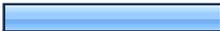


1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

		Response Percent	Response Count
Always		10.8%	30
Mostly		32.9%	91
Sometimes		44.8%	124
Seldom		9.0%	25
Never		1.4%	4

What is working? What is not working? What would help to improve the situation? Please add recommendations or suggestions. 156

answered question	277
skipped question	6

2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

		Response Percent	Response Count
Always		4.0%	11
Mostly		24.5%	67
Sometimes		48.7%	133
Seldom		17.9%	49
Never		2.9%	8

What is working? What is not working? What would help to improve the situation? Please add recommendations or suggestions. 152

answered question 273

skipped question 10

3. How is Vermont doing in providing jobs and employment supports?

		Response Percent	Response Count
Excellent		3.7%	8
Very Good		13.9%	30
Okay		37.5%	81
Fair		22.2%	48
Not Good		19.0%	41

What is working? What is not working? What would help to improve the situation? Please add recommendations or suggestions. 112

answered question 216

skipped question 67

4. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

		Response Percent	Response Count
Excellent		3.9%	9
Very Good		16.9%	39
Okay		36.4%	84
Fair		20.3%	47
Not Good		19.5%	45

What is working? What is not working? What would help to improve the situation? Please add recommendations or suggestions. 118

answered question 231

skipped question 52

5. How is Vermont doing in providing transportation and related supports to hold jobs and participate in social and leisure community activities?

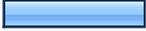
		Response Percent	Response Count
Excellent		3.3%	7
Very Good		15.3%	33
Okay		30.7%	66
Fair		24.2%	52
Not Good		22.8%	49

What is working? What is not working? What would help to improve the situation? Please add recommendations or suggestions. 107

answered question 215

skipped question 68

6. How is Vermont doing in providing housing and home supports?

		Response Percent	Response Count
Excellent		4.6%	10
Very Good		20.8%	45
Okay		30.1%	65
Fair		18.5%	40
Not Good		23.6%	51

What is working? What is not working? What would help to improve the situation?

Please add recommendations or suggestions.

104

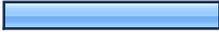
answered question

216

skipped question

67

7. How is Vermont doing in providing health care and related supports?

		Response Percent	Response Count
Excellent		11.7%	27
Very Good		32.2%	74
Okay		27.4%	63
Fair		16.5%	38
Not Good		10.0%	23

What is working? What is not working? What would help to improve the situation?

Please add recommendations or suggestions.

86

answered question

230

skipped question

53

8. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

		Response Percent	Response Count
Excellent		15.1%	32
Very Good		31.1%	66
Okay		28.8%	61
Fair		13.2%	28
Not Good		8.5%	18

What is working? What is not working? What would help to improve the situation?
Please add recommendations or suggestions.

99

answered question

212

skipped question

71

9. How is Vermont doing in providing special education to children, including transition services to youth?

		Response Percent	Response Count
Excellent		4.1%	9
Very Good		24.4%	53
Okay		29.0%	63
Fair		25.3%	55
Not good		15.2%	33

What is working? What is not working? What would help to improve the situation?
Please add recommendations or suggestions.

112

answered question

217

skipped question

66

10. How is Vermont doing in providing high-quality services and supports, and does it have ways to regularly evaluate them? (Quality Assurance)?

		Response Percent	Response Count
Excellent		1.9%	4
Very Good		18.3%	39
Okay		30.0%	64
Fair		23.5%	50
Not Good		20.7%	44

What is working? What is not working? What would help to improve the situation?
Please add recommendations or suggestions.

107

answered question

213

skipped question

70

11. How is Vermont doing in providing individualized services, including choice about supports, services, and providers?

		Response Percent	Response Count
Excellent		5.4%	12
Very Good		21.9%	49
Okay		32.6%	73
Fair		20.5%	46
Not Good		15.6%	35

What is working? What is not working? What would help to improve the situation?
Please add recommendations or suggestions.

86

answered question

224

skipped question

59

12. How is Vermont doing in providing education about civil and other rights and self-advocacy?

		Response Percent	Response Count
Excellent		4.1%	9
Very Good		28.1%	61
Okay		27.2%	59
Fair		24.4%	53
Not Good		11.1%	24

What is working? What is not working? What would help to improve the situation?
Please add recommendations or suggestions.

77

answered question

217

skipped question

66

13. How is Vermont doing in advancing the rights of people with developmental disabilities and offering freedom from exploitation, abuse, and neglect? Examples are voting, protection from use of seclusion and restraint, effectiveness of Adult Protective Services, etc.

		Response Percent	Response Count
Excellent		5.5%	12
Very Good		29.5%	64
Okay		31.8%	69
Fair		18.4%	40
Not Good		9.2%	20

What is working? What is not working? What would help to improve the situation?
Please add recommendations or suggestions.

71

answered question

217

skipped question

66

14. Overall, how is Vermont doing locally and state-wide in reaching out to and including those with developmental disabilities in recreation, social, and other aspects of community life?

		Response Percent	Response Count
Excellent		1.8%	4
Very Good		18.5%	42
Okay		35.2%	80
Fair		19.8%	45
Not Good		20.3%	46

Other Comments What is working? What is not working? What would help to improve the situation? Please add any recommendations, suggestions or solutions. 67

answered question	227
skipped question	56

15. Please add anything else you think is important for VTDDC to know:

	Response Count
	91
answered question	91
skipped question	192

16. Based on the federal definition, please check all the boxes that apply to you. You can use the box at the end to explain or add details.

		Response Percent	Response Count
Person with a developmental disability	<input type="checkbox"/>	7.7%	18
Person with another disability	<input type="checkbox"/>	11.9%	28
Family member of a child with a developmental disability	<input checked="" type="checkbox"/>	34.9%	82
Family member of an adult with a developmental disability	<input type="checkbox"/>	25.1%	59
Direct Service Provider	<input type="checkbox"/>	23.8%	56
Work for a non-profit/community or advocacy organization	<input type="checkbox"/>	27.2%	64
Work for a local or state government agency	<input type="checkbox"/>	21.3%	50
Volunteer member of a community or advocacy group	<input type="checkbox"/>	16.6%	39
Volunteer member of a public policy board	<input type="checkbox"/>	4.7%	11
Public policy maker		0.0%	0
Other	<input type="checkbox"/>	8.5%	20

Please add an explanation or details about the boxes you checked above:

64

answered question	235
skipped question	48

17. Where do you live?

		Response Percent	Response Count
Addison County		4.7%	11
Bennington County		5.5%	13
Caledonia County		2.1%	5
Chittenden County		26.0%	61
Essex County		1.3%	3
Franklin County		6.0%	14
Grand Isle County		0.0%	0
Lamoille County		6.0%	14
Orange County		1.7%	4
Orleans County		5.5%	13
Rutland County		11.1%	26
Washington County		11.5%	27
Windham County		6.4%	15
Windsor County		7.2%	17
Other. Please tell us where.		5.1%	12
answered question			235
skipped question			48

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

1	Connections with other families are helpful. Not many other opportunities other than Special Olympics.	Mar 26, 2011 12:51 PM
2	Housing for low income. I have called several people and each gives different info and/or new info I didn't get from someone else.	Mar 26, 2011 12:45 PM
3	I & R at VCIL, VT 2-1-1 is working. However the State of VT website is hard to use & finding information about programs & services is difficult.	Mar 26, 2011 12:31 PM
4	Due to eligibility (such as IQ) services are not always available to individuals that do not qualify but need the help.	Mar 26, 2011 6:37 AM
5	In the beginning we fell through the "cracks" & didn't get services until my daughter was 10. Things have improved through schools, doctors office, etc.	Mar 26, 2011 6:30 AM
6	only if you have been peeor and then its too late.	Mar 26, 2011 5:53 AM
7	Developmental Home, HCRS Case Mg., Job Support	Mar 25, 2011 12:11 PM
8	Lori's group. Families Together [NOTE: Newport=VTDDC grant funded.]	Mar 25, 2011 12:04 PM
9	Communication	Mar 25, 2011 11:55 AM
10	211 and most information sources may have information that may be up to 6 to 12 months old; agencies and suppliers must make information available within 30 days and update.	Mar 24, 2011 10:16 AM
11	I have an adopted child with DD. We work with post adoption social workers who are very helpful. I know families with birth children with DD that do not take part in any programs. I don't know if it's because they don't want to or don't know about them. I don't believe any programs are done at the schools to help.	Mar 18, 2011 2:34 PM
12	there seems to a assumption that everyone has a computer/internet. Not everyone has a computer,and,has no access to information. Its a very complicated and confusing system to understand and navigate. Its hard to know where to start. Lack of local resource areas, everything seems to somewhere else.	Mar 18, 2011 6:49 AM
13	Perhaps because I've worked with special needs individuals and been one my entire life I've just learned were to seek out info. When I was on the DDC we did recommend a single state info number where we could get the info we needed. I don't know if this has transpired.	Mar 15, 2011 5:58 PM
14	Vermont should sponsor one website that provides information and/or links to information that would be helpful to individuals with disabilities and their families.	Mar 15, 2011 7:28 AM
15	I find the HCRS team very responsive and if they do not know the information they tell you they will get back to you, and they do! It has always been in a timely manner.	Mar 15, 2011 5:08 AM
16	some "front line" people are helpful and willing/knowledgeable in area resources and some are not. Front line people are the folks one gets on the phone, or in reception, when someone calls or walks into various human services organizations (SSI, Employment services, Parent Child Centers, VAB, VSAC, AHS, localized support programs (like Another Way), GMUW, etc.)	Mar 14, 2011 3:55 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

17	Many of those adults with autism are unable to access services. There is just no help for them. Mandate services for all who meet the criteria and who need help.	Mar 14, 2011 11:34 AM
18	Each agency (school, mental health, DAIL, etc) seems to know a small piece of the support available, but no one seems to know it all. No one stop shopping. In addition, children's services specific to DD are limited through the designated agencies.	Mar 14, 2011 10:13 AM
19	I used to work for the old FITP so I know alot about services in our area and state. Also having children who are disabled helps. I think more training and communication between state agencies is important. (i.e. having social workers with DCF more knowledgable in services for children in custody so that they can point foster parents on where to go to get help.) I think that if more foster parents new that there was support out there, more kids might get adopted. We adopted two with significant special needs that had been in the system for a while and without services.	Mar 14, 2011 9:10 AM
20	Too many players on too many teams. Families with students 'aging' out of school are given information that is not complete or is deliberately deceiving in regards to the significantly less hours of services they will be receiving when out of school. We work very hard in school programming to make gains that are often totally unrelated to what is in the future for a student with significant physical and cognitive challenges. There needs to be more realistic planning and educational goals to meet the real needs of a student who is an adult and out of school programming. Adult programming is very poor in Rutland County both in amount of services and quality of life services overall. Some of the relevant learning and training that was done in educational setting is lost altogether in the adult service programming due to lack of knowledge or understanding or insufficient staffing for service provision. There does not appear to be much oversight of staff / consumer programs in day services. On a regular basis, it is possible to witness staff engaged with one another and not with consumer(s) in public places (bowling alley, mall, library, etc.).	Mar 13, 2011 2:40 PM
21	I am an slp for a developmentally and physically challenged man. He would like more hours outside the home with his agency, hcrs, but there is only enough money for him to have around 14 hours per week. He would like more activites, Such as art, music, and things that he can do. He would like to work, and suggests that for folks like himself who cannot find a job, there might be a daily or at least 2-3 days a week where people can participate in a workshop where they could be productive and possibly earn some cash, but even work without the cash to feel productive And part of something useful. He would like and needs more funding in his respite budget. Five thousand dollar yearly respite budget is not enough.	Mar 12, 2011 5:18 AM
22	I think having designated agencies helps to receive info about needed services	Mar 11, 2011 2:28 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

23	<p>Look, I work at VFN in Early Intervention, I want to tell you that up front. I learned the most from FITP family resource coordinators (who are parents), from my supporting parent at VFN (then P2P), and from other parents I sought out. It feels like all the supports are stretched thin -- FFF, CSHN respite, and CDD special accomodation grants --- and that, for that reason, there is pressure on parents NOT to use the supports. Also it feels like the scarcity of funding for these supports means they don't like to publicize them for fear they will be exhausted. I know it sounds self-serving but the state should support VFN in these parent-to-parent connections. A mailing once a year to the family of a child with autism, with a list of up-to-date resources and how to access them would be very helpful. PCA is a life-saver. These kids are so demanding, and unpredictably unsafe that PCA is essention to keep families intact.</p>	Mar 7, 2011 10:11 AM
24	<p>Not working: many agencies, many budgets, need more cooperation between them. More than a letter like DOE and AHS. Joint budget with trainig and programs for parents and schools. Developmental Services: UCS doing what they can with little money. DD is not a high priority when the proirities are life or death. I don't like waiting list either. Bridges program good idea. Need for services and programs. example I need a music therapies or dentist great who? Respite: Again, need for qualified people with ASD training. State wide program an idea. Special Ed: SVSU poor communication (check website www.svsu.org) No new information in 2010. old information, little parent support. Supports yes they need them check out the MGT of America, Inc. Audit pgs, 33-47, First sentence page 33 under findings: "The SVSU does not have a strategic plan for its special education services" I see an oppotunity for VTDDC to reach out. overall, information is out there if you know where to look, bad news the information may not help. working: I don't know what we would have done without Flexible Family Funding.</p>	Feb 21, 2011 2:29 PM
25	<p>As a parent of a special needs child I have had to rely on people telling me what is out there. If you don't go on the internet you are unaware of services. It is frustrating that alot of services are based on income. We are middle class and still have it difficult to get my daughter what she needs.</p>	Feb 21, 2011 8:12 AM
26	<p>Agency doesn't update information</p>	Feb 16, 2011 11:33 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

27	<p>No information, misinformation or conflicting information received regarding State programs such as FIT, CUPs, Bridge, Respite, etc. Communication between agencies is poor. Where to go for information is terribly unclear. Everybody points you in different directions. Ideally, after a child is diagnosed, the school district or state program that assisted in obtaining the evaluation should provide you with a booklet of information to start you off about disabilities, similar to the pilot program conducted in Bennington that Claire Bruno and Liz Fennick directed. As a parent, I was the one who searched out all information concerning my son's disability so I could be informed, what tests/evaluations he should have, what programs he may be eligible for, who performs the necessary tests/evaluations, where to gain financial assistance to meet his needs, etc. In addition, you have to read the Parental Rights for Special Education, be in close contact with State consultants, etc. VFN was unable to assist me in developing an appropriate IEP for my son as they did not have anyone on staff with more information than I. The other issue is location. The State offers many programs, such as Children with Special Health Needs, but just try to get someone to perform a Nutritional Evaluation on your child utilizing this organization! They are not allowed to travel far to assist parents with meeting their child's food needs through School Meal Programs or in obtaining District funding to do so even though IDEA Part B allows for accommodation. We have no access to VFN and their community events without traveling, we have no access to the Child Developmental Clinic except when it's convenient for them, we are the ones that have to travel and many of us do not have the means such as gas or reliable vehicles. There are also limited physicians/psychologists/psychiatrists that are considered qualified by the State to assess/diagnose ASD children. We endure huge financial drains not to mention long waiting periods just to have our kids assessed/evaluated. The applications for each State program as well as the necessary supporting documentation and income guidelines are all different as well making it a paperwork nightmare that is very overwhelming for families not to mention many programs are full and their is a waiting list. Those families dealing with disabled individuals may not have the ability to locate resources or advocate for the disabled individual whatever the reason. Child Integrated Services is a start, but what about the rest?</p>	Feb 14, 2011 1:42 PM
28	<p>It helps to know the key people in the community who provide these services. Generally, it is difficult to know the services available in the county if you haven't gone through the process of coordination of services/intake with the individual or family in need. It would be helpful if these agencies did some outreach to the community on a regular basis. Once a year or twice a year. With some outreach the community partners can get a better understanding of the intake process and services available. Programs change frequently or funding disappears. For those of us who try to connect families with resources, it can be a giant source of frustration when we advocate to the family a service that is no longer available.</p>	Feb 14, 2011 7:19 AM
29	<p>I was lucky and had a friend who guided me through services available and supports but I have heard from many families with newly diagnosed children who do not know what is available to them. Perhaps you could have a system in place that any family with a child diagnosed with a disorder is contacted by a representative to go over all services available and supports and how to apply for them. Perhaps someone from VPIC or other similar organization which is run by parents as well as other professionals.</p>	Feb 10, 2011 8:57 PM
30	211 works	Feb 10, 2011 11:25 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

31	I feel that depending on who is looking for the information determines what people can find. People who are not necessarily familiar with the system do not know what is available, how to search for information, or how to get started.	Feb 10, 2011 7:13 AM
32	When my son was at an acute state - hospitalized twice over two years. It took a third hospitalization until we received information on a waiver in order for him not to be institutionalized. It shouldn't take 1.5 years of debilitating behavior for the child, which greatly impacts the family, to get increased services.	Feb 8, 2011 1:48 PM
33	Consistent training for all who offer services, or answer phones for those who offer services, is needed. Mixed answers, different answers, or no answers are confusing and frustrating.	Feb 8, 2011 10:42 AM
34	In homecare, have found that adults who are not seniors and who are getting services through Medicaid are falling through the cracks.	Feb 7, 2011 7:09 PM
35	Early dissemination of information to parents concerning diagnosis, needs and services.	Feb 7, 2011 4:43 PM
36	Sometimes we have found out about services or coverage based on word of mouth or by asking people that we know - there really isn't a good reference for Vermonters that I am aware of at least for this. Two examples are ARIS/PCA support and youth sized diapers being provided by vendors and covered by Medicaid. I work in healthcare, so tend to know how to go about getting questions answered. I feel fortunate in regard to this.	Feb 7, 2011 2:26 PM
37	I am a case worker so I have a lot of contacts. To access the more obscure supports within the state (such as VT Crisis Intervention Network) it takes persistence and often a bit of luck. I cannot imagine a working parent with a difficult child being able to take the time to find these supports. Education has the VT Family Network - it would be helpful to have similar "clearing houses" for Developmental services.	Feb 7, 2011 2:20 PM
38	It is very difficult to get information for children who don't present clearly as DD or Autism, but who may be eligible. There is a disconnect between the best way to navigate for a child in the school systems versus a child/family navigating the state system. A DD diagnosis within school districts often results in tracking a child to a lower level of daily academics, functioning peers, typical class environment. However, if once you get to the high school level you need the diagnosis to get support for post high school. If you are not already "in" the system it is extremely difficult to navigate. The websites are entrenched with legalese and poor "how to" info. It is toooo complicated and not family friendly.	Feb 7, 2011 12:19 PM
39	I am not always able to attend meetings through Vermont Parent Information. I rely on my son's case manager at Howard Center to keep me up to date on available programs, funding, etc.	Feb 7, 2011 12:01 PM
40	It is helpful when diagnosis is made for those facilities to have resources: books, support services lists, support groups lists, flow charts (what next) to give to parents/ caregivers. Doctors still are not believing parents - dismissing their concerns concerning their children's development/ and difficulties	Feb 7, 2011 10:51 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

41	Different school districts seem to apply the special education laws differently. In some school districts, it is relatively straightforward to get an IEP for a child who has a behavioral disability or developmental trauma issues. In other schools, it is virtually impossible, with the same set of behaviors, diagnosis, etc. Those schools will not entertain a request from parents to evaluate for an IEP. Sometimes it is a little difficult to find the people you need to ask questions about adult DD services and how to apply for them for a child who is going to turn 18 soon. I still haven't found an agency or a program that helps children with PDD or FAE and their families to access respite, social skills training, etc. Information also seems to be difficult to find.	Feb 7, 2011 9:51 AM
42	I think it is more difficult for families who are not already in the mental health system with a case manager to help navigate the system.	Feb 7, 2011 9:44 AM
43	Hard to know who to contact?	Feb 7, 2011 8:45 AM
44	I have had good experiences getting information regarding services and supports through 211 and through verbal referrals from co-workers. I find it easier to get information for children than for adults.	Feb 7, 2011 8:42 AM
45	Lack of funding prohibits services after individuals hit 22 years of age.	Feb 7, 2011 8:16 AM
46	When students move from Special Education to Developmental Services the orientation of services goes from a process of teaching to one of "support". Along with that change seems to come the notion that people have reached their full potential and are best served by maintaining the status quo.	Feb 7, 2011 8:11 AM
47	Transition from school to community is challenging. Finding information about supported employment is extremely challenging.	Feb 6, 2011 6:58 AM
48	I often find out about things from other parents, not professionals (so many of whom are "case managing" for us), and often years after we would have been eligible. Eg. it took me a few years to learn from another parent about compensation for travel, meals, and hotel when my son has hospitalizations in Boston. Each "case manager" should do a "focus group" type interview to assess needs in the family and try to find resources PROACTIVELY.	Feb 6, 2011 5:44 AM
49	The way ceratin funding streams are set up you are not able to access services that are needed for clients. For example, in residnetial programming if you you have a client who is placed and is funded either through DCF or DMH then you can't get funding to access DS services also. So if you have a client who is DS eligible and would benefit from the expertise and resources within the DS world this is not an option.The same goes for other specialized services such as speech for example when thsi type of service is not built into the current residential daily rate it is very complicated to allow for funding to access these services.	Feb 5, 2011 4:18 PM
50	more mental health supports are needed	Feb 5, 2011 10:45 AM
51	Good cooperation and networking when someone has a problem	Feb 5, 2011 9:38 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

52	Rutland is not a welcoming county either through DCF or RMHS/CCN or their LIT process. People do not want to collaborate here, get into major power struggles about resources and do not get creative. You need to open up competitive processes for grants and funding and re-examine the DA system. Where the heck is Richard Giddings? We need him back NOW.	Feb 5, 2011 8:45 AM
53	In my experience I have found that Doctors, Teachers, Speech, O.T.ect... do not offer enough info. This is our first stepping stones of our childrens lifes. Parents should also be a part of passing the info along. I think it is important to have other families to talk to .	Feb 4, 2011 8:02 AM
54	What is working? My brother is currently under "Specialized Community Care" and has been living years with Jay Ransom in Orwell, VT. We are kept up to date with upcoming medical appointments and any special needs that my brother is needing, as we are currently having monthly meetings. Also, we have my brother here often to visit. My mother is guardian and I'm co-guardian and we are very happy with the care that is given. He is not a person that can just sit around, he has to have something to do to use energy and goes out daily to be in the community. What is not working? I think that the person that is responsible for taking my brother out into the community should get paid for mileage. He brings my brother here to visit and out into the community. There should be more out there in the community for our people to do. We used to have a wood shed that my brother used to enjoy going to and it was closed. Recommendations or suggestions: Funding needs to keep going for these people so that they can have as much a quality of life as possible. We also need to keep the money available for caregivers to be able to get respite when needed. Funding needs to be kept in place for all the needs of Mentally Challenged people, in all aspects of the education, services, respite, travel, ect.	Feb 4, 2011 7:23 AM
55	the c3 program has been key to helping us allow our son to stay at home and give us the supports to stay regulated.	Feb 3, 2011 4:12 PM
56	It takes alot of effort to navigate the system that is very un	Feb 3, 2011 11:08 AM
57	"Partner" agencies or organizations often do not know about each others' services or have information about those partner organizations. Places that people are comfortable going/go to regularly (for example: schools, doctors' offices, libraries etc.) should be utilized as resource centers. Information about local services, state services and supports should be available in those places so families are directed in useful/helpful ways when they are needing extra/new/futher support.	Feb 3, 2011 8:55 AM
58	It needs to be better organized. Also when you do call the appropriate place for the needed support and you are told to call somewhere else does not help.	Feb 2, 2011 1:32 PM
59	finding the information is much easier then actually getting the services and/or support	Feb 2, 2011 12:21 PM
60	Unfortunately, there are several clients who are falling in the cracks due to IQ scores. These same individuals do not qualify for any services because of their IQ or because they are not severe enough to be hospitalized. They however, are not able to handle finances and are unsafe and vulnerable to others in their community. We are helping others who qualify under DD services or those with Mental illnesses but are doing nothing for those in between.	Feb 2, 2011 11:25 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

61	It would help to have clearer information about what types of supports are even available--particularly from developmental services. Often folks find out last minute (upon "graduation") whether they even qualify and what they qualify for. Special Ed follows laws and mandates--adult services are delivered at the discretion of over burdened and untrained "case managers". I would suggest some "standards for care" and programatic standards be developed. If they already exist, there needs to be a way that families can access this information and agencies need to be held accountable.	Feb 2, 2011 10:47 AM
62	School personnel working with students with developmental disabilities often do not have the necessary basic training in designing and implementing programs and adapting curriculum and materials. Often their position in the school (general special educator) is a barrier to seeking out the information that could make a difference for the students with ISE needs who they serve. Personnel working in other agencies vary in their knowledge base, experience, and in their ability to advocate and/or support families to advocate for themselves/their sons or daughters. As a result the information that is disseminated is variable as are the types of services to which children/young adults have access.	Feb 2, 2011 10:40 AM
63	The process is extremely slow. There is no sense of urgrancy on the part of any of the players: DAIL, VR, DAs.	Feb 2, 2011 10:22 AM
64	There are resources at face value such as the Autism Society of Vermont which helps with awareness and conferences for parents- but some parents can't even use this because of lack of appropriate childcare. When my preschool aged child at the time was diagnosed with autism I was referred to the Autism Society of Vermont and Parent to Parent for help with childcare costs. However most childcare providers were not prepared to meet his needs and wouldn't even accept him. My point is that information resources are helpful to a point but childcare and afterschool care would help parents go to work and educate themselves on how to be more effective. Educating childcare providers, educators, and pediatricians on all the possible resources available would be a good 1st step but only that.	Feb 2, 2011 9:36 AM
65	We have two children that are disabled. For our family, information regarding support and services initially began via physicians/hospitals once diagnosis was made....after that, obtaining information became OUR mission as parents, as it became clear that support and services in Vermont came with much persistance, assertivness and "name dropping". Our boys have two very different diagnosis/disabilities and accessing developmental services, respite, reliable and proficient therapists, SPED/504 services and contact with parents of children with similiar issues is a full time job. There are few data bases in VT, that we are aware of, that help families to, "step by step", explore services their child may qualify for.	Feb 1, 2011 9:54 PM
66	Special education department totally fails kids who are on the spectrum but intelligent and doing well academically.	Feb 1, 2011 2:19 PM
67	A website specifically dedicated to housing all of this information that has links to all related sites	Feb 1, 2011 1:39 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

68	My son is in a JOBS program, but his casemanager does not give him all the information; or she doesn't apply everything to him. Also the mental health agency won't look at any delopmental services because he wasn't diagnosed with PPD-NOS until he was 18, even though his condition was present before he turned 18. We had a hard time getting him diagnosed because people didn't feel he was on the spectrum. The state mental health agencies need to follow the federal guidelines so that individuals don't "fall through the cracks" as my son seems to be doing.	Feb 1, 2011 12:33 PM
69	First and formost the State of VT needs to recognise that children with DD such as autism become adults with autism and not throw them to the mercy of no services. There is no help for many after 18 or 22 so they committ suicide, become homeless or live under bridges. The only way my adult child could get help was if I provided it.	Feb 1, 2011 12:28 PM
70	I would say that for the most part, both as a parent with a child with a disability and a professional, services and information can be somewhat sporadic depending on who you ask. Younger children's information seems to be working well. Teens/young adults seem to need additional supports. Concentrated efforts with area agencies like YITG and things like that are good sources.	Feb 1, 2011 12:15 PM
71	have received information on transition services from Voc Rehab, Stowe High School and LCC	Feb 1, 2011 10:25 AM
72	As a parent of a child with a developmental disability (ASD/high functioning/aspergers...whatever you call it these days), my husband and I have had to navigate these waters ourselves. We are both communicators and will ask questions/find answers ourselves. Often, we were leading the school professionals and our physician in asking the right questions. While all has gone relatively well, and our daughter has thrived - I do feel like it would have been just as easy to find ourselves in a mess...if we had NOT had some advocacy skills ourselves and known the system a bit (I'm a teacher/curriculum consultant in another K-12 public school system and know some ins and outs.) I wish the information/support system for families w/ developmental disabilities was more accessible/transparent/explicit...and that sometimes it actually sought US - versus us always feeling around in the dark. While every child w/ this diagnosis is unique and seems to need a unique set of interventions and responses - there still should be some obvious "go to" spot. Perhaps if our daughter had been lower on the spectrum, been violent/aggressive, had more extreme behaviors or impairments...assistance would have been more obvious because it would have been at a crisis need level. But - what about being more proactive - and seeing that the potential of such individuals, wherever they are on the spectrum, can be positively or negatively affected, by the available service model.	Feb 1, 2011 9:44 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

73	FIT staff are generally knowledgeable about programs and services. However, there is no one place to go for families receiving a new diagnosis! I am a trained social worker and have worked for AHS for over 20 years, yet navigating the state system has been challenging. And I have resources, skills and knowledge that many others do not have. What happens to the child of the person that works at Walmart, who doesn't have access to a computer to research programs and supports, and cannot make calls during the work day to schedule appointments? And what happens when they can't attend meetings and appointments during their work day? I have usually heard about programs/services from OTHER PARENTS instead of from the professionals who are supposed to be helping. We need an Autism Center in this state!!! At the very least, we need a center for developmental disabilities that has all the information, providers and services IN ONE PLACE. The amount of time and energy and effort families currently spend trying to get basic programming in place is ludicrous! We need help now! This impacts the welfare of the state AND the economy. I still work full-time, but my son's dad had to quit his job to provide supports after school and during breaks, as well as attend daytime meetings and appointments.	Feb 1, 2011 8:01 AM
74	Once we know about a service, it is easy to access. Finding out that a particular service exists (respite funds, CSHN evaluation, I-Team assessments, ect.) is the tricky part. I have only found out about these things from other parents. It would be helpful if there was a website that listed all of the resources available to children with special needs.	Feb 1, 2011 6:49 AM
75	>Too many questions not enough answers >Vague eligibility requirements benefits and knowledge by agency staffing >phone communication is difficult to find the right people with useful info >Everyone is busy or in meetings it seems. Most calls are returned but sometimes timeliness is crucial	Jan 30, 2011 12:52 PM
76	I am able to get the info needed to get the best services possible for my 22 year old son with Down Syndrome...BUT... NO ONE from the state appointed agencies tells you about the possible services available. It seems to me that all info I have gotten through other sources and the State of Vermont online, and then, after presentation to an area rep I get "oh yes, those services are available for your son. How sad that Employees who "specialize" in Human Services/Special Needs have to get a list of available services pried out of them.	Jan 29, 2011 4:30 PM
77	There are many opportunities for services in Vermont. Very accessible.	Jan 28, 2011 6:04 PM
78	Transition Help after 18 is difficult	Jan 28, 2011 9:53 AM
79	Information is sparse and proprietary in cases. One needs to know the questions to ask in many cases.	Jan 28, 2011 9:52 AM
80	What you find out appeared to be dependent on who you are working with. Teams are great, generally. But getting caught up in the invisible IEP vs mental health struggle (the one that nobody wants to acknowledge it because nobody can fix it) caused unbelievable stress. Seems like Mental Health is very handy if the family has obvious issues- in which case it doesn't take a lot to improve parents' -and therefore childrens' -functioning. Where the family is functioning, but the child came with issues through foster care, real help does not appear to be available (ie: crisis support, realistic respite, etc.). Moral support can be a boon.	Jan 27, 2011 8:53 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

81	Since coming in contact with CIS /Family infant toddler program, information has been great, however it was like getting water from a rock with the pediatrician.	Jan 27, 2011 4:22 PM
82	Services and supports can be easy to find but difficult to navigate. People that I work with have been able to access the services, but have had a difficult time when it came to utilizing the services, such as respite. Families with adult children living with them often don't have the time or understanding to navigate the world of human services.	Jan 27, 2011 3:28 PM
83	You need to make information more accessible. There are times one wonders if your guarding the crown jewels.	Jan 27, 2011 11:31 AM
84	The approach that Families First (Wilmington VT) has taken in attending to its clients is extremely effective! Their ability to serve the needs of the individual without succumbing to the bureaucratic norm gives me hope of a promising future for my son.	Jan 26, 2011 5:10 PM
85	one never knows quite where to get the info.	Jan 26, 2011 4:39 PM
86	Hospitals should be more organized and better informed about options and be prepared with printed information that parents can access at their leisure, as well as provide access to a person who is available to guide parents and answer questions.	Jan 26, 2011 12:15 PM
87	Some times it seems like the people trying to get us info are as overwhelmed and under staffed as we are.	Jan 26, 2011 11:37 AM
88	It would be helpful if each person with a disability is assigned a case worker so they can tell us about our options. I havent heard from anyone from the state in several years!	Jan 26, 2011 11:13 AM
89	My son is autistic and has a diagnose since he was 2 years old. Getting basic support and services in Vermont is like pulling teeth. Networking with other parents and recently, becoming a part of Families First, has been the only way I have heard or been able to access services for my child.	Jan 26, 2011 10:27 AM
90	Maybe this could be an educational program offered on PEG TV here in rutland.	Jan 26, 2011 8:53 AM
91	For folks that have already been diagnosed with a disability it is easier to access funding and information. The process of getting assistance prior to diagnosis, and getting diagnosed initially can be time consuming, frustrating, and overall a challenge for families and others supporting/advocating for individuals. It would be helpful to have a more proactive approach at the elementary and middle school levels to indentify children in need of evaluation. Additionally parent education about this process and their rights need to be more easily accessible.	Jan 26, 2011 8:16 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

92	As a parent we continue to meet families that are just beginning their journey down this road. Our first instinct is to ask them basic questions about knowledge of services available? Have you applied for medicaid? Do you have PCAs? Have you applied for respite? Have you connected with other families? What are you getting for supports? Have you lined up OT/PT, Speech? It continues to be disheartening to hear that families continue to receive a handshake and a basically empty folder and a 'good luck'. Families should be immediately assigned a case manager; who will walk them through the ins & outs of what VT has to offer. Many struggle to search for info on their own, and happen on info by chance. This is not acceptable. Families are 'treading water' to continue functioning. They need a great deal of additional support at this time to function and 'find their way'.	Jan 26, 2011 7:55 AM
93	Sometimes it is difficult to know what is available and who or what agency is responsible for a particular service	Jan 26, 2011 7:34 AM
94	We had to search our own way through the system in order to get our son the services that he needs. We would recommend that for every family that has a child with a development disability be given copies of all special ed laws, including education. Professional family advocates would be of great asset to families at doctor appointments, clinics and school meetings to help families understand what and how to advocate for their family member.	Jan 25, 2011 5:54 PM
95	You have to be very proactive and be willing to search for the things that your child needs, though. Our family has recently begun receiving some help through the Bridge Program (through NKHS), which has been extremely helpful.	Jan 25, 2011 5:20 PM
96	in Lamoille county, where we live, the school is the main source of information for developmental services; the county agency won't help my son as he lives with his family, not in DCF. It would be great to have a social worker to help us find educational, recreational and social resources in Vermont when it comes to autism.	Jan 25, 2011 3:55 PM
97	What is working: CSHN's Programs, CPCS, CDCI - UVM (I-Team & Deafblind Project), Family-managed supports What is NOT working: The nursing agencies (not having them be accountable for consistent, high-quality support. Special Education - parents have to work too hard to get good programs in place or to have their children included. Some special educators try hard but it is the	Jan 25, 2011 3:28 PM
98	It seems that if you don't know the right questions to ask, it's hard to get complete information. And how can a person know what to ask if they aren't aware of what's available? A "one-stop-shop" for information would be terrific, and anyone contacting an agency or group other than that "one-stop-shop" should be referred to it for more complete information.	Jan 25, 2011 2:30 PM
99	If there is a good case manager who's case load is not so high that he or she has time to do the research, then information is available as to whether or not there are services out there to meet a given need. Unfortunately there are both fewer case managers and fewer services available and the need for both is rising.	Jan 25, 2011 12:53 PM
100	We have always gotten accurate information and help for these services	Jan 25, 2011 12:19 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

