



VERMONT DEVELOPMENTAL DISABILITIES COUNCIL

Five-Year State Plan for **2017-21**

Section Plan Goals [Section 124(40); Sections 125(c)(5)]

Every five years the Vermont Developmental Disabilities Council engages in a review of the needs of people with developmental disabilities in our state. From this, the Council builds a new Five-Year State Plan that will guide how the Council uses its resources -- including VTDDC's annual allocation of federal funds -- to improve the lives of people with developmental disabilities.

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Part I. Comprehensive Review and Analysis

Introduction

The Vermont Developmental Disabilities Council (VTDDC) was founded in 1978 as a federally funded board dedicated to building the connections, supports, and policies that bring people with developmental disabilities and their families into the heart of Vermont’s vibrant local communities.

Vermont is well known as an early adopter of progressive social change in disability services. It was among the first to close its state-run institution for people with disabilities, and sheltered work ended in 2002. At the same time, Vermont faces economic challenges and demographic trends that stress many of its support systems. If there is a single theme that unites the finding in this report and the plan it has generated, that theme would be “closing the gap.” Vermonters impacted by disability reported a disconnect between community aspirations and economic reality, a gap between state policy and lived experience, a change from what “the system” was designed to do and how it must operate today.

VTDDC’s Five-Year State Plan represents the Council’s best efforts to think strategically about current and future opportunities to close those gaps.

Methodology

VTDDC sought out a high quality, independent firm to collect input from stakeholders, including self-advocates, family members, professional advocates, service providers, and policy makers. Because of the complex web of overlapping relationships among stakeholders in Vermont, it was important to choose an impartial, uninvolved research firm to collect impressions about need, service quality, and the role of the Council. VTDDC contracted with Human Services Research Institute (HSRI) from Cambridge, MA to collect stakeholder input, conduct focus groups, and prepare a preliminary needs assessment. HSRI performed this work over a three-month period, from March through May, 2016.

HSRI conducted three focus groups with self-advocates and allies at three venues:

1. A monthly meeting of the Board of Directors of Vermont's statewide self-advocacy organization, Green Mountain Self-Advocates (GMSA), where HSRI heard from approximately 50 self-advocates from all regions of Vermont.
2. A meeting with 15 self-advocates in the Northeast Kingdom, which is an isolated, rural part of Vermont and has the highest regional poverty rate in the state.
3. A conversation with six self-advocates at the Vermont Center for Independent Living in Montpelier, VT in order to hear from individuals who are served outside of the developmental services system.

To gather input from parents, HSRI conducted telephone interviews with six parents, supplemented by comments from an on-line survey (n=50). HSRI also interviewed representatives from a wide range of stakeholder organizations: They spoke with state agency leaders from four

divisions within the Agency of Human Services, two Vermont legislators, and directors from seven partner organizations, including Vermont's Protection and Advocacy Organization (P&A) and its University Center for Excellence in Developmental Disabilities (UCEDD). Findings were supplemented by data from state and national sources. HSRI organized this qualitative data thematically and summarized it for the Council. VTDDC's Executive Director then culled numerous public reports and data sets to provide a more detailed policy framework for this collection of statements and stories.

Analysis of Life Domains

HEALTH AND HEALTHCARE

General information

Thanks to Vermont's aggressive approach to health care and payment reform, the vast majority of state residents have health insurance. Over all, about 93% of Vermonters have coverage, and among people with disabilities, the rate is 95%. The Division of Developmental Disabilities has Health and Wellness guidelines for adults receiving HCBS, including the requirement that all individuals have an annual primary care visit. Adherence to this regulation is high, with 88% of adults who receive HCBS accessing preventative health services in 2014.

However, there is increasing national attention on the health disparities experienced by people with developmental disabilities. Public health data points to markedly higher rates of chronic diseases, including diabetes, hypertension, and cardiovascular disease. At the same time, routine health screening rates are low compared to people without disabilities and issues around reproductive health, depression, and even nutritional guidance are more likely to be overlooked during health care visits.

A new campaign by the Vermont Department of Health is the first public health effort to include a focus on individuals with cognitive disabilities as a special population. The **3-4-50 Campaign** focuses on three health behaviors -- lack of physical activity, poor diet, and tobacco use -- that contribute to four chronic diseases -- cancer, heart disease and stroke, type II diabetes, and lung disease -- that account for more than 50% of all deaths in Vermont. According to data from the Behavioral Risk Factor Surveillance System (BRFSS, 2013-14), Vermonters with cognitive disabilities had significantly higher rates in all four disease categories when compared to the general Vermont population. Moreover, Vermonters with cognitive disabilities were more likely to smoke (38%, compared to 18%), be obese (34%, compared to 25%), have high cholesterol (48%, compared to 35%), and drink two or more sugar-sweetened drinks/day (18%, compared to 12%)¹. Interestingly, Vermonters with cognitive disabilities had a similar profile in terms of health behaviors when compared with Vermonters of low socio-economic status (defined as earning less than 250% of the federal poverty rate). However, disease rates were significantly higher,

¹¹See: http://healthvermont.gov/prevent/3-4-50/documents/db_cognitive_impairment.pdf

suggesting that poverty alone -- and attendant cultural factors -- do not fully explain these health disparities.

Health and Healthcare Disparities in Vermont

In order to better understand how health disparities impact Vermonters with developmental disabilities, the VTDDC was awarded a community project grant through the Vermont Health Care Innovation Project (VDCIP), a System Innovation Model (SIM) grant from the Centers for Medicaid and Medicare. In partnership with Green Mountain Self-Advocates (GMSA), VTDDC published a white paper titled *Removing the Barriers, Improving Health Care for Adult Vermonters with Developmental Disabilities* (2015). Project participants found that consistent with national data, significant health disparities are experienced by Vermonters with developmental disabilities. Moreover, in many cases these disparities are more pronounced for the subpopulation of people with developmental disabilities who do not receive home and community-based supports (HCBS) through the Developmental Disabilities Services Division (DDSD).

In a particularly telling example, the team reviewed Medicaid claims data and compared the rate of emergency room admissions for adults with developmental disabilities who receive HCBS (Cohort 1) to those who have a developmental disability as defined by federal law but do not receive HCBS through the DDSD (Cohort 2). The average Vermonter visits the Emergency Department (ED) .48 times/year. In contrast, individuals in Cohort 1 make an average of .78 visits/year, and those in Cohort 2 make almost twice that many, at 1.27 visits/year. For both groups, a high percentage of ED use was for non-emergent causes (38-44%). The mean cost for Cohort 1 was \$40.27, while for the second group -- again, individuals who receive little or no community-based support -- the mean cost was a staggering \$274 or seven times higher.

In all, the project team interviewed over 100 Vermonters about the state's healthcare system including self-advocates, family members, physicians, and developmental services administrators. There was remarkable agreement as to the drivers behind the health disparity data:

1. Persistent problems with the transition from pediatric to adult health care;
2. A lack of health care providers who have training or experience caring for adults with developmental disabilities;
3. Inadequate care coordination, especially for individuals with developmental disabilities who qualify for Medicaid but do not meet the more stringent criteria for HCBS;
4. Lack of inclusion in public health initiatives and other wellness programs;
5. Difficulty in obtaining private insurance or Medicaid coverage for specialized equipment and long-term therapies;
6. A health care financing system that does not reimburse providers for the additional time needed to deliver quality care to patients with developmental disabilities.

VTDDC conducted this study in anticipation of healthcare reform initiatives that continue to unfold in Vermont. Thanks to a \$45 million investment by the Centers for Medicaid and Medicare, capitated rates and accountable care models with quality-based incentives have taken hold in Vermont. Active conversation continues as to how HCBS might be rolled into a global capitated

rate for special populations -- a so called "bundled rate" that includes acute care, routine prevention, and long-term services and supports.

This rapidly changing landscape in health policy presents opportunities to integrate care and improve health for people with long-term care needs. At the same time, it presents serious concerns. Advocates are quick to point out that to be both equitable and successful, payment reform in disability long-term services and supports (DLTSS) must include significant up-front investment to shore up deteriorating infrastructure in the designated agency system. This includes increasing direct support provider rates and expanding capacity for quality assurance and care coordination. As VTDDC's white paper points out, however, there are also serious deficits within the traditional medical system that urgently need attention. Within health reform, VTDDC has taken a lead role in advocating for training across all provider groups, development of cognitively accessible health information and health promotion tools, and a structure that will allow for the additional time needed to assess and educate patients with complex intellectual and developmental disabilities.

