



Content for Comprehensive Review and Stakeholder input summary report

Prepared for the Vermont
Developmental Disabilities Council:

*This summary report is prepared to assist the VT DDC in developing their
5 year plan. June 3, 2016*

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Vermont Comprehensive Review, 2016

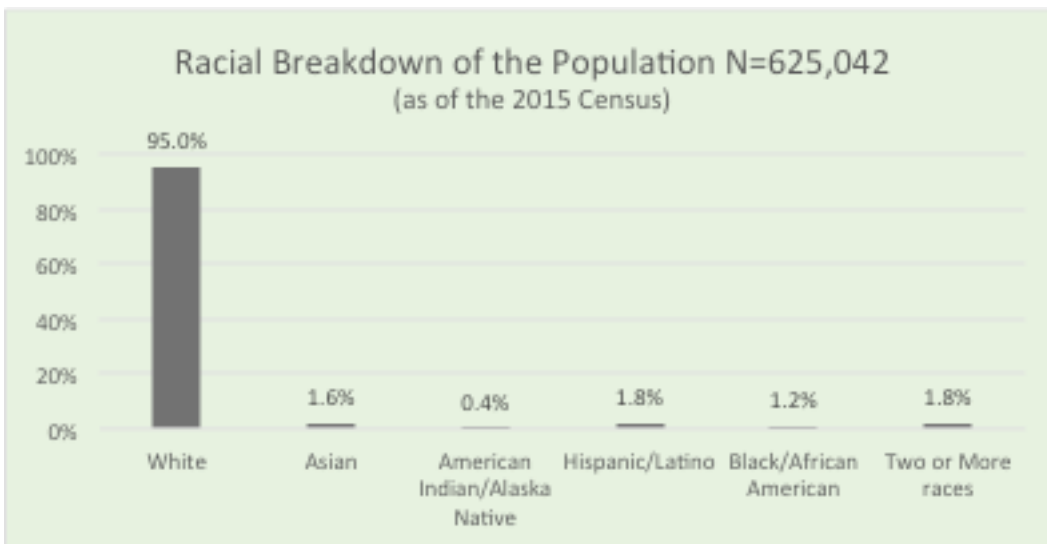
Introduction:

What follows is information collected from a variety of sources. It is intended to provide a picture of what's happening in Vermont for people who have disabilities and their families. Sources for the information include published and/or written reports, interviews with a wide range of stakeholders from around the state, DD Council and other survey results, and focus groups. Instruments were developed jointly with DD Council staff, and in some cases, were informed by instruments that were used by other DD councils.

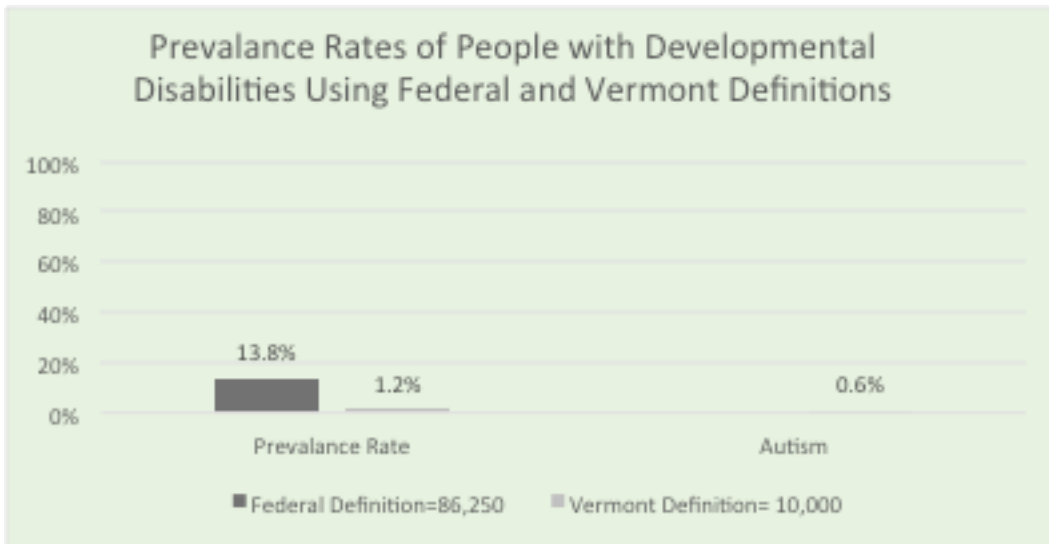
The report is organized to give Council members a window into several segments of services and supports in Vermont. In each section, there is some summary material from the sources identified above, followed by themes that emerged from state agency and advocacy interviews. When interviewees expressed thoughts about ways the Council could go about its work, we took note of suggestions; many of the same suggestions were made by different sources, and these suggestions/ recommendations are noted as well.

Demographics:

Total population and racial diversity: 625,042 (as of the 2015 Census), with the following racial breakdown:

