have a 1-800 number for support services.” (*A man trying to access services for his elderly mother with multiple disabilities.*)

“My (school-age) daughter has multiple disabilities and we’ve found that the services are available but disintegrated. Acquiring knowledge of what’s available is very difficult.” (*Testimony from a father who is also a psychiatrist at a community mental health center.*)

“A one-stop shop, so to speak, would be very helpful to anyone with a disability. One place that would give you all of the available resources, with people who could explain to you how to go about filing all the necessary paperwork for resources, even integrate all the paperwork between agencies so that it would not have to be duplicated over and over again. Someone who could explain to you about Medicaid, SSI, Katie Beckett, IEP’s, respite care, residential housing, etc.” (*Written testimony from a woman living with a child with autism and founder of a parent support group.*)

➤ ***Income limits are too low: choosing to work or marry causes people to lose their benefits too quickly***

“We’re being taught to lie to survive. People avoid getting married because they fear losing stuff.” (*Woman with a traumatic brain injury at a focus group.*)

“Medicaid does not allow a person to put aside enough money to maintain a home and a handicapped accessible van. The financial box closes very quickly. I hope Olmstead can move us beyond this box.” (*A man with a significant physical disability.*)

“Threat of losing SSI/Medicaid discourages working full-time because of very low income limits. There should be some health plan for folks like this at a low cost.” (*Man with a disability at a focus group.*)

“Several of our group members don’t qualify for services due to their income level. It is not a choice that both parents work, but they do so just to keep a roof over their head and to stay above water. This also means that they are disqualified for services that are based on level of income. They cannot afford a variety of therapies and services even with 2 incomes, which ultimately hurts the child. Would it be possible to increase that income level so that more families would qualify?” (*Written testimony of woman living with a child with autism and founder of a parent support group.*)



➤ ***Personal Care Services and Respite are essential, yet extremely difficult to find and maintain***

“Vermont has a wonderful personal care program but no case management so parents must recruit, train, and supervise staff but there are no benefits, no sick leave.” (*Mother of a school-age boy with autism.*)

“I am only as good as my attendants I can combine services from multiple agencies and hire my own attendants. It works to be able to hire people myself but the snag is paying people a livable wage, \$8 an hour is not OK.” (*A man with significant physical disabilities.*)

“It is very hard to find people for respite. I find most of the qualified folks are already para-educators with these kids. Why can’t there be a central agency that maintains a pool of employees?” (*Mother of an 18-year-old son with autism, feeling pushed to get him out of the family home.*)

“Providing health and disability insurance would go a long way in attracting caregivers.” (*An attendant care-provider.*)

➤ ***Not enough has been done to change the presumption that the only option for the frail elderly is nursing home care***

“People are often railroaded into nursing homes; doctors can be very quick to recommend them. When a nursing home resident is asked what is the worst thing about living in an institution they say, ‘Control, I have no control over my life.’” (*A man who works at the Area Agency on Aging.*)

“Staying at home is best for the frail elderly if they want to and can. There is PASARR for folks with a developmental delay diagnosis to get some more services. In nursing homes this helps them get more activities and there are vans to get these folks out. Other seniors will say, ‘Take me, take me.’” (*A woman who works with seniors in nursing homes.*)

“When I was at home I had a roommate to help with bills and on other things. When she died it was hard for me. When I came here I left behind my dogs and my friends, I miss my dogs.” (*A resident at the Crescent Manor Nursing Home.*)

“I was lonely at home so I’m happy to be here around the nurses and aids. Maybe if I had company at home it would have been better.” (*A resident at the Crescent Manor Nursing Home.*)

“In the 20 years I’ve worked with seniors I’ve only seen one man, out of the scores of people I’ve worked with, actually want to go to a nursing home.” (*Another man who works at the Area Agency on Aging.*)

➤ ***Elders are worried about the future for their adult child with disabilities***

“My son is 42-years-old now and for the last 3 years his program has been good but it has been a constant fight. As parents get older it is harder to help a child remain stable financially and otherwise. As the population ages we will need to confront aging parents caring for a disabled child.”(*Father of an adult son with developmental disabilities.*)

➤ ***Integration and Participation is not possible without Transportation***

“Transportation is a major issue. For example, I had to hitchhike to get to tonight’s meeting because there is no public transportation in the corridor I live in.” (*A woman at a public hearing.*)

“When I was home it was hard to find transportation to get out. Sometimes I couldn’t get to my quilting class. If it wasn’t for the community center van many people would be trapped in their homes.” (*A resident at the Crescent Manor Nursing Home.*)

“It is difficult to find accessible vans in Vermont, and there’s no program to buy accessible vans.” (*A man whose wife has physical disabilities at a focus group.*)

“For the deaf/blind transportation is very difficult. I wrote a grant for special support providers (SSP). This is someone who provides transportation and knows American Sign Language (ASL). (*A man who is deaf and visually impaired*)

A group of developmentally disabled adults attended a public hearing by receiving a ride from their caseworker. For transportation they often depend on rides since buses at \$4 can be hard to afford.

***People with disabilities in Corrections have unique issues.***

Individuals who participated in the legal forum said that although DOC has made progress in how they treat inmates with disabilities, several challenges still remain, especially for inmates with serious mental illness. Participants said inmates with mental illness, developmental disabilities, traumatic brain injury, and sensorial disabilities (eg. deafness) are not always afforded equal access to:

- Rehabilitation programming
- Mental health and other medical treatment
- Appropriate discharge planning
- Communication accommodations to deaf inmates (e.g. sign language interpreter, TTY or Video phone to make phone calls, etc.)

They cited a lack of training for corrections staff in how to recognize people with disabilities that then results in a lack of appropriate accommodations being made in programming and treatment. They also said DOC staff has not been trained to recognize when misbehavior is disability-related resulting in some unfounded DR’s being issued. They pointed out that people with serious disabilities often need special help with housing and community re-integration as they are being discharged.

### III. Description of Vermont's Services and Supports for People with Disabilities

As was previously noted, Vermont has consistently been a national leader in de-institutionalization and creating services and supports to assist citizens with disabilities to be integrated within their communities. This Chapter provides a detailed description of the services and supports available within Vermont for persons with disabilities, and also identifies the challenges which exist within these domains.

The Chapter begins with descriptions of the status of core resources that all people with disabilities need in order to avoid institutionalization and live, learn and work in the setting of their choice. These are:

*Access to Information, Referral, and Assistance*

*Housing*

*Transportation*

*Healthcare*

*Employment*

*Education*

*Family Supports*

*Assistive Technology*

*Trauma-informed Services*

*Legal System and Protections*

*Voting and Citizenship*

This is followed by sections that provide an overview of services and supports that are tailored for individuals with specific disabilities:

*People with Mental Health Disorders*

*People with Developmental Disabilities*

*Elders and People with Physical Disabilities*

### **Core Services and Supports for All People with Disabilities**

#### **INFORMATION, REFERRAL AND ASSISTANCE**

People with different types of disabilities need accurate, complete and unbiased information about their service and support options in order to make informed choices. There are several resources within Vermont that address this need:

The **Vermont Parent Information Center (VPIC)** is a statewide network of support and information for families who have a child with special needs or disabilities and the professionals who work with them.

The **Vermont Center for Independent Living (VCIL)** offers information about state-wide disability-related resources.

Mental health consumer and family programs across the state, such as **Vermont Psychiatric Survivors** and **NAMI-Vermont**, provide information and referral regarding mental health services.

The **National Family Caregiver Support Program** provides an array of services and support specifically designed for older family caregivers, such as Information and Referral, Case Management and Respite.

The **Vermont Assistive Technology Project (VATP)** coordinates with other disability-related organizations to provide education, outreach and information dissemination about available assistive technology resources.

A toll free **Senior HelpLine** provides information on programs and services for persons age 60 and older and their families and friends. When individuals dial the toll free number, they are automatically connected to their local AAA and an Information & Assistance Specialist, specifically trained to provide accurate and useful information, using extensive databases of information, which are updated regularly. Requests for information sometimes lead to a home visit from a case manager who can provide very specific information based on an assessment of the individual's needs and circumstances. In FY 2003, the AAAs received a total of 25,612 I&A calls, and it is anticipated that the number of I&A calls to the AAAs will increase as a result of public information and education activities underway which publicize the Senior HelpLine.

A new **Vermont 211 system**, a statewide health and human services information and referral program, is now available throughout United Ways of Vermont. Vermont 2-1-1 Community Information Specialists help solve problems, and link callers throughout Vermont with government programs, community-based organizations, support groups, volunteer opportunities, donation programs, and other local resources. Some of the community services they can help Vermonters find include Child Care Resource and Referral, Clothing, Computer Classes, Consumer Services, Discrimination Assistance, Domestic and Sexual Violence Services, Employment Services, Food Shelves, GED Instruction, Health Support Services, Homeless Prevention Services, Housing Programs, Independent Living Services, Legal Services, Mother and Baby Care, Medical Transportation, Mental Health Care and Counseling, Senior Information, Smoking Cessation Programs, Support Groups, Substance Abuse Treatment, Tenant Rights Services, Utility Assistance, Youth and Family Services, Veteran Benefits, and Advocacy.

To find out about possible eligibility for Vermont Agency of Human Services (AHS) programs, the Agency has recently implemented the **Screen Door**, a web-based tool that provides Vermonters with access to information about services and supports that

may meet their needs. By providing confidential, protected information about their particular circumstances and needs, the web-based tool provides them with a profile of services that might meet their needs and contact information about how to apply for these services.

Even with the above resources, gaps still exist in the information, referral and assistance infrastructure for people with disabilities in Vermont. A new Centers for Medicare and Medicaid Services **Real Choices System Change Grant** is facilitating the creation of an accessible, seamless, cross-age and disability system of Information, Referral and Assistance (I,R&A). Through this grant, existing I,R&A systems were assessed; strengths, gaps and deficiencies were identified; and a final report summarized the findings and proposed action steps to fully develop a "seamless" system of I,R&A within Vermont. Department of Disabilities, Aging and Independent Living (DAIL) staff and consultants are working with staff of the state 211 system, AHS and community partners to pursue the action steps described in the report.

In September 2005, Vermont was awarded an Aging and Disability **Resource Center grant** issued jointly from the Administration on Aging and the Centers for Medicare and Medicaid Services. This grant will operationalize the recommendations from the Real Choices grant and create a seamless way for people with physical disabilities and older Vermonters to enter the long term care system. It will also ensure that elders and persons with physical disabilities know where to find information about services and programs that can assist them to live as independently as possible. However, this project will need to be expanded to fully serve as an information and referral system for all individuals with disabilities, such as developmental disabilities and mental health disorders.

DAIL also has contracted with a marketing firm to design a multi-media campaign to promote both the Senior HelpLine and the "I-Line", the new name for the Vermont Center for Independent Living information and referral line. This campaign uses television, print media and the radio to inform people about these **two toll-free numbers** and urges them to contact these help lines for assistance.

As part of its re-organization, AHS also committed to developing a system of personal supports for helping individuals and families with complex needs navigate through the multiple programs offered to access needed services. A first component of this function has been implemented this year through a **Family Support "360"** federal grant that funds a locally based part-time resource specialist in each of the twelve regions of the state to serve as a "peer navigator" for parents with developmental disabilities. While this grant funding is specific to parents with developmental disabilities, the focus may be expanded based on available resources.

People who are **deaf, hard of hearing, late deafened and deaf blind** need a specialized information and referral system that is accessible to this population. For example, these individuals need to use video phones, TTY, and emails to access information. In turn, staff need to be knowledgeable on the issues related to deafness and have resources readily available.

## ***Information, Referral and Assistance Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Need for streamlined accessible information system.	It would require approximately \$480,000 to \$600,000 total for 12 navigators, depending on state or non-profit affiliation.	<ul style="list-style-type: none"> <li>• Promote use of 211 system</li> <li>• Implement recommendations of AHS Navigation Task Force</li> <li>• Implement Real Choices grant recommendations through the Resource Center grant</li> <li>• Ensure that the new state Strategic Enterprise Initiative includes a plan for accessible IT equipment and services.</li> </ul>
Specialized supports for people who are deaf, hard of hearing, late deafened and deaf blind	It would cost approximately \$30,000 annually to contract with a deaf related agency to handle information and referral.	<ul style="list-style-type: none"> <li>• Provide training for AHS staff regarding the needs of these individuals.</li> </ul>

### **HOUSING**

***Affordable housing*** is essential for the full participation and integration of people with disabilities in the community, and lack of an affordable place to live can be a major factor related to people becoming institutionalized or remaining institutionalized. Affordable and accessible housing, located near transportation and employment, is key to long-term economic security and ability to participate in the workforce to one's potential. However, many people with disabilities may face difficult choices between general living expenses and the cost of rent, homeownership, accessibility modifications and maintenance.

***Renting.*** People with disabilities often have the lowest incomes and need housing located near transportation, services or support systems. When they cannot access a unit developed for low-income elders or people with disabilities, it is difficult to find a housing unit they can afford.

Many people with disabilities rely on SSI funding as their primary source of income. Based on the affordability standard of paying no more than 30% of income on housing, a person who relies on SSI benefits can afford only \$185 per month rent.<sup>13</sup> However, fair market rents have risen 24% since 1996, to \$698 per month for a two -bedroom unit and \$568 for a one-bedroom unit. As such, SSI beneficiaries face the prospect of paying 69%-92% of their for SSI check for an efficiency or 1-bedroom housing unit unless they can access a subsidized housing unit or Section 8 voucher.

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<sup>13</sup> Ibid., page 8.

Vermont has the lowest subsidized housing vacancy rate in the nation, primarily due to the state's commitment to providing assistance to low income and disabled citizens. Of the more than 6,000 Section 8 households served by the Vermont State Housing Authority (VSHA)<sup>14</sup>, two-thirds are elderly or disabled and one-third are families. Historically, these Section 8 Certificate and Voucher programs funded by the U.S. Department of Housing and Urban Development (HUD) and related programs funded by the U.S. Department of Agriculture Rural Development (USDARD) have given Vermont's housing providers the means to make housing available to the neediest families and individuals. However, recently HUD has shifted its national housing policy to focus on individuals and families whose need for a housing subsidy is likely to be temporary, and the availability of vouchers for low-income individuals and families and project-based assistance is decreasing.<sup>15</sup> As a result, VSHA's program waiting list is at an all-time high, and the typical wait is three to five years.

Peer Navigators, working with parents with disabilities through the Green Mountain Family Support 360 Project, recently identified housing as the greatest need among the families they support. For some families, Section 8 housing may be accessed through **Family Unification Vouchers**. Family Unification, a component of the Housing Choice Voucher program (HCV), is administered in partnership with the Vermont Department for Children and Families (DCF) and targets rental assistance to families at risk of breaking up due to housing crises. Families are referred to the Vermont State Housing Authority by DCF for rental assistance. These vouchers are used specifically to promote the reunification of families by providing rental assistance for whom the lack of adequate housing is a primary factor in: (a) the imminent placement of the family's child, or children, in out-of-home care; or (b) the delay in the discharge of the child, or children, to the family from out-of-home care. VSHA sets aside 100 vouchers from the HCV program to assist families and maintains a waiting list separate from the list under the HCV program. Turn over of these vouchers is consistent for a variety of reasons and the waiting list is fairly short.

Since 1997, VSHA has participated in the Mainstream Housing Opportunities program that provides rental assistance for non-elderly families with disabilities. In addition, to assist Vermonters to find affordable vacant units, there is a statewide comprehensive and searchable on-line directory of available subsidized rental housing, including information on units that are reserved for people with disabilities, units without such restrictions, and wheelchair accessible units. Because the Directory relies on sponsors to list vacancies, the list may not always be complete.

Most likely due to income constraints, privately owned wheelchair accessible units are not fully utilized by tenants needing such accommodations. One possible solution is to

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<sup>14</sup> Vermont State Housing Authority serves as the public housing authority for all areas of the state without a local housing authority.

<sup>15</sup> HUD'S State and Local Housing Flexibility Act of 2005 substantially changes income targeting for the voucher program, allows time limits, changes rent setting policies in both the voucher and public housing programs and removes current protections for project-based Section 8 residents. The USDA Rural Development Section 515 Rural Rental Housing program has been reduced, the competition is now nationwide and rural development funding for direct loans has decreased.

explore creating a registry of such units based on a model developed by Massachusetts so that people with disabilities who can afford it can locate accessible units available through the private market and not just subsidized housing.

The state recently completed an update to its Analysis of Impediments to Fair Housing, which lists specific recommendations that will increase the number and availability of accessible and affordable units in communities across the state. Fair housing complaints related to disability comprised more than a third of all Vermont fair housing complaints and were the largest category of complaint from 2003-2005. In addition, there appears to be a gap in managers' ability to communicate with tenants who have disabilities about accommodation needs in housing. It appears that many Vermonters fear retaliation if they discuss their fair housing needs, request an accommodation or file a complaint, and that many managers are unsure of how to handle reasonable accommodation requests, or how to respond to unusual needs.<sup>16</sup>

**Home Ownership.** The median purchase price of a house in Vermont is projected to reach \$174,000 in 2005. Given that the housing affordability standard is 30% of income used for housing costs, home ownership is not attainable for most low-income Vermonters unless they can locate a housing unit that was developed and assisted to be affordable.

Fortunately, VSHA and the Burlington Housing Authority have an active Section 8 Homeownership program, which allows clients to use their Section 8 subsidy for mortgage payments rather than rental payments (a few other housing authorities participate in the use of Section 8 for homeownership on a more limited basis). Unfortunately, the constraints on Section 8 discussed under Renting, above, also hinder homeownership. While using Section 8 vouchers to purchase homes remains an option, it is only available to people who already have vouchers or are on wait lists in areas where wait lists are closed.

There are other areas of assistance for home ownership. The Neighborworks Homeownership Centers, often in partnership with Vermont's network of land trust organizations, counsel and assist low-income households toward homeownership. US Department of Agriculture Rural Development Housing programs have loans for acquisition or rehabilitation of homes, and some elder homeowners with lowest incomes can qualify for modest grants for necessary repairs. Vermont Affiliates of Habitat for Humanity builds and rehabilitates homes for low-income families using volunteer labor. All these organizations have included significant numbers of households with people with disabilities in their efforts and some have run sessions targeted to specific populations, such as education sessions made accessible to people with developmental disabilities.<sup>17</sup>

**Home Access Modification.** Much of the existing housing stock in Vermont is older, making it more expensive to maintain and increasing the likelihood that an owner or

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<sup>16</sup> J-Quad and Associates LLC, 2005, Draft Analysis of Impediments to Fair Housing Choice and Action Plan for the State of Vermont

<sup>17</sup> U.S. Department of Housing & Urban Development, public information regarding Home Ownership option in Vermont, 2005



renter with a disability may need to make accessibility improvements.<sup>18</sup> The Vermont Center for Independent Living (VCIL) operates a Home and Community Access Program for Vermonters who have a disability and need financial and technical assistance to make accessibility improvements to a bathroom or main entrance. Fletcher Allen Health Care also operates a small home modification program for residents of Chittenden County who are Medicaid eligible, which has a maximum amount of \$700 per person. USDA Rural Development makes loans and, in some cases, limited grants available for home rehabilitation. Homeownership Centers also coordinate rehabilitation resources for home ownership. Vermont State Housing Authority has an ENABLE fund that is available to renters and providers that participate in its programs.

The best indicator of the gap in the unmet need for basic access modifications is the VCIL wait list and demand rate. VCIL continues to receive 10-12 applications per month and had a wait list of 224 households as of December 31, 2004. The average cost of a modification has risen to \$7400, and the value represented by the wait list is estimated at \$1.7 million.<sup>19</sup> Because demand continues to outpace available funds, a specialist staff position has been funded in a grant from DAIL to VCIL. This staff person's role is to leverage more than \$200,000 of local and participant resources to reduce demand for state funds. In addition, meetings between VCIL and other stakeholders are set to develop a plan to assure the future full utilization of an earmark of \$100,000 per year of Vermont Community Development Program funds to help meet part of the need.

Most of the above programs focus on meeting the most basic levels of home accessibility. Vermonters with the highest needs for access in a home can face costs of more than \$50,000 (such as for homeowners who become quadriplegic, or people with mental health disabilities who require special accommodations throughout a home).

Specifically for people who are deaf, hard of hearing, late deafened and deaf blind, we need to ensure that housing is in compliance with the Americans With Disabilities Act (ADA) by providing visual alert systems such as a fire alarm with strobe lights, smoke detectors with a flasher, a door bell with a flasher, or any type of alert system that meets this population visual needs.

***Promoting Visitability and Accessibility.*** Representatives of DAIL, the Vermont Housing Finance Agency, the Department of Housing & Community Affairs, the Assistive Technology Project, the Vermont Center for Independent Living, and Cathedral Square Corporation have begun to jointly explore ways to encourage universal design and "visitability" standards. Such a shift would reduce the long-term need for home modifications. The group concluded that action on several fronts is needed to promote building accessible or "visitabile" dwellings:

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<sup>18</sup> State of Vermont, Department of Housing and Community Affairs, HUD Consolidated Plan for Housing and Community Development Programs 2005-2010, Volume I

<sup>19</sup> State of Vermont, Department of Housing and Community Affairs, HUD Consolidated Plan for Housing and Community Development Programs 2005-2010, Volume I

Consumers need more opportunities to see and learn about innovations so that they increase the demand for better designed housing.

Vermont builders and contractors need training opportunities so that accessible and “visitable” features are made to appropriate standards.

Vermont architects, builders and contractors need a way to have plans quickly approved before construction. Some projects are constructed with flaws that defeat the purpose of our “visitability” statute, and correction of defects after initial construction can be very expensive.

Architects need further training in universal design, accessibility and “visitability”, and access to specialist consultation to improve design.

This ad hoc work group agreed to work together to identify new resources that can be applied to these problems. Vermont Center for Independent Living will hold a conference to promote universal design and visitability in the spring or summer of 2006.

**Shared housing** is another form of support for elders and people with disabilities. Vermont has two HomeShare programs; one serving Chittenden County and parts of Addison and Grand Isle Counties, and a second in Central Vermont serving the greater Barre-Montpelier area (with future plans to expand to serve the entire central region).

In SFY 2004, more than 550 Vermonters inquired about participating in matchup arrangements. The two programs supported 50 homesharing arrangements. HomeShare Vermont (northwestern region) also supported 47 live-in caregiving arrangements and 111 hourly caregiving matches. About 85% of persons participating in HomeShare have incomes at or below 80% median income. A range of matchup services from homesharing through caregiving promotes aging in place for vulnerable seniors or disabled adults while providing housing and/or employment for younger adults who support them. A review of elders served by the northwest program’s live-in caregiving component showed that more than half met nursing home level of care criteria or were returning home from a nursing home with support from this program. DAIL’s goal is to see the statewide development of HomeShare programs and estimates that this goal could be achieved by 2015 if planning and implementation funds could be secured. Of note, the new program in Central Vermont is exceeding its targets, suggesting that replication is feasible if resources can be developed.

DAIL also provides **residential supports** in congregate housing for elders and individuals with disabilities through the Housing and Supportive Services (HASS) program, which provides service coordination, wellness activities and supportive services. Currently, 25 HASS sites throughout the state help 1,217 residents to remain healthy and safe in their homes by providing services such as homemaker services, senior companion, case management, and foot clinics. Until this year, the program was wholly funded with unmatched state dollars. With the approval of the 1115 Choices for Care program, the HASS program will be offered at existing sites only to persons eligible for enrollment in a Moderate Need Group. Services will be limited to homemaker visits and service coordination, and the impact on moderate need enrollees will be evaluated as part of the 1115 program. This raises concerns by some about the

potential loss of services for individuals who would benefit greatly from services which could help stabilize their condition before they are clinically eligible for HAAS.