101	Getting the information is very important, and in developmental services we need up to date information asap to best help our clients. The most crucial issue now is funding, we need the state to realize that cutting our funding actually drives up the costs for our clients care. If a client needs guidance or reassurance to get through their day, and their funding has been eliminated for our programs, they will go to the emergency room or police station for advice or comfort, which definately costs considerably more than our services.	Jan 25, 2011 12:02 PM
102	More effort on part of state to let people know of the oppotunites for becoming Home providers and respite providers for people with disability's as an alternative to a regular job.	Jan 25, 2011 11:41 AM
103	As a new 501c3, the mission of Vermont Horse-Assisted Therapy, Inc. is to provide safe, effective and fun therapeutic horseback riding experiences for students with mental, physical, social, emotional or economic challenges. We are working to gain more recognition as a resource for the central VT community, but it has been hard to make the proper connections with area mental health agencies and find ways to alert mental health professionals about our existence and services. Is there a central website where we might post a link to our website, www.VHAT.org?	Jan 25, 2011 11:05 AM
104	It has been a challenge to find past reports on the website. When Challenges for Change was trying to set its outcomes, I found that AHS had thrown out all the work of the past decade on state outcomes. I had to dredge up my old copies of reports. I found I had more in my past files than had been kept by the state. June Bascom is very good about giving answers to data questions. NO ONE is keeping data on parents with disabilities who have children in the DCF system. We had a project that kept that data on families served by or project over 6 years--855 families served, 495 of whom had DD. Only 17 had their parental rights terminated. Now no one is collecting that data, so no comparisons can be made.	Jan 25, 2011 10:28 AM
105	I find that parents are less likely to understand and know how the sywsatem works. It's cumbersome and complicated. Very often people w/disabilites have to wait long periods of time for funding to be approved before recieving services. Very often sdervices can not be provided due to lack of resources.	Jan 25, 2011 10:13 AM
106	Would be helpful for families to have wrap around services/case management to help with access.	Jan 25, 2011 9:54 AM
107	My son has a didability he has depression,anxiety,and an eating disorder. He has special education and is in therapeutic day school. I have access to a lot of supports here.	Jan 25, 2011 9:22 AM
108	I think what would be helpful is a network between schools, medical professionals, and agencies who are serving individuals with developmental disabilities. It has been my experience that schools inparticular are un educated about who we serve, our eligibility requirements, and services. Agencies need to supply schools and medical professionals in thier areas with literature so that individuals and professionals have information.	Jan 25, 2011 7:41 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

109	Our main concern is respite. We have been getting enough until this year. We had to have a new furnace installed in mid october just when it started getting cooler. I asked if there was emergency bed available. was told that there was not. I was informed to use the respite waiver which I did. And was told that if we ran out they could get more. Now I am soon going to run out and I am now told that I cannot get anymore. Thanks	Jan 25, 2011 7:40 AM
110	I have been able to do it because I have been overly persistent but it wasn't given to me, it was my research that shed light on these things. If I was a parent who couldn't do the research, I wouldn't have had the resources. These things should be presented to the parents upon diagnosis. Such as calling in VT Family Network to sit down with a family within one week of the diagnosis.	Jan 25, 2011 7:16 AM
111	most information comes from other families. it can be difficult to get timely information from "professionals". The work that advocacy agencies like VFN does is very helpful.	Jan 25, 2011 6:48 AM
112	As the mother of a child with dwarfism age 9 who moved from MA to VT I found a huge shortfall in my child's care. While at Childrens Hospital in Boston for his 0-3 years my child had a Coordinated Care Specialist. It was through the notes I had from his care during that time that I was able to really follow a care plan once we came to VT. Often times I have found myself requesting specialists visits based on those notes he had early on while still at Boston Childrens. The CSHN department wraps my child into a MILO clinic which really isn't what he needs. Seperate appointments needed to be made with specialists through the Childrens Hospital in Burlington only to find the specialist was no longer working there. I am now seeking treatment for my son at a Skeletal Dysplasia clinic in Wilmington,DE. Through my connections with Little People of America I find that I am more aware of my child's needs then those caring for my son within VT's current system. I see adults who have been through the VT system with multiple physical and mental health needs left untreated and I do not want that for my son as he approaches adulthood.	Jan 25, 2011 6:34 AM
113	Vermont Family Network is a great resource to get the information about services and supports. Betty Morse is an angel to work with and she is always there to support our family.	Jan 25, 2011 6:26 AM
114	I have never rec'd a comprehensive list of all that is available. I continue to hear of new programs by chance--like katie beckett waiver or the bridge program. I feel like there should be a comprehensive website and printed material that is distributed upon diagnosis--whether that is at birth or further down the line when a child is diagnosed.	Jan 25, 2011 6:17 AM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

115	<p>I wrote my answer as sometimes because since my son started receiving services over 11 years ago, I have learned the most about services by networking with other families. Also I started advocating hard for specific changes more than a year ago and only by doing that did I really begin to understand the system and services. For example I only learned about family managing a waiver a couple of years ago. I then learned that the agency was suppose to inform me about this option but they never had. When I decided it was the best option for us I met some slight resistance from the agency as they tried to convince that my son would have less money when in reality he has access to more while saving the state money. Only the agency lost money when I moved to family managing. I am concerned about the lack of transparency and the power an agency can have when they are more concerned with there own interest at times. I also feel that the lack of flexibility in the money being spent creates waste. Each individual receiving services is so different that in order to make the money work more efficiently, there needs to be a drastic change in the flexibility of how the money is used. For families with severely disabled individuals like mine, allowing parents to be paid is an important and federally legal option. As my son gets older, less and less people can provide the quality of care that I do but since I need to earn a living I must depend on others less qualified to provide care when in fact I am willing and want to do it myself. That being said respite is important for any care giver. I believe that the system also needs to create some type of scale of level of needs that may be the catalyst for determining flexibility as well as determine that pay of those employed to provide care. I currently care for a mildly disabled woman. The support staff gets paid more per hour than those who care for my son. The level of care of my son is far more intense therefore it is extremely difficult to get consistent care givers for my son. The training of support staff and shared living providers is inadequate. As a new shared living provider myself, I often wonder how I would have been able to do a good job if I didn't already know what I know about the system. After completing the required training I realized it is filled with gaps. Also after completing the training I know that it is unlikely I would ever choose that option for my son with anyone other than someone who already loves him and knows him. The training is not good enough.</p>	Jan 25, 2011 6:12 AM
116	<p>mental health issues are becoming quite the challenge and services are available for families that get connected, but not nearly as much available as needed.</p>	Jan 25, 2011 6:03 AM
117	<p>Not a user friendly system. You really need help to know where to turn to get information.</p>	Jan 25, 2011 5:05 AM
118	<p>Working: Some DAs. Not working: Being limited to your local DA, not necessarily the one best for you. What would help: Matching needs to the best resources, regardless of location.</p>	Jan 24, 2011 7:29 PM
119	<p>People need to be vigilant about looking for information how to help their children. There is no case mgt for a majority of families, someone who meets with them to tell them what they are entitled to...to do followup research on their own families needs, to get treatment programs running smoothly , if they are available at all in certain regions.</p>	Jan 24, 2011 6:22 PM
120	<p>I have had to get my information from other parents - rarely does it come from a health professional or teacher.</p>	Jan 24, 2011 4:53 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

121	depending on where you are living, needed services and supports might not be available	Jan 24, 2011 4:29 PM
122	The Succeed program. It help me to move into an apartment. Self Advocacy the IDA program that helps people save for college and to start their own business. Case Management	Jan 24, 2011 4:00 PM
123	The path to obtaining respite is confusing. We didn't know about applying for Katie Beckett for a long time, and the time without it was a financial hardship.	Jan 24, 2011 3:49 PM
124	I do not know if there is any respite fund this year - or who to call to find out now that CSHN no longer has any direct connection to me. Mardie Knowles in Central VT used to be my go-to for answers. I no longer have that. PCA annual review change has me nervous. I read everything that comes in the mail, but I am not confident I will not make a mistake somewhere that will throw me out of the system.	Jan 24, 2011 3:20 PM
125	Our pediatrician, EEE, and school officials have been our main source of information about services and supports. While I feel they have shared what they know as a need surfaced, I wish there was a centralized source of information that would explain all the different types of services and support available in VT. You can't ask for help if you don't know that such help exists. I worry that my son has not had an opportunity to benefit from services simply because I did not know that such services were available. Why don't VT pediatricians, EEE providers, VT Children with Special Health Needs, and public schools provide lists of all VT resources to parents of children with developmental disabilities? I also wish there was someone to help us navigate the system and help us anticipate future needs. I am so focused on helping my child succeed in elementary school that I have no time to think about what he will need down the road--even though I know that time will be here in a blink of an eye. I know how important it is to plan ahead, but I have such limited time now to also teach myself everything I will need to know in the future. I wish I did not have to "re-invent the wheel" over and over simply because I do not know what needs to be done and what resources are available. There must be a way for identified parents of children to routinely be sent information about future issues.	Jan 24, 2011 3:14 PM
126	Training for professionals e.g. Higher Ed Collaborative is improving. Lack of expertise is largely the cause of why things do not work. Service models/delivery are being changed....i.e. SLPA's being used in place of SLP's. Although SLP's are "under the supervision" of the SLP, there are huge gaps in what that supervision actually is. " Job supports leave a lot to be desired. Students are not eligible for job supports unless they have a paid job upon leaving school, but they are unable to obtain that paid job due to no support. Families are multi stressed and trying to obtain any kind of appropriate services is a nightmare.	Jan 24, 2011 2:56 PM
127	Working-VFN Families Together group in my area. Not working- cuts in DD services.	Jan 24, 2011 2:11 PM
128	Information on services is extremely hard to come by. Seems as if it's mainly word of mouth from other families.	Jan 24, 2011 2:02 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

129	Really no one has been in touch with us for at least a 1 1/2 years possibly more. I felt very let down and that the agency or investigator didn't see the importance or need of the situation from my point of view. I do realize there were a lot of cuts. I did enjoy the one conference I was able to attend. I would like to again. I think parents need to be made aware you are out there.	Jan 24, 2011 2:02 PM
130	One can always get information on these things. What is not working is the services with cuts and lack of money!	Jan 24, 2011 1:46 PM
131	It takes a while to know what you might be eligible for. Information is sometimes lacking and because of the state v. federal definition, we don't always qualify for stuff. By State definition, my son doesn't qualify for DD. This can be confusing.	Jan 24, 2011 1:45 PM
132	Coordination of school and agencies, especially with regard to transition support and workplace training is very weak. Also, agencies should be able to direct us to other organizations that we will need to work with as the time approaches instead of leaving it to us to figure it out all the time. Coordination of care/services needs a LOT of work.	Jan 24, 2011 1:31 PM
133	Information is always available but knowing what to ask for and who to ask is information that is not made available. Adding contact information to brochures with commonly asked questions would be helpful.	Jan 24, 2011 1:28 PM
134	Mental health services are so weak and the time spent searching for high quality mental health care for children is burdensome for parents with good support webs. For those without.... it is a nightmare and kids are hurting.	Jan 24, 2011 1:27 PM
135	Special education - options are not always known and not always clearly communicated, in full fashion.	Jan 24, 2011 1:27 PM
136	Without an advocate to navigate this complex system many individuals who qualify do not get served.	Jan 24, 2011 1:25 PM
137	Fortunately, getting information about programs/supports for my son with autism has been fairly easy in the educational and health care arenas. Respite programming works in general - there are times when it is challenging to find individuals to provide the care.	Jan 24, 2011 1:24 PM
138	Doesn't seem to be ONE really good place that has information about the WHOLE state and that is widely advertised/marketed so people know who to call. It also seems that the access to information and funding depends on where you live and who you know. Some schools and areas do much better with outreach than others and it should be consistent.	Jan 24, 2011 6:07 AM
139	do not know who to ask or where to go.	Jan 22, 2011 10:06 AM
140	Calling to make sure that things are handled properly. Make it easier to apply for MediCare Part D. There also seems to be a lot of confusion at the moment over which services have gotten cut by Montpelier & which ones haven't...	Jan 21, 2011 7:54 PM
141	Information is available.	Jan 21, 2011 8:23 AM
142	It is difficult to understand the "funding Priority" issue when it comes to kids needing services to prevent out of home placement and they don't meet the funding priority.	Jan 20, 2011 4:26 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

143	There are many gaps in what had been promised for on-going and expanded services and supports with the closure of the state "training school" in Brandon and what is available today. These promises that had been made seem to have been forgotten by the Douglas administration's push to reduce the operating expenses for the state agency of human resources.	Jan 20, 2011 9:16 AM
144	Children are not adequately served by DAIL and the DA's. Services to youth in custody who are dx'ed with DD have the availability of more services than children with similar presentations who are not in custody. The philosophy to not use residential services is antiquated. Residential services can play a very positive role in the life of a child or adult. DAIL needs to look carefully at the Enhanced Family Services as a tool to better serve the high end youth in the system	Jan 20, 2011 8:07 AM
145	I feel that while there are many places people can go to get information, it seems that there is not one place a person can go. For example special education services come from one place mental health services from another, child services are different then adult services etc. A clearinghouse where clients have one stop shopping would be ideal. As a DCF social worker i may encounter 4 or more persons working in a specialized area with 1 client. It is extremely frustrating when service providers are not communicating or overlapping services or there are gaps in services.	Jan 20, 2011 6:36 AM
146	In my job, I am frequently asked by police, daycare providers, and others about services available to people with disabilities. I am always shocked at the lack of information coming out of the designated agencies DS units explaining what they do, what they have available and how they can help. Secondly I am quite stunned about the failures of their intake people to respond to clients and their families when people try to reach them.	Jan 19, 2011 2:11 PM
147	In my experience, there are supports and information out there, but one really has to know who to talk to and where to go to find the information. Often, special educators, don't volunteer what they know or what the child might benefit from due to their own agenda and it isn't until a parent/advocate etc learns about it and presents it that school systems acknowledge. Also, many providers for children with developmental disabilities are young and their jobs are at entry levels. Often one has to educate the provider about where they might help get information that is needed, and often they don't either ask all the questions or know what to specifically ask. Also, a number of supports are located in certain geographical areas and not others, limiting who has access. Also, a number of families miss out on services due to income eligibility requirements. It takes a long time for Katie Beckett Medicaid to be accessed and in the interim, it limits services that are medicaid driven and only creates additional financial expenses to families that may already be struggling, but not enough to qualify for Economic Services Support.	Jan 19, 2011 1:44 PM
148	information is hard to come by. finding answers requires the mildest parent to become assertive which really doesnt work until they become aggressive. There seems to be lots of money for placement and respite but finding the people is a struggle. I think schools are getting more educated about DS services although it is overwhelming because they took so long to get aboard.	Jan 19, 2011 1:16 PM
149	Is it hard to access special education services and to actually understand what is out there and what schools are required to do.	Jan 19, 2011 12:49 PM

Page 2, Q1. Have you ~ and other people you know in Vermont ~ been able to get information about needed services and supports? Examples are special education, developmental services, respite, etc.

150	Websites are most helpful and having a computer to access the information is superb.	Jan 19, 2011 12:48 PM
151	I had a difficult experience working with a woman who did not qualify for DD services through Howard, but had a documented disability that prevented her from meeting her child's needs. The child was repeatedly exposed to great risk as a result. There were efforts to support the mother in parenting her child, but these were unsuccessful. We have a huge gap in our system if a client who is parenting is not found eligible for services through Howard. These situations present a high risk to the child and the experience is painful to those most vulnerable individuals, specifically the child and person with the disability who is attempting to parent.	Jan 19, 2011 12:44 PM
152	Through the connection with UVM and our counter part, Easter Seals psychologist, Auguste Elliott I was able to access research, ideas and evaluations. I have not needed respite in any special way, we were able to access foster homes in the Newport area that did well with boys with very low IQ's.	Jan 19, 2011 12:42 PM
153	New to the state! (2 weeks)	Jan 19, 2011 12:37 PM
154	developmental disabilities is heavily defined as mental impairment or an IQ below 70. Parents of children with developmental disabilities are not informed or served by the designated agencies. It depends where you live. Thses supports and services should be equitable across the state. They should be clearly advertised and should help intact families. Parents should not have to give up custody of their child to access services and supports.	Jan 19, 2011 12:16 PM
155	I hear that in some areas of the state, DS workers are at the table for students prior to graduation and are helpful partners. In other places, they do not see themselves a splayers unless the student has alreday been found eligible.	Jan 18, 2011 12:53 PM
156	There is less ability to find who to call for services or questions since the Department of Mental Health and Developmental Disabilities disappeared and developmental services has been relegated to a unit within a division within a department and only half the unit name mentions developemental services. They are basically hidden from the public.	Jan 18, 2011 11:58 AM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

1	Uneven services and supports around the state. In Chittenden County people with well-defined needs and advocacy support oftgen get good services and support. However, in smaller, rural areas supports often not available.	Mar 26, 2011 12:51 PM
2	I have to spend hours on the phone because no one seems to know what is going on. I have to be my own advocate because of system mistakes.	Mar 26, 2011 12:45 PM
3	There are so many people w/ developmental disabilities struggling to live at home. Families are becoming unable to care for their loved one because they need support either through respite or day services.	Mar 26, 2011 12:31 PM
4	Due to eligibility (such as IQ) services are not always available to individuals that do not quality but need the help.because of eligibility there are not always funding available if you do not qualify for certain services.	Mar 26, 2011 6:37 AM
5	Urgent. The Safe Choices program in Lowell VT is said to get \$200,00 per client (see article January 19,2011) Orleans The Chronicle newspaper.	Mar 26, 2011 6:01 AM
6	Right nw everyone is hurting fuel assistance because to many are on it.	Mar 26, 2011 5:53 AM
7	One year my adult daughter received significant heat money -- then she received \$50 years ago and now nothing -- because she live with Mom who is on SSI!	Mar 26, 2011 5:35 AM
8	Developmental services & autism support has not always had funding for us.	Mar 25, 2011 12:04 PM
9	Figure out a budget	Mar 25, 2011 11:55 AM
10	not eligible-age-income = every one I have asked for help = will just talk about other programs = and not ever help you find a program you can get help from.	Mar 24, 2011 10:16 AM
11	We have applied for grants and have been accepted. We are working to get our child signed on with HCRS We need to know more about where our child is going as an adult. We have no idea what is available and noone seems to know.	Mar 18, 2011 2:34 PM
12	Budget cuts are hurting everyone,. Too many restrictions,red tape, not enough qualified people, poor pay for PCAs, high turnover. funding should be more flexiable, in what it can be used for, for example, Personnal Care money should be more flexiable in what is allowed. You shouldnt lose funding because you dont use it all up in the year. Transision from school to work, in order to gain supported employment funding, client has to have a paid job, of 15-20 hrs at minium wage. how does client get supports to get a job, such as ride,support people. Need better working relationship with school and adult services and voc-rehab	Mar 18, 2011 6:49 AM
13	Unfortunately as an older retired person technology is not an affordable option and there is no agency which provides it without reinbursement.	Mar 15, 2011 5:58 PM
14	Yes, I think when you are clear about the needs and what would benefit your son/daughter than that helps. I di not want to see any of the resources for services or staff reduced as this would clearly impact this process.	Mar 15, 2011 5:08 AM
15	funds are being cut everywhere, making it harder for folks to either be eligible, or limiting the resources even if one is eligible for support.	Mar 14, 2011 3:55 PM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

16	Not available if the person is low income but not Medicaid eligible. Charge services on a realistic sliding scale if a person is able to work. Leave the person with enough money to encourage working and provide good supports.	Mar 14, 2011 11:34 AM
17	I work with families who have children with some sort of disability. Within the current system the children with DD have limited services available for them in the community setting. Those with explosive behaviors are generally contained with the school, but do not have enough supports at home. They "system" frowns upon long term placement of these children even if the treatment team determines that this is the safest option for the child.	Mar 14, 2011 10:13 AM
18	It is hard because certain things are not covered by insurance. With all the budget cuts state wide, programs like CSHN are finding it harder to support parents for unusual items. Stop cutting the programs that help families and start looking at other systems that allow people to sit home and play on the computer and not work. Quit making tax payers pay for methadone and use that money to fund programs helping children and adults with disabilities.	Mar 14, 2011 9:10 AM
19	As above, the schools are spending many dollars and hours through the course of 15+ years and then sending students to adult services with inadequate funding/staffing/programming to meet needs of adults. Either we should be making changes to adult services or tweaking the school services to be more in line with the reality of adult life. Spending money is not the answer, quality programs and appropriate planning for future adult life is the answer	Mar 13, 2011 2:40 PM
20	Not enough money in any of my clients budget. There are not enough cos workers, nor do they get paid enough for the wonderful job each one of them does.	Mar 12, 2011 5:18 AM
21	working : PCA and wonderful Jennifer Garabedian.; CSHN respite not working: having a vast wait list for FFF. Schools are not helping families with school age children access PCA, CSHN respite, FFF, summer grants; schools feel it is not their job but they are the main contact for the families.	Mar 7, 2011 10:11 AM
22	New people may be on waiting list, people in the system have to do with less. Even with funding I need more professionals and services. If autism insurance happens to age 22 (and it will) I need related services and program in southern VT. There is a need for UCS to be able to fund servies for DD, funds now are only covering those with huge daily life situations.	Feb 21, 2011 2:29 PM
23	The state plan is too rigid to address the needs of many folks with disabilities!	Feb 21, 2011 11:30 AM
24	The PCP is a really nice asset to have. Again alot is based on money.	Feb 21, 2011 8:12 AM
25	Funding is very much based upon the ability of a family to qualify for a particular funding silo. While it may be clear that a family should qualify for funding because the need is high, it appears that the State agencies push back on "owning" the family to address their needs, claiming they don't meet funding priorities.	Feb 17, 2011 1:22 PM
26	Not sure what is available to us	Feb 16, 2011 11:33 AM
27	Children and youth with developmental disabilities are woefully underserved.	Feb 16, 2011 9:16 AM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

28	So many deadlines, so many applications, so much reading to identify eligibility, so many different income guidelines, so much supporting documentation, so many phone calls, so many meetings, so many fighting for the same limited program funds available! I have been fortunate, but it has become a full-time job!	Feb 14, 2011 1:42 PM
29	With the population that my organization serves, in most cases funding is available if a child comes into custody. This seems to be a great disservice to our community because we want to prevent custody with wrap around support. If the State is going to pay for these supports anyway (meaning that we are all under the umbrella of AHS), why can't the funding be shifted?	Feb 14, 2011 7:19 AM
30	It is hard to get total funding needed sometimes for afterschool and weekend care and for consultants for children with significant disabilities. Also the low wages allowed on Personal Care funding make it hard to find responsible, educated individuals who will endure.	Feb 10, 2011 8:57 PM
31	I work under a grant from ADAP but the funding has not included cost of living increases for the past 4 years. We are not alone in barely hanging on to just stay opened. This makes it impossible to provide the services our clients need at the level we should be providing them.	Feb 10, 2011 11:25 AM
32	Money is tight throughout the state and I think this is having a large impact on the folks who need services.	Feb 10, 2011 7:13 AM
33	PCA services have been more accessible than I thought they would be in these tough times.	Feb 9, 2011 3:16 PM
34	not alot of budget available	Feb 8, 2011 2:11 PM
35	Getting the initial PCA monies wasn't difficult, given the challenging level my son faced. It has been getting appropriate training for the PCAs and even getting staff in Southern Vermont that has been a challenge. Once we received a waiver and went through an agency that has been much more active with has have we been able to get staffing.	Feb 8, 2011 1:48 PM
36	We are INCREDIBLY appreciative of our son's Katie Becket coverage through Medicaid. It allows us to access PCA funds. I hope that with a new single payor system on the horizon, services such as this and the C3 program are not compromised. I wish that somehow PCAs could be paid for a bit of vacation time and had an opportunity to have some benefits.	Feb 7, 2011 2:26 PM
37	With money tight, it is harder and harder to find funding. Also, it seems that the big 4 (education, DCF, Mental Health and DD services) are very protective of holding onto their own money. It would be helpful if foks could be more collaborative "across the aisle" sharing supports and money for kids with numerous needs.	Feb 7, 2011 2:20 PM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

38	<p>PROBLEM: Knowing how to request help.....who to ask, when to ask, how to ask. The "appeal" process requires someone to quit their job (so they have time) and hire a lawyer (to navigate the law and available resources) and a psychologist (to maintain sanity). WORKING: The individuals within the system are largely helpful, committed and supportive. They are respectful, but sometimes feel a bit like "cogs in the wheel" and don't lay out the steps...they've excepted the "rules" when sometimes they should facilitate pushing against the rules. SOLUTIONS; Consolidate processes and agencies: If I get an evaluation for speech-language from my school, why do I need a new eval for Disability Determination? If I get an evaluation for Disability Determination, why can't it be shared with the school to decrease time, money and confusion. Clearer and consistent process for access to programs like respite, Succeed. IT seems the school districts do not know enough about the community services and visa versa....COMMUNICATION would be great.</p>	Feb 7, 2011 12:19 PM
39	<p>Again, I rely on Howard Community Services to provide me with information that directly affects my son or is beneficial to him.</p>	Feb 7, 2011 12:01 PM
40	<p>More support getting the word out about grants, services, agency programs that are already available.</p>	Feb 7, 2011 10:51 AM
41	<p>I am able to get PCA services for many of the kids I work with.</p>	Feb 7, 2011 9:51 AM
42	<p>There is very little funding for services for individuals under age 18, and no dollars it appears for Autism services except for those provided through Success beyond Six funding through the schools.</p>	Feb 7, 2011 8:45 AM
43	<p>If medicaid covers a service, it happens. If medicaid does not cover it, or if the practitioner does not accept medicaid, the service doesn't happen.</p>	Feb 7, 2011 8:42 AM
44	<p>THE DS Sstem of Care priorities rule out most people under the age of 22. As a result those people move into the "high risk pool" for funding. The process of that movement is slow and laborious. DAIL/DS seems to be a less than enthusiastic participant.</p>	Feb 7, 2011 8:11 AM
45	<p>IT always takes A LOT of advocacy work on the part of the parent/caregiver....sometimes too much.</p>	Feb 7, 2011 6:30 AM
46	<p>Pleasantly surprised BUT I'm devoting a lot of hours to understanding/tracking down/following up on this kind of stuff. I have a stable marriage, a master's degree, etc. Can't imagine if I weren't assertive or had other stressors that made it difficult to access all the funding there is.</p>	Feb 6, 2011 5:44 AM
47	<p>See what I have noted above.</p>	Feb 5, 2011 4:18 PM
48	<p>Pretty much. I see too many time people who do not really quality getting services - if more of these "clients" were vetted and denied - the system would work better</p>	Feb 5, 2011 9:38 AM
49	<p>Same as above</p>	Feb 5, 2011 8:45 AM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

50	Finding the right people to follow thru with suggestions for the childs program. What is not working is a Special Educator who doesn't know how to set up a program for their students. When it takes a whole school year to get an Assitve Technology Evaluation done, and then the Special Educator does not follow thru with the recommendations because she doesn't work well with computer technology. What recommendation do I have ? Re-place the person if they can't do the job!! I Have to sing the I-Team their praises. The people that I have come to know are wonderful.They are willing to go that extra mile for the children.They talk to you nor at you , they use terminology that is understandable. I did not take a college course in understanding how a teacher can out talk you with all the terms that are meaningless! The schools need to be more open with info that is understandable. They don't always let you now what services are available to the families.	Feb 4, 2011 8:02 AM
51	The person responsible for taking my brother out into the community (Zach Ransom) needs to be reimbursed for the money that he has to spend to do his daily activities. With the price of gas that keeps going up, we are going to start losing our support people. We can't afford to do that. The Developemental Homes are going to get burned out and that would be a tradgedy.	Feb 4, 2011 7:23 AM
52	when we attempted to get funding for a floortime approach, we were told he was denied, since he was not in risk of an institution. we need to not cut funding for folks with disabilities. we need to cut payroll at the state level and offer a good retirement fund to incentivize opportunities for folks to exit.	Feb 3, 2011 4:12 PM
53	Anyone who has a physical disability has to get a loan.	Feb 3, 2011 2:20 PM
54	Once you find the correct area, ex voc rehab, or other services the support takes a while to actually get an interview to find out what is available. After that if you know what you need and want it is good. If you don't know it seems to be difficult to find out what you need, and where to go.	Feb 2, 2011 12:21 PM
55	I think the economy is making it more difficult to get funding.	Feb 2, 2011 11:25 AM
56	Funding is very interesting. You can get "funded" for a community support position and the agency can take 6 months to actually fill that position (this happened to us). There is a gap between funding and actual service delivery. I also think the standard for getting funds--"in danger of becoming homeless" is absurd. It places tremendous burden on the family and does not benefit the person with special needs. I would suggest a different standard for funding--diagnosed lifetime disability (known developmental disabilities like Williams Syndrome, Autism, Down Syndrome, etc) should automatically qualify someone for support.	Feb 2, 2011 10:47 AM
57	Assistive technology supports for mobility and positioning tend to be available. Communication devices have become more readily funded but the need for trained personnel to support teams to model use of the devices. Educational technologies are extremely variable depending on where people live. There is a tremendous need for access to assistive technology supports and for personnel to provide training and technical assistance for tools that have been funded. Many of the educational tools available currently can make the difference between active participation in school and community life and little to no access.	Feb 2, 2011 10:40 AM
58	Funding is not adequate and there is a sense of "oh well" from the agencies involved.	Feb 2, 2011 10:22 AM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

59	My family has been lucky that we were able to obtain PCA hours for respite and the Flexible Family Funding program via HowardCenter Developmental services which helps with some of my son's supplements, however we still pay out of pocket for many needs and often go without. I was able to access these two programs because I am a trained social worker, learned about them on my own and persisted until I was granted access but I've met many parents who have no idea about either program or the first thing about accessing them. The only thing I can think of would be to have regional centers that are somehow getting referral from schools/daycare/childcare centers since school is the most affordable common denominator for families. CHSN would also be a good place for parents and families to be connected to regional centers. To put the burden of information, and help with resource access as well as all the other support that follows I believe would be an extreme burden for the already overburdened school system.	Feb 2, 2011 9:36 AM
60	Funding will always be an issue with the current economic status in VT, however, we have found that since our youngest was placed on a waiver, his worker through developmental services has advocated for special funding to support our sons needs as well as the needs of the family. I believe that our situation is unique and we are thankful, yet are left wondering how other families manage without strong advocates through agencies.	Feb 1, 2011 9:54 PM
61	Again, the system works best for those who are very low functioning and poor. Middle class families haven't a hope to get the services that would benefit their child if that child somehow survives in public school. Also, in our district the special educators do not seem to be aware of the differences between people on the spectrum (ie, they treat them all alike) and many are not receptive suggestions from people who might know best.	Feb 1, 2011 2:19 PM
62	There is a lot more that can be done. A lot of funds get cut especially when a client turns 21. Also its hard to motivate individuals to stick around if they don't have any room for financial growth and promotion	Feb 1, 2011 1:39 PM
63	Again because of the lack of accepting of his diagnoses, there are funding areas that he should be able to access but can'tbe.	Feb 1, 2011 12:33 PM
64	No services	Feb 1, 2011 12:28 PM
65	"Middle class" families seem to be left out of many programs-over income, etc. when in fact, they are the ones who can use the most help since they are not receiving additional benefits. Upper class, upper middle class often have the resources they need. Coordination of benefits, continued legislative efforts	Feb 1, 2011 12:15 PM
66	We have received a scholarship so our son canb participate in adaptive skiing at Sowe for free. We did receive some respite money. Our son receives PCA support (although we have a difficult time finding competetent help), and he does receive medical insurance through Medicaid	Feb 1, 2011 10:25 AM
67	Well - I guess the evaluations done by the school (not at our cost) suggest there have been funds tapped to meet my daughter's needs. However, there has NOT been any obvious professional development for the wider community.	Feb 1, 2011 9:44 AM
68	We're told we aren;t eligible for anything. We have to pay out of pocket or hope its covered by insurance. Expanding the Autism Insurance Bill to include kids OVER age 6 would help!	Feb 1, 2011 8:01 AM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

69	I have been pleased with the funding my daughter has recieved. This includes supplemental health insurance, respite funds, and personal care assistant hours.	Feb 1, 2011 6:49 AM
70	With only having the school to help me with my son, what I feel is needed services for my son they don't think so. Knowing of other ways to get the funding for services needed would be helpful. Our health insurance company bought my sons dynavox (communication device so he could tell us his needs) but now it needs repair and they wont pay for it.	Jan 31, 2011 4:45 PM
71	>my county agent on aging is very good but is slow in getting me through the necessary hoops to be ellegeble for services >funding was cut for transportation for appointments and food shopping without notice from 8 rides to 5 >the elderly disabled seems to be the most vulnerable and powerless in the face of funding cuts priorities	Jan 30, 2011 12:52 PM
72	State of VT does very well with individual funding when it has been properly presented to the state for evaluation. State of VT does extremely poor in helping to provide housing for adults with special needs.	Jan 29, 2011 4:30 PM
73	Funding is lacking. There are not enough support workers available because wages are insufficient.	Jan 28, 2011 6:04 PM
74	Need to be stronger about communicating about guardianship options	Jan 28, 2011 9:53 AM
75	I have been able to access most of the funding our family needs, but this is because I understand what I need to do to get it - which is sometimes humiliating and degrading for an individual with a developmental disability and family. Not sure how to change this without the system eliminating the priorities.	Jan 28, 2011 9:52 AM
76	16 year old needed a life skills campus placement. Act 264 team was unanimous- went to LIT twice- we were turned down because we had kept him out of prison and hospital and because we would not call him "homeless" (ie: abandon a child we adopted at 10 yo).	Jan 27, 2011 8:53 PM
77	Howard center youth services autism program is first rate and should be mire available to extend services past 3 years old and more children should get to go.	Jan 27, 2011 4:22 PM
78	Speaking from an employment standpoint, June graduates, need to already have a job to qualify for employment services. This disqualifies a lot of capable people who would like to have this service.	Jan 27, 2011 3:28 PM
79	If one gets the information in time one might get the services, now more than ever, as cutbacks are coming. When the information and the recipients meet the system works. When they don't it doesn't... again it is all about exposure.	Jan 27, 2011 11:31 AM
80	I would like to see more funding of course. But really would like to see more flexability with the funding I have, i.e, I need for funds for respite then personal care, its not always possible to flex it. Also, I wonder if less should be going to the middle man so it could be used for more personal care or what ever is needed by the client or family.	Jan 26, 2011 4:39 PM
81	I use Children's PCA services. I would like to have the option to set a rate of pay for my PCA's, within reasonable limits. If I was given a monetary PCA budget (as opposed to an hourly budget) with the option to pay anywhere between 1 and 1.5 times the current rate it would help me retain the more highly qualified and trained PCAs.	Jan 26, 2011 12:15 PM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

82	With all we need to do taking care of two disabled children,it's hard to weed through all of the red tape involved for some of the services.	Jan 26, 2011 11:37 AM
83	see above comment	Jan 26, 2011 11:13 AM
84	The school district over the years have cut down on many services such as one on one paraprofessionals, IEP meetings where no teachers come because they do not have a sub, and basic transportation or summer support.	Jan 26, 2011 10:27 AM
85	We are working in a crisis driven system due to budget constraints at the state and federal level, therefore some people who need services do not get funded for them unless risk is very, very high.	Jan 26, 2011 8:16 AM
86	Respite Care and Flexible Family Funding has been cut from \$1300 to \$1,000, with each year remaining under fire to be cut even more. For many of us with children with special needs, this is all we tap into, and it is life altering. Please don't cut it even more!	Jan 26, 2011 8:00 AM
87	As the economy has worsened, even more VTers are competing for the same small pool of grants and scholarships to access services and supports not covered by insurance. Too many families are slowly sinking into poverty, bankruptcy, etc to provide the services their children need to have successful services.	Jan 26, 2011 7:55 AM
88	Although last year there have been significant cuts to early intervention services to low incidence disability population. Seems to me this cut could have been disbursed amongst a larger group of providers to this population (the larger EI service providers) so that the hit on these specialized services was not as great.	Jan 26, 2011 7:34 AM
89	It is not working when the state makes cuts in DS services, a loss of a funding criteria takes away needed services for individuals who could be successful at home, school, work and or in the community. A loss of a DS worker is huge as well, if there are not enough front line workers to work 1x1 with the individuals then the services are no good to the individual. Funding criteria needs to go to back QUALITY of life, why wait until the individual are either homeless unemployed or in the hospital work together with the individuals family, friends and outside resources. You wait for their family and friends to get burnt out and then when the individual is at their lowest point in life then you step in to help (This comes at a GREAT cost.....financially, emotionally, & physically).	Jan 26, 2011 7:17 AM
90	I see families that make over \$100,000.00 a year and get funded for car seats and yet other families go without any support. A more fair funding scale would be most beneficial to make sure that those families that really need the supports get it and those that are making a sizable income would get what they need in accordance with what they can do to support themselves instead of the tax payers.	Jan 25, 2011 5:54 PM
91	We are having difficulties finding funding for PT equipment--is there such a thing?	Jan 25, 2011 5:20 PM
92	only if we find where to ask and then pursue it doggedly	Jan 25, 2011 3:55 PM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