EMPLOYMENT

General information

Vermont funds no sheltered employment. As set out in the principles of service (18 VSA Sec. 8722), "The goal of job support is to obtain and maintain paid employment in regular employment settings." Vermont closed its last segregated work program in 2002. In FY 2015, the Developmental Disabilities Services Division (DDSD) provided 1213 people -- more than half the individuals served through the Division -- with supported employment services. Vermont's employment services have been recognized as a national model, with a 27% increase in the number of people on the job over the past five-year period (FY 2010-15). Vermonters who experience significant developmental disabilities earned over \$4.27 million in total wages, with the average wage at \$9.81/hour and the average work week at 9 hours/week.

In addition, more Vermonters with developmental disabilities are going on to post-secondary education than ever before through the "Think College Vermont", "College Steps" and "SUCCEED" programs. In 2015 five colleges and universities issued 2-year certificates to 74 graduates with developmental disabilities. Seventy-six percent of the SUCCEED program graduates went on to live independently. Data is not available regarding other longer term outcomes.

However, when the full range of Vermont citizens with disabilities, including developmental disabilities, is considered, there are some concerning signs. According to findings by the non-partisan joint fiscal committee of the Vermont legislature published in 2015, Vermont has one of the highest rates of young people receiving federal disability benefits in the country. The prevalence of Vermonters under age 35 receiving Social Security Disability Insurance (SSDI) was 2.12%(2,017 people) in 2013. The only state with a higher rate for that age group was Maine at 2.31%.

Overall, there were 22,534 Vermonters who received SSDI in 2013, a rate of 6.15% of the population — well above the national rate of 4.8%. The analysis also showed that between 2000 and 2013, the rates of people under age 45 on SSDI in the three northern-most New England states increased at a rate four times higher than the national average. The reasons, however, are not well understood. High rates of young people on SSDI may reflect that Vermont is particularly adept at getting people who are eligible for benefits enrolled. The numbers could reflect that many able-bodied young Vermonters leave the state for job opportunities elsewhere, leaving people on public assistance behind. Vermont has seen an out-migration of 20-year-olds and 30-year-olds. Others have suggested that the numbers are linked to the growing rate of opiate addiction among young Vermonters. Substance abuse qualifies as a mental disorder to receive SSDI, and it can be linked to other mental illness issues as well.

Also of concern is the significant gap in the rate of poverty for Vermonters with disabilities and those without disabilities. In 2013, only Maine and the District of Columbia had a wider gap. In 2014, Vermont made progress in narrowing the gap but still placed sixth from the bottom. That year, the poverty rate for civilians with disabilities, ages 18 to 64 and living in the community, was 29.2%, while the rate for civilians without disabilities was 10.2%. This reflects the fact that while Vermont's economy has seen slow but steady growth, residents with disabilities are not enjoy the same benefits from this trend as those without disabilities.

Themes from interviews and focus groups

Several stakeholder groups mentioned the need to examine employment through a more complex lens, one that accounts for longevity on the job, opportunities for advancement, and benefits, as well as the way that employers are engaged in hiring people with disabilities. Both state agency staff and self-advocates talked about how important it is to stop training employers to hire people with developmental disabilities -- often in the stereotypical jobs of "food and filth" -- and to start asking employers what they need and train people with developmental disabilities in those skills.

A number of those interviewed by HSRI, spoke about what one self-advocate termed "low expectation syndrome." Parents worry that their children will never have jobs that they like and are talented at doing. Self-advocates spoke about how pre-conceived ideas about what they can and cannot do, limit the opportunities that may be available to them. These stakeholders said that Vermont does not have high enough expectations for its youth with disabilities, for its employment programs, and for its HCBS. "How many people leave school and go sit in a mall?" asked one stakeholder.

Under the Workforce Innovation and Opportunity Act, recently finalized federal regulations for vocational rehabilitation may force Vermont to look in new ways at real outcomes in employment. The regulations strengthen reporting requirements, focusing attention on the kinds of supports that agencies provide to help people get jobs where they will thrive. Additional requirements about relationship building with employers may make the employment climate more welcoming to a wide range of job seekers.

INFORMAL AND FORMAL SERVICES AND SUPPORTS

General information

The Developmental Disabilities Services Division (DDSD) plans, coordinates, administers, monitors and evaluates state and federally funded services for people with developmental disabilities and their families within Vermont. DDSD provides funding for services, systems planning, technical assistance, training, quality assurance, program monitoring, and standards compliance. DDSD also exercises guardianship on behalf of the Secretary of Human Services for people who are under court-ordered public guardianship.

In FY '15, DDSD served 4408 individuals. Of these, 2917 received a full package of home and community-based services and 1086 received a lower level of support called "Flexible Family Funding" (FFF). DDSD contracts with 15 private, non-profit provider agencies. Ten of these are required to serve a geographic region of the state and five provide a distinctive approach or serve a specific subpopulation. All agencies undergo a periodic re-designation process that includes multiple opportunities for self-advocates and family members to speak to the quality of their services. In the last five years, two agencies have received low scores in this review process, and DDSD has worked pro-actively with regional stakeholders to address the deficits immediately and aggressively, eventually resulting in re-designation.

Services for children

Vermont does not have a waiver specifically for children. Those with the most significant needs receive service coordination, respite, and home support through the regional designated agency system (64 children) or through the pediatric hospice program (approximately 30 children). Families frequently report that outside of these two programs, services for children are fragmented and difficult to access. The array of potential supports includes:

1. Therapeutic interventions that are covered by Medicaid's Early Periodic Screening, Diagnosis and Treatment (EPSDT) program, including Applied Behavior Analysis (ABA, a much sought intervention for children with autism).
2. The Bridge Program, which is an EPSDT service that provides care coordination to help families access medical, educational, and other services for a child with a developmental disability before the age of 22. The Bridge Program served 300 children in FY'15.
3. Flexible Family Funding (FFF) provides a very small grant of up to \$1,000/year made available for respite and goods for a child or adult of any age who lives with their biological or adoptive family or legal guardian. FFF was provided to 750 children in FY '15 and 201 transition age youth (18 to 22 years). The modest funds a family can receive through this program have failed to keep pace with inflation and, in fact, been reduced at least twice in the past decade.
4. Family managed respite (FMR) has been available since FY '13, when Vermont redefined and narrowed children's personal care services to assistance with activities of daily living

such as bathing and eating. FMR is available to children with either a developmental disability or a mental health condition who do not receive HCBS. It supported 191 children in FY'15.

Services for adults

The vast majority of individuals in DDS are adults. They receive service coordination, residential services, supported employment, transportation, community support, home modifications, clinical and crisis services, and several kinds of family support. Adults in DDS live in a variety of settings with most living in typical family homes. In FY '15

- 1352 adults were supported in a shared living model at an average cost of \$31,271/person.
- 91 Adults were supported in a group home setting of 6 or fewer individuals at an average cost of \$87,557/person.
- 46 adults were supported in a staffed living situation with around the clock supervision at a cost of \$107,318/person.
- 6 adults resided in an ICF/DD at a cost of \$224,622.
- 359 adults lived independently with supervision.
- 176 adults lived independently with no paid home supports.

It was noted that an increasing number of individuals in DDS live with their families: 47% in 2015, up from 30% in 1996. The DDS population appears to be growing at both ends of the age continuum, with more people under the age of 30 or age 50 and over. The presence of more older individuals raises concerns about aging family caregivers, and the rising number of younger people meeting eligibility raises concerns about the long-term cost of an increased caseload.

Although a variety of management options exist in Vermont, 71% of HCBS are managed by agencies. A quarter of enrolled individuals choose to manage some home and community-based services, while only 3% choose to self-or family-manage all services.

Themes from HSRI Review

Participants in family interviews and self-advocate focus groups shared strong feelings with the researchers about the lack of respect they experience in discussing their individual and collective needs.

"People with developmental disability were almost united in feeling like they have no role in policy or program development within the state. Even though there may be a representative on an advisory board, they do not feel empowered as members, and they do not see that their comments or opinions matter. While there is a written or verbal commitment from state agencies to plan and provide services on an individual basis, that commitment feels remote to self-advocates and parents who say they want X (one thing) and are offered Y (a different thing) routinely."