Some similar and in some cases more comprehensive programs are being promoted by U.S. Department of Housing and Urban Development. However many models promoted federally only work at larger scales than are common in Vermont, or at sites where virtually all residents have incomes below poverty. Still, the relative cost to partner services with congregate housing and perhaps spread access to persons living near congregate housing pales in comparison to the cost to develop and operate more specialized or licensed forms of supportive housing.

Many properties managed by VSHA also have service coordinators who work to help keep seniors and other populations independent by matching their needs with social services while creating a sense of community among residents. Since 1993, VSHA also has expended approximately \$2.7 million in funds for the Stewart B. McKinney Homeless Assistance continuum of care programs. Vermont's continuum of care system joins together all of the partners addressing homelessness in Vermont in an effort to maximize resources and coordinate services. This model recognizes that the homeless population requires more than housing but also access to mental health services, substance abuse treatment, transportation, assistance with daily living skills and other services. More specific funding for Housing for Persons with AIDS (HOPWA), implemented in 1996, is used to prevent homelessness by providing rental assistance to low-income persons with AIDS and their families.

There also are a number of ***housing alternatives specifically for elders and people with disabilities***, often referred to as "special needs housing," which are a core resource for enabling individual to avoid institutionalization.

As of January 2005, Vermont had 112 residential care homes (RCHs) in operation with a capacity to serve up to 2,306 aged and disabled Vermonters in need of room, board, 24-hour supervision, and personal care. The median size of a Level III RCH climbed to 17 beds, and Level IV homes to 9 beds, reflecting consolidation, and a trend toward larger sized homes.

While some homes report that recent increases in health insurance and liability insurance were leveling off, these costs continue to cause financial pressure. Recent fuel price increases and continuing ineligibility for residents or homes to participate in Fuel Assistance programs together with new uncertainty about insurance costs in the wake of Hurricane Katrina losses raise concern. Homes that were not exempted from property taxes are also reporting financial pressure from new education-related taxes. Such tax burdens are unusual, in that many states provide tax relief and tax exemptions to support affordable RCHs and assisted living facilities. Preservation and stabilization of RCHs remains a long-term, high priority of DAIL and the Agency of Human Services. A portion of FY'06 waterfall funds allocated to DAIL to support implementation of the 1115 Choices for Care program will be targeted to fund accessibility improvements to RCHs with the capacity to care for residents who would otherwise be eligible for nursing home care.

Vermont's Assisted Living Residences (ALR) regulations, implemented in March 2003, emphasize privacy, aging in place, and building on the proven base of RCH regulations. Residents live in a private apartment or suite and receive comprehensive services that must increase with changing needs (aging in place) to a minimum level of need. Elders and their families who have utilized ALR as a housing option are very satisfied as are the providers who have ventured into the new arena. Currently, there are five licensed facilities and another three in process of being reviewed for licensure. Ten other groups are exploring the potential development of assisted living.

The Vermonters Coming Home Grant Advisory Group (a grant that supports the development of affordable assisted living) has identified a need for at least one affordable assisted living residence in every county. To date, two affordable residences have opened through the program. As assisted living facilities emerge, effort will continue to ensure the development of affordable units. With the recent opening of a second affordable assisted living residence, the percentage of units accessible to persons who may need to use Medicaid to pay for care and services is almost 20%.

The greatest challenge to the development of affordable assisted living is the total complexity of the projects. Assisted living brings together the challenges of developing and operating affordable housing (at higher code requirements than general congregate housing) plus the challenges of developing and operating quality long-term care services at public rates to quality outcomes. The scale of most successful models remains much larger than is feasible in Vermont. Still, with approval of the 1115 Choices for Care program, the Vermonters Coming Home program is poised to define the minimum necessary conditions to develop residences at the common sizes needed in a new pro forma tool that will be freely available to funders and potential sponsors.

Sponsors of assisted living residences will also be consulting with local communities about property tax relief. Because Medicaid requires that all income above a protected limit be spent on health care costs, many Vermonters are not left with enough money to pay for assisted living plus the full cost of housing, meals and required transportation services. In addition to property taxes, DAIL will continue to work with state and federal partners to expand this program and will target a portion of waterfall funds for the startup of the 1115 Choices for Care program to support new assisted living residences.

There also may be a need for a specialized residence home for individuals who are deaf/hard of hearing who have developmental disabilities or have mental health disorders, with staff who are fluent in American Sign Language (ASL), knowledgeable in deaf culture and are trained to work with this special needs population to ensure that the deaf/hard of hearing are getting services that they need.

In addition, there are not enough temporary respite homes for people with specialized needs.

***Real Choices Grant - Integrating Long Term Supports with Affordable and Accessible Housing.*** In 2004 Vermont was awarded one of eight three-year grants from the Centers for Medicare and Medicaid Services to integrate or coordinate services with affordable and accessible housing. Vermont's grant application focuses on increasing supply of housing and adding services that are key to early and late aging in

place. While targeted to elders - who continue to be the population most likely to be institutionalized in Vermont - all grant activities address forms of housing and services that are relevant to Vermonters across disability groups. From 2004-2007 the grant will:

Increase Vermonters' ACCESS to affordable supportive housing by a) providing consultant services from Cathedral Square Corporation to at least 14 projects (new construction, rehabilitation, addition of services, and workout of services) and investing in Cathedral Square Corporation knowledge and skill base, b) supporting a first demonstration of affordable assisted living at a public housing site, and c) making 3 grants to local leaders to support organizing efforts leading to supportive housing projects.

Study and develop solutions to Vermonters' needs for medication assistance in unlicensed congregate housing. Currently, use of available insurance benefits, assistive technology and referrals is inconsistent throughout the state and many unsafe reminder practices have been observed. Without appropriate supports to properly take medication, many Vermonters are believed to be at risk for adverse events with the potential for hospitalization, institutionalization or move to a more restrictive setting.

Plan for the co-location of two PACE (Programs for All-inclusive Care for the Elderly) sites with senior housing to serve seniors who meet nursing home care guidelines and qualify for both Medicare and Medicaid. The program can meet the long-term care needs of the highest needs seniors in the community and represents a powerful way to increase elders' chances of aging in place in all forms of housing.

Assistive Community Care Services (ACCS) is a Medicaid service which pays for the care of persons who live in a RCH or assisted living residence, but do not yet need nursing home care. In 2000, DAIL called for a reimbursement level that would support total reimbursement of \$50/day; however, that goal, adjusted for inflation factors, has not yet been achieved. ACCS payments are crucial to the sustainability of affordable residential care and to affordable assisted living.

The former Division of Developmental Services (DS) brings extensive experience to DAIL in managing adult family care, also known as shared living. DAIL staff are working on standards and practices for Medicaid Waiver adult family care services, building on the history and capacity of the DS system, with the goal of creating a new residential alternative for elders and adults with physical disabilities across the state.

Recognition of the importance of housing issues for people served by the Agency of Human Services (AHS) resulted in the creation of a new position of **AHS Director of Housing and Transportation** to assist in coordinating the housing issues facing individuals and their families.

## ***Housing Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Reductions in HUD Section 8 vouchers.	An additional \$27 million per year from the federal government for rental assistance for the 5,000 Vermonters on waiting lists.	None identified.
Reductions in Section 515 Rural Rental Housing program and rural development funding for direct loans.	Unknown, as the USDA Rural Development appropriations bill for this fiscal year has not been passed.	None identified.
Lack of affordable housing in Vermont's existing housing stock.	Vermont could consider appropriating more revenue to develop more affordable housing units as an alternative to direct rental assistance.	<p>AHS and the Governor's Housing Council are considering how to coordinate highest priority needs of people with disabilities in the next Memorandum of Understanding between AHS and housing funders.</p> <p>USDA Rural Development's Vermont/New Hampshire office continues to coordinate priorities via the "highest needs place" list to assure that the highest needs remain competitive in national applications.</p> <p>Begin expending the \$100,000 annual set-aside of CDBG funds from the Department of Housing and Community Affairs</p> <p>Support existing organized efforts of the Affordable Housing Council, the Governor's Housing Council, the Vermont Housing Awareness Campaign and others to reduce "Not In My Backyard" / local resistance to affordable housing projects and to reduce pre-development costs so that more units can be developed/supported with existing resources.</p>

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Privately owned wheelchair accessible units are not fully utilized by tenants needing such accommodations.	None identified.	Explore creating a registry of such units based on a model developed by Massachusetts so that people with disabilities who can afford it can locate accessible units available through the private market and not just subsidized housing.
There are long Waiting Lists for Housing Modifications Programs	The program is estimated to cost \$1,080,000 per year, and one-time funding of \$1,830,000 would eliminate the wait list.  Specific accommodations for people who are deaf/hard of hearing would require \$440 per person for a visual alert system, smoke alarm, and door bell.	Maintain coordination of existing resources and the VCIL specialist position to assure that public funds are used as dollars of last resort. Develop a plan for the funding, production and promotion of a model universally designed, affordable home to raise awareness of consumers, designers, contractors and funders about the opportunity to increase the supply of accessible housing. Better publicize the VSHA Enable program.
Residential Care Homes need preservation and stabilization.	Information not available.	None Identified.
Assistive Community Care Services payments are not keeping up with inflation.	It would require a total of approximately \$613,200 each year to increase the ACCS payments to an adequate rate.	Continue periodic meetings of government entities and the industry to assure the industry obtains all possible support to cope with the changing operating environment and to prevent closures wherever possible.
Development of additional Assisted Living Residences is jeopardized due to property taxes.	None identified.	Vermont Housing Finance Agency has worked with the Department of taxes to adjust the valuation of assisted living units to buffer this impact. The issue should be monitored to determine whether further action is needed in the future.

Challenges	Financial Implications	Other Actions Needed
Residential settings that are adapted for people who are deaf/hard of hearing and have significant developmental disabilities and or mental health disorders may be needed.	Such a residence may cost approximately \$500,000-\$600,000 for start up and the same amount each year for operational expenses.	Provide consultation to staff who work in residential settings where a deaf / hard of hearing person lives.
HomeShare programs are not available statewide and the demand for this cost-effective alternative is far exceeding availability.	To develop three new regions would require \$15,000 in planning funds and annual operating support of \$84,000. If initial start-up funding is not available from Vermont Community development program, an additional one-time allocation of \$630,000 over three years might be needed.	None identified
New rules regarding access to Housing and Supportive Services (HAAS) may have a negative impact on individuals who would benefit greatly from services which could help stabilize their condition before they are clinically eligible for HAAS.	None identified.	Evaluate and closely track the impact of the new rules regarding access to HAAS for people who are not eligible.



## TRANSPORTATION <sup>20</sup>

Access to transportation services which are reliable and responsive to the varied individual needs of older persons, people with vision impairments and persons with other disabilities is a necessity for individuals to be independent and able to live and participate in their communities. Vermont's rural landscape makes the provision of adequate transportation all the more challenging. Getting to work, a grocery store, a social event, or spiritual locations usually requires access to a car or bus.

As reported by individuals with disabilities, access to transportation and transportation services in Vermont varies widely by region. There is often inconsistency in the availability of transportation with the necessary accommodations, particularly for individuals who require transport in a wheelchair accessible vehicle.

The Americans with Disabilities Act (ADA) and its accompanying regulations, is one of the most sweeping federal laws that advances the goals of disability policy by defining eligibility, prohibiting discrimination, and establishing standards for accessible vehicles, facilities and services. ADA regulations require certain transportation providers to provide "paratransit" services, or other special service, to individuals with disabilities that is comparable to the level of service provided to individuals who use the fixed route system. Vermont's Agency of Transportation (VTrans) Office of Civil Rights is responsible for overseeing compliance with the ADA and other relevant federal and state transportation regulations. However, there are at least **62 federal funding streams** that may be used to support transportation - all with different target populations, eligibility guidelines, uses, limits and funding. Therefore it is very challenging to coordinate services and insure that those services are not duplicated.

Since the late 1980's VTrans has had a specific program to meet these federal mandates, the ***Vermont Elders and Persons with Disabilities Transportation Program (E&D Transportation Program)***. The E&D Transportation Program provides a variety of services, including trips for medical appointments, adult day, senior meals, employment and shopping. Each year Vermont transfers federal funds from the Surface Transportation Program (STP) to provide these services. STP funds are awarded to local public transportation (and human service) organizations as ***Section 5311 grants*** to provide services; grant recipients must also match the federal funds with at least 20 percent in local resources.

For the 2005 fiscal year, VTrans awarded E&D Program funds to nine public transportation providers and one human service organization. Public transportation providers are the designated brokers for regional transportation services; in this function they contract with local human service organizations and deliver the required transportation services. At the same time, most public transportation providers manage

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<sup>20</sup> Portions of this section were drawn directly from *Vermont Elders and Persons with Disabilities Transportation Program Review*, submitted to Vermont Department of Aging and Independent Living by Wilbur Smith Associates, March 2004.

an even wider array of transportation services (i.e., fixed route, inter-city and other on-demand services) to a broader population (i.e., members of the general public, and tourists).

The goal of the E&D Transportation Program is to meet the unmet transportation needs for elders and persons with disabilities. Increasing numbers of individuals are relying on the E&D program to provide transportation services. In FY 2004, the E&D Transportation Program provided 168,000 trips to approximately 5,800 clients.

The E&D transportation program is complex. It serves a diverse population that includes all persons in the State of Vermont who are over the age of 60 and/or have a disability. While sharing several common attributes, these two populations are distinct and have different needs and expectations with regards to transportation. In addition, an individual's requirements for transportation services is dynamic; needs are influenced by changing internal and external circumstances. Travel needs, for example, vary with changes in health, employment status or residence. The E&D program also delivers a diverse set of trips spanning regularly scheduled and ad hoc services.

As required by the Vermont legislature in 2004, a ***study of the E&D program*** was completed in March 2004. Findings included the following:

- ◆ Generally speaking, many of the participants of the E&D program said they do have access to most of their essential trips, such as medical appointments. They were less confident, however, in their ability to access reliable transportation for vocational purposes and quality of life trips, services they need to be active and engaged in the community. Many individual elders and persons with disabilities are resourceful about finding solutions to immediate needs. Focus group participants spoke of how they barter for rides with home cooked meals or baked goods, but are frustrated by their inability to find flexible and reliable transportation options.
- ◆ Program funding is not adequate to meet needs and expectations of program participants. The Study Team concluded that current program funding is inadequate to meet the needs and expectations of program participants. While funding has increased annually, these increases have not kept pace with rising inflation or increasing rates of qualifying participants. As a result, the program is continually losing ground over time, both in the proportion of the population served and in the number of services provided.
- ◆ Public Transportation's funding method impacts the ability of human service organizations to deliver consistent and reliable services. Although not yet adopted across Vermont, several public transportation agencies are using a funding system for their E&D transportation services that invoices local partners at the actual monthly program costs rather than a set rate. While a necessity for many public transportation providers, because costs can change from month to month, this funding system creates uncertainty and presents challenges to human services organizations as they try to plan and budget for services. This has led to considerable frustration on the part of the human service organizations.

- ◆ Local and State organizations view program objectives differently. While it is not uncommon for local and State organizations to have different program priorities, to the extent possible they should be in agreement on the program's main goals and function. General program goals and guidance are provided via the grant process, but discussions with stakeholders suggested that more specific and clear program goals articulated by the State would be useful by many organizations involved with the program. Providers believe there should be a policy and procedures manual developed through VTrans in conjunction with the local partners throughout the State.
- ◆ Despite considerable national and local attention on demographic changes, especially the impact of the aging population on public resources, very little information is available with regards to elders and persons with disabilities needs, expectations and demand for transportation services.
- ◆ There is a lack of clear, relevant performance mechanisms. Current program monitoring mechanisms summarize rather than evaluate and analyze the types of services are provided. While existing monitoring mechanisms meet federal funding requirements, they do not highlight success towards meeting the needs of program participants. Their ability to track changes in areas of program success and weakness and consequently future planning, is limited.
- ◆ As previously mentioned, despite fears associated with further strain on existing resources, program outreach and marketing should be carried out to ensure services associated with the E&D program are delivered in a consistent and reliable way.
- ◆ Several local innovations have improved service delivery. This study has noted a number of best practices such as the Ticket to Ride program and strategies for leveraging of private funds to augment the program activities.

There are other program and initiatives that provide transportation resources for people with disabilities. Eligibility for the various transportation programs are both categorical and functional, with some programs targeted to children, others to elders, people with low-incomes, or individuals participating in specific programs. This assistance with transportation needs may come in the form of passes, tickets, vouchers and/or contracts for services, vehicle or equipment purchases and repairs, and volunteer cars.

For example, **Area Agencies on Aging and Adult Day Centers** receive funding from DAIL to purchase, provide and help coordinate accessible transportation services on the local level. Beyond providing funding, these agencies invest significant effort into working, negotiating and communicating with transportation providers to ensure that elders and people with disabilities can access community services and events.

People with traumatic brain injury or developmental disabilities receiving Medicaid waiver services also have access to transportation services to assist with medical, social, work and other community activities. Medicaid also pays for medically necessary trips for consumers.

The **United We Ride Initiative**, a partnership of the U.S. Departments of Transportation, Health and Human Services, Labor, and Education, was established in

2003 to promote better coordination of human service transportation. VTrans has applied for a state coordination grant that will assist in the updating of the State Transportation Policy Plan. This plan will summarize the current state goals for public transportation, survey the existing conditions of public transportation, assess unmet transit needs of all citizens, examine funding issues and resources and make recommendations to promote the goals of public transit. VTrans will be working closely with AHS and other state and local agencies to gain input and promote coordination. An example of a change already underway is a change in the funding mechanisms of transportation for elders and people with disabilities. Funds flexed into the Section 5310 Program (Transportation for Elderly Persons and Persons with Disabilities – “E&D Program”) will now be put into the Section 5311 Program (Non-Urbanized Public Transportation) with the intent of better coordination of the available resources.

A recent ruling from the federal Department of Transportation clarifies that fixed route services funded under §5311 must meet ADA complimentary para-transit requirements, the same service provided in urban areas with fixed route city bus lines and most rail systems. Some rural transit providers in Vermont need to develop para-transit services to comply with these requirements. Transit providers and VTRANS will need to work with disability advocacy organizations and local planning commissions to plan and implement para-transit services for any transportation route covered by this requirement.

AHS, including DAIL and OVHA, continue to be closely involved with VTrans, the public transit providers, and human service agencies to ensure that Vermonters get where they need to go. As previously mentioned, on July 1, 2004, the new position of **AHS Director of Housing and Transportation** was created. A **Memorandum of Understanding between AHS and VTrans** was established to ensure collaboration between the agencies regarding activities affecting E&D transportation. DAIL continues to assist AHS in carrying out this collaboration, including maintaining a **database of E&D services**. This database will help to identify unmet needs and ensure that transportation services remain available and accessible. All of the above needs to be integrated to ensure that there is a comprehensive approach to transportation for Vermont citizens with disabilities.

Special attention must be paid to unique needs of people with specific disabilities. For example, people who provide transportation need training regarding how to better accommodate people with hearing and visual disabilities, and digital displays are needed to alert people who are deaf/hard of hearing about approaching destinations. As mentioned previously, there needs to be more wheelchair accessible transportation available routinely, especially in rural areas of the state.

Another unique need by individuals with disabilities is to be able to obtain affordable modified vehicles and keep those vehicles in good repair. To address this issue, Vocational Rehabilitation (VR) provides financial assistance to adults with disabilities by spending almost 13% (\$550,000 to \$575,000 annually) of their case service dollars on transportation related expenses, and provided adapted vans or vehicle adaptations for at least 22 people in SFY2005. There are currently eleven people on the waiting list for adapted vans with an expected cost between \$60,000 and \$110,000 per van, which

means that less than half of those on the waiting list will receive assistance with van purchases this year. In addition, VR serves people whom are of working age (16-65), so these numbers exclude those with potentially the greatest needs, i.e, those over age 65. This also does not reflect the need by families with children still in school or preschool.

Finally, as Vermont's population of elders and persons with disabilities increases, understanding the impact of urban design/form of aging in place is essential. To address this issue, opportunities to coordinate land use and transportation planning with human service program design should be pursued. In some cases, there may be potential to build on "quality community" initiatives sponsored by federal agencies.

## ***Transportation Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Inadequate resources to assist families that have children with disabilities and adults with disabilities to be able to obtain affordable modified vehicles and keep those vehicles in good repair.	Approximately \$935,000 would provide assistance to 11 adults on the waiting list for assistance with adapted van (at an average cost of \$85,000). Similar funds would be needed annually to avoid waiting lists.	None identified
The capacity of the Elders and Persons with Disabilities Transportation Program is not adequate to meet needs and expectations of program participants. This includes specialized accommodations for people who are hearing or visually impaired.	An annualized total of approximately \$2.6 - \$8.1 million would be needed annually to meet the needs due to increased populations and/or service expansion.	Transit providers and VTRANS should work with disability advocacy organizations and local planning commissions to plan and implement para-transit services for any transportation route covered under the new §5311 requirements.
There is little to no accessible outreach or marketing about E&D Transportation program and services.	None identified	Increased outreach efforts to deliver a clear, accessible message about the types of services available and how they are accessed
The impact of urban design/form of aging in place needs to be emphasized.	None identified.	Opportunities to coordinate land use and transportation planning with human service program design should be pursued and explored. There may be potential to build on "quality community" initiatives sponsored by federal agencies.

## HEALTHCARE

For many individuals with disabilities, health care and health care coverage or the lack thereof often serves as the resource- or barrier- that most significantly affects their ability to live in the most integrated setting and successfully participate in employment, education, recreation and community life. People with disabilities use medical services more than those without disabilities, but face a range of barriers to getting the health care they need. These barriers include limited access to care, lack of accommodations, and issues regarding eligibility and financing.

Healthy People 2010 by the US Department of Health and Human Services, reports that persons with disabilities are often ***poorly served in our health care systems*** and notes our national disregard and under-emphasis on health promotion and disease prevention activities for these Americans. This national report highlights troubling findings that individuals with disabilities receive significantly fewer screening and preventive services such as mammograms and counseling on tobacco use than other individuals. It also notes that these gaps in health and wellness services contribute to the high cost of health care for these individuals due to the ***lack of preventive and intervention services*** that could improve their health, functioning and wellbeing.

Similar trends are reflected in Vermont. Recent data about the health of Vermonters indicates that adults with disabilities report higher incidents of diabetes, osteoporosis, risk of cardiovascular disease and hypertension and are at greater risk for depression compared to adults without disabilities. One quarter of adults with disabilities smoke compared to one fifth of adults without disabilities. Adults with disabilities are less likely to report good to excellent health status (60%) compared to older adults (80%) and adults without disabilities (90%). Adults with disabilities are more than twice as likely to report not having money for food at least one time a month and to report trouble with tooth or mouth problems that affect eating. People who are deaf and hard of hearing are at a higher risk of being infected by HIV/AIDS and other diseases due to a lack of information and communication accommodations.