93	I have tried to get my child a Katie Beckett waiver, for which we qualified when living in another state. However, I am repeatedly told by the Child Development Clinic that she won't qualify, not disabled enough, etc. We have primary insurance, however in today's economy and instability with jobs, I fear losing that and being completely without, at which point she might qualify but it would take so long to get through the process that she'd lose out. My understanding of "Katie Beckett" waiver is that it's based on diagnosis, not ability. She has medical concerns (primarily controlled at the moment but with regular testing needed) and considerable need for therapies, which are primarily provided through the school right now. But again, schools are cutting budgets and staff, her OT was scaled back due to lack of staff (and apparently not filling open positions) and I would like to be able to afford outside therapies to augment.	Jan 25, 2011 2:30 PM
94	Both money and funding priorities have been tightening for years. Needs are going under met or not met at all.	Jan 25, 2011 12:53 PM
95	We feel very fortunate to be able to get the support and services that our son gets.	Jan 25, 2011 12:19 PM
96	In the past funding has not been a major issue, but now, it is very difficult to secure funding and it is starting to take it's toll with clients in need. Some of these clients are getting into trouble with the local police departments for wasting their time.	Jan 25, 2011 12:02 PM
97	Cuts in budgets have impacted the simplicity of getting funding for people with disabilities. You have to do a huge song and dance to get what the individual needs.	Jan 25, 2011 11:41 AM
98	Again, we need to find appropriate avenues for funding--therapeutic riding has documented value in building body strength, balance, and mobility, in improving speech and language and interpersonal skills, and in developing sequencing and other psychomotor skills. Our educational model using professional registered instructors from NARHA (a national certifying organization of riding instructors for students with special needs) is effective, and far less costly, than the medical model, called "hippotherapy" which relies on licensed physical and occupational therapists.	Jan 25, 2011 11:05 AM
99	We have been able to get most of what we need, but that is because we are well established on the waiver. Other families/individuals are very insecure about whether or not they will get what they need. Respite/Flexible Family Funding is now funded at a lower amount than it was back in 1992. Respite for Children's Mental Health goes directly to the agencies to decide how to use, and it is not getting to the families to use for respite.	Jan 25, 2011 10:28 AM
100	There are long waiting lists for funding and services. The longer folks with developmental disabilities sit at home waiting for services the faster their skills fade. This population needs support. Without the necessary support we're looking at re-institutionalization which is not only immoral but most costly.	Jan 25, 2011 10:13 AM
101	Alot of funding sources found for individuals living with ASD....again, having a case manager who knows what is "out there" would help.	Jan 25, 2011 9:54 AM
102	Yes, my son had to go to an eating disorder hospital located in Waltham Massachusetts I had no problem with mediacaaid as he needed to go there because Vermont does not have one. The only problem is VT does not have places like this.	Jan 25, 2011 9:22 AM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

103	I think funding is more and more unavailable to qualifying consumers. Quality supported employment services are key, in that trained employment professionals can develop opportunities for independence on job sites. Work is a meaningful and fulfilling activitie that can be supported naturally in the community through guidance and follow along. I also feel that Those who utilize assistance from developmental home care providers, should be assured that they will meet their daily needs for rec, work and medical services and not necessarily need a seperate day person. I do realize we have many of those situations across the state and it is proven to save money.	Jan 25, 2011 7:41 AM
104	Wanda was able to get funding to make improvements tio her bathroom this summer, but apparently that was a one time deal, and now she is not going to be able to get additional for this year.	Jan 25, 2011 7:40 AM
105	There is not enough funding out there and not all of the individuals have the same needs. My son's is more behavioral but it is because of his diagnosis. He needs sensory integration, behavior training, social skills training and more, not equipment for accessability. Funding for this is hard to come by and you have to look everywhere for it.	Jan 25, 2011 7:16 AM
106	The funding issues are immense and stressful. With the limited availability for Developmenal Waivers for children it makes raising a child with significant needs very challenging. The funds are limited and very much focused on Autsim. Families without ASD diagonsis in VT are being left out of the funding loop. Funds for other children with special needs are very limited and being eroded. Cuts in programs that do exsist - Flexible Family Funding -respite and CSHN fundiing makes keeping pace with child and family needs exhausting.	Jan 25, 2011 6:48 AM
107	I have recieved no information on how to fund my medical trips to Delaware.	Jan 25, 2011 6:34 AM
108	I think that the baseline for income levels need to be higher. In this economy there is not a whole lot of extra money in our paychecks to go towards extra classes that our children may need to help them.	Jan 25, 2011 6:26 AM
109	Medicaid follows whatever decision my primary insurnce makes. ideally, my 4 year old would receive in home pt and ot since that is where she needs the help. but she is not homebound so she gets denied by primary and medicaid follows suit. i feel like providing the most suitable services will reduce long term costs of therapies.	Jan 25, 2011 6:17 AM
110	Again flexibility is lacking. Also special education in Vermont is not adequate for many individuals. I am so disappointed that we do not have alternate school options. In my case my son needs a therapy based school. Adapting to a regular school system and environment was so wrong that I now home school my son thereby losing a great deal of support. The lack of ability to purchase goods and services is an issue and actually can cause more money spent than saved. For example if a gym membership can be purchased instead of clinical therapy to allow family members and support workers to implement therapy then money is saved. Getting funding but not being able to use it efficiently is the problem more than access to money.	Jan 25, 2011 6:12 AM
111	children on IEPs or simular situations are connected with services. It's those kids that don't qualify for sp ed but still have significant needs that flail in the system.	Jan 25, 2011 6:03 AM
112	It is difficult to get funding. Money is tight and I do not think that developmental services is a priority.	Jan 25, 2011 5:24 AM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

113	Tighter stringent rules have made things hard. DD population now suffers by not being able to purchase things that would make their life easier. Families suffer because they are doing the best that they can to make life as good as it can be for DD population. Often going without themselves. If you are a paid home provider things are easier, families are not compensated at all to have family members stay "home".	Jan 25, 2011 5:05 AM
114	A menu of what is entitled to the families. A list of qualified providers. A funding mechanism easy to navigate.	Jan 24, 2011 6:22 PM
115	For years, we were in a situation that we had the funding for services, but couldn't find the services or providers	Jan 24, 2011 4:29 PM
116	Home supports are good. In order to get a job coach -work support you either need to be a health and safety risk or a high school graduate which is not helpful if you need work support and can't rely on always depend on supervisor to provide all the job support. Not all agencies have transition supported employment grants funded through VR. VR needs to provide more long term support. We need more public transit in rural areas The state needs more primary care doctors that take Medicaid Medicaid needs to cover glasses , and orthotics. The Medicaid waiver should be allowed to be used for post secondary education . The goods budget should be reinstated	Jan 24, 2011 4:00 PM
117	Respite (PCAs) work fairly well, though further trainings, such as the ones provided by Autism Support Daily, need to be in place & offered regularly. Public school has been terrible. Schools do not have accurate information about autism, or about sensory diet/sensory issues, and overload. They are still trying for one size fits all approach, but people with autism are such individuals with very unique needs.	Jan 24, 2011 3:49 PM
118	But it seems like a treasure hunt. I just keep calling and asking and calling another place and asking until I get a yes somewhere. Luckily we have BC/BS that covers most medical expenses. I do have to campaign though for large DME items. And appeal at times. I would not have a track system in the house (and it is mandatory or son would be in bed 24/7) if a bystander heard our insurance/Medicaid/CSHN plight and paid for it themselves. There is no assistance for track systems or vehicle modifications that are worth even a significant portion of the cost required.	Jan 24, 2011 3:20 PM
119	Our medical insurance has a high deductible and many service providers don't accept insurance anyway (because of the hassle-factor and low reimbursement rates). Also, so many services are deemed "mental health" and therefore, are reimbursed by insurance at an even lower rate. Even the medication coverage is very limited under our insurance and other family members have had to forego needed medication in order for us to afford to provide medication for my child with a disability. Our school system has been reasonably good at funding services, but offers little in areas not directly related to educational needs. Our pediatrician has been excellent at accepting insurance payments as payment in full for his services. Our community recreation programs are not adequate for our disabled child, so we have to restrict him to recreation programs for the disabled that we can afford to pay for or "do our best" on our own.	Jan 24, 2011 3:14 PM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

120	Many families are forced to live on one income so the other parent can care for the child with special needs. Schools are overwhelmed. Parents are not able to receive additional supports in the home that are needed to assist the child in the ability to generalize skills learned in the school setting. The disability does not end when the school day does. PCA services are helpful and appreciated by families, but it not enough. The challenge is training, managing and retaining qualified caregivers is a challenge for most.	Jan 24, 2011 2:56 PM
121	Funding is getting tighter and tighter. More funding would be nice.	Jan 24, 2011 2:02 PM
122	Only for the conference I attended. I didn't even know you had funds. What supports? What services?	Jan 24, 2011 2:02 PM
123	Cuts in funding = cuts in services and supports	Jan 24, 2011 1:46 PM
124	Big gaps include no funding for home modifications and lack of funding for van modifications. My son uses a power chair, but we cannot get any funding to help him access different levels of our home or for a van. Transporting him and the chair are becoming increasingly difficult as his disability progress and he can no longer transfer.	Jan 24, 2011 1:45 PM
125	I have written some grants that I found on my own for autism to fill in the gaps. Also, as a result of our parent support group, we learned that some of us get funded and some not for the same devices! For example, an IPAD for autistic kids for time management, communication facilitation, and schoolwork support.	Jan 24, 2011 1:31 PM
126	It is getting difficult with the recent budget cuts to be able to get any extra funding for respite or community hours. It is easier to get extra employment hours when necessary. I have no recommendations as to how to find the extra monies for respite and community services especially with talk of more budget cuts.	Jan 24, 2011 1:28 PM
127	We go out of state and pay for it ourselves. Insurance did not cover an out of state doctor for our child. An out of state doctor correctly diagnosed him and saved his life. In Vermont he was getting docs not understanding the complex level of his diagnosis and its' severity. Unlike the out of state docs, they were quite confident and kept pumping meds that made the situation worse. Oncology care for kids in the US is standard thanks to those docs great networking. We are in the dark ages here with brain and mental health conditions in children.	Jan 24, 2011 1:27 PM
128	C3 program for Personal Care is WORKING. It's a fantastic way to utilize funding in ways you most need.	Jan 24, 2011 1:27 PM
129	Though Flexible Family Funding has decreased, it is still available. Summer schooling has also been available.	Jan 24, 2011 1:24 PM
130	Many people can't get funding for what they really need and some who could benefit from supports have to jump through hoops to get and keep them. It shouldn't be so difficult to get the supports one needs or could use to really be active, involved, engaged in the community.	Jan 24, 2011 6:07 AM
131	Calling to make sure that things are handled properly. Upgrading the state's infrastructure to use more Open Source Software would save a lot of money.	Jan 21, 2011 7:54 PM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

132	DD waiver services for children who are in DCF and ready to be adopted. It is my understanding these waviers do not continue post DCF involvement.	Jan 21, 2011 2:08 PM
133	Always with in reasonable requests. Most of the denials have been for recreation, alternative txs, respite. I would regulate and continue with management and oversight.	Jan 21, 2011 10:08 AM
134	For a child who needs DS services access is limited to those who are in DCF custody. This is a limitation that places additional burden on families (ie: change of custody), and the children. This should be a service that is available to those who are not in the custody of the State.	Jan 21, 2011 8:23 AM
135	I marked sometimes because there are such a wide range of supports and services that are needed by individuals within the DD community and not all are being met by the folks that are in need.	Jan 20, 2011 9:16 AM
136	See above answer	Jan 20, 2011 8:07 AM
137	This the beiggest problem area that we have serving our clients. Funding sources vary from agency to agency and some services are covered others are not depending upon is it a pre-existing condition, or other eligability factors it would be extremely helpful if workers had a manuel that clearly states this is where to go for x service or y service etc. i spend many hours doing referrals to agencies that provide y service but not x service. Again a one stop agency that knows their clients and their specific needs would be extremely helpful. Just having the ability for our computer networks to be able to speak to other networks would be incredible helpful, so that when i am talking to a client I can pull up what services they are receiving and who is providing it would be amazing.	Jan 20, 2011 6:36 AM
138	Service dollars (including waivers) have been significantly cut in the last 6 or so years. Families have not been able to get the services they need, and when they do they are not getting the amount/hours/days of services they need. This has resulted in children and youth entering State's custody, where in the past they would not have. DCF does NOT do well with these youth - they do not have the background, the training, or the appropriate foster care situations to serve these children well. Their work with families of these children is still approached with a "child protection" mind set, which places these children at risk of long-term custody.	Jan 19, 2011 4:55 PM
139	I have a difficult time accepting the double standards in the process of dealing with applicants for disability income- people who desperately need it are denied and people whose only disability appears to be dropsy of the heart- get it with nary a whimper.	Jan 19, 2011 2:11 PM
140	The family flex spending money is great. When there was a consideration to cut the availability it was really concerning. Caring for a speical needs child is a job in itself. It limits a parent's ability at times to seek employment or other child care assistance due to limited resources. Parent's who stay home with a special needs child should be given a grant or made eligible to recieve something similar to PCA hours. Not all parents are eligible for social security and then there are few other available resources.	Jan 19, 2011 1:44 PM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

141	Funding is always an issue of course. It is particularly difficult I think when clients don't quite meet the eligibility requirements but their over-all adaptive abilities are very low. I know that this is taken into consideration, but I wonder about using IQ at all as a measure of need. Further, if a client does meet DD guidelines, they are apt to get decent funding, but the people who really fall through the cracks, are young people with mental illness who turn 18, have no where to go and no where to turn. They pose a risk not only to society, but to themselves. We really need to look at how this population is treated, and how we can better begin to provide appropriate funding for them. Unfortunately, we are usually looking at the cost of a staffed apartment, or something like that. We need to start looking at other living models for these young people that will allow them to continue to mature and live to their potential.	Jan 19, 2011 1:25 PM
142	Again, only after a fight. I think local and state agencies have made up the difference when it should have been DS who does the work. Maybe we are all learning as we go... but it is tough on the ones in front.	Jan 19, 2011 1:16 PM
143	There is inadequate funding availability for children. It appears the expectation is for parents to provide all or most of the care for their disabled children to the point of exhaustion, loss of income and sometimes to the point of being the alleged perpetrator of abuse/neglect.	Jan 19, 2011 12:53 PM
144	You have to know who to ask and follow the bouncing ball to get to the end of the line.	Jan 19, 2011 12:48 PM
145	What worked is going through the education piece and having it part of that plan. I will say, I transferred a DD child to Maine and they have enormous wrap around type services for the child and family!	Jan 19, 2011 12:42 PM
146	Chronic mentally ill with developmental disabilities have difficulty receiving services	Jan 19, 2011 12:38 PM
147	There is a lot of barriers in getting funding for youth with developmental disabilities. It seems that everyone that you talk to wants to hand the responsibility over to someone else.	Jan 19, 2011 12:38 PM
148	New to the state! (2 weeks)	Jan 19, 2011 12:37 PM
149	Not for children in intact families. Much easier for adults if the parents are willing to put the young adult out of their home. Respite services is not usable in its current format. Who can find someone to care for a very special needs child for \$10 per hour that can be trusted? Many of these children have breathing or feeding problems that make choking a chronic hazard.	Jan 19, 2011 12:16 PM
150	The most significant problem I have run into is a two part answer; am unable to connect with group, agency, etc. that deals with the specific issue or question. The specifications to qualify for services is too specific, not allowing for multiple disabilities, issues that need to be addressed which means either the person doesn't qualify for services or the service offered needs to be tweaked to meet true needs and policy doesn't allow any flexibility.	Jan 18, 2011 5:45 PM
151	VR Transition Counselors often express their frustration with obtaining DS services for youth they know of or are working with. If a youth is not eligible for DS services, VR is often the only other option.	Jan 18, 2011 12:53 PM

Page 2, Q2. Have you ~ and people you know ~ been able to get funding for needed services and supports?

152 We are not addressing need anymore. We are starting from a set budget without consideration of raising revenues to address need. That leaves many VTers without developmental services - people who could be leading productive, contributing and meaningful lives with some support and accommodation. Jan 18, 2011 11:58 AM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

1	Difficult to find and sustain employment supports.	Mar 26, 2011 1:03 PM
2	There is not enough coordination between providers of services. They don't seem cognizant of the urgency.	Mar 26, 2011 12:48 PM
3	Each group is trying to find employment. However the job market in VT is terrible. Employers are not hiring people w/ disabilities. Also working with Social Security is even more difficult. You can never speak to a worker.	Mar 26, 2011 12:41 PM
4	Constantly fighting for services (Voc. Rehab.)	Mar 26, 2011 6:41 AM
5	They are trying to find job for everyone taht fit & the support to keep people working. What they should NOTdo is cut funds!	Mar 26, 2011 6:32 AM
6	Transportation is difficult for someone able to be independent and have work without "support." Contributing to our staying "out of the system" is the demeaning attitude and presentation of service providers -- BAD experience w VOC REHAB worker!	Mar 26, 2011 5:45 AM
7	State employment office will not help = send you to VR: VR wants you in job but you can't live on pay- Equal pay!!! access!!! -- health care protection = Up Train !!!	Mar 24, 2011 10:36 AM
8	fair for non disabled, otherwise very diffucult	Mar 21, 2011 7:37 PM
9	onec again funding also need more active role b/w school, adult human services, and employment at a earlier starting. Less red tape clearer info, better info sharing. more seamless, long term thinking.No loss of supports because of age, or school.	Mar 18, 2011 7:26 AM
10	I hear that they are doing well but I really don't know. Someone I support has no job support and it's not in her ISA and I don't know why.	Mar 16, 2011 9:17 AM
11	Vermont and individuals with disabilities would benefit from an increase in employment options and support for participating in employment opportunities. Businesses also need support & incentives for providing employment opportunities for individuals with disabilities. We need to educate the employers as to the potential opportunities for everyone.	Mar 15, 2011 7:41 AM
12	When my son first came to Vermont I had a very hard time acquiring services and getting Jeffrey tested but in the past 3 years I have been more than pleased with the services and supports HCRS provides.	Mar 15, 2011 5:15 AM
13	Most areas are totally incompetent. There are a few good providers. Use their expertise. Stop wasting money on bad providers. Those with autism may need ongoing support - housing, transportation, job suport. Those with autism need to be placed in appropriate jobs rather than telling them to just go fill in an application. Stop wasting money on things the ASD person will never be able to do. Be realistic! Give the support level needed.	Mar 14, 2011 12:02 PM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

14	There are few jobs for people who have educational preparation, job history and experience. It is not always possible to have a JOB in the sense of payment for services. It is important to also consider jobs that are volunteer or training only. Doing productive activities and work is good for self confidence and self worth. Getting paid is nice, but doing meaningful work of any kind or type is better than walking the mall for hours. Job skills and training are about learning that doing something for a finite time, showing up on time, staying with it when it is not easy, and completing a task. We cannot expect employers to pay for services that are not up to the standard that other paid employees provide.	Mar 13, 2011 3:15 PM
15	A daily workshop designed specifically for the developmentally challenged where they could feel useful and productive	Mar 12, 2011 5:26 AM
16	Excellent collaboration between Developmental Services and Vocational Rehabilitation. In most cases funding is available to meet support needs, and service delivery seems adequate.	Mar 8, 2011 9:53 AM
17	I hear tough stories from families (esp Addison Co.) where there is little help to find AND KEEP jobs for even high-functioning young adults. Again, it may sound self-serving but VFN's Families Together group for families with young adults transitioning is the biggest help I've heard of.	Mar 7, 2011 10:29 AM
18	Ok now, but what happens when the 658 sped students reach 22? (See audit exhibit 2-2 pg 34). Will UCS be able to help these folks with work and daily supports? Need to develop programs with schools before age 22 on life skills and employment. Can the Governor smell what I'm cooking here!!	Feb 21, 2011 2:36 PM
19	Peopel need more individual supports in employment. Too many are either not working or work too few hours per week. The state needs to refocus on supporting individuals and assisting them in competeive employment.	Feb 21, 2011 11:47 AM
20	My disability and my community (from early childhood in lower Fairfield County, CT) is the reason that I am attempting to move to Burlington. The area. Two of my people - two of my friends, my community members - they were involved in my life and are vital reasons why I am now attempting to be near the University. It's weird - hard to explain. I hope that this move works well. IT's hard to explain. Why I am crying right now.	Feb 18, 2011 7:22 PM
21	There used to be a group work model that kept more people engaged in productive activity - individual programs do not seem to fill this niche and are much more expensive to carry out.	Feb 16, 2011 9:21 AM
22	I started working with a disabled boy more than ten years ago and was making 10.50 an hour. More than ten years later, I make 11 dollars an hour. How are we going to attract decent people to this field if we can't pay them decent wages?	Feb 15, 2011 8:24 AM
23	I cannot answer as I have not utilized this service.	Feb 14, 2011 3:06 PM
24	I don't have much experience with this service	Feb 14, 2011 8:13 AM
25	To many people are living below the poverty level and unable to afford decent housing or food. Jobs are scarce. Making it worse are the out of state second home owners that have driven property tax so high many Vermont'ers are loosing there homes.	Feb 10, 2011 11:48 AM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

26	special needs folks get more support, which is helpful, however people with criminal records need more assistance	Feb 8, 2011 2:14 PM
27	My son is in 8th grade - can't answer.	Feb 8, 2011 1:59 PM
28	The problem is that people are not working. We need job developmebnt, placement and OTJ along with various support options.	Feb 7, 2011 4:46 PM
29	Don't know how to rate this because I work mostly with kids. I am also sensitive to the fact that funding is low and jobs are scarce - still helping transition aged kids with disabilities find work seems to not be doing so well. Voc Rehab and DD services could use more \$\$\$\$ to help in this area. VR supports seems to be fewer and wider spread these days.	Feb 7, 2011 2:37 PM
30	We got Voc Rehab and Transition II, but they worked at finding a place to work, but did not have a good program or focus to help develop the needed job skills once the person was placed in the job. The support was present by phone and random meetings and the job quickly fell apart (twice)! More support on the job, with a method to identify the level of support needed and then staff trained to provide that support. IT is important to monitor staff too. Some are well meaning and nice, but overworked. WHat if you had something like "Americore" for people with DD who could participate in programs where volunteers are needed and blend the vocational training with more choices for creative jobs.	Feb 7, 2011 12:33 PM
31	My son did his job training while in high school and I thank god for that. When he graduated the Vocational Rehab was unable to assist him because of having a large number of applicants who needed assistance. I am grateful that the school worked with him and he was able to keep his job after high school (Burlington High School).	Feb 7, 2011 12:20 PM
32	More training	Feb 7, 2011 10:57 AM
33	Running out of funding has been an issue. Schools have been most helpful through interships and "work experience" in helping the kids to have a job	Feb 7, 2011 9:59 AM
34	Don't know.	Feb 7, 2011 8:29 AM
35	N/A - my son is a child	Feb 6, 2011 5:53 AM
36	Again difficult to access unless you are an adult or receieving services within the DS system.	Feb 5, 2011 4:23 PM
37	job info and retraining is offered often and in many different parts of the state	Feb 5, 2011 9:41 AM
38	we are not there yet	Feb 4, 2011 9:00 AM
39	we need more quality opportunities other than doing the garbage at burger king.	Feb 3, 2011 4:22 PM
40	for those of us with psyfical diaabilities creativity in the job market is limited to the VR counselor budget and knowledge more information would help on internet jobs	Feb 2, 2011 2:05 PM
41	I do not have personal experice with this, but I do know that there are several openings posted in the papers for job shadowers.	Feb 2, 2011 12:29 PM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

42	some poepl have em some people do not Voc Rehab is pretty useless	Feb 2, 2011 12:04 PM
43	-Services and supports of jobs is quite variable from school to school. -Funding is only available to people who meet the priorities of care after leaving school. - School personnel do not have the training in job development and job coaching; these positions may be cut when funds are cut. -Transportation can be a barrier to designing appropriate job training programs in school districts. -Getting students to jobs can be a substantial financial investment given the rural nature of the state. -Many services and supports that are being created use public dollars to segregate people with developmental disabilities from the general population still. Suggestions: -Public awareness of the importance of employment for people with developmental disabilities. -Limitations on how dollars are spent esp. on segregated programs and settings. -Funding for transportation and adaptations that increase job availability in local, regional, and state businesses.	Feb 2, 2011 11:53 AM
44	I have had many people complain about Voc. Rehab. services as well as transitioning youth not getting the help they need.	Feb 2, 2011 11:30 AM
45	Schools need to introduce students to volunteer work and jobs earlier (upon entering high school). There also needs to be more job training opportunities within schools and adult services programs.	Feb 2, 2011 11:07 AM
46	I was very lucky to be able to obtain PCA hours to help with respite for my son, however it took me very long to find a suitable PCA. I've known people who have lost some of their hours due to not having access to a PCA to provide all the respite they needed for a period of time. There are still many PCA's that don't necessarily have training to work with special needs children or adults but parents and families overlook that because there is no one else willing to do the work. The PCA I have now is a friend who is doing this to help me because he knows there is no one else who would do the job. Many of the past PCA's my son has had have ended up being family or friends trying to help. Because of the low wages offered for such a challenging job it's difficult to obtain and secure the needed population of skilled and dedicated workers needed to work with children or adults with high needs. Because there is no afterschool care that can meet my child's needs working full time has been extremely challenging to the point that I had to use FMLA to manage.	Feb 2, 2011 10:37 AM
47	Again, no sense of urgency on the part of VR. They see no problem with it taking a year or more to find employment and are satisfied with minimal hours.	Feb 2, 2011 10:32 AM
48	Unsure as our children do not qualify for these types of services currently	Feb 1, 2011 10:19 PM
49	My son spent almost 8 years dealing with almost totally incompetent vocational people until I moved him to another part of the state where there is someone who truly understands autism and is helping my son again be productive. If a person with autism has a college degree and sucessful work experience you would think that someone in Voc Rehab could help him do something. Nothing happened for eight years. They just had no interest or competence to do their job which was to help someone re-enter the job market. Need to hire competent people and KEEP them.	Feb 1, 2011 1:17 PM
50	I would say in general that the developmental disabilities are doing a good job providing jobs and employment supports. It seems like many people are not aware of the programs available to them sometimes like the ticket to work program, etc. Perhaps it's due to people hitting "walls" in the past?	Feb 1, 2011 12:49 PM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

51	Not sure I have enough to go on here - I know that a person from the VT Rehab/Disabilities talked to our daughter about post - HS, but she is college bound...yet, she has never had any kind of part-time or summer job. It would be a good experience, but I'm not sure this question is pertaining to someone in her situation.	Feb 1, 2011 11:13 AM
52	We have been pleased with the support of Lisa Allen from Dept. of Vocational Rehab. and very much so with Sherry Jones, transition specialist at Lamoille Community Connections. We, as a family, came up with the business ideas and wrote the business plan, but the supports to make it happen have been great so far. I do worry about who our son's job coach will be long-term and what kind of training they have to deal with a multiply disabled, medically fragile young adult. I also worry that our son will not get enough job coach hours to make his business successful	Feb 1, 2011 10:43 AM
53	I have a six year old and cannot comment on this question accurately.	Feb 1, 2011 7:09 AM
54	we have not encountered this yet but will be soon	Jan 31, 2011 5:03 PM
55	22 year old with Down Syndrome has on & off worked approx 5 years for free on "internships" for those with special needs.	Jan 29, 2011 4:48 PM
56	Overall, the movement and philosophy around employment is excellent by the AHS is excellent. However, the bar needs to be raised for Developmental Services and Mental Health programs providing supported employment. We all deserve to have dreams, and some of us need supports in fulfilling them.	Jan 28, 2011 10:13 AM
57	For my son not much help	Jan 28, 2011 9:58 AM
58	Vt family network and Howard center youth services are top notch care providers	Jan 27, 2011 4:24 PM
59	The economy has been very challenging, but the people here are great at recognizing the talent that the clients we work with have to offer.	Jan 27, 2011 3:34 PM
60	not great more communication needs to occur, voc rehab. is hard to work with.	Jan 26, 2011 4:42 PM
61	My son is not yet of employment age - do not yet have experience with this.	Jan 26, 2011 1:29 PM
62	It's hard enough for all of our neighbors in the job market in rural Vermont right now. Nobody really feels that they want to talk about jobs for the disabled.	Jan 26, 2011 12:43 PM
63	It's been challenging finding jobs during this difficult economic time. We have been fortunate to get some jobs through risk free trial work experiences. I'm concerned that the challenges might get greater when these funds are no longer available. During times when the economy isn't good, much more effort is needed to keep the team motivated to continue seeking employment for the client's they serve.	Jan 26, 2011 12:34 PM
64	Employment in most agencies is used as a cash cow to pay for upper management. The result is that this vital service is run on a shoestring. Employment funds allocated by Medicaid wavers should stipulate a lion share percentage that must be used for employment. Currently, less than 40% of Medicaid waver funds for employment are used for employment personnel.	Jan 26, 2011 12:07 PM
65	not sure on this one- my son is too young to get a job	Jan 26, 2011 11:19 AM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

66	The career center in Brattleboro has great programs for kids to have job skills up through high school. why not extend that for kids with developmental delays?	Jan 26, 2011 10:35 AM
67	I work for a supported employment program and feel that the services we provide are excellent. However, recent discussions indicate that employment may be on the chopping block in regard to upcoming budget cuts. I feel that such a cut would be a significant disservice to our clients as employment is an effective means to integration and community inclusion, not to mention there are other benefits to the individual, community members and government agencies when people are employed versus unemployed. I would like to see additional funding put into employment programs for people with disabilities so that the staffs working in these programs could receive the salaries that they deserve, and also so that more people can be served; everyone should have the opportunity to work and earn a living.	Jan 26, 2011 8:27 AM
68	My son is a pre-teen and I see little to no supports for him/us as he becomes an adult	Jan 26, 2011 8:04 AM
69	Hartford DS Employment has a HUGE success rate. Wish the rest of the state could follow in their example. Their office not only builds a trusting relationship with the individuals but they are there for their family, and employers as well.	Jan 26, 2011 7:21 AM
70	My family member with a disability (severe schizophrenia) has not been able to get a job and desperately wants one, but I think this is because he is extremely disabled in terms of being able to get along with and relate to others. Not sure the state can do much for one so severely afflicted.	Jan 25, 2011 5:08 PM
71	The agency I deal with is actually doing an excellent job by thinking out of the box. They have had especially good luck setting up small private businesses for the clients. However, all around the state, providers of employment services are faced with significant loss of standard kinds of jobs. As the economy has become more and more precarious and such employers as remain will not or cannot offer charitable employment. They are also trying to meet increasing need with decreasing staff who are offered level or diminishing pay. Any agency that does not have so creative a director as ours is going to be increasingly unable to meet its client's needs.	Jan 25, 2011 1:48 PM
72	Overall, Vermont has to be more open minded in these very difficult times, which are far from resolve by the way.	Jan 25, 2011 12:21 PM
73	Working with the schools and there employment programs for young adults aging out of school is most important and even as cuts at the state level and the down economy are always looming, they've managed to find promises of paid employment after graduation.	Jan 25, 2011 11:57 AM
74	As a service provider, we are not engaged in providing jobs although we have been approached to provide supervised work activities at the farm---this would be a good avenue for further exploration as many farm jobs are well suited to children and adults with physical, mental, social or emotional challenges.	Jan 25, 2011 11:19 AM
75	Programs and funding have been cut. Training and technical assistance from Brian Dague at CDCI has been cut. For people with more severe disabilities, nothing is happening. Voc Rehab never serves them, and no one seems to be paying attention to their potential as workers.	Jan 25, 2011 10:50 AM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

76	More support is needed. More funding is needed to provide needed support to a population that does not have the resources our ability to advocate well!	Jan 25, 2011 10:19 AM
77	This is an area I am just experiencing as a parent of an young adult with intellectual disabilities. Not only do the agency support limited but employment opportunities for people with disabilities is dismal in VT. We have been given hope of only 3-5 hours of employment as our son transitions for high school to work. This is an issue I've heard repeatedly when talking with parents of older adult children. People with disabilities need to have access to part and full time jobs (20-40 hrs) when they are able to work these hours. The state of VT needs to do more to actively change the attitudes of employers in VT. Maybe even give them some \$\$ incentives (is that too radical?)	Jan 25, 2011 9:00 AM
78	I know of a surprising number of adults with dwarfism who have found only low paying jobs or are unemployed. Those adults I do know have moved from out of state and were afforded greater options in schooling and employment. Often times I believe this is due to the lack of awareness on the part of our schools as to the need to reinforce skills to help "sell" a person with a "disability" as a viable employee and student. They just are not given enough life skills to meet the challenge of being both able and worthy.	Jan 25, 2011 8:36 AM
79	I feel VT developmental services has one of the strongest supported employment systems. Partnering with Voc Rehab has been successful. I am concerned about this new initiative derived from the Challenges for change within the Agency of Human Services. I believe it has the potential to defocus agencies from their mission of serving their specific populations	Jan 25, 2011 8:22 AM
80	Wanda is not able to work.	Jan 25, 2011 7:50 AM
81	this is an issue I feel has to do with employers. With the economy as it is, they are put in the hard position of consolidating their job needs with the minimal amount of employees. I don't have an answer, but that is where I see the issue lies. Employers are unable to give the split up a position and do so economically so a lot of the chores that our population used to do are now being rolled into one position which saves money for the employer. We need to, maybe, get incentives for employers who are willing to do that split-position situation so our people could have a job they can do and again feel good about themselves while being productive in their communities.	Jan 25, 2011 7:49 AM
82	I think we are better than many places but can still do better. Many of these individuals can do more than the basic cleaning and such and we should try to set higher goals and have more agencies in the area that work with them on training and such.	Jan 25, 2011 7:36 AM
83	I can't answer this because we are not in that situation yet.	Jan 25, 2011 6:35 AM
84	n/a	Jan 25, 2011 6:33 AM
85	just like industry, schools are cutting back budgets and supports in the classroom is where the cuts usually take place. We have lots of math specialists, science specialists... but the close to the kid money is what get cut and those are jobs, not even good paying at that.	Jan 25, 2011 6:15 AM
86	idk n/a	Jan 24, 2011 7:22 PM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

87	We don't know. The examples of successful outcomes tend to be from higher functioning clients. What is offered for the more challenging population?	Jan 24, 2011 6:40 PM
88	We need more supported employment for people who do not meet funding priorities Our supported employment programs needs to be proactive	Jan 24, 2011 4:24 PM
89	We are not there yet (my son is 11) so I cannot comment.	Jan 24, 2011 3:40 PM
90	I employ PCA through ARIS payroll and I do not feel there are any supports for me or that PCA.	Jan 24, 2011 3:32 PM
91	see above.....	Jan 24, 2011 3:06 PM
92	Voc rehab does not always follow through. They are also not very family centered.	Jan 24, 2011 2:19 PM
93	New systems have been put in place to support individuals that wish to work. Employment specialists from our agency works with VR and the local schools as partners to find employment for everyone. With the economy problems it is getting to be a challenge to find work.	Jan 24, 2011 2:11 PM
94	Individuals with disabilities are under to un employed. Most individuals are isolated. Lack of transportation is a huge issue.	Jan 24, 2011 2:08 PM
95	NOTHING is working. Our local designated agency/DS services and Voc Rehab Transition Coordinator either do not return phone calls or you wait forever to hear from them. We got very little in the means of supports or help when our daughter graduated. We did our own case management and helped her ourselves to find a job that gave her some supports. It was difficult to find the perfect fit for her.	Jan 24, 2011 1:58 PM
96	We have not had to look for jobs or employment supports yet. My son is 14.	Jan 24, 2011 1:52 PM
97	It's hard to know what is the result of a poor economy and what is the result of people who don't have time or desire to "get out there and beat the pavement" to turn up job leads. As I said earlier in this questionnaire, coordinatio of work-related transition and training between school and agencies is very poor.	Jan 24, 2011 1:37 PM
98	Not our fault. Low population is the good and bad with this area.	Jan 24, 2011 1:34 PM
99	Although I have not experienced obstacles myself (and it is too soon to know how my son will fare when he is of employment age), in my work as an advocate for individuals with disabilities, I have witnessed employment challenges (both failure to hire or failure to retain) for individuals with developmental disabilities.	Jan 24, 2011 1:32 PM
100	I literally had to apply for my job at the Ilsley Public Library in person. Eliminating all of the confusion & mis-communication that resulted in my Employment Counselor thinking that there wasn't even an available job in the first place...	Jan 21, 2011 8:12 PM
101	Urealistic goals and expectations. No middle ground.	Jan 21, 2011 10:19 AM
102	with monies being cut from support services, there has been major cut backs in both personnel and available hours for job support supervision.	Jan 20, 2011 9:37 AM

Page 3, Q1. How is Vermont doing in providing jobs and employment supports?