This theme was so striking that the Council believes it merits serious attention and further exploration. It did resonate with the experience of several Council members who offered an interpretation: Vermont's designated system is relatively de-centralized, with quality, approach, and resources varying from one agency to another. Because there was an effort to reach out to self-advocates living outside of the relatively affluent Burlington area, the majority of self-advocates participating in HSRI's focus groups came from less populous and lower income regions of Vermont. This theme may reflect the underservice experienced by individuals with developmental disabilities from poorer rural parts of Vermont.

A second theme commented upon by HSRI was the distrust that family caregivers feel toward the DDS. They shared their concerns about the system's lack of capacity to monitor quality and to retain staff and worried about whether their family member could count on supports and services when they were no longer able to advocate for them.

Third and finally, HSRI noted the strong and frequently voiced recommendation that more resources need to be directed toward DDS. Designated and specialty agencies (the DA/SSA system) have struggled for the past decade to absorb funding cuts with the least impact on direct services. In early 2016, Vermont Care Partners, an affiliate of the state's trade council for regional agencies, published a white paper calling attention to meager wages paid to direct support workers.

"Unless proactive steps are taken immediately, the future of the Vermont DA/SSA system is in jeopardy... Vermont Care Partners and our member agencies are experiencing the negative effects of the long standing practice of the state to not include in its budgets any provision that allows us to provide regular COLA increases to our staff. Our current ability to recruit and retain a workforce that is adequately credentialed, trained and skilled to treat and support the needs of vulnerable Vermonters with developmental, mental health and substance abuse issues is at a breaking point."

Interagency Initiatives

Two promising interagency initiatives in Vermont are Integrating Family Services (IFS) and Vermont's Health Care Innovation Project (VHCIP). Both use payment reform to drive more integrated models of care.

Integrating Family Services

At the conceptual level, IFS has been under discussion in Vermont for over a decade. In broad outline, participating communities are offered funding for a wide array of child and family support programs as a bundled payment. When a child is identified as needing services, the IFS team comes together to provide a wraparound program based on individual need, rather than the need to slot an individual into specific funding categories. According to the IFS website:

"Integrating Family Services creates a cultural shift in the way human services does business. We are moving the focus from counting how much we are doing to looking at how well we are doing. Is anyone better off because of our investment? This shift is enabled by giving communities more flexibility with funding and decision making, so agencies can offer children, youth, and families the right supports and services, at the right time."

As promising as this model sounds, IFS has been slow to get out the gate. Participating communities must demonstrate that they are ready for the challenging work of cross-disciplinary care planning. Calculating a fair payment to a participating community has been controversial. To date, two areas of Vermont deliver services to children and youth using the IFS model -- Addison County, which is centrally located along the western boarder of the state, and the Franklin-Grant Isles region just south of Canada. The creation of structures for cross-disciplinary dialogue and learning have been critical to their success.

Early indicators of the promise that IFS holds include:

- In the first year of implementation in Addison County (FY12), the same level of funding provided an increase of 2163 service hours.
- Since IFS implementation, there has been a nearly 50% decrease in crisis interventions needed for children in Addison County.
- While all 11 other counties have seen a spike in children coming into state custody, Addison county's rate has remained stable.
- Through Northwestern Counseling and Support Services more children with autism are receiving applied behavior analysis (ABA) than in any other region of the state, despite the fact that this is a relatively underserved, low income, and remote region.

Vermont Health Care Innovation Project (VHCIP)

It is beyond the scope of this report to describe all of initiatives under the umbrella of the VCHIP, a System Innovation Model (SIM) grant from CMMI that seeks to achieve the triple aim of healthcare reform: Improving the experience of care, improving population health, and reducing the per capita cost of health care. This grant-funded project is slated to end in 2017. However, the positive impact of its interagency collaboration is likely to continue. The VCHIP has fostered this collaboration at two levels.

As the regional level, providers are growing in their appreciation for the social determinants of health and medical professionals are connecting in structured ways with regional social service agencies. In practical terms, what this means is that care coordination, long the hallmark of excellence in the primary care medical home, has widened its scope: The Health Home grows into a Health Community. Through the VHCIP providers of traditional health care services are seeing that regional collaboration allows communities to unlock resources that are critical to achieving desired health outcomes. While discussion continues at the level of systems change, the stories of individual Vermonters are telling:

A Vermonter from the Northeast Kingdom visited the Emergency Department at his community hospital almost daily for routine adjustments to his ostomy bag. With targeted intervention it was discovered that this individual, a "high utilizer" in health care reform terms, could be better served by his local federally qualified health center (FQHC). More importantly, his care coordinator learned that he was living in his car and that his prognosis was terminal. He was unable to access hospice because, technically, he did not have a home. Through multiple agencies, the community found a place for him to live, along with the supportive hospice services he needed as his disease progressed.

Regional health collaboratives, such as the one that supported this Vermonter, represent a significant opportunity for systems change.

At the policy level, stakeholders across many partner organizations have begun an earnest conversation about the integration of disability long term services and supports (DLTSS) and other, more traditional medical care funded by Medicaid. The model that is taking shape through this dialogue involves not only better communication and planning, but shared benefits and even shared risks. Research increasingly points to the relatively small impact of medical care, in comparison to social services and community-based supports, on overall health. If DLTSS providers are making a crucial contribution to health outcomes, shouldn't they share in the financial benefits that accrue to hospital and ambulatory care centers enrolled in accountable care organizations when population health improves? The risks inherent in this realignment of resources are noted above (see Healthcare), and they are serious. Moreover, few disability advocates and even fewer self-advocates have been brought into the decision-making process. There is, however, the potential for providers of DLTSS realizing increased funding that reflects the important role that community-based support plays in the overall health and wellbeing of individuals. Given that the momentum behind these potential changes, allies must remain involved and seek to support the involvement of self-advocates and families.

EDUCATION/EARLY INTERVENTION

General Information

Vermont is often recognized for its relatively high per pupil spending and its low classroom size. Fourth and eighth graders in the Green Mountain State score among the best in the nation on the National Assessment of Education and Progress (NAEP) tests in reading and math. But the story for students receiving special education is not as positive. Increasingly, students with Individualized Education Plans (IEPs) learn in segregated settings for a significant part of their day. The number of placements out-of-district, even out-of-state, has risen despite the cost. At the same time, Vermont denies access to special education for certain students. Specifically, Vermont is the only state in the nation that does not include functional limitations, such as impairment in communication or social skills, as a factor in establishing eligibility for special education. Students who cannot prove an adverse impact on academic tests do not receive an IEP with the rights and comprehensive programming required by the Individuals with Disabilities Education Act and its reauthorizations (IDEA).

Marked disparities in disciplinary actions are also apparent. A white paper prepared by the Disability Law Project titled *Kicked Out! Unfair and Unequal Student Discipline in Vermont Schools* (2015) found that students with disabilities were nearly three times more likely to be suspended than students without disabilities.

In its analysis of education, HSRI noted that Vermont continues to embrace the value of small, locally controlled schools that are open to all students. However, this is increasingly at odds with the legal requirement to provide adequate resources for students with significant educational needs. Legislators see opportunities for efficiency and property tax relief in school consolidation and fiscal restraint. Ironically, this has increased pressure to place students with low incidence, high need disabilities in expensive out-of-state institutions, where costs are shifted from the local education authority to catastrophic aid and the Medicaid to Schools program.

School Services

According to the Vermont Agency of Education (AOE) Child Count 2014, the state served about 13,990 children in special education or 16.7% of all enrolled children and youth. Of these, 767 students were in their regular classrooms less than 40% of their day; 1518 were in their regular classroom 40-79% of their day; and 9150 students were in their regular classroom 80% or more of the time. In addition, 748 students received their education in a segregated school, residential setting, or another alternative placement.

Recent attention has focused on the fact that Vermont has the highest rate of students identified with emotional disturbance for the purposes of special education in the country. As a percentage of all students who received special education services in the 2012-13 school year in Vermont, about 16% -- more than twice the national average -- were identified with an emotional disturbance, according to federal data. The reasons are not well understood, but poverty, high rates of substance abuse including heroin addiction among both youth and parents, homelessness, and domestic violence are all thought to play a role. It is also noted here that mental health issues are frequently comorbid with some developmental disabilities, especially autism spectrum disorder.