In 2003, the Area Health Education Center at UVM surveyed family physicians and general internists in Vermont. The survey was returned by 71.4% of the practitioners. Seventy-three percent (73%) of the respondents estimated that they care for patients with disabilities less than ten percent of the time, while the actual incidence of people with disabilities is 22% of the population. Self-reporting by survey participants also identified barriers to engaging persons with disabilities in health promotion which physicians identified as very important or somewhat important. These included lack of time (88%), need to attend to primary disabling condition (91%), lack of patient interest (88%); lack of insurance coverage (71.9%), lack of appropriate materials (80.7%), disability prevents barrier to receiving services (64.2%), lack of physical resources to accommodate disability (54.5%) and difficulty talking with patients about health promotion (28.3%).

In a 2003 survey of FAHC Family Medicine physicians and midlevel practitioners, only 6 of the 25 respondents reported any formal training to prepare them in providing health care to individuals with disabilities. None of the respondents strongly agreed with the

statement, "I am comfortable with my **knowledge of disabilities.**" The Area Health Education Center and VCIL staff heard similar concerns during four medical grand round trainings that they held at three Vermont hospitals.

UVM Medical School has developed the Interdisciplinary Leadership Education for Health Professionals (ILEHP) to train allied health practitioners which provides specialized training on disability to practicing health professionals. The program is well thought of but is only able to serve a small number of participants each year and primarily focuses on developmental disabilities and treatment of children and adolescents. The program does help students begin to understand the life-span issues of living with disabilities and offers a valuable model for future development.

For the past two decades, Parent to Parent of Vermont has collaborated with the UVM Medical School to offer training to medical students through its Medical Education Project which matches families with third year medical students. The F.I.R.S.T. program works with Pediatric Residents over all three years of their residency, and involves the residents in home visits, participation in education team meetings, and provides seminars on topics such as Medical Home, Culture, and Adolescence.

Vermont's Office of Vermont Health Access has also tested new uses of the "**Medical Home**" approach to helping physicians and primary care practices build their capacity to provide effective services to individuals with disabilities and a new 2 million dollar grant from CMS is designed to help Vermont coordinate the financing and delivery of acute and long term care to seniors and individuals with disabilities in Vermont. Finally, Vermont's Blueprint for Health is looking at ways to improve **treatment and reduction of chronic conditions** and could be implemented to promote the inclusion of individuals with diverse disabilities fully in the project with the goal to reduce secondary conditions experienced by individuals with disabilities. This would take considerable commitment on the part of Vermont providers and policy makers but would go a long way in designing an inclusive approach to health promotion in Vermont. Much has been learned in Vermont's use of recovery education, consumer directed long term care supports, and person centered care planning that could be used to shape approaches to diabetes, weight management, osteoporosis, and heart disease that do not leave individuals with disabilities behind.

To address **physical and communication barriers**, the American's with Disabilities Act requires all health providers to make reasonable modifications to policies practices and procedures that are needed to make programs and services accessible to those with disabilities. These elements of the ADA require health practitioners to make reasonable and "readily achievable" modifications to buildings, facilities and services and are intended to ensure that individuals with diverse disabilities (including sensory, intellectual, psychiatric, and mobility conditions) have equal access and benefit from health care programs and services offered to members of the public. This requirement has improved accessibility of health care offices and clinics and has expanded use of services such as interpreters and other services for people who are deaf/hard of hearing. However, much work is still needed.

Department of Justice reports indicate that building access is still a concern but that



effective communication and program access are greater problems. Health providers need additional training and sensitivity in providing effective communication and other accommodations (large print, accessibility of office equipment, and communication strategies for providing respectful person centered care to individuals with communication, sensory, psychiatric and cognitive disabilities). For example, for people who are deaf with minimal language skills (MLS) or whose reading level is below 4<sup>th</sup> grade, there is a lack of education/resources regarding health care issues, such as HIV/AIDS, breast cancer, heart disease. Many hospitals and other health care providers are not familiar with ADA or understand their responsibility to provide and pay for interpreter service. Also there is a dire need for emergency rooms to provide remote interpreting service in case they are unable to locate an interpreter on a local level. Similar issues exist for people with physical disabilities. For example, lack of hooyer lifts in exam rooms result in decreased access to routine physicals, mammograms, and other imaging techniques for people who are not independently mobile.

Finally health practitioners staff need training in treating their patients with disabilities as equal partners in their health care planning and in understanding how to support full participation of individuals with different and multiple disabilities in health programs.

Less attention has been paid to the availability of **exercise and wellness programs** for individuals with disabilities. Vermont has developed some highly respected services, such as Adaptive Ski and Sports but is significantly behind many other states in the development of accessible wellness and athletic programs in local communities. Some providers are very interested in marketing to and serving individuals with disabilities; but overall the issue of accessibility and universal design has not been on the radar screen of these programs– even of public health and senior programs. The state's Disability and Health Promotion Project in the Department of Disability, Aging and Independent Living as been working with Vermont partners and with projects in states with experience in accessible health and recreation programs, seeking ways to expand the accessibility and inclusiveness of Vermont programs and services. A pilot project is planned for fall of 05 which will test ways to make exercise and wellness services more available to individuals with disabilities.

People with disabilities also face issues related to **eligibility** for health care benefits and the way health care is financed. Evidence of disability triggers eligibility to some health and long term care benefits but the nature, scope, and definition of a person's disability can also result in eligibility denials or cause them to need uncovered services. Many people believe that individuals with disabilities are more likely to be insured. In fact, studies show that a significant number of individuals with disabilities are uninsured or underinsured and unable to access needed health and disability specific services. Some health insurance companies are not willing to pay for audiology services or for hearing aids.

Beginning January 1, 2006 the Medicare Part D prescription drug benefit will start. This benefit was created by the Medicare Prescription Drug, Improvement and Modernization Act of 2003 (MMA) in order to provide more people on Medicare with some prescription drug coverage. The day before this new benefit begins, existing Medicaid prescription drug coverage ends for individuals who are dually eligible for both Medicaid and

Medicare. This beneficiary group, which includes many people with disabilities, were auto-enrolled in a Part D prescription drug plan (PDP) in November 2005. Because there are many prescription drug plans available, there is no guarantee that the plan an individual was auto-enrolled in will be the right plan for them. Since the plan may not cover the medications the beneficiary currently uses, it is important that the individual, or their caregiver, evaluates the drug formularies (the list of covered drugs) of the various plans. Also, there are certain classes of drugs that are excluded under the MMA, such as those for anorexia, weight loss, or weight gain, benzodiazepines, barbiturates, non-prescription drugs, and drugs for cosmetic purposes or fertility. To help ease this transition, Vermont has created a wrap around Part D coverage called VPharm. This wrap will maintain the same cost sharing that existed under VHAP Pharmacy and will provide coverage for the drugs in the excluded classes as long as they are medically necessary.

In summary, the limitations and challenges in our medical and public health care services relating to services for individuals with disabilities concern Vermont's Olmstead Commission because poor health affects the four core policy areas addressed by the Americans with Disabilities Act: equality of opportunity, full participation, independent living and economic self sufficiency. Without health and adequate access to needed health and preventive services Vermont's with disabilities are less likely to experience successful employment, sustain their independence, and participate fully in society and benefit from the equal opportunity protections promised by the ADA. The social and economic costs to individuals and families and to society are significant.

## ***Healthcare Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Individuals with disabilities receive significantly fewer prevention and intervention services than other individuals.	Information not available.	Vermont's Blueprint for Health and the new Real Choices initiatives should identify and promote preventive and health promotion interventions and services for individuals with disabilities.
Family Medicine specialists, physicians and midlevel practitioners lack formal training in providing health care to individuals with disabilities	Information not available.	UVM, Area Health Education Centers, the Departments of Health and DAIL, and VCIL and other interested organizations should explore ways to continue and expand the regional grand round educational forums on disability and health promotion held at regional hospitals in 2003 and 2004 and should explore ways to enhance disability education in degree programs and post graduate programs offered to medical practitioners in Vermont.
Issues of physical accessibility, communication barriers and universal design are not well understood or addressed within the health care and recreational communities	Information not available.	Vermont should look for ways to continue the initial planning for accessible and inclusive health, wellness and recreation programs begun in the Disability and Health Promotion Partnership Project.  DAIL should begin to assess the gap in specific accommodations for people with disabilities in health care offices, and work with the medical community to develop strategies to address them.

## EMPLOYMENT

The importance of employment for people with disabilities is evidenced by the numerous components of Vermont state government that are oriented towards assisting individuals to obtain and maintain jobs.

***The Division of Vocational Rehabilitation (VocRehab Vermont)*** is a federal program whose mission is to help Vermonters with disabilities prepare for, obtain, and maintain meaningful employment. VR accomplishes this by providing counseling and guidance, vocational assessment, training, tools and equipment, worksite accommodations and support, post-employment services, and other support and resources to assist individuals with disabilities to work. VocRehab Vermont partners with many organizations such as the VT Association of Business, Industry and Rehabilitation, the Department of Children and Families, the Division of Disabilities and Aging Services, mental health agencies and employers to ensure that individuals receive wrap-around services to meet their unique needs. VocRehab Vermont operates a number of special programs, including transition services to youth with disabilities, services to individuals with disabilities who receive welfare benefits; and benefits counseling for individuals receiving Social Security benefits and other public programs.

The mission of the ***Division for the Blind & Visually Impaired (DBVI)*** is to help Vermonters who are blind and visually impaired to achieve or maintain economic independence, self-reliance, and community integration. DBVI operates a variety of programs and services to support this mission. DBVI assists Vermonters with vision impairments to find or maintain employment consistent with their informed choice, goals, unique strengths and capabilities. Individuals choose a vocational goal and supporting services, directing those services with the assistance of the DBVI counselor. Services provided may include vocational training, visual restoration, skills training, guidance, job placement, technology, adaptive equipment, education, orientation and mobility and other services to find or maintain employment. DBVI also operates a Business Enterprise Program, providing business opportunities to individuals who are blind or visually impaired. Under the mandate of the Randolph-Sheppard Act, these opportunities (food service, vending) are located in state and federal buildings.

While there are no state or federal statutes that require the ***Department of Corrections*** (DOC) to provide employment assistance, there are DOC Community Correctional Service Centers and Court and Reparative Service Units throughout the state that have developed informal networks and/or employment programs that provide individualized assistance to offenders seeking employment. A recent study commissioned by Vermont Offender Work programs with assistance from the National Institute of Corrections, *Workforce Development and Employment Services for Offenders*, identified and mapped employment resources available to offenders throughout the state.

***Division of Mental Health***, through contracts with private, nonprofit agencies, provides statewide services to people with a wide range of emotional, behavioral and other mental health problems. The Community Rehabilitation and Treatment (CRT) program assists adults diagnosed with serious and persistent mental illness. The program serves approximately 3,000 people and about 36% of those people are receiving

employment services. In fiscal year 2003, 835 individuals served in employment programs were working in competitive employment positions at an average statewide wage of \$5,574. Approximately 23 employment specialists provide an array of supported employment services, including assessment, job development, job coaching, benefits counseling and on and off the job supports and long-term follow-up.

***Division of Disabilities and Aging Services (DDAS)*** provides oversight to designated agencies providing supported employment services to individuals with cognitive disabilities. The goal of each project is to provide a full range of employment services to consumers using quality practices, with a goal to responsiveness and on-going career enhancement. DDAS promotes the belief that anybody can work regardless of severity of disability if supports are tailored to the individual and support is consumer/family directed. There are 17 employment services that assist over 797 people currently working out of 2,089 adults aged 18-65 served by Developmental Services in FY2004, or 37% of those served. Also housed with DDAS is the Traumatic Brain Injury Program (TBI). This Medicaid waiver program provides intensive case management services to assist individuals in remaining in their homes while receiving rehabilitation services to increase their independent living skills and potentially return to work.

***Department of Employment and Training (DET)*** represents the State's efforts to provide services, information, and support both to individuals to obtain and keep good jobs, and to employers to recruit and maintain a productive workforce. DET accomplishes this through the twelve Career Resource Centers (CRC) located throughout Vermont. Job seekers are able to receive skills assessment, career guidance, labor market information, and explore training options and access educational workshops. In addition, DET is able to fund on-the-job training, work experiences/training, youth services, apprenticeship programs, and other support services.

***Department of Education and local schools*** also play a vital role in eventual employment for youth with disabilities. To be more successful in these efforts, high schools and secondary education programs need to provide more of an employment focus, more education about poverty issues, and consumer education for more positive attitudes about their abilities to work and about labor market information. As discussed in the following section, schools are required by the IDEA to do transition planning for students receiving special education services pursuant to an Individual Education Plan (IEP). More education to school districts about this requirement as well as increased communication between school districts and agencies that provide employment services for adults could lead to more job readiness, job development, and long-term job placements.

***Vermont Association of Business, Industry, and Rehabilitation (VABIR)*** is a private non-profit organization dedicated to increasing the employment of people with disabilities through education, employer outreach and direct job placement services. VABIR Employment Representatives work closely with Vocational Rehabilitation counselors to find competitive employment opportunities across the State. VABIR also maintains close contact with employers, local Chambers of Commerce, Rotary Groups and Human Resource associations to develop relationships that encourage recruitment

and hiring of Vermonters with disabilities. Employment Training Specialists work with individuals who need more intensive job placement services, including short-term job coaching.

**Division of Economic Services (DES)** within the Department of Children and Family Services administers state and federal programs such as Medicaid, Food Stamps, and Reach Up to assist eligible Vermonters in need. The mission is to help Vermonters find a better way of life through employment coaching, health insurance, crisis management, and career planning. DES serves about 75,000 families (or 150,000 people) each year. In addition to providing financial support for the most needy families, DES assists individuals to comply with federal mandates and become employed. To accomplish this, DES partners with many organizations to provide support services, including the Division of Vocational Rehabilitation (VocRehab Vermont). VocRehab Vermont receives referrals from DES of individuals with disabilities and provides intensive, wrap around services and vocational counseling. The VocRehab Vermont counselor becomes the individual's case manager for both welfare benefits and VocRehab Vermont assistance, and provides an array of VR services aimed at assisting an individual to understand the disability and needed accommodations and to obtain training, education, and rehabilitation services to become successfully employed.

**Governor's Commission on Employment of Persons with Disabilities** has a mission to promote equal access to employment for all of Vermont's citizens with disabilities. Members serving on this commission are appointed by the Governor and represent various disability, business, and provider organizations.

Federal legislation regulating the Division of Vocational Rehabilitation and the Division for the Blind and Visually Impaired is the **Rehabilitation Act of 1973** as amended. In addition, the Americans with Disabilities Act and its regulations protect individuals with disabilities in employment practices. Other supporting legislation includes Medicaid Waiver rules, the Workforce Investment Act, the Mental Health Parity Law, Social Security Work Incentive Act and Fair Labor Polices.

To inform this Olmstead Plan, representatives of the above employment organizations developed the following list of the **effective programs and practices** that currently assist individuals with disabilities to become and remain employed:

- Supported employment - providing people with severe disabilities with intensive and long-term on and off work-site support.
- Interagency collaboration and excellent leadership that promotes collaboration.
- Benefits counseling - providing people receiving Social Security benefits with information about work incentives and how work will affect their benefits.
- Community Rehabilitation Treatment programs' case rate funding system.
- Professional development resources and technical assistance.
- VocRehab Vermont Transition counselors to assist students with disabilities transitioning out of high school.
- The Jump On Board for Success (JOBS) Program serving youth with emotional/behavioral disabilities.

- Apprenticeship programs.
- Increased focus on employment in the Agency of Human Services.
- Availability of assistive technology, particularly in the DET Career Centers.

Representatives prioritized three population groups where there are ***gaps in employment services*** for people who do not meet existing eligibility criteria: those with IQ scores between 70 and 80 who are not eligible for supported employment services, those with disabilities in the Corrections system, and those who need outpatient mental health services. Individuals with traumatic brain injuries are also in need of employment supports. In addition, shortages were identified in funding for services for those individuals not eligible for other employment programs; job training programs such as job shadowing, on-the-job training programs, internships, etc.; and summer youth programs and job programs for youth over the age of 18.

Infrastructure gaps were identified as being in the areas of transportation, providing information to consumers regarding housing, positive attitudes toward work, work incentives, and in housing options for individuals with low incomes. There also is a need for specialized programs and or accommodations for people who are deaf, hard of hearing, late deafened and deaf blind, including summer youth employment programs for deaf children; vocational rehabilitation service geared towards people who are deaf/hard of hearing, and the need to educate companies about using interpreters when interviewing deaf/hard of hearing candidates, for meetings, and so forth.

## ***Employment Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Need for expanded supported employment programs.	A total of approximately \$2,380,000 would be required annually to address the unmet need for services for approximately 1,000 individuals.	Employer education; Service coordination
Need for targeted case management and supported employment services for those with disabilities that do not meet existing program criteria (e.g. IQ's between 70 and 80, mild to moderate traumatic brain injuries, etc.)	A total of approximately \$250,000 would be required annually to address the unmet need for services.	Assessment of need; Service coordination
Lack of summer youth employment programs	A total of \$522,000 would be needed annually to address this need.	Job development; service coordination with DOL.
Need for work experience and on-the-job training programs	A total of \$522,000 would be needed annually to address this need.	Job development; employer education; coordination with State Dept. of Human Resources
Need better transition planning for students receiving special education services to increase job readiness, job development, and long-term job placements.	None identified.	Increased communication between school districts and agencies that provide employment services for adults, including education to school districts about the IDEA federal requirement for transition planning



## EDUCATION

One of Vermont's core Olmstead populations are children with developmental disabilities, or children with serious emotional disturbance, who are vulnerable to institutionalization, or are at risk of receiving services or supports in more restrictive placements. Many, though not all, of these children are eligible to receive special education. The federal **IDEA**<sup>21</sup> (**Individuals with Disabilities Education Improvement Act**) of 2005 and its implementing regulations mandate that children with disabilities who are eligible to receive special education be provided with a free and appropriate public education (FAPE) in the least restrictive and most integrated manner possible.<sup>22</sup> The Vermont Department of Education (DOE) has the ultimate responsibility to ensure the IDEA's implementation; the responsibility to provide a free and appropriate public education lies with the local educational agency (LEA) which in Vermont is the local school district, or supervisory union. Vermont's Agency of Human Services (AHS) and its member departments are responsible for supporting these children and their families toward successful outcomes in their broader functioning.

In FY2000 three major reports regarding special education became the impetus behind the passage of a major piece of Vermont education legislation known as **Act 117**. The act required a comprehensive plan to increase the consistency and quality of special education and to lower cost increases. The legislation assigned responsibility of the Educational Support System in every school system to superintendents and principals. It requires the Commissioner of the Department of Education to report annually on: special education expenditures by school district, the rate of growth or decrease in special education costs, outcomes for special education students, the availability of special education staff, and the consistency of special education program implementation.

Regulations for Part B of the IDEA require each state to have a written agreement, or some other mechanism, for ensuring that services are coordinated and delivered in a timely and appropriate manner.<sup>23</sup> In Vermont this agreement is called the "**Vermont Interagency Agreement**." The most recent agreement<sup>24</sup>, signed by the Commissioner of the Department of Education and the Secretary of the Agency of Human Services in June 2005, provides expanded access to state and local interagency teams and to facilitate planning for wrap-around supports. This agreement sets out the guidelines by which services are organized and financed for those students that receive special education as well as services from one or more departments or divisions of the Agency of Human Services. The major components are summarized below:

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<sup>21</sup> Known as the Individuals with Disabilities Act, or IDEA, prior to this year's reauthorization. From July 1, 2005 through June 30, 2006, schools will operate under the new IDEIA statute along with state regulations promulgated under the IDEA of 1997. The department is preparing for the revisions of state regulations and will seek public comment during this process.

<sup>22</sup> For people who are deaf or hard of hearing, the term "integrated" may be more accurately described as "communicatively accessible."

<sup>23</sup> See 34 CFR 300.142

<sup>24</sup> This document may be found at [www.state.vt.us/educ/](http://www.state.vt.us/educ/).

- Coordinated Services Plan – Children who are eligible to receive special education and services by at least one AHS department are entitled to receive a Coordinated Services Plan. Those responsible for developing the plan include representatives of education, the appropriate departments of the Agency of Human Services, and parents or guardians or other natural support persons. The Coordinated Services Plan includes the Individual Education Plan (IEP) as well as human services treatment plans, and is organized to assure that all components are working toward compatible goals. Funding for each element of the plan is identified and a lead service coordinator is assigned to serve as a contact person and assure the plan is regularly reviewed.<sup>25</sup>
- Local Interagency Team - Local Interagency Teams (LIT) exist in each of the 12 AHS regions, they include: a special education director, the local children’s mental health director, the Family Services director, a family consumer representative, local leaders from developmental services and substance abuse, and a Voc Rehab (VR) representative. This team supports the creation of a local system of care and assures that staff are trained and supported in creating Coordinated Services Plans. Their other roles include assuring there is a structure to focus on the particular needs of transition-age youth to support transition from school to adult life. Similarly, special attention is given to address the needs of children ages 3 to 6 that must include the Child Development Division.

If there is a problem, or failure, in the forming of a service coordination team, or if the Coordinated Services Plan is not satisfactory an involved party may request a meeting of the LIT to address the situation. If a team believes that a child or youth requires highly intensive services in residential care or intensive wrap-around services, the plan shall be reviewed and approved by the Case Review Committee (see below), except as otherwise provided by law.

- State Interagency Team- The State Interagency Team (SIT) includes a high level manager from the following departments and divisions: Department of Education (DOE), Division of Mental Health (DMH), Division of Disability and Aging Services (DDAS), Division of Family Services (DFS), Division of Alcohol and Drug Abuse Programs (ADAP), Division of Vocational Rehabilitation (VR), AHS Field Services, and other units as determined by the AHS Secretary. A family consumer representative will also be a core member. The SIT is responsible for overseeing development and maintenance of the system of care to address the needs of children with eligible disabilities, for assuring the consistent development of Coordinated Services Plans, and is part of the dispute resolution process.
- Case Review Committee- The SIT is required to establish a Case Review Committee that meets regularly to review the recommendations of service coordination teams for intensive services like residential care and wrap-around services. The CRC serves both as a control to assure the appropriateness of high cost placements in the least restrictive environment, and also as a consulting body for local teams.

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<sup>25</sup> From “Interagency Agreement with Vermont Department of Education and Vermont Agency of Human Services”, June 2005.

Following are other laws, policies, and programs that support children and youth with disabilities in the educational system:

**Vocational Rehabilitation Services-** Voc Rehab (VR) is required under the Rehabilitation Act of 1973, as amended by the Workforce Investment Act of 1998, to coordinate policies and procedures with education officials to facilitate the transition of students with disabilities from school services to the receipt of vocational rehabilitation services from the VR agency.<sup>26</sup>

**VR Transition Counselors-** VR Transition Specialty Counselors are available in many Vermont high schools. These specialized counselors exclusively serve youth in transition and therefore offer a higher level of expertise and service on transition issues and requirements. At least one of these counselors is based at one of the largest high schools in the state the others are on-site in the schools multiple times per month.

**Bridges to Self Sufficiency-** The Bridges Project makes benefits planning and other assistance available to every student with a disability of transition age and provides accurate information to youth and their families on the impact of employment on all the federal and state benefits they receive. Benefits Counselors from each AHS district office work with the special education staff in the schools in their district on a regular basis.