103	We continue to cut employment services to save money, this should be the opposite of how to do things we want more employment specialist working with the unemployed or underemployed to help them secure good jobs in return a employed person is less likely to need other government funded services.	Jan 20, 2011 6:52 AM
104	I can't say that I have a lot of experience with this but it does seem from what I can determine that we could do a better job with this.	Jan 19, 2011 1:34 PM
105	I think voc rehab is providing that service.	Jan 19, 2011 1:26 PM
106	While supports appear to be available for disabled persons looking for employment opportunities. I do not have direct information about which or how many employers are providing these opportunities as I have only directly observed 3 companies.	Jan 19, 2011 1:09 PM
107	My experience is limited in this realm.	Jan 19, 2011 12:54 PM
108	There are no jobs available at this time. Although for some kids, they are lucky and can work through the conservation piece/Jobs program.	Jan 19, 2011 12:51 PM
109	Those individuals that are motivated get the most support. The State needs more staff that are willing to knock on doors and help motivate people. More training needs to be provided to help casemanagers work with the ones that are not motivated.	Jan 19, 2011 12:45 PM
110	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
111	Just what does voc rehab do???? I have not seen any positive outcomes of folks getting training or skills or jobs. Vermont educational system is sorely lacking for kids with disabilities. They push kids through high school and graduate them into nothing. Too many kids get pushed along because they are a behavioral problem. The school personnel have no shame in handing a high school diploma to a youth who cannot read. What good is his diploma? It is meaningless. The youth needs to know how to dress, be on time, follow directions, keep hair and hands clean and have social skills to be able to hold a job. Have we done a disservice by mainstreaming?	Jan 19, 2011 12:28 PM
112	It works because it is a priority in adult services. It does not work well at all if your local school does nothing to assure a person is working before they leave school at 22. They leave without a need for employment support due to a lack of work and therefore do not receive services from DAs.	Jan 18, 2011 12:07 PM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

1	Social connections and networks of friends exceedingly difficult for most adults in their 20s. Flexibility in living options would help young people live in the community and hopefully build a social network.	Mar 26, 2011 1:03 PM
2	I need to get out, but everything is geared to senior citizens.	Mar 26, 2011 12:48 PM
3	Need more integrated social activities.	Mar 26, 2011 12:41 PM
4	companions don't want to work on weekends. won't take to parades, fairs, etc local events. Don't have money for special events. No transportation -- There should be transportation to fun events: movies, dinners, concerts	Mar 26, 2011 12:25 PM
5	Some supports available but not a variety.	Mar 26, 2011 6:41 AM
6	I have no idea what is going on currently.	Mar 26, 2011 5:45 AM
7	have a place for recreation, social, & other activities in Barre.	Mar 25, 2011 12:30 PM
8	Special Olympics, Special Needs Support Center, "Girl's Group"-provided by Hartford H.S. teacher.	Mar 25, 2011 12:14 PM
9	No money/funds for ski pass. Respite providers were cut. Due to our son's demanding medical treatments he is stable. Therefore he is not eligible for SSI & related supports & services.	Mar 25, 2011 12:09 PM
10	Non Profits had to pick this up! Many sites closed to disabled. State needs to stop putting price and liability tag on disabled!	Mar 24, 2011 10:36 AM
11	depends on your location in the state	Mar 21, 2011 7:37 PM
12	Local associations are doing better at that than "state" or DAs	Mar 21, 2011 6:18 PM
13	Grants usually help with this. So grant writing is extremely important.	Mar 18, 2011 4:23 PM
14	lack of funding, and restrictions on how to spend money.	Mar 18, 2011 7:26 AM
15	The community support hours are there for many individuals but options are repetitive and very few. There is a lack of connection for many individuals who share the need for community supports. Although there is a resource center in our area, the activities are not really geared for everyone and it has become boring for my client. Quality and consistency are definitely issues. Home providers and families need help to come together to create better opportunities.	Mar 16, 2011 9:17 AM
16	There seems to be limited support for individuals to participate in recreational, leisure and social opportunities. I believe this is due primarily to lack of funding. Additionally, increasing awareness of the need and ways to support and implement opportunities for increased options for recreation, social and leisure activities.	Mar 15, 2011 7:41 AM
17	My son's case worker actually provides bowling activities once monthly to all developmentally disabled adults on her own time.	Mar 15, 2011 5:15 AM
18	Next to no social and recreation supports for adults with autism in my area. When he asks for help he is told just to attend a NAMI meeting, there no other help.	Mar 14, 2011 12:02 PM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

19	Again, when considering children with disabilities the family often needs to rely on PCA's for support. Paying someone less than \$10 per hour does not attract skilled individuals who are able to safely manage a disabled individual so that they may access community supports. Further, finding someone to hire is difficult, at best. Since the only database with names of possible applicants requires a membership, it is largely inaccessible. (We are not allowed to pay for memberships to websites)	Mar 14, 2011 10:27 AM
20	Some programs seem to be working when the individual is considered in regards to interest, ability and availability of resources. Mall walking, sitting in a library looking at a newspaper (or not looking at a newspaper) while staff are chatting or reading on their own, is not social or active. Again, supervision is minimal and the tendency to put it 'on paper' and pretend it is happening is a constant.	Mar 13, 2011 3:15 PM
21	Not enough programs, need more social interaction, more recreation and leisure activities. I see a lot of boredom	Mar 12, 2011 5:26 AM
22	evenings and weekend coverage are a constant struggle, and unfortunately, that's when most social and leisure activities take place	Mar 11, 2011 2:37 PM
23	Financial support is needed to fund summer camps for teenagers. These kids need structured, fun programs to get them through the summer.	Mar 7, 2011 10:29 AM
24	Need for more affordable summer camps in south. Silver towers (Elks) ok, Camp kaleidoscope vegen and pricy, camp Maple Leaf pricey and only a daycamp. BART center limited to kayaking and hiking. Need more camps and social oportunities year round. No YMCA or Easter Seals in the South. No VFN in the south. (sorry Nancy R)	Feb 21, 2011 2:36 PM
25	Too much is left to individual home providers; there needs to be many different ways that an individual gets outinto the community if he or she is to have a truly integrated life.	Feb 21, 2011 11:47 AM
26	Gatherings once a month are important to this population. Also in Hardwick there are weekly community luncheons that are welcoming of the DS population and this is very positive.	Feb 16, 2011 9:21 AM
27	There is never an adequate budget available for activities.	Feb 15, 2011 8:24 AM
28	I did not know they provided such supports. No funding for summer camps & programs, adaptive programs, academic or training programs for those with disabilities through the State as far as I know, but again, this could be because no one has told me or I haven't discovered it myself yet.	Feb 14, 2011 3:06 PM
29	Where is this happening?	Feb 10, 2011 11:48 AM
30	As a family who lives in southern Vermont, there are few, if any, opportunities. When Holly Beatty's (sp?) position was cut, it cut the lifeline for many families to have activities.	Feb 8, 2011 1:59 PM
31	Not many recreational oportunities that I am aware of for my 6 yo who has trouble with mobility adn is non verbal.	Feb 7, 2011 2:39 PM
32	This is simply terrible	Feb 7, 2011 2:37 PM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

33	Doing a wonderful job with people in the lower IQ ranges. More difficulty with people in the higher grey areas. I don't know how to solve this. Wish I did.	Feb 7, 2011 12:33 PM
34	This again is where Howard Center comes into play! They provide me with the information about upcoming activities at the Resource Center and then I pass that information to my son's Community Access Person.	Feb 7, 2011 12:20 PM
35	Outside grants and school programs are doing better. But not all schools are willing to have adaptive programs and not everyone hears about the grants available.	Feb 7, 2011 10:57 AM
36	I know of no opportunities for kids on the autistic spectrum to have a supported social life.	Feb 7, 2011 9:59 AM
37	I don't know what might help or improve the situation but it seems that we could look beyond trips to other towns, mall walks and restaurant meals with paid support workers. Are congregate settings really that awful?	Feb 7, 2011 8:29 AM
38	Not sure what you mean, but we've had to advocate and reinvent the wheel for most of my son's community activities.	Feb 6, 2011 5:53 AM
39	Same barriers exist as defined above.	Feb 5, 2011 4:23 PM
40	The film The Blood in this Town about Rutland is really wonderful and needs to be shown more statewide. We need a bike path that connects the Western part of the state to Burlington's bike path.	Feb 5, 2011 8:55 AM
41	I have tried to find things for my child to do in our community .There is not much. I try to find age appropriate recreation ,social, and leisure. It is very hard because there isn't many children in my area. I wish we could start a club for teens with disabilities in this area. Probably in many areas!	Feb 4, 2011 9:00 AM
42	the c3 gives folks the opportunity to provide those supports that allow regulation to happen and more participation instead of these folks to live a life of the "observer".	Feb 3, 2011 4:22 PM
43	Limited resources or transportation to activity.	Feb 3, 2011 2:26 PM
44	I think part of the problem here is the availability of public transportation in rural areas to get individuals to work, recreational or social activities.	Feb 2, 2011 12:29 PM
45	it sure is alot harder when the flex money has dried up and we no longer have a goods budget	Feb 2, 2011 12:04 PM
46	-A new adapted bike program AMBUC VT Chapter is fund-raising for bikes that will enable any child or adult to ride with family and friends. This has a lot of potential for increasing healthy living and fitness but depends on fund-raising effort of volunteers. -Vt Adapted Ski & Sport is great as is VSA Arts. -Many services and supports that are being created segregate people with developmental disabilities from the general population still. Suggestions: -Public awareness of the importance of rec/leisure and fitness for people with developmental disabilities. -Limitations on how dollars are spent esp. on segregated settings. -Funding for transportation and adaptations that increase participation in local and regional recreation and leisure activities.	Feb 2, 2011 11:53 AM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

47	One of the biggest barriers to participation in leisure activities is facilitation from neurotypicals (and interaction with neurotypicals) and transportation to such activities.	Feb 2, 2011 11:07 AM
48	I think there are some cool and interesting opportunities available mostly for short seasons. Not sure why but my family still feels very disconnected. Not sure how this could be resolved. It seems as though the activities are in small pockets. Children on the autistic spectrum require regularity and routine. I would like to see a few programs that are long term as throughout the school year. Perhaps something connected to afterschool programs that offers recreational, social, and leisure activities on a regular basis to establish that sense of grounding in the community for people with special needs who so often feel marginalized.	Feb 2, 2011 10:37 AM
49	There could be more done, a lot of responsibility is left to families who have limited resources.	Feb 2, 2011 10:32 AM
50	n/a...we have friends who provide day services for an adult with developmental delays and they are pleased with the support they have received via Sterling agency they work with.	Feb 1, 2011 10:19 PM
51	There are no social or recreational activities for my son with autism. State needs to develop social training and activities. State needs to hire competent people and keep them.	Feb 1, 2011 1:17 PM
52	Special Olympics, Vermont Adaptive Ski Program, etc are good programs Recreation programs should be offered some assistance/advice on ways to include all populations in their programs. Schools should be more apt to do peer programs for social activities where peers and differing abilities have the opportunity to do events like bowling, skiing, etc.	Feb 1, 2011 12:49 PM
53	What Vermont has going for it is a beautiful state that values family recreation and neighborhood communities. We have had a good experience in our community. However, any time I have sought anything for us/my daughter regarding ASD/aspergers ... it has NOT been available. It seems this level of ASD is well hidden ... people function "well enough" ... but sometimes, you know that things would be better if you could just talk, or if your child could know that she is not the only one that thinks this way, experiences life this way. Perhaps it's the fact we are a small state w/ rural communities ... unless you live in a city, it seems hard to find/network individuals that have similar challenge. Therefore, if you would like to create a social/recreational network - you just don't have the quorum. As a whole - we have done fine in this area because we do live in a small rural town that values individuals/family. I feel fortunate. If the community was less accepting, or if our daughter presented w/ more extreme needs, I think we would have had much more stress in this area.	Feb 1, 2011 11:13 AM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

54	Our son loves to swim and swims at the local "Swimming Hole" in Stowe. The lift to get him out of the pool is old and rusty and I pray every time that we use it (3 to 4 times a week) that it works!! The adaptive ski program at Stowe has been excellent. The accessibility into area restaurants and shops remains difficult for an individual in a wheelchair! The recreation path in Stowe is great for walks using a wheelchair. We have found several accessible trails (or relatively) nearby including the View Trail at Camel's Hump State Park, but I would love to know of more possible options. There are quite a few social opportunities available through Lamoille Community Connections and Vt. Center for Independent Living.	Feb 1, 2011 10:43 AM
55	There really aren't many.	Feb 1, 2011 8:19 AM
56	I am not sure what this question is referring to; again my daughter is 6. I am pleased that she is in a regular classroom with an aid five days a week. My personal care attendant helps her participate in leisure activities like going to the library.	Feb 1, 2011 7:09 AM
57	I don't know what is out there and I don't have the money to pay for recreational activities.	Jan 31, 2011 5:03 PM
58	I help find my son community supports because after almost 5 years in the St Albans area, no agency or group or individual has come forward to OFFER . Agencies are not in touch with the people and communities they serve.	Jan 29, 2011 4:48 PM
59	Again, it is a matter of wages. If workers were paid more then there would be more support.	Jan 28, 2011 6:07 PM
60	Families First in Wilmington has a most excellent program. I'm not aware of any other like it.	Jan 28, 2011 3:05 PM
61	Need to work on Community building. Be more CREATIVE and open regarding housing options.	Jan 28, 2011 10:13 AM
62	Had to find our own respite	Jan 28, 2011 9:58 AM
63	Support workers do a great job accessing the community.	Jan 27, 2011 3:34 PM
64	Here in Orange County most social activities for people with disabilities are geared for people much older than my 10 year old son. Finding groups for kids his age always means lots of travel which often isn't possible for us. It would be great if there was a regular playgroup for kids with disabilities in his age bracket. He feels so much more comfortable with other kids with disabilities than he does with typical kids.	Jan 26, 2011 1:29 PM
65	I can't see that it's really a Vt. supported thing. It more seems like just local people with access to pools,fields for playing ball, bowling agreeing to let some of their neighbors with disabilities use their facilities. Sometimes because they don't understand these same disabilities it doesn't always work out.We've had issues and it's been hard for the children. They don't understand what they do isn't always acceptable. As parents or grandparents we want our kids to be able to do some of the fun things that we did as children.Now times being what they are that isn't always possible. The funds are not there,The personel are stretched to the limit.	Jan 26, 2011 12:43 PM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

66	We are fortunate to have a resource center with a director that is creative and offers lots of recreational activities for our clients.	Jan 26, 2011 12:34 PM
67	Similar to employment, community support funding is largely used to pay for upper management. Medicaid dollars should stipulate a percentage that is available for overhead costs leaving the lion's share to provide the service it is intended for.	Jan 26, 2011 12:07 PM
68	I have never heard anything about recreation, social and leisure activities...	Jan 26, 2011 11:19 AM
69	The only supports I see is through programs like families first.	Jan 26, 2011 10:35 AM
70	Again, more funding to pay staff a livable wage would be so helpful in retaining quality staffs would be greatly helpful.	Jan 26, 2011 8:27 AM
71	There are a couple of recreational activities, but they are location driven and not accessible for all VTers	Jan 26, 2011 8:04 AM
72	Cutting staff is making community hours are to fill.	Jan 26, 2011 7:21 AM
73	Not sure, as my family member rejects most efforts to help him.	Jan 25, 2011 5:08 PM
74	this seems to be completely dependent upon where one lives.	Jan 25, 2011 4:06 PM
75	I can't speak for the whole state, but I feel very fortunate to be in Franklin County where Betty Morse and the Vermont Family Network is very strong. Our local community recreation department has also been very accepting of our daughter and including her in regular programming.	Jan 25, 2011 2:35 PM
76	Budget cuts have required cuts in hours of services to clients, cuts in staff and an 8 hour per week cut in the hours the remaining staff can work. Such staff as are left, are have had level pay which equals loss of pay as health insurance has gone up while providing less coverage. When staff replacement is allowed, it is difficult to find workers as they can't afford to work at our agency.	Jan 25, 2011 1:48 PM
77	Vermont has made budget cuts across the board, so these activities are also cut back .	Jan 25, 2011 12:21 PM
78	It's really an Agency by Agency effort to find creative , fun and positive activities for the Special needs population in their communities. Some agencies fare better at it than others.	Jan 25, 2011 11:57 AM
79	Being with horses means you are outdoors, away from computers and food, and engaged in physical activity; therapeutic riding is an excellent way to support exercise and healthy leisure and recreational choices for all citizens.	Jan 25, 2011 11:19 AM
80	Once again, our situation may be better than the average person because we have a good waiver and an excellent support worker.	Jan 25, 2011 10:50 AM
81	They have done a great job with the few resources available.	Jan 25, 2011 10:19 AM
82	There are a lot of services out there	Jan 25, 2011 9:24 AM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

83	It's not working - too many adults are sitting home alone or in some isolated activity being held by some support agency. VT needs to do more to support inclusive recreational opportunities. I know that some parents have taken this issue on themselves to create opportunities. Where is the state of VT for them?	Jan 25, 2011 9:00 AM
84	I feel the supports are there for extensive needs children but not for children who would not benefit from being in an environment where mental challenges are not the issue. Obesity in dwarfism is a major contributing factor to early onset pain issues and early death. This should be a major point of assistance for children with dwarfism.	Jan 25, 2011 8:36 AM
85	I would like to see more community natural supports developed. I think in order to do that staff have to be available at any day and time in order to develop meaningful activities and relationships. For example; if a person would like to attend church every Sunday morning that should be part of a day program. The mission would be to develop the supports in the community so that staff can eventually fade out of that obligation.	Jan 25, 2011 8:22 AM
86	She gets out into the community almost every day with swimming and bowling and shopping.	Jan 25, 2011 7:50 AM
87	I had an example of this recently. My son is Developmentally Delayed and is going to High School next year. He has a High IQ and is Verbal but has PDD-nos. After school time is a challenge and I was told by the local teen center that they can't have him there after school because he will be in High School unless he wants to volunteer to socialize as a volunteer. That is his biggest deficit. The parks and rec's departments don't do much in the High School Ages and the Schools don't help much either. So in order to have programming after school for a teen with DD, you have to make your own or use mental health services which makes them stand out instead of being in an inclusive environment with their peers.	Jan 25, 2011 7:36 AM
88	fine if you live in communities, but if you are rural transportation is very limited.	Jan 25, 2011 6:15 AM
89	It seems to me that once you are out of high school supports just drop off especially for recreation and social activities. Caregivers have to be creative and constantly on the look out for opportunities. I worry about the people whose caregivers do not have the time or the inclination to do research and find the few activities that are available/ I am sure that those people spend lots of time at home alone.	Jan 25, 2011 5:32 AM
90	tight budget. if your person is unable to work, VT does not have a high value on recreation, social and leisure activities.	Jan 25, 2011 5:09 AM
91	Huh? recreation? social? leisure? activities?	Jan 24, 2011 7:22 PM
92	We don't know. It appears self initiated by families. Would be great to have a menu for this too, show families what to expect.	Jan 24, 2011 6:40 PM
93	Many support workers only work during the week, most leisure and social activities are on weekends or after hours, mich makes it hard to support an individual who wants to participate. Special Olympics in my county also struggles with this, as service providers are often not willing to transport or support an individual after hours. It would be great to have support workers who could work evening or weekend shifts	Jan 24, 2011 4:48 PM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

94	We have individualized services but due to budget cuts agencies have gone to day programs. Spend more money on Self advocacy.	Jan 24, 2011 4:24 PM
95	High Horses in Wilder, VT is excellent (though costly). We also have used the New England Handicapped Skiing Association services (based in NH), and that is excellent as well (and costly). No town recreation programs accommodate our son--they group kids by age and not skill level and our son cannot keep up with his peers. We do our best to include our son in family recreation, but we are limited by our abilities to independently support his needs. I wish there were a program to help disabled kids learn to bicycle. I wish there were a program to teach disabled kids to train dogs (and build skills) and take care of pets. I wish there were low-cost facilitated social skills groups that would teach social skills and include both children with social skill deficits and "typical" children. I wish there were training courses to teach teenagers how to babysit children with special needs.	Jan 24, 2011 3:40 PM
96	Local Montpelier Rec dept offices are not accessible. Pool has no accessible bathrooms. Adaptive sailing program in Burlington is expensive. There are few community sponsored social, rec or leisure activities for children who use wheelchairs unless it is in a school building.	Jan 24, 2011 3:32 PM
97	Never heard of this type of support, except for those on a waiver, this is needed for everyone with a developmental disability. Lack of social connections with peers and social activities are one of the largest problems in working with this population. If you are not in the few slots for a waiver, then it is likely that social isolation is a huge problem. The correlation of social isolation with increased depression is well documented, as well as noncompliance with treatment and declining physical health, thus the lack of these social/recreational supports cause a greater burden on the financial system in the form of long-term medical costs. The situation would be improved if community supports to social/leisure was acknowledged to be as important to health as medical appointments and medication. The need to acknowledge the person holistically takes courage on the part of the state. Committing resources to social/leisure engages individuals in the community and may allow a greater system of natural supports and thus less of a dependence on funded supports.	Jan 24, 2011 2:30 PM
98	With the current budget cuts community services have been eliminated for many consumers. Our agency does try to work this out with the developmental home providers to help with supporting consumers to participate with community recreation and social events in the community.	Jan 24, 2011 2:11 PM
99	Organizations like VASS and Special Olympics and Partners in Adventure are great.	Jan 24, 2011 2:08 PM
100	Laughing here.....	Jan 24, 2011 1:58 PM
101	Children's Personal Care works well if you are in the C3 program. Trouble is finding qualified people willing to work without benefits. Also need to find accessible activities. Many businesses are still not accessible.	Jan 24, 2011 1:52 PM
102	Special Olympics in our area is a hit or miss thing. Either you know everything or you know nothing. It's hard to get information about when/where/etc. Once you're plugged in, it's great.	Jan 24, 2011 1:37 PM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

103	For children on medicare this area works. They do not have profecient medical care but there does seem to be respite support for medicaid eligible families. I also have to say that UVM has wonderful support for students with disabilities.	Jan 24, 2011 1:34 PM
104	The idea of inclusion in organized recreation and social events and activities has not yet caught on. People still seem to fear it - to be afraid of liability of one sort or another.	Jan 24, 2011 1:32 PM
105	Grants for disabled people to learn things like pottery at the Frog Hollow Studio School. Offering more classes like that would help people to learn new hobbies & interests.	Jan 21, 2011 8:12 PM
106	Need trained.... I mean really trained people with structured activities. It is an embarassment the lack of training and trips to cumberland farms or McDonald which count as community involvement.	Jan 21, 2011 10:19 AM
107	Many of the community supports are being supplied by volunteers as well as self advocates. These work as long as there are advisory staff avialable but again, these staffing positons have been reduced in state budgets.	Jan 20, 2011 9:37 AM
108	I can't think of to many places that offer such oppotunites without cost. we do a very poor job of advertising such programs.	Jan 20, 2011 6:52 AM
109	There are limited programs, or programs that aren't accessible to those who live rurally. For children with autism, the spectrum of abilities is so great that often you find children with really high demands teamed with children who have greater functioning. Schools are not equiped to provide an education to special needs children and segregating them out to independent programs is not good as it limits access and opportunities. It is also difficult to access social activities due to a lack of information about what to expect or anticipate for space and support. There is a cost associated with some services, such as adaptive programs for music.	Jan 19, 2011 2:09 PM
110	As compared to others in need, by and large folks with developmental disabilities have cadillac services.	Jan 19, 2011 2:00 PM
111	I believe that part of the difficult with all of these things is finding staff and paying them properly to do these jobs.	Jan 19, 2011 1:34 PM
112	Community activities happen only when there is enough support - if a parent or caregiver is capable of dealing with issues that may come up, then it works.	Jan 19, 2011 1:26 PM
113	Disabled adults who are eligible for benefited (salary/medical/etc) staff -managed by an agency- receive better services as private family members who are required to self employ have more difficulty finding providers and struggle to "fill" their family members "hours" when their "staff" call out due to illness/personal reasons/vacation etc.	Jan 19, 2011 1:09 PM
114	If you have access to a newspaper or websites you can find out about many more supports that have been created for folks with disabilities.	Jan 19, 2011 12:54 PM
115	If in general for the average child there are some community supports. For a DD child there are minimal that have the ability to handle some of the behaviors or have the patience needed.	Jan 19, 2011 12:51 PM

Page 3, Q2. How is Vermont doing in providing community supports to participate in recreation, social, and leisure activities?

116	Like many of our programs. This is usually the one that has the least funding and staff to support	Jan 19, 2011 12:45 PM
117	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
118	We do better than most states but are backsliding into congregate settings. Training is terrible to non-existent. The only light is GMSA.	Jan 18, 2011 12:07 PM

Page 3, Q3. How is Vermont doing in providing transportation and related supports to hold jobs and participate in social and leisure community activities?

1	Within Chittenden County possibilities are better. Rural & town settings almost impossible, outside families' efforts.	Mar 26, 2011 1:03 PM
2	Transportation is always a problem. Accessible transportation is almost nonexistent in rural VT.	Mar 26, 2011 12:41 PM
3	Medicaid only pays for medical visits. No transportation -- there should be transportation to fun events: movies, dinners, concerts.	Mar 26, 2011 12:25 PM
4	Not always available to transport. Makes it difficult to hold a job.	Mar 26, 2011 6:41 AM
5	We don't have any	Mar 26, 2011 5:53 AM
6	Difficult to arrange -- Limited time of service. For instance: Moives open early evenings, no transportation Transportation is difficult for someone able to be independent and have work without "support."	Mar 26, 2011 5:45 AM
7	Daughter is transported to work by Dev. Home provider. Parents transport to Spec. Olympics, * Art Lesson, * Cooking Classes *provided by Spec. Needs Support Center Leb. NH	Mar 25, 2011 12:14 PM
8	Transportation is not reliable (bus)	Mar 25, 2011 11:56 AM
9	Not one system works: SSTA holding list for Medicaid not good: We used right to be able to call curb service 24 hours	Mar 24, 2011 10:36 AM
10	rural Vermont is a problem and gas prices have only made thing much worse	Mar 21, 2011 7:37 PM
11	OK if you are in 'city" rural areas not so much!	Mar 21, 2011 6:18 PM
12	My experience is with afterschool programs (21 Century at Bellows Falls Middle School) and they bus the kids home.	Mar 18, 2011 4:23 PM
13	lack of funding impacts everyones ability to help support individual. Also lack of public transpouation. If a client has a job, and they lose funding they probably will lose their job. it make individuals look unreliable. lack of reliable support people	Mar 18, 2011 7:26 AM
14	There is no transportation funding for community support workers so it makes the job undesirable for many. It's already too low of pay and too few hours to find and keep consistent people.	Mar 16, 2011 9:17 AM
15	I have not had personal experience with public transportation, but individuals who rely on public transportation due to disability related issues, I have heard that there is not adequate or flexible public transportation options especially in the Rutland and rural VT areas.	Mar 15, 2011 7:41 AM
16	My son was taught the bus system and has effectively made use of it for coming and going to work.	Mar 15, 2011 5:15 AM

Page 3, Q3. How is Vermont doing in providing transportation and related supports to hold jobs and participate in social and leisure community activities?

17	Need more transportation services. Many with autism just can't deal with multiple things like living alone, working without support and taking a bus. The RCT ride service works well but there needs to be more flexibility such as emergency transportation. Son had to leave doctors appointment before seeing doctor because ride was waiting or friend lost job because he refused to work overtime (no advance notice given) and would have had to walk home 6 miles in the dark. Need good transportation supports.	Mar 14, 2011 12:02 PM
18	There is little available for families in rural areas	Mar 14, 2011 10:27 AM
19	Not enough funding not enough supports, the supports that are in place are great, but again not enough of them	Mar 12, 2011 5:26 AM
20	we are a rural state - transportation is an issue	Mar 11, 2011 2:37 PM
21	Extend public transportation. Rural areas suffer from no transportation to jobs. What about a volunteer corps to drive disabled adults to their supported jobs?	Mar 7, 2011 10:29 AM
22	There is a bus in Bennington for now, and is needed and necessary in winter.	Feb 21, 2011 2:36 PM
23	Medicaid transportation has gotten stricter and that may be alright, but there needs to be alternative ways for non-drievrs to get to work and to get from place to place that allow more freedom to participate in a wide variety of community activities. Bus vouchers would be desirable in some areas and in others perhaps a better network of volunteer drivers would help.	Feb 21, 2011 11:47 AM
24	hope	Feb 18, 2011 7:22 PM
25	Transportation is a huge barrier for families in this State.	Feb 17, 2011 1:25 PM
26	Doesn't seem that they even exist.	Feb 16, 2011 9:21 AM
27	Please see answer to question 2.	Feb 14, 2011 3:06 PM
28	It is hard to get funding for mileage at times in a rural setting to pay staff for community supports.	Feb 10, 2011 9:07 PM
29	Most of our clients are unable to get transportation to their medical and counseling appointments let alone transportating for leisure activities. ROSC meetings have brought up the transportation problem as one of the things they will consider in their next meeting. They meet every 3 months and have met twice and have not started to provide any support yet.	Feb 10, 2011 11:48 AM
30	No transportation needed	Feb 8, 2011 1:59 PM
31	I don't know what I would do without SSTA (Special Services Transportation Authority)!!! They have enabled my son to have some sense of independence but still be protected while traveling to his job and back. Without their assistance he would be unable to work as he does. I work a full time job and would be unable to take time off to provide transportation myself! Thank GOD for SSTA!!!	Feb 7, 2011 12:20 PM
32	No info.	Feb 7, 2011 9:59 AM
33	Don't know	Feb 7, 2011 8:29 AM

Page 3, Q3. How is Vermont doing in providing transportation and related supports to hold jobs and participate in social and leisure community activities?

34	Not sure what you're asking. We use SSTA through a contract with school to get my son to school, but no other supports as we have an adapted van and he's a child.	Feb 6, 2011 5:53 AM
35	Our BUS in Rutland sends out the para-transport to all the rural areas of our county	Feb 5, 2011 9:41 AM
36	need more transportation support.	Feb 3, 2011 4:22 PM
37	Vermont is not very wheelchair friendly	Feb 3, 2011 2:26 PM
38	Rural Areas need more public transportation to be able to adequately provide this service	Feb 2, 2011 12:29 PM
39	transportation is #1 issue	Feb 2, 2011 12:04 PM
40	Transportation is less available in rural areas. Many families are not able to transport their children to recreation/leisure event and may need personnel to support these experiences. My experience is their is a broad range of experiences. Those families who have the personal resources to seek out transportation and supports and/or have knowledgeable teams working with them tend to have more services. Access to the internet and cell phone coverage is variable. Suggestions: -Expand public transportation options - Training for personnel to support families -Broad band available in all parts of the state	Feb 2, 2011 11:53 AM
41	Funding would help but we all know there is no money.	Feb 2, 2011 11:07 AM
42	I am not familiar with this aspect of services yet. I drive my son everywhere. His school has done a great job in helping him be successful on the school bus however.I have been very impressed with their detail orientation to his needs to the point that now he can be successful with minimal support on the school bus. I can't say that this would be the same in every district. I feel we are very lucky to be in a great school district but there are discrepancies throughout the state from what I've heard from other parents. Perhaps some unified state wide practices would be a good place to start. I currently have to move to a different town in Vermont but I'm terrified of what the school district to move to because of the school district differences in addressing special needs.	Feb 2, 2011 10:37 AM
43	Most Vermont communities have inadequate transportation options in general and less so for people with disabilities.	Feb 2, 2011 10:32 AM
44	We receive compensation for medical appointment travel which is significant between our two boys and is helpful in defraying the actual cost.	Feb 1, 2011 10:19 PM
45	Most care givers and COS's don't get compensated for their milage!	Feb 1, 2011 1:41 PM
46	Only now after more than nine years is my son getting transportation help and that is after years of asking for help and this help is not from DD but mental health.	Feb 1, 2011 1:17 PM
47	Transportation is a very unmet need in Vermont. Buses can be very difficult to accomodate and schedule and many times free transportation is very medical appointments only.	Feb 1, 2011 12:49 PM

Page 3, Q3. How is Vermont doing in providing transportation and related supports to hold jobs and participate in social and leisure community activities?

48	The Bus and the ACTR (name?) transportation network is very valuable. We have used this a bit to get our daughter to/from a class in Middlebury. At times, I wish there were more runs throughout the week.	Feb 1, 2011 11:13 AM
49	Our son is just graduating form high school this spring, so not sure of this yet. We have been mainly responsible for providing transportation to social and community events. The school system does help with either busing or RCT as able.	Feb 1, 2011 10:43 AM
50	Again, I cannot answer this.	Feb 1, 2011 7:09 AM
51	N/A	Jan 31, 2011 5:03 PM
52	I am able to get transportation for a job my son has - 2 days a week - 2 hours each day. Transportation for any other activity or event has to be privately arranged..."no one available"... We only live 6-1/2 miles from exit 20 St Albans but can't seem to get enough agency assistance for transportation for any other social or recreational activities.	Jan 29, 2011 4:48 PM
53	Some areas have great bus service. Most communities do not. Collaborative funding may be one answer - provider agencies, pubic transportation companies, VR, etc. pooling their resources.	Jan 28, 2011 10:13 AM
54	Never offered help	Jan 28, 2011 9:58 AM
55	SSTA has been a great addition in the transportation world. The company continues to grow and our clients are very fortunate to have this service. This service provides independence and reliability and a safe commute.	Jan 27, 2011 3:34 PM
56	In Randolph we have the StageCoach - thank goodness!! This is a great service.	Jan 26, 2011 1:29 PM
57	Most of the time it is left to the parent to get them where ever if they want the child to participate. If you have more than one child with a disability sometimes thats impossible.	Jan 26, 2011 12:43 PM
58	We're more fortunate in the Burlington area with public transportation. Obviously this isn't the case in other parts of the state.	Jan 26, 2011 12:34 PM
59	Vermont is a rural state. As such it is a challenge to find transportation to reach clients. Currently, a community support worker is needed to be hired to provide transportation due to the inability for Medicaid and state dollars to pay for transportation. Even a modest amount of transportation funding would be well spent because it would drastically reduce the need for community support assistance which is comparatively expensive. Particularly affected is work transportation.	Jan 26, 2011 12:07 PM
60	my son gets transportation 3 days after school. this is good. see above comment	Jan 26, 2011 11:19 AM
61	I drive my child everywhere..if there was transportation available to get him to a job site..I d be thrilled.	Jan 26, 2011 10:35 AM
62	Medicaid bus passes for CCTA in burlington is very helpful. Also funding for SSTA is helpful in allowing people to access thier communities more readily and with greater independence.	Jan 26, 2011 8:27 AM

Page 3, Q3. How is Vermont doing in providing transportation and related supports to hold jobs and participate in social and leisure community activities?

63	No transportation services only local buses	Jan 26, 2011 7:21 AM
64	Not sure	Jan 25, 2011 5:08 PM
65	Green Mountain Community net is doing a good job for us.	Jan 25, 2011 1:48 PM
66	Transportation is also affected by these cuts, local volunteer groups are trying to provide as much support as they can.	Jan 25, 2011 12:21 PM
67	transportation has always been an issue for the different Agencies to deal with and there should be an effort to establish more options for Agencies to choose from for the transportation needs of there populations.	Jan 25, 2011 11:57 AM
68	Transportation is an ongoing difficulty; many people would like to use our services but have trouble getting their students to the farm in Middlesex.	Jan 25, 2011 11:19 AM
69	This is an ongoing challenge for people who want to travel, especially if they want to do it outside of regular working hours.	Jan 25, 2011 10:50 AM
70	Because of the rural nature of the state transportation is always a challenge. Buses are seldom available and folks need to rely on community supports, which is limited.	Jan 25, 2011 10:19 AM
71	Transportation is very limited and is often not available when needed.	Jan 25, 2011 9:00 AM
72	I feel more should be done.	Jan 25, 2011 8:36 AM
73	Transportation continues to be an employment barrier for individuals. The rural nature of where we live limits transportation opportunities. I dont have the solutions for this one, but would like to see more development and attention to this subject.	Jan 25, 2011 8:22 AM
74	They provide provide transportation top the facility. and back home, but do not always provide it to the respite workers residence.	Jan 25, 2011 7:50 AM
75	Again, this is a funding problem that I have no answer for.	Jan 25, 2011 7:49 AM
76	Unless you are in a wheel chair or unable to function enough to ride a bus (which sometimes they determine but appearance), there is no transportation. Having a 1:1 isolates kids/teens from others also.	Jan 25, 2011 7:36 AM
77	I'm not sure as we have not had a need to use this.	Jan 25, 2011 6:35 AM
78	I work with children with disabilities in a community that is rural. Preschool children who do not have a vehicle or driver can not access public preschool like other kids can and they are the ones that need it the most.	Jan 25, 2011 6:15 AM
79	My son does get a ride to work. If he didn't, he would not be able to get there. There is no transportation for social or leisure activities.	Jan 25, 2011 5:32 AM
80	idk n/a	Jan 24, 2011 7:22 PM
81	Again could be those that don't receive adequate services voice them but we need to see how its done. Transparency.	Jan 24, 2011 6:40 PM

Page 3, Q3. How is Vermont doing in providing transportation and related supports to hold jobs and participate in social and leisure community activities?