Given the prevalence of emotional issues and attendant behaviors, it is surprising that **Positive Behavioral Interventions and Supports (PBIS)** has not been universally implemented in Vermont. According to the Vermont Center on Disability and Community Inclusion (CDCI, Vermont's UCED), 44% of Vermont schools have or are implementing PBIS. In a letter sent August 1, 2016, the U.S. Department of Education signaled its concern over data that shows students with disabilities are disciplined far more often than their typically-developing peers: "Recent data on short-term disciplinary removals from the current placement strongly suggest that many children with disabilities may not be receiving appropriate behavioral interventions and supports, and other strategies, in their (individualized education programs)," wrote Sue Swenson, acting assistant secretary of special education and rehabilitative services, and Ruth Ryder, acting director of the Office of Special Education Programs.

Transition Services

As described in the section above on employment, a number of high quality, best practice programs exist in Vermont to support the transition from special education to work and greater independence. Along with opportunities to attend college, special education students in some districts are participating in Project Search, a sector-based training program for young adults in their final year of special education. Project Search offers total workplace immersion designed to facilitate a seamless combination of classroom instruction, career exploration, and hands-on training through worksite rotations. Through a partnership with Dartmouth Hitchcock Medical Center in Lebanon, NH, the program has been open to students in east central Vermont for several years. In 2016, Project SEARCH added a program in the Burlington area, placing students in a regional chain of fitness centers. Additional sites are under development in Rutland and the Northeast Kingdom.

These opportunities, however, do not have the capacity and variety to meet the transition needs of the majority of students with developmental disabilities. Several stakeholders interviewed by HSRI spoke about the need to take full advantage of new opportunities under the Workforce Innovation and Opportunity Act to expand opportunities for youth in transition to explore and prepare for competitive employment. Self-advocates also shared their vision that more peer-to-peer mentoring could help young people with developmental disabilities to advocate for themselves throughout the transition process.

Analysis of the State Issues and Challenges [Section 124(c)(3)(C)]

Criteria for eligibility for services

Vermont policy makers have chosen to embed a diagnostically based and relatively narrow definition of "developmental disability" in statute. This definition is the initial criteria for the purposes of identifying who will receive home and community-based supports (HCBS) through the developmental services designated agency system. Adults with an IQ of 70 or below or who have an autism spectrum disorder that significantly impacts their functional abilities are deemed clinically eligible for Medicaid and potentially eligible for HCBS through the Developmental Disabilities Services Division (DDSD).

Eligibility for HCBS is a two-step process. Individuals must not only be clinically eligible for Medicaid, but their life situation must also meet a System of Care Plan Funding Priority. These priorities are reviewed and redefined every three years through a public process set in statute. Current priorities must be revised and renewed in 2017. At this time, an individual meets a priority if they fit one or more of the following descriptions:

1. **Health and Safety:** Ongoing, direct support and/or supervision are needed to prevent imminent risk to the individual's personal health or safety.
2. **Public Safety:** Ongoing direct supports and/or supervision are needed to prevent an adult who poses a risk to public safety from endangering others. Additional criteria apply.

3. **Preventing Institutionalization -- Nursing Home:** Ongoing, direct supports and/or supervision are needed to prevent or end institutionalization in a nursing facility.
4. **Preventing Institutionalization -- Psychiatric Hospital or ICF/DD:** Ongoing, direct supports and/or supervision are needed to prevent or end stays in an inpatient psychiatric hospital or to end institutionalization in an ICF/DD.
5. **Employment for Transition Age Youth/Young Adults:** Ongoing, direct supports and/or supervision are needed for a young adult, ages 19 to 26, who has exited high school to maintain employment.
6. **Parenting:** Ongoing, direct supports and/or supervision are needed for a parent with developmental disabilities to provide training in parenting skills to help keep a child under age 18 at home. This priority category has a cap to \$7,800 annually.

As VTDDC developed its Five-Year State Plan, public input and Council member interest focused significant attention on the System of Care Priorities, noting that with the possible exception of number 5, an individual must be in crisis in order to receive services. "Immanent risk" is defined as "presently or expected to occur within 45 days," with the result that some clinically eligible individuals who would benefit from longer term preventative and developmentally supportive strategies -- for example, someone who is slowly acquiring a new communication method - cannot come into services until or unless they experience significant frustration and exhibit unsafe behaviors.

The Council also identified a serious concern on the part of individuals who experience disabilities that in many other states are classified as developmental in nature -- for example, cerebral palsy, childhood traumatic brain injury, or degenerative physical disabilities. These individuals remain outside the DDS, arguably the system best prepared to serve them. They often qualify for Medicaid and SSDI, and they may be eligible for other Medicaid-waiver funded programs such as Vermont's Choices for Care. However, the level of service and menu of options in these other DLTSS programs are more limited.

Vermont now operates under a single 1115(a) Demonstration Waiver called "Global Commitment to Health." This initiative has developed gradually since 2005 as different special populations, defined economically or by category of need, have been gradually brought under this single agreement with Medicaid, which permits the Agency of Human Services to act as a public managed care entity. Among the stated goals of Vermont's Global Commitment to Health is the ability to "apply a multidisciplinary approach, including the basic principles of public health... and program flexibility."

Throughout the development of the Five-Year Plan, the Council expressed its desire to strengthen advocacy in three areas: specifically, that the principles underlying the Global Commitment to Health be realized in greater coordination across programs, program parity across disability groups, and increased attention to proactive, long-term crisis prevention.

Barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families

VTDDC spent considerable time working to better understand which groups of people with disabilities experience disparities in access to or the quality of services and supports. As a first step, Council members learned to draw a distinction between a disparity, which involves an element of historical injustice, and a simple difference. So, for example, children in general get only very limited services outside of special education in the State of Vermont; but this applies to all children and represents a policy decision, not a true disparity. On the other hand, children with disabilities and children who are black or Hispanic are three times more likely to be suspended from school, according to a recent study. This represents a systemic injustice and qualifies as a true disparity.

The Council identified three groups that may experience disparities across a wide range of services that promote full inclusion, such as special education, healthcare, and HCBS. Some barriers to full participation are shared by all three groups, while other challenges are unique to the specific population. The following summarizes this information:

- ***People with developmental disabilities who are part of Vermont's small communities of New Americans.*** The majority of New Americans in Vermont have arrived through refugee resettlement programs. They come from all over the world -- Somalia, Nepal, Bosnia. Since 1989, more than 7000 men, women, and children have resettled in Vermont. Most move to small cities initially.

BARRIERS. People with disabilities who are new Americans face many of the same barriers as people without disabilities. Language is challenging and some of these groups face local prejudice. A recent effort to settle people from Syria in Rutland, VT has been met with suspicion and fear by some residents. Providers of disability-related services, especially local special education programs, Children with Special Healthcare Needs, and Vermont Family Network have made significant efforts to reach out and to provide additional resources to New Americans. Thanks to these supports, healthcare, education, translation services, and other necessary services appear to be in place.

- ***People with developmental disabilities who reside in certain cities characterized by high rates of poverty.*** Certain cities in Vermont have significant pockets of poverty, well in excess of the regional poverty rate. These include Barre City in central Vermont (poverty rate 26.5%), Rutland in west central Vermont (43.8% poverty rate), and St. Johnsbury in northeast Vermont (37% poverty rate).

BARRIERS. Ironically people with disabilities living in small cities characterized by poverty have somewhat better access to certain resources that people living in rural areas. The majority of Section 8 housing, for example, has been built in downtown areas, and Vermont small cities have at least some public transportation. This is not to diminish the challenges faced by all people living in these areas, including crime and very high rates of substance use.

- ***People with developmental disabilities who reside in rural Vermont in areas characterized by high rates of poverty.*** The vast majority of communities in Vermont are rural, and many of these are characterized by significant economic poverty. For example, Essex County, which lies along the Canadian border in eastern Vermont, has a countywide poverty rate of 19.6%. In the Green Mountains of south and central Vermont, communities are not only poor but isolate by substandard roads, some of which are closed during the winter months.

BARRIERS. Publicly funded resources in poor, rural areas of Vermont are sparse and usually of lower quality than those in towns and cities. There is little affordable or accessible housing and virtually no public transportation. Because Vermont schools are heavily dependent upon local property taxes, schools in sparsely populated areas have fewer resources for special education and transportation makes accessing therapeutic services and clinical expertise difficult.

Based on this analysis, the VTDDC has chosen to focus its goal related to underserved communities in rural areas with significant economic poverty.

The availability of assistive technology

There continues to be little hard data regarding any unmet needs in the area of assistive technology. Vermont's Olmstead Report (FY'06) estimated that 9% of Vermont households have someone who either needs or uses assistive technology.