**JOBS Program-** The JOBS Program offers vocational services and intensive case management to high-risk youth with emotional behavioral disabilities in 11 of 12 AHS districts through a partnership between VR, DMH, DFS and the Department of Corrections (DOC). The program serves high school drop-outs and those at high risk of dropping out and engages them in employment services while providing a bridge to more intensive mental health and case management services.

**Vermont Assistive Technology (AT) Project-** The AT project provides services to schools and students through the Assistive Technology Act of 2004 and through a formula grant from the Department of Education. The project provides evaluations, consultation and technical assistance to children with disabilities in public schools. Equipment tryout and training is provided to students, educators, other providers and family members. Access to AT is a slow process with students often waiting an entire school year before AT recommendations are implemented, if at all. When AT is purchased for a student, its use is often abandoned because there is no one at the school to provide technical support. Few school personnel are informed about the use

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<sup>26</sup> “Transition Services” are defined in the IDEA as a coordinated set of activities for a child with a disability that: Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. Is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests. [Underlined words were added in the IDEA, 2004]

of AT and how much it can impact a student's educational experience. For those schools who do request an AT evaluation, finding a qualified person in Vermont can be challenging.

There is very limited access to Driver's Education for students with disabilities, as there are only two places in Vermont that conduct adaptive drivers' evaluations. In addition, many of the driver education programs do not provide sign language interpreters for driving classes/training.

**Building Effective Supports for Teaching Students with Behavioral Challenges (BEST)**- One of the requirements of Act 117 is to strengthen the educational support system by focusing on prevention and intervention for students with emotional and behavioral challenges. The BEST project is an initiative of the Department of Education and the University of Vermont that works to build the capacity of educators in all regions of the state to develop effective strategies, interventions, and curricula for the students that are experiencing these challenges.

**State Improvement Grant (SIG)**- This is a three-year competitive grant from the U.S. Department of Education that runs from October 2004 through September 2007. The grant helps to fund the Early Childhood/Early Childhood Special Education program and the Intensive Special Needs Program. In addition it provides funding for training for speech language pathologist assistants; transition services for students with disabilities; and support for related service providers.

**Autism Consultant**- The passage of Act 117 facilitated the hiring of an Autism Consultant within Department of Education (DOE). This person provides technical assistance and presentations to school teams and other interested parties as well as spearheading and coordinating a variety of other initiatives around the state designed to increase Vermont's capacity to serve children with autism and their families effectively. During the past 10 years, there has been an increase from 27 students with autism in the 1993 child count to 315 students with autism in the 2003 child count. More recently, as part of its re-organization, an **AHS Autism Specialist** was hired to provide technical assistance across all of AHS regarding service provision for people with autism, including coordination with the Autism Consultant at DOE. These new positions are vital for raising awareness and providing training opportunities and other resources related to autism, as many families encounter difficulties due to the lack of qualified school staff who can develop and implement programs for students with autism.

**Department of Education's Special Education Technical Assistance Line**- (802) 828-5114. Parents, educators or other providers may call this line and speak with a special education consultant at the Department of Education.

**Community High School of Vermont (CHSVT)**<sup>27</sup> CHSVT Is a statewide alternative school that primarily serves individuals in the custody of the Department of Corrections (DOC). There are 15 campus sites composed of 8 sites in the correctional facilities and 7 community-based sites. Vermont state law has a mandatory education requirement

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<sup>27</sup> Information summarized from: *Community High School of Vermont (CHSVT) Annual Report July 2001- June 2002.*

for anyone in custody under the age of 22 and without a high school diploma; therefore these individuals are automatically enrolled in CHSVT upon entering custody. The DOC also is required under state and federal law<sup>28</sup> to provide a free appropriate public education to all incarcerated youth with disabilities who are under the age of 22 and who require special education and related services. These regulations also require that educational staff contact the individual's former school and determine the status of their individual education plan (IEP) within two weeks of the intake interview. The education staff are required to follow all other appropriate state and federal laws and regulations concerning special education for incarcerated youth eligible for those services. On average, forty-five percent of CHSVT students have prior histories of Special Education, creating high demands for DOC resources.

Obviously, there many programs and services in Vermont to assist children and youth with disabilities to be successful in school. However, there are still gaps. First, there are **not enough qualified individuals** (such as para-educators, special educators, and specialized providers) to work with children receiving special education services. Additionally, special education services and consultants for children with autism spectrum disorders and emotional and behavioral disabilities are not fully available, especially in rural settings. There also is a need for **additional supported services** such as case management and teaching independent living skills for youth who are deaf with minimal language skills (MLS) who tend to be overlooked in the special education program.

Many youth that were eligible for special education and related services throughout their school careers do not meet the **stricter eligibility definition for adult developmental services** creating a "black hole" of adult services for this population. These individuals may only be eligible for services from the Division of Vocational Rehabilitation that are not designed to provide the full array of services that this population so often needs to successfully transition from school to adult life.

While federal special education law provides the mandate and funding reimbursement for special education related expenses, school personnel know too little about **transition planning and services** to provide equitable and comprehensive access to community employment, independent living, community participation, and post secondary education and training for students with disabilities 14 through 22. Many children with disabilities graduate from high school without being evaluated for, or connected with, adult services. This problem is being compounded by a push by many schools to graduate children with significant disabilities earlier than had been the custom. Traditionally, children with more severe disabilities were able to remain in school through their 21<sup>st</sup> year. Given the potential lack of services once they graduate, transition services should include the provision of case management to teach independent living skills. Most children need this support to transition to independent living, but this is especially true for children who are deaf or hard of hearing who are usually ineligible for case management once they become adults.

Finally, AHS has convened a transition work group to address issues related to youth aged 16 – 22. Recommendations have been forwarded to the Secretary.

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<sup>28</sup> 16 VSA § 120(e) and 34 CFR § 300.2(b)(4).

## ***Education Challenges to Community Integration Faced by Children and Youth with Disabilities***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Transition from school is difficult for some students due to differences in the categorical disability designation for “learning impaired” (developmental delay) for special education and the eligibility criteria for Adult Developmental Services.	None identified.	<ul style="list-style-type: none"> <li>• Review the eligibility criteria for the two systems to identify possible strategies for facilitating transition.</li> <li>• Better coordination between adult employment and human service agencies and schools to plan for transition.</li> </ul>
Transition services are not provided equitably due to lack of school personnel knowledge about transition planning	None identified	DAIL provides in-service training for key school personnel about transition planning and available services.
There is a lack of services within schools to assist students with transition.	Information not available.	Increase the availability of services within schools, such as case management and teaching Independent Living Skills for all students with disabilities.
There is a waiting list for Community Based Transition Services due to lack of job coaches and lack of available transportation to access other community based transition services.	Information not available.	Transportation could be considered a related service and therefore a responsibility of the IEP team.
Limited access to Assistive Technology Evaluations, Equipment and Training in each school district.	It would require approximately \$1,650,000 annually to fund a .5 FTE for each school district	<ul style="list-style-type: none"> <li>• More accountability in IEP process around the use, purchase and support of AT</li> <li>• Provide more training for school personnel and other service providers about accessing AT and AT use.</li> </ul>
Limited Access to Adaptive Driver’s Education, as there are only two places in Vermont that conduct adaptive driver’s evaluations and almost no availability of interpreters.	Information not available.	None identified.

## FAMILY SUPPORTS

Family support has been defined as “supports...provided to people with disabilities living with their natural or adoptive family,”<sup>29</sup> or more broadly by family advocates as “whatever it takes to promote family integrity and enhance the quality of family life.”<sup>30</sup> In the area of Family Support, Vermont ranks consistently at or near the top in the country across measures of developmental services<sup>31</sup>, children’s mental health<sup>32</sup>, and health care<sup>33</sup>.

Federal Laws enacted to advance and protect the rights of people with disabilities also contribute to advancing family supports and integrity. The major federal laws are: Section 504 of the Rehabilitation Act of 1973 as amended, the Americans with Disabilities Act (ADA), the Developmental Disabilities Act (DD Act, which incorporates the Support for Families of Children with Developmental Disabilities Act), the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI Act), the Individuals with Disabilities Education Act (IDEA), and the Fair Housing Act. These all share the goal of eliminating discrimination against people with disabilities and supporting their inclusion in the community.

The federal **home and community-based Medicaid waiver for developmental services** is one of the primary vehicles for accomplishing a totally community-based system. These services include: service coordination, employment, community supports, home supports, respite, clinical interventions, and crisis services. In addition, in 1993 Developmental Services expanded the options in its respite program to create **Flexible Family Funding**. Families have the discretion to use this funding for anything they feel will strengthen their ability to maintain their child or adult with a disability at home. Even though the funding per family per year is limited to \$1122 this program is one of the most appreciated by those it serves.

In Children’ Mental Health Services, Vermont’s ten designated agencies and one specialized services agency served 10,040 children and adolescents in SFY 2004. Vermont has a strong commitment to serve children and adolescents in their own home, school, and community as articulated in **Vermont’s System of Care Plan for Child, Adolescent, and Family Mental Health**. Despite this preference many parents ended up relinquishing custody of their children to the state because that was the only way federal funds became available to assist their children. In 1996 the Vermont Legislature passed **Act 137**, targeted to prevent this unnecessary release of children into state custody. The Act states, “the receipt of appropriate services for a child or adolescent

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<sup>29</sup> *Annual Report Division of Developmental Services*. (2004) DDMHS, State of Vermont, p.42.

<sup>30</sup> “Position paper on family support,”VCDR Committee on Family Support, in *Family Support Services for People with Disabilities*. (1993). Vermont Developmental Disabilities Council.

<sup>31</sup> Rizzolo, M.A., Hemp, R., Braddock, D., & Pomeranz-Essley, A. (2004). *The State of the States in Developmental Disabilities*. Washington, DC: AAMR.

<sup>32</sup> *Vermont System of Care Plan for Children and Adolescents with a Severe Emotional Disturbance and their Families*, 2001, DDMHS, p. 41.

<sup>33</sup> Murphey, D. (2004). *The Social Well-Being of Vermonters*. Waterbury, Vermont Agency of Human Services.

with a severe emotional disturbance or the child or adolescent's family, including an out-of-home placement, shall not be conditioned on placement of the child or adolescent in the legal custody, protective supervision, or protection of the department of social and rehabilitation services." Since the passage of this law the **numbers of children entering custody** as "unmanageable" and the number of families voluntarily relinquishing custody have declined dramatically. Other changes during the same period that contributed to this decline include the initiation of the **Children's Mental Health's "Access Vermont" crisis outreach program** which began to serve unmanageable children, and the decision of the former SRS to stop accepting custody of children over 16 years old except in exceptional cases.

Families and advocates have called for **equity in funding, consistency of practice across geographical regions, and functional eligibility criteria across programs versus categorical criteria**. Although some disability determination is based on limitations in activities of daily living (ADL's), eligibility for developmental services also still mandates an IQ measurement of 70 or below (with the exception of people with a diagnosis of Pervasive Developmental Disorder). Vermont Coalition for Disability Rights (VCDR) has sought to create equity and expand Flexible Family funding to other groups. Attempts to create a single Children's Waiver across programs have not been successful due in large part to rules that maintain distinctions between different Medicaid programs.

**Workforce issues** repeatedly top the list of concerns for people with disabilities and their families in Vermont. The lack of available support workers puts tremendous stress on families. At an Olmstead public forum a mother spoke of going for many nights without sleep when LNA's called in sick; another mother spoke of being reported to SRS because she had no choice but to leave her son with autism in the car so she could pick up some groceries for her family; a man with mobility impairments worries every year that the legislature will change the attendant care program and disallow payments to his wife. The *Paraprofessional Staffing Study* completed in 2001 by Joy Livingston found that, "While the demand for services may grow up to 50% (in the next 15 years), national estimates suggest that the labor force will increase by only 12% over all age groups."

Studies have found the major barriers to recruiting and retaining a paraprofessional support workforce to be: lack of training, lack of benefits, and low wages. For example, support workers may attend trainings provided by Developmental Services and designated agencies free of charge but, since all funding is based on individual budgets, the only method of payment available for the hours they spend in training is by using hours from a recipient's respite/flexible family funding or waiver budget. In other programs, this mechanism is not available. No specific training is available for workers in families who self-manage their personal care services. Often, benefits are only available for support workers hired as employees of agencies. Wages for support workers tend to be low and are not aligned across programs, potentially leading to workers following the pay.

The state and non-profit advocacy organizations are attempting to work on these issues. In 2003, the Community of Vermont Elders (COVE) received a three-year grant from the Robert Wood Johnson Foundation to expand training programs, broaden the



reach of support workers in rural areas, and advocate for higher wages and benefits for support workers. Also, a professional organization for care providers has been formed and will make recommendations regarding support workers across providers.

**Service Coordination** is particularly difficult for people with multiple disabilities and families with children with multiple disabilities. Families are juggling staff from multiple agencies which may not or will not communicate with one another. Many families do not receive case management for their child with multiple needs unless the child receives Home and Community Based Waiver services. Vermont has not implemented the EPSDT (children's Medicaid) case management for personal care services. Studies recommend Vermont pursue this option.

One way Vermont is addressing care-giver shortages and the issue of multiple case managers is by **paying certain family members of adults to provide care**. The Home-based Medicaid Waiver under the Department of Disabilities, Aging and Independent Living pays all family members of adults except spouses and civil union partners. The Attendant Services Programs pays all family members of adults, including spouses and civil union partners. Parents, spouses, or civil union partners cannot be paid under Developmental Services Home and Community Based Waiver and Flexible Family Funding programs; however, siblings and other family members can be employed as supports. The inconsistency across these programs regarding which family members can be paid, and whether parents should be paid, often is a source of disagreement, confusion and frustration for people and their family members.

**Self-management of services** is available in Children's Personal Care Services, Developmental Services waivers and the Attendant Care Programs. Self-management may maximize money available for direct support and increases personal choice and control for people with disabilities and their families. Overall this option has been positively received with the exception being when individuals and families have no other option in regions where there is not a personal care service provider. (Note: This availability of more money for direct support occurs most dramatically in Children's Personal Care Services, where families are able to pay \$10 an hour, versus the \$8 rate for services provided by an agency.)

**Supports for parents with disabilities** has been identified as a priority by the Division of Disability and Aging Services, Vermont Developmental Disabilities Council, Vermont Protection and Advocacy, and the Center on Disability and Community inclusion at the University of Vermont. Statistical projections of the numbers of parents with disabilities raising children 6 and under in Vermont is approximately 600 families and presumably a comparable number of families are raising older children. There were 48 parents with developmental disabilities raising children at home who were supported through developmental services in FY '05. A new grant has been awarded to the Agency of Human Services from the federal Administration on Developmental Disabilities to provide support to parents with disabilities not supported through existing programs.

**Aging parents of people with disabilities** is also a major concern, as many people with disabilities still live at home. These parents are concerned about continued support for their children as they age, and the availability of services if they can no longer care for their adult sons or daughters.

**Parents of deaf children or deaf parents of deaf or hearing children** also need more support and resources in order to be better parents and to help manage their responsibilities. All family support services need to be better aware of these issues, and provide communication accommodation when needed (i.e. sign language interpreter, Computer Aided Real Time Captioning (CART), or other assistive devices depending on each individual's needs). Family support services could contract with agencies that are "experts" on deafness to provide support/and or resources; these agencies could also assist with communication for deaf children who are in DCF custody.

**Public input from people with disabilities and their families** has a proud history in Vermont. In 1997 advocacy by disability groups resulted in the passage of the Governance Bill that mandated the majority membership of people with disabilities and/or their families on boards of community mental health / developmental disability centers. The Agency of Human Services Reorganization has emphasized stakeholder and family input throughout the process. Input was received through focus forums, a State Advisory Group, the State Team for Children and Families and regional Consumer Advisory Boards.

## ***Family Support Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
<p>Support for a valued, adequately reimbursed and well-trained workforce.</p>	<p>see sections on workforce needs for Mental Health, Developmental Disabilities, and Elders and People with Physical Disabilities</p>	<ul style="list-style-type: none"> <li>• Develop a strategic plan for recruitment, including high schools, vocational programs, colleges, churches or synagogues, people who have attended CCV trainings</li> <li>• Collaborate with Refugee Resettlement to match workers to jobs</li> <li>• Compile statewide and regional registries of workers</li> <li>• Investigate new approaches to building job satisfaction in the Direct Support Workforce</li> <li>• Identify outstanding workers and “shadow” them, documenting with video, identifying elements of success</li> <li>• Investigate on-line courses from National College of Direct Support</li> <li>• Establish incentives tied to achievement of Individual Service Agreement objectives</li> <li>• Investigate equity in wage scales; establish clear criteria for competitive wages</li> <li>• Investigate rates for pooled insurance costs covering all direct support workers across system</li> <li>• Encourage workers to join new direct service worker organization</li> <li>• Hold an annual conference for direct support staff</li> </ul>

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
<p>Need for better service coordination, flexibility, service equity, and support for aging parents and parents with disabilities.</p>	<p>see section on Developmental Disabilities</p> <p>Support for parents with disabilities would require an additional \$600,000 annually for 70 families to receive a minimum of 8 hours direct support plus 2 hours case management weekly.</p>	<ul style="list-style-type: none"> <li>• Develop the capacity in each AHS region for navigators, case managers, service coordinators, and community partners to work collaboratively as a team with the individual and family to provide integrated services and supports that are responsive and respectful.</li> <li>• Identify areas where rules can be applied more flexibly (and equitably across regions)</li> <li>• Educate families and service providers on Act 137 and about best practices</li> <li>• Hold a conference for aging parents with examples of successful strategies for building good lives in the community for their sons/daughters; have good service coordinators available to do pre-planning; have parallel meeting for individuals (similar to Real Choices workshops for students in transition and their families)</li> <li>• Investigate why some eligible individuals/families do not apply for funding/services</li> </ul>
<p>There is a gap between those diagnostically eligible for developmental services and those who meet annual funding priorities for access to services.</p>	<p>see section on Developmental Disabilities</p>	<p>Explore implications of implementing the demand model within the Designated Agency Consultant report</p>
<p>Moratorium on Medicaid waiver services for children.</p>	<p>see section on Developmental Disabilities</p>	<p>see section on Developmental Disabilities</p>

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Need support services for deaf parents of either hearing or deaf / hard of hearing children.	Cost is unknown.	
Need for transparent appeals and complaints procedures, and inclusion of people with disabilities and their families in outcome reporting.	It would require a total of approximately \$50,000 annually to fund a DS Ombudsman.	<ul style="list-style-type: none"> <li>• Implement Real Choices Quality Assurance Grant</li> <li>• Assure uniform grievance and appeals processes across all programs under the Global Commitment to Health Medicaid Waiver</li> </ul>

## **ASSISTIVE TECHNOLOGY**

Nine percent (21,657) of Vermont households have someone who needs or uses assistive technology to help them work, attend school or manage day-to-day activities. As previously noted, the mission of the Vermont Assistive Technology Project (VATP) is to increase awareness of and provide access to assistive technology (AT) for all Vermonters with disabilities. Their goal is to expand the availability of AT services, devices, training and support to help Vermonters with disabilities to have greater independence, productivity and confidence in their homes, at work, at school and in the community.

In part, VATP carries out its mission by coordinating with other organizations to provide education, outreach and information dissemination. These organizations include the rest of DAILE, Department of Education, Department of Labor, Vermont Parent Information Center, Vermont Center for the Deaf and Hard of Hearing, Vermont Center for Independent Living, and the UVM Center for Disability and Community Inclusion, just to name a few.

In FY '04, VATP provided services to over 2,700 consumers. Targeted groups were senior citizens, special education professionals, employers, and parents of children with disabilities, childcare providers, and health professionals such as speech language pathologists, occupational therapists and physical therapists. Services included technical assistance, awareness activities and training; demonstration, try-out and loan of AT equipment.

There is a tremendous need for opportunities to try out AT devices, do research on appropriate devices and their applications, and training for individuals (and their support persons if applicable) to use these devices. Follow-up and technical assistance are also needed. Federal AT funds do not allow for direct services to individuals; however, a limited number of students are provided direct services with a grant from the State Department of Education. In addition, VATP has a loan fund program administered

through the Vermont Opportunities Credit Union which offers low interest, long term loans to consumers for AT. In October 2003, Vermont received \$635,000 from a federal grant to increase the number of AT loans available to Vermonter with disabilities. The total amount of the loan fund is approximately \$1,200,000.

At a minimum, people who work for or with nursing homes, home health agencies, councils on aging, community care homes, community mental health agencies, and community action councils should be knowledgeable about the existence of AT and how to access AT information and services for their consumers and how to get AT and related services reimbursed. Currently, this knowledge is not wide-spread. Adding one ATP (Assistive Technology Practitioner, a nationally recognized credential) in each AHS region would be a first step. ATPs would work with VR, DOL, DDAS, home health, nursing homes, etc. to assist people to stay in their communities by using AT in employment, education, housing and activities of daily and independent living.

Assistive technology for people who are deaf, hard of hearing, late deafened and deaf blind is also lacking. There is limited access to high speed internet, which makes it difficult for the deaf and hard of hearing to make video calls. There also is limited coverage for pagers (e.g., blackberry, T-mobile sidekick, Sprint Treo). To make services and community resources truly accessible, real-time captioning should be available everywhere. Emergency response capacities must also be accessible for people who are deaf or hard of hearing (e.g., televised emergency messages should be close captioned). Finally, all public buildings should provide a FM loop system for better communication.

### ***Assistive Technology Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Limited access to affordable AT services, including assessment, evaluation and purchases.	It would require approximately \$600,000 annually to fund one Assistive Technology Practitioner in each AHS region to work with VR, DOL, DDAS, home health, nursing homes, etc. to assist people to use AT.	Inclusion of AT needs in discharge planning in hospitals and other healthcare and rehabilitation facilities.
Limited access to AT evaluations, equipment and training in each school district.	See section on Education	See section on Education
Specific assistive technology is not widely available for people who are deaf, hard of hearing, late deafened and deaf blind	Information not available.	None identified.

## TRAUMA- INFORMED SERVICES

The effects of trauma on the lives of people with disabilities directly relate to the goals of the Olmstead Commission. For example, data indicate that up to 70% of the individuals accessing mental health and substance abuse services in Vermont have histories of significant physical and sexual abuse; more than 70% of women offenders in the Corrections system were abused as children, and the same percentage were abused as adults. The effects of these experiences can be devastating to individuals' abilities to succeed in life, and also can have consequences for the willingness of people to accept or engage in services and supports. Workforce recognition and understanding of these dynamics is vital to effective engagement and service delivery.

Building on a 2000 Legislative Report of the Summer Study Commission on Psychological Trauma, in March 2001 the AHS Secretary created an internal AHS Trauma Workgroup. This workgroup drew together representatives of all the AHS Departments, as well as the National Trauma Center of the White River Veteran's Administration. In the fall 2002, the Trauma Workgroup added consumer and direct service provider representatives to enhance its knowledge and expertise. The mission of the Trauma Workgroup has been to assist the Agency to have a "**trauma-aware and trauma-sensitive human services environment**" which acknowledges the role that trauma of all kinds – experiences of abuse and violence, natural disasters, and terrorist attacks – play in the lives of many individuals served by AHS and their families, and which is void of potentially re-traumatizing practices.

Through the work of the formalized interagency workgroup (the "Trauma Policy Cluster"), AHS has provided trauma training and consultation for its leadership (in 2002) and promulgated an **AHS Policy Statement on Trauma** in 2004. In addition, individual departments have supported various efforts to identify and work on issues related to trauma, but they have been relatively isolated events. Notable achievements include trauma training for all Department of Correction staff working on its women's units, as well as over 600 AHS staff.

