



Appendices for
**Content for Comprehensive Review
and
Stakeholder input summary report**
Prepared for the Vermont
Developmental Disabilities Council:

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- A: Health Care Funding*
 - B: DDS Services and Recipient*
 - C: Eligibility Definitions*
 - D: Self Advocates' Focus group summary*
 - E: Parent Focus group / interview summary*
 - F: State Agency Interviews*
 - G: Advocacy Organization Interviews*
 - H: Data Collection Instruments*
 - I: Agencies / organizations included in interviews*

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Appendix A: Health Care Funding

VT Spending:

Total I/DD spending 2013

State: \$68.7 M

Federal: \$109.9 M:

77% HCBS waiver

21% SSI/ADC waiver

2% Title XX and related Medicaid

MCH Block grant 2014: \$1,625,665

7,124 pregnant women were served

5,783 children under one year of age

169,677 children and adolescents

21,790 children with special health care needs

Other MCH grants to VT:

\$86,500 – integrated community systems for CSHCN (Bi-State Primary Care ASSN)

\$100,000 – state systems development initiative – Agency of Human Services

\$517,825 – LEND – UVM

In FY2011 Vermont became the first state to pass single payer medical coverage. State programs cover 26% of Vermonters, and pay 17% of health care costs (Total \$4.7 billion in FY2009):

- Catamount Health Program full pay or premium assistance
- Dr. Dynasaur (Federal Children's Health Insurance Program, known as SCHIP)
- Employer Sponsored Premium Assistance
- Medicaid - 82,748 adults and 62,528 kids including Katie Beckett (569)
- Prescription Assistance.

Appendix B-DDSD Services and Recipients

Service Coordination

- Community Supports
- Work Supports
- Home Supports: 24-hour – Shared Living, Staffed Living, Group Living
- Supervised Living: hourly home supports in person's own home

- Supervised Living: hourly supports in the home of a family member people served

- Respite
- Clinical Interventions
- Crisis Services

- Home Modifications

- Transportation

(See Appendix C: Developmental Disabilities Services Definitions for more details.)

Other services:

- Targeted Case Management
- Flexible Family Funding
- Vocational Grant (minimal follow along employment supports)
- Specialized Services (minimal supports in a nursing facility)
- Intermediate Care Facility (six-bed facility with intensive specialized services)

Appendix C: Eligibility definitions.

Special Education

EARLY INTERVENTION (Part C) Families with children birth through 3 who have a developmental delay or a diagnosed physical or mental condition which has a high probability of resulting in a developmental delay.

EARLY ESSENTIAL EDUCATION (Part B) For children 3 up to 6 meeting at least one of the following:

—Autism Spectrum Disorder —Emotional Disturbance —Multiple Disabilities —Deaf-blindness —Specific Learning Disability —Hearing, Learning or Visual Impairment —Traumatic Brain Injury —Speech or Language Impairment —Other Health Impairment

-OR-

— Evaluation and planning team finding of disability caused by a developmental delay presenting need for special education

— Medical condition which may result in significant delays with need for special education -OR-

—Meets eligibility criteria for children 6 through 21 including determination of a disability, adverse effect on educational performance and need for special education

SCHOOL AGE

School Ages 6 through 22 birthday, with one or more of the disabilities described in EEE eligibility; the disability results in an adverse effect on the child's educational performance in one or more of the basic skill areas and the child's need for special education to benefit from his or her educational program cannot be provided through the educational support system, standard instructional conditions or supplementary aids and services provided in the school.

Vocational Rehabilitation: Eligibility is determined by a counselor from the Department of Vocational Rehabilitation [VocRehab or VR]. Any Vermonter may be eligible who has a disability that is a barrier to work, and requires VR services to become or remain employed. As of July, 2016, The person must have a

medically verified disability that is an impediment to employment; funding is then prioritized according to the following:

- has a loss in four areas of adaptive functioning and needs multiple services for six or more months
- has a loss in two areas of adaptive functioning and needs multiple services for six or more months
- has a loss in 1 area of adaptive functioning and needs services for six months or more
- has a loss in 1 area of adaptive functioning and needs services for six months or less

Long Term Care for People with Intellectual Disabilities (Developmental Disability Services)

Vermont defines a developmental disability as an IQ of 70 or below or Pervasive Developmental Disorder, accompanied by substantial deficits in adaptive behavior occurring before age 18. People must also meet Medicaid eligibility requirements as well as at least one priority in Vermont's System of Care Plan. The SOCP is rewritten every 3 years and updated annually. Its funding priorities triage who is funded based on emergencies, with limited funds for high school graduates with jobs. More details are provided above at Informal & Formal Community Supports, and also below.

Long Term Care for Vermonters with Physical Disabilities and Elders

CHOICES FOR CARE [C4C] is a Medicaid waiver program, with care based on level of need.

HIGHEST NEEDS level – You must be a Vermont resident, 65 years of age or older or 18 years of age with a physical disability & need extensive or total assistance with at least one Activity of Daily Living [ADL] and require at least limited assistance with any other ADL, OR need skilled nursing on a daily basis OR have a severe impairment with decision-making skills OR a moderate impairment with decision - making skills and one behavioral condition which occurs frequently and is not easily altered.

HIGH NEEDS level requires extensive to total assistance on a daily basis with at least one Activity of Daily Living (ADL) OR skilled teaching required on a daily basis to regain control of, or function with gait training, speech, range of motion or

bowel or bladder training OR have impaired judgment or impaired decision-making skills that require constant or frequent direction to bath, dress, eat, use the toilet, transfer or attend to hygiene OR exhibit constant or frequent wandering, behavioral symptoms that are persistent, physically or verbally aggressive or have a condition or treatment that requires skilled nursing assessment, monitoring and care on a less than daily basis and who require an aggregate of other services on a daily basis.

MODERATE NEEDS level requires a resident be 18 or older who has a physical disability or a limitation due to aging and whose needs cannot be effectively met with existing services.