Vermont makes assistive technology available to children and adults at Medicaid expense when medical necessity is verified by a physician and/or speech language pathologist. The Vermont Assistive Technology Program offers technical assistance, device demonstrations, training and equipment loans. Vermont has a system in place to repurpose equipment that is no longer appropriate for its user. The Center for Disability and Community Inclusion (CDCI, Vermont's UCED) partners with the Vermont Assistive Technology Program to increase the use of technology by children and adults with disabilities and functional limitations.

Waiting Lists

State Pop (100,000)	Total Served	Number Served per 100,000 state pop	National Average served per 100,000	Total persons waiting for residential services needed in the next year as reported by the State, per 100,000	Total persons waiting for other services as reported by the State, per 100,000
6.26 ²	2917 ³	466	207.6	10.7	23.3 ⁴

1. a. **Entity who maintains waitlist data in the state for the chart above**

Regional designated agencies with reporting requirements to the Developmental Disability Services Division (DDSD).

2. b. **There is a statewide standardized data collection system in place for the chart above**

Yes No

3. c. **Individuals on the wait-list are receiving (select all that apply) for the chart above**

- No Services
- Only case management services
- Inadequate services

4. d. **To the extent possible, provide information about how the state places or prioritizes individuals to be on the wait-list**

- Comprehensive services but are waiting for preferred options
- Other

Use space below to provide any information or data available related to the response above

The relatively small number of people on the waiting list do not meet a funding priority. Until their situation changes, they remain on the list.

5. e. **Description of the state's waitlist definition, including the definitions for any other waitlists**

Vermont adopted legislation in 2009 clarifying that its developmental services waiting list is for people who meet clinical eligibility for developmental services but do not

² U.S. Census, 2015. Vermont population was 626,042.

³ Developmental Disability Services State Fiscal Year 2015, Annual Report (January 15, 2016), page 37.

⁴ Ibid., page 60. Total wait list is 213, with 67 waiting for a residential setting and 146 waiting for other services. None of the individuals on the waiting list meet a System of Care funding priority, so they will not receive the desired service until their situation or the funding priorities change.

currently meet a Developmental Disabilities System of Care Funding Priority. According to DDSD's FY 2015 report, the Vermont's waiting list consists of 182 individuals waiting for at least one developmental service, 30 individuals waiting for Flexible Family Funding, and one individual waiting for targeted case management. This data is slightly different from the number reported by Vermont to the Residential Information Systems Project (RSPI), which reported 367 individuals waiting in 2013.⁵

6. f. **Individuals on the wait-list have gone through an eligibility and needs assessment**

Yes No

Use space below to provide any information or data available related to the response above

Individuals who are on the waiting list in Vermont are clinically eligible for Medicaid and potentially for HCBS. Their assessment indicates that their life situation is not sufficiently urgent to meet a Vermont System of Care Priority.

7. g. **There are structured activities for individuals or families waiting for services to help them understand their options or assistance in planning their use of supports when they become available (e.g., person-centered planning services)**

Yes No

8. h. **Specify any other data or information related to wait-lists**

N/A

9. i. **Summary of Waiting List Issues and Challenges**

The primary issue in Vermont is not the existence of a long waiting list, but rather the narrow way in which the state defines eligibility in order to "manage to budget." The Vermont legislature appropriates an annual budget and the DDSD uses the System of Care Plan and other eligibility tools to ensure that the number of individuals found eligible to enter the system is roughly equal to the amount appropriated.

During the past year, individuals who use supported typing to communicate faced a significant challenge from the Department of Vermont Health Access, which manages Medicaid regulations. At the request of the Medical Director, the Agency of Human Services (AHS) reviewed whether the one-on-one direct support provider who is crucial to this form of alternative communication, could be funded by Medicaid when providing a service that is not said to be evidence-based. Self-advocates who use supported typing and their allies worked diligently to educate AHS about their support needs, and ultimately the Secretary of AHS ruled that the agency would continue to support facilitated communication as a community-based service.

⁵ See <https://risp.umn.edu/state-profiles>, 2013 Vermont Profile.

Analysis of the adequacy of current resources and projected availability of future resources to fund services

Vermont has struggled for at least a decade with tight budgets and frequent mid-year adjustments when revenue falls short of predictions. The legislature has little will to raise taxes and so has relied on raising fees and other short-term tricks to balance the state budget. Structural pressures on the budget include an aging population and a shrinking pool of younger tax-paying workers. The crisis of opioid addiction has further drained resources. These fiscal challenges are faced across all departments of government but are starkly worse in human terms when speaking about critical supports for vulnerable populations.

Vermont's Developmental Services System, once a national model, is said even by its champions to be near the breaking point. The average statewide turnover rate for direct support providers, the backbone of the Developmental Services System, has hovered just over 27% for the past 3 years. The gap between increases in funding for the designated and specialty agencies and increases in the consumer price index has widened to 15%, bringing already inadequate compensation levels even lower. The loss of workforce is expensive, disruptive, and detrimental to the system's capacity to deliver quality services. In addition, since July 2015, the following unanticipated changes have further strained agency budgets:

- Restructuring and reduction in rates for applied behavior analysis (ABA)
- Changes in the Federal Fair Labor Standards Act that broaden the definition of non-exempt workers, thereby increasing overtime payments.
- Changes in the Federal Home Health Care Exemption.
- Changes in the ICD-10 billing codes, necessitating changes in electronic health records.
- Efforts by private insurers to recoup revenue from paid bills for errors associated with Vermont's healthcare exchange.

Sadly, this crisis has been well anticipated, but with little will to act. According to a 2004 review by the Pacific Health Policy Group:

"Decisions need to be made with respect to the state's commitment to the community based system of care for people with mental health and developmental needs. Policy makers and stakeholders need to work collaboratively to develop a five-year funding plan that is consistent with both fiscal realities and the state's commitment to its citizens. the financial plan should address both the inflationary effects in the system (cost of living increases for personnel, rising energy and insurance costs, facility maintenance, etc.), and funding for caseload growth... The people whose lives are deeply affected by these decisions are counting on responsible and compassionate stewardship."

In short, VTDDC can anticipate serious challenges to the adequacy of funding for services.

Analysis of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive

The six Vermonters with developmental disabilities who reside in the state's one ICF-DD, located in Rutland, VT, receive the mandatory health services according to ICF-DD regulations. These services are overseen by the ICF-DD's nursing staff and monitored by the Department of Disability, Aging and Independent Living (DAIL) through its developmental services quality assurance review team, which includes a nurse. The ICF-DD is subject to DAIL's *Health and Wellness Guidelines* which outline quality standards. People with developmental disabilities living in VT nursing homes are monitored along with other residents by nurses from the Division of Licensing and Protection (DLP). Pre-Admission Screening and Resident Review (PASRR) mandates the screening of all nursing facility residents and new referrals to determine the presence of developmental disabilities and/or related conditions and the need for specialized services. Services include pre-admission screening and development of community placements and specialized services. Specialized services provide support to these few individuals with developmental disabilities who live in nursing facilities and improve their quality of life by addressing social and recreational needs.

To the extent that information is available, the adequacy of home and community-based waivers services (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c)))

Vermont is currently undergoing a systematic review of its Home and Community-based Services (HCBS) to assess their consistency with CMS's new Home and Community-based Setting Rule (the Rule). It is thought that in at least three areas, Vermont may need to make changes.

1. Vermont is home to one residential community, Heartbeet Lifesharing in Hardwick, VT, that may qualify for heightened scrutiny under the Rule.
2. Congregate day programs are operated by some agencies and may be inconsistent with the intent of the Rule.
3. While there are many examples of excellent person-centered planning taking place within DDSD, there may also be: (1) inconsistency in adherence to this best practice; and (2) an inherent conflict of interest in that it is frequently the case that services are planned by the same agency that ultimately delivers those services. Providers have expressed concern that in a state as small as Vermont, independent case management is not a realistic option.

The VTDDC Executive Director participates on the committee reviewing these issues. Additional information will be available in the next reporting cycle.

Part II. Goals and Objectives for 2017 - 2021

RATIONALE FOR GOAL SELECTION

GOAL 1

In weighing the needs of three underserved communities in Vermont, the Council was persuaded by the reasoning reviewed above in the Analysis of State Issues that people with developmental disabilities living in low income, rural communities presented both the greatest need and the greatest opportunities for positive social change. The Council selected healthcare, pro-employment initiatives, and peer-to-peer support as three issue areas to address in underserved communities because of the following opportunities and the availability of clear indicators of underservice.