AHS has recently hired a **Trauma Coordinator** who sits within the Secretary's Office. The Coordinator's role is to develop a statewide plan for enhancing the delivery of trauma-informed services throughout AHS and its contracted providers, including developing a self assessment protocol for departments and divisions; identifying and modifying policies and practices which may re-traumatize, or otherwise constitute barriers to access to services; promote the incorporation of relevant screening for trauma of AHS clients into existing service activities; identify and disseminate information about examples of "best practice" currently in use in Vermont and nation wide; establish competency-based training goals and resources to ensure that AHS services are provided in a trauma-sensitive culture; collaborate and coordinate activities with other related organizations and projects; and develop tools to enhance treatment services for trauma such as a resource directory, brochures and other information venues to assist trauma survivors in choosing service providers and therapists. As mentioned in the section on mental health services, lack of trauma-specific services in the community is a major impediment to effectively supporting Vermonters with disabilities that also have trauma histories.

## Trauma-Informed Services Challenges to Community Integration

Challenges	Financial Implications	Other Actions Needed
Need to create trauma-sensitive systems and work environments within AHS through staff training and through reviews of policy and practices and revisions.	\$30,000 Total annually (staff training)	Revision of policies and practices that are not conducive to serving people with trauma histories
Lack of availability of trauma-specific services that provide treatment and supports to individuals affected by trauma	See section on Mental Health Outpatient services	Inventory existing professional resources available throughout the state with the expertise to treat individuals with trauma histories.
Lack of information about best practices, and guides for finding trauma-specific services.	None identified	Develop best practice and resource guides for finding trauma services; broadly distribute in accessible locations and on the web

### LEGAL SYSTEM AND PROTECTIONS

The Olmstead Commission identified the legal system and access to justice for people with disabilities as areas of great importance in determining the degree to which Vermont is meeting the goals of state and federal disability policy. A commission sub-committee asked the providers of legal services for people with disabilities, the Court Administrator's Office, the Attorney General's Office, the Defender General's Office, the Department of Children and Families, the Department of Corrections and others to attend a forum on legal issues and/or submit comments in writing. The organizations and departments were provided with information on the Olmstead Commission, the key analytical questions and other questions directly concerning access to justice issues.<sup>34</sup>

Section 504 of the Rehabilitation Act and its amendments, the Americans with Disabilities Act (ADA), The Developmental Disabilities Act (DD Act), the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI Act), and the Protection and Advocacy for Individual Rights Act (PAIR Act) are the primary federal laws **protecting the civil rights** of people with disabilities.

There are several organizations in Vermont whose mission is in whole, or in part, to provide legal services to protect and advance the human and civil rights of people with disabilities:

**Vermont Protection and Advocacy (VP&A)** is a statewide independent agency dedicated to advancing the rights of people with mental health and disabilities issues.

<sup>34</sup> The set of questions are contained in the legal plan brief.



VP&A investigates complaints of abuse and neglect (verbal and physical abuse, sexual assault, restraint and seclusion, forced treatment) and complaints of violations of individual rights (right to refuse treatment, right to privacy, access to medical records, confidentiality).

**Vermont Legal Aid, Inc.** has two projects dedicated to providing free legal services to Vermonters with disabilities: the *Mental Health Law Project* which represents people facing involuntary psychiatric treatment; and the *Disability Law Project* which represents people with disabilities in legal matters related to their disability such as: discrimination, public benefit issues, special education, and guardianship.

**The Human Rights Commission** conducts impartial investigations of discrimination complaints regarding housing, state government, employment, and public accommodations for people with or without disabilities. Discrimination based upon disability may or may not be the basis of a person's complaint.

The Barrier Free Justice Project and the Communication Support Project are two grant-funded programs whose mission is to insure that people with disabilities have equal access to the justice system:

The **Barrier Free Justice Vermont (BFJV)** provides advocacy, support and legal representation to Vermonters with disabilities who have been victims of crime. Project staff provide support and advocacy to victims/survivors of crime from initial disclosure through resolution in District or Family Court.

The **Vermont Communication Support Project (VCSP)**, funded by the Vermont Developmental Disabilities Council, serves people with disabilities whose communication problems prevent them from participating fully in certain Family Court (Children in Need of Supervision, Termination of Parental Rights, Divorce/Parentage, Abuse Prevention Order) and Probate Court proceedings. VCSP serves victims in criminal proceedings through the Vermont Center for Crime Victim Services. They will provide a communication specialist to assist the person with a disability in communicating with the judge, court staff, attorney, or other necessary persons.

Public defender offices need social workers or caseworkers to assist in identifying and **accommodating disabilities in the criminal and family court systems**. Busy attorneys who are not trained in disabilities can miss cognitive impairments or not follow up on creating community plans for people in the criminal system. Having a trained social worker to assist in evaluating the individual's strengths and weaknesses and to help organize a plan to keep the individual living safely and successfully in the community would significantly reduce incarceration and recidivism. Coordination of services is crucial in most cases. Finding community supports in addition to agency support can also make a tremendous difference.

When the Disability Law Project seeks public comment on priorities for Vermonters with disabilities, which is done annually, employment and access to health care are consistently identified as the areas of greatest need for people with disabilities. The Mental Health Law Project has had a 20% increase in cases in the last three years with no increase in funding. Additionally, the MHLP does not receive any funding to offer

advice to people being held for a 72 hour hold related to potential involuntary civil commitment, and only minimal funding (executed by VP&A) to advocate for these individuals. Lawyers for people with mental disabilities also are needed in divorce and child custody cases. Landlord/tenant and eviction cases are another area where legal assistance is needed. Currently, the Vermont Volunteer Lawyers Project does not have enough lawyers available to assist in this area. Suggestions to address this need include: increased funding to Vermont Legal Aid/ Disability Law Project; seeking grant funding; using law students to assist and working with the Vermont Bar Association to try to fill this need.

In addition, **training** for everyone that staffs Vermont's justice system is critical to achieving equal access to the court system for people with disabilities. Vermont has an ADA compliance officer in the office of the Court Administrator. Courts are generally good about accommodating deaf litigants and are improving on accommodating people with developmental disabilities thanks to the Communication Support Project. They still need improvement regarding how to handle TTY calls, how to provide Computer Aided Real Time Captioning (CART), and how to provide a sign language interpreter for all court proceedings. Also, courthouses need to install FM loop systems for people who are deaf or hard of hearing. Courts also could be better at accommodating people with other communication impairments resulting from TBI or strokes, and at accommodating people with mental illness.

The Department of Corrections needs specially trained officers to support community integration of persons with disabilities. All too often, persons with developmental disabilities are given conditions of probation that they may not understand or have the ability without accommodations to comply with. In this case, the probation officer interprets the person's failure to comply with these conditions as willful and deliberate, and files a charge of violation of probation. These often result in incarceration of the individual. Trained probation officers are needed to provide accommodations to enable these individuals to succeed on probation. Similarly, DCF workers need to receive adequate training in recognizing and accommodating people with disabilities.

Some courts have been receptive to training in the ADA and from the Communication Support Project. Some public defenders also are well-trained in the ADA; they have had ADA training at many of their staff colleges. However, all court staff, especially court clerks, need to be trained in recognizing people's needs for accommodation. In addition, lawyers need to be aware of their legal obligation to provide interpreters and other accommodations. The DLP (Disability Law Project of VLA), VP&A, the CDCI (Center on Disability and Community Inclusion) and other stakeholders have developed a curriculum relating to accommodations for people with disabilities in the legal system and are currently scheduled to begin training for Family Court Personnel in Rutland and DCF caseworkers statewide. An additional training gap is for police and other law enforcement staff about how to respectfully and effectively interview people with disabilities (e.g., people with autism).

**Adult Protective Services (APS)** is a public safety program within the Division of Licensing and Protection (DLP) charged with investigating allegations of abuse, neglect and exploitation of vulnerable adults in Vermont. APS also coordinates protective services for victims of abuse and conducts community education around the state to

improve reporting and the effectiveness of timely interventions that reduce or prevent abuse. APS is committed to proactively addressing the safety concerns of vulnerable adults through preventative, cooperative and solution-based interventions.

In FY 2004, APS received 2,061 reports of suspected abuse, neglect or exploitation of vulnerable adults. This marks the seventh consecutive year that abuse reports have increased. Physical and emotional abuse comprises 45% of the total number of APS investigations and financial exploitation comprises 31%. The percentages of sexual abuse and self-neglect cases have remained constant over the years at 7% and 4% respectively. Investigations into neglect of care allegations have increased recently from 8% to 13%. In FY 2004, 50% of investigations involved alleged abuse of vulnerable adults over the age of 60. In 41% of investigations, the vulnerable adult had a significant physical disability and in 37% of cases, a mental health or developmental disability was present.

Family and friends continue as the people most often reported for possible abuse of a vulnerable adult, which comprised 52% of reports. Professional staff were involved in 20% of the APS investigations. Private caregivers were involved in 10%. Concern has been raised by advocates that there is no systemic process for removing individuals who are being abused by caregivers from their situation, such as the child abuse system in Vermont, and that there also is a lack of available placements for long-term solutions.

Ongoing community education efforts by APS and collaborative efforts with other concerned groups and organizations have enhanced the public awareness of abuse issues, preventative actions and reporting responsibilities throughout the state. Continuing education, timely reporting, APS consultations and proactive interventions are critical activities to address the abuse issues of our vulnerable adult population. In FY 2004, APS made 1,129 protective service referrals to community service providers on behalf of vulnerable adults during abuse investigations to ensure that vulnerable adults received necessary care and services to enhance safety and quality of life.

AHS departments that contract with external agencies for services for people with specific disabilities also provide oversight regarding service quality and protections for vulnerable individuals. For example, DAIL has a nationally recognized system of monitoring and quality assurance for services received by people with developmental disabilities from the contracted designated agencies. The Division of Mental Health within the Department of Health also provides significant oversight for contracted services provided to children with severe emotional disturbances and adults with serious mental illness.

Another role of the Division of Licensing and Protection (DLP) within the Department of Disabilities, Aging and Independent Living is to ensure quality of care and quality of life to individuals receiving health care services from licensed or certified health care providers. One of its major activities is to provide regulatory **oversight of health care facilities and agencies** to ensure quality of care and services. DLP accomplishes this by conducting unannounced onsite visits both routinely and as a result of complaints received. The purpose of onsite reviews is to evaluate provider performance and to determine whether consumers are satisfied with the care and service. Surveys consist

of on-site reviews of all care and services, including interviews, record reviews and observations.

Most health and residential facilities are monitored / surveyed on at least an annual basis. Inspections, reviews, or surveys are designed to evaluate if care and services are safe and appropriate. Onsite visits, whether for a full review of the range and scope of services or for a complaint investigation, are unannounced and are conducted by registered nurses who have had extensive training in how to conduct broad-based or focused reviews. Providers receiving regulatory oversight and/or periodic review include: Nursing Facilities, Residential Care Homes, Therapeutic Care Residences, Assisted Living Residences, Home Health Agencies, Renal Dialysis Units, Rural Health Clinics, and Rehabilitation or Psychiatric Units.

Last year, staff of the Division conducted over 455 health care facility and agency onsite visits. Visits ranged in scope from a one-day focused review conducted by one staff person, to a five-day comprehensive review conducted by a team of registered nurses. All on-site reviews are followed by a written report to the facility. Reports that result from focused or comprehensive reviews and substantiated complaint investigations are public information.

The New England area, and Vermont in particular, continues to have among the best home health care and residential care services in the country. Vermont has relatively few regulatory deficiencies when compared to the rest of the country. In addition, indicators of nursing home care collected by the federal government show that Vermont homes frequently do better than the national averages, even though the average Vermont nursing home resident is sicker and more frail than the average US nursing home resident.

However, there are at least 12 private unlicensed agencies providing home care services (e.g. skilled nursing personal care, homemaking, assistance with medications and therapy) to elderly and disabled individuals. These agencies provide an unknown level and unknown quality of home care services. At present, there is no system of regulatory oversight for home care agencies that do not participate in the federal certification program. DAIL has no authority to respond to complaints.

## ***Legal System and Protections Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
<p>Better Training for Court, Corrections and DCF staff re: recognizing and accommodating people with disabilities.</p>	<p>All agencies receiving money from the Bureau of Justice Assistance (BJA) in the Department of Justice are eligible for free ADA training from BJA. Additional training specifically geared to judges and lawyers may be necessary, and would cost approximately \$4,000 per group (all judges) (all public defenders and assigned counsel).</p>	<ul style="list-style-type: none"> <li>• Implement training for Judges re: understanding developmental disabilities to avoid misunderstanding of individuals who appear before them.</li> <li>• Implement training for Public Defenders and Assigned Counsel re: recognizing persons with cognitive or mental disabilities and in advocating for the appropriate accommodations to enable safe community integration.</li> <li>• Incorporate specific accommodations for people who are deaf and hard of hearing into the training curriculum for court staff.</li> </ul>
<p>Defendants with disabilities have fewer resources to assist with Communication Barriers.</p>	<ul style="list-style-type: none"> <li>• An annualized estimate of \$5,000 for communication support project persons to provide assistance to developmentally disabled persons in the court process.</li> <li>• Approximately \$40,000 per caseworker per year to assist in identifying and accommodating disabilities in the criminal and family court systems</li> <li>• Continuation of the Communication Support Project currently funded by the DD Council= approximately \$50,000 annually</li> <li>• Resources for qualified interpreters for the deaf to provide for communication between law enforcement and access to the justice system</li> </ul>	<p>None identified.</p>

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
More legal representation of people with disabilities is needed in the areas of mental health, access to health care, guardianship, and employment discrimination	An annualized amount of approximately \$720,000 would be needed to meet the need for legal representation in these areas.	<ul style="list-style-type: none"> <li>• Seek grant funding</li> <li>• Use law students to assist</li> <li>• Work with the Vermont Bar Association to try to fill this need.</li> </ul>
There is no system of regulatory oversight for home care agencies that do not participate in the federal certification program.	An annualized amount of approximately \$160,000 would fund staff to provide this oversight.	Examine need for any state statutory changes.
There needs to be improved ability to respond promptly to allegations of abuse, neglect and exploitation against vulnerable adults and the capacity to focus on abuse prevention activities.	An annualized amount of approximately \$80,000 would fund staff to improve this capacity.	<ul style="list-style-type: none"> <li>• Review recommendations from APS study committee</li> <li>• Explore the need for revision of the APS investigative process to include a protocol for emergency abuse situations and placements outside of the home for abused vulnerable adults.</li> <li>• Domestic Violence programs develop and implement transition plans for facility and programmatic accessibility in partnership with DAIL and the Center for Crime Victim Services.</li> <li>• Explore implementation of activities to support prevention of abuse.</li> </ul>

## VOTING AND CITIZENSHIP

The Help America to Vote Act (HAVA), passed by Congress in November 2002 in response to the problems uncovered by the 2000 election, mandated states to pursue election reforms with the goal of making voting systems universal and consistent. The legislation requires states to make voting accessible to all citizens, especially those with disabilities. These mandates came with large appropriations to each state, starting with a planning grant followed by 3 federal fiscal year cycles of funding. Vermont received a total of 16.6 million dollars to comply with the act.<sup>35</sup> The mandates include:<sup>36</sup>

- Creation of a statewide voter checklist.
- Ensuring people with disabilities can vote privately and securely.
- Physical accessibility of polling locations.
- Voter and voting official education.
- A requirement for touch screen voting or a voter template by 2006.

In August 2005, Vermont became the first state to certify “Inspire Vote-by-Phone”, a voting system that allows voters to cast their ballots using a regular telephone.<sup>37</sup> The system was developed in cooperation with a variety of disability groups such as the Vermont Association of the Blind and Visually Impaired and Vermont Protection and Advocacy. To use the system, a voter with a disability signs in at their designated polling place and asks to vote by phone. Poll workers use a designated telephone to call the system, enter the appropriate access IDs and give the phone to the voter. The system reads the ballot to the voter, who indicates his or her choices by pressing the corresponding numbers on the telephone key pad. The system then generates a paper ballot, scans it and reads it back to the voter so that he or she may verify that the ballot is correct before it is cast.<sup>38</sup> The system’s initial cost is \$525,000, and thereafter will cost approximately \$110,000 to operate annually.

Vermont election law is designed to make it easy to vote with only four voter eligibility requirements (U. S. Citizenship; Vermont residence, 18 years or older by Election Day; take the voter’s oath on or before Election Day).<sup>39</sup> There are no competency standards for voters in Vermont, so a person cannot be challenged on that basis and towns cannot require people with disabilities to meet any additional criteria.

People with disabilities have many options in how they can register to vote and in getting assistance both in voting and in registering to vote. Voters need to register at

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<sup>35</sup> From the Secretary of State’s press release of August 10, 2005. “*Vermont’s Disabled Voters to be Among the First to Vote by Phone.*”

<sup>36</sup> From remarks made by the Deputy Secretary of State, Bill Dalton, to the Olmstead Commission, April 19, 2004.

<sup>37</sup> Ibid. Inspire Vote-by-Phone is produced by IVS, a voting services company located in Louisville, Kentucky.

<sup>38</sup> Ibid.

<sup>39</sup> 17 V.S.A. § 2121.

least 8 days before the election (primary or general). Voter registration forms are easily available from the town clerk, the Department of Motor Vehicles, the Secretary of State's website, social service agencies, and others. Disability rights organizations also provide people with disabilities opportunities to register. The Annual Green Mountain Self-Advocates Conference always provides a table where people with developmental disabilities may register to vote. When registering to vote a person can: <sup>40</sup>

- Ask for assistance in filling out the voter registration form. A person unable to sign their name may mark an X or take an oath swearing to the statement on the form.
- Receive assistance from social service agencies. If a person requests help the agency must help him or her fill out the voter registration form whether the service is provided to the person in a government office or the person's home.

If assistance is needed to cast their vote a voter can:<sup>41</sup>

- Ask election officials to provide curbside voting. Officials must bring a ballot to the car of a person who is sick or disabled.
- Bring a person in to help him or her read the ballot, fill out a paper ballot, or use the voting machine. The voter only need tell election officials that they have someone to help them with the voting process.
- Ask election officials for help. When the voter checks in to vote he or she simply tells the election workers that he or she needs assistance. With no questions asked, the voter must be provided that assistance.
- Ask for assistance to put their ballots into the ballot box or optical scan machine.
- Bring in their service animal. People with a disability who use service animals must be allowed to bring them into the polling place.
- Request auxiliary aids, such as sign language interpreters, large print or Braille ballots, physically accessible voting booths, wheelchair-height voting tables. Voters must request these aids at a reasonable time before the election so that officials have enough time to provide the aids.<sup>42</sup>
- Use vote-by-phone technology by 2006.

Vermonters in institutions also can vote. Persons in institutions may choose whether to vote as citizens of the community where they have their home, or the town where the facility is located. The Secretary of State's Office ensures that all of the necessary information goes out to the Vermont State Hospital and correctional facilities.

The Help America Vote Act (HAVA) requires all polling places for federal elections to be physically accessible to people with disabilities. In Vermont, accessibility mostly has been achieved by moving elections from town halls to schools. Other towns are doing physical improvements.

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<sup>40</sup> From *Equal Access to Voting in Vermont*, by the Office of the Secretary of State Deborah L. Markowitz with assistance by Susan Sussman, Esq. 2004.

<sup>41</sup> Ibid.

<sup>42</sup> Required by Title II of the Americans With Disabilities Act.



While Vermont has generally good law and practices regarding access to voting by people with disabilities, same-day registration would be considered very desirable by some. In addition, awareness by local officials of the right to the assistance of one's choice by people with developmental disabilities needs improvement, as does physical access in some jurisdictions.

For people who are deaf, hard of hearing, late deafened and deaf blind, local officials need to recognize that they also must provide communication accommodations for people to participate in town meetings, and staff at many polling places need training on how to assist deaf and hard of hearing people to vote. There also is a need for sign language interpreters that are fluent in other countries' sign language, such as French Sign Language, Mexican Sign Language, Russian Sign Language etc., to provide interpretation for deaf immigrants to attend citizenship classes.

***Voting and Citizenship Challenges to Community Integration***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Actions Needed</b>
Need for improved physical access for voting in some jurisdictions.	None identified.	Work with Secretary of State's Office to standardize physical access for voting.
Need for improved communication accommodations for people who are deaf, hard of hearing, late deafened and deaf blind to participate in local governance and voting.	None identified.	Work with Secretary of State's Office to improve communication accommodations for town meetings, voting and citizenship classes.

## **Services and Supports for People with Mental Health Disorders**

### **COMMUNITY DESIGNATED AGENCY PROVIDER SYSTEM FOR MENTAL HEALTH AND DEVELOPMENTAL DISABILITY SERVICES**

By state statute, publicly-funded services for people with mental health disorders and with developmental disabilities are provided by seventeen private, nonprofit community-based Designated Agencies (DAs) across the state provide. While Vermont's financial commitment to the services provided by the community-based DA system has been relatively high in absolute terms and as a percentage of state income, only a small and unpredictable amount of that revenue has been directed to cover workforce "cost of living" increases. These needs include the natural inflation requirements for staff salaries and benefits, dramatic increases in workers compensation rates which reflect their service provision for increasingly risky populations, and increases in health and liability insurance costs. This situation has led to very concerning rates of staff turnover, which affect access to services and quality of care.

To address this issue, in the summer of 2004 the Secretary of the Agency of Human Services (AHS) contracted with external consultants to conduct a study of the financial sustainability of the designated provider system and to make recommendations for the future. The consultants found that:

*The non-competitive nature of the DA system and the bottom-line regional responsibilities delegated to the Designated Agencies has fostered the development of a system of care that is highly effective in meeting the unique needs of Vermont communities. The agencies work with local organizations and providers to identify needs and develop responsive programs.*

*As the demands on the system have grown, the Designated Agencies have responded with innovative approaches to providing the highest level of service possible to the most people in need from a funding base that is largely comprised (86.5%) of public funds. ... However, the DAs are struggling to meet the growing needs of their communities.*

Using historical expenditure data from state fiscal years 1998 – 2004, the Consultants identified three sets of forecasts for state fiscal year 2006 through 2011 for the Secretary of AHS to consider:

*General Fund Growth Model* – This model assumed that Designated Agency budgets would be restricted to an average annual rate of growth equal to what is anticipated for the General Fund over the next five years, or 3.2 percent. This model would dictate a reduction in the level of services relative to current service availability and caseload.

*Health Care Inflation Model* – This model set the growth rate equal to the projected average annual health care inflation rate, as published by the Department of Banking, Insurance, Securities and Health Care Administration (BISHCA), or 7.6 percent. (BISHCA bases its projections on data from the National Healthcare Expenditure Survey.) This model would permit modest program growth, but established a growth rate below the average annual growth in expenses between FY1998 and FY2004 (equal to 9.3 percent).

*Demand Model* – This model targeted program components within the Designated Agencies that were reported by the various stakeholders, including the agencies, to be under funded, and contributing to a reduction in access to services. Most significantly, it included a three

percent annual increase for DA providers in 2006, 2007 and 2008 to address wage issues as well as other pressures on operating budgets. The three-percent increase is applied across all agency expenses; therefore, the three-year adjustment would enable agencies to increase all staff salaries by ten percent or more, depending on other budget priorities.