Developmental Disabilities Services Division

- Have an IQ of 70 or below
- have clinical deficits in two areas of adaptive functioning or have a diagnosis of autism and have deficits in two areas of adaptive functioning

Appendix D: Self-advocates focus group summary

SYSTEMS CHANGE	
<p>Themes: 1. Perception that big systems do not include or respect or listen to people with disability</p> <p>2. There are opportunities to help self-advocates be better self-advocates that are not being used – such as training in middle and high school, where assistance with DD could be hired to do this work</p> <p>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</p> <p>4. People with DD and families can't get accurate information anywhere.</p> <p>5. Agency/provider staff do not respect us, and do not respect that we know ourselves better than anyone else. (eye rolling when questions are asked)</p> <p>6. There is a need for more coordination around some services - transportation - school busses, local taxis, local buses, provider transport etc could be built into a useful system. Council should coordinate this.</p> <p>7. An online platform for applying for jobs is not the best format.</p> <p>8. Help with college funding is needed.</p>	
<p>What does systems change mean to you?</p>	<ul style="list-style-type: none"> • Budget cuts • Educating people in power (stated 3 times) • Getting more education • Basic needs • Paying livable wages to providers • Making things work better • Improving system to make it work better for all people with disabilities • Educating people in school and at the local campus (stated twice) • Self-advocates need to have more input at the agencies • Agency is willing to change • Make sure there is enough money for services
	<ul style="list-style-type: none"> • Transportation is an area near and dear to my heart as a non-driver. Transportation is one big area, you can have all kinds of programs but if people can't get to them, they aren't any good. Rural nature of VT means no public transportation for people with disabilities. Working on what other modes of transportation are. • Knowing who to contact in regards to transportation. Unified sports or Special Olympics are held in places that are not on bus routes. Being able to coordinate transportation is important.

Appendix D: Self-advocates focus group summary

	<ul style="list-style-type: none">• There is a school bus that goes to where he lives and if he could get on that bus, he could get close enough to where there is public transportation. Coordination is very important.• I have a disability and my son has a disability and if I didn't work for a service organization, I wouldn't know what services were available. If it wasn't for my job, I wouldn't know what to get for him. There needs to be more outreach to parents of children with disabilities.• There are a lot of cancellations, when I really wanted something, they didn't let me. (DMH). She wanted to work in childcare, they did what they wanted to, not what I wanted to.• They don't have a very good self-directed model.• It is a medical model not a peer based model. We are the experts to our own needs. They treat us like we are all our diagnosis.• my daughter says all the time, they're just not listening to me. Case managers, supervisors, etc. She talks about her disability being invisible. Her seizures and autism are invisible. She cannot be a part of the hiring process of the staff, they say that they can't expose staff to a client before hiring them.• when I would ask for help to do something, they would be very disrespectful, roll their eyes, etc. They are always late, they don't call – agencies that are supposed to pick you up.
	<ul style="list-style-type: none">• The systems should have more connections to the trade schools than to college• We have college steps, not at trade schools.• The system of services is focused on college

Appendix D: Self-advocates focus group summary

	<p>and not on trade schools</p> <ul style="list-style-type: none"> • Getting your permit-multiple clients have found it hard to learn what they need to learn to obtain driver's permit. • After taking the voc rehab class it doesn't count as driver's ed • VT associates-people over 55 trying to get a job. Income guidelines were prohibitive. A woman gave an example of her husband not being able to get a job through this program because she makes too much money. He couldn't qualify. • Employment services, everything is online. • Applying for jobs: people don't show up to meet with you, it is all on the computer • More financial grants for people who have a hard time paying for schooling • Help people to get a payment plan set up immediately on their student loan
<p>What systems of support need changing in VT?</p>	<ul style="list-style-type: none"> • Transportation more accessible(stated several times) • Paying better cost of living • Affordable housing • Raising accessibility and affordability in housing (stated several times) • Healthcare more affordable • Funding for DD services • Courts-right now we have to take a day off from work to go to court • Gaps in medical services-dental coverage • Hours that people get for community time are not enough. • Want more work and more hours (stated twice) • Separation between job coaching and actual work support • Agency should hire self-advocates to work in the agencies instead of trying to train case managers (THIS GOT A LOT OF APPLAUSE)
<p>How would you like to see systems of supports change?</p>	<ul style="list-style-type: none"> • They need to provide training for peer centered models.
<p>How can the council promote systems</p>	<ul style="list-style-type: none"> • Bring more advocacy and spread

Appendix D: Self-advocates focus group summary

<p>change in a positive direction for people with dd and their families?</p>	<p>throughout Vermont</p> <ul style="list-style-type: none"> • Transportation • Advocating to people in power • Train the Trainer • Conflict resolution • Self-advocates have more input into DDS System • Put your needs directly into Agency's policy • Have Self-Advocates voices be heard • Educating schools and community (Stated two or three times)
<p>Are there issues that the Council should focus on in systems change?</p>	<ul style="list-style-type: none"> • To try to get conversations going about different modes of transportation. Trying to coordinate to make more transportation options available. • Having classes for parents, around IEPs and 504 plans. I want a place that I can go to talk with other parents of children with disabilities. It is harder to be an advocate for my own child. There is nothing around Central VT for this. Good information needs to be available.
<p>How would you like to see systems of supports change?</p>	<ul style="list-style-type: none"> • They need to provide training for peer centered models.
<p>SELF-ADVOCACY</p>	
<p>Themes: 1. Actually including self-advocates as trainers, employees, recruiters 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 form several sources) 4. SA orgs need to be more local, and more open to a range of disability 5. Some sort of buddy/Mentoring system would be great (look at some other state models-Partners with Disabilities in MA) 6. A parent group of parents with disabilities would be great - regular parents just don't get us. - Council could set up a model for others to replicate. 7. When self-advocates don't hear back from the Governor or legislators, they are not being heard. They should receive a response of some kind.</p>	