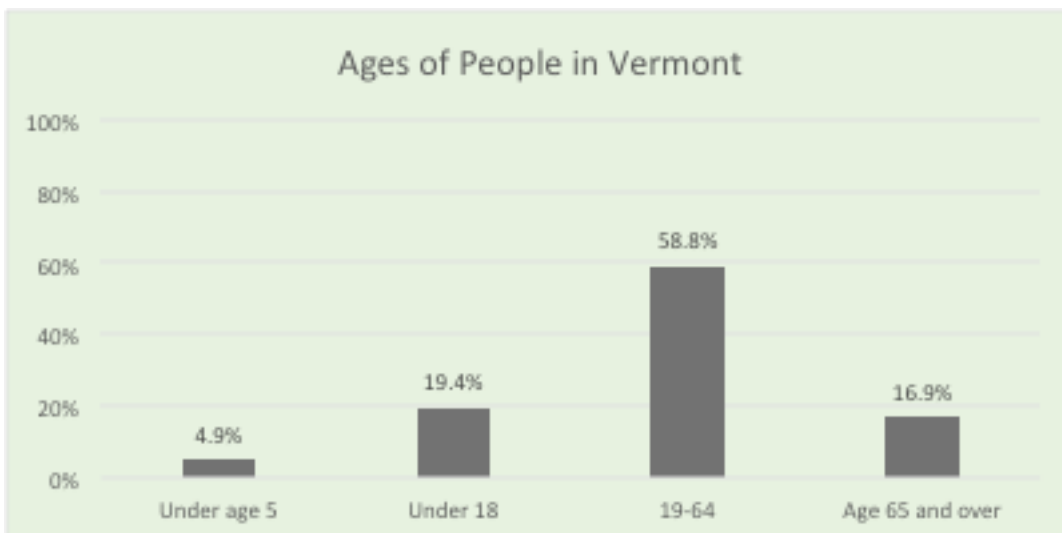


Prevalence rates: federal and Vermont

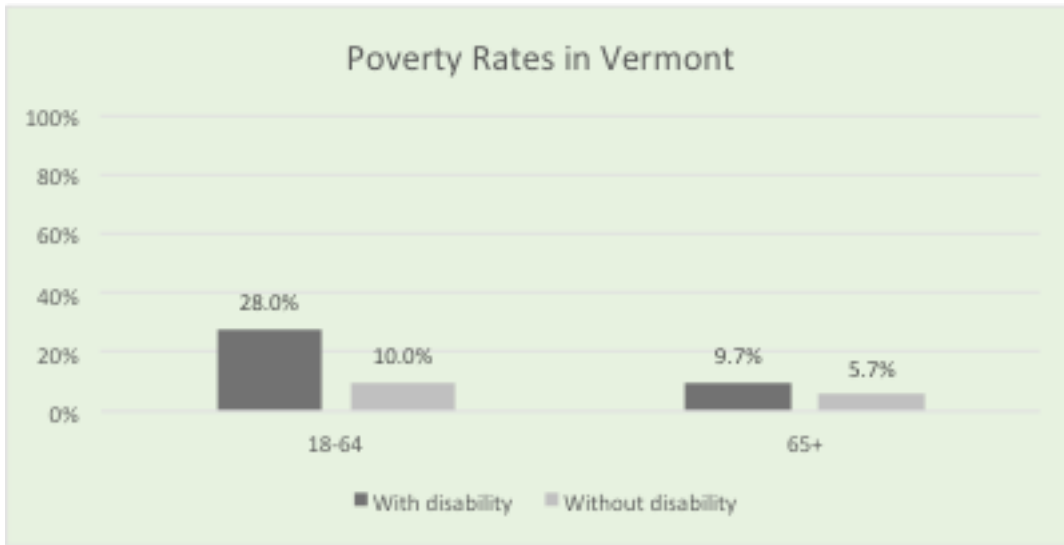


Total number of people with developmental disabilities, using the federal DD definition and the CDC's 2015 prevalence of 13.8%: about 86,250; using Vermont's definition of DD, and a prevalence rate of 1.2% (DD) and .6% (autism), the number is about 10,000.

Ages of people in Vermont:

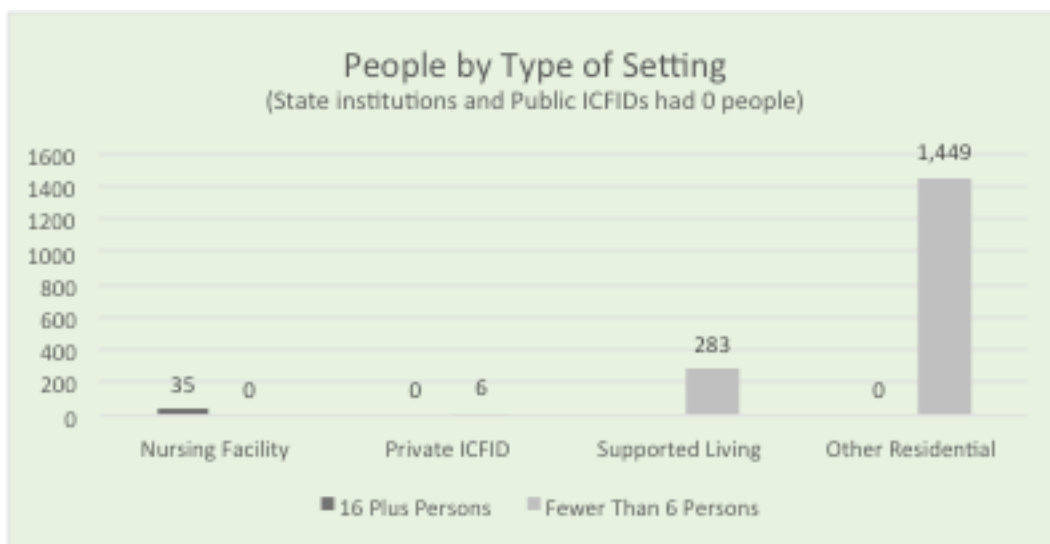


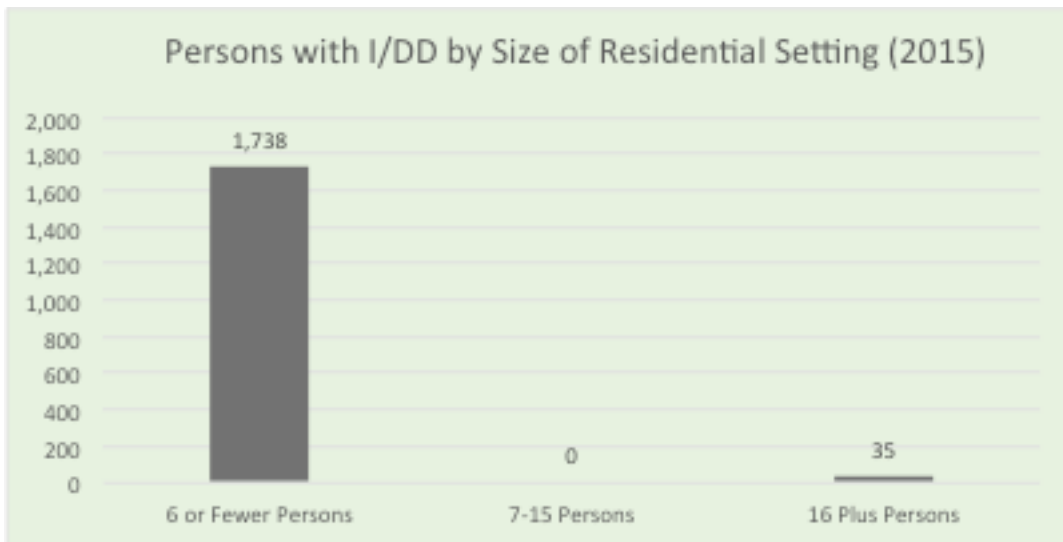
Poverty in Vermont:




Where people with DD live:

General information: People with developmental disabilities in Vermont live in a variety of places. Many still live at home with their families, while others live in residential settings. Data show the range of numbers of individuals with DD by type of setting and the number of settings by size of the residential unit (source: Braddock: State of the States, 2015):





Housing

General information about housing: Two Medicaid Home and Community Based Services waivers provide residential supports for people in Vermont. One of these, called *Choices for Care*, serves elders and those with physical disabilities; the other, called *Global Commitment*, is managed by the Developmental Disabilities Services Division (DDSD) and serves adults with developmental disabilities. Of the 2768 people served by this waiver, 1773 are served in the various residential settings identified above (data from DDSD); the remaining 995 are served in their family home. Those living at home appear to get minimal supports. 

Information from surveys and focus groups: Several comments from families, self-advocates and parents indicated that Vermont relies too heavily on the service model called shared living, and would like to see Vermont try out other things. No one suggested a specific alternative to explore, but many felt that other states, perhaps those with more robust funding, might be doing some work around residential supports and options that Vermont could learn from. Several self-advocates commented that Vermont has very limited affordable housing available, and, because so few people with DD in Vermont get services from DDSD (speaking proportionally), a lot of people who need housing help won't ever get it.

Several of the questions on the Vermont Council's survey asked about housing. People with DD who answered were mostly living in own home or apartment (75%), and about 57% of people with DD were satisfied with where they live. Almost 90% of family members who responded had a family member living in the home. About 55% of family members said they were satisfied with their family's living situation. 40% said it was 'ok for now'.

Data from the National Core Indicators Project (NCI) (2015) offer some interesting points of view with respect to housing. About 68% of Vermonters with DD say they have some input into where they live, and 64% say that they choose their housemates, have some choice in their housemates, or choose to live alone. About 16% own or rent their own homes.

Themes from interviews: Many self-advocates talked about living in their current place for five years or more, data consistent with NCI findings. They also said that there are a lot of people with DD that the state doesn't know about or who aren't eligible for services, so those people aren't getting any help with housing, or jobs, or anything.

Suggestions/recommendations: In Vermont, where there are limited housing options, several stakeholders suggested collaborating with many housing advocates and planners to see if some kind of more comprehensive housing plan might be developed that could address many needs, including cost, accessibility, location to community services, and so on.

Health Care:

General information: The vast majority of people in the state have health care (about 93%), thanks to Vermont's single payer system of health care, combined with various federal programs. About 95% of people with disabilities in Vermont have health care coverage, and about 88% of those over the age of 22 have access to preventive health services. The DDSD has developed health and wellness guidelines that are to be used through its system of services, and it monitors the implementation of these guidelines. However, for all those outside of the DDSD services system, health guidelines do not affect availability or access of services.

(funding information about health care is described in Appendix A.)

Information from surveys and focus groups: Data from the National Core Indicators Project reveals that 51% of Vermonters with DD (who are receiving services) report their health as very good or excellent, with 45% reporting it to be fairly good and 4% reporting that their health is poor.

Self-advocates discussed health care from several points of view. Most talked about getting “good regular care”, but they also mentioned that dental care was a problem. Families mentioned that regular health care was “okay”, but had a great deal to say about mental health care. Several families had extensive experience in using mental health services when their children with DD were in crisis, and they all commented that the system didn’t work. They expressed concerns that the professionals charged with providing care didn’t know much about children with developmental or other disabilities, and they commented that the experts who were available to them locally were often over-whelmed.

Themes from interviews: State agency staff expressed confidence that Vermonters are getting good quality primary care, and that for those in the service system health care monitoring is of good quality. Several self-advocates pointed out that there are a lot of people with DD who are not being served by state agencies, and we don’t know anything really about their health situations, beyond what NCI tells us.

Suggestions/recommendations: While most people report that the health care they receive in Vermont is at least good, there are still some areas where work needs to be done to improve the overall quality of care. One of these areas is crisis care. Health Services around crisis care need to be examined to identify areas of local/regional strength, and need. Almost every family talked about one bright spot in their son’s or daughter’s crisis journey, even though most of the journey was difficult. Finding ways to share the expertise that does exist across the state and perhaps outside the state was suggested as something that should be done right away. Many families and self advocates thought that training – of direct support workers and the wide array of professionals – would enhance the state’s ability to address the crisis needs of Vermonters with

developmental disabilities. While this is a limited need in terms of population size, it becomes a significant need when issues of medication, therapy, family disruption and personal disruption are factored in.

The second area of need is in **dental services** for people with developmental and other disabilities. While it was mentioned only a few times, both parents and self advocates struggle with finding a dentist who can offer them high quality services. Other states, notably Massachusetts, have programs at dental schools and through dental societies through which both pre and in-service dentists develop and hone their skills in working with people with DD. Sharing those resources in some way was seen as very important.