82	Transportation was a continuing issue for my daughter. School support staff often was told that they couldn't transport in their own vehicles, school transportation wasn't available. See my comment about Special Olympics in the previous box	Jan 24, 2011 4:48 PM
83	Burlington needs ticket to ride. We need to have more buses in the rural parts of the state . like Calis, Worcester, northfield , Randolph etc. The buses need to go into the cities. Gives high gas prices its time for the state to spend for money on public transit. Unless you live in the city public transit is very limited.	Jan 24, 2011 4:24 PM
84	Not applicable	Jan 24, 2011 3:40 PM
85	Local bus route will do deviations during the day hours. There is no accessible taxi in Central VT. School provides accessible bus for school related events.	Jan 24, 2011 3:32 PM
86	Opportunities for employment are extremely limited for those without the financial means to have a car or for those who are unable to physically drive. If you live off a busline, you are out of luck, and that is a huge percent of Vermont's population. If the infrastructure of public transportation cannot be increased in rural areas of the state other options may be tried; a match service for volunteers providing transportation--incentives for private individuals to do so. Why does Medicaid pay for medical appts yet there is no source for transportation to employment. People are staying in their homes collecting SSDI. Isolation reduces options and goals for individuals.	Jan 24, 2011 2:30 PM
87	If they have the available staff to do transporting then the person may hold a job or participate in community activities. Reliability of staff is an issue.	Jan 24, 2011 2:19 PM
88	With budget cuts many consumers were faced with transportation cuts. Everyone who works will be provided with transportation but very few have enough mileage to cover community activities.	Jan 24, 2011 2:11 PM
89	I am not sure that I agree that Vermont should be paying for transportation to social and leisure community activities. They are doing okay in providing transportation, so I hear from others. We provide our daughter with transportation.	Jan 24, 2011 1:58 PM
90	There is NO Funding for Van modifications.	Jan 24, 2011 1:52 PM
91	Not sure how Vermont is doing as a whole, but in Addison County, transportation is a BIG issue. Often the ACTR bus means well, but the schedule is not consistent and does not always go where the worker needs to go when they need to go. Hard to coordinate a schedule with inconsistent transportation.	Jan 24, 2011 1:37 PM
92	For those with significant disabilities and low income it works. There are MANY families hurting and caring for their own after having burned out with medical care available.	Jan 24, 2011 1:34 PM
93	ACTOR & ACTRA appear to be working great. It would be nice if there was a train going from Middlebury to Burlington on the pre-existing line. The Link that buses people up to Burlington only leaves & arrives either really early in the morning or very late in the afternoon: it would be nice if it ran more frequently instead...	Jan 21, 2011 8:12 PM

Page 3, Q3. How is Vermont doing in providing transportation and related supports to hold jobs and participate in social and leisure community activities?

94	fine. That is not the problem. Real jobs that are based on abilities and functioning levels. And social activities that are structured and supported with trained individuals and based on actually functioning levels.	Jan 21, 2011 10:19 AM
95	Transportation is limited to larger communities if families reside in rural communities.	Jan 21, 2011 8:30 AM
96	This is a major problem and issue for folks that live remotely from village centers. Volunteer drivers and support persons are not always a reliable source for transportation services.	Jan 20, 2011 9:37 AM
97	A think Vermont does a fair job with public transportation and community action buses to the urban areas of Vermont.	Jan 20, 2011 6:52 AM
98	RCT often does not keep appointments to pick up clients.	Jan 19, 2011 2:19 PM
99	Transportation is a significant hurdle. Parents are often expected to be the responsible parties for this and are often asked to "be back up" if there is a problem.	Jan 19, 2011 2:09 PM
100	I don't know about this.	Jan 19, 2011 1:34 PM
101	Most appear to utilize cab services, this can create challenges as the companies utilized have limited availability during certain times of the day as they relate to school opening/closing which results in shortened services provided to the client when they need to leave early due to being dependent on taxi services.	Jan 19, 2011 1:09 PM
102	We have lots of clients who need transportation to groups that are not covered by medicaid and there is no other way to fund rides.	Jan 19, 2011 12:52 PM
103	There is RCT great! But transportation costs are high, not always reliable and complicated for young or DD children. Creativity is a requirement in most of these areas!	Jan 19, 2011 12:51 PM
104	I work with youth and am not aware that they provide this service.	Jan 19, 2011 12:45 PM
105	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
106	depends where you live. VT lacks infra structure for public transportation.	Jan 19, 2011 12:28 PM
107	The state needs to invest heavily in transportation for people with low income and people with disabilities.	Jan 18, 2011 12:07 PM

Page 3, Q4. How is Vermont doing in providing housing and home supports?

1	My home is very old and cold. I can only afford to fix so much . . . I have called all of the support agencies included BROOC, Shareheat, the Senator's Office . . . article stating that no Vermonter will go without heat . . . The Senator's office told [me] to call 2-1-1 for help which was a dead end for me. BROOC actually told me that the electric company has to shut off my electricity for me to get help. . . I have a huge outstanding bill from last winter. The pipes in the kitchen have froze for lack of heat this winter. . . I can still drink from the bathroom. . .	Mar 26, 2011 1:26 PM
2	Again, for some. There needs to be more living/housing options that include flexibility and creativity to meet individual & family needs. Small group homes that provide natural living and friendship frameworks must be allowed with safeguards. The present options are few and not suitable for many individuals and families.	Mar 26, 2011 1:03 PM
3	Let people know the possibilities!	Mar 26, 2011 12:48 PM
4	VT needs to have more universal affordable housing & add more services so people w/ disabilities can live independently.	Mar 26, 2011 12:41 PM
5	Too many people unable to get housing. Sent from one AGENCY to ANOTHER with no real help. Too many hurdles to jump. Workers don't care "Not their job." Always another AGENCY'S job.	Mar 26, 2011 12:25 PM
6	Lack of housing -- not a lot available.	Mar 26, 2011 6:41 AM
7	See Cialis as therapy in The Chronicle news paper weekly Journal of Orleans Jan. 19	Mar 26, 2011 6:10 AM
8	I have a neighbor who comes to my house to take a shower because he has no hot water at his house.	Mar 26, 2011 5:53 AM
9	Dev. Home,	Mar 25, 2011 12:14 PM
10	respite cut	Mar 25, 2011 12:09 PM
11	Why did Douglass & Housing send back 2000 section 8 vouchers: we need access & safe Housing!	Mar 24, 2011 10:36 AM
12	Have no idea what exist in this regard.	Mar 18, 2011 4:23 PM
13	Need more options, and parents and individuals need more control in how to use the money for housing home supports. More and clearer info	Mar 18, 2011 7:26 AM
14	As an SLP I find the compensation for the time investment a struggle. As a family with our own child, I find the system tries to compensate other people to help me keep my child in my home but not our family. It is very difficult to have manage a life with a child with special needs or an adult and be able to adequately earn a living. Instead of paying people who consistently turn over to try and keep a person in a home, pay the family.	Mar 16, 2011 9:17 AM
15	We really need to increase the options and supports for more independent living.	Mar 15, 2011 7:41 AM
16	Jeff lives with me so they do not provide housing but definitely home supports, HCRS has provided activities three times a week for Jeff which I could not do without.	Mar 15, 2011 5:15 AM

Page 3, Q4. How is Vermont doing in providing housing and home supports?

17	Care was so bad I had to take over my son's care at home. His life was in danger. If he had the care level I am providing he would have done very well.	Mar 14, 2011 12:02 PM
18	From the perspective of someone working with children with disabilities, not good. If a family chooses to keep a child in the home, they rely on unskilled PCA support. DD case management and support for children NEEDS to be expanded. Mental health is currently supporting these families and not fully meeting their needs.	Mar 14, 2011 10:27 AM
19	For the physically challenged population, there is not many options available and adaptations for homes are very expensive and not always something shared living providers want to do to their homes. Having an adapted bathroom is not going to add to the value of the home unless you are selling to someone who needs this. And having a ramp off the home is not usually very visually appealing. Making this worth the providers while is necessary to open more options for those with significant physical challenges. Using ADA as the 'gospel' for accessibility in a home is not usually going to make that home accessible to the more challenged population. Having grab bars around a toilet is useless for someone who needs an adapted seat to sit on a toilet. Having grab bars at a specific height in a tub is unnecessary for someone who is not able to get in/out of the tub without full assistance. At times the 'supports' are in the way of doing effective and safe transfers for those with physical challenges. Having this evaluated by someone who actually USES the adaptations, makes sense, but is rarely done. And when consults are obtained, it is after the fact and little can be done without structural changes which are not supported financially.	Mar 13, 2011 3:15 PM
20	Perhaps more group type homes with enough staff to work with individuals on a daily basis.	Mar 12, 2011 5:26 AM
21	What is working for us is a great team of people that truly support the client. We work as a team, act like a team and are there for each other as well as the client.	Mar 11, 2011 1:35 PM
22	I don't know. I do know parents of disabled children and teens, esp with autism, are extremely worried about the availability of supported housing. They know a tremendous number of kids are going to come of age in the next 10 years.	Mar 7, 2011 10:29 AM
23	don't know	Mar 2, 2011 8:48 AM
24	Always a need for housing for DD folks with supports. The need will increase in up coming years.	Feb 21, 2011 2:36 PM
25	Many placements and livig sotuations are good, but too many people have no options outside of staying with families when they might want to live on their own with support.	Feb 21, 2011 11:47 AM
26	we'llsee	Feb 18, 2011 7:22 PM
27	Housing continues to be one of the major issues for the families I support.	Feb 17, 2011 1:25 PM
28	Unknown as I do not utilize this service. However, it is my understanding that the State budget to assist in this area has been cut again.	Feb 14, 2011 3:06 PM

Page 3, Q4. How is Vermont doing in providing housing and home supports?

29	It seems that there is limited housing available. There is a large population of folks that fall through the cracks with housing, especially when they have children. These people have some adaptive skills, so they appear higher functioning and can meet a lot of their own needs. When you add the needs of their children, there is a greater need for home providers/in home support people.	Feb 14, 2011 8:13 AM
30	I have yet to see anyone get approved for subsidised housing. The best excuse I have heard so far from someone clearly in need was that her credit score was to low. It was low from extensive medical bills. How dare you!!	Feb 10, 2011 11:48 AM
31	Once we received the waiver, the agency that is helping us has been able to provide much better home supports. Had my son needed to be "institutionalized"- there would have been no place to go. There was only one "home placement" option, which wasn't sufficient for his needs. Fortunately, we were able to keep him at home with the PCA supports.	Feb 8, 2011 1:59 PM
32	Support Services need to be giving correct information. Many different stories or answers sometimes. This can be disappointing and frustrating for families in need of housing.	Feb 8, 2011 10:47 AM
33	Very few options available.	Feb 7, 2011 4:46 PM
34	We have just begun this search and it feels like it is going to be very long and hard.	Feb 7, 2011 12:33 PM
35	There are limited housing options for people like my son. He will probably live at home for the rest of his life. I purchased the home and had his name put on the deed so that he would always have a roof over his head. We were homeless for the first four months we lived in Vermont and I did not want that to ever happen to him (or me!) again.	Feb 7, 2011 12:20 PM
36	No info	Feb 7, 2011 9:59 AM
37	It seems that many people with disabilities are being warehoused in single family homes. How much of an improvement is this over congregate care?	Feb 7, 2011 8:29 AM
38	No idea - suppose I'll find out when Ben is older?	Feb 6, 2011 5:53 AM
39	For youth within residential programs under the DCF or DMH sysytem this is not an option until they are 18.e	Feb 5, 2011 4:23 PM
40	I seriously believe that income eligibility requirements need to be reviewed and changed, a lot of people are in that margin where they are having trouble, but are just above the line to get any help needed.	Feb 5, 2011 9:34 AM
41	What home supports??	Feb 4, 2011 9:00 AM
42	alot live way out where it is difficult to drive in and out. it would be great to get folks centrally located to the city, attractions, library or have more access to these places.	Feb 3, 2011 4:22 PM
43	Once again, people with physical disabilities don't get as many services as someone on the autism spectrum.	Feb 3, 2011 2:26 PM
44	you have to fight like hell to get housing	Feb 2, 2011 12:04 PM

Page 3, Q4. How is Vermont doing in providing housing and home supports?

45	Not sure.	Feb 2, 2011 11:53 AM
46	Not alot of options for housing in Vt. especially in NEK.	Feb 2, 2011 11:30 AM
47	Housing is easier than home supports. Again, being "awarded" home supports is different than actually getting the service.	Feb 2, 2011 11:07 AM
48	I think the PCA program is excellent and a great component to a great project, however the low wages make it nearly impossible to find good help. Because many of the PCA's that have worked with my child were university students (the only population that would work for the wages) we've had much turnaround in PCA help. This can be unsettling to some children and adults with special needs. Perhaps a program in conjunction with some of the colleges, or universities in the area that makes the work be a part of an internship with set time frames (say 2 full school terms or 1 year minimum). Part of the requirement would be that in doing this type of internship it will be like a real job where the employee doesn't get to take vacation during every school vacation, break and long weekend (this isn't possible in real jobs) and there would be accountability not just to the parent/employer that is already overwhelmed and has no other options but to the school and have their grades depend on it-perhaps this will help this particular population take the assignments more seriously. In other words the Personal Care Attendant job would be a paid internship where the parent serves as the Field Instructor and would communicate with a university/college liaison to resolve any scheduling or training issues.	Feb 2, 2011 10:37 AM
49	The shared living model is seriously flawed. Many clients are bounced from home to home. It is little more than adult foster care.	Feb 2, 2011 10:32 AM
50	n/a	Feb 1, 2011 10:19 PM
51	The state was totally able to help my son with safe housing and when it was clear he would die if left much longer on his own I brought him home. State needs to consider all types of housing including group,shared, mother-in-law apartments, living with family as well as adequately supported single ocpacy apartments.	Feb 1, 2011 1:17 PM
52	Overall, affordable housing and home supports are struggling statewide.	Feb 1, 2011 12:49 PM
53	Not sure...we looked into our daughter living in Burlington as a student; sounds like there are some support systems through Howard Center. However, I just happened to call the right agency. I don't know how the word gets out for some of these resources. It is not clear to me at all....	Feb 1, 2011 11:13 AM
54	We do get funding for up to 30 hours a week for a Personal Care Attendant for our son. It is extremely hard to find qualified staff at the wages provided by the state (\$9.78/hour).	Feb 1, 2011 10:43 AM
55	Cutting PCA pay to \$9.78 an hour instead of \$10 an hour is NOT saving the budget and instead impacts our kids, families and our workers. Its made it even more difficult to find decent trustworthy people to work with out kids. Another thing that could help would be to expand the C3 pilot project and make it an option for ALL families recieving PCA hours. The flexibility in spending would help-the staff could recieve TRAININGS, get more pay, etc. This would help keep families from burning out. And if families get burned out due to the ongoing stress, it could lead to more people needing a higher level of care (ie institutionalized).	Feb 1, 2011 8:19 AM

Page 3, Q4. How is Vermont doing in providing housing and home supports?

56	We do not need housing. Home support for us in the personal care attendant each day after school so I can work and tend to my other two children also.	Feb 1, 2011 7:09 AM
57	N/A	Jan 31, 2011 5:03 PM
58	My son was prepared to move on to a house or apartment until I found out that he would have to sacrifice all but \$115 monthly of his SSI checks. He can not possibly live any type of a substantial life on such a meager "allowance".	Jan 29, 2011 4:48 PM
59	Need group homes.	Jan 28, 2011 3:05 PM
60	Not enough choice in options. People living in developmental homes do not have security. PWD have to meet priorities.	Jan 28, 2011 10:13 AM
61	Not identifying soon enough	Jan 28, 2011 9:58 AM
62	I will be eternally grateful to the state of Vermont for weatherizing my 120 year old house.	Jan 26, 2011 1:29 PM
63	Theres just not enough qualified people out there for what is needed. The ones that are out there are working two or three jobs to make ends meet.	Jan 26, 2011 12:43 PM
64	We're lucky to now be able to offer safety connetions that allows people to live independently.	Jan 26, 2011 12:34 PM
65	Current Shard Living models and roommate models are over used and expensive. Vermont should invest in utilizing on-call and first response systems with a scheduled staff contact. The staff could cover multiple clients in a geographic area and electric devices, mentioned above, could serve in emergency situations. Many individuals with Shared living providers could live independently with limited support around household chores, cooking, and groceries, etc.	Jan 26, 2011 12:07 PM
66	my son is too young to move out	Jan 26, 2011 11:19 AM
67	There is not enough housing supports.	Jan 26, 2011 10:35 AM
68	The Safety Connections program at Howard Center has been very successful in keeping people housed in safe and independent living situations at a much lower cost than institutionalization or Shared Living Provider models. I think it is a helpful program for those clients able to live more independently.	Jan 26, 2011 8:27 AM
69	My only real experience is with Pathways for Housing. They have been able to find an apartment for my son after 5 weeks of looking. So far so good, so I would say that organization is working well; better than any others in the past for my son. Somehow they have managed to not alienate him, which is quite an accomplishment.	Jan 25, 2011 5:08 PM
70	Money is scarce, system priorities are tightening and need is increasing.	Jan 25, 2011 1:48 PM
71	Again, with the budget cuts this area is also affected, but for the most part housing does seem to be a priority.	Jan 25, 2011 12:21 PM
72	More state wide efforts to inform the public of the employment options in the area of Home Providers and respite providers. Not enough people are aware of the opportuniy.	Jan 25, 2011 11:57 AM

Page 3, Q4. How is Vermont doing in providing housing and home supports?

73	We are not involved in housing/home support	Jan 25, 2011 11:19 AM
74	Long waiting lists for Section 8 housing.	Jan 25, 2011 10:50 AM
75	So much more could be provided with additional monies!	Jan 25, 2011 10:19 AM
76	VT models for living arrangement is too limited and restrictive. I don't think much is working well here. There has been some parents meeting on this topic but it got overwhelming. It takes soo much parent energy to get things changed in VT	Jan 25, 2011 9:00 AM
77	I feel more should be done. Housing is a huge problem in VT as a whole and really needs to be evaluated. Accomadations to help families make their homes more dwarf friendly would be a real benefit.	Jan 25, 2011 8:36 AM
78	Not sure, I haven't hit this point yet.	Jan 25, 2011 7:36 AM
79	Have not needed.	Jan 25, 2011 6:35 AM
80	not sure as I have not had this as an issue with the families I work with.	Jan 25, 2011 6:15 AM
81	Huh?	Jan 24, 2011 7:22 PM
82	N/A should be an answer here. We don't know.	Jan 24, 2011 6:40 PM
83	Howard Center's Safety Connection program is great peace of mind when it comes to living alone . The state should look at expanding the safety connection program which could help promote more independent living arrangement instead of just shared living. give agencie incentive for people to live with peers. The challenges the lack of affordable housing.long waitlist for section 8.	Jan 24, 2011 4:24 PM
84	Not an issue for us yet.	Jan 24, 2011 3:40 PM
85	It took us 3 years to secure accessible apartment in Montpelier -- waited on list for the 300 Barre St apts to be built. And we could afford housing of moderate price.	Jan 24, 2011 3:32 PM
86	Does this need to be a question? The waiting list for Section 8 was frozen, that translates into the state has given up. Housing is the largest state problem in supporting disabled populations. Those with disabilities are at a much greater risk of homelessness. When things get to a crisis level they are much more expensive to fix. The reality is the demand far surpasses the supply and the short-term future supply. Something creatively needs to be tried, pilot program many ideas, poll the citizens at town meeting day--give out questionnaires--the people there are the ones that are invested locally.	Jan 24, 2011 2:30 PM
87	Finding good homes is gettting challenging! If agencies could pass on good home that they are not using to other agencies could improve this situation.	Jan 24, 2011 2:11 PM
88	Children's PCS works well when you can find someone. The C3 program helps with providing some flexibility. I hope the program becomes available for all.	Jan 24, 2011 1:52 PM
89	Don't know. My son lives at home.	Jan 24, 2011 1:37 PM
90	There is a caveat here, though. In Vermont, finding affordable housing has been difficult across the board, not just for individuals with disabilities. Regarding home supports, there are constant challenges.	Jan 24, 2011 1:32 PM

Page 3, Q4. How is Vermont doing in providing housing and home supports?

91	I currently receive SSI & SSA to help pay my rent each month. Unlike other states like Minnesota & others in Vermont only one person from each household is allowed to claim the renter's tax rebate. It would be nice if the state tax code were updated to allow each renter in every rentable home to claim the renter's rebate instead.	Jan 21, 2011 8:12 PM
92	Unregulated...by outside agencies. Hide behind loft and warm and fuzzy vocabulary. Need regulated, trained and outside oversight to theraputic homes or shared living.	Jan 21, 2011 10:19 AM
93	Independent living supervision is a must and a necssity for folks with limited safety skills and who are vulnerable to predatory folks who live on the street. Reduced state funding has put many folks at risk.	Jan 20, 2011 9:37 AM
94	Perhaps more capacity in the area centers	Jan 20, 2011 8:15 AM
95	Although we have seen a dramatic increase in teh need for low income housing i feel the need now is for more fuel assitatnce and helping people stay in their home due to rising costs taxes, fuel, food, medicene etc. We need a single payer health care system for starters.	Jan 20, 2011 6:52 AM
96	This depends on the target population being asked; adults, children, adults with disabilities who are parenting.	Jan 19, 2011 2:09 PM
97	See my anwer to the above question about funding. We really need to begin to develope models for individual and community living that meet the person's needs, while allowing them to continue to grow and develop.	Jan 19, 2011 1:34 PM
98	Home supports are provided when there are resources, qualified support	Jan 19, 2011 1:26 PM
99	When clients are eligible for out of home services there appears to be more services available. It would be helpful for families if more services were available to assist with maintaining in their homes as prevention to needing out of home supports.	Jan 19, 2011 1:09 PM
100	The cost of housing continues to climb while benefits and earnings decrease or stay level funded.	Jan 19, 2011 12:52 PM
101	What is working - we have the supports to go into the home and they do a pretty good job. What is not working is the availability of housing that is at an affordable cost!	Jan 19, 2011 12:51 PM
102	The adults that I have worked with get limited in home supports. There SSI usually supports their rent. More work could be done on basic living needs and more regular home visits.	Jan 19, 2011 12:45 PM
103	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
104	As long as parents state they cannot maintain their youth in their home. The DD home providers are well paid to care for clients.	Jan 19, 2011 12:28 PM

Page 3, Q5. How is Vermont doing in providing health care and related supports?

1	I go 5 to 14 days a month without food because I tire of begging for help.	Mar 26, 2011 1:26 PM
2	Complicated and bureaucratic accountability is a problem. There is a huge burden on families keeping up with the paperwork.	Mar 26, 2011 1:03 PM
3	Nothing is working. It's only getting worse. VT needs to focus on creating jobs where employer pay for some benefits. Everyone is hiring temps so they do not have to pay benefits.	Mar 26, 2011 12:41 PM
4	Too many tests for ORDINARY problems: Too much spent on medical services that aren't needed. If you compared my health care bills to my home provider you will see I get thousands per month. She gets 0. No health insurance. No care. not fair. Even I know what's fair. If she gets sick who will care for me?	Mar 26, 2011 12:25 PM
5	I do know the current system is not working. The health care is very poor. . . I live off my husband's social security. Very hard to make ends meet. Premiums, deductibles and co-payments are hard. I don't get the care I need. It's like I go to the doctors and I'm not listened to. I have to have [procedure] every year. Now it sounds like I'm going to be cut because I can't afford it. My poor husband needed so much and we couldn't afford it. He died, or was let die. There are so many people out there that struggle no help for them either . . . like the Government doesn't even care. . . .	Mar 26, 2011 6:26 AM
6	Too many drugs ALL drugs are proteinaceous cause loss of nutrients in the body (IE reduce health) 98% of drugs are proteinaceous. Drugs interfere with brain development . . . period. Chickens that are literally cannibalizing each other STOP when you correct their diet. You now have an aging population @ say 30-50 age group who ARE children. This is due to poor quality food too much junk food. As well as not understanding HOW food is prepared changes its nutritional value. IE same food cooked different ways gives different nutrition.	Mar 26, 2011 6:10 AM
7	My daughter has been diagnosed as legally blind (a 2nd disability) and thus has to privately pay deductibles as her SSDI (from DAD) and deductible is just over limit for Medicaid . . . her cane was stolen & she had to pay for a replacement as she didn't "fit" somehow in Visually Impaired system!! It seems that our services have found always to determine one is not or no longer eligible , vs. how can we continue to support!!	Mar 26, 2011 5:45 AM
8	Due to our son's demanding medical treatments he is stable. Therefore he is not eligible for SSI & related supports & services.	Mar 25, 2011 12:09 PM
9	PC Plus/Medicaid/Medicare/ We need Rx Access -- more doctors or program eval - simple/single Forms/ review (Person must not be forced to use narcotics for pain care (acupuncture) (1) Person must not be limited to narcotics for pain control: Acupuncture for pain control.	Mar 24, 2011 10:36 AM
10	Extremely good health/preventative care.	Mar 18, 2011 4:23 PM
11	I have no complaints.	Mar 16, 2011 9:17 AM
12	Not sure...	Mar 15, 2011 7:41 AM
13	OK but insurance paperwork is a nightmare. Mental health is poor.	Mar 14, 2011 12:02 PM
14	This is a strength with Medicaid availability and Medicaid paratransit.	Mar 14, 2011 10:27 AM

Page 3, Q5. How is Vermont doing in providing health care and related supports?

15	When the Brandon Training School was in operation (and I do not want to see institutions re opened at all!) medical and rehabilitation supports were provided as needed and requested. No one waited for a wheelchair for months and months. No one waited for braces to be approved before receiving them. No one had to sleep on a mattress that did not provide adequate skin relief until they actually got an ulcer or skin breakdown to get what they needed. All of these things happen all the time now. I stood in the audience when Howard Dean promised that the folks at BTS would have equal or better lives outside of the institution. I think that living in a home is everyone's right. But the trade off of not having anything to do, anyone to do it with, or equipment and services that provide for safe and adequate health supports is not ok. Howard Dean meant what he said, but it has not been the reality.	Mar 13, 2011 3:15 PM
16	My client has a several health issues and does receive good care,	Mar 12, 2011 5:26 AM
17	Vermont does well for the clients healthcare needs. Vermont really needs to look into the possibility of health care and related supports to the home providers. If there is one complaint that I hear about more often than ever is the lack health care. I would be interested in seeing what the home providers might be willing to negotiate on to receive healthcare for themselves.	Mar 11, 2011 1:35 PM
18	Hurray for Katie Beckett and Dr. Dynasaur; the paperwork is bewildering, duplicative and inconsistent, but the coverage is marvelous.	Mar 7, 2011 10:29 AM
19	Need for doctors and dentist. UCS could use a doctor, always need dentist no floride in the water here. I won't go there.	Feb 21, 2011 2:36 PM
20	Good. But in addition to a health program, I wish they provided a Dental program as well since Dental issues have a significant impact on the overall health and well being of an individual.	Feb 14, 2011 3:06 PM
21	Not really certain	Feb 14, 2011 8:13 AM
22	Best area of services in Vermont.	Feb 10, 2011 11:48 AM
23	Cost.	Feb 8, 2011 2:14 PM
24	Medicaid would not pay for the \$100 dedicutible for each of three ambulance runs for our son. They stated that the ambulance "charged too much" and would not pay. That's \$300 that has had to come out of our pocket. This is a crime. Otherwise, Medicaid has picked up all other dedicutibles.	Feb 8, 2011 1:59 PM
25	Some delays in Reachup result in Medicaid being stopped. Reachup is difficult to contact since it is mostly automated. Reaching a person is tedious, time-consuming, and sometimes impossible.	Feb 8, 2011 10:47 AM
26	My son's Medicaid coverage through Katie Becket has been extremely helpful to us. He has upcoming major surgery and this extra support again, is very helpful.	Feb 7, 2011 2:39 PM
27	VT is doing an excellent job providing health care and related supports to this population. The lack of trained adolescent psychologists is discouraging. However, overall access to health care is incredibly good compared to other states.	Feb 7, 2011 12:33 PM

Page 3, Q5. How is Vermont doing in providing health care and related supports?

28	My son had expensive medical issues when we first arrived in Vermont. Medicaid and the Child Development Clinic took care of all his needs. He sees his medical professional when needed.	Feb 7, 2011 12:20 PM
29	Care for kids is good, but with the changes in Catamount and VHAP we need to remember the caregivers who can't work full time due to providing care for the disable person in their lives	Feb 7, 2011 10:57 AM
30	Don't know.	Feb 7, 2011 8:29 AM
31	I don't understand the question - excellent in terms of VHAP/Dr.Dynasaur coverage and availability of excellent providers who accept these.	Feb 6, 2011 5:53 AM
32	We need single payer health care per Dr. Hsiao's recommendations. Mental health service are nothign but waiting lists and RMHS needs to be defunded	Feb 5, 2011 8:55 AM
33	health care is still there but very expensive for middle class families who do not have a waiver and are above income for services	Feb 2, 2011 12:04 PM
34	Health care is available but may not be accessed if the transportation and personnel supports are not available. Suggestions: -Regional health centers that provide a broad range of services and supports in one location. -Training for health professionals in the importance of interdisciplinary care	Feb 2, 2011 11:53 AM
35	I think this is something that our state does pretty well. The only very large gap is mental health. We have no day programs for people who have both a DD and an acute mental health problems. What we have now is pieced together and staffed by untrained workers. Trained care providers and day programs are a huge need.	Feb 2, 2011 11:07 AM
36	I feel lucky to live in Vermont due to the state's health care priorities. I do wish there were more providers. Although my son has appropriate health care coverage he is not receiving all the help that he could be getting now to limit the amount of help he will need later. In other words the earlier the interventions the more independent he can be as an adult. I think its the most cost effective option. Most of the help my son has received has come from my own efforts as a clinical professional. I am confident that he will be independent from the state as an adult, however I have skills that many parents don't have. What will happen to those individuals if they can't receive the necessary therapies due to lack of providers. I think a good idea would be a loan forgiveness program for other professionals (occupational therapists, physical therapists, coaches, mental health, etc) such as the programs offered for nurses and doctors but state funded so that part of the requirement for these graduating professionals would be to work in the Vermont community as a means to have student loans forgiven.	Feb 2, 2011 10:37 AM
37	We are pleased with the healthcare our children receive. Our oldest receives most services via DMHC in NH and we have never had issue with referral or management of his care, which is BEST provided for him via his specialist at DMHC	Feb 1, 2011 10:19 PM
38	General health care is fair but mental health is inadequate due to incompetence and lack of availability. Very, very poor emergency services.	Feb 1, 2011 1:17 PM
39	Health care in Vermont is struggling as well. High costs, prescription payments, copays are often difficult to pay.	Feb 1, 2011 12:49 PM

Page 3, Q5. How is Vermont doing in providing health care and related supports?

40	Please, please help get medical providers more educated about developmental challenges, including ASD. We have had some situations where a medical provider was unknowingly very insensitive to our daughter - because they simply had no idea how change, speed of information dissemination, waiting room environments, etc., could affect her. As she approaches adulthood, we have had some challenges explaining that while she is nearly 18, she sometimes needs a slower approach. They either seem to treat her like she is cognitively impaired (which she isn't - and which insults her greatly), or they discount her needs and speed along, asking too many questions, doing too many procedures (which she finds invasive and threatening). A young woman on the spectrum who has a traumatic first visit w/ a gynecologist can really find herself w/ questions about her body and personal choices and no one to go to. I feel my daughter is ready to work w/ a physician on her own terms and is starting to push me away in this area (understandably...it's time). Yet, she still feels very threatened by working w/ new physicians who clearly don't know her and the nature of high functioning aspergers/ASD. Health Care Providers NEED training!!!!!!!!!!	Feb 1, 2011 11:13 AM
41	We had trouble initailly getting our son established as disabled (really!?? would you like to meet him??!!) Once he qualified, the services through Medicaid have been very thorough and effective.	Feb 1, 2011 10:43 AM
42	My daughter has hearing aids, glasses, and ortho inserts in her shoes. She goes for regular dental and pediatrician checkups. Additionally, she received funding this year for an augmentative communicaiton device. The funding came from her primary insurance and Medicaid. She receives PT, OT, and speech services at school. We could not provide these things for my daughter without the help of insurance. I am very pleased with the level of health care she receives.	Feb 1, 2011 7:09 AM
43	I have been lucky that what ever my insurance doesn't pay medicaid has.	Jan 31, 2011 5:03 PM
44	Okay but could be better !!!	Jan 31, 2011 8:58 AM
45	Top of the line	Jan 29, 2011 4:48 PM
46	.	Jan 28, 2011 3:05 PM
47	Katie Beckett helpful	Jan 28, 2011 9:58 AM
48	If you keep the funding up Vermont should be OK in the future.	Jan 27, 2011 11:39 AM
49	We are very happy with and thankful for Dr. Dynosaur, and the input from CSHN.	Jan 26, 2011 1:29 PM
50	The children get the care they need.	Jan 26, 2011 12:43 PM
51	My son receives Medicare.	Jan 26, 2011 10:35 AM
52	All vermonters need healthcare at an affordable cost. Currently healthcare is a huge expense and I would like to see a universal healthcare system implemented in the state; free of charge just as it is in Europe or Canada.	Jan 26, 2011 8:27 AM
53	Hard to know because my loved one in need usually refuses the health care he needs.	Jan 25, 2011 5:08 PM

Page 3, Q5. How is Vermont doing in providing health care and related supports?

54	Again, see comment about unable to get a Katie Beckett waiver for my child. This would be back-up health care coverage in the event our primary coverage is lost.	Jan 25, 2011 2:35 PM
55	Health care is an issue that could be improved.	Jan 25, 2011 12:21 PM
56	We are an under utilized resource for wellness and preventive care	Jan 25, 2011 11:19 AM
57	Need more dentists who will work with people with disabilities. Need higher dental funding under Medicaid. Need attention to transition from Children with Special Health Care Needs to adult physicians.	Jan 25, 2011 10:50 AM
58	There are limited health care supports. Dental supports need to be improved.	Jan 25, 2011 10:19 AM
59	healthcare should be free for all Vermonters that cannot qualify for medicaid	Jan 25, 2011 9:24 AM
60	No one is available but me as a parent to coordinate my adult child's health care. No medical home is available. He has complex medical issues that I feel the adult support system is not ready to address.	Jan 25, 2011 9:00 AM
61	More needs to be done because VT has such a small population to make sure that health care is not done as a mass illness but treated individually. Dwarfism and mitochondrial issues are not the same and one "size" does not fit all.	Jan 25, 2011 8:36 AM
62	I feel Home Care Providers should have an opportunity to have health care coverage through state initiatives. We expect them to view the care they give to consumers as a full time job and we should recognize that need.	Jan 25, 2011 8:22 AM
63	All Doctors should be trained on these disabilities. Not many of them seem to get it.	Jan 25, 2011 7:36 AM
64	I am very pleased with the health care. We do have private health care along with Medicaid. Medicaid has picked up all of the therapies that are not covered under our health care plan. I do wish that the State of VT would encourage the private insurance companies to cover autism therapies.	Jan 25, 2011 6:35 AM
65	Need access to more appropriate medically based therapies--ie feeding.	Jan 25, 2011 6:33 AM
66	great docs and health care here	Jan 24, 2011 7:34 PM
67	Huh?	Jan 24, 2011 7:22 PM
68	Specialized medicine is sorely lacking. ie Gastroenterologists need to understand psychiatric drugs on patient. Often families need support in their treatment plan, an assigned first rate nurse to help navigate procedures, who will accompany family to appointments preparation to those appointments.	Jan 24, 2011 6:40 PM
69	Add the coverage Eye glasses back into the medicaid state plan. Add the coverage of orthodontics to the Medicaid state plan.	Jan 24, 2011 4:24 PM
70	I think there are experts available, the trouble is that our insurance is not very good at paying for them. Our insurance covers so little of the provider fees and we have to pay what the insurance doesn't cover. Why do VT insurers cover so little? How come providers are not restricted from billing the differences? Under the current system, the provider gets to set his fee, the insurer gets to decide how much it wants to pay, and the consumer has absolutely no say.	Jan 24, 2011 3:40 PM

Page 3, Q5. How is Vermont doing in providing health care and related supports?