Appendix D: Self-advocates focus group summary

<p>What would make SA organizations in Vermont more successful?</p>	<ul style="list-style-type: none"> • More networking • Disability awareness • Expanding beyond high school • Peer support • Allied support • Organizational structure • Having yearly stipend to inspire action (I think this meant be paid to be a SA) • More participation by self-advocates • Need to be looked at as resources by state agencies • More trainings to get more people involved in self-advocacy(Stated several times) • Building social skills and self-esteem for self-advocates • Prioritizing funding for self-advocates • Access to reliable updated computers • Better advertising • New members-young members • Hiring assistants with DD • Teaching students
	<ul style="list-style-type: none"> • my daughter struggles because she really wants to be involved in GMSA. The one in Winooski/Burlington area does not feel as accessible to her. Making the connections is really a challenge. How do we make this happen? For mom, how do I find the information to be an advocate. • have a buddy system so they can pair up with someone who wants to be more involved, learn more. Etc. Transportation, if you had a bus buddy, you could learn. If there were SA buddies, that would help her make those connections. • when people ask me to speak up, they wouldn't listen. • everything comes down to funding. I think about bus buddies and chat rooms, etc. I think about VCIL taking days to comparison shop or go do fun things. We can't do that because of

Appendix D: Self-advocates focus group summary

	<p>funding. Maybe if we could take some funding to do something fun.</p> <ul style="list-style-type: none"> • The Council could help find ways to help you find funding. • It would be nice if there were parent groups for parents of kids with disabilities. This would be helpful if self-advocacy groups were able to have these parent groups. •
<p>Are there issues that the Council should focus on in self advocacy? What strategies would you like to see the Council engage in?</p>	<ul style="list-style-type: none"> • Breaking barriers • Bringing advocates along in the workforce • Educating schools and families about services available(stated several times) • SPREADING THE WORD • Getting the agency to listen to self-advocates • Check on our progress, offer us help, give us money to do awareness trainings and keep giving money to have our conferences • Educating high school students, hire assistants with DD(stated several times) • Finding funding opportunities to go to college <hr/> <ul style="list-style-type: none"> • Help us fund these groups. • Groups for individual disabilities are better attended. The council can help better network different types of disabilities. Using the St. Johnsbury TBI group as an example.
<p>Do people really listen to you?</p>	<ul style="list-style-type: none"> • Not really, I don't really see the point more or less. You are not advocating for yourself if you can't speak your mind. • Life isn't always about having fun. It is about helping people. People let you speak your mind if you do it in a positive way. No one wants to hear the negative way because it effects people are around you. • Giving back to VFW because they let us have their dances there. Or Greenup day. We are giving back to the community. • It is sad for people to feel like they are being heard, but they are being heard. • When we start talking we have to keep repeating because people aren't listening.

Appendix D: Self-advocates focus group summary

	<ul style="list-style-type: none"> • Voice is not being heard. • We aren't always heard. I see people acting like they understand us or they assume we are lazy. Versus making the best of our situations.
<p>How can the council help self-advocates be more effective in VT.</p>	<ul style="list-style-type: none"> • We have been trying to have our group be seen as people who are capable and gives back instead of a group who asks for things and takes from the community • Some support in getting the legislators to read and respond to the letters we have sent to them. Does the governor read our letters and know we exist? • Publicity campaign • The group has sent the governor and legislators many many letters and has not heard a response. Could the Council reach out to the government to ask them to read and respond? • Letters are asking for no budget cuts, cost of living increases, etc. • Letters come from individuals, not the organization • Clients being able to have more input into how well the worker who is working with them is doing
<p>Unserved or underserved populations</p>	
<p>Themes: 1. Find out who these people are and why they aren't getting services (again, a theme from several sources)</p> <p>2. make many ways for people to learn what' available (schools should do this for kids was mentioned several times)</p> <p>3. Re-evaluate 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.</p> <p>4. Council fund a think tank to examine limitations for services, ranges of services, funding limits, etc. so we would have real data about what is and what needs changing.</p> <p>5. Council should fund a comprehensive, statewide look at who is served, not served in each county (region?) and what services are in each county/region.</p> <p>6. People need a better mileage allotment.</p> <p>7. People don't like carpooling.</p>	
<p>One of the things that the council cares about is all of the people in the state that have DD who are not getting services. What do you think the council could or should do about these people?</p>	<ul style="list-style-type: none"> • Find out why are they not getting services and help them get services • Raise money at statehouse to get money to hire staff • Funding to do something • Educate people about services that exist, both for people who need services and

Appendix D: Self-advocates focus group summary

	<p>people to raise money for services</p> <ul style="list-style-type: none">• Case managers have overloaded cases because they are underfunded• Working with state to reevaluate guidelines for services• Awareness in the community• Should work on qualifications for getting services• More waiver money, provide training to self-advocates, more jobs• Put more money into hiring people with DD to be peer mentors• Definition on how to identify people who need services
	<ul style="list-style-type: none">• I think a more comprehensive look statewide of all the underserved populations. We need to look at all populations. And determine who needs services. Put your resources in the right places.• my daughter has experienced trauma and needs therapy. Is trauma an underserved population. I don't know what the council can do, do they do a study to find out what can change. Why is it that the therapy goes down so much from one year to the next.• people with disabilities experience trauma at twice the rate of people without disabilities need trauma care.• we arbitrarily set all kinds of limitations on people who get services. Even if they need them. There are things you can do, have ranges instead of hard lines. There are all kinds of unmet needs.
	<ul style="list-style-type: none">• The range of services is a big range there is nothing between all and nothing• They cut the mileage• They cut the hours• There should be more funding• Each person is allotted a certain amount of miles per week for their program. For some people it is an unreasonably low

Appendix D: Self-advocates focus group summary

	<p>number of miles.</p> <ul style="list-style-type: none">• The lack of miles causes depression and sadness because we can't get out of the house.• If I want to work, I have to work in town.• Transportation and mileage are the big issues• Money doesn't grow on trees• More hours• More mileage• Some people will carpool they double up we don't like that.• Not enough staff, not enough workers• Targeted case management is frustrating that their things happen after hours and on weekends and our services stop at 5:00 on Friday. Lives don't stop at 5:00.• How can they get a ride on the weekend?• RCT doesn't go out to the trailer parks.
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Appendix E: Parent Focus Group Summary