Employment and post-secondary education:

General information: Vermont funds no sheltered employment programs; all of its' employment funding is focused on real work. The Department of Developmental Disabilities services provides 1213 people 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. Vermonters who experience disabilities are earning total wages of over \$4.27 million.

New federal regulations in vocational rehabilitation that will go into effect in July may force Vermont to look in new ways at real outcomes of employment because there are requirements about reporting and about the kinds of supports that the agency provides 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.

More Vermonters with disabilities are going on to post-secondary education than ever before through the "Think College Vermont", "College Steps" and "SUCCEED" programs. Last year five colleges and universities issued 2-year certificates to 74 graduates; 76% of the SUCCEED program graduates went on to live independently.

Information from surveys and focus groups: Parents worry that their children will never have real jobs, jobs that they like and are talented in doing. Self-advocates spoke to feeling like others have low expectations of them, and they feel strongly that these low expectations limit the opportunities that might be available to them. They also suggested that more opportunities to keep going in school – that is, have access to post- secondary school – would make them more employable.

The NCI project had data to share about employment. About 41% of Vermonters reported having a paid job in the community; about 85% of those were supported jobs and about 12% were competitive employment positions. On average, those in supported employment report working about 17 hours every two weeks. About 9% reported having access to vacation or paid sick time at their jobs, and about 49% report that they would like a real, paid job in the community. 48% report that community employment is a goal on the individual service/support plans.

Themes from interviews: Several stakeholder groups mentioned the need to examine employment through a more complex lens, one that accounts for longevity in the job, opportunities for advancement and benefits, and the ways 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 DD and start asking employers what they need and training people with DD to provide those skills. Several state agency staff reiterated the agency's commitment to use funds to support real employment outcomes for people with DD.

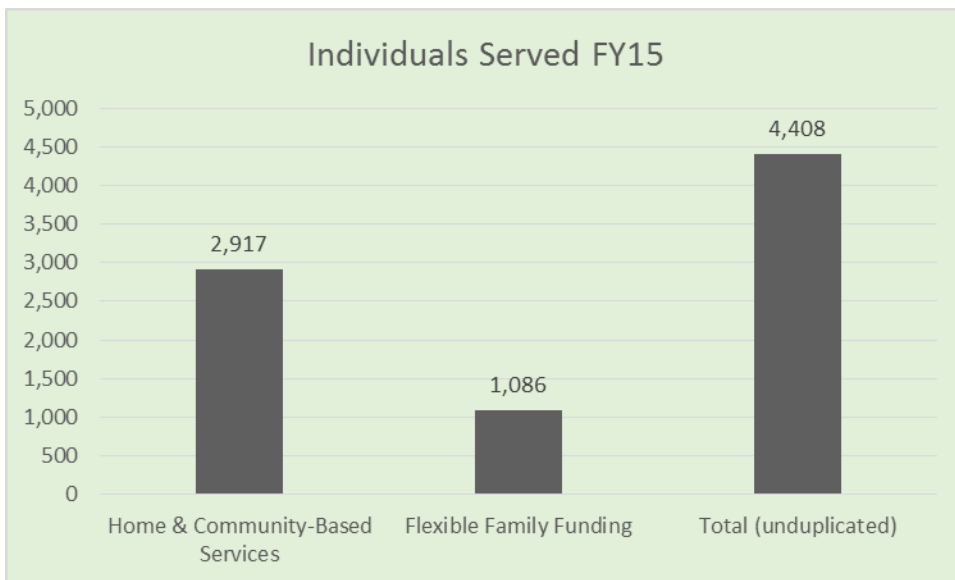
Several stakeholders said that Vermont does not have high enough expectations for its youth and for its employment programs. As a state, Vermont doesn't look carefully enough at what happens to people whose jobs are not fulfilling, who are not working up to capacity, who are not doing what they want to do. The real outcomes do not get measured; "how many people leave school and go sit in a mall?" was one comment that was made. As a state, Vermont doesn't know what is really happening, and so can't begin to fix it.

Suggestions/recommendations: Self-advocates spoke about the need for more training and more opportunities to work, while at the same time saying that the barriers of transportation and low expectations were real and serious. Several parents mentioned how important training for real jobs was for their children, as well as how important it was for their children to see themselves as having jobs and contributing to the community. “It would be great if the Council could help people see us as real people” said one self-advocate.

Services from the Developmental Disability Services Division, including children, adults and families:

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 commissioner for people who are under court-ordered public guardianship.

Individuals served (FY 15):



DAIL oversees most of the services for children with developmental disabilities and their families in Vermont through the network of

Vermont's Designated Agencies (DAs) and Specialized Services Agencies (SSAs).

Children with developmental disabilities with the most intensive needs are eligible for home and community-based services (HCBS) funded under the Global Commitment to Health 1115 Waiver. Services include service coordination, respite, home support and clinical interventions. Many other support services exist for children through Early Periodic Screening, Diagnosis and Treatment (EPSDT), medical services (up to age 21), and the education system. In 2015, 64 children received services through HCBS.

Young adults may receive HCBS funding by meeting new funding priorities (health and safety and public safety) once they turn age 18. Employment for transition age youth to maintain employment after high school is also a priority for youth starting at age 19. Individuals served (FY 15) include 194 – Transition age youth (age 18 up to age 22) who received HCBS funded services.

The Bridge Program: Care Coordination for Children with Developmental Disabilities. The Bridge Program is an EPSDT service that provides support to families in need of care coordination to help them access and/or coordinate medical, educational, social or other services for their children with developmental disabilities up to age 22. In FY 2015, 300 children received Bridge services.

Flexible Family Funding Flexible Family Funding (FFF) provides funding for respite and goods for children and adults of any age who live with their biological or adoptive family or legal guardian. The maximum per person annual allocation of FFF is \$1,000. In FY 2015, flexible family funding was made available to 750 children (up to age 18) and 201 transition age youth (ages 18-22).