- **HEALTHCARE:** There is significant momentum toward payment reform, the development of regional health collaboratives, and the recognition of the critical role that social determinants play in health. VTDDC will build on the groundwork laid by its white paper on health disparities for Vermont adults with developmental disabilities (2015). Moreover, health disparities are a well-documented measure of medical underservice.
- **EMPLOYMENT:** VTDDC has built a successful partnership with the State Treasurer in establishing an ABLÉ program under a Vermont brand. Announcement of a Vermont ABLÉ Savings Program, anticipated by the end of 2016, will create an opportunity for outreach and education throughout the state about pro-employment programs, financial literacy, and how savings can leverage additional opportunities for advancement out of poverty. The gap between the poverty rate for Vermonters with disabilities and those without disabilities is a key indicator of the disparities in work and asset acquisition experienced by Vermonters with disabilities.
- **PEER TO PEER SUPPORT:** VTDDC will build on the expertise in peer-to-peer support at both GMSA and VFN, as well as current interest in supported decision making, which is an interest of the DDSD. Measures of success will include a reduction in the number of young adults under full guardianship in Vermont.

GOAL 2

In considering how best to support a statewide self-advocacy organization —and grassroots advocacy generally—the Council was persuaded by HSRI's findings regarding the lack of meaningful participation of self-advocates and family members. This was striking, especially given that Vermont has an unusually high number of consumer advisory groups. Clearly people are present at decision-making forums but failing to have an impact. This suggested to the Council that people with disabilities and their families need more opportunities for advocacy and leadership training. It also led the Council to consider how it could help facilitate more successful legislative campaigns through the power that comes with increased citizen participation in a well-organized and large grassroots group. Issues common across disability and other groups are means of amplifying public pressure. For example, the failure of developmental services to provide a livable wage to direct support workers, would receive more attention in the budget

process if advocates from the mental health and aging communities joined forces with disability rights groups.

GOAL 3

The Council struggled the most with identifying priority issues for systems change efforts. Previous strategy has relied heavily on advocating for resources for the DDS and the designated and specialty agencies. This remains very important and is reflected in Objective 2 of this Goal. However, the Council is increasingly aware of the needs of the broader community of people with developmental disabilities -- potentially 86,000 strong in Vermont.

Far more children with developmental disabilities receive specialized instruction and accommodations throughout their school career than go on to have -- or, in some cases, need -- a full package of HCBS. However, relatively little is known about the experience of people who do not meet a System of Care Priority. This is thought to be a reflection of the fact that Vermont does not keep a waiting list or offer much in the way of alternative, lower level programming that might support another segment of the continuum of functional needs presented by people with developmental disabilities. There exists an unknown number of adults who receive significant public assistance through State Plan Medicaid and Social Security, but lack access to care coordination and community-based supports. VTDDC's previous work on healthcare disparities suggests that this group has significant unmet medical needs. Objective 1 under this goal reflects the need to know more about this group of Vermonters with developmental disabilities. Objectives 3, 4, and 5 represent what the Council considers to be achievable steps toward creating a broader continuum of services.

Collaboration [Section 124(c)(3)(D)]

In a state as small as Vermont, there is understandably a great deal of collaboration. Traditionally, VTDDC has close working relationships with the following:

- *Vermont's statewide self-advocacy organization, **Green Mountain Self-Advocates (GMSA)**, and its statewide family support organization, **Vermont Family Network (VFN)***: These are VTDDC's closest working partners. In the last five-year cycle (2012-16), VTDDC issued grants to these two organizations in order to accomplish numerous State Plan Objectives. Over this five-year period, these grants totaled: \$392,250 to GMSA and \$185,000 to VFN. VTDDC partners with both organizations to plan and implement the Vermont Leadership Series, an annual introductory training for self-advocates and family members held over three winter weekends. VTDDC contracted and partnered with GMSA to develop the 2015 white paper on healthcare for Vermont adults with developmental disabilities. In 2016, VTDDC secured a second grant from the Vermont Healthcare Innovation Project (VHCIP) to create and deliver in person and on-line training in disability core competencies, and again contracted and partnered with these two organizations.
- *VTDDC's Network Partners, the **Center for Disability and Community Inclusion (CDCI)** and the **Disability Law Project (DLP)** at Vermont Legal Aid*: Similarly, these are close working relationships but could be strengthened in the new Five-Year State Plan Cycle. VTDDC has collaborated with DLP in the recent past, seeking technical assistance with complex legal issues and advocacy strategies. In 2015 this resulted in the first changes to Vermont's DD Act since it was originally passed, increasing DDS's accountability to the legislature. Because DDS is actively engaged in rulemaking as a result of this legislative change, VTDDC anticipates continuing to work with DLP on system quality assurance in support of Five-Year State Plan Goal 3. VTDDC has partnered with CDCI in the past to support leadership training and looks forward to developing a more specific project to make advanced leadership training available in Vermont, per Objective 2.2.
- *The **Coalition for Disability Rights (VCDR)**, which is composed of 20-plus small disability-related groups and acts as the face of the cross-disability movement in Vermont*: VTDDC staff attend monthly VCDR meetings and participate fully in developing and supporting their cross-disability platform. In the last Five-Year Plan Cycle, VTDDC provided VCDR with close to \$150,000 in grant support. VTDDC also partners with VCDR to plan and host a widely attended annual Disability Awareness Day at the State House. VTDDC is aware that they have a challenging decision to make in early FFY'17 as to whether or not it will continue to fulfill some of its systems change objective through a sub-contract with VCDR. VTDDC will also consider whether there is additional in-kind support that it could offer VCDR.

5 Year Goals

GOAL #1: UNDERSERVED COMMUNITIES

Description



VTDDC will reduce barriers to competitive employment and effective healthcare services for people with developmental disabilities in two (2) underserved Vermont communities characterized by significant economic poverty.

Expected Goal Outcome

NOTE 1: To clarify, the Council intends to support one (1) healthcare-related demonstration project in one (1) underserved community [Objective 1.1] and to undertake a series of initiatives [Objective 1.2, 1.3, and 1.4] that target both the underserved community selected for the healthcare demonstration project and a second, underserved community. Both communities will be characterized by significant economic poverty. Projects supporting Objectives 1.3 and 1.4 may be statewide, but with emphasis on outreach to the two specific underserved communities identified for Goal 1.

NOTE 2: The Council intends to issue statewide requests for proposals in support of these objectives. In the judgment of VTDDC's Executive Director, naming the specific communities at this time would be in conflict with the competitive process required by the AHS Grant Issuance and Monitoring Plan (July 1, 2015). Any community or region that is: (1) Designated as a medically underserved community by the Health Resources and Services Administration; and (2) Identified as have a poverty rate at or above the statewide rate of 12.2% will be eligible to submit proposals.

EXPECTED GOAL OUTCOMES:

-  Vermont will have an evidence based, multi-pronged strategy to reduce the health and healthcare disparities experienced by Vermonters with developmental disabilities, especially those in low income health services regions, that can be replicated statewide as part of Vermont's health care reform efforts.
-  The gap in the poverty rate for Vermonters with disabilities and those without disabilities will narrow.

Objectives

Objective 1. In collaboration with partner organizations, work to bring health outcomes for people with developmental disabilities closer to those of people without developmental disabilities in an underserved Vermont community.

Objective 2. Promote the use of available funding and programs for competitive employment for Vermonters with developmental disabilities living in two (2) underserved communities characterized by significant economic poverty.

Objective 3. Support initiatives that position Vermont as a leader in developing and expanding entrepreneurial opportunities and innovative approaches to job training for people with developmental disabilities, especially those living in underserved communities.

Objective 4. Promote peer-to-peer training and support as a highly valued part of person-and-family-centered care planning for people with developmental disabilities.

Goal #2: Supporting advocacy by individuals with disabilities and family members

Description

VTDDC will nurture and support a powerful movement of self-advocates and family members prepared to advocate for policies, programs, and funding that realize the vision of the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 [42 USC 15,001 et seq (2000)].

Expected Goal Outcome

EXPECTED GOAL OUTCOME



Vermont has a cross-disability, grassroots advocacy organization built by and for self-advocates and family members that plays a leadership role in shaping policy and public opinion about disability issues.