Parent interview report as of May 25, 2016 – six families

System change: problems:

- lack of coordination among agencies (comment was that coordination of services is a train wreck); 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 we say
- they realize that all services can't be local because some are very specialized, but there should be at least county coordination of difficult services - eg crisis teams that actually know what to do, police who collaborate, people who know what they're doing who are not four hours away, etc.
- no one actually evaluates the services objectively so there is no data on which to base placement decisions, or even data that says "visit this program, not that one"
- 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
- no one is courageous enough to try to work with Medicaid to stretch the rules, change the rules so that real people with real needs can get what they need
- Case managers don't manage, they have no authority and all kinds of responsibility
- Designated agencies can't/don't do the work they're set up to do and no one monitors this objectively
- There really is no good continuity of care so too many kids get sent out of state because the continuum isn't really available, and really those out of state resources are institutions
- "we won't give you names of residential program that might serve your child because children belong with their parents"

What the council could do:

- Serve as a watchdog by gathering real data and sharing it, publicizing it, bringing agencies to the table to deal with it
- Find and train stakeholders who are ready to make sure they're heard

Appendix E: Parent Focus Group Summary

- and get them involved in agency boards, etc.
- Publicize good models for rural services (like mobile crisis teams in North Carolina) and maybe support some replication of that, or at least coordinate a group to plan for replication

Self advocacy: problems

- Families don't have the information they need to make good decisions, and they don't have ways to learn from one another
- 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. Parents don't know how to demand.

What the Council could do:

- 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
- Train for families for leadership (continue current program and expand), being a board member, how to make themselves heard, etc
- Work with other agencies to create a single point of entry for information so it's all in one place
- 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.
- 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)
- 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.
- Support more family to family connections, the way that Vermont Family Network used to do but doesn't so much any more.
- Have agencies think together about how to integrate their service/service coordination across the lifespan
- Find a way to create access to real information for anyone, that is objective, not colored by the provider agency, for example

Appendix E: Parent Focus Group Summary

Unserved/underserved: problems:

- lots of very low incidence disabilities, especially complex medical ones/mental health 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
- 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)
- no one wants to identify the under/unserved because there's no money to serve them, to tell them what they might be eligible for, for the same reason
- there is no continuum of care so people are stuck with not enough or are shipped out of state or get nothing

What the Council could do:

- Be a real watchdog about what's happening
 - Coordinate and bring new ideas to agencies along with families and other SAs
 - Council's power lies in its ability to publicize the truth, 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; support agencies as they re-orient their practices
 - Develop a short brochure that could go to every family who registers for school that gives a few major points: talk to your primary care physician, here are a few contact numbers, include other parent org. contacts, etc etc
 - Keep training primary care staff/professionals to work with people with all kinds of disabilities and their families; help them provide better information to families and individuals with disabilities.
- **Pick one or two goals and focus efforts, resources on those.**

Appendix F: State Agencies Interviews

Questions	Disability Aging and Independent Living	Developmental Disabilities Services	Vermont Centers for Independent Living	Vocational Rehabilitation	University Center for Excellence in DD
Mission	Make VT the best state to age with a disability.	Be the best state to grow old in and live a life with DD that is full and inclusive	statewide group providing CORE IL services, including peer to peer counseling, I&R, architectural access assistance, disability rights advocacy	provide vocational rehabilitation(VR) and other services to individuals with disabilities to maximize their employment, independence and integration into the community and the competitive labor market	inclusion , real inclusion, through training, service, dissemination. Focus on education and employment;
#’s/ eligibility	For eligibility you have to have an IQ,<70 or diagnosis of ASD and need help in 2 areas of functioning	About 2800 people. And there are about 4000 others that are not getting services. For eligibility you have to have an IQ,<70 or diagnosis of ASD and need help in 2 areas of functioning		About 9000 per year; medically verifiable disability plus in priority: a need for 6 plus months of treatment in 4 areas of need: 2 areas of need; 1 area; 1 area with a need for less than 6 months treatment	NA
Does well	Keep the person at center of planning. They express a commitment to	The state agencies collaborate brilliantly both across themselves and with providers,	Have fostered some small wins: like keeping issues of community support and housing in play,	Nimble agency; strong relationship of long standing with other agencies, advocacy community;	lots of work with schools across the state, lots of inclusive practices in the

Appendix F: State Agencies Interviews

	new thinking/models	self-advocates, and families.	although there has been back tracking. Some new emphasis on the planning part of transition from school to work and that's encouraging, and there seem to be more people talking in terms of believing that people with DD can lead full lives.		high school years. VT Interdisciplinary team works with all the schools in the state, many each year, inspiring inclusion across the curriculum. Also a focus on not over using parents within the schools
Outcome measures	They use traditional outcome measures but what they would like to do is measure are people living the lives they want to live and be less focused on the numbers	They are doing: Results based accountability. They would like to use the CQL measures.		Has been simple count – who has a job; as of July; who has a job and for how long; does job offer benefits; opportunity for advancement.	Are wrong. Need to look at outcomes, really measure what's happening – VT employment rate doesn't reflect whether jobs are full time, part time, well paid, benefitted, etc. so the picture of employment isn't accurate.
Could do better	They would like to be the idea	To maintain a well trained and well paid		More with TBI, but feds require short term	People with DD are still not living