Family managed respite (FMR) became available at the end of FY 13 to assist with filling the need for respite for children affected by changes in the Children Personal Care Services (CPCS) program administered by the Vermont Department of Health (VDH). This includes children with a mental health or developmental disability diagnosis who do not receive home and community-based services funding. Family managed respite served 191 children in FY 2015.

Adult services: The primary funding vehicle for services for adults with DD is the HCBS waiver called Global Commitment. Services under this waiver include service coordination, residential and employment supported, clinical and crisis services, and several types of family support.

A more complete list of services provided by DDS is in Appendix B

Here is some data about who is receiving these services:

- 2549 - Number of people living in 24-hour paid home supports (June 30, 2015)
- 1,352 – Shared Living (1,197 homes)
- 359 – Supervised Living (less than 24-hour paid hourly supports) (339 homes)
- 535 - number of people with limited or no paid home supports
- 176 – Independent Living (no paid home supports) (164 homes)

As the number of people who are living with their families has risen, from about 30% in 1996 to about 47% in 2015, the demand on aging parents has risen as well. Some of these parents may receive some support for the Aging network, but their sons and daughters are not guaranteed services. In terms of residential programs, except for nursing facilities, there is no program in Vermont where more than six people live together.

Information from surveys and focus groups: 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 a 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.

Themes from interviews: Several parents expressed concerns about what would happen to their children when parents got to be elders. They didn't trust that the DD network, even if it was connected to their

sons and daughters, would really be able to meet their evolving needs, especially after parents were no longer there to advocate for them.

Suggestions/recommendations: One suggestion emerged here from parents and self-advocates: that DDS try as hard as possible to document the real need (in terms of numbers and types of services) that people with DD in Vermont and their families experience. Several self-advocates talked about how important it is for parents and other family members to learn to be good self-advocates so they can speak to their own needs as well as those of family members with DD. Several stakeholders suggested greater coordination with the aging network, mentioning that there might be similar problems to solve as well as the possibility that there might be solutions and strategies to share. An example of a strategy is that older families in the DD world are much more able to be good advocates than are elders in general; teaching advocacy strategies to elders would be a welcome cross-fertilization. Another strategy is that the friendly visitor program in the aging system could use volunteers from the DD system as friendly visitors.

Probably the most stridently presented recommendation from all stakeholder groups was the need for better, more generous resources, more commitment to examining ways to get more money into the system, more people to work in the system, more value attached to the human services field in general.

Education:

General information: Vermont is recognized for its' per-pupil spending and low classroom size. Education is still grounded in 260 school districts and boards statewide. Vermont does not have county government units; instead, the state is divided into 60 supervisory unions that group school districts, but may not have a high school. Vermont funds education through a complicated income sensitive state-wide property tax. There has been resistance to reforms to consolidate school districts for efficiency. Special education is often a target when budget concerns arise.

As a rural state, Vermont has embraced its values about person centered services to create a network of local schools, which are

charged with meeting the needs of all students. For those children whose needs cannot be well met in the local school, a well-designed continuum of placements within the community (or at least, within the region) would guarantee that for the majority of students, educational services would be provided close to home. This continuum does not exist, so Vermont relies on expensive, out of state residential schools to meet the needs of its more challenging students.

Some data about Vermont's educational programs: early intervention, mandated by Part C of I.D.E.A., provides services to approximately 896 children, 96% of who are white, 65% of whom are male. In its Early Essential Education program, Vermont serves about 2000 students, of whom about 60% have developmental delay or disability, and about .05 percent have an autism diagnosis. NOTE: Early Essential Education services numbers were not available from the DOE website. Using 2013 data, the proportion of EES students was determined, and that proportion was applied to the total number of special education students from 2015 to determine an approximation of the number of EES students being service in 2015. This number should be understood as an estimate since it does not take into account any special circumstances that may have influenced participation in EEES in the last two years.

According to Vermont's Department of Education Child Count 2014, Vermont serves about 13, 990 children in special education. Of these, 767 children are in their regular classrooms less than 40% of the time; 1518 are in their regular classrooms between 40-79% of time; 9150 children are in their regular classrooms 80% of the time or more.

Other children receive their educational services in more specialized settings, as follows:

- In correctional facilities: fewer than 11 students
- In hospitals or homebound: 21
- In private/public residential facilities: 132
- In private/public separate schools: 584

Transition services are a concern across the country, for students who are looking to move on to post secondary education, to jobs, or to

greater self directed, perhaps independent living. The kinds of supports that students need vary widely, from greater opportunities to be independent, to examining interests and talents for work and careers, to skill building toward greater self determination. Vermont has undertaken several initiatives to assist students in special education make transitional planning and implementation be more personal, both through its educational and developmental disabilities services.

Information from surveys and focus groups: Self-advocates focused on their teenaged years by describing what did not happen. They felt like no one really listened to what they wanted, and they felt that people didn't expect much of them. One family member also reported wondering how she was going to maintain high expectations for her daughter's future when it seemed like no other people on her team had them.

Themes from interviews: Several stakeholders describe the need for greater opportunities for youth with disability to explore their skills and interests, and several talked about wishing there were more ways to collaborate with schools to reach youth while they were beginning their thinking about the future. One agency reported anticipating real changes in this area as new federal regulations dictate relationships with both schools and employers.

Suggestions/recommendations: several stakeholders suggested that while kids are in middle school there should be cooperative planning and integrations of services from DDS and VR. There was a strong sense that these agencies can help schools provide the kind of transition planning and supports that youth need. Further, self advocates who are young adults should be involved in some ways in the school, both in reaching out to students to help them be better self advocates and by taking part in training school staff to insure that they learn how to listen effectively to career/future goals of their students.