71	It is sometimes very difficult to navigate the healthcare/medicaid system.	Jan 24, 2011 2:19 PM
72	A challenge is getting doctors to recognize that people with developmental disabilities should be treated the same as individuals without disabilities. Doctors are not willing to have certain tests done nor are they willing to pass on medical information that we need.	Jan 24, 2011 2:11 PM
73	I think that certain disabilities are a "shoo in" for getting services and supports and others have to fight to get them.	Jan 24, 2011 1:58 PM
74	Although the individual specialists in healthcare are incredible, there is not the expertise here. We choose to go to a clinic in Philadelphia for the expert care. Our pediatrics office is a medical home for us and we appreciate that.	Jan 24, 2011 1:52 PM
75	My son is funded through Katie Beckett waiver and my employer based insurance. We just finished applying for SSI/Medicaid. We'll see what happens there.	Jan 24, 2011 1:37 PM
76	Green Mountain Health Care is great. Some people on MediCaid, MediCare & MediCare Part D currently have to pay co-pays. If we had a singly payer system this wouldn't be an issue...	Jan 21, 2011 8:12 PM
77	Absolutely. AND truly better then the average working person in Vermont	Jan 21, 2011 10:19 AM
78	This works for folks who are heavily supervised but we seem to be losing dental and medical services from doctors and dentists who see their services being reimbursed less than their operating costs.	Jan 20, 2011 9:37 AM
79	i see less and less medical providers willing to except medicaid patients. i have seen an increase in immediate health centers which is good but those needing long term care these services are shinking.	Jan 20, 2011 6:52 AM
80	More organized and formal organizations are available, such as Child Development Clinic or specialist in the area of need. The challenge is when they need to make referrals to community based supports or trying to include medical providers in meetings for school or community agencies that also work with the family.	Jan 19, 2011 2:09 PM
81	I think that VT does a pretty good job making sure that people have health insurance. and ensuring that folks have access to care.	Jan 19, 2011 1:34 PM
82	Excellent doctors etc and great access to hospitals when needed!	Jan 19, 2011 12:51 PM
83	Mental Health supports need to be more available with dependable follow through when folks needing supports are living in the community.	Jan 19, 2011 12:48 PM
84	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
85	State Medicaid works in VT. Families can find Medicaid providers in most communities.	Jan 19, 2011 12:28 PM
86	Medicaid reimbursement rates limit choice. Finding a dentist is extremely tough.	Jan 18, 2011 12:07 PM

Page 3, Q6. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

1	CIS-EI in Chittenden County provides excellent services. Not sure about other regions. Difficult to find and keep PCAs (low pay, transportation costs, no benefits.) [PCA=Personal Care Attendants.]	Mar 26, 2011 1:03 PM
2	We are providing good quality intervention. However there needs to be more support for families.	Mar 26, 2011 12:41 PM
3	Too many children labeled with disabilities. Families come to depend on services.	Mar 26, 2011 12:25 PM
4	Support he parents. Teach the parents not grab their children.	Mar 26, 2011 6:10 AM
5	I should say POOR! My daughter was fortunate to have been bron in a state that began servics at 2 month-- beginning K -- VERY GOOD!!	Mar 26, 2011 5:45 AM
6	We need staff at every level every town: we are forcing people to move - lose jobs - disrupt homes to ge services - if any !!! Mobile response teams -- pay members of household for services provided. : target colleges to train care staff/grants.	Mar 24, 2011 10:36 AM
7	It's hard to find out where to access programs.	Mar 18, 2011 4:23 PM
8	It depends on where you live, what school you go to. itseems to be all over the map in this area	Mar 18, 2011 7:26 AM
9	It seems to be going well. It's not relevant to my life at this point though.	Mar 16, 2011 9:17 AM
10	Based on the EEE programs that I have visited in the Rutland, Bennington and Addison counties, I would say that the staff and programs are excellent. However, they are working overtime and struggling to keep up with the needs and could benefit from increased numbers of providers and ongoing training for adult providers	Mar 15, 2011 7:41 AM
11	Can't comment but nothing when my son was a child.	Mar 14, 2011 12:02 PM
12	Funding cuts continue to interfere with progress	Mar 14, 2011 10:27 AM
13	Early intervention is essential to make sure that children are getting what they need when they can most benefit from it. The folks in early intervention programs do a good job with families but there are not many support services available for families in the areas of Speech, OT and PT in areas outside of Chittenden County. The decision by the state to have providers bill for their own services and take the CSHN piece out of the equation, resulted in many skilled providers taking themselves out of the game. CSHN clinics (again outside of Chittenden County) provided excellent contact with families, keeping tabs on needs and meeting those needs. Taking this away and not replacing it adequately with oversight and services has been a loss for Vermont children.	Mar 13, 2011 3:15 PM
14	Not familiar with this area of supports	Mar 12, 2011 5:26 AM
15	my daughter is 20 and I the early childhood years were outstanding. It was very family centered. Just because my daughter is older, everything she does still affects our family.	Mar 11, 2011 2:37 PM

Page 3, Q6. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

16	The funding cuts are going to result in a decline in services; kids will be grouped at playgroups and served less effectively, less privately, and with less opportunity to coach parents. You need to pay EI providers a better wage. In Chit Co, no raise for SEVEN YEARS! CCR is great. Childcare providers need support to continue to run integrated programs.	Mar 7, 2011 10:29 AM
17	early intervention getting better EEE is very good. Childcare needs pca's to help because kids need more supports, limited slots in childcare and more providers need trainings.	Feb 21, 2011 2:36 PM
18	It seems this has gotten harder. Families have to work harder to find coordinated supports and services for their young children with needs.	Feb 17, 2011 1:25 PM
19	I'm not aware of any specialized supports to these children - nor are there sufficient supports to parents with developmental disabilities - especially those that don't qualify to live with a home provider.	Feb 16, 2011 9:21 AM
20	Even though the State has been informed by many organizations such as Autism Speaks and the National Research Council regarding the need for preschool children with disabilities to receive maximum intervention in effort to minimize their service/support need once they begin their educational career, the State refuses or is unable to follow these recommendations and instead, we spend more supporting these children throughout their educational career and into adulthood because these individuals did not receive the maximum amount of life skill training and/or intervention when they were young, when there was a better opportunity to reduce and/or eliminate their need of support/services. Do I dare reference Claire Bruno's and Clare McFadden's White Paper on Autism??? It's on the DDAS website.	Feb 14, 2011 3:06 PM
21	Streamlined referral system through CIS seems to catching children at an early age. Only suggestion is to keep this going.	Feb 14, 2011 8:13 AM
22	I really don't know about this.	Feb 10, 2011 11:48 AM
23	Not applicable.	Feb 8, 2011 1:59 PM
24	i find services in other states ie new york are far superior children seem to get services more times a week for example i moved here from new york when my son was 4 he was receiving speech services 5x a week there he was reduced to 2x a week here there he went to school from 9-3 5 days a week here was only allowed 4x week for 2 hours we have a great need for early intervention specialist in the nek so the children can the services they need when they will be the most help i feel if we put more into children when they are little the budget for the older kids and adults wouldn't be so strained because the need wouldn't be as great	Feb 8, 2011 10:42 AM
25	We need more intensive, comprehensive services especially for children with an Autism Spectrum Disorder.	Feb 7, 2011 4:46 PM

Page 3, Q6. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

26	We had wonderful support through NCSS's FITP program with a good transition to EEE. I believe that school's are limited by funding and therefore limit PT and OT services, saying that they are not educationally based or that they can only supply a consultative model, which I know is not the case. I have been very disappointed at the level of PT and OT that has been provided to my son, given the high degree of his gross and fine motor deficits. When you have to explain to an OT that she could justify seeing him for fine motor so that he can turn the pages of a book, there is a problem. Again, I believe that this is a downstream effect of funding issues - I could be wrong though.	Feb 7, 2011 2:39 PM
27	There is too little money in this area and we rely to heavily on schools to provide these supports; therefore the supports generally stop after school and on vacations. These parents and kids could certainly benefit from more supports.	Feb 7, 2011 2:37 PM
28	Excellent. early intervention. Committed people and programs.	Feb 7, 2011 12:33 PM
29	My son received EEE services at the age of 3, after an assessment at the CDC. I was impressed with the knowledge and advancement in understading developmental disabilities. By the way, my son is now 26 years old and I credit his growth (developmentally, etc) with the early intervention he received and the hard work I did with him! Early intervention is key to assisting those children with special needs.	Feb 7, 2011 12:20 PM
30	Maybe very early intervention works, but supports by the time the kids on the autism spectrum are middle schoolers, it seems very scattered with little support.	Feb 7, 2011 9:59 AM
31	The philosophy of CIS "model" seems to focus on prevention. Early intervention seems to be paid lip service. Children with developmental services seem to be an afterthought.	Feb 7, 2011 8:29 AM
32	More services are needed for children Birth to 5, especially in the area of Speech Language Therapy. Often children are seen once a month but that is not best practice. Even once a week would be better and result in many more gains so that some children could catch up before kindergarten.	Feb 7, 2011 8:19 AM
33	The questions need to be much more specific - this is frustrating. What are you measuring here? My son did EEE and was supported to attend a neighborhood daycare with a para - those were both excellent experiences.	Feb 6, 2011 5:53 AM
34	CAP is part of RMHS/CCN. There are no services.	Feb 5, 2011 8:55 AM
35	From my point of view, I think we need to start when a child is first born. We also need a better reading program for our children .	Feb 4, 2011 9:00 AM
36	we had a great EEE experience, but felt like we were dropped when we entered elementary ed. getting quality personnel to assist is always a challenge.	Feb 3, 2011 4:22 PM
37	Some counties would rather not have new clients, but just work with the clients they all ready have.	Feb 3, 2011 2:26 PM
38	Head start provides a great boost from prebirth to preschool, I think there are a lot of conflicts once children get into k-12	Feb 2, 2011 12:29 PM
39	having worked recently in early childhood i do think this is an area where we are holding the line	Feb 2, 2011 12:04 PM

Page 3, Q6. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

40	Personnel have variable levels of training; may not have experience with children with significant multiple disabilities Computer technology is frequently not available in early childhood environments creating wide discrepancy between children's technology literacy in a highly technological society Communication supports are often not provided to children until they reach Kindergarten in spite of the lack of speech development or significant delays in speech. This has far reaching effect on their ability to participate in school if they are still acquiring foundational skills in addition to the basic academic skills. Suggestions: - Assistive technology and communication supports available in all CIS programs - Ongoing training for personnel on embedding communication supports in play, early literacy, and other activities. -Computer technology embedded in early literacy (reading, writing), math, concept development activities	Feb 2, 2011 11:53 AM
41	Again, a strength area.	Feb 2, 2011 11:07 AM
42	I think Vermont is doing well in terms of providing early intervention services. In my family's experience appropriate childcare for my son with autism has been impossible to find. Many home-based childcare centers have appeared (in our experience) completely unable to address his needs both in staffing as well as in education. This is extremely important for inclusion purposes and for making individuals with special needs learn to socialize with neurotypical peers as well as to feel as part of the community. One suggestion would be that in order to receive any assistance or grants home-based childcare centers as well as bigger centers need to obtain education on how to help populations with special needs- they already do this for families in crisis I believe. The trainings should be extensive and not just overviews (classes that just provide overviews of special needs might encourage more biases than help home care providers with real tools to help them address special needs) and must take an agreed upon number of children with special needs (one or two spots). This would increase the overall quality of childcare as well as create spaces for children with special needs in the real community and not just in their special ed classes.	Feb 2, 2011 10:37 AM
43	Our opinion is that while early ed/eee services are available they are lacking in Lamoille county regarding understanding and training of employees that work with children with multiple and severe chronic disability. Professional not only are unsure "what to do" with our child, but have offered little support in finding other qualified individual that can provide services for our child	Feb 1, 2011 10:19 PM
44	No opinion but hearsay is not good	Feb 1, 2011 1:17 PM
45	CIS is excellent Affordable child care and payments to child care providers could be improved	Feb 1, 2011 12:49 PM
46	Probably better now then when my nearly 18-year-old was a young child. Again, I think had we not been professional parents w/ some knowledge base of educational supports ... not sure some things would have happened. It was a very skilled daycare provider and preschool teacher would happened to spot certain behaviors...and then it was my husband and I would persisted to get certain things looked at when she was 3-5 years old.	Feb 1, 2011 11:13 AM
47	we did not live in Vermont during our son's earlier years.	Feb 1, 2011 10:43 AM

Page 3, Q6. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

48	FITP came along side our family since birth. They are well versed in what their program offers but could have been more informative about servivces available to us in VT. I did not know about CSHN clinic until my daughter was 3 (found out from a friend at a coffee shop). I did not know about Personal Care service hours until my daughter was 4. (again found out from a friend). FITP could have also told me about the I-Team at UVM who has become an intregal part of my daughter's team now that she is 6.	Feb 1, 2011 7:09 AM
49	at least they did a few years ago. There is so much more our there for the younger children but once they get older there is very little	Jan 31, 2011 5:03 PM
50	Glad to see VT recognizes the importance	Jan 29, 2011 4:48 PM
51	don't know	Jan 28, 2011 3:05 PM
52	rock on FIT project!	Jan 28, 2011 10:13 AM
53	?	Jan 28, 2011 9:58 AM
54	I am not sure, as I do not personally deal with this.	Jan 27, 2011 3:34 PM
55	All early intervention services, EEE preschool, and the PCA services are wonderful. My experience with these services was and is wholly positive. Would like to have the latitude to pay my PCA's a little more.	Jan 26, 2011 1:29 PM
56	With very young children they do a great job .It's the older children that seem to fall through the cracks. Nobody seems to know what to do whith them.We don't have any thing in place for these kids as they start to grow and become teens.It's hard enough to deal with regular teens...autistic teens seem to be left out in the cold.	Jan 26, 2011 12:43 PM
57	I'm not as familiar in this area as we work with adults. HowardCenter does provide good services for children though and interventions do occur at a younger age	Jan 26, 2011 12:34 PM
58	not sure on this- its been 12 years since my son was diagnosed	Jan 26, 2011 11:19 AM
59	School systems cut special education first thing. They delay and drag their feet in referrals and often use the excuse that they don't have any funds.	Jan 26, 2011 10:35 AM
60	Unknown	Jan 26, 2011 10:22 AM
61	Once you have the diagnosis there are lots of supports available; getting to the diagnosis can be a very challenging process for parents especially without supports to navigate the system and know thier rights.	Jan 26, 2011 8:27 AM
62	The focus in VT has been for the newly diagnosed and EEE age group. We have also managed to get insurance to cover these. As they age, it goes downhill rapidly..... Time to focus on the needs of 7-21 and adults...	Jan 26, 2011 8:04 AM
63	I addressed this above	Jan 26, 2011 7:35 AM

Page 3, Q6. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

64	My son is now 25, so it may be better now and probably always was better for children with MR, but the school system was clueless as to what to do for him and so were the two child psychiatrists to whom I took him. One thing that might help would be to educate school nurses and guidance counselors more about developmental disabilities, including those categorized as "mental illnesses," but it's sort of unfair to expect them to know what child psychiatrists don't!	Jan 25, 2011 5:08 PM
65	there is the PCA program, but it's up to the parent to find, train and try to retain good individuals to help my son so I can have a job outside the home.	Jan 25, 2011 4:06 PM
66	I don't know.	Jan 25, 2011 1:48 PM
67	Vermont needs more child care supervision and check ups at home, but again there are only so many budgeted workers to enforce guidelines.	Jan 25, 2011 12:21 PM
68	We see children as young as 5, this is a great adjunct to in-office therapy because it is so much fun, it gives the student and therapist a wonderful avenue for initiating conversation on many subjects including safe and unsafe touch, etc.	Jan 25, 2011 11:19 AM
69	Not in touch with many families with very young children, but the groundwork has been laid, and i would expect the programs to be good.	Jan 25, 2011 10:50 AM
70	Not sure.	Jan 25, 2011 10:19 AM
71	There are some excellent schools here that cater to those needing the special services	Jan 25, 2011 9:24 AM
72	I believe this is an area that some best practice is happening.. In Chittenden Cty we have an effective Evidence Base Practice that works great for families. Cuts and changes to the CIS- EI system in the coming year will probably greatly effect that. Funding is always an issue. VT needs to look at the research that shows early intervention works and fund it properly.	Jan 25, 2011 9:00 AM
73	The case loads are huge and the resources minimal. More could be done to help that.	Jan 25, 2011 8:36 AM
74	I am involved in the adult sector of the DD system and do not know enough about what we provide to children to answer.	Jan 25, 2011 8:22 AM
75	She is a 40 year old adult. This question does nnot apply	Jan 25, 2011 7:50 AM
76	I really don't know.	Jan 25, 2011 7:49 AM
77	My son had issues that showed up at age four but he was in a home daycare and the doctors didn't know what to suggest so it was undiagnosed for 2 years.	Jan 25, 2011 7:36 AM
78	Family Infant Toddler in Chittenden--Theresa Soares, Kelly Morrison, Marinelle Newton, Odette Taylor, Lisa Cannazao should be the model of how services are rendered throughout the state.	Jan 25, 2011 6:33 AM
79	Intervention is there but getting to the social opportunities for some families don't happen.	Jan 25, 2011 6:15 AM
80	idk n/a	Jan 24, 2011 7:22 PM

Page 3, Q6. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

81	I think everybody realizes the importance of Early Intervention. Vermont is very big on mainstreaming.	Jan 24, 2011 4:48 PM
82	I feel that our pediatrician was excellent at picking up on my child's needs. Referalls to EEE, then to the school system, were seamless and nothing fell through the cracks. I still have never received any information about what the VT Children with Special health Needs program is about, since they NEVER provide me with any information when asked (even though my son has been in the program for 10 years!). I just wish there were more funding to help us pay for what our insurance will not cover, or to help us with funding for recreational services.	Jan 24, 2011 3:40 PM
83	It took a year for my son to be diagnosed with DMD in 2002. He was picked up by EEE then after He had to leave his childcare TIsland becuase the teachers said he wasn't trynig hard enough to keep up.	Jan 24, 2011 3:32 PM
84	I think that early intervention is doing okay - with CIS services are somewhat watered down. Most childcare care faciiliites will not take children with developmental disabiliites without an aid.	Jan 24, 2011 1:58 PM
85	Early intervention is excellent. I can't speak to child care.	Jan 24, 2011 1:52 PM
86	We moved here when my son was already a teenager so I can't speak to this.	Jan 24, 2011 1:37 PM
87	Again, the money is there and so are the places but the actual structure, methodology and oversight is lacking.	Jan 21, 2011 10:19 AM
88	The co pays that some parents need to pay are a barrier to using child care services.	Jan 20, 2011 4:28 PM
89	Parental support is a primary concern in that unless there is an increase with early childhood identifications, many parents will be at a loss as to gaining positive behavior reinforcement skills. With the loss and reductions of medical insurance options, many parents aren't able to make visits to available pediatric services.	Jan 20, 2011 9:37 AM
90	The new change in requiring copays be paid by the parent is a barrier to accessing childcare, it is not affordable.	Jan 20, 2011 9:00 AM
91	See #1 answer	Jan 20, 2011 8:15 AM
92	This is agrowing concern funding for these services are not keeping pace with the number of people needing these services.	Jan 20, 2011 6:52 AM
93	This area has developed well over the past several years. More and more agency's and organizations are aware of getting to kids early. Transitioning children to school is harder and there are few options.	Jan 19, 2011 2:09 PM
94	Don't know.	Jan 19, 2011 1:34 PM
95	There is a gap in services for children who are just under the "need" "eligible for services" in the age group of 3-6. Some communities appear to have more services than others for this age group. All communities should have access to free preschool despite VT law that children under 6 do not need to attend school.	Jan 19, 2011 1:09 PM

Page 3, Q6. How is Vermont doing in providing early intervention and child care to children with developmental disabilities:

96	No problems noted in this area!	Jan 19, 2011 12:51 PM
97	When identified there are many services for early intervention.	Jan 19, 2011 12:45 PM
98	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
99	see above.	Jan 19, 2011 12:28 PM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

1	Uneven around the state. Some schools and teachers do an outstanding job w/ meaningful, real inclusion. Again, flexibility according to the child's needs must be paramount. One model doesn't fit all. Real, meaningful education & employment are possible, but not available in many areas.	Mar 26, 2011 1:03 PM
2	Private schools should be expected to pay and/or accept disabled and special ed children.	Mar 26, 2011 12:48 PM
3	Youth are still struggling to transition. HS Counselors are not even suggesting youth w/ disabilities even think about higher education. It is sad.	Mar 26, 2011 12:41 PM
4	drugged. ruined for life. Never graduate out of the system.	Mar 26, 2011 12:25 PM
5	Struggled with transition plan for my grandson.	Mar 26, 2011 6:41 AM
6	we transport our own kids	Mar 26, 2011 5:53 AM
7	My experiences were miserable, but I advocated and filed complaints & today have an independent, proud, confident young woman with Downs!	Mar 26, 2011 5:45 AM
8	School's are underfunded & therefore slow and reluctant. The funding laws are unreasonable for everyone.	Mar 25, 2011 12:17 PM
9	VFN's Lori Christopher help us with this.	Mar 25, 2011 12:09 PM
10	Education system needs to pay better! grants to students in high school and colleges to train in senior for compulsive service - 4/6 years.	Mar 24, 2011 10:36 AM
11	there is still a disconnect between school and adult services	Mar 21, 2011 6:18 PM
12	Seems like the programs change so frequently there is not a good foundation to work on. Windham county has a large percentage of SPED kids and I think the Department should be better prepared to help them. Grants for program providing tutoring for children on reduced lunch should be offered to all kids needing help.	Mar 18, 2011 4:23 PM
13	IT depends on where you live, and funding. to many students in spec ed who shouldn't be in spec ed. Schools need to do a better job in seeing the potential in students w/ DD. Still very much an adversarial environment b/w parents and educators. Schools need to better prepare students to transition employment and adult services. Needs to be seamless, start earlier. greater expectations for students. Why is spec-ed so expensive? get back to basics, one on one, longterm thinking, where is the money going You don't have to spend a lot of money to teach. schools will say they can't or don't offer certain services. too much bureaucratic oversee and control	Mar 18, 2011 7:26 AM
14	Special education is not done well in Vermont. Including everyone is not the answer. Vermont does not seem to be specialized in any specific area of special needs and it's completely dependent on the district and the family's ability to fight for what they need for any success.	Mar 16, 2011 9:17 AM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

15	The special education services and programs provided to children in VT with disabilities varies from school to school. There is not consistent response to children's educational needs. By and large schools are providing special educational services. Some are working very diligently and successfully at including students with disabilities into the mainstream general education classes with accommodations and supports as needed. Other schools choose to segregate and only on a token basis invite the student with disabilities to participate in the general education environment and activities.	Mar 15, 2011 7:41 AM
16	This is case and school specific. Several schools are accessing very creative ways of meeting needs.	Mar 14, 2011 10:27 AM
17	As previously stated above, there is not much planning ahead in education for what the future is going to be for students when they reach adulthood. It has become less and less about the needs of a particular student and more about the way programs are offered up in schools. There are students spending time in classes during instruction time that they cannot participate in or understand. These are lost hours and opportunities for these students. An IEP should honor the I as Individual. If schools are going to be putting square pegs in round holes they should call the legal document a GEP for generic Educational Plan. There is alot of talk about how wonderful things are going in all areas of both education and adult services. This is like the fable The Emperor's New Clothes. No one wants to admit that things are as bad as they are, so they praise the situation in hopes that it will hide the fact that the emperor is in his underware!	Mar 13, 2011 3:15 PM
18	Not familiar with this area	Mar 12, 2011 5:26 AM
19	there is no alternative to mainstream education for children who can't handle school. my daughter is currently in an out-of-state school, where for the first time she has friends. many graduates are not ready for life after school - we could do much better with transition services	Mar 11, 2011 2:37 PM
20	Varies widely by school district. Some districts are notorious for not providing adequate special ed, and the amazing thing is, it is known at the state and NO ONE DOES ANYTHING FOR THESE POOR FAMILIES. Need to expand the ABA programs such as Washington County Collab and Howard autism program. The state needs to SHOW SOME LEADERSHIP WITH THIS EXPANSION.	Mar 7, 2011 10:29 AM
21	SPED, need statewide model, each SU on there own budget and agenda. KIDS WITH THE MOST NEED ARE GETTING THE LEAST SUPPORT ASD kids need program unique to there needs, aspies' need social programs Schools are going to have to carry out IEP's I don't think SVSU is ready. Inclusion is still a work in progress. How many SPED kids are working after age 22? Yeah, scary isn't it. Watch out for that cliff!!	Feb 21, 2011 2:36 PM
22	There is a lot of good in the system, but it is not uniform around the state and transitin services are not what they should be. There is not enough support for families who are having trouble with their school systems!	Feb 21, 2011 11:47 AM
23	If the child has a sweet disposition they get better service and help. Schools and IEP's do not address the need to feel productive in earning a living.	Feb 19, 2011 9:35 AM
24	Very little follow through here. It really depends on the specific case worker.	Feb 15, 2011 8:24 AM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

25	<p>We need more help! I'm not a specialist in my son's disability. I was not trained, nor did I go to school. But I expect those supporting him in such environments to be trained to do so. However, many are not. Many Special Educators, Paraprofessionals, Support Center staff and Regular Educators have not received training is ASDs. WHY NOT? Why is this not a requirement for a teaching certificate within the State of VT? 1 in 110 children are on the Spectrum. How are we going to help those with disabilities if we do not train and educate those working with them on a daily basis. I have informed many special educators about free ASD training, only to see 1 individual in a District show up. WHY! How are transitional teams supposed to help the youth when they don't understand what it is the individual needs? Who is advocating for our youth to receive the life skill training necessary to be an independent adult PRIOR to leaving High School so they may have a successful transition into the workforce, especially when there are virtually no funds in the State budget to assist these individuals as they are now adults? Have Patty Prelock prepare a course on ASDs that is required for those providing direct student services in an educational environment. Create a program and funding that ensures our youth receive the maximum life skill training appropriate to become as independent and self-supporting as possible within their community. But again, transitional services are being cut.</p>	Feb 14, 2011 3:06 PM
26	<p>School systems are doing a good job. Very flexible in incorporating alternative ideas. School systems need to improve their engagement with families. School providers have their own in house language that parents do not understand.</p>	Feb 14, 2011 8:13 AM
27	<p>We have been in Vermont for 3.5 years - it was horrible in the beginning. It is just this past September that the school district has provided an adequate program.</p>	Feb 8, 2011 1:59 PM
28	<p>Communication between service providers and schools is not always happening. Understanding each providers' role would help with this.</p>	Feb 8, 2011 10:47 AM
29	<p>i have issues with iep accomodations not be followed, services not being meet in a timely manner, or not being provided at all. there seems to be no accountability for anything or anyone. my sons speech services went unmeet again this year for the first the three months of school. it was me who found the error and contacted the casemanager and the head of spec. ed at the school. after waiting 2 weeks for them to rectify the situation i ended making the phone calls to get him the services out of school all they had to do is send the refferal and i still had to send three e-mails and call twice before that got done</p>	Feb 8, 2011 10:42 AM
30	<p>The teachers that my son have had have been great with the exception of one who made a statement to me that she was here for the other students and his one on one was here for him. The other teachers and his one of one have just been fabulous with finding ways to help him learn. SLP has also been a great support to his learning.</p>	Feb 7, 2011 2:39 PM
31	<p>My experience takes me into a lot of different school systems. The disparity of services between systems is striking. I think it would be valuable for the state to take a look at this and try to create some uniformity. Some schools I work with do not have much experience with transition plans and when parents follow the schools lead their child can be vastly underserved.</p>	Feb 7, 2011 2:37 PM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

32	Special education varies by district, some do well. At the lower ages Burlington does very well. The high school program is in the dark ages. Youth in the "special classes" (located where???...F building) aren't given text books or homework. The special educators have long ago given up trying to fight for help and support from the district.very very sad situation.	Feb 7, 2011 12:33 PM
33	We had some difficulty in transitioning from high school to adulthood, as the support base of high school is no longer there! It was kind of a shock to no longer have the support services that had been so prevalent throughout his 7 years in high school!	Feb 7, 2011 12:20 PM
34	Great willingness in the schools to be supportive. But the tuition is outrageous. Having state run facilities at strategic locations around the state would be more efficient and save us a lot of money.	Feb 7, 2011 10:57 AM
35	Some schools are doing very well. Others not. I think Vermont has some very dedicated special ed teachers and staff who go the extra mile to help kids out. It would be nice if there were more "outside the box" ideas. Pull outs sometimes are not enough. Sometimes access to PT and OT services is very limited.	Feb 7, 2011 9:59 AM
36	Many schools do good work with children with developmental services. As youth transition into the DS system the focus moves from learning to maintenance.	Feb 7, 2011 8:29 AM
37	Need more programs like SUCCEED at UVM but that are more affordable.	Feb 7, 2011 6:33 AM
38	This needs to be two questions, as we haven't experienced transition services. We've been happy with my son's special ed experience with full inclusion and a strong team at school, but we've had to be VERY involved and proactive. As I said above, not sure everyone would have the same experience without the level of time, energy, and skill we're bringing to the table as parents.	Feb 6, 2011 5:53 AM
39	Too many children are out of state 25-30 of them. Get them back to VT.	Feb 5, 2011 8:55 AM
40	In the area that i live in I don't feel that the schools are educated for this day and age! Teachers and Para's need to have training for the individuals needs, not a general training for all.	Feb 4, 2011 9:00 AM
41	not enough supports, the staff is not trained, lots of people inexperienced, but we are going to keep trying	Feb 3, 2011 4:22 PM
42	transition services are very weak	Feb 2, 2011 2:05 PM
43	It differs from one district to another and also at schools within district.	Feb 2, 2011 1:34 PM
44	special ed is a mess transition services are often missing in age appropriate students IEP's	Feb 2, 2011 12:04 PM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

45	Transition planning is extremely variable in it quality and detail from school to school and district to district Training is sporadic and there is little availability for coaching of personnel Suggestions: -Training program(s) for Employment Specialist/Job Development/Job Coach -Ongoing training and coaching in best practices in transition and job development and training -Ongoing training and coaching in essential transition steps -Smaller case loads especially for teachers/personnel of students with more complex disabilities -Awareness of the importance of job training for people with developmental disabilities. -Limitations on how dollars are spent esp. on segregated programs and settings.	Feb 2, 2011 11:53 AM
46	Transition plans are getting stronger but still need work in preparing our young adults for after High school.	Feb 2, 2011 11:30 AM
47	The disparity in services varies greatly from region to region (services in Charlotte are very different from services in Randolph). Special educators and regular ed teachers need more teaching around inclusion strategies and adapting academic curriculum. They also need to have more training about transition--philosophies and programs vary greatly throughout the state.	Feb 2, 2011 11:07 AM
48	so far my family has had very good experiences with our school system although my child is not there yet ready for transitioning. The special education has been inclusive but aware of his needs as well. I feel that we are privileged due to the town that we live in. I have heard stories from other parents in other towns whose experiences have not been as positive as ours. Having to move to another town I am hesitant because of the school system I will end up with in my new home. Also its nearly impossible to know for sure how the school in the new town will provide for my child's needs without doing extensive research which may or may not end up being significant. Parity across Vermont's schools in terms of policy of how to address special needs with earmarked funds for training, hours of personnel, and standardized best practices for various special needs while allowing for personal/family input to be part of iep's. Some schools get away with providing no services because of lack of funding. Once funding is earmarked for special needs services it cannot be used for anything that isn't special needs related. This will encourage the schools to use those funds or lose them in next year's budget. Also a state wide rating system for schools would be a good place to start for parity and transparency.	Feb 2, 2011 10:37 AM
49	SPED, in our opinion, in our district, still takes much time, energy and parental advocation to develope appropriate goals and meet objectives. While we understand that there are "many children who receive SPED services which consumes much time of educators" (I believe those were the words the educators used), OUR priority is that our childs needs be met.....this is often an exhausting process for parents	Feb 1, 2011 10:19 PM
50	Not working well in many areas	Feb 1, 2011 1:17 PM
51	I would say overall special education continues to be difficult for many parents and their children. It seems like schools are pushing to remove children off IEP or 504 plans before they are ready and often times, parents have to "fight" with schools and districts to get the services they need. Transition services to youth are a very unmet need and it's something that Vermont needs to continue to support. YITG is a great project!	Feb 1, 2011 12:49 PM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

52	Well, here's the thing - if your child does not present w/ adverse affect, due to all the good work that is done in the household and w/ adjunct therapists (e.g., physical therapist, 3x week outside of school day) ... there really isn't a sense that people want/need to know about your child's differences/needs. Between 3rd - 8th grade, when we had a "softer" diagnosis of 'possible asperger traits, general anxiety disorder, and sensory integration dysfunction," it really depended on the skill base/interest of the teacher and our vigilance. Once there was a major traumatic event for our daughter in 8th grade P.E., there was a shift in attitude - resulting in a new evaluation that fully defined aspergers and a respectful treatment of the 504 planning needed to ensure our daughter's physical and emotional safety ... what she needed in order to fully engage in learning. Despite a couple rough spots in HS, things have gone pretty well. But, I still remember how hard it was to get the works going, since our daughter's needs were not "adverse" enough. Why is it that public education systems take so long to respond to individual needs? I ask this question as a committed and passionate public educator. Ironically, the best practices my daughter has needed to thrive are actually best practices all students should have access to....	Feb 1, 2011 11:13 AM
53	I think we are very fortunate with our school dsistrict (Stowe High School) becasue they have been extrememly proactive and progressive in transitioning services for our son.	Feb 1, 2011 10:43 AM
54	spotty across the state, it really depends where you are AND how hard you advocate for your child. If you don;t know your childs rights AND fight for them, your child gets nothing. That is wrong.	Feb 1, 2011 8:19 AM
55	I don't know about "transition services". The special education my daughter received in preschool was phonomenal. The transition to kindergarten has been trickier. The adults at my daughters school are not educated about Down Syndrome and haven't been the most receptive about learninga about it.	Feb 1, 2011 7:09 AM
56	So far special education hasn't been the best. When ever the school is unable to provide a service they have it removed from the IEP. It's done by a vote and I, against the school staff never get to keep the services for my son. This has happened three times so far at Harwood and this is my sons second year there! I have done mediation before, it can be a long process and very time consuming when you don't know the laws as well as the school. As a parent I get so tired of having to fight for my child's rights.	Jan 31, 2011 5:03 PM
57	Voc Rehab does above & beyond - the schools,well, they were actually arguing about their responsibilities.	Jan 29, 2011 4:48 PM
58	Need "life skills college" transition to adulthood for developmentally challenged, cognitively impaired youth! Especially for high functioning adopted children. For some, attachment/abandonment issues can make it nearly impossible to facilitate a relatively non-traumatic transition.	Jan 28, 2011 3:05 PM
59	My child is a june grad and has no job lined up, has had 3 IEP meetings this year. I am told it is my responsibility to find her a job if, especially since I am so unreasonable to request that she be indepentant in traveling to and from work (bus runs 7 am - 6 pm, M-F). She is able to navigate the bus. Some transition age youth I know are not even connected with VR because of the schools.	Jan 28, 2011 10:13 AM
60	It's a battle the family is made to feel like they are bad parents	Jan 28, 2011 9:58 AM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

61	Administration at our public school seems to be resentful of the the fact that I'm homeschooling my son, but he became VERY stressed out and developed health issues when he went to the public school past Kindergarten, and hates the idea of going back. His physical health is remarkably better since he stopped attending public school after 1st grade. I think he would do much better being able to attend part time there, but they say that they're not allowed to enroll him for anything less than full time. When he was there his activity schedule had to conform to very rigid standards that didn't work for him. The school faculty seem to be very limited by the administration and have very little latitude to be able to take parental concerns seriously and implement changes. Mainstreaming in our public school was not implemented very well, and my son felt much more singled out as opposed to feeling like one of the bunch. I wish there was a public school NON-mainstreaming option. Mainstreaming is not for every kid, although if it is done well I'm sure it is great for some of them. I find Vermont Public Special Education Administration to be rigid and self-satisfied. They tend to have a one solution fits all mentality which is responsible for a lot of anxiety and hardship for those who need and would benefit GREATLY from a different solution. Administrators don't seem to want to listen to parents and take their knowledge and instincts seriously, and the administrators I have had experience with DON'T take criticism well at all. If you would like to talk to me about this I can be contacted at 802-728-6208 (Kate Porter)	Jan 26, 2011 1:29 PM
62	Our community is having a real hard time figuring what to do with these older kids. The ones that cannot go to class with the main stream students. The budget is tight and the cuts are hurting all of us.	Jan 26, 2011 12:43 PM
63	I wish that funding could be put into place more quickly so that there is more time to transiton students from school into adult services.	Jan 26, 2011 12:34 PM
64	DVES did a fantastic job,, middle school is ok, but i am worried about high school	Jan 26, 2011 11:19 AM
65	Transitional services are provided from small groups that are often filled and aren't excepting new clients.	Jan 26, 2011 10:35 AM
66	Unknown	Jan 26, 2011 10:22 AM
67	Your child need to be in crisis to receive attention from external programs (i.e Howard Center) Schools attempt to provide services for children that are out of their skill level. They need to fail to the point of crisis before admitting they are outside their skill set and pull outside services in. Why is there no interim program; A Howard like group that provides supports to teams (training, ongoing support) to children not in crisis so that school teams learn the skills needed to support these children without hiring on Howard FT at the district & state's expense?	Jan 26, 2011 8:04 AM
68	There needs to be more oversight of special education programs in schools, especially those schools that are not meeting standards. If they are failing the overall student body, what is happening to their special education students?	Jan 25, 2011 5:25 PM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