Appendix F: State Agencies Interviews

	<p>bringers and focus on technical assistance instead of worrying about compliance and health and safety.</p> <p>They would like to keep up with tech savviness of kids coming out of high school.</p> <p>Find a way to measure what real outcomes are.</p>	<p>workforce.</p> <p>Young people leave, not enough money.</p> <p>Find a way to be in touch with as many people with DD as possible even if they don't meet the criteria.</p>		<p>placement/svs which aren't approp. for TBI; invest in more skills based job training and individual certification programs to match what employers need now. Would like to do more to help clients advance in the workforce, through post secondary education/ training.</p>	<p>the lives they want – can't get jobs, don't have friends, are not healthy. Need a different focus from birth on – great expectations for all kids with DD. Lots of people sitting at the mall, doing nothing, being lonely.</p>
Barriers	<p>There are not enough staff who are paid enough or trained enough. Because of this, we are stuck with using the old models.</p> <p>They have no</p>	<p>Because there is only one waiver, they are essentially trying to build a managed care model in state government. They are having to embrace results based accountability.</p>	<p>Three significant ones. First, attitudes about people with DD are still not what they need to be – especially in communities and with legislators. Full participation is</p>	<p>Short term nature of rehab services; federal regulations</p>	<p>NA</p>

Appendix F: State Agencies Interviews

	<p>control over their own budget. They just get what comes out of the legislature.</p> <p>There is major policy turnover every 2 years. Can't gain any traction because people are gone.</p> <p>Can't keep up with the tech savviness of kids coming out of high school.</p> <p>Guardianship. People use guardianship in oppressive ways.</p>	<p>Resources, both money and actual people.</p>	<p>not really on their radar. Second, access remains a concern. There just isn't full access, especially thinking beyond ramps and doorways and bathrooms. There is little thought to environments that can support and nurture, in homes, schools, etc. Third, money is a problem. Legislators who say that understand the problem don't support additional funding requests, won't raise taxes, and generally keep their heads down. Only a small fraction of people with ID/DD get services and the rest are just out of luck. VT uses the narrow IQ definition, so it</p>		
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Appendix F: State Agencies Interviews

			<p>looks like things are better than they are.</p> <p>Three others, still significant: parents with disabilities re still not supported and often lose their kids, even though VT's law is good. VR focuses on people other than those with ID, so people with ID aren't getting good VR services. There still is not equal access in transportation, health care, housing.</p>		
Unservd population?	Children are pretty much left out. Family support is not extensive.	<p>Kids really only get services if they are at risk of institutionalization.</p> <p>There are a few kids services: service coordination through age 21,</p>		Those who need long term services, but agency not authorized to serve them	NA

Appendix F: State Agencies Interviews

		<p>Respite for both dual diagnosis</p> <p>\$1000 flexible family funding</p>			
<p>New initiatives?</p>	<p>Fostering post-secondary education.</p> <p>Trying to find ways to use technology to support independence.</p>	<p>Project Youth Search. It is a way of connecting senior youth with post-secondary education. Find a way to be more independent.</p>		<p>New fed regs as of July: create business account mgrs. within VR who will work with employers; more realistic outcome measures; employment staff who work with client to find jobs; develop progressive employment –short term placement that may become a job, as a way to figure out what clients want to do/are good at doing.</p> <p>VR working actively in schools with students aged 14 and up til graduation, and they are supposed to spend 15% of federal allotment on this population. They have a commitment to supported employment</p>	<p>Maybe use some \$ to pay a grant writer to get more money into the state to do examination of variables that work to promote real outcomes that people want.</p> <p>Stop spending small amounts of money on small grants. Instead use the clout that a lot of money brings. Use grants to make a cohesive picture and then operationalize it. Think about how funding for VT</p>

Appendix F: State Agencies Interviews

				to adults with DD and would like to see them working at higher levels of employment and increase employment outcomes	Coalition for Disability Rights could play into this.
Thoughts about the VDDC: self advocacy		Finding a way for transitioning youth who have been in Project Youth Search to make results more public.	Continue leadership training		Develop a different way of thinking about what should be happening with kids – teens – adults. What happens now is not good enough. New concept has to come from people with DD, who are making demands for their own lives. Need to have high expectations. Biggest barrier is inertia – we’ve been doing inclusion and we’ll keep doing it.

Appendix F: State Agencies Interviews

Thoughts about the VDDC: Systems change	Foster collaboration	<p>Help with thinking about meaningful outcome metrics for services.</p> <p>To partner with other state agencies with a focus on provider training and provider organization financial health.</p>	<p>The Council's focus on health care has been a real plus, more work in this format would be great- coordinating its plans with others (the ILC is working on its 3 years plan now, so that the bang for the buck and the effort is maximized</p> <p>It would be WONDERFUL if the Council's findings and the ILC's (or any other agency's) findings could be coordinated – we'd all learn more and have a greater impact.</p>	<p>Ages 14-22 is a new area for them and would love to have Council assistance in making their money do what's necessary.</p>	<p>There have been a million projects over the years, and we don't know still what the variables are for success. Don't learn from what we do, do delve into the why, just look at the what. The Council could help examine the variables. IN its next plan, the Council should think about using its significant resources to leverage change, to try to foster the kind of in-depth learning that could change the way processes and outcomes are viewed.</p>

Appendix F: State Agencies Interviews

Thoughts about the VDDC:					
Unserved					

Appendix G: Advocacy Organization Interviews

Mission	#'s criteria	What is the greatest success	Barrier to full participation	DD Council should address	DD Council NOT address
state legislature		<p>Two things that come to mind, one was an effort to require insurance coverage for people with autism or developmental delays. That was an important victory. I still think there are some implementation that people are not totally satisfied with. They might want to keep an eye on, that's important. The other thing that comes to mind is something I worked on for a really long time and that was to create changes in the sates system of care is facilitated. Until the govt was able to make changes in the system of care without govt oversight could decide to limit services. What they were able to do was to make changes without any real oversight. We made a change last year that requires more oversight. Makes public debate a possibility. They were limiting the access to the services. Now those changes have to go through legislature. The DD Council may not have had anything to do with this but I will tell you anyway.</p>	<p>Breaking down the barriers is doing a lot of peer to peer work. I don't have an answer to this. Barriers around discrimination. But we do a good job around this. We have reach up program. It is our version of welfare. There was a decision made last year to cut supports if they had someone in their family with a disability because they counted the disability income as income. Created a real struggle for families with a person with a disability.</p>	<p>The key thing is to build a movement that we can better fund the things they need. The unwillingness of state govt to fund the services that people need still exist. We need to find a way to rebuild the system of care and rebuild the services we need. BUDGET, we need to be willing to more adequately fund the range of services people need. Particularly family friendly services. TO help keep people stay with their families.</p>	

Appendix G: Advocacy Organization Interviews

People who are deaf or blind there was a school that went out of business and we passed a law that a council of people who are deaf/blind/hard of hearing to come up with a plan to provide services after the school closed.