Transportation:

General information: Like many rural states, Vermont is challenged to find ways to help its citizens get from one place to another. There is insufficient funding to mount a fully accessible, comprehensive public transportation system, and the bits and pieces of transportation services that do exist are disconnected. All 14 counties in Vermont have in-county transportation that is funded through Vermont's Department of Transportation, such services as ride match, Medicaid transport, ride share and Para transit, and demand/response ridership. Other sources of transportation funding include family support funds for Children with Special Health Care Needs, which funds out of state travel and lodging if it is related to medical need; adapted vans and vehicle adaptation can be funded through the state's Vocational Rehabilitation Division, and the Vermont Association for the Blind offers both volunteers and paid drivers to transport clients around the state. Additional transportation for people with DD is provided by families and by agencies that may be providing some kind of residential support.

Information from surveys and focus groups: Members from all stakeholder groups had something to say about transportation. The most common comment was that there are resources, and their lack of coordination makes a public transportation system impossible. There is little understanding that different systems function under different authorities, or that it might be possible to coordinate transportation among several systems to create a more useful public transportation opportunity. Self-advocates comment that they live in rural areas, and can't really consider taking jobs because they have no prospect of getting to a job. The Council Survey reflected this concern as well: When asked about what gets in the way of people living the lives they want, transportation and getting a job were common responses.

Themes from interviews: Several people spoke about transportation to medical services being generally acceptable, but that transportation to other things – jobs, recreation – was very difficult to find. One family member said that she expected to be the primary transportation provider for her daughter for the rest of her life.

Suggestions/recommendations: It would be wonderful for the Council to bring together these various transportation providers, perhaps find a way to pool some funding or seek additional funding for the purpose of

developing a more comprehensive transportation plan. No one expects it to be perfect, but with everyone at the table, it could certainly be more useful and comprehensive than it is now.

Crisis Services:

General information: The Department of Disabilities, Aging and Independent Living (DAIL) authorizes one Designated Agency (DA) in each geographic region of the state based on county lines as responsible for ensuring needed services are available through local planning, service coordination and monitoring outcomes within their region.

The Vermont Crisis Intervention Network (VCIN) develops services and supports for people with the most challenging needs in the community to prevent their being placed in institutional care (e.g., psychiatric hospitals, out-of-state residential placements). VCIN provides two crisis beds and is responsible for training staff to provide local support to those in need. The three facilities in Vermont that provide Level 1 psychiatric inpatient treatment- Brattleboro Retreat, Rutland Regional Medical Center and Vermont Psychiatric Care Hospital – are occasionally called upon to provide services to individuals with developmental disabilities. Families who are experiencing a crisis situation can call the VCIN with the expectation that trained staff will be available to offer support, direction, guidance, and sometimes to coordinate and connect services and supports, all consistent with the values that Vermont holds.

Vermont has a network of crisis intervention services, as well as teams in each region of the state to respond to people that are in crisis. There appears to be no universal design for the service array available within each region; additionally, there are specialized services, like the Brattleboro Retreat, in some regions that try to serve the very specialized needs of the whole state.

Information from surveys and focus groups: This topic brought comments from almost all of the parents in the focus group. Several of the self-advocates mentioned that they didn't feel safe when they found themselves in crisis and they didn't trust others to know what to do. Parents also mentioned that their other children, often traumatized

by what happened to their siblings, found no resources to help them to understand what was going on.

Themes from interviews: Each of the parents interviewed had a story about their child's being in crisis and having no help available. Either staff people who were sent didn't know what to do, or services that the parents knew would be helpful were not made available. Three parents described in detail how strategies were suggested that they knew would not work for their children and were told that that was the only suggestion on offer. Several also talked about how suggestions to involve police, when situations were seen as putting family members and the individuals involved at risk were not successful, because the police did not receive training on how to engage successfully with someone with a developmental disability who is in crisis. There were several comments as well about psychiatrists who were not trained in working with people with developmental disabilities. Families described feeling that there were no competent resources for them, going on to say this: "the crisis system is a disaster from every point of view – too few resources, inadequately trained and prepared resources, no honesty about what really happens on the ground".

Suggestions/recommendations: Finding a way to have competent, DD trained professionals in each region was a suggestion made by several families and self-advocates. Making sure that there were several response protocols besides behavior modification that were in regional staff member's toolkits. Knowing something about medication and being able to listen to parents who know more about their children than anyone else came up several times, from both parents and self-advocates. Finally, when there is a staff person/service in one region that seems to work well, it would be great to find a way to disseminate information and skills training so everyone in Vermont could benefit.

Access to Information:

General information: There are several sources for information about supports and services in Vermont, among them are the Designated Agencies, various advocacy organizations and independent living Centers, the Senior Helpline, the Brain injury Association, the State Health insurance Program, Vermont Family Network, and Vermont

211. All these agencies are challenged by keeping information current, making sure that it is presented in a way that families and consumers understand and can use, and if possible, coordinating efforts to insure that families and consumers know who to call for various kinds of information.

Information from surveys and focus groups: Parents in several forums mentioned that it is difficult to get good quality, accurate information.

Several reported that the Vermont Family Network used to be a good source but that they haven't found it helpful in recent past.

Several parent and self-advocacy voices united in saying there is not enough peer-to-peer networking. Parents would like to talk with other parents who are facing similar problems, and self-advocates want to talk to youth with disabilities about self-advocacy, their rights, how to talk to others about disabilities and needs, to work with youth to explain the kinds of support available from peers. Connecting with peers can be therapeutic as well; building strengths and sharing ideas helps everyone.

Themes from interviews: Several state agencies mentioned that information provision is important to the work they do, but that often people are looking for information about services that may not be available to them. Several mentioned that there are really two agendas for most callers who say they seek information; the first is information about services and the second is access to those services.

Suggestions/recommendations: no specific suggestions emerged, but finding a way to make clear where to go for what kinds of information seemed a common idea.

State issues and challenges, to the state and for the Vermont DD Council:

ELIGIBILITY FOR SERVICES: Vermont prides itself as a state that embraces consumer choice and its mission to make Vermont the best place for people to live in, grow old in, and have the lives that people choose to have. While state policy may be designed with the whole population in mind, state agencies have 'gates' that keep some people

away from the supports and services they need. As in every other state, the needs of Vermonters outstrip Vermont's resources for services and support.