As a result, upon the advice of the Secretary of the Agency of Human Services, the Governor's FY2006 Budget contained a plan for a 3 year state funding increase for the designated agencies, equal to 7.5% of the current expenditure of state funds for each year (Option 2 above). The portion of the 7.5% increase dedicated to meet inflationary demands, including workforce compensation, and the percentage dedicated to new services will be established each year.

For mental health services in FY06, this amount was divided to include 4.75% targeted for a cost of living adjustment and 2.75% targeted for caseload and other service growth requirements. For developmental disability services in FY06, 3.75% was directed to new caseload plus a 2% reduction in existing services was required to support new caseload; and 3.75% was directed to the DAs for inflationary increases, including workforce compensation and worker's compensation coverage, which was not fully funded in FY05.

## **MENTAL HEALTH SERVICES FOR ADULTS**

The Designated Agencies provide ***acute and long-term behavioral health care services for adults***, including the following:

- Emergency Services
- Adult Outpatient Services
- Elder Care
- Homeless Assistance
- Consumer/Family Initiatives
- Comprehensive Community Rehabilitation and Treatment (CRT) services for adults with serious and persistent mental illnesses
- Specialized services including services for people with co-occurring mental health and substance abuse services, trauma services, and services for elders.

The purpose of ***Emergency Services*** is to provide a rapid response to evaluate and stabilize a situation and to provide or arrange whatever treatment and support is needed to help people and communities cope with a crisis. Services may be provided over the phone, in a person's home (in some parts of the state where outreach is available), or in a hospital emergency room. Because many of the services are not easily reimbursable by public or private insurance, emergency services are consistently in financial stress. Emergency Services programs have run deficits for at least the past eight years. In addition, this funding dilemma has also resulted in variation across the state regarding outreach capability, the expertise of emergency staff to address the needs of children and adolescents and the ability to provide follow-up connections with DA staff,

community resources, and families. Finally, often law enforcement officers are often the first responders to crisis situations. Without adequate training, they lack the necessary skills to deal with complex emergency situations and accommodate the needs of people with disabilities.

**Adult Outpatient programs** assist individuals and families experiencing high emotional distress or that have behavioral difficulties that disrupt their lives. People are typically seen for one to ten visits. Annually, Adult Outpatient Services from Vermont's Designated Agencies (DAs) serve more than seven thousand (7,000) people. The programs offer a range of mental-health services that vary somewhat across DAs. Some of the services typically available are:

- Evaluation
- Family, individual and group therapy
- Medication prescription and monitoring (in nine of ten DAs)

The severity of life experiences of the people who access these services has dramatically increased over the past decade. Now, many of these individuals are living in poverty, are unemployed, have had multiple psychiatric hospitalizations, have been involved with the criminal justice system, and experience significant problems in their daily lives due to their mental health disorders.

Outpatient programs are struggling against financial pressure on the system and increasing demand for services. For example, Adult Outpatient programs served 7,268 clients in Fiscal Year 2001 and 7,345 in Fiscal Year 2002. Over the same period of time, clients with at least some kind of insurance coverage other than Medicaid and/or Medicare declined from 39 percent to 31 percent, while those with no insurance coverage increased from 20 percent to 22 percent. Outpatient programs for both adults and for children / adolescents at Vermont's designated agencies have posted losses for seven years in a row.

**Eldercare Clinicians** provide mental health services for older Vermonters statewide through the Designated Agencies (DAs). The Eldercare Mental Health program is a joint initiative of the Division of Mental Health (DMH) and the Department of Disabilities, Aging and Independent Living (DAIL). Fifteen full- and part-time Eldercare Clinicians are located either at the DA or at the Area Agency on Aging offices and provide evaluation and treatment to elders, usually in their homes, as well as assistance to other community agencies working with elders. About 400 people, most of who have not been served by the DA system previously, are served each year. This program, which started in 2000, has an annual appropriation of state funds of \$250,000, and a total annual operating budget (counting federal receipts from Medicaid and Medicare, and commercial insurance) of over \$700,000. Most Eldercare Clinicians have waiting lists and are unable to meet the demand for their services.

About 800 people get **Homeless Assistance** services each year through federal funding to provide assistance to people in Vermont's homeless shelters who need mental health services, and to help them find housing and get on-going mental health services and supports. Services are provided jointly by homeless shelters and the Designated Agencies.

The **Comprehensive Community Rehabilitation and Treatment (CRT) program** is operated under a federal Medicaid demonstration waiver, and is specifically designed to assist adults with serious and persistent mental illness to avoid institutionalization. Annually, approximately three thousand (3,000) people receive services through this program, which is offered through the DAs. The program assists individuals and their families to develop and maintain skills and supports important for living the life they want for themselves, including:

- medication prescription and monitoring
- community supports and outreach
- help in finding and keeping a job
- help in finding and keeping a place to live
- getting an education
- education to help individuals understand their mental illness
- help in getting life goals met
- crisis services
- social and recovery skills

**Psychiatric services** are vital for assessment, medication management and consultation to other physicians about the appropriate diagnosis and treatment of mental health disorders. However, the availability of psychiatrists within the publicly-funded DA system has diminished over time. The shortage of psychiatrists in the Vermont public mental health system is a complex problem with important market and reimbursement factors not readily influenced by mental health authority policy actions.

Families and individuals diagnosed with a mental illness can be a great assistance to one another. The Division of Mental Health (DMH) provides some financial assistance to independently operated **consumer and family programs**. These organizations provide assistance to over four hundred (400) individuals a month by:

- providing information
- offering support groups
- providing telephone emotional support
- offering education and training oriented towards recovery
- advocacy and referral
- training for providers

DMH also supports specialized services for people with particular needs. Some of the newer specialty services are organized into three groups: Evidence Based Practices, Value Based Practices, and Promising Emerging Practices.

**Evidence Based Practices** are services or programs for which there is considerable scientific evidence showing that the services improve client outcomes. Currently, six practices have been identified as Evidence Based, and most are available through all of the DAs:

- Assertive Community Treatment (ACT): ACT is a multi-disciplinary clinical team approach providing comprehensive mental health and rehabilitation services. Team members provide long-term intensive care in natural community settings. The team provides all services rather than referring clients to different providers, programs, or other agencies.
- Family Psychoeducation: An approach where the clinician establishes a rapport or bond with a client and his/her family members to help the family system develop increasingly sophisticated coping skills for handling problems posed by mental illness in a family member.
- Illness Management and Recovery: Recovery Education and Illness Management are a broad set of strategies designed to help individuals with serious mental illness manage their mental illness, reduce their susceptibility to the illness, to cope effectively with their symptoms, to identify the supports that are effective for them, and to advocate for receiving these supports. Recovery Education and Illness Self-Management are educational and support approaches that promote hope, healing, and empowerment.
- Integrated Mental Health and Substance Abuse Treatment: An approach in which both disorders are treated simultaneously by the same team. Treatment interventions are conceptualized in stages. Individual and group supports are used in addition to assertive case management.
- Pharmacological (drug) Treatment: A systematic approach that translates the latest available knowledge about medications into practical pharmacotherapy suggestions and promotes the optimal recovery in the consumer population.
- Supported Employment: Helps people with the most severe disabilities participate in the competitive labor market, work in jobs they prefer with the level of professional help they need and helps people advance in their careers.

In addition, two practices which offer a comprehensive program of individual and group treatment and support and services for trauma survivors will probably meet the standard of evidence based in the next several years:

- Dialectical Behavioral Therapy (DBT) is designed to reduce self-harming behaviors, impulsivity, and treatment interfering behaviors. It involves a structured, cognitive-behavioral approach to treating individuals diagnosed with a borderline personality disorder. The focus of DBT is on behavioral change balanced with acceptance, compassion, and validation of the consumer. DBT treatment requires individual therapy, a skills development group, brief coaching by the therapist to reinforce the use of skills, and a consultation group for all staff involved in DBT treatment. DBT is currently offered throughout all the DAs.

- **Trauma Services** for people having mental health problems related to a traumatic experience include some services that people with other mental health issues also use—for example case management, therapy, medication, substance abuse treatment—as well as services specifically designed to help people who have trauma in their history. Specialized services usually include making sure that the trauma survivor is now in a safe situation and, help with symptoms related to the trauma. While data indicate that a majority of individuals who access mental health and many other AHS services have experienced significant trauma in their lives, only one DA currently offers a comprehensive trauma-specific program. (See previous section on Trauma-Informed Services)

**Value based practices** are those practices for which there is limited scientific evidence of their effectiveness but are approaches that consumers and families particularly request and find helpful. Examples include:

- Family-to-Family education
- Recovery Education Project
- Transitional residential services

The first two are currently offered statewide through consumer and family organizations.

**Promising Emerging Practices** are those services for which the scientific evidence is not yet available, but which address a widely acknowledged client need or gap in our service system. Supported Housing, which is offered throughout Vermont, is an example of a promising emerging practice.

In addition, the Division of Adult Mental Health, along with the Department of Disabilities, Aging and Independent Living, is the recipient of a federal **Real Choices Systems Change grant** from the Centers for Medicare and Medicaid Services (CMS). The grant provides resources for both departments to work collaboratively with broad stakeholder groups to increase community integration, real choice, and control for elders, younger adults with physical disabilities, people with developmental disabilities and their families, and adults with severe mental illness. The Division of Mental Health's project under the grant involves making recovery education approaches (such as the Wellness Recovery Action Plan, or WRAP, designed by Mary Ellen Copeland and pioneered by Sherry Mead) and peer support available and useful to some of the individuals who have the least choice in Vermont's public mental-health system: those who are on involuntary community status under Orders of Non-hospitalization (ONH)<sup>43</sup>. The Department and an advisory panel of stakeholders completed a qualitative research study of adults on ONH and are now piloting new approaches to bring recovery education to them.

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<sup>43</sup> Orders of Non-hospitalization (ONH) are court ordered, or court approved, outpatient commitment orders that mandate an individual undergo community mental health treatment. Between 140-160 people are on an ONH at any one time.

## ***Vermont State Hospital***

Vermont currently has one state-run hospital that is dedicated to providing inpatient psychiatric care: Vermont State Hospital (VSH). Founded in 1891 by the Vermont State Legislature, the Vermont State Hospital serves the needs of mentally ill Vermonters unable to receive treatment and care in other settings.<sup>44</sup> At its height in 1954, VSH had an average daily census of 1350. Since that time, the locus of care for serious mental illness has gone from the institution to the community due to major political, cultural, and medical advances over the past forty years. The Community Mental Health Act of 1963 resulted in a great expansion of Vermont's community mental health centers. Grant funding and a study calling for the closure of the state hospital in the mid 1980's helped to bring an even greater array of services to the community; and advances in psychopharmacology have helped control the life disrupting symptoms of major mental illness. During the same time period, the consumer rights movement emerged and became a driving force behind deinstitutionalization. Consumers have demanded mental health care parity, consumer and family-driven care, and care that is focused on recovery.

VSH serves adults with serious and persistent mental illness as part of a comprehensive continuum of care. VSH provides intensive psychiatric care for individuals with:

- Higher acuity of illness
- Greater complexity of illness
- Dangerousness to self or others
- More refractory, that is, difficult to treat illness

Who require:

- Higher staffing levels
- Longer stays
- Involuntary medication

In FY2005, VSH treated approximately 218 adults (VSH does not accept individuals under the age of 19), and had an average daily census of 52.

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<sup>44</sup> Title 18 § 7611 of the Vermont statutes directs that, "No person may be made subject to involuntary treatment unless he is found to be a person in need of further treatment." A person in need of treatment is defined at § 7101 of Title 18 as: A person who is suffering from a mental illness and, as a result of that mental illness, his capacity to exercise self-control, judgment, or discretion in the conduct of his affairs and social relations is so lessened that he presents a danger of harm to himself or others. Title 18 contains numerous substantive and procedural safeguards to insure that no person is held involuntarily who could otherwise be in a less restrictive setting. [18 V.S.A. § 7101et seq].



Over the past two years, VSH has faced significant challenges regarding its services and future financial health. In the fall of 2003, the Centers for Medicare and Medicaid Services (CMS) decertified VSH as a Medicaid provider due to concerns about staffing, the ability to provide active treatment for patients refusing medications, and safety concerns as a result of two suicides in close temporal proximity. Although the hospital regained certification within a year, it was quickly de-certified again due to the elopement of two patients.

Concurrent with the above events, the State began a process to develop a plan to replace the services currently provided at VSH within the next 3 years. The Department of Health, Division of Mental Health is currently working with stakeholders to define the detailed elements of this plan.

### ***Involuntary Psychiatric Inpatient Services Provided by Designated Hospitals***

Vermont has taken a multi-faceted approach to the planning, development and implementation of a comprehensive array of services for residents with severe and persistent mental illness. The primary goal is to ensure that mental health services are provided in a person's community of residence on a voluntary basis under the least restrictive conditions consistent with safety. Currently however, in some situations involuntary care is utilized while the system continues to work toward the ability to provide all needed services without coercion.

One element of the current array of services is capacity to provide local emergency psychiatric involuntary care at Designated Hospitals (DH). This reflects the commitment of the Vermont mental health service system to assure appropriate care for people with serious mental illness as close to their homes as possible. The preference for local care is based on the need for access to a person's natural and usual supports that play a significant role in helping to facilitate the transition between levels of care and reintegration into the community. In addition, many individuals admitted to Vermont State Hospital (VSH) either accept voluntary treatment or can be served clinically in a less restrictive setting and thus can be stepped-down to a less restrictive setting or voluntary status at a DH.

The Division of Mental Health has designated four local general hospitals with psychiatric units for limited involuntary care: Fletcher Allen Health Care (FAHC) in Burlington, Central Vermont Medical Center (CVMC) in Berlin, the Rutland Regional Medical Center in Rutland, and the Windham Center (WC), operated by Springfield Hospital, in Bellows Falls. These four hospitals, along with Retreat Healthcare in Brattleboro, provide acute behavioral health-care services with a focus on keeping individuals close to their communities where they can receive ongoing services.

**Current Vermont Psychiatric Inpatient Services at Designated Hospitals  
(other than VSH) for Adults in the CRT Program and /or Involuntary Care**

Hospital & Location	Total Number of Psychiatric Beds	Average Bed Use			
		CRT Voluntary	CRT Involuntary	Non - CRT Involuntary	% of Total Beds Available*
Fletcher Allen Health Care, Burlington	28 (12 doubles, 4 singles)	12%	1%	4%	17%
Central VT Medical Center, Berlin	14 (6 doubles, 2 singles)	23%	7%	4%	34%
Windham Center (Springfield Hospital), Bellows Falls	19 (9 doubles, 1 single)	8%	3%	2%	13%
Rutland Regional Medical Ctr., Rutland	19 (7 doubles, 5 singles)	12%	3%	6%	21%
Retreat Healthcare, Brattleboro	46 (4 doubles, 38 singles)	2%	0.2%	0.4%	2.6%

\* All other bed use is comprised of voluntary patients not enrolled in the CRT program (e.g., people with private insurance or Medicaid / Medicare who do not have a serious and persistent mental illness that requires state provided- wrap around services).

**Mental Health Services for Individuals in Correctional Facilities<sup>45</sup>**

Concerns involving the provision of mental health services in Vermont’s correctional facilities have increased over the past three years. Spurred by a review of mental health services and an independent investigation of several inmate deaths, as well as growing numbers of anecdotal staff reports, complaints by inmates and advocacy groups, and concerns voiced by clinical staff, the General Assembly mandated that the Department of Corrections develop a **comprehensive mental health services plan**. This plan, which was presented to the Legislature in January 2005, provided recommendations and identified the necessary resources to improve mental health services oversight and delivery within the correctional system in the following areas: strengthen leadership and management; increase mental health service capacity; better support and supervision of staff related to the provision of mental health services; and improve accountability of service delivery.

Pursuant to 28 V.S.A. §907, the Department of Corrections “shall administer a program of mental health services which shall be available to all inmates and shall provide adequate staff to support the program.” The statute requires that all inmates must be screened for any signs of mental illness within 24 hours of admittance to a correctional facility. It further requires evaluation, treatment planning, and access to a variety of services for inmates with serious mental illness. Based on this statutory definition of services required, and in light of the resources available or likely to be available for this

<sup>45</sup> The content of this section was excerpted from the *Comprehensive Mental Health Services Plan*, a Report by the Commissioner of Corrections to the Joint Legislative Corrections Oversight and Mental Health Oversight Committees, January 15, 2005.

purpose, this plan will focus on meeting the Department's statutory mandate; that is, provision of comprehensive mental health services to inmates with serious mental illness.

The Department of Corrections currently provides four levels of mental health clinical service:

1. Inpatient hospitalization at the Vermont State Hospital, based on acceptance of the inmate by VSH, for those inmates with serious mental illness (SMI) whose mental health care goes beyond the scope of services available at a correctional facility. At present there are no inmates at the Vermont State Hospital.
2. Secure mental health treatment for SMI inmates who are a danger to themselves or others, or who cannot otherwise be housed safely in other units of a Correctional facility. Secure mental health treatment is provided in a close custody unit. At present there are eight inmates with serious mental illness in the secure mental health unit at the Southern State Correctional Facility.
3. Intermediate-level mental health treatment for SMI inmates who are in need of concentrated mental health services and/or cannot be housed safely in general population units. Intermediate mental health treatment is provided in an open custody unit separate from the general population units. At present there are 26 inmates in the mental health unit at the Southern State Correctional Facility.
4. "Outpatient" treatment (for inmates in general population and special needs units), including crisis services, medication management, group therapy, and individual therapy. At present there are approximately 500 inmates receiving "outpatient" treatment.

Mental health delivery in the correctional facility environment is unique. While professional autonomy must be preserved for mental health practitioners, this must be carried out with regard to administrative and security practices that serve to guide an effective correctional system. Professional mental health judgment can be exercised freely and the requirements of security can be maintained when each works in conjunction with the other to bring about an orderly system.

Mental health delivery must also be closely coordinated with medical services and risk reduction programs. It is a goal of the Department of Corrections to implement an integrated treatment plan for inmates with serious mental illness that incorporates treatment goals encompassing mental health, medical, and risk reduction needs.

The Department of Corrections recognizes that nearly all of the inmates in its custody will at some point return to the community. It is essential that mental health services be available to those inmates whose mental status may interfere with their ability to function appropriately and productively in the community, and community services must be available at the time of, or prior to, release.

## MENTAL HEALTH SERVICES FOR CHILDREN AND ADOLESCENTS AND THEIR FAMILIES

The private, nonprofit, community-based DAs across the state also provide services for children and adolescents with a wide range of emotional, behavioral, and other mental health problems, and their families. Core capacity services provided by each DA include:

- Immediate Crisis Response
- Clinic-based Treatment
- Outreach Treatment
- Family Support
- Prevention, Screening, Referral and Community Consultation

In addition, statewide capacity exists for:

- Emergency or Hospital Diversion Beds
- Intensive Residential Services
- Hospital Inpatient Services

Each Designated Agency (DA) provides access to an ***immediate crisis response*** service and/or short-term intervention for children and adolescents who are experiencing a crisis and their families. Crisis services are time-limited (usually up to 2-3 days) and intensive and include the following:

- Assessment, support, and referral over the telephone
- Crisis assessment, outreach, and stabilization face-to-face
- Family and individual education, consultation, and training
- Service planning and coordination
- Screening for crisis bed (hospital diversion) and for in-patient psychiatric hospitalization

Each DA also offers a comprehensive array of ***clinic-based treatment*** services for children and families. These services employ best practice in office-based clinical service delivery and are available during daytime and evening hours for school-age children and/or when families can easily access them. The intensity of the service is based on the clinical needs of the child and family and the family's request for one or more the following elements:

- Clinical assessment
- Group, individual, and family therapies
- Service planning and coordination
- Medication services

In addition, each DA offers the above services through its **Outreach Treatment** programs in the home, school, and general community settings when appropriate for the child and family, as well as family and individual education, consultation, and training.

**Family Support Services** can be instrumental in reducing family stress and providing parents and caregivers with the guidance, support, and skill to nurture a difficult-to-care-for child. Each DA provides and/or has direct community connections to a comprehensive array of support services for families and youth. These services are offered in partnership with parents and consumer advocates. Participation in one or more of the following support services is voluntary and based on the family's needs and desires:

- Skills training and social support
- Peer support and advocacy
- Respite
- Family and individual education, consultation, and training

**Prevention, Screening, Referral And Community Consultation** is offered by each DA to provide and/or have direct involvement in creating and/or maintaining community protocols that promote psychological health and resilience for families and youth across any community environment. Primary prevention efforts focus on promoting healthy lifestyles and healthy communities for all youth and families. Secondary prevention efforts focus on reducing the effects of risk factors, minimizing trauma potential, and maximizing resiliency potential. Tertiary prevention (e.g., treatment) efforts focus on reducing any trauma and poor functioning that may be created by a difficult event or situation. The prevention protocols may focus on one or more of the following elements:

- Work with families, community groups, schools, and other health and child care providers to improve situations/environments for children and families through education, consultation, and training
- Education activities about mental health for the public at large
- Screening and referral

**Emergency or hospital diversion beds** are community-based programs that provide a very high level of care and have the ability to divert youth from in-patient hospitalization. Typically, youth who do not require around-the-clock medical monitoring can be stabilized in a smaller treatment setting. Like the intensive residential services, emergency bed programs have 24-hour awake night staff, 24-hour psychiatric and in-house crisis back-up, and have the ability to conduct psychological, neurological, and other specialized testing as needed. The typical length of stay in these services is one to ten days.

DMH contracts with five **residential treatment programs** for youth in Vermont. Residential placement options include: The Baird Center for Children and Families;

Brookhaven; Community House; Northeastern Family Institute; and Retreat Healthcare. All of these services are characterized by 24-hour awake night staffing, 24-hour medical and psychiatric back-up, 24-hour in-house crisis back-up, and an in-house array of psychological assessment and treatment services. Residential services include:

- **Short-term residential placement** (30 - 60 days) for assessment and stabilization
- **Long-term residential placement** (6 - 18 months) to address psychiatric or multiple mental health needs when other less intensive services have failed or when the type and intensity of out-patient care is not available in the child's own community.

DMH has the philosophy that, whenever possible, families should be supported to remain together. For long-term success, families must be actively included in the treatment process. Family treatment is an integral component of these residential settings.

Service	Provider	Ages	Beds Available
Short-term assessment and stabilization (30 to 60 days)	The Baird Center	6-13	4
	Community House	6-13	7
Long-term Residential (6 to 18 months)	The Baird Center	6-13	12
	Northeastern Family Institute	13-18	6
	Retreat Healthcare Inpatient	6-13	10
	Retreat Healthcare Inpatient	13-18	12
	Brookhaven	6-13	10

***In-patient hospitalization*** may be required for youth with a mental illness who:

- Require around-the-clock medical monitoring for such things as drug overdoses, suicide attempts, or other complicating medical conditions;
- Have complex and uncontrollable behaviors such as harm to themselves and/or others;
- Cannot be stabilized in a smaller and more individualized hospital diversion treatment setting; and/or
- Meet the criteria for an emergency exam (EE).

Three hospitals provide psychiatric in-patient services for Vermont youth:

- Champlain Valley Psychiatric Hospital in Plattsburgh, New York;
- Cheshire Medical Center in Keene, New Hampshire;
- Retreat Healthcare in Brattleboro, Vermont.

A child meeting the criteria for an emergency exam (i.e. evaluation on an involuntary basis) may be placed only at Retreat Healthcare.