Respectful language bill. This made a law that language needed to be removed from prior laws that used disrespectful language from all the state laws and made a commitment that going forward that the state will not use that language anymore. You could have your marriage annulled if you were married to a retard or imbecile. It was interesting because people with disabilities testified and talked about how traumatic those words are. Got rid of N word but we still use the R word.

Appendix G: Advocacy Organization Interviews

Primarily people age 60 and older. We receive support from multiple sources but an important part is through the Older American act. We do serve some people with disabilities, mostly physical. Our focus is on enabling people to remain in their homes and their communities. We target people in the greatest social and economic need. We administer the senior help line.

VT was leading in the country for using HCBS waivers. There is a strong commitment to keeping people in their homes and communities and avoiding institutionalized and reducing institutionalizing people. Maintaining enough support for home and community based options

Older adults or people with DD. DD has done better than older adults in educating policymakers. I would want to commend publicly people with dd and their families for educating policymakers. A barrier is that policy makers are not willing to look at the demographics or needs of older adults and plan responsibly for the future. They do much better for dd. The other barrier is that there is not coordinated advocacy for older adults. Advocates and providers have not worked well together and have not been as strong a voice as they should be. Families have done a good job of making policymakers aware of their concerns for their children as their children age.

Love to see looking at connecting with aging. I would be very interested in doing that. I should reach out to Kirsten. Maybe can't happen at the state level but could at the regional level. Some collaboration between the 2 on policy issues. Local things, welcoming communities, accessibility, etc. Livable communities. Love to see DD and aging collaborate. Would be interested in working with council to bring those 2 populations together. Friendly visitors, we have people visit seniors. It would be great to have people with disabilities do some of this volunteering.

I guess what I would say is that one concern I would highlight is that there is a lot of money coming into the state from medicare. I would worry about backsliding. There is temptation because there is money to be had by adopting medical models. There may be opportunities for funding coming through medical sources. While it is great to be collaborating. It is important that people are not defined by their medical conditions in an effort to gain funding. Keeping a good balance of work is important. It is nothing that anyone in the dd field has done it is just that I think

Appendix G: Advocacy Organization Interviews

is important to
maintain their valu
and not morph int
medical model
because there is
money to be had.

Appendix G: Advocacy Organization Interviews

with respect to DD Council, we do systems advocacy for persons with D/DD. Contracts and grants with others

The greatest one I guess would be maintaining at least the level of funding that we have now for developmental services. Advocacy around the budget. We haven't gotten more but we haven't been cut too much. We stopped the state from refusing to give back "one time funding". There was litigation that preserved funding for childrens personal care services, to get the state to use the right tool to evaluate needs.

When I think about it, it would be tempting to say housing or but it all ties back to lack of awareness of abilities and general attitudes about people with disabilities.

Educating the legislature about our system and the lives of people with intellectual disabilities and the lives that they could live. And about our system of service delivery works in VT.

No. If there was a might give priority but I don't think that is something they should not address.

Appendix G: Advocacy Organization Interviews

our members are made up of people with DD/ID. In terms of age group, it is pretty diverse. Most members are in their 20s or 30s and members up to 70s or 80s and some high school students. 75-80% receive some services and about 20% do not receive any services.

People seeing that having a disability is not a bad thing. Having friends and people who they can go to for advice. People don't cut themselves now after becoming involved in self-advocacy. Peer to peer connection, they realize that they are not alone. SA has a therapeutic feel to it. Helped to develop strengths because of their relationships. Not sugar coated, advocates speak the truth. Advice is actually truthful because it comes from people with disabilities. We have this network of 22 peer support groups throughout the state. 650 people meet once a week or every other week, once a month. The peer to peer support happens there. We have this core office and a really strong website. People from all over the country compliment us on our website. Lots of resources. Another strength is going to the legislature. Active role in making that information accessible. Getting word out to groups and provider organization. As an office, we use media and are always looking for new ways to use media

Transportation. That is big because people live in rural areas, they have a tough time getting to and from work. There is no public transportation in many parts. They do everything they can to get to and from work but they live too far from any kind of close towns that have transportation. Affordable housing is a barrier. 2 things come to mind, one is that increasingly there is a very small percent of people with DD (about 20%) who get services so they don't have support to work. They live their whole lives and don't get a lot of support. Employment is a big one. A lot of people don't have jobs and they want jobs. Also, a lot of people don't have relationships in their lives other than people who are paid to be in their life. Our state system of care plan there is a cap of 25 hours for community support and employment supports. The caps are low on what services people need.

five year plan? Max: the importance of peer to peer connections. Any time self advocacy organizations get funding. They need to know how important peer to peer relationships are. Nicole: supported decision making, moving away from guardianship. Karen: in peoples relationships making them feel comfortable in their decisions whether they have a guardian or not. Karen: like to see a focus on youth involvement. It would be a good way to get at a lot of this. Skye: more involvement by families. Families with adult children and siblings to get involved in the advocacy movement. Keep focusing on self-advocacy, we need them to do that.

In the past the Co has gone down the road of recreation programs. DO not focus on segregation make sure they focus on inclusion. They should stay true to their mission and inclusion and pay attention to the federal mandate require.