69	My older son who is now 30 has dyslexia and the school was very good at providing him with special ed. His teacher and I thought he also had ADD and the psychologist the school contracted with said he did not. Ultimately a private pediatrician diagnosed it, but by then he was a junior in high school. Again, better diagnosticians would help, but that's not something the government or schools have much control over. I do think our school system is very good at providing special ed to those correctly diagnosed.	Jan 25, 2011 5:08 PM
70	the inclusive model is entirely dependent upon the LEA's interest in seeing my son a work in progress with a sustainable future. The school teachers and staff can be amazing or not, if the LEA does not believe my son is worth the commitment, all requests will be delayed or denied.	Jan 25, 2011 4:06 PM
71	Currently very good, as least from our experience. I know of others who have dealt with considerable challenges regarding their child's special education needs. St. Albans City School kindergarten is doing a wonderful job. I am concerned about the pressure to cut school budgets and that support staff could be cut resulting in loss of special education programming.	Jan 25, 2011 2:35 PM
72	Money is scarce, system priorities are tightening and need is increasing.	Jan 25, 2011 1:48 PM
73	Vermont is doing as best as they can, but more funding is needed to properly serve children.	Jan 25, 2011 12:21 PM
74	More funding supports for schools who have significant special needs populations in setting up more individualized programming for students who are on the spectrum and exhibit more extreme challenging behaviors. The schools need more well trained staff to handle the complexities of these children so they get the individualized attention they deserve.	Jan 25, 2011 11:57 AM
75	We would love to be more involved in the transition programs for students 18-21, who see their school services end as soon as high school is over. We did one clinic for such students at U-32 and found it rewarding for all involved.	Jan 25, 2011 11:19 AM
76	The peak times of inclusion are past. We need to reestablish summer institutes for school inclusion, where teams can plan together on effective inclusion. Too many alternative programs and life-skills segregated classes.	Jan 25, 2011 10:50 AM
77	Not sure.	Jan 25, 2011 10:19 AM
78	Too many kids are left out in the cold once school services are over.	Jan 25, 2011 8:36 AM
79	There still is a lot of work to do in regards to ensuring that transition plans are recognized and have appropriate goals that align with adult service eligibility requirements. Such as; psychological exams completed before the age of 18yrs, VR involvement from at least age 16yrs, and realistic goals established for graduation	Jan 25, 2011 8:22 AM
80	As my son has benefited from these services, I was very pleased with his supports.	Jan 25, 2011 7:49 AM
81	It depends on the school and district you are in. A few schools give the students what they need and most do not. They are too worried about the \$\$ and they would rather cut special education funding then extra curricular activities to the "neuro" kids.	Jan 25, 2011 7:36 AM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

82	Teachers are dedicated. But budgetary restrictions are obvious even though my daughter's educational NEEDS are not being met--appropriate space at school, access to the autism specialist, etc. Summer programming seemed like glorified babysitting. And if a child NEEDS summer programming in order to not regress, shouldn't transportation be provided?	Jan 25, 2011 6:33 AM
83	transitions is what we are working on to make it better and it is getting better	Jan 25, 2011 6:15 AM
84	follow thru is lacking.	Jan 25, 2011 5:09 AM
85	Not working: Autism still treated as if it were new and rare. Autistics disciplined like regular students who misbehave.	Jan 24, 2011 7:40 PM
86	great in shelburne - not as good other places	Jan 24, 2011 7:34 PM
87	idk	Jan 24, 2011 7:22 PM
88	For us excellent. But it took a lot of years in getting the right team. MAPS (Making Action Plans) from a well trained facilitator is excellent.	Jan 24, 2011 6:40 PM
89	As long as the services available work for a child it is okay, but if a child needs additional services, children get lost and family worn out in the struggle trying to change the system. I wish Vermont would have a residential option for developmentally disabled children	Jan 24, 2011 4:48 PM
90	More social skills training for adults/youth with autism-pdd Start transition process earlier- nobody told me I had to take college level classes into order to go to college!	Jan 24, 2011 4:24 PM
91	Our special education services have been very good so far, but we feel we are in a constant struggle to make sure that the school actually follows through on providing services as agreed upon. So many appointments are cancelled last minute, or the provider just doesn't show up.	Jan 24, 2011 3:40 PM
92	i am impressed by montpelier school system services. not sure about transition services yet.	Jan 24, 2011 3:32 PM
93	Inclusion needs to happen everywhere, the support to the students and trainings for all educators needs to continue. It seems like Alternative schools are popping up everywhere and the ones in our area are more of an expensive babysitting service than beneficial to the individual.	Jan 24, 2011 2:19 PM
94	lack of money and expertise. Transition services are laughable!	Jan 24, 2011 1:58 PM
95	Have to fight for all things special education. Terrible. Not sure about transition services yet.	Jan 24, 2011 1:52 PM
96	As I indicated above, in Addison County, I feel that, coordination of work-related training and services between school and agencies is very inconsistent and frustrating.	Jan 24, 2011 1:37 PM
97	I have had an overall good experience regarding the educational system and my elementary-school aged son. I do not know how well transition services are working, but I have heard anecdotal information that there is much room for improvement.	Jan 24, 2011 1:32 PM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

98	Inclusion is not successful - it is about more than a physical location. Constraints on time and resources in schools is an obstacle. Teachers are feeling pressures and seem to forget why they wanted to be teachers sometimes.	Jan 24, 2011 1:32 PM
99	Set best practices, oversight, and experience professionals who actual have worked in fields.	Jan 21, 2011 10:19 AM
100	Statewide, less then 25% of our grade school graduates make it through the secondary school programs. Some of the 25% receive some additional education from within correctional facilities, but some fall between the widening cracks of our social welfare programs.	Jan 20, 2011 9:37 AM
101	This is slowly improving	Jan 20, 2011 8:15 AM
102	I feel we do a good job of identifying these children yet as they become older it is more and more difficult to have them finish school and receive job training and support as they age.	Jan 20, 2011 6:52 AM
103	not adequate transitation services.	Jan 19, 2011 2:19 PM
104	As one educator told me, "we only need to provide you a vehicle, not a cadillac" in terms of services and supports. Schools too often look to alternative programs to send child to. This limits children with disabilities from making important community connections and further isolate families from locate supports. Rural schools lack resources and options. It is good enough for students to show progress, and the bar is really low at times, in terms of making sure kids with developmental disabilities are being asked to perform at grade levels, which only further isolates them from peers and singles them out from other aspects of mainstream school participation.	Jan 19, 2011 2:09 PM
105	We have very good sp ed services but transition age youth who are mentally ill, especially those who have both mental illness and developmental disabilities, need some new models of care that will allow them to continue to grow and develop as young adults. The funding is not there and I currently have at least 2 young men on my caseload who are going to require long term adult supervision and care. Both of them currently receive services, but one of them will be able to continue after age 18 and the other will not due to funding issues. It is very worrisome.	Jan 19, 2011 1:34 PM
106	transition services are lacking as by the time the young adult reaches high school graduation or age 22 parents/families are stressed which can result in unsafe situations for the entire family.	Jan 19, 2011 1:09 PM
107	It really depends on your town and your advocacy skills.	Jan 19, 2011 12:54 PM
108	Again - if you don't know how to work around the systems stuff than you probably won't get the needed support or services.	Jan 19, 2011 12:52 PM
109	There are still bugs in working out transportation for some children. Transition services would equal a big red flag -- especially how to adequately help those that have issues that get in the way of planning and making plans for their own good!	Jan 19, 2011 12:51 PM
110	I think the educational system works pretty well for youth with special needs. I believe we can always improve on the services offered to teens.	Jan 19, 2011 12:45 PM

Page 3, Q7. How is Vermont doing in providing special education to children, including transition services to youth?

111	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
112	see above	Jan 19, 2011 12:28 PM

Page 3, Q8. How is Vermont doing in providing high-quality services and supports, and does it have ways to regularly evaluate them? (Quality Assurance)?

1	spotty around state; dependent on where family lives.	Mar 26, 2011 1:03 PM
2	I have been very discouraged by mistakes and laissez faire attitude. SLOW!	Mar 26, 2011 12:48 PM
3	I don't see much Quality Assurance, especially with state services.	Mar 26, 2011 12:41 PM
4	Too many agencies & regulations. Agencies demand conflicting with advice. Not consistent. One agency worker told me I had to let a disabled man talk about molesting my granddaughter. He had a "right to speech." It would be abuse if I didn't let him talk & describe what he did.	Mar 26, 2011 12:25 PM
5	Surveys	Mar 26, 2011 6:41 AM
6	You need a watchdog like me who spent 20 years on themountain healing. I quickly see "wrong" thigns when I relook at society.	Mar 26, 2011 6:10 AM
7	never seen any high quality services	Mar 26, 2011 5:53 AM
8	Not good in our area	Mar 26, 2011 5:45 AM
9	Fund independent non-profits/social workers as evaluators: with empowerment to change harmful actions!	Mar 24, 2011 10:36 AM
10	no checks and balances within the depts or agencies until it is way to late	Mar 21, 2011 7:37 PM
11	over site is spotty and not consistant	Mar 21, 2011 6:18 PM
12	Don't know how to access them easily. We are lucky to have state agencies and a post adoption agency to help us wade through this.	Mar 18, 2011 4:23 PM
13	I am not impressed with how privitized agencies seem to be. There is no where to turn to advocate or give input. The system is confusing and very few people understand the whole system. Agencies take policies and use them however they want. There is no connection between SLPs, support workers, PCAs, or families. When opportunities like this arise for input, it never seems to amount to results.	Mar 16, 2011 9:17 AM
14	I am not sure...	Mar 15, 2011 7:41 AM
15	Yes I have appts with Jeff's case worker and his job case worker. These interactions are very positive as it is a time for feedback and recommendations for Jeff's quality of life.	Mar 15, 2011 5:15 AM
16	None for adults with autism	Mar 14, 2011 12:02 PM
17	Oversight is not happening and more documentation is not the answer. In a given day, more time is spent on CYA (covering your a..) than actually doing the work you are documenting about. This has to stop and there needs to be real oversight and accountability that is meaningful and motivating for everyone.	Mar 13, 2011 3:15 PM
18	There seem to be many evaluations built in as long as you are getting services. we are not doing so well documenting the services we can't provide	Mar 11, 2011 2:37 PM

Page 3, Q8. How is Vermont doing in providing high-quality services and supports, and does it have ways to regularly evaluate them? (Quality Assurance)?

19	Hard to evaluate what is not in front of you at all times. I believe the life of the client and what improvements have been made in their life and personal progress is the best evaluator.	Mar 11, 2011 1:35 PM
20	More money for Howard MH services for children. Wait lists are not acceptable.	Mar 7, 2011 10:29 AM
21	I'll let you know when I see them, the people I've worked with have been great. We need to get our great people in programs that work.	Feb 21, 2011 2:36 PM
22	Quality assurance has really diminished in the state and I don't think that anyone really has a handle on what is happening with some people with disabilities. Adult Protective Services is really weak and with as little oversight as there is of many placements, there could be really dangerous situations that we don't even know about. There needs to be better monitoring of developmental homes.	Feb 21, 2011 11:47 AM
23	I'm not sure how these are evaluated.	Feb 17, 2011 1:25 PM
24	The monthly home visits are important to this process as is having an involved guardian.	Feb 16, 2011 9:21 AM
25	The wage issue is the major concern here again.	Feb 15, 2011 8:24 AM
26	How does Vermont ensure quality assurance now? Many surveys are provided to recipients of programs, but how many actually provide feedback to the State? Is this an accurate assessment tool?	Feb 14, 2011 3:06 PM
27	Can't rate this, I don't know if there are regular evaluations or what the QA entails	Feb 14, 2011 8:13 AM
28	Higher criteria for educational background and experience is needed for hiring staff to work with children with disabilities in order to provide better quality of care instead of just baby sitters.	Feb 10, 2011 9:07 PM
29	V-HAP and the sliding scale plan based on income is excellent as well as VA medical benefits. Not familiar with how any services are evaluated. I have a Master's in Financial Economics and would have to statistically evaluate them myself before assuming high-quality.	Feb 10, 2011 11:48 AM
30	In Vermont, and particularly southern Vermont, I feel like we have to "take what we can get." Our home program coordinator is woefully underprepared to implement a home program. The mantra has been that it is difficult to find a behaviorist in this area. My son continues to get the short end of the stick when it comes to training of PCA staff.	Feb 8, 2011 1:59 PM
31	again no accountability	Feb 8, 2011 10:42 AM
32	This would be an interesting study.	Feb 7, 2011 2:39 PM
33	See above - the disparity between services in various areas is HUGE.	Feb 7, 2011 2:37 PM
34	I don't know and don't have a sense that anyone evaluates the services.	Feb 7, 2011 12:33 PM
35	I am not asked to regularly evaluate the services my son does receive so I am unsure as to how to answer this question.	Feb 7, 2011 12:20 PM

Page 3, Q8. How is Vermont doing in providing high-quality services and supports, and does it have ways to regularly evaluate them? (Quality Assurance)?

36	CDC has declines in their ability to provide adequate diagnosis and support	Feb 7, 2011 10:57 AM
37	No info	Feb 7, 2011 9:59 AM
38	Difficult to keep high quality staff/clinicians with such low salaries. Due to budget cuts, more work for folks making it increasingly difficult to attend to cases as closely as they should be.	Feb 7, 2011 9:49 AM
39	The program review process delivered by DAIL seems cumbersome, intrusive, excessively long, and unencumbered by any knowledge (or desire to know) of the community system. The focus seems to be on what the bureaucrats think a system/services 'should be' with little regard to what might be possible and less regard for what alternatives might be available. The evaluators seem more concerned with evaluator defined, politically correct best practices than on practical solution to serve people with the resources available.	Feb 7, 2011 8:29 AM
40	I don't think that there are good checks and balances to insure highest qualified providers.	Feb 7, 2011 8:19 AM
41	Can you describe the supports and services you're asking us to rate? I have trouble seeing how you're going to get accurate helpful info from this survey when it's so vague!	Feb 6, 2011 5:53 AM
42	The services and types of help that are offered are EXCELLENT but evaluating them, seeing if they really do what they are supposed to - if they really effect the change that is anticipated - that is lacking. This is what leads to abuse of the system and resentment from many sides - including clients and community members	Feb 5, 2011 9:41 AM
43	I'm not a fan of the Evals that have come our way . I think a lot of the people that do these evals don 't like to step on the schools toes so they go with the schools opinion. Again these evals should be about our children! My child had a Speech Pathologist that would speak her mind at meetings (she is awesome) the school ignored her recommendations. The school s need to EVALUATE the Teachers!!!!	Feb 4, 2011 9:00 AM
44	getting there with c3 but not there yet	Feb 3, 2011 4:22 PM
45	Some agencies seem to get away with their own agenda.	Feb 3, 2011 2:26 PM
46	we have slipped terribly .. quality assurance folks - where are they ? how to hey measure outcomes ? from their desks in waterbury ?	Feb 2, 2011 12:04 PM
47	-There doesn't appear to be any systematic review of how dollars are spent relative to best practices in services, supports, including transition to adult services. -Many services and supports that are being created use public dollars to segregate people with developmental disabilities from the general population still. These programs can be deceiving as many take place in the community but there is little attempt to support involvement in the typical activities with typical peers. Rather, the people with developmental disabilities may travel as a group. Suggestions: -Awareness of the importance of inclusion of all people with developmental disabilities in community life. -Criteria used to prevent dollars being spent to support segregated programs. -Funding for transportation and adaptations that increase participation in local, regional, state community	Feb 2, 2011 11:53 AM

Page 3, Q8. How is Vermont doing in providing high-quality services and supports, and does it have ways to regularly evaluate them? (Quality Assurance)?

48	Continue doing surveys and giving opportunities for parents to vocalize what needs are through groups such as Families Together group.	Feb 2, 2011 11:30 AM
49	More training for administrators, regular ed teachers and special ed teachers. You cannot just train special educators--all levels must be on board for a high standard to exist.	Feb 2, 2011 11:07 AM
50	I'm not sure what quality assurance methods are being used to evaluate the quality of Vermont's services & supports. I believe I have received a survey or two in the mail for that purpose but it doesn't seem to be a regular process. Perhaps online oriented surveys that individuals and families can complete on a regular basis--first to establish baselines and then to measure improvements in certain areas as needed.	Feb 2, 2011 10:37 AM
51	I have not seen any Quality Assurance (Improvement). When i have asked i have been told everything is good, with no indication how we know that.	Feb 2, 2011 10:32 AM
52	Perhaps "high quality" is too subjective a term....I believe in a "best practice" model for all aspects of care and support and I believe that is lacking in VT....and certainly this survey might be the first steps in developing a QA process and some accountability for services provided.	Feb 1, 2011 10:19 PM
53	Do not see competence at the top particularly for autism, never seem to follow up on parent recommendations such as this survey and QA seems to go nowhere.	Feb 1, 2011 1:17 PM
54	I am not sure if ways that Vermont regularly evaluate services and supports. Hopefully they are utilizing resources like VFN, CIS, etc.	Feb 1, 2011 12:49 PM
55	I would stress the need for more proactive services and supports that reach beyond the students in the high needs category. Reaching beyond will reduce the number of children/adults that need services at a later time in their life. I truly think the 504 system needs to be reevaluated and become part of a full RTI system for all children, wherever they fall on the developmental spectrum.	Feb 1, 2011 11:13 AM
56	I am not sure what the QA measures are that may or may not be in place. I have been very pleased with the special help of UVM's I-Team consultants and their parent support person, Tammy Wiley.	Feb 1, 2011 10:43 AM
57	People need more training, esp related to Autism Spectrum Disorders.	Feb 1, 2011 8:19 AM
58	I think there is a system set up to evaluate the supports but unless the parent knows their rights and is a bulldog about pursuing them, they are not always evaluated or even administered. I just found out I signed a waiver giving up my rights to have an eval.done for my daughter's IEP. I was told it was not required because she wasn't quite 6 yet. I didn't realize it was her right and how much she would benefit from the eval. going forward.	Feb 1, 2011 7:09 AM
59	Funding keeps getting cut for the programs that are needed and working!	Jan 31, 2011 5:03 PM
60	Fair but more should be done.	Jan 31, 2011 8:58 AM
61	Long way to go	Jan 29, 2011 4:48 PM
62	don't know	Jan 28, 2011 3:05 PM

Page 3, Q8. How is Vermont doing in providing high-quality services and supports, and does it have ways to regularly evaluate them? (Quality Assurance)?

63	Not aware of much	Jan 28, 2011 9:58 AM
64	This is a process that is always changing to better itself.	Jan 27, 2011 3:34 PM
65	Not sure what you are referring to here.	Jan 26, 2011 1:29 PM
66	I don't know	Jan 26, 2011 12:43 PM
67	we try to give my son everything he needs on his IEP	Jan 26, 2011 11:19 AM
68	I fill out lots of forms and questionnaires...and maybe I see a result sheet..but not the actual improvement.	Jan 26, 2011 10:35 AM
69	If you can access Howard they are beyond amazing. Why should a child be failing and in crisis to be able to access this type of quality services?	Jan 26, 2011 8:04 AM
70	Don't know	Jan 25, 2011 5:08 PM
71	What supports are provided are good but with money being less and less available, system priorities tightening and need increasing, our good record is eroding.	Jan 25, 2011 1:48 PM
72	What services Vermont provides, is very good, but more funding is needed.	Jan 25, 2011 12:21 PM
73	We evaluate our own programs with teacher and parent written evaluations, student feedback and videotapes of our classes.	Jan 25, 2011 11:19 AM
74	Quality Assurance has been drastically undermined by the cuts of the past 3 years. It used to be that everyone could expect to have their program reviewed every 3 years. Now I've been told that it is unlikely that my son's program will be reviewed for the next 10 years. The number of QA personnel at DS have been cut drastically, and they admit themselves that they can no longer conduct the same level of review as in the past. Now it depends on the agency--if they have strong values regarding quality, the quality will be maintained. If they don't, the quality of service will likely decline.	Jan 25, 2011 10:50 AM
75	Beyond the special ed monitoring system who monitors services for people with special needs? I'm not aware of a systematic way that VT monitors their agency services.	Jan 25, 2011 9:00 AM
76	No one really checks on this.	Jan 25, 2011 8:36 AM
77	Employment has always had a mechanism for tracking quality assurance through statistics of how many consumers are working in quality jobs. As funding becomes more difficult I see a movement toward documentation being tied to ISA goals. This should provide more quality assurance and concrete evidence of how funding can improve lives.	Jan 25, 2011 8:22 AM
78	she is evaluated every year and a program is set up for her care.	Jan 25, 2011 7:50 AM
79	This question is not completely clear, are you looking for answers in our out of schools. Services and supports are far and few and most don't collaborate including schools. So it would be hard to review these services to make sure they are all working.	Jan 25, 2011 7:36 AM

Page 3, Q8. How is Vermont doing in providing high-quality services and supports, and does it have ways to regularly evaluate them? (Quality Assurance)?

80	FIT is awesome...everything else has been a disappointment.	Jan 25, 2011 6:33 AM
81	laying the expectations that support staff be better qualified did help and the evaluation process that accompanied too.	Jan 25, 2011 6:15 AM
82	Most direct services are provided by untrained amateurs, while professionals do case management, evaluation, and have lots of meetings to discuss what the amateurs will do next.	Jan 24, 2011 7:40 PM
83	I am not saying anyone is good or bad. Maybe it is just because no one has ever really told me what the agency is all about. I would be open to learn more.	Jan 24, 2011 7:22 PM
84	Yes 1)evaluation process, 2) accountability - how are we doing has to be priority. Input from all team members.Goal setting . Making the goal.How we going to get there.	Jan 24, 2011 6:40 PM
85	The services available are regularly evaluated. There should be a measuring tool about the children these services are not sufficient for.	Jan 24, 2011 4:48 PM
86	The state should bring back the Consumer Quality Reviewer Position. Reduce paper work for case managers.	Jan 24, 2011 4:24 PM
87	Not familiar with any quality assurance efforts on the past of the state.	Jan 24, 2011 3:40 PM
88	Re: quality assurance....this should be studied. It does not make sense that MH agencies interview consumers who are unable to understand or answer the question with accuracy, yet do not first obtain the opinion of parents, caregivers , shared living providers , etc. as to the appropriateness of these questions to the adult child/consumer.	Jan 24, 2011 3:06 PM
89	Surveys are good for professionals, how are consumers being reached?	Jan 24, 2011 2:30 PM
90	Hlgh quality services are difficult to provide with the recent budget cuts. Quality assurance is not done as regulary as in the past due to budget cuts.	Jan 24, 2011 2:11 PM
91	don't know	Jan 24, 2011 2:08 PM
92	Good heavens, do they regularly evaluate the services and supports? News to me!	Jan 24, 2011 1:58 PM
93	I don't really know	Jan 24, 2011 1:52 PM
94	I get and complete surveys from the agencies we work with every year but I never hear anything back and I don't know how the individuals providing service are evaluated.	Jan 24, 2011 1:37 PM
95	If your child is in a school with high quality special ed staff you are all set. That is not standard throughout the state.	Jan 24, 2011 1:34 PM
96	No. the system is set up for self proclaimed experts, and self proclaimed excellence in service. Who at the state would evaluate service for Autism? Our current specialists has no direct experience or education.	Jan 21, 2011 10:19 AM

Page 3, Q8. How is Vermont doing in providing high-quality services and supports, and does it have ways to regularly evaluate them? (Quality Assurance)?

97	Sometimes it seems as though there are a lot of man-hours spent on reviews and accountability formula that could be put to better use in hands on supervision and support programs.	Jan 20, 2011 9:37 AM
98	There is no internal review system. Once a waiver is approved, I do not think anyone at the local level reviews it from a utilization perspective. You are expending money which is not being used as it was intended.	Jan 20, 2011 8:15 AM
99	As a DCF worker after a child leaves our care i rarely hear if our interventions were successful. if there are studies being performed on children who leave State's custody and where they are are a year, 5 years out i don't know where or how to access this information. We spend a ton of money yearly of children in custody yet we do not know if our interventions helped without input from the adults who had these services as a child.	Jan 20, 2011 6:52 AM
100	apparently not. DS directors need to have less control and more oversight	Jan 19, 2011 2:19 PM
101	There are a few really great providers and services. It is hard to access them as they are in such high demand. Parents know who and what is valuable to them.	Jan 19, 2011 2:09 PM
102	I believe Vermont does provide high quality services. I also believe though that the current Quality Assurance evaluation relays on a system that is not objective; in it's appropriate zeal for partnering (state and community mental health service providers) the state has lost it's edge in an effective audit management.	Jan 19, 2011 2:00 PM
103	Nothing noted of concern.	Jan 19, 2011 12:51 PM
104	I am really not sure how DD services are evaluated around the state. Like many programs they are understaffed and under funded.	Jan 19, 2011 12:45 PM
105	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
106	Becasue eveything goes through the designated agencies and there is no supervisory oversight of the DA's each one gets to decided what they will and will not do.	Jan 19, 2011 12:28 PM
107	Supports are as good as they will get with the lack of training, supervision and oversight. We are handing people to well intentioned folks and saying good luck.	Jan 18, 2011 12:07 PM

Page 3, Q9. How is Vermont doing in providing individualized services, including choice about supports, services, and providers?

1	Families often have to settle for what's available, so most don't have choices. Chittenden County provides a few, but often families don't hear about the 3 private non profit choices.	Mar 26, 2011 1:03 PM
2	Everyone (agency) is different. Personally I think anyone should have choices about their services.	Mar 26, 2011 12:41 PM
3	Offer choices but choices not available. Long waiting lists. Too much talk of cuts to needed services.	Mar 26, 2011 12:25 PM
4	Due to eligibility issues, no supports are available although my grandson has several issues.	Mar 26, 2011 6:41 AM
5	except for DD cuts	Mar 25, 2011 12:09 PM
6	-access - case management - communications and independent review: personal care review every six months.	Mar 24, 2011 10:36 AM
7	I don't believe that individuals and families are aware of all their options	Mar 21, 2011 6:18 PM
8	Not sure about this	Mar 18, 2011 4:23 PM
9	While individual services are provided, there is a huge lack of flexibility within the system. The current model is only good for some people but is not nearly as effective as it could be for most. Inclusion seems more important than success. Inclusion isn't the only measure of success.	Mar 16, 2011 9:17 AM
10	Very poor for adults with autism. Listen to the parents.	Mar 14, 2011 12:02 PM
11	This seems to be a little better with families taking the reins and saying NO to what is the expectation for them. But it is not easy for them to do this and no one offers them the choices. They find out about it from other families, not agencies. And until agencies are not so top heavy in executives (this goes for schools too) and more invested in doing than documenting, this will not change.	Mar 13, 2011 3:15 PM
12	Everything is very individualized - maybe it is time to also have group options	Mar 11, 2011 2:37 PM
13	Need more services in the south, special education needs to step up and build a program, that meets the recommendations in the MGT audit. Very few choices in the south with supports, services and providers. Choices would be welcomed.	Feb 21, 2011 2:36 PM
14	hoping	Feb 18, 2011 7:22 PM
15	When services are available, the providers do a ncie job of tailoring them to the family's needs.	Feb 17, 2011 1:25 PM
16	Sometimes the mold is a little hard to break. It is not always that one size fits all.	Feb 15, 2011 8:24 AM
17	The individual is the one who has to identify, request, and access a means of funding the support as well as find a provider unless it is part of FAPE, so I would guess that a streamlined process/procedure would help.	Feb 14, 2011 3:06 PM

Page 3, Q9. How is Vermont doing in providing individualized services, including choice about supports, services, and providers?

18	I don't agree with the idea of designated agencies. I think this system prevents agency from evolving their practices. I see the community benefitting from healthy competition. It is my understanding the the only way the individual can get services through an alternative agency is if they are refused services by the designated agency.	Feb 14, 2011 8:13 AM
19	We were able to choose our providers.	Feb 10, 2011 9:07 PM
20	Once again from what I have seen Vermont's Medical system is excellent and that includes recovery and mental health services.	Feb 10, 2011 11:48 AM
21	As stated above, there are few, if any, choices regarding well-qualified individuals trained to work with individuals with autism.	Feb 8, 2011 1:59 PM
22	A general Clearing house of potential supports would be useful so that consumers could go to one place to see what is available. For instance, I don't know that people know that they can shop around for a Comm. Mental health Center....at least I think they can?!	Feb 7, 2011 2:37 PM
23	Don't know	Feb 7, 2011 12:33 PM
24	I think there is a need for mor pay for more qualified educational assistants.	Feb 7, 2011 12:20 PM
25	In most areas, it seems that there is little choice in agency that provides supports and services. I understand that to have several agencies in an area, especially a rural area, would be prohibitively expensive	Feb 7, 2011 9:59 AM
26	We do a good job of talking about this and congratulating ourselves than we do in delivering good services with the resources available.	Feb 7, 2011 8:29 AM
27	I'm not sure what you're asking, but my son has an individual support agreement with Howard and they are very family centered and we are very involved in choosing goals, etc.	Feb 6, 2011 5:53 AM
28	Get rid of the Designated Agency system and allow more choice. RMHS is terrible. They are terrible to staff and to clients, they only care about \$. Ask anyone that has worked there, which is about half the town. You need affordable day care if single mom's are going to get jobs. See The Motherhood Manifesto at Mom's Rising.com	Feb 5, 2011 8:55 AM
29	c3 is allowing more flexibility. state needs to understand more about non-verbal folks who communicate too.	Feb 3, 2011 4:22 PM
30	Choice seems limited when someone is on medicaid	Feb 3, 2011 2:26 PM
31	the slow erosion of choice breaks my heart and is the reason we no longer self manage	Feb 2, 2011 12:04 PM
32	Some choice and control exists but often the program/personnel running program decide what is available Often school personnel/ care providers use what is in their 'tool box' regardless of appropriateness for individual Time and funds for training have been decreasing over the last few years though this is variable from school to school Suggestions: Build awareness of the importance of self-advocacy and self-determination principles Training program(s) especially for personnel working with students/adults with more complex needs	Feb 2, 2011 11:53 AM

Page 3, Q9. How is Vermont doing in providing individualized services, including choice about supports, services, and providers?

33	Again, varies greatly depending on quality and training of special educators and staff.	Feb 2, 2011 11:07 AM
34	In this area I feel that Vermont strives to respect choice and providing individualized services. Its more than just the system but almost the way of many Vermonters. This is why I live here. I think a Public Service Announcement or other community effort to continue to encourage that Vermonter spirit of community, cooperation and respect would be a great way to continue to encourage this mentality among the Vermont community.	Feb 2, 2011 10:37 AM
35	There is an illusion of choice. Choosing something other than the standard results in reduced funding.	Feb 2, 2011 10:32 AM
36	As noted in #8	Feb 1, 2011 10:19 PM
37	None need adult autism sevices by competent people who actally understand autism. The people we work with just do not have any concept and think anyone with autism must have a very low IQ. This just isn't true even most in state administration seem to cling to this idea.	Feb 1, 2011 1:17 PM
38	Again, depending on who the person has for a case worker may determine what supports they get.	Feb 1, 2011 12:49 PM
39	Expand the PCA pilot project!!! (see above)	Feb 1, 2011 8:19 AM
40	Agian, I think the options are available but educating ourselves about them is very difficult. I feel like I am reinventing the wheel most days.	Feb 1, 2011 7:09 AM
41	My son is 17 and like I said the older he gets the less is available. How do I find out what there is?	Jan 31, 2011 5:03 PM
42	Once again, once I find out about available services and ask about them, I will admit they are very accessible...BUT...the state needs to become more forward with info for parents and caregivers	Jan 29, 2011 4:48 PM
43	Teams need better facilitation. Meeting agendas tend to be shrouded in very mysterious process. While agendas can't be made with cookie cutters, the process needn't be demoralizing.	Jan 28, 2011 3:05 PM
44	Son should have been offered other options	Jan 28, 2011 9:58 AM
45	Not sure what you are referring to here.	Jan 26, 2011 1:29 PM
46	I think the lack of money and man power hurts everyone	Jan 26, 2011 12:43 PM
47	I feel that we do our best in our agency to self empower the individuals we serve. We have some amazing Program Managers who really work on the client's being strong self advocates.	Jan 26, 2011 12:34 PM
48	Case Mangers and other service professionals struggle putting clients first. This is particularly true when a non-guardian parent's wishes are contradictory to the clients. Further education for support workers and caser manger's regarding guardianship and client services should be emphasized.	Jan 26, 2011 12:07 PM
49	i have no info on supports, services and providers	Jan 26, 2011 11:19 AM

Page 3, Q9. How is Vermont doing in providing individualized services, including choice about supports, services, and providers?

50	Choices have to be presented to parents and then allowed access.	Jan 26, 2011 10:35 AM
51	My main experience is with "mental illness." I think Vermont does fairly well helping those who are accepting of such services and supports.	Jan 25, 2011 5:08 PM
52	quite frankly, it's a crap shoot. You get what you get, there do not seem to be any choices at all.	Jan 25, 2011 4:06 PM
53	same concerns	Jan 25, 2011 1:48 PM
54	Due to funding, these services are definately affected. What they can provide is good, it is just very limited.	Jan 25, 2011 12:21 PM
55	Not involved in this aspect	Jan 25, 2011 11:19 AM
56	In our case, very well; however, some agencies are moving to congregate day programs and may be contemplating congregate residential settings. If this is really the desire of the individual receiving services it is one thing; if it is imposed as the only choice by the agency, it is going in the wrong direction.	Jan 25, 2011 10:50 AM
57	Insurance/medicaid dictates what families can access	Jan 25, 2011 9:56 AM
58	I really believe more should be done to help people make connections to the organizations and medical facilities that can best help the individual. VT should not be in the service of supporting one Medical Ctr if it does not have the knowledge.	Jan 25, 2011 8:36 AM
59	I think VT is the leader in this arena - we just have to figure out how to continue this approach more effciently.	Jan 25, 2011 8:22 AM
60	Yearly reports are helpful	Jan 25, 2011 7:50 AM
61	I think Vermont is doing better than some states but still has a lot of room for improvements.	Jan 25, 2011 7:36 AM
62	PCA money should be more flexible. It should be possible to pay PCA's more for the purpose of retaining good workers. It isn't even close to a livable wage. It limits hiring choices. Additionally, it should be possible to use funds for swimming, and rec activities tha will enhance person's life.	Jan 25, 2011 6:33 AM
63	often there is not lots of choice as what is available in the community limits those types of options.	Jan 25, 2011 6:15 AM
64	Services can happen as long as the person with a disability has a good advocate.	Jan 25, 2011 5:32 AM
65	Can you explain?	Jan 24, 2011 7:22 PM
66	Needs work.Train highly skilled people. Evaluate their performance annually. Give incentive plans for high achievement teams. Just like a private company! The evaluator needs to have specific training in this . Recruit these highly skilled people from the private sector!	Jan 24, 2011 6:40 PM
67	once again, it depends on where you live and the availablility of services and providers	Jan 24, 2011 4:48 PM

Page 3, Q9. How is Vermont doing in providing individualized services, including choice about supports, services, and providers?

68	Wrap services where homeprovider does all jobs/community support day programs	Jan 24, 2011 4:24 PM
69	EEE services were individualized as are all the school based services.	Jan 24, 2011 3:40 PM
70	i can choose the DME provider which is good as I have changed once. i would like to have choice of PT, but there are few in area and we get what we get. I would like somebody to provide hippotherapy but i lost that battle with CSHN years ago.	Jan 24, 2011 3:32 PM
71	Consumers choice individualizes everyone services.	Jan 24, 2011 2:11 PM
72	Your choice is your designated agency. So, there is not choice!	Jan 24, 2011 1:58 PM
73	Don't know	Jan 24, 2011 1:52 PM
74	I often feel that the services are there, or may be there, but I just don't have the information to find out, and I don't get the guidance from our case manager either. I often find out the most useful information from other parents!	Jan 24, 2011 1:37 PM
75	Lack of providers available	Jan 21, 2011 2:12 PM
76	it is to individualistic not state best practices. It is a sea of gobbled, cobbled services. NO consistencies within schools, year to year, class to class , etc	Jan 21, 2011 10:19 AM
77	This is limited when we have to contract with our Designated Mental Health Agency and they are not providing services that are as good as other providers in the community.	Jan 21, 2011 8:30 AM
78	Again, the cracks are widening and unless there are increased supports, many individuals and families will descend into oblivion.	Jan 20, 2011 9:37 AM
79	I do not think services are individualized. A package is offered and if it does not meet the needs and is not used by the family, the family is viewed as not cooperative and unable to use what is offered. There does not seem to be much consideration given to what the family really needs or meeting the family at their level.	Jan 20, 2011 8:15 AM
80	In our system of care the person does not get to choose their workers and in most cases there are mandates in place for which services they qualify for. Also to recieve one service say medicaid the person neds to fill out forms for food stamps, fuel assistance etc etc etc. WHY? if they only need the one service?	Jan 20, 2011 6:52 AM
81	understaffed	Jan 19, 2011 2:19 PM
82	Services are not individulized, particularly at Community Mental Health Agencies. They offer cookie cutter programs and services. Private agencies are better at offering individualized programming to meet a child's or family's need, but there is an expense to access private services.	Jan 19, 2011 2:09 PM
83	Nothing noted of concern.	Jan 19, 2011 12:51 PM
84	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
85	There is no choice. Families must go to the DA for any service.	Jan 19, 2011 12:28 PM

Page 3, Q9. How is Vermont doing in providing individualized services, including choice about supports, services, and providers?