Objectives

Objective 1. Identify and collect information about Vermonters who have a developmental disability, including those who meet the federal definition of “developmental disability” [42 U.S. Code §15002(8)] but who do not meet the State of Vermont definition of “developmental disability” for the purposes of receiving home and community based supports (HCBS) [18 V.S.A. §8722(2)].

Objective 2. In collaboration with VTDDC’s Network Partners – Disability Rights Vermont and the UVM Center for Disability and Community Inclusion -- conduct multiple leadership training opportunities where self-advocates and family members come together to learn how to model and advocate for inclusion, self-determination, productivity, and independence.

Objective 3. Engage self-advocates and family members through the dissemination of information and alerts; through soliciting their input about the issues impacting their lives; and through assisting them in practicing advocacy skills, including at the local and regional level.

Objective 4. Build a repository of stories from self-advocates and family members in multiple formats (audio, video, or written) that can be used as advocacy and training tools.

GOAL #3: SUPPORTING SYSTEMS CHANGE

Description

VTDDC will vigorously seek changes in Vermont’s many service systems so that Vermonters with developmental disabilities – including those who are currently not identified as having a developmental disability under Vermont law [18 V.S.A. §8722(2)] – and their family members have greater and more equitable access to supports that foster the four values in the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000: community inclusion, self-determination, productivity, and independence.

Expected Goal Outcome

EXPECTED GOAL OUTCOME:



Vermont pro-actively responds to the emergent needs of people with developmental disabilities across the lifespan in a manner that is individualized, well-coordinated, and flexible. There is parity among disability long-term services and supports programs and “no wrong door” to services.

Objectives

Objective 1. Through a public awareness campaign, disseminate information widely about the prevalence, accomplishments, stories, and needs of the estimated 86,000 Vermonters with developmental disabilities, including those who do not qualify for home and community based services (HCBS) through the state Developmental Services System of Care Plan.

Objective 2. Advocate that the Developmental Services System of Care Plan place greater emphasis on pro-actively supporting individuals rather than reacting to crises, and expand the percentage of eligible individuals under the Plan. who receive home and community based services (HCBS).

Objective 3. Promote access to existing care coordination services through provider training, appropriate accommodations, and targeted outreach for people with developmental disabilities.

Objective 4. In collaboration with VTDDC’s Network Partner, Disability Rights Vermont, which is Vermont’s the Protection and Advocacy Agency, advocate that the Choices for Care program offer the same services and supports to people 18 to 64 years of age as the Developmental Services program offers to people with developmental disabilities, including supported employment.

Objective 5. Advocate to expand family support funding, including funding for respite.

Evaluation Plan [Section 125(c)(3) and (7)]

VTDDC will evaluate its progress in implementing the Five-Year State Plan using three complementary approaches:

1. At the level of individual initiatives, all projects -- whether implemented by Council staff or by another entity through a grant agreement or contract -- provide periodic reports using DD Suite. For outside organizations, installment payments are contingent upon proof of deliverables. The Council's Program Committee, a subcommittee of the Council, meets twice annually to discuss the quality, relevance, and future use of collected deliverables. The results of this biannual review are shared with the full Council, grantees and contractors, and the general public.
2. At the level of the Five-Year State Plan, VTDDC contracts with an independent firm to conduct an annual evaluation guided by the Council's logic model and by the annual work plans. Data sources include collected deliverables, DD Suite project reports and performance measures, consumer satisfaction surveys, and the Program Committee's biannual review. The results of this independent evaluation are provided as supporting documentation for VTDDC's annual Program Performance Review (PPR).
3. Consistent with a 2014 Vermont law (Act 186), VTDDC will also provide an annual evaluation of four specific objectives using Results-based Accountability (RBI, see <http://resultsaccountability.com/>). For the 2017-21 State Plan, the four objectives will be: Objective 1.1, healthcare demonstration project; Objective 1.3, innovative employment models; Objective 2.2, leadership development; and Objective 3.3, expanded access to care coordination. RBI is an approach used across Vermont State government. It is especially helpful in assessing outcomes at the population level. RBI asks three fundamental questions, illustrated here using Plan Objective 1.1:
 - How much did we do? For example, how many encounters were there between individuals in the target population -- who are adults with developmental disabilities living in a low-income, underserved community -- and healthcare professionals who have agreed to use stipulated supports, protocols, or other best practices?
 - How well did we do it? How faithfully did the practitioner follow the required care guidelines? Did the training provided to healthcare professionals increase their knowledge of disability-related core competencies?
 - Is anyone better off? Has the rate of obesity changed in the target population? Have emergency room visits by participants been reduced? Do participants report greater rates of physical exercise or more positive encounters with health professions?

By using this multi-level approach to evaluation, VTDDC ensures that its federal funder, designated state agency, and the general public see both short-term accountability and a measure of long-term community impact.

Projected Council Budget FFY '17 [Section 124(c)(5) (B) and 125(c)(8)]

Goal	Subtitle B \$	Other(s) \$	Total
GOAL 1. Underserved Communities	\$127,344	\$96,246	\$223,590
GOAL 2. Supporting advocacy by individuals with disabilities & family members	\$138,381	\$20,200	\$158,581
GOAL 3. Supporting systems change	\$108,381	\$17,200	\$125,581
General management (Personnel, Budget, Finance, Reporting)	\$113,405	\$3,000	\$116,405
Functions of the DSA	\$0.00	\$50,000	\$50,000
Total	\$487,511	\$186,646	\$674,157

For additional details, see Attachment C.

Public Input and Review [Section 124(d)(1)]

Describe how the Council made the plan available for public review and comment. Include how the Council provided appropriate and sufficient notice in accessible formats of the opportunity for review and comment

The VTDDC posted its draft Goals and Objectives from June 27, 2016 to July 28, 2016 on its website. Two versions were made available: The first simply stated the Goals and Objectives as adopted by vote of the Council at its June 23, 2016 meeting. The second version, which was designed to be cognitively accessible, included explanations of each goal and objective in plain language as a sidebar. Visual icons and large type were also used to guide the reader's attention in the accessible version.

Comments were collected through Survey Monkey with an open-ended field after each goal and objective. Council staff encouraged public comment by reaching out through social media and through the list serves of partner organizations. Because relatively few family members participated in focus groups during the development of HSRI's contribution to the comprehensive needs assessment, a special effort was made to solicit comments from parents and other family caregivers.

VTDDC was pleased to see that 48 members of the public provided comments. Additionally, Green Mountain Self-Advocates, which is Vermont's statewide self-advocacy organization, submitted a short report reviewing each goal and objective. They commented positively and with appreciation for the work done to prepare an easy-to-understand, accessible version of the State Plan Goals and Objectives.

Describe the revisions made to the Plan to take into account and respond to significant comments

The majority of the comments received were positive, usually suggesting additional details to consider when implementing a specific piece of Vermont's Five-Year State Plan. There were no comments indicating disagreement with the issues that the Council had selected as priorities to be addressed during the next five-year cycle.

VTDDC met on July 28, 2016 to review public comment and consider adjustments to the plan. All members received a full set of comments prior to the meeting. In addition, the Council Executive Director and the President shared guidance recently received at NACDD's annual conference. They emphasized to the Council that the State Plan must state which goal(s) or objective(s) would be undertaken collaboratively with Network Partners. They also urged the Council to be as specific as they could be in identifying one or two underserved communities to be targeted in the Plan.

In light of public comment and guidance from NACDD, three changes were made:

1. The phrase "characterized by significant economic poverty" was added throughout the objectives under Goal 1 to make clear the Council's decision to focus on isolate rural

poverty as the proxy for underservice to individuals with disabilities and their family members.

2. In three places, the phrase "...and family members" was added to indicate that the activity would focus on both self-advocates and on their family members. This change was recommended by several parents who provided public comment.
3. Objective 2.2 was revised to make explicit VTDDC's intent to work collaboratively with Network Partners on various leadership training opportunities.

Attachment A. Designated State Agency and Assurances

The Designated State Agency is:	<input type="checkbox"/> Council Itself	<input checked="" type="checkbox"/> Another Agency
Agency Name:	Vermont Agency of Human Services	
DSA Official's Name:	Dawn O'Toole, Chief Operations Officer	
Address:	280 State Drive - Center Building, Waterbury, VT 05671	
Phone	802-871-3009	
Email	dawn.otoole@vermont.gov	
Calendar Year DSA was designated	1978	

Q: Does the DSA provide or pay for direct services to persons with developmental disabilities?