Appendix G: Advocacy Organization Interviews

	to get the word out. We have a pretty strong presence online.			
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Appendix G: Advocacy Organization Interviews

We serve individuals with Brain Injury, their families and support people

Intake and referral help line 1000-1500 calls per year. We count emails as calls as well. Options counseling program/neuro resource obligation serves 80 people per year. Outreach and education conference reaches about 400 people per year. Also we have seminars and talks about 500 people a year. We do not require any documentation, we take their word for it. No one is left out, if BI is involved, we are more

Lots of successful people with brain injury, how much of a role we play in their success. Vietnam veteran was homeless and saw our sign on the road. Never been diagnosed with a brain injury but had been diagnosed with PTSD. He has now started his own non-profit organization, he bought a farm and is setting up a place for veterans to go and work on a farm. Whether you do it well or not it's the fact that we are the voice for BI in VT. There is a state TBI program but it is limited and only serves a tiny amount of people in VT. The help line is something we do really well.

Brain injury is not a steady state, unlike DD. If something happens to alter their life structure, they can decompensate and have set backs.

We need to be able to hire more staff. Money/funding is always an issue.

It would be wonderful if the council could include people with BI into their community. Clubhouses, etc.

Appendix G: Advocacy Organization Interviews

than willing to help and work with them, unless they are from out of state.

Appendix H: Data Collection Instruments

Interview questions for VT DD Council project: Advocacy organizations

organization:

person being interviewed:

interviewer:

date:

1. Please describe the focus/ purpose/ population focus of (organization):
2. What would you say is the greatest success in providing supports/services to people with (whatever the org says in #1) in Vermont in the last five years?
3. What do you think is the most significant barrier to full participation in society for (whatever the org says in #1) in Vermont?
4. What would you like to see the DD Council address in its next five year plan?
5. Is there anything that you think the Council should NOT address in its next five year plan?

Appendix H: Data Collection Instruments

VT Stakeholder questions - state agency interviews

Name of person:

Title and agency

Date:

Interviewer:

Pre-populate as necessary.

Give a little explanation of what we're doing - helping the Council prepare its next five-year plan, collecting data for that as well as stories to inform Council decisions about priorities or projects. Asked to contact the person by Kirsten Murphy

1. Briefly, what's (your agency)'s mission? (As appropriate: legislation that created it? people served/characteristics?)
2. How many people do you serve? What eligibility criteria do those people meet? Who is left out? Have there been any new initiatives in whom you serve in the last five years? Has there been any narrowing of who you serve or reductions in level or type of services funded?
3. What services does your agency provide?
4. What's your annual budget? State dollars (proportion)? Federal dollars (proportion)? Federal sources: (include M'Caid, Title V, IDEA, match.. ?)
5. What do you think your agency does very well? What outcome measures do you use to track progress/quality in this area?
6. What do you wish your agency could do better/ more of? (e.g.

Appendix H: Data Collection Instruments

particular population that needs service, region, type of service) What outcome measures do you use to track progress/quality in this area?

7. What gets in the way of your doing this?

8. Is there a population that doesn't get any services at all? (a particular type of disability)

9. Are there any big initiatives or new things you see on the horizon for your agency. (Positive or negative)

10. Is there a success story that you can share with us?

Appendix H: Data Collection Instruments

Focus group questions

The Mission of VTDDC is to help build connections and supports that bring people with developmental disabilities and their families into the heart of Vermont communities.

The VT DD council is developing its 5 year plan and as part of it, we are having conversations with people around the state of Vermont to hear about what is most important for the VT DD council to work on in the next 5 years. Today's discussion will be to hear from you as a resident of Vermont who cares about supports and services for people with DD.

We want to learn what connections and supports you think the VERMONT DDC should be building into their plan for the next 5 years of work.

System change (System Change: We all have experiences with systems - government, agency, family. The DD Council is interested in working with agency and government systems to make them more responsive to the needs of the people they serve. For the Council, system change describes actions that the council can be involved in that help to bring greater effectiveness and efficiency to these systems.)

1. What does systems change mean to you?
2. What systems of support need changing in VT.
3. How would you like to see them change? They need to provide training for peer centered models.
4. Are there issues that the Council should focus on in systems change? What strategies would you like to see the Council engage in?
5. [How can the council promote systems change in a positive direction for people with dd and their families?](#)

Self-advocacy: (Self advocacy: This is the opportunity and ability to speak for yourself and make your opinions know. Its most common use is with people with disabilities; but for the DD Council's purposes, we're also interested in the self advocacy capacity of families and providers as well as those with a wide range of disabilities) – ppl with DD

1. What would make SA organizations in Vermont more successful?
2. As self-advocates: do people really listen to you or your group and do something different because of what you are saying?
3. Are there issues that the Council should focus on in self advocacy? What strategies would you like to see the Council engage in?
4. [How can the council help self-advocates make their work more effective, deeper?](#)

Self advocacy: give def) – families

1. Do people hear you and make changes because of what you are saying

Appendix H: Data Collection Instruments

2. Do you know how to advocate for your needs
3. Are there issues that the Council should focus on in self advocacy? What strategies would you like to see the Council engage in?
4. What can the council do to help what you say, matter more.

Unserved/underserved: (Unserved/underserved: This term refers to people with disabilities who could benefit from services but they don't get them. This might refer to people who have access to a limited menu of services, and who find that what they need is not on the menu. It might refer to people who don't know about services or their own eligibility for them; it might be that they need services but are not eligible for some reason. It might also be that they are not interested in receiving services.)

1. One of the things that the council cares about is all of the people in the state that have DD who are not getting services. What do you think the council could or should do about these people?
2. Are there issues that the Council should focus on in the area of unserved/underserved people? What strategies would you like to see the Council engage in?

Appendix H: Data Collection Instruments

Survey:

Introduction: Human Services Research Institute (HSRI) has been asked by the Vermont Developmental Disabilities Council to gather some information about what people in Vermont think about the services and supports that they may receive or provide. There are 13 questions. Your individual answers will be anonymous; your answers will be added to all the other answers we get, and the totals will be provided to the Vermont DD Council.