Mentioned in almost every information collection venue, issues of eligibility concern most Vermonters, because they find definitions confusing, inconsistent, and exclusive. There are many reasons for state agency's defining their eligibility narrowly and in detail; primary among these is funding. When funding is reduced, agencies are forced to find ways to limit access to the services that can still be supported, and changing eligibility creates a uniform way of saying who can and who cannot receive services. Compounding this issue is that services are provided by many agencies, some of which have federal statutes that dictate their roles and responsibilities. Inconsistencies and complexities among these agencies make it difficult for people with developmental and other disabilities to find the supports they need to live the lives they choose. Eligibility definitions can be found in Appendix C.

THE VOICES OF CONSUMERS OF SERVICES AND CHOICE:

Often the conflict between what people need and want and what's available for services and supports results in service availability that doesn't really meet the need. Families and consumers mentioned in several of the focus groups this mismatch; one consumer went so far as to say she didn't think people (at the agency she was working with) really cared about what she wanted, because they never even responded to the services she said that she needed. Several consumers talked about their experience that Vermont doesn't believe in "Nothing about us without us"; they said that they feel powerless and unwelcome at policy discussions at the state and county level, and often feel like their voices are not heard at planning meetings that are supposed to be addressing their own needs. Several families reported being referred over and over to the same services that did not and do not meet their children's needs.

At the same time, agencies in Vermont express the importance of consumers being able to live more independently and more as they choose. There is strong state interest in finding ways for technology to play a role in increasing independence. The possibility of expanded supported decision making was mentioned often by state level staff,

with a parallel concern about how to find ways for guardianship to be used more judiciously, without infringing on the civil rights of individuals with disability.

Several people interviewed, described Vermont as committed to holding the individuals in the center of planning and service provision, describing a depth of passion and history that continues to drive the state toward more individualized, choice based services. At the same time, several said that the state has to learn to trust what people want, and with several limited training funds, find ways to inspire this view in staff across Vermont.

QUALITY ASSURANCE/MONITORING: There are plusses and problems in this area. At the state level, two staff that were responsible for monitoring have left and their positions have not been filled, so the capacity to provide quality monitoring is reduced. Self-advocates and family members describe a monitoring system in which the agencies providing services are monitoring themselves: one went so far as to say that monitoring comes down to saying what people want to hear. On the other side of the ledger, as of July, federal vocational rehabilitation monitoring procedures will require a new effort in tracking and measuring success, including duration of job, access to benefits and promotions, and strong connections between the business community and job finding and preparation. While numbers will still be counted, much more detailed information will be collected that speaks to satisfaction, progress, and the benefit that taxpayers are getting for the money that is being spent on services.

Beyond the funding barrier to more objective monitoring, the state has workforce issues that make objective monitoring challenging. Vermont is second only to Maine in the age of its population; many younger people are leaving the state for jobs and lives elsewhere. With too few staff to do the work required, caseloads are high and the time to really examine the work being done is hard to find.

Several state staff expressed a commitment to results based accountability and trying to answer the question of whether the services provided actually helped each person have more of the kind of life he/she wanted. While health and safety concerns continue to be important indicators of service quality, there is real momentum in the

state to look far beyond these to find out whether people are better off because they receive services and supports for the state of Vermont. An example of this comes from the Vocational Rehabilitation Division, where outcome measures will include identifying whether a job meets the consumer's need after 90 days on the job; also monitored will be job status after two and after four quarters past the date of case closure and skills attained/certification received.

Performance measures may apply to some kinds of services, and Vermont uses them to generate data about number of people served and where they're served. However, prevention, an important component of a comprehensive service array, gets little opportunity for funding, so monitoring of prevention, which would require a more sophisticated approach, doesn't happen.

According to the Developmental Disabilities Services State Report for 2015, D.A.I.L. has made a commitment to examining quality in the upcoming years: "in the upcoming year our division will invest in strategies that will allow us to better understand and improve service satisfaction through measurement of personally defined outcomes. Using methods developed by the Council on Quality & Leadership we hope to engage our community partners in learning methods for interviewing and gathering information that will further our state's proud tradition in promoting principles that support person-centered quality of life – self-determination, choice and self-advocacy."

COLLABORATION AND CONSULTATION: Vermont is fortunate to have many examples of active collaboration among agencies, and often between agencies, providers and consumers. Among these efforts, the DD Council is responsible for bringing a wide range of stakeholders to the table to examine health care; there is a 40+ yearlong collaboration with the UCEDD and public schools in sharing inclusive practices. The VR Division celebrates an extensive partnership with community agencies and a strong relationship with the advocacy community. Still, there may be opportunities to learn and connect that are not being taken. What happens to students who leave school and don't get jobs? What do they need and what happens to their lives? Why don't we all start with great expectations for everyone and go one from there? A specific need for collaboration comes from the Vocational Rehabilitation staff who for the first time will

have a mandate to service youth from aged 14 and up, and would love to see a way to work with school so that both parties could learn how to use the best practices that exist to help these young men and women succeed.

Vermont can see collaboration as a way to accomplish several things: planning and problem solving; maximizing the impact of limited funding; insuring that people with DD are active participants in planning; and finding ways around other kinds of limited resources. For example, playing a role in the Post-Secondary Education Consortium might enable the Council to guarantee that voices of people with DD are heard and their opinions matter there. Several of the people interviewed for this report talked about the important role the Council could play as convener of additional collaborative efforts, including, perhaps, collaborative planning with other entities in the state like the Independent Living Center.