Similar to the CRT Program for adults, the Child, Adolescent and Family Services Unit has a federal Medicaid demonstration waiver that is specifically designed to provide **comprehensive services for children and youth with severe emotional disorders** to avoid hospitalization. Annually, approximately 250 children and adolescents receive services through this program which is offered through the DAs. The intensity of the service is flexible and is based on the clinical needs of the child and family. The following services are available:

- Clinical assessment
- Group, individual and family therapies
- Service planning and coordination
- Intensive in-home and out-of-home community services to child and family
- Medication services
- Family and individual education, consultation, and training
- Emergency and Hospital Diversion Beds
- Intensive Residential Services
- Respite Services

An innovative program is the **Vermont JOBS (Jump On Board for Success) program**, which has had a very successful record of improving the outcomes for transition aged<sup>46</sup> youth with serious emotional disturbance who drop out of school. The data show that youth who complete the program have reduced their relapse rates with substance abuse and the Correctional system and boosted their level of educational achievement and rate of employment. JOBS is a supported employment and therapeutic case management program collaboratively funded by the State Divisions of Vocational Rehabilitation, Mental Health, and Family Services, and by the Department of Corrections. However, it is only available to youth in 7 of 10 mental health regions of Vermont.

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<sup>46</sup> Transition age is defined in the Federal IDEA (Individuals with Disabilities Education Act) as beginning at age 14 and requires by age 16 a statement of needed transition services and interagency linkages in the students IEP (Individual Education Plan). This means that by age 14 the IEP team needs to begin to focus on life after high school for the student with a disability.

While all of the above services ideally should be available consistently across the state, the capacity of mental health services for children and adolescents varies across regions. As a result, children and adolescents may have to leave their home communities to receive necessary services and supports.

An area needing improvement across all age groups is the provision of accommodations for people with mental health disorders who are deaf, hard of hearing, late deafened and deaf blind. Many of the designated mental health agencies do not have the expertise or staff to provide ***mental health services to culturally deaf persons***. While the designated mental health agencies often subcontract with other mental health providers who do have the expertise to work with this low incidence group, there is no uniform referral process and the rate setting process is not clearly communicated to the sub-contractor. As a result, the services may be delayed for quite some time until the referral and rate-setting processes are completed. Therefore, the deaf consumers are not getting the services they need in a timely manner. As such, there is a need for the designated mental health agencies to have qualified case managers and therapists that are fluent in American Sign Language (ASL) and knowledgeable about deafness.



## ***Service Challenges to Community Integration Faced by People with Mental Health Disorders***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Support for a valued, adequately reimbursed and well-trained workforce.	A total of \$3,610,500 would fully support the 7.5% state funding increase, much of which would be dedicated to workforce compensation.	see Family Supports section
Varied Emergency Service capacity across the state	An additional \$3,800,000 annually would be needed to support a state wide capacity for minimal outreach.	<ul style="list-style-type: none"> <li>• Develop and implement procedures to insure that minimal capacities are developed.</li> <li>• Provide systematic training for law enforcement personnel to better respond to crises involving people with disabilities.</li> </ul>
Limited access to Outpatient Services	Approximately \$1,070,500 would be needed at a minimum annually to meet current deficits.	DMH and the DAs need to develop a policy framework to implement decisions about priority populations and services within outpatient programs over the next few years.
Varied capacity for the full array of mental health services for children and adolescents in regions	Information not available.	Identify gaps and prioritize strategies for addressing them.
Needed improvement in mental health service delivery for Correctional Inmates	<p>7 additional mental health aides would cost \$210,000 annually</p> <p>Increase in contracted hours for mental health professionals would cost \$170,000 annually</p>	<p>Continued monitoring of the quality of mental health service delivery.</p> <p>Continued efforts must be directed to support the on-going close working relationship between DOC and DMH delivery systems, policy development, and administration.</p>
Lack of accommodations for people with mental health disorders who are deaf, hard of hearing, late deafened and deaf blind.	Accommodations are estimated to cost \$200,000 annually.	None identified.

## **Services and Supports for People with Developmental Disabilities**

In November 1993, the Brandon Training School closed its doors for the last time. That event over 10 years ago was a turning point in the history of services for people with intellectual disabilities in Vermont. Since that time, no Vermonter has lived in any state institution because of their developmental disability.

The Brandon Training School (BTS) opened its doors in 1915 as the “Vermont State School for Feebleminded Children”. Over the years, residents of the school included not just children with mental retardation and other developmental disabilities, but also youth and adults whose schools or families or communities were not prepared to support them. Between 1915 and 1993, a total of 2,324 people resided at BTS. The peak year was 1968 when the census reached 667. After that, the population of the institution steadily declined until its closure 25 years later.

A 1980 class-action lawsuit known as “the Brace Decree” prompted the creation of a plan for developing alternative resources around the state. Vermont became one of the first states to use the Medicaid Home and Community-based Waiver to develop individualized community supports. The advent of “the waiver” revolutionized services to people with developmental disabilities in Vermont, providing the resources people needed to move out of the institution and into their communities. The new waiver-funded programs proved decisively that community-based services could support even the most severely disabled residents of BTS.

With the closure of the Brandon Training School in 1993, Vermont was the second state in the nation to eliminate state institutions for people with developmental disabilities. As a result, approximately 3,100 people with developmental disabilities, 750 of whom are children under age 18, are served by the state through community-based services and supports provided through the Designated Agency system. The issues facing the Designated Agency workforce for developmental services are identical to those described in the previous section on Challenges facing Services for People with Mental Health Disorders.

One of the primary vehicles for accomplishing a totally community-based system of care is the existence of a federal **home-and community-based Medicaid waiver** for developmental services. In FY2004, the waiver funded comprehensive services provided by the DAs for 1,961 people and accounted for 96.4% of all funding for people served through the State. Through this waiver, institutional services have been replaced with individualized and flexible supports funded through individual budgets that are based on an independent needs assessment process and incorporated into the person’s individual support plan. Additionally, the development of the Vermont Crisis Intervention Network (VCIN) has enabled most individuals with developmental disabilities to avoid institutional mental health care, and added significantly to the successful closure of the Brandon Training School.

There are no large congregate settings for people with developmental disabilities. Vermont is the only state in the country that has 100% of the people funded for home supports living in residential placements with six or fewer consumers.<sup>47</sup> Residential “placements” now just look like people’s homes. Group homes gave way to individualized options of shared and supported living that, statewide, average only 1.2 people per setting, the lowest in the nation. Furthermore, current State policy limits any new expansion of congregate settings to those serving no more than 4 individuals with developmental disabilities in any single location. In addition, people with MR/DD who live in nursing facilities reached an all-time low of 27 people as of December 31, 2004, including a dramatic 31% decrease in the last two years, and all of those individuals are a priority for funding if they desire to leave the nursing home.

This personalized approach also set the stage for people with disabilities and family members to have the option to self- or family-manage their supports, allowing for full control over the hiring of support workers and directing services.

The services provided encompass a wide range of support options designed around the specific needs of an individual, and include:

- Service Planning & Coordination - assists individuals and their families in planning, developing, choosing, gaining access to, coordinating and monitoring the provision of needed services for a specific individual
- Community Supports - specific, individualized, goal oriented services which assist individuals in developing skills and social supports to promote positive growth
- Employment Services - assist individuals in establishing and achieving career and work goals; including employment assessment, employer and job development, job training and ongoing support to maintain employment.
- Home Supports - services, supports and supervision to individuals in and around their residences up to 24 hours a day; includes Supervised/Assisted Living (hourly) provided to an individual who lives in his or her home, or the home of a family member (i.e., in-home family support); Staffed Living; Group Living; individualized shared-living arrangements offered within a contracted home provider's home; and an Intermediate Care Facility for people with Mental Retardation
- Respite - services (hourly or daily) provided on a short-term basis because of the absence or need for relief of family members/significant others or home providers normally providing the care to individuals who cannot be left unsupervised
- Clinical Interventions - assessment, therapeutic, medication or medical services provided by clinical or medical staff
- Crisis Services - time-limited, intensive supports provided for individuals who are currently experiencing, or may be expected to experience, a psychological, behavioral or emotional crisis; includes crisis assessment, support and referral and crisis beds.

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<sup>47</sup> Source: Prouty, R, Smith G. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, June 2004.

The Court, when making the Olmstead ruling, suggested that states have a comprehensive working plan for addressing placement needs of people with disabilities in less restrictive settings in order to comply with the ruling. Even prior to the implementation of Olmstead, Vermont had a legislatively required State System of Care Plan that describes the nature, extent, allocation and timing of services that will be provided to people with developmental disabilities and their families. The plan outlines the funding priorities that people must meet in order to qualify for home and community-based waiver services. Once a person is found to be clinically eligible, he or she must also meet the funding priorities that are determined by assessing the person's needs and circumstances that address fundamental health and safety, security, legally mandated services and community safety. Therefore, prior to the legal mandate under Olmstead, Vermont had an effectively working plan to allocate resources and set priorities.

Services for people with developmental disabilities are generally lifelong. As such, people typically no longer need services only due to death or moving out of state. As a result, approximately 220-240 (net of high school graduates and public safety) individuals each year meet the funding priorities and require services for the first time or need additional services as a result of medical, behavioral or other support needs.

While the *State System of Care Plan for Developmental Services* indicates that providing funding for **children with developmental disabilities aging out of the State's custody** is a priority, the presence of co-occurring mental health issues, trauma and in some cases public safety issues, places significant challenges on the service system to develop alternatives for these young men and women to be successful in adult life.

In addition, the number of children who accessed new **Medicaid waiver services for children** doubled in fiscal years 2000 and 2001. A moratorium on funding to serve newly identified children with comprehensive services was implemented on December 1, 2001 due to fiscal pressures.<sup>48</sup> Supports needed for children and their families are extensive and exceed the system's capacity, yet no new Medicaid waiver funding to children has been available since that time. However, Flexible Family Funding (\$1,122/year/child) and Children's Personal Care Services (averaging between 20-25 hours/week/child) continue to be available to support children with disabilities.

Children receiving special education services are entitled to services until they reach age 22. There were an estimated 106 **graduates from Special Education** programs who have a developmental disability and are expected to exit the educational system in FY'05-FY'06. These young adults look to the developmental service system to provide the necessary supports and services to help them continue to learn new skills, live in their own homes and find or maintain employment. Of those 106, it is expected that 96 people will be eligible under current funding priorities for home and community-based waiver funding. However, because of limited funding, effective July 1, 2005 individuals graduating from high school must be 19 years old to obtain adult services. Ten (10) individuals will be eligible for the Division of Vocational Rehabilitation grant-funded employment services. This number of high school graduates is at an all time high, primarily due to an increase in the number of young adults who are graduating earlier (at age 18 and 19 years old, rather than at age 22). As noted in the previous chapters on

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<sup>48</sup> Funding is still available to prevent or end psychiatric hospitalization or institutionalization.

Employment and Education, there needs to be better coordination between school systems and adult services to plan for transition after graduation from school.

**Offenders with disabilities** also need specialized supports. When individuals with developmental disabilities commit crimes, the courts and correctional system may not be able to respond to their special needs for supervision and treatment, and the public looks to developmental services to meet the need. Approximately 150 offenders with developmental disabilities are supported by developmental services agencies, a number that has increased steadily in recent years. Developmental services agencies experience many stresses and challenges when expected to serve a public safety function for these individuals in the context of a system that was designed to promote self-determination and community participation for law-abiding Vermonters with developmental disabilities and their families.

People often need additional supports as their parents age. **Aging parents** who have never asked for help before are seeking to arrange support for a child while the parent is still able to do so. It is significant that an estimated 23% of family caregivers for people with developmental disabilities are age 60 or over. This will add a significant burden to the need for state-supported services in the coming years.

Traditionally, designated agencies have managed all the services funded through the State on behalf of people with developmental disabilities and their families. Over the past few years, four options have been developed to provide people with a choice of who will manage their services:

- **Agency-Managed Services:** When the developmental service provider manages all of a person's services, whether it is by the Designated Agency or other contracted provider. This is the most common method by which services are managed.
- **Shared-Managed Services:** When the developmental service provider manages some, but not all, of the services for the person or family. For example, the service agency provides service planning and coordination and may arrange for other services, such as home supports, while the person or a family member manages the community and work supports separately. Many family members, as well as some people with developmental disabilities, have chosen a shared-management arrangement.
- **Self-Managed Services:** When an individual chooses to manage all of his or her developmental services. This means that the person has the responsibility of hiring his or her own staff and overseeing the administrative responsibilities associated with receiving developmental services funding. Some of these responsibilities include contracting for services, fulfilling the responsibilities of the employer, developing a service plan, and planning for back-up support or respite in the case of an emergency. An Intermediary Service Organization (ISO) is available to people who self-manage and will do many of the bookkeeping and reporting responsibilities of the employer. A person may also choose to hire or contract with an Independent Support Broker (ISB) to assist in self-management responsibilities. A guide to people who are self/family managing their services has been developed by the Department of Disabilities, Aging and Independent Living's (DAIL) Division of Disability and Aging Services (DDAS) to assist individuals, families and service providers with the development and

maintenance of these arrangements. Additionally as of July 1, 2005, a supportive ISO began providing assistance to individuals self-managing their services, such as training for staff and assistance with hiring workers.

- Family-Managed Services: When a person's family member chooses to manage all of his or her developmental services. The same responsibilities and resources noted above for self-management are also associated with and required for family-managed services. The supportive ISO also is available to families managing their own services.

In addition to the comprehensive services and supports provided through the Waiver, the state operates a **Flexible Family Funding** (FFF) program that provides limited funds to eligible families with children or adult family members with disabilities living at home to use at their discretion toward services and supports that are in the person's/family's best interest. The maximum amount available is generally \$1,122/year. Also, some individuals receive only Medicaid state plan services, such as targeted case management, rehabilitation, transportation and clinic services.

DAIL/DDAS also provides **Public Guardian Services**. Guardianship services are provided to individuals with developmental disabilities and people aged 60 and over who have been determined by the Family Court or Probate Court to be in need of supervision, protection and assistance to live safely within the community and to protect them from violations of their human and civil rights. The program's 25 Public Guardians work with individuals living throughout Vermont. They make regular home visits to the people they serve and take part in planning and monitoring. They make sure people have the supports needed to be safe and protected from abuse and exploitation. They help people to make their wishes and needs known, to become more independent, and to make connections with friends and family. Public Guardians may provide active medical advocacy and coordination and make decisions about medical treatment. Public Guardians are available for emergencies 24 hours a day. The program also obtains court-ordered evaluations for guardianship cases, coordinates forensic services for individuals with developmental disabilities accused of a crime, and provides financial management to individuals with disabilities. In FY2005, the Office of Public Guardian provided services to 657 people, plus representative payee services to 306 individuals.

The Division of Disability and Aging Services is also a participant in several federal **Real Choices Systems Change grants** from the Centers for Medicare and Medicaid Services (CMS). As previously noted, the funds provide resources to work collaboratively with broad stakeholder groups to increase community integration, real choice, and control for consumers. Examples of the specific activities related to these grants are to (1) research the option and implement a pilot project for providing direct funding for supports and services to people with developmental disabilities and their families; (2) contract with self-advocacy and parent organizations for materials development and training to conduct a minimum of 30 workshops/trainings; (3) integrate affordable housing with supportive

services; developing an integrated acute, primary and long-term health care system; and, improve quality assurance and quality improvement across all DAIL waiver programs. DDAS also will use a grant issued jointly by the Administration on Aging and the Centers for Medicare and Medicaid Services to develop an aging and disability resource network.

***Service Challenges to Community Integration Faced by People with Developmental Disabilities***

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Moratorium on Medicaid waiver services for children	It would require a total of approximately \$2,000,000 annually to eliminate the current waiting list of 72 children for these services; ongoing costs would be \$1,100,000 to serve approximately 40 children per year.	Restore Funding Priority for Children’s Medicaid Waiver Services in the System of Care Plan
Waiting list and increased demand for Flexible Family Funding.	It would require a total of approximately \$71,000 to support the 28 families on the current waiting list and the estimated 30 additional families/ year who need this support; ongoing costs to serve approximately 20 families per year would total \$24,000 annually.	Insure continued flexibility for families given coverage of the program under the Global Commitment
Support for Special Education Graduates	It would require a total of approximately \$1,840,000 to fully support the estimated 65 new individuals who will be eligible for these services each year.	<ul style="list-style-type: none"> <li>• Consideration of eliminating the age requirement of 19 years old to access adult services</li> <li>• Better coordination between school systems and adult services to plan for transition from high school.</li> </ul>

<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
There is a discrepancy between eligibility criteria in the Vermont Developmental Disability Act and the federal definition of developmental disability.	Information not available.	Explore a service system based solely on functional criteria rather than a combination of IQ, diagnostic criteria and adaptive functioning.
People who live with aging parents often need additional supports.	See Emergency Caseload below	Education and information to older parents to assure them that supports for their family member will be available
Need capacity for children aging out of the custody of the Department for Children and Family Services	See Emergency Caseload below	None identified
Offenders with disabilities need specialized supports	It would require a total of approximately \$1,375, 000 to fully support the estimated 25 newly identified offenders with developmental disabilities each year.	None identified.
Support for a valued, adequately reimbursed and well-trained workforce	A total of \$3,130,000 would be needed to fully support the 7.5% increase.	see Family Supports section
Emergency Caseload: Each year approximately 220 to 240 individuals require services for the first time and or need additional services as a result of medical, behavioral or other support needs.	It would require a total of approximately \$5,044,000 to fully support this need each year.	None identified



## **Services and Supports for Older Vermonters and Adults with Physical Disabilities**

Services that help older Vermonters and adults with physical disabilities maintain their independence are provided through many programs.

***The Home-Based Medicaid Waiver and Enhanced Residential Care Medicaid Waiver (to be transitioned to the Choices for Care 1115 Medicaid Waiver)*** are the foundation of Vermont's home- and community-based services for Vermonters who are aged or physically disabled. These two waivers provide individualized services to Vermonters in their own homes and communities, preventing or delaying the need for placement in a nursing facility. Current Home-Based Waiver services include personal care, adult day services, respite care, companion care, personal emergency response systems, assistive devices and home modifications, and case management. Enhanced Residential Care Waiver services are delivered in 57 selected Level III Residential Care Homes, which provide 24-hour care (personal care, medication management, nursing assessment, recreational activities, supervision, and case management services).

Staff from local Home Health Agencies and Area Agencies on Aging (AAAs) currently manage access to the Waiver programs, although that process will change with the implementation of the Choices for Care waiver on October 1, 2005. DAIL Long-Term Care Clinical Coordinators will assess the needs of people in their own communities, work with waiver teams to prioritize access to waiver services if a waiting list develops, and develop service plans to meet each person's needs. This process identifies those Vermonters with the greatest needs and attempts to meet those needs in the settings that people choose.

At any given time in fiscal year 2005, the Choices for Care Waiver will serve about 1,500 people in home and community-based settings and another 2,100 people in nursing facilities. This growth reflects the continued demand for home- and community-based services as an alternative to nursing facility services. The average age of participants in the Home and Community Based Waiver in 2004 was 78, with a range of 19 to 103 years. The average Waiver participant received more than 30 hours of in-home services each week.

***Consumer-Directed and Surrogate-Directed service options***, which give the consumer or his/her surrogate the ability to directly employ workers (including family members other than spouses), have helped to meet the growing demand for home and community-based care. Under these options, the consumer or surrogate is responsible for hiring, training, supervising and, if necessary, terminating caregivers. A contracted payroll agent manages payroll and tax responsibilities. These options have encouraged some people to become caregivers who might not otherwise have provided care.

Since their inception in 1997, the use of Consumer-Directed and Surrogate-Directed options have steadily increased so that they now provide more than 60% of the personal care services delivered through the Waiver. These services are a cost-saving alternative to those provided by Home Health Agencies.

Many people are not able or willing to manage their own care and do not have a surrogate to manage their care for them. These people rely on services available from Home Health Agencies, Area Agencies on Aging, Adult Day Centers, and other local agencies.

**Traumatic Brain Injury (TBI) Waiver** serves individuals 16 years and older recovering from a recent brain injury. The goal of this short-term program is to assist individuals in obtaining their optimal level of functioning and to successfully resume living and working in their own communities. Prior to the development of this service, individuals were placed in expensive out-of-state facilities, often remaining there for years, with little hope of returning to Vermont. Since implementation:

- Out-of-state placements dropped from a high of 20 to an average of 1 per year.
- The State has utilized resources more effectively; this program cost is 50% less than out-of-state facilities.
- Approximately 40% of individuals served have secured competitive employment.
- 100% of individuals improved their quality of life and level of functioning.

As noted on the Table in Chapter One, there is a waiting list for the TBI Waiver program. As a result, individuals with TBI may require services from other programs, including Enhanced Residential Care (ERC), which diminishes the capacity of ERC to meet the demand for its program. In addition,

The **Attendant Services Program (ASP)** has provided personal care services for adults with disabilities for over 20 years and has grown steadily during that time period. A nationally recognized program, ASP has led the way in consumer direction. Participants hire, train and supervise their own caregivers. An Eligibility Committee of program participants awards the hours of service received by each participant, based on individual need. The program provides payroll services to manage the wages paid to attendants including paychecks, tax withholding and reporting, unemployment, and workers' compensation insurance.

In FY 2004, the Attendant Services Program served about 300 people. The average participant was approved to receive approximately 5 hours of personal care each day. Some participants need the Attendant Services Program to meet their personal care needs so they can work. The average age of participants is 59 and the age range is 19 to 100 years. Currently there are 61 individuals on the waiting list for attendant services. Another challenge facing the program is finding and keeping qualified care attendants. Workers are paid \$8.00 for the initial six months of employment and \$8.50 thereafter. Attendants do not receive holiday pay, paid overtime, sick leave, vacation leave, or health insurance. Unfortunately, the current wages and lack of benefits make it difficult for some participants to recruit and retain attendants.

There are currently about 1220 children receiving **Children's Personal Care Services (CPCS)** in Vermont. These services are available to children with physical, cognitive and emotional disabilities. Current data indicates that utilization of CPCS is 63% of approved hours of service. There are about 25 new requests a month for CPCS and about 5 new requests a month for High Technology Home Care services. Both of these programs permit children who would otherwise be served in an institutional environment to live at home with their families and in their communities.

As one of the few programs that provide 1:1 staff support for children with disabilities, there is an ever growing demand for CPCS. With this demand comes a number of challenges including:

- \* Estimated annual growth of 20%
- \* Low utilization of allocated hours (~63%)
- \* Families/Agencies report difficulty finding and retaining workers
- \* Fluctuating Medicaid eligibility/enrollment
- \* Improving transition into adult services

In addition, there are about 104 children and adults who require and receive skilled nursing services in their home, including ventilator dependent children, through Vermont's **High Tech Home Care (HTHC) program**. Preliminary utilization data for HTHC indicates that there are also some issues with filling hours of home-based nursing.

Of these challenges, the greatest is the lack of availability of care providers, both in the CPCS and HTHC programs. This places a greater responsibility and significant strain on families with little to no respite because access to those services is not there. Data indicates that the lack of children's personal care providers is related to inadequate pay, lack of benefits, the limited number of hours of service required by each child and the time frame during which the services are needed - often at the beginning or end of the day. With respect to the HTHC program, the lack of nurses, generally, is a barrier that also places greater responsibility on families to provide the care themselves resulting in a greater strain on families. The lack of available care providers may explain a good part of the underuse of hours in the program.