For the this questionnaire, a “developmental disability” is a significant disability that begins before age 22 and affects three or more activities of daily life such as self-care, communication, movement, learning, self-direction, independent living, and employment. This definition is broader than the one used by the State of Vermont to determine eligibility for adult services through a designated agency.

VT DD Council Survey

1. Please select the ONE category that best describes you. I am:

A Person with a developmental disability/self advocate

A Parent/Guardian/Relative of a person with a developmental disability

A Sibling of a person with a developmental disability

An unpaid caregiver of a person with a developmental disability

A paid caregiver working with people with developmental disabilities

Other Citizen

2.a Which race/ethnicity best describes you? (Choose only one.)

2b 2c Which race /ethnicity best describes the person with dd who will be the

Appendix H: Data Collection Instruments

focus of your answers to the following questions?

American Indian or Alaskan Native

Asian

other

Black or African American

Hispanic

White / Caucasian

Race unknown

Multiple ethnicity / Other (please specify)

Country of origin (if applicable)

3.a and b: your age:

3b: the age of the person who is the focus of this survey:

3c: the age of the ppl with DD for whom you provide services and support:

Under 16

16-22

23-29

30-54

55 or Older

I prefer not to answer

4. Your county:

5a. I live:

5b: the person who is the focus of the survey lives:

5c. the people I serve live:

In my own home or apartment

Appendix H: Data Collection Instruments

In my family's) home

In an enhanced family care home

In a group home

Somewhere else: text box

5b and c: own home

family home

In an enhanced family care home

group home

somewhere else: text box

6. a. How satisfied are you with where you live?

Satisfied

OK for Now

Not Satisfied

Text box

6b: how satisfied are you with where your family member lives?

6c: how satisfied are you with where the people you serve live:

7. Do you receive services or supports from a designated agency for developmental services? Y/N

If yes, which of the following services/supports (mark all that apply)

a. Home and Community Based Services through a developmental services agency

b. Home and Community Based Services through the Choices for Care program

c. Flexible Family Funding

d. The Bridge Program

e. Family Managed Respite

f. Targeted case management

g. Integrated Family Services (IFS)

h. Children's Personal Care

Appendix H: Data Collection Instruments

- i. High Technology Home Care
- j. Supported employment through a developmental services agency
- k. Employment services through Vocational Rehabilitation
- l. Special education service through an Individual Education Plan (IEP)
- m. other (please specify)

7b: does your family member receive services or supports from a designated agency for developmental services Y/N If yes, which of the following services/ supports (mark all that apply)

- a. Home and Community Based Services through a developmental services agency
- b. Home and Community Based Services through the Choices for Care program
- c. Flexible Family Funding
- d. The Bridge Program
- e. Family Managed Respite
- f. Targeted case management
- g. Integrated Family Services (IFS)
- h. Children's Personal Care
- i. High Technology Home Care
- j. Supported employment through a developmental services agency
- k. Employment services through Vocational Rehabilitation
- l. Special education service through an Individual Education Plan (IEP)
- m. other (please specify)

7c: Which of the following services/supports are you funded to provide

- a. Home and Community Based Services through a developmental services agency
- b. Home and Community Based Services through the Choices for Care program
- c. Flexible Family Funding
- d. The Bridge Program
- e. Family Managed Respite
- f. Targeted case management
- g. Integrated Family Services (IFS)
- h. Children's Personal Care

Appendix H: Data Collection Instruments

- i. High Technology Home Care
- j. Supported employment through a developmental services agency
- k. Employment services through Vocational Rehabilitation
- l. Special education service through an Individual Education Plan (IEP)
- m. other (please specify)

8a. How satisfied are you with the package of services or supports that you receive?

Very Satisfied

Satisfied

Somewhat satisfied

Not Satisfied

Text box

8b: how satisfied are you with the package of services/supports that your family member receives?

Very Satisfied

Satisfied

Somewhat satisfied

Not Satisfied

Text box

8c: how satisfied are you with the package of services/supports you provide?

Very Satisfied

Satisfied

Somewhat satisfied

Not Satisfied

Text box

9.a What are the most important things you need to live your life the way you want? text box

9b: what are the most important things you wish your family member had to live

Appendix H: Data Collection Instruments

his/her live as he/she wishes?

9c: what do you wish you could provide to enable the people you serve to live the lives they wish?

10.a What gets in the way of you being able to live life the way you want? text box

10b: what gets in the way of your family member living the life he/she wants?

10c. What gets in the way of your being able to support people in the lives they want to lead?

11a b. What services or supports do you wish you had or had more of? text box

11b: what services/supports do you wish your family member had more of?

11c: what services or supports do you wish the people you serve/support had access to ?

11 a,b,c, should these services supports be paid? Unpaid? Both?

12. abc What do you wish you had that isn't available to you in VT in terms of services/supports?
text

13. Please provide any additional comments here.

Thank You!

Thank you for taking the time to complete this survey and share your opinions with us. Remember, the information you provided will only be used together with all the other information gathered.

Appendix I: Agencies/Organizations Included in Interviews

Written reports:

- David Braddock's State of the States, 2015
- AMCHP Vermont State Profile
- Vermont Developmental Disabilities Services State Fiscal year 2015 Annual Report
- The US Census Bureau
- disabilitycompendium.org
- Federal Department of Education website
- National Core Indicators Report for Vermont, 2014-2015 (N=327)

Interviews: Guided by questions designed by HSRI and reviewed by the Executive Director of the DD Council.

With state agency leaders from:

- DAIL
- AHS
- The Department of Health
- Vocational Rehabilitation
- UCEDD
- The Vermont Legislature

With advocacy organizations:

Appendix I: Agencies/Organizations Included in Interviews

- Green Mountain Self Advocates
- Brain Injury of Association of Vermont
- Vermont Center for Independent Living
- Vermont Area Agencies on Aging
- Vermont Legal Aid
- Disability Rights Vermont
- The Disability Law Project

Focus Groups and statewide survey (N=50): Guided by questions developed by HSRI and reviewed by the Executive Director of the DD Council:

- Self Advocates
- Parents