Several of those interviewed expressed a strong desire to examine and implement new models of services, and worried that new rules from the federal government would make creative use of Medicaid funding more difficult. Agencies would like to see themselves as bringing new values and approaches to the table, perhaps providing technical assistance toward new approaches, but feel constrained by spending all their effort in compliance with health and safety. Having many masters, they said, makes doing the work that both needs to be done and that could be done difficult. Perhaps greater collaboration among state agencies, with partners from across the stakeholder array, could enable some limited exploration into new approaches or models. It was suggested several times that the Council, beyond being the convener of such effort, could assist with this effort by securing outside funding through grants that could support some collaborative efforts.

Another area for collaboration emerged from several stakeholders: Transportation. From parents and self-advocates point of view, there are transportation resources that could be examined for opportunities for cross-use. Thinking about school buses, whatever limited public transportation may be available, transportation opportunities from provider organizations and so on might be able to be brought together

into a comprehensive overview of what needs and opportunities exist, and the Council was suggested as perfectly suited to do this.

Priority areas of ‘system change’, ‘self-advocacy’ and the ‘un-served or underserved’ population

Finally, there are three areas of interest identified by the federal government that Councils should attend to: those are system change; self-advocacy; and un-served/underserved. In each of these areas, themes, problems, and suggestions emerged from the interviews, surveys, and conversations held by HSRI. These are as follows:

System change

Themes

1. There is a strong perception among self-advocates and families that big systems do not include or respect or listen to people with disability.
2. There are opportunities to help self-advocates be better advocates that are not being used – such as training in middle and high school, where assistants with DD could be hired to do this work; peer support should influence all the work in this area.
3. Self-advocates need to be at the table with policies or procedures are being developed, and more importantly, they should be working in the agencies that are making these policies.
4. From several stakeholder groups came the comment that Vermont is not “courageous” about trying to stretch what Medicaid will pay for, to make its services more relevant and responsive to need.
5. Inertia is an issue in Vermont – let’s keep doing what we’re doing. There are plenty of initiatives, but we don’t know what to attend to, what the critical variable(s) might be to really change the system for the better.

Problems

- There is a lack of coordination among agencies (the comment was

- that coordination of services is a train wreck); you have to tell your story over and over, give the same details over and over.
- What agencies think happens and what actually happens on the ground are totally different and agencies don't know this.
 - Agencies don't listen well to parents and often don't believe what parents say.
 - People in Vermont realize that all services can't be local because some are very specialized, but there should be at least a county resource that can look at coordination of difficult services, for example crisis teams that actually know what to do, police who collaborate, etc.
 - Access to peer support groups is a challenge for many self-advocates, and several older adults see their families as a barrier to their living their own lives.

What the council could do

- It could serve as a watchdog by gathering real data and sharing it, publicizing it, bringing agencies to the table to deal with it
- It could find and train stakeholders who are ready to make sure they're heard and get them involved in agency boards, etc.
- It could get money from another source (like a grant) to design and field test a way to monitor services that is comprehensive, looks at health and safety, but also asks some of the "what does it matter?" questions that the Center for Quality Improvement asks.
- It could publicize good models for rural services and maybe support some replication of that, or at lead/coordinate a group to plan for replication.
- It could research ways to do values based training for staff so that staff can do their jobs and always embrace person-centered self-direction.

Self-advocacy:

Themes

1. Actually including self-advocates as trainers, employees, recruiters would help self-advocates have a real voice in what happens.
2. More training about what was available for services and supports to self-advocates and families would be great, done by self-advocates and families

3. Working with agencies to help them appreciate how to really listen to self-advocates (not listening came from several sources) would benefit both the advocacy community AND the agencies.

Problems

- Families don't have the information they need to make good decisions, and they don't have ways to learn from one another
- There isn't enough parent to parent mentoring, sibling support and social connections for siblings to be comfortable as advocates
- Parents aren't listened to, and aren't treated as team members, but they could be if they demanded that treatment
- Expectations for what people with DD can do with their lives are too low

What the Council could do:

- It could create a strong family council at the state level that could work on ideas and would have state agency investment, not a place to bitch about problems
- It could find ways to train families for leadership (continue current program and expand), being a board member, how to make themselves heard, etc.
- It could develop and field test a reliable way for people being served to give feedback to agencies, providers, families, etc. that doesn't get messed with.
- It could collect real data and publicize it and use it to broker system change, policy change, etc. Like how many kids are in out of state placements for how much money)
- It could build partnerships out of adversaries - parents and DOE for example, and forge a relationship that is trusted and that can then provide real info to legislators, etc.
- It could support more family to family connections, the way that Vermont Family Network used to do but doesn't now.

Unserved/underserved:

Themes

1. There should be a way to find out who these people are and why they aren't getting services (again, a theme from several sources).

2. Make many ways for people to learn what's available (schools as a potential source for for kid-specific was mentioned several times, as were parent organizations).
3. Re-evaluate the impact of changing state guidelines so more people are eligible, and let people with the money know who is not served and could be and how much it would cost. The basic point is that it's hard to argue for more resources when legislators don't really appreciate the scope of need.

Problems

- Lots of very low incidence disabilities, especially complex medical ones, aren't connected to others with similar situations, so families feel very alone and aren't listened to
- Inclusion only works well if there is support behind it, culturally, language-wise, disability-wise, etc. and there isn't that support
- There are lots of huge problems - transportation, housing, etc - but no one is bringing all the relevant people together (like thinking outside the box about all the transportation resources that exist - it could be done, but no one is doing it)
- It seems people are hesitant to identify the under/un-served because there's no money to serve them, to tell them what they might be eligible for
- There is a need for statewide/perhaps county specific services, like crisis response, where all the relevant parties have participated in the design of the services AND the needed staff are available, but this does not happen.

What the Council could do

- It could be a real watchdog about what's happening
- It could coordinate and bring new ideas to agencies along with families and other self-advocates
- The Council's power lies in its ability to publicize, bring people together, try out new ideas and share what's learned; be the think tank for the big picture, *not for short term* but to make systems and services make sense. The Council should not be funding a lot of little services that meet unmet needs; rather, it should be figuring out ways to examine the unmet needs in a comprehensive way.