A. Yes. The Agency of Human Services provides direct services to people with developmental disabilities through multiple departments, including: the Department of Disability, Aging and Independent Living; the Department of Health; the Department of Mental Health; the Department of Children and Families; the Department of Corrections; and the Department of Vermont Health Access (Medicaid). Among these, home and community based services are primarily managed by the Developmental Disability Services Division and the Division of Adult Service, both operated under the Division of Disability, Aging and Independent Living.

Q: Describe DSA Roles and Responsibilities related to Council.

A: AHS provides administrative support including: personnel and benefit management; financial management and account reconciliation for federal reporting; oversight of purchasing and contracting; support for information technology and telecommunications; and access to rented equipment and office space.

Q. Does your Council have a Memorandum of Understanding/Agreement [Section 125(d)(3)(G)] with your DSA?

A. No

Assurances [Section 124(c)(5)(A)-(N)]

Written and signed assurances have been submitted to the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, United States Department of Health and Human Services, regarding compliance with all requirements specified in Section 124 (C)(5)(A) -- (N) in the Developmental Disabilities Assurance and Bill of Rights Act.

Approving Officials for Assurances

For the Council (Chairperson)

Designated State Agency

A copy of the State Plan has been provided to the DSA

Attachment B, Council Membership, Staff, and Diversity

Council Membership

Agency/Organization <ul style="list-style-type: none"> • Rehab Act : A1 • IDEA : A2 • Older Americans Act : A3 • SSA, Title XIX : A4 • P&A : A5 • University Center(s) : A6 • NGO/Local : A7 • SSA/Title V : A8 • Other : A9 • Individual with DD : B1 • Parent/Guardian of child : B2 • Immediate Relative/Guardian of adult with mental impairment : B3 • Individual now/ever in institution : C1 • Immediate relative/guardian of individual in institution : C2 	Gender <ul style="list-style-type: none"> • Male : M • Female : F • Other : O Race/Ethnicity <ul style="list-style-type: none"> • White, alone : D1 • Black or African American alone : D2 • Asian alone : D3 • American Indian and Alaska Native alone : D4 • Hispanic/Latino : D5 • Native Hawaiian & Other Pacific Islander alone : D6 • Two or more races : D7 • Race unknown : D8 • Some other race : D9 • Do not wish to answer : D10 	Geographicals <ul style="list-style-type: none"> • Urban : E1 • Rural : E2
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Name	Race/Ethnicity			Membership Category	Agency/Organization Name
	Gender	Geographical			
Breunig, Fred	D1	M	E1	B2	
De Carolis, Gary	D1	M	E1	B2	
Emerson, Stacy	D1	F	E1	B2	
Holden, Terry	D1	F	E1	B2	
Hybels, Catherine	D1	F	E1	B2	
LeShay, Dion	D1	M	E1	C1	
Rudiakov, Lisa	D1	F	E1	B1	
Ryan, Marcy	D1	F	E2	B1	
Smith, Cynthia	D1	F	E1	B2	
Stambler, Kay	D1	F	E1	B2	
Stoll, Miriam	D1	F	E2	B2	
Vaut, Adrian	D5	M	E1	B1	
Paquin, Ed	D1	M	E1	A5	Disability Rights Vermont
Ryan, Susan	D1	F	E1	A6	UVM, Center for Disability and Community Inclusion
Stratton, Jennifer	D1	F	E1	A7	Lamoille County Mental Health Services
Hassler, Carol	D1	F	E1	A8	Children with Special Health Care Needs
McFaddan, Clare	D1	F	E1	A3	VT Agency of Human Services, Department of Disability, Aging, and Independent Living (DAIL)
Spinney, John	D1	M	E1	A2	VT Agency of Education

NOTE: Current vacancies A1 (1), A4 (1), and either B1 or B2 (2).

Council Membership Rotation Plan

The Executive Order establishing VTDDC -- as well as the Council's By-laws at Article 4 Section 4 (B) -- provide that Governor-appointed members who are not state and public agency representatives are limited to two full terms after appointment of three years each. If they fill a mid-term vacancy, they may serve 2 more full terms. Although people may be reappointed after a hiatus of at least one year this has been rare and would require a complete re-application. These requirements ensure that there is regular rotation of members. It is noted here that the Vermont Secretary of Human Services has been asked to fill at least two of three vacancies: A representative for the Rehabilitation Act (A1) and a representative for Social Security, Title XIX (A4). Executive Order 05-07 also provides for a fifth representative from the Agency of Human Services at the discretion of the Secretary of Human Services and from any department within the agency; previously this position was held by a representative from the Department of Children and Families.

Staff

Race/Ethnicity	Disability Options	Gender
<ul style="list-style-type: none"> • White, alone : D1 • Black or African American alone : D2 • Asian alone : D3 • American Indian and Alaska Native alone : D4 • Hispanic/Latino : D5 • Native Hawaiian & Other Pacific Islander alone : D6 • Two or more races : D7 • Race unknown : D8 • Some other race : D9 • Do not wish to answer : D10 	<ul style="list-style-type: none"> • Yes : Y • No : N • Does not wish to answer : DWA 	<ul style="list-style-type: none"> • Male : M • Female : F • Other : O

Position Title	Status	Name	Race/Ethnicity	Gender	Disability
Executive Director	Full Time	Kirsten Murphy	D1	F	no
Administrative Assistant	Full Time	Chelsea Hayward	D1	F	no

NOTE: VTDDC is seeking to fill a third staff position for a Senior Planner and Policy Analyst by the beginning of FFY'17 (October 1, 2016).

Attachment C, Projected Budget FFY'17, Details

Goal	Subtitle B \$	Other(s) \$	Total
GOAL 1. Underserved Communities	\$127,344 ²	\$96,246 ⁷	\$223,590
GOAL 2. Supporting advocacy by individuals with disabilities & family members	\$138,381 ³	\$20,200 ⁸	\$158,581
GOAL 3. Supporting systems change	\$108,381 ⁴	\$17,200 ⁹	\$125,581
General management (Personnel, Budget, Finance, Reporting)	\$113,405 ¹	\$3,000 ⁶	\$116,405
Functions of the DSA	\$0.00	\$50,000 ⁵	\$50,000
Total	\$487,511.00	\$186,646	\$674,157

Regulations

- General management under Subtitle B may not exceed 30% of total allocation
- Grants to external entities must demonstrate that 25% of the project budget comes from another, non-federal source of funding.

Assumptions

- Salary is apportioned as: Executive Director @ 50% General Management and 50% Goal Activities; Project Planner/Analyst @100% Goal Activity; and Administrative Assistant 75% General Management and 25% Goal Activities.
- Benefits are 43% of base salary
- In parity with salary distribution, 40% of general operating goes to General Management and 60% goes to Goal Activities.
- Goal Activities for Subtitle B: BASE allocation to each goal: \$64,822
 - (\$145,145 salary and benefits + \$25,320 overhead) / 3 = \$56,822/goal
 - \$24,000 Council Expenses / 3 = \$8,000 / goal
- SEEDS (small, capacity-building grants) distributes \$36,000 evenly over 3 goals

Calculations for Subtitle B Funds, VTDDC's Annual Allocation

1. General Management: \$96,525 salary/benefits + \$16,880 overhead = **\$113,405**
2. Goal 1: \$64,822 base + \$12,000 SEEDS + \$50,523 large grants = **\$127,345**
3. Goal 2: \$64,822 base + \$12,000 SEEDS + \$22,000 in-house + \$40,000 large grants = **\$138,381**
4. Goal 3: \$64,821 base + \$12,000 SEEDS + \$32,000 large grants = **\$108,380**

Calculations for Matching and Other Funds⁶

5. In-kind support from AHS as Designated Agency: **\$50,000**
6. Estimated payment to VTDDC through VHCIP Grant, 1st quarter: **\$3,000**
7. Goal 1: \$75,571 (VHCIP Grant) + \$3,000 (SEEDS match) + \$17,675 (lg grants) = **\$96,246**
8. Goal 2: \$ 3,000 (SEEDS match) + \$3,000 (DAD match) + \$13,200 (lg grants) = **\$20,200**
9. Goal 3: \$ 3,000 (SEEDS match) + 14,560 (lg grants) = **\$17,200**

⁶ To be recalculated for FFY'17 budget when reported to AIDD in Program Performance Review.