**Dementia Respite Program** offers a range of educational, community and direct services to individuals with Alzheimer's Disease and Related Disorders and to their caregivers. Funds are available to enable family caregivers to hire in-home caregivers or to assist with payment for out of home services (such as adult day services). Respite gives family caregivers the break they need to reduce stress, remain healthy and maintain overall well-being. In FY'05, the program served 395 people.

**National Family Caregiver Support Program** provides an array of services and support specifically designed for family caregivers, such as Information and Referral, Case Management and Respite. Eligibility is limited to family caregivers of older adults, and grandparents over the age of 60 who are caring for children under the age of 18. Family caregivers provide most of the needed care to older adults and children with disabilities

and contribute their own funds to care for their family members, after giving up or limiting employment, personal goals and other interests. The program serves an estimated 12,000 caregivers in Vermont annually.

**Case Management.** Case managers play a vital role in helping elders and younger adults with disabilities to build upon their strengths, garner new resources, and achieve their goals. Currently 130 certified case managers provide case management services under the Older Americans Act (OAA) and the Aged and Disabled Waiver (soon to be Choices for Care) programs. DAIL has worked closely with the Area Agencies on Aging (AAAs) and the Home Health Agencies to develop a comprehensive approach to the provision of case management services. In FFY 2003 the AAAs served 8,212 case management clients and case management services were provided to approximately 1,638 participants in the Home-Based Medicaid Waiver and Enhanced Residential Care Waiver programs. DAIL standards for the provision of case management services were established in SFY02 and will be revised slightly in SFY06. A strong case management training program continues through a contract with the Central Vermont Council on Aging.

The Department also provides **Older Americans Act Nutrition Programs**, as good nutrition is a crucial aspect of maintaining physical health and quality of life. Vermont's Nutrition Program supports good nutrition for both older adults and adults with disabilities. Nearly 12,000 older adults participate in the program. Nutrition services are provided locally through contracts with the five Area Agencies on Aging (AAAs), and help improve the nutritional quality of participants' diets and contribute to their independence and quality of life. Participants receive a variety of nutrition services including nourishing meals, screening for nutrition risk, nutrition education and health promotion and disease prevention information. The program also provides opportunities for social interaction, volunteerism, and links to other important services.

The total number of meals served in FY 2004 increased to 1,033,625, a 1% increase over FY 2003 (1,018,369 meals served). Although the number of meals served in community group settings remained constant (404,482 in FY 2004, compared with 404,928 in FY 2003), the number of home delivered meals served increased by 3% (629,143 in FY 2004, compared with 613,441 meals in FY 2003). Community meals accounted for 39% of the total meals served; home delivered meals, 61%.

The **Vermont Center for Independent Living (VCIL) home-delivered meals program** provides meals for persons with disabilities under the age of 60 who, because of their disability and/or chronic health condition, are unable to prepare their own meals and do not have meal preparation assistance available. Three categories of meal service are available. Peers (persons with disabilities) with an ongoing need for assistance may receive up to five (5) meals per week in the long-term program. The short-term program provides up to sixty (60) meals to help peers address temporary or episodic needs (for example, recuperation from an illness). Peers requiring crisis intervention, such as services related to a hospital discharge following surgery, may receive emergency meals until other arrangements can be made. The number of home-delivered meals served continues to outpace meals served at community congregate meal sites, reflecting service to an increasingly frail population. VCIL must often create waiting lists for long-

term meal service as the year progresses, since demand for home delivered meal service continues to grow. Additionally, the rising cost of fuel has sparked additional pressures and increased program costs. In FY 2004, 447 peers received a total of 56,200 meals (a 13% increase over FY 2003).

The **Vermont Homemaker Program** provides services, such as shopping, cleaning, and laundry, to elderly and/or disabled adults to assist them to maintain their independence. These services, provided by Home Health Agencies, help people live at home in a healthy and safe environment. During 2004, 850 people were served, and it is estimated that the same number will be served in 2005. To be eligible for the Homemaker program, a person must be a Vermont resident, aged 18 or over; and need help with activities like dressing or bathing; and/or need help with household tasks like housekeeping or shopping, and/or need help due to a cognitive impairment.

**Adult Day Centers** provide community-based non-residential day services to elders and adults with physical disabilities. Adult Day Centers provide a safe, supportive environment where participants receive a range of professional health, social and therapeutic services. Adult Day Centers also provide respite, support and education to families and caregivers.

Vermont's Adult Day Centers have continued to experience steady growth. The hours of service provided by the Adult Day Centers hit an all-time high of 462,111 hours in SFY04. The number of Vermonters served increased from 931 in SFY03 to 950 in SFY04, an increase of 6%. Currently 13 providers operate 16 sites, each certified to provide State-funded and Medicaid-funded Adult Day services. One additional Adult Day Center is certified to provide only Medicaid-funded services. All Centers offer supervision, therapeutic activities, nutritious meals, socialization opportunities, personal care and professional nursing services (16 of the 17 Centers have a registered nurse on site daily). Many Centers also provide professional social work, physical therapy, occupational therapy, and/or speech therapy. In 2004, the Department and the Vermont Association of Adult Day Services (VAADS) developed a set of six quality indicators that will now be used by all certified centers in Vermont to assess the quality of adult day services.

A consistent theme in all of the programs described above is the need for a **valued, adequately reimbursed and well-trained workforce**. The number of people with high levels of need continues to increase, resulting in the demand for a larger workforce to provide in-home care. This creates an ongoing challenge for agencies that provide home- and community-based care, i.e. the need to find increasing numbers of qualified caregivers. Perhaps the single most important issue for these agencies, both in Vermont and across the country, is finding and keeping enough qualified, caring attendants. DAIL continues to work with to find sustainable ways to improve direct care worker wages, benefits, and working conditions to ensure that there is an adequate supply of competent caregivers.

Over the past three years, DAIL has been working on this issue with funding from the Centers for Medicare and Medicaid Services **Real Choices System Change Grant**. This grant supported the development of an association of direct care workers and implementation of other recommendations from the *Paraprofessional Staffing Study* to create a stable, valued, appropriately trained and adequately compensated workforce.

As such, a statewide Vermont Association of Professional Care Providers (VAPCP) has been created and is now housed at the Community of Vermont Elders.

### ***Long-term Care Reform***

In 1996 the Vermont legislature passed a law, Act 160, requiring the State to take saved dollars from reduced Medicaid nursing facility utilization and reinvest those funds in home-based long term care. Prior to Act 160, Vermont spent 88% of its public long term care dollars on nursing facility care leaving only 12% for home based care. Now 70% of those dollars goes to nursing facilities leaving the remaining 30% to be spent on home and community-based care services. The current number of licensed nursing facility beds in Vermont is 3,400, with less than 90% of those being occupied at any one time.

In 2003, Vermont had 45 licensed nursing facility beds per 1,000 people age 65 and older compared with the nation's rate of 49. Compared to other states, Vermont ranked 31st (high to low) in beds per 65+ population. The number of Vermont nursing facility beds has decreased by 369 during the period 1996 to 2005, even as the number of frail elderly citizens is slowly rising.

In 2003, DAILE applied to the Centers for Medicare and Medicaid Services (CMS) for approval to restructure Vermont's long-term care Medicaid program to respond to consumers' requests for choice and equal access to services that will meet their needs for long-term care and help control the ever-increasing long-term care budget. This waiver was approved in August 2005 and the Choices for Care program started on October 1, 2005.

This demonstration program, the first of its kind in the country, is aimed at giving adults with physical disabilities and the frail elderly access to real choices. Under the current system, if an individual needs long-term care and meets the clinical and financial eligibility requirements, she/he can enter a nursing facility and Medicaid will pay for that care. However, if that same individual prefers to receive care in a home or community-based setting, she/he must wait for a Waiver "slot" to become available. The number of slots is limited by the available funding. As a result, individuals who want to receive care in settings other than a nursing facility often do not have that choice because no slots are available. We need to give consumers equal access to the service they prefer.

The new 1115 long-term care Waiver program (Choices for Care) will constitute a wholesale replacement of most of Vermont's existing Long-Term Care Medicaid program and will include the Medicaid nursing facility population. The program is financed by combining the funding appropriated for nursing facilities and the current Home-Based Waiver and Enhanced Residential Care Waivers into one budget. At the start of the program, all individuals who are currently eligible for Medicaid and receiving long-term care services in a nursing facility or through the Aged and Disabled Waivers will be automatically enrolled in the demonstration. Today approximately 2,200 individuals are benefiting from the entitlement to nursing facility care. Under the current system, there is no "entitlement" to home and community-based care. That scenario will change under the proposed program. Vermont projects that under the new program, nearly 3,000 individuals will benefit from the broader entitlement to both nursing facility and HCBS by allowing an additional 800 individuals equal access to service in a variety of settings.

Historically the long-term care budget for nursing facilities has increased due to case mix and cost of living increases. The change between FY05 and FY06 was approximately 6%. The shift to more options and equal access to community-based care is expected to ameliorate some of this increase; however, the mix between community-based and institutional care will unfold as the waiver begins operation.

The waiver will also test the hypothesis that by targeting preventive services such as early interventions, assessment, case management and certain home- and community-based services (HCBS) to frail elders and adults with physical disabilities who would not otherwise be eligible for these services, an individual's health status will be able to be maintained or improved and/or the need for higher levels of care will be delayed.

While acknowledging that the overall goal of the waiver is beneficial, some advocates have expressed concern that it will result in a lack of guaranteed services for high needs individuals who would previously have qualified for nursing home care. This issue will need to be closely monitored as the waiver implementation proceeds.

Quality assurance and quality improvement efforts will be enhanced under this program by having face-to-face interviews with more consumers, requiring that case managers visit their clients at least monthly and adding an ombudsman component to home-based care, similar to that provided in nursing facilities and residential care homes.

**Challenges to Community Integration Faced by Elders and People with Physical Disabilities**

Challenges	Financial Implications	Other Actions Needed
<p>Support for a valued, adequately reimbursed and well-trained workforce, including increased wages and benefits, and aggressive recruitment</p>	<p><u>Information regarding wage and benefits not available</u></p> <p>An aggressive marketing campaign would cost approximately \$100,000 total</p>	<ul style="list-style-type: none"> <li>• Improve working conditions               <ul style="list-style-type: none"> <li>- Promote involvement of care provider in care planning.</li> <li>- Develop strategies to provide recognition, status and respect.</li> <li>- Promote the new Vermont Association of Professional Care Providers</li> </ul> </li> <li>• Provide thorough orientation and training               <ul style="list-style-type: none"> <li>- Apprenticeships, mentoring and job shadowing opportunities</li> <li>- Continuing education opportunities</li> </ul> </li> <li>• Strengthen supervision and management using inclusive and coaching management styles.</li> <li>• Establish partnerships with a range of social service providers working with persons changing careers, entering or re-entering the work force (e.g., Community Action Agencies, Area Agencies on Aging, shelters) and educational institutions. to tap into potential student interest in employment. Efforts to recruit older workers are also important.</li> <li>• Explore the cost to make the reimbursement for state-funded personal care service workers consistent with personal care workers under the Choices for Care program</li> </ul>



<b>Challenges</b>	<b>Financial Implications</b>	<b>Other Actions Needed</b>
Need for increased capacity within Traumatic Brain Injury Services.	Approximately 10 additional individuals each year require intensive, ongoing supports that are likely to be life long. Case management services could also prevent the need for more costly waiver services. Approximately \$550,000 per year would be required.	None identified
Need for increased capacity and wages within the Attendant Services Program.	It would require a total of approximately \$1,880,000 annually to serve the 61 persons currently on the waiting list and increase wages to be consistent with other attendant programs.	Examine the feasibility of covering individuals in the Attendant Services Program either through an expansion of the Choices for Care Program or the Global Commitment
Need for increased capacity for the Vermont Homemaker Program	It would require a total of approximately \$63,000 annually to meet the need of approximately 62 people on the waiting list.	Examine the feasibility of including all homemaker services in the Choices for Care Program
Increasing Unmet Need for Children's Personal Care Services.	It would require a total of approximately \$2,135,800 annually to address the estimated annual growth of approximately 20% in new demand for these services each year.	Issue program guidelines to help better inform recipients and providers.  Investigate the feasibility of expanding case management services to a subset of families

## IV. Conclusion

The statute that created the Vermont Olmstead Commission instructed the Commission to develop a comprehensive plan by undertaking the following activities:

- To meet, gather testimony from consumers, advocates, providers, other state advisory bodies, and interested others, and hold public hearings to identify barriers that prevent people with disabilities from living in the most integrated settings;
- Determine whether any existing state or federal administrative policies, rules, and organizational structures constitute barriers that prevent people with disabilities from living in the most integrated settings;
- Examine the current allocation of resources and identify what additional resources are needed to ensure that Vermont's comprehensive plan is effective.
- Propose to the general assembly, in consultation with the secretary of human services, a long-term financial plan supporting implementation of the comprehensive plan that includes anticipated revenues and expenditures, and any other information needed to insure financial sustainability.

These directives were within the context of the U.S. Supreme Court Olmstead decision which requires states to discharge *institutionalized* people with disabilities to community settings once their treatment providers determine community placement is appropriate. The Court also suggested that state's could comply with this ruling by developing a "comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace..."

As evident from the Table on Page 2 of this plan, there are very few Vermonters on waiting lists for community-based services, and most that are on waiting lists are not institutionalized, but rather are *at risk* of institutionalization. This is a testament to the commitment within Vermont to value all members of our state and the prioritization of (often) scarce resources to ensure that our most vulnerable members receive needed services and supports.

The directive from the Vermont Legislature further attests to this commitment, in that it broadens the scope of the Vermont Olmstead Plan to "identify barriers that prevent people with disabilities from living in the most integrated settings," not just those institutionalized. Given this charge, this Plan presents the wide range of services and supports that would be needed to enable all people with disabilities and their families to have access to the same community options and opportunities afforded to all Vermonters, and to live, learn and work in the most integrated setting of their choice.

This Plan identifies challenges that face our State in order for us to achieve this vision. It also identifies both fiscal and non-fiscal (e.g., policies, rules, and organizational issues) implications related to these challenges. As identified in this plan, the costs to remove all of the current barriers to full integration of Vermonters with disabilities are quite substantial.

There is a general consensus within Vermont that we need to do as much as possible to embrace our citizens with disabilities as full community members. This Plan is a good foundation for our current policy and budget discussions. We recommend that the Plan be utilized by all stakeholders to collaboratively address the community support needs of Vermonters with disabilities. The Plan can also serve as a guide for future decisions about resource allocations, especially in light of the new 1115 Medicaid demonstration waivers for health care (Global Commitment to Health waiver) and long-term care (Choices for Care waiver).

## **Appendix A: Vermont Olmstead Commission Legislation**

### **NO. 135. AN ACT RELATING TO REPORTS OF ABUSE, NEGLECT AND EXPLOITATION OF ELDERLY AND DISABLED ADULTS. (S.224)**

It is hereby enacted by the General Assembly of the State of Vermont:

#### **Sec. 19. POLICY**

Beginning more than a decade ago, the state of Vermont embarked upon an effort to enable persons with disabilities to live in settings they prefer and ensure they are not confined unnecessarily in institutional settings. In the ensuing years, Vermont has implemented policies and programs promoting consumer choice, independence, and self-determination, but more work remains to be done in order to realize the goal of ensuring that no Vermonter with a disability is unjustifiably isolated or denied the opportunity to live with respect and dignity in the community.

#### **Sec. 20. LEGISLATIVE FINDINGS**

The General Assembly hereby finds that:

(1) In June 1999, the United States Supreme Court ruled in *L.C. and E.W. vs. Olmstead* that the Americans with Disabilities Act (ADA) requires a state to provide community-based services for persons with disabilities when the state's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such placement, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with disabilities.

(2) The Olmstead Court also suggested that development of a comprehensive, effectively working plan for placing qualified persons with disabilities in the most integrated settings and a waiting list that moves at a reasonable pace could be an important way for a state to demonstrate its commitment to achieving compliance with the ADA.

(3) Vermont now has an opportunity to plan its own future and reduce its vulnerability to claims that it discriminates against Vermonters with disabilities by developing a comprehensive, effectively working plan that takes account of:

(A) people with developmental disabilities living in nursing homes, group homes, and ICF/MRs (intermediate care facilities for persons with mental retardation);

(B) elderly Vermonters and others with physical or cognitive disabilities living in nursing homes and residential care homes because of the lack of personal care attendant and other community-based supportive services;

(C) persons with psychiatric disabilities confined to institutions or at risk of institutionalization or involuntary treatment;

(D) persons with psychiatric or developmental disabilities who are at risk of placement in correctional facilities;

(E) other persons with disabilities who are at risk of not having or receiving services or supports in the most integrated settings.

(4) An Olmstead advisory commission is needed to assist the secretary of human services with the development of a comprehensive, effectively working plan for placing qualified people with disabilities in the most integrated settings so that Vermonters with disabilities are not unjustifiably isolated and denied the opportunity to live with respect and dignity in the community.

Sec. 21. 3 V.S.A. § 3096 is added to read:

§ 3096. OLMSTEAD ADVISORY COMMISSION

- (a) The Olmstead advisory commission is established in the agency of human services.
- (b) The commission shall consist of:
- (1) three members appointed by the secretary of human services;
  - (2) the commissioner of the department of education, or his or her designee;
  - (3) the secretary of transportation, or his or her designee;
  - (4) four individuals appointed by the governor from a list of at least ten individuals recommended by the Vermont Center for Independent Living to represent the interests of Vermonters with disabilities;
  - (5) the commissioner of the department of corrections, or his or her designee;
  - (6) the executive director of the state housing authority, or his or her designee; and
  - (7) two individuals appointed by the governor from a list of at least ten individuals recommended by the secretary of human services to represent nongovernmental providers.
- (c) The commission shall be attached to the office of the agency of human services for administrative support. Consumer representatives shall be entitled to per diem compensation and reimbursement of expenses in accordance with section 1010 of Title 32.
- (d) The commission shall be authorized to meet no more than six times per year, and shall:
- (1) meet, gather testimony and other information from consumers, advocates, providers, other state advisory bodies, and other interested persons, and hold public hearings to identify barriers that prevent people with disabilities from living in the most integrated settings;
  - (2) determine whether any existing state or federal administrative policies, rules, and organizational structures constitute barriers that prevent people with disabilities from living in the most integrated settings;
  - (3) examine the current allocation of resources and identify what additional resources are needed to ensure that Vermont has a comprehensive, effectively-working plan for placing qualified people with disabilities in the most integrated settings and a waiting list for community-based services that moves at a reasonable pace. The commission, in consultation with the secretary of human services, shall propose to the general assembly a long term financial plan supporting implementation of the placement plan that includes anticipated revenues and expenditures by state agencies and community organizations, recommendations for aligning revenues and expenditures, and any other recommendations or information needed to ensure that the placement plan is financially sustainable.
  - (4) in consultation with the secretary of human services, develop a comprehensive, effectively working plan for placing qualified people with disabilities in the most integrated settings and a waiting list for community-based services that moves at a reasonable pace; and
  - (5) submit a status report on or before January 1 of each year to the governor and the general assembly.
- (e) All agencies of state government are directed to cooperate with the commission in providing information needed by the commission to accomplish its mission.

Sec. 22. SUNSET

3 V.S.A. § 3096 is repealed, effective July 1, 2005. Approved: June 13, 2002

## APPENDIX B: OLMSTEAD COMMISSION MEMBERSHIP

Statutory Requirement	Appointed Olmstead Commission Members
(1) three members appointed by the secretary of human services;	<ul style="list-style-type: none"> <li>• Susan Besio, AHS Director of Planning<sup>49</sup></li> <li>• Patrick Flood, Commissioner, Department of Disabilities, Aging and Independent Living<sup>50</sup></li> <li>• Theresa Wood, Deputy Commissioner, Department of Disabilities, Aging and Independent Living<sup>51</sup></li> <li>• (John Michael Hall, Principal Assistant to AHS Secretary)<sup>52</sup></li> </ul>
(1) the commissioner of the department of education, or his or her designee;	<ul style="list-style-type: none"> <li>• Michael Ferguson, Department of Education</li> </ul>
(2) the secretary of transportation, or his or her designee;	<ul style="list-style-type: none"> <li>• Lori Valburn, Chief, Civil Rights and Labor Relations, Department of Transportation</li> </ul>
(4) four individuals appointed by the governor from a list of at least ten individuals recommended by the Vermont Center for Independent Living to represent the interests of Vermonters with disabilities;	<ul style="list-style-type: none"> <li>• Susan Yuan, family member, Center for Developmental Disabilities, UVM</li> <li>• Deborah Lisi-Baker, Executive Director, Vermont Center for Independent Living</li> <li>• Heidi Pfau, consumer, Champlain Valley Agency on Aging<sup>53</sup></li> <li>• Ed Paquin, Executive Director, Vermont Protection and Advocacy</li> </ul>
(5) the commissioner of the department of corrections, or his or her designee;	<ul style="list-style-type: none"> <li>• David Peebles, Director, Community &amp; Restorative Justice, Department of Corrections</li> </ul>
(6) the executive director of the state housing authority, or his or her designee;	<ul style="list-style-type: none"> <li>• Richard Williams, Executive Director, Vermont Housing Authority</li> </ul>
(6) two individuals appointed by the governor from a list of at least ten individuals recommended by the secretary of human services to represent nongovernmental providers.	<ul style="list-style-type: none"> <li>• (Todd Centybaer, Executive Director, Howard Center for Human Services)<sup>54</sup></li> <li>• Marlys Waller, DS Staff Coordinator, VT Council of Developmental &amp; Mental Health Services<sup>55</sup></li> <li>• Janet McCarthy, Executive Director, Franklin County Home Health Agency</li> </ul>

<sup>49</sup> Current Chair; originally appointed as Commissioner, Department of Developmental and Mental Health Services

<sup>50</sup> Former Co-Chair

<sup>51</sup> Originally appointed as Director, Division of Developmental Services, Department of Developmental and Mental Health Services

<sup>52</sup> Original Chair; resigned from Commission in September 2003.

<sup>53</sup> Now at COVE

<sup>54</sup> Resigned from Commission in November 2003.

<sup>55</sup> Replaced Todd Centybaer

## **AD HOC COMMISSION MEMBERS**

- Juanita Cook, Co-Chair, Statewide Independent Living Council
- Maureen Kelly, Vermont Center for Independent Living
- John Pierce, Assistant Director, Division of Mental Health
- Lila Richardson, Disability Law Project, Vermont Legal Aid
- Joan Senecal, Deputy Commissioner, Department of Disabilities, Aging and Independent Living
- Karen Hammer-Williamson, Department of Disabilities, Aging and Independent Living
- Michael Sirotkin, Esq., of Sirotkin and Necrason
- Julie Tessler, Executive Director, VT Council of Developmental & Mental Health Services
- Cathy Voyer, Director, AHS Housing & Transportation
- Alicia Weiss, Executive Director, Vermont Coalition for Disability Rights
- Janet White, Advocate, COVE
- Peter Youngbaer, former Executive Director, Vermont Coalition for Disability Rights
- Carrie Foster, AHS Deaf and Hard of Hearing Services Director

## **OLMSTEAD COMMISSION STAFF**

- Bessie Weiss, Olmstead Commission Coordinator
- Karen Vasseur, Administrative Assistant
- Candi Young, Administrative Assistant