86 Compared to other states, pretty good.

Jan 18, 2011 12:07 PM

Page 3, Q10. How is Vermont doing in providing education about civil and other rights and self-advocacy?

1	Very Good compared to other states. Okay in terms of what yet needs to be done. GMSA are publicly engaged & a strong advocacy voice. VCIL has eom excellent staff, but limited visibility.	Mar 26, 2011 1:03 PM
2	VCIL does a good job educating people. However they need more advocacy dollars to continue and reach people.	Mar 26, 2011 12:41 PM
3	Mostly agencies getting money. Clients not getting help.	Mar 26, 2011 12:25 PM
4	As long a syou know what resources are available.	Mar 26, 2011 6:41 AM
5	I would like to know how to stop abuse from your sisters? Is there any law when one takes from you and does not return?	Mar 26, 2011 6:26 AM
6	Police are knocking on doors in a threatening way. People need to know how to answer them.	Mar 26, 2011 6:10 AM
7	Contributing to our staying "out of the system" is the demeaning attitude and presentation of service providers -- BAD experience w VOC REHAB worker!	Mar 26, 2011 5:45 AM
8	VFN Lori provides assistance.	Mar 25, 2011 12:09 PM
9	not one local system in providing protections = no empowerment. Often parties fear even reporting out of fear of retaliation - exploitation!	Mar 24, 2011 10:36 AM
10	great for people who can get to voices and choices conference not so much for those who don't and there seems to be a prevailing opinion that people with DD need guardianship always?	Mar 21, 2011 6:18 PM
11	As always, it comes down to where to easily access the information.	Mar 18, 2011 4:23 PM
12	I believe most people have no idea how to advocate. I have tried to no avail. I keep being told things like we are too busy cutting the budget or the administration is new so they are getting their feet wet.	Mar 16, 2011 9:17 AM
13	I attended the fall VT FAmily Network conference and was very impressed with the activities and supports available to educate and advocate for self-advocacy.	Mar 15, 2011 7:41 AM
14	Jeff is not signed up to be a voter and that happened as a result of HCRS assisting with this process.	Mar 15, 2011 5:15 AM
15	If there is nothing to get then education about civil rights is wothless.	Mar 14, 2011 12:02 PM
16	Some areas do this well, some not so well. Having programs for self advocacy is great but really allowing folks to exercise their rights would be the answer.	Mar 13, 2011 3:15 PM
17	Need self advocates more visible and vocal in the south.	Feb 21, 2011 2:36 PM
18	Many people do not know or understand their rights.	Feb 21, 2011 11:47 AM

Page 3, Q10. How is Vermont doing in providing education about civil and other rights and self-advocacy?

19	hoping - trying to get funding through EPSCOR (the NSF and VT is one of the states that is involved in the way that I hope the NSF will understand my research... better than here in CT, where the only "work" is money. That is not only an imprecise/incorrect STUPID definition - it makes no sense. "Financial services" there are only too few actual servants - the problem. Meaning: if you're job is to hand over the mortgage, the stocks/shares blah blah blah... those monies initiated from promises that were BROKEN LIES.	Feb 18, 2011 7:22 PM
20	When you have an active guardian this is well handled.	Feb 16, 2011 9:21 AM
21	Can I tell you how many times I've been told to read the Parental Rights? How many have referred me to Wright's Law? IDEA Part B, Rehab Act 1973, ADA, 7CFR Part 15 and so on? Many disabled individuals are unable to advocate for themselves, and many more are not educated about their civil and other rights. It's their care providers, friends, family, etc. that do so for them. They are the ones spending the time to research the legal reference as to why an accommodation must be made and why a disabled person has the right to request the service and/or accommodation. It is not automatically done through the education of the disabled individual, but more so, the education of the individual, agency or organization refusing the accommodation/service.	Feb 14, 2011 3:06 PM
22	Not sure	Feb 14, 2011 8:13 AM
23	I haven't seen any education on these topics.	Feb 10, 2011 11:48 AM
24	I am not aware of any education in this area.	Feb 8, 2011 1:59 PM
25	I'm not sure but again, I don't think people know where to go to lodge a complaint.	Feb 7, 2011 2:37 PM
26	Don't know....because I haven't heard much...so maybe that means they could do better.	Feb 7, 2011 12:33 PM
27	I have been provided with the reading material in the past but having someone sit down and explain the information is better. Sometimes it's hard to understand what you don't know until you are able to discuss it with someone who is more knowledgeable.	Feb 7, 2011 12:20 PM
28	Don't know.	Feb 7, 2011 8:29 AM
29	Not sure - I don't see "Vermont" as providing these - we've searched it out on our own by connecting with other families, role models in the community, etc.	Feb 6, 2011 5:53 AM
30	hospital is ill equipped to handle individuals with communication gaps. we need to get these supports in place. these are people too that have rights, however they need support! and the families of these people too.	Feb 3, 2011 4:22 PM
31	I think it depends on the area of the state one is in.	Feb 2, 2011 12:29 PM
32	although grossly underfunded , GMSA and those self advocacy initiatives are a bright spot in a dismal picture	Feb 2, 2011 12:04 PM
33	I am aware of training that is provided on an ongoing basis in the bullying and harassment area. Not sure of the current status or funding level for Green Mountain Self Advocates Suggestions: Continue to support above groups	Feb 2, 2011 11:53 AM

Page 3, Q10. How is Vermont doing in providing education about civil and other rights and self-advocacy?

34	Certainly much stronger than it has been in the past.	Feb 2, 2011 11:30 AM
35	Again, more training and better ways to share information.	Feb 2, 2011 11:07 AM
36	I think Vermont is excellent at this from my family's experience. In many ways my answer is biased as I have always been our advocate (based on my profession & training).	Feb 2, 2011 10:37 AM
37	Unsure.....as parents we are the primary advocates for our children, both able bodied and disabled.	Feb 1, 2011 10:19 PM
38	Lip service only. I have been to far too many fake meetings and advisory committee meetings to waste any more of my time when none of the recommendations of the group as a whole are followed atleast as far as adults are concerned. I know many other people who will no longer attend such meetings.	Feb 1, 2011 1:17 PM
39	I think every high school should have an ASD support group and be more public about the educational strengths and needs of this group. It is a continuum disorder - and while I think students on one end of the spectrum receive services - I think it is mostly because these individuals would disrupt learning, create unsafe situations for themselves/others, and require additional support for their mandated education. If you are NOT at this end of the ASD spectrum, you are pretty much invisible. I think my daughter would say this as well I've seen her develop a voice after many years, and she has learned to accept her ASD qualities. But, I do think the wider school community, staff and students, need a better understanding of autism as a spectrum disorder. She struggled w/ some self esteem issues, and I do think a more accepting community would have helped.	Feb 1, 2011 11:13 AM
40	We have been given information on several occasions from several different sources regarding self-advocacy.	Feb 1, 2011 10:43 AM
41	I have utilized the I-team and VFN for guidance and education here.	Feb 1, 2011 7:09 AM
42	To improve the situation people need to know what is out there.	Jan 31, 2011 5:03 PM
43	State is trying to establish statewide self -advocacy...doing okay but still a fairly new project.	Jan 29, 2011 4:48 PM
44	don't know	Jan 28, 2011 3:05 PM
45	There are sources if you dig	Jan 28, 2011 9:58 AM
46	Civil rights in Vermont? ROFLMFAO.	Jan 27, 2011 11:39 AM
47	Case Mangers and other service professionals struggle putting clients first. This is particularly true when a non-guardian parent's wishes are contradictory to the clients. Further education for support workers and caser manger's regarding guardianship and client services should be emphasized.	Jan 26, 2011 12:07 PM
48	see above comment	Jan 26, 2011 11:19 AM
49	A parent must fight continually for their child to receive minimum services.	Jan 26, 2011 10:35 AM

Page 3, Q10. How is Vermont doing in providing education about civil and other rights and self-advocacy?

50	This depends on the quality and availability of the case manager and whether or not they are over loaded.	Jan 25, 2011 1:48 PM
51	They are doing as best they can with the funding that is available.i	Jan 25, 2011 12:21 PM
52	Not involved other than the leadership training we do as part of the horse therapy	Jan 25, 2011 11:19 AM
53	GMSA is good about informing people about their rights, especially using resources from VSA. DRN (P & A) and the Disability Rights Project are working diligently to protect people's rights. VCDR has improved its legislative update system, and does a good job of Disability Awareness Day. DRN is good at disseminating information about voting.	Jan 25, 2011 10:50 AM
54	Not until a complaint is made do families realize what their rights are.	Jan 25, 2011 9:56 AM
55	Very limited resources to support self advocates. At one point the state had only 1 person at the State level doing this - think they may have had their job cut? How can the 1000's of adults with intellectual disabilities have access to opportunities and support to advocate. Their voices are minimized by the lack of support state wide	Jan 25, 2011 9:00 AM
56	More should be done by non biased people. I recently attended a leadership series that was so politically derogatory towards republican politicians I felt extremely uncomfortable. More needs to be ensure that the assistance is not a way to indoctrinate one political parties views.	Jan 25, 2011 8:36 AM
57	she is trying to learn about self advocacy, by being allowed to communicate by typing her message.	Jan 25, 2011 7:50 AM
58	I know there are groups out there for this but you have to be linked with a mental health agency to hear about them and not everyone is.	Jan 25, 2011 7:36 AM
59	even in early education as part of the social emotional development, children are being offered and supported.	Jan 25, 2011 6:15 AM
60	Would need to talk about this too.	Jan 24, 2011 7:22 PM
61	A good case mgr trained in this would be essential in teaching the families what this means and their means of resource.	Jan 24, 2011 6:40 PM
62	The state needs to make a commitment to supporting self advocacy! It is the promise that was made when Brandon was closed!	Jan 24, 2011 4:24 PM
63	We are not there yet.	Jan 24, 2011 3:40 PM
64	VCIL is good resource. HRC does not seem to enforce laws to protect students with disabilities. It would be nice is ADA education were provided in schools along with other civil rights laws.	Jan 24, 2011 3:32 PM
65	Once a year information is provided to every consumer at our agency regarding rights and self-advocacy.	Jan 24, 2011 2:11 PM
66	Vermont Family Network has been very helpful!	Jan 24, 2011 1:58 PM
67	No sure	Jan 24, 2011 1:52 PM

Page 3, Q10. How is Vermont doing in providing education about civil and other rights and self-advocacy?

68	GMSA is great. It would be nice if there was a statewide self-advocacy association for people living without disabilities too...	Jan 21, 2011 8:12 PM
69	Over the top. Need people who actual can do the work not just give advice.	Jan 21, 2011 10:19 AM
70	Vermont remains one of the most liberal states and whitest states in America. I rarely hear this as an issue/	Jan 20, 2011 6:52 AM
71	Once people are "in" at the DA, they sometimes get adequate education.....	Jan 19, 2011 2:19 PM
72	If you know where to look and who to talk to, then the information is available.	Jan 19, 2011 2:09 PM
73	The Developmental Disabilities Law Project has been extremely helpful in assistance for advocacy for families.	Jan 19, 2011 12:54 PM
74	I never hear about this issue one way or another!	Jan 19, 2011 12:51 PM
75	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
76	Is this even done? Where? How? With whom?	Jan 19, 2011 12:28 PM
77	GMSA does a bang up job where people know about them.	Jan 18, 2011 12:07 PM

Page 3, Q11. How is Vermont doing in advancing the rights of people with developmental disabilities and offering freedom from exploitation, abuse, and neglect? Examples are voting, protection from use of seclusion and restraint, effectiveness of Adult Protective Services, etc.

1	Very Good compared with other states. Not Good in RBI school statutes "Unnecessary pain" is being discussed in RBI school legislation -- not a good indicator of the thinking of some responsible for school policies.	Mar 26, 2011 1:03 PM
2	There are still problems voting. People w/ disabilities are usually poor & low income & do not have access to lawmakers. Not an equal voice.	Mar 26, 2011 12:41 PM
3	Rlghts for disabled. No rights or protections for caregivers.	Mar 26, 2011 12:25 PM
4	Police are knocking on doors in a threatening way. People need to know how to answer them.	Mar 26, 2011 6:10 AM
5	I feel that "we" are put on the "back burner" & are not taken seriously & are neglected often. It's like "our" obstacles don't exist!	Mar 26, 2011 5:57 AM
6	SA: Protective Service Leagal aid = Disability law - local police abusive of powers: Public Review Board/Grand Jury/Training!	Mar 24, 2011 10:36 AM
7	they need more people to do ckecks	Mar 21, 2011 7:37 PM
8	Things can always be improved but I think VT really works hard for these rights.	Mar 18, 2011 4:23 PM
9	I don't really know.	Mar 16, 2011 9:17 AM
10	I'm not sure VT is doing a good job of this for most Vermont children at risk of abuse, neglect, exploitation	Mar 15, 2011 7:41 AM
11	As previous, voting was brought about by HCRS	Mar 15, 2011 5:15 AM
12	Many in higher level positions dealing with autism turn a blind ear.	Mar 14, 2011 12:02 PM
13	In general, I have found APS to be miles ahead of DCF in regards to stepping in and making changes or helping when made aware of concerns. This is especially true with the severely physically challenged population. There is a tendency to not step in very quickly or well when there is 'no place to put them' which is something I have actually been told!	Mar 13, 2011 3:15 PM
14	I think Vermont is doing okay with this. This is one of those areas that depends on the quality of the home providers and the community outreach specialists, staff and whomever else. It takes a special person to do this work. You are asking the home provider to take on the tremendous job of keeping the client equal to all that he or she comes into contact with. Commitment is essential.	Mar 11, 2011 1:35 PM
15	I am very concerned about reports of seclusion and restraint at Allenbrook and Central schools in Williston. Perhaps a behavioral team that can travel and trouble shoot for schools where kids are out of control.	Mar 7, 2011 10:29 AM
16	don't know	Mar 2, 2011 8:48 AM
17	We could use more trainings through UCS	Feb 21, 2011 2:36 PM

Page 3, Q11. How is Vermont doing in advancing the rights of people with developmental disabilities and offering freedom from exploitation, abuse, and neglect? Examples are voting, protection from use of seclusion and restraint, effectiveness of Adult Protective Services, etc.

18	Many more people are educated about voting and actually do vote but any right that is dependent on money for services has either suffered or is about to with the budget cuts coming and the current emphasis on providing "bare minimum" services..	Feb 21, 2011 11:47 AM
19	we'll see	Feb 18, 2011 7:22 PM
20	I dont' believe there is consistency across the State with this issue. Restraint is a necessary tool for professionals to use to keep kids safe in their home schools but its safe use is not consistent across the State. Families also don't have access to training on how to do this safely even though many tell me that they have to restrain their children.	Feb 17, 2011 1:25 PM
21	I have seen more intervention regarding the rights of people with disabilities and Vermont is leading the way regarding inclusion. But, ideally, I would like to see physical restraint totally eliminated from the educational environments. Surely, there must be a better way. Many times the need for physical restraint comes from the educational environment failing to either identify or meet the need of the disabled individual for whatever the reason - budget, staffing, etc. I understand the need for safety, and recognize that sometimes it can't be prevented to ensure that no harm or damage occurs, but I wish we'd come up with an "out of the box" idea to meet the need.	Feb 14, 2011 3:06 PM
22	not sure	Feb 14, 2011 8:13 AM
23	I do not know so I can not answer.	Feb 10, 2011 11:48 AM
24	Can't respond as I do not know ...	Feb 8, 2011 1:59 PM
25	Not sure	Feb 7, 2011 2:39 PM
26	Not sure	Feb 7, 2011 2:37 PM
27	My son was sexually assaulted when he was 18 but no charges were ever issues due to it. He was assaulted by a man and Adult Protective Services said that he was "able to consent to this type of sexual contact." Since his developmental age was far below 18 I did not agree but without a confession by the aggressor the case was unable to move forward in the legal system.	Feb 7, 2011 12:20 PM
28	I think folks are going in the right direction however, given the example for banning restraints, people need to remember the individuals with severe intensive needs who often need restraints to keep them safe. If banning them, my fear is many of those individuals will no longer be able to be served in their community.	Feb 7, 2011 9:49 AM
29	APS investigations can long, cumbersome and costly. Decisions to investigate sometimes seem random.	Feb 7, 2011 8:29 AM
30	Don't know anything about these efforts	Feb 6, 2011 5:53 AM

Page 3, Q11. How is Vermont doing in advancing the rights of people with developmental disabilities and offering freedom from exploitation, abuse, and neglect? Examples are voting, protection from use of seclusion and restraint, effectiveness of Adult Protective Services, etc.

31	seclusion and restraints, this is an area that needs to be re thought So many ways it is wrong! I t degrades our children and people wonder why kids get violent,they are embarrassed because you are not looking at the situation to see that something is wrong and sometimes this is how the kid gets their point across. Better Training !	Feb 4, 2011 9:00 AM
32	APS seems overloaded and only chooses abuse cases and not neglect cases	Feb 3, 2011 2:26 PM
33	adult protective services is about to be sued .. its a travesty .. having worked at DCF and with DOC I am horrified at the level of care that they are provided and the di respect and ignorance of the DCF staff	Feb 2, 2011 12:04 PM
34	This is variable though in my experience students with complex, multiple disabilities continue to frequently be placed in educational programs that are segregated and are prevented from having access to interesting, rich learning experiences because of how they look and/or how they communicate. Suggestions: Training for all personnel working with people with developmental disabilities: least dangerous assumption, assistive technology, literacy and academic instruction as a basic human right and life long learning opportunity.	Feb 2, 2011 11:53 AM
35	Seclusion and restraint is getting looked at and Adult protective services.We need to continue to monitor these areas to protect the vulnerable.	Feb 2, 2011 11:30 AM
36	I think Vermont is striving to encourage community inclusion and safety from exploitation, abuse and neglect. I think the shortage of providers affects this effort by limiting the outreach though.	Feb 2, 2011 10:37 AM
37	The wait for Adult Protective services makes them useless.	Feb 2, 2011 10:32 AM
38	not sure about "advancing rights".....I beleive our system of reporting and monitoring abuse is a good attempt at maintaining safety for disabled individuals. As our children age, our knowledge base around these issues will broaden.	Feb 1, 2011 10:19 PM
39	Poor protection - just plain unsafe living conditions for many. Poor supervision, no emergency care, inappropriate care for some difficult cases. Again need cometenent people and care.	Feb 1, 2011 1:17 PM
40	Working-VCIL, disability rights Vermont, Vermont Family Network Effectiveness of APS-not good, I've been told they are short staffed and backlogged!	Feb 1, 2011 12:49 PM
41	My 6 year old daughter has had numerous aids this year due to injury of her primary aid. Her IEP clearly outlines a behavior plan. On day one of training a new long term replacement aid, I walked in the classroom to see my daughter being verbally abused and her behavior plan not adhered to at all. While the VTDOE clearly outlines what constitutes abuse, the school was not so quick to see the severity of the problem. If I had not educated myself (thru VFN) I would not have known that I have the right to ask for mediation. People in positions of educating those with developmental disabilities need to understand the disability they are dealing with.	Feb 1, 2011 7:09 AM
42	N/A	Jan 31, 2011 5:03 PM

Page 3, Q11. How is Vermont doing in advancing the rights of people with developmental disabilities and offering freedom from exploitation, abuse, and neglect? Examples are voting, protection from use of seclusion and restraint, effectiveness of Adult Protective Services, etc.

43	Adult Protective Services has a standard for intervention that is far too "hands off." Also- It is terrifying that an individual can be found criminally incompetent by a judge, but then, when finding oneself facing charges- having defended himself during a break in in his home- the previous standard set by a judge may not come forward in the proceedings. Further, they may not impact proceedings when they are brought forward.	Jan 28, 2011 3:05 PM
44	not happy about the situation at Lincoln Street - allowing a person who clearly qualifies for developmental services be responsible for another person with a DD and be PAID for it is questionable.	Jan 28, 2011 10:13 AM
45	I have heard some horror stories about restraints and discipline in the public schools - not sure what to believe. I do believe that the courts and Vermont law are on the side of the disabled and actively work to protect the disabled. Unfortunately for everyone in Vermont, disabled or not, there seems to be an old and ingrained cultural tolerance for domestic, spousal and child abuse. Vermonters are very good at "not casting the first stone", but that doesn't help in protecting the innocent and the vulnerable. I would like to see a MUCH more ambitious educational outreach aimed at identifying abusive behaviors and teaching all children and vulnerable adults how to see it coming, how to say no to it, and how to get help. THERE IS NO EXCUSE FOR ABUSE, OR FOR TOLERATING ABUSE.	Jan 26, 2011 1:29 PM
46	i have no idea	Jan 26, 2011 11:19 AM
47	A very broad question that depends on the individual situation. The mentally ill are still often sent to jail because of their illnesses and then "exploited" beyond belief. Those at VSH still are put in seclusion and restraints often, but this is usually done for safety reasons to patients who are violent and unable to perceive that they have the illness and thus refuse treatment. They are waiting for months for a judge to decide if they can receive "involuntary" treatment. (The psychiatrists are not allowed to prescribe for such patients. Judges decide.) Recommendations: 1. Stop criminalizing the mentally ill 2. Change act 114. Make it legal in Vermont to treat those who are psychotic and thus subjected to worsening illness, restraints, etc in a timely fashion, such as within about a week, not 2 or 3 months as is currently the case.	Jan 25, 2011 5:08 PM
48	it's getting better regarding seclusion and restraints but still, not even the standard that law enforcement and corrections must abide by	Jan 25, 2011 4:06 PM
49	Vermont has always been a leader in this area, and does a very good job in this area.	Jan 25, 2011 12:21 PM
50	There is nothing like being able to groom, lead, saddle, mount and ride a 1000 lb animal to increase self-esteem and foster a strong sense of what are and are not appropriate action and reactions!	Jan 25, 2011 11:19 AM
51	Compared to other states, doing well, but compared to what we want, still a ways to go. Students are still being restrained and secluded, and the effort to get prone restraint and seclusion banned is an uphill battle against the education organizations who oppose any ban. APS has been weakened by budget cuts; the number of people served by each Public Guardian has been increased.	Jan 25, 2011 10:50 AM

Page 3, Q11. How is Vermont doing in advancing the rights of people with developmental disabilities and offering freedom from exploitation, abuse, and neglect? Examples are voting, protection from use of seclusion and restraint, effectiveness of Adult Protective Services, etc.

52	See comment above. I believe there is a definite leaning of advocate supports in our VT community to try to push a very one sided political agenda. I personally feel it is in our best interest to give knowledge not mandate political agendas. I may want a lot of services for my child but I, as a citizen of VT, need be aware of all issues affecting VTers.	Jan 25, 2011 8:36 AM
53	time away rooms need to be vanished. They are over used and inappropriate. Essex Town Schools is an example of this. I haven't had any experience with an adult. I do think that safety officers in the schools helps in their understanding of the disabilities that kids face and they will be our future adults.	Jan 25, 2011 7:36 AM
54	strong point for our area	Jan 25, 2011 6:15 AM
55	mmm Interesting question. Complicated.	Jan 24, 2011 7:22 PM
56	Loaded question. You need to define all of that to families. Again case mgt is key.	Jan 24, 2011 6:40 PM
57	Not applicable	Jan 24, 2011 3:40 PM
58	I think people are in danger every day in Vermont and due to rural isolation and dependence on overstressed family care givers and small pool of underpaid PCAs, there is a lot of danger of abuse of those who rely on care to survive. Nobody reports to APS anymore as they know they won't do anything unless there is immediate threat of loss of life or limb.	Jan 24, 2011 3:32 PM
59	Disability Law Project and Vermont Center for Independent Living offer excellent supports and guidance in advancement of rights and protections from abuses for this population.	Jan 24, 2011 2:30 PM
60	With the self-advocacy movement in Vermont consumers are well informed about their rights and about exploitation. There are many work shop offered through self-advocacy to educate everyone.	Jan 24, 2011 2:11 PM
61	not sure	Jan 24, 2011 1:52 PM
62	The hold up in schools on seclusion and restraint is discouraging.	Jan 24, 2011 1:32 PM
63	Disability Day is great & provided disabled Vermonters with a much needed voice. No comment on the other two questions.	Jan 21, 2011 8:12 PM
64	Reports to APS are not always followed up on.	Jan 21, 2011 2:12 PM
65	It is all smoke and mirrors. No real oversight. We say the right things, we have the right feel good policies but no independent oversight.	Jan 21, 2011 10:19 AM
66	too many inexperienced casemanagers	Jan 19, 2011 2:19 PM
67	I'm not aware of what is currently being done.	Jan 19, 2011 2:09 PM
68	Honestly I have no idea regarding this issue -- we have minimal (bare bones) services for children that are aging out that need DD or Mental Health Services (CRT) It is very disconcerting at best!	Jan 19, 2011 12:51 PM

Page 3, Q11. How is Vermont doing in advancing the rights of people with developmental disabilities and offering freedom from exploitation, abuse, and neglect? Examples are voting, protection from use of seclusion and restraint, effectiveness of Adult Protective Services, etc.

69	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM
70	Some counselors for example don't consider isolation a valid reason for needing their services once a week.	Jan 18, 2011 5:50 PM
71	Except in areas where traditional behavior analysts are working in schools writing demeaning and devaluing programs involving punishment. Schools can be horror shows depending on who they are listening to. Timeout rooms, restraints and seclusion have no role in a child's life.	Jan 18, 2011 12:07 PM

Page 3, Q12. Overall, how is Vermont doing locally and state-wide in reaching out to and including those with developmental disabilities in recreation, social, and other aspects of community life?

1	VSA (Arts), Radion (Radiator), Unified Sports (schools) -- some programs working, but largely confined to Burlington area, and for people capable in certain areas. Not available to others.	Mar 26, 2011 1:03 PM
2	VT is a rural state. Agencies are cutting back on time/mileage. Staff is asked to do more with little. They are not able to reach people in need & bring them the opportunities.	Mar 26, 2011 12:41 PM
3	State doing terrible job. Local people helping - churches helping - schools helping.	Mar 26, 2011 12:25 PM
4	We still have a ways to go - information mreoo available, things are getting better.	Mar 26, 2011 6:41 AM
5	A tortase moves quicker than our local state government.	Mar 26, 2011 5:57 AM
6	We could not get money for ski pass. Our respite provider was cut due to funding. SSI guidelines caused our son with severe chronic medical issues not to be eligible for SSI.	Mar 25, 2011 12:09 PM
7	Most public sites limit access = use = private sties don't want us: State needs to fund access = force access = right to use!	Mar 24, 2011 10:36 AM
8	Not enough ways for these people to get together. Support groups, social groups and athletic groups. I have search for a support group for my daughter and can't find one that is age appropriate (she is 13).	Mar 18, 2011 4:23 PM
9	Vermont does try to include people but there are still so many things inaccessible to people with special needs especially if they are in a wheelchair. Many people don't understand the Americans with Disabilities Act. There is a lack of connection in the world of disabilities. As a family with a child I often feel isolated.	Mar 16, 2011 9:17 AM
10	What reach out is there for adults? I see nothing.	Mar 14, 2011 12:02 PM
11	How many accessible playgrounds do you know of in the state. Public funds are in all schools and most schools are woefully inaccessible inside and outside provide no play space for children in wheelchairs. How about shopping when you are in need of a wheelchair for mobility. Try it sometime and see if you can get down an aisle which is stuffed with items to sell. Been hiking lately with your wheelchair, or to a museum? And bathroom accessibility if you need to be have clothing changed while lying down.. well it is not happening in VT or almost anywhere else. Better wear your astronaut diapers!	Mar 13, 2011 3:15 PM
12	Most boards and committee required DD folks this is good. Need for more social and recreation opportunities that aren't expensive. Need in the south for weekend activities need collabation on programs in school and community agencies and business.	Feb 21, 2011 2:36 PM
13	same	Feb 18, 2011 7:22 PM
14	Not enough money available for activities. Classes and recreational activities are expensive and unless parents can pay, there never seems to be an adequate amount of money for this.	Feb 15, 2011 8:24 AM

Page 3, Q12. Overall, how is Vermont doing locally and state-wide in reaching out to and including those with developmental disabilities in recreation, social, and other aspects of community life?

15	I want more! I want Vermont to become proactive! I'm being forced to quote legal reference, to read page after page of research and recommendations to ensure that my son is receiving adequate support. I'm the one taking course after course and attending seminars, workshops, etc. to become as informed as possible so that I can make the best decisions on how to meet his needs. No one is coming to him or me and saying, "Can we do more? Do you know how else we can help you?" It costs money to send children to camp, that's if the camp can manage a child with a specific disability. Then we are all fighting private organizations for the same funds, not those provided by the State. If a child needs prags and social skill training, extended school day is purely for academics, so what do they do all summer? Many families of disabled children are on one income. 80% face divorce due to the stress. Add the expense of rigid food preferences taking up 40% of the budget, \$3.99 per gallon fuel oil bill, in addition to the gas required to commute 30 mins. North to a job 2X a day because there is only one working car, a \$240 per month medical premium just to have a policy with a \$5,000 deductible, transportation costs associated with specialist appts, etc. Now ask me how we are going to prevent our socially needy child from spending the summer alone because we can't afford to send them to most summer camps which charge \$100-\$200 per week. Explain again how the State of Vermont helping my child(ren) participate in recreational or social aspects of community life?	Feb 14, 2011 3:06 PM
16	Few, if any, opportunities offered by the state in the southern most region.	Feb 8, 2011 1:59 PM
17	i had to fight for three years to get my son to be able to participate on the down hill ski team finally this year i succeeded in get him on the team what happens to the ones out there that don't have a family member who knows a little about the rights of persons with disabilities and advocates for them	Feb 8, 2011 10:42 AM
18	Very few supports in rural areas - I worry about isolation particulary when kids leave school.	Feb 7, 2011 2:37 PM
19	I would liike to see more social oppourtunities for adults with developmental disabilities. No one wants to do things "after hours".	Feb 7, 2011 12:20 PM
20	We try hard and publicize pretty well. There are more people with more needs than we currently serve. Unfortunately I have no concrete suggestions.	Feb 7, 2011 8:29 AM
21	I don't generally feel "reached out to," but feel we're doing the reaching all the time. Not sure what this would look like to rate an excellent, but I'd like to live in that world!	Feb 6, 2011 5:53 AM
22	We all need to work on Ability Awareness! Have you seen the DVD from Tyler? this is the best DVD that I have ever seen . This should be passed along to everyone . www.IM TYLER.org	Feb 4, 2011 9:00 AM
23	Stop the "Not in my backyard" folks from discrimination	Feb 3, 2011 2:26 PM
24	regionally i believe this differs	Feb 2, 2011 12:29 PM
25	where are they ? I myself want to provide services yet cant get funded ... its considered too expensive and not important to provide art to people with disabilities or the people already doing it are doing it with skeleton crews and theres is no room for another practitioner	Feb 2, 2011 12:04 PM

Page 3, Q12. Overall, how is Vermont doing locally and state-wide in reaching out to and including those with developmental disabilities in recreation, social, and other aspects of community life?

26	Not sure.	Feb 2, 2011 11:53 AM
27	Transportation is a tremendous barrier for folks with disabilities.	Feb 2, 2011 11:07 AM
28	I think Vermont is definitely trying. I feel that the efforts in place are a work in progress. I believe the scope has to be greatly expanded as the needs of individuals with special needs can be complex, however as the process matures and develops it has the makings of a very supportive system. I particularly feel that regional centers would provide checks and balances for schools in smaller towns as well as provide access to those in smaller towns which are often the individuals whose needs go unmet.	Feb 2, 2011 10:37 AM
29	Specific communities do very well. There are also many family initiated options available. The State has done very little in this area.	Feb 2, 2011 10:32 AM
30	We participate in Special Olympics within our community and as I mentioned previously, having an advocate via an agency has been instrumental in obtaining services	Feb 1, 2011 10:19 PM
31	Nothing being done for most adults. Need competence and services.	Feb 1, 2011 1:17 PM
32	not aware of specific programs	Feb 1, 2011 12:49 PM
33	I again speak to one end of the spectrum of ASD. Being "nearly normal" can still create feelings of disenfranchisement. I suspect my daughter will always deal with this - that feeling that she has to always adapt and reframe her own presentation ... rather than experience environments where there is inclusivity and respect of all individuals. Her own self acceptance has led her to embrace labels like "geek" in a positive light But, our state, while tolerant, does not always reach out to people with differences. As long as things are going well for my daughter - all is good. But, I do worry that Vermont does not have a transparent network for people to prevent stressors that she may face as a young adult with ASD. Especially if you don't live in one of Vermont's few cities where there is more of a network established.	Feb 1, 2011 11:13 AM
34	My son's school does a decent job of inclusion during the school day. However, my son is pretty much on his own the rest of the time. He is not included in anything unless we specifically and laboriously set it up for him. Vermont Adaptive Ski and Sports is great-but very expensive. Our community doesn't have a Unified Sports, Special Olympics is great but isn't set up for my child with Autism, and after school programs and the recreation department wouldn't be able to deal with him and his needs (plus on top of paying for the program, we would need to pay additionally for someone to be there as his one on one) . The community has not reached out to or included my son, or our family, in any way.	Feb 1, 2011 8:19 AM
35	I am not sure how VT reaches out in these situations.	Feb 1, 2011 7:09 AM
36	The only info I get is from the school which means nothing even when I ask.	Jan 31, 2011 5:03 PM
37	Families First is doing a phenomenal job with this.	Jan 28, 2011 3:05 PM
38	Not finding activities that are welcoming	Jan 28, 2011 9:58 AM

Page 3, Q12. Overall, how is Vermont doing locally and state-wide in reaching out to and including those with developmental disabilities in recreation, social, and other aspects of community life?

39	I think that many of these efforts tend to be somewhat disorganized. The Vermont Family Network is WONDERFUL and does great work in this area, but individual programs can be very haphazard and sloppy in their outreach.	Jan 26, 2011 1:29 PM
40	again money and personel arn't always there	Jan 26, 2011 12:43 PM
41	There is always more outreach that can occur but overall Vermont is progressive and values	Jan 26, 2011 12:34 PM
42	Vermont is a rural state. As such it is a challenge to find transportation to reach clients. Currently, a community support worker is needed to be hired to provide transportation due to the inability for Medicaid and state dollars to pay for transportation. Even a modest amount of transportation funding would be well spent because it would drastically reduce the need for community support assistance which is comparatively expensive. Particularly affected is work transportation.	Jan 26, 2011 12:07 PM
43	no idea	Jan 26, 2011 11:19 AM
44	There are many more offerings currently for folks with disabilities than in the past, however many of them continue to be segregated.	Jan 26, 2011 8:27 AM
45	We need more services and support for those transitioning into adulthood.	Jan 26, 2011 8:02 AM
46	Don't know	Jan 25, 2011 5:08 PM
47	It seems to be entirely up to the family or guardian. I have to discover the opportunities, arrange to attend. Again, people in the rural areas have little to nothing to turn to. Every school district and county should have unified sports, arts, and entertainment ops for our loved ones. There is nothing in my school other than PT or OT. As a single mom, 4 kids, a farm and part-time off the farm job; I can't really get anything organized for this and don't even know where to begin. Again a social worker to help navigate the DS community, culture and supports would be very empowering.	Jan 25, 2011 4:06 PM
48	Services are being eroded even in the agencies that are managing to keep ahead of the constant recisions and tightening of priorities.	Jan 25, 2011 1:48 PM
49	Vermont does very well overall, considering the tight budget it has to run on.	Jan 25, 2011 12:21 PM
50	Not sure statewide, the central Vermont community is geographically underserved in terms of therapeutic riding opportunities	Jan 25, 2011 11:19 AM
51	For people in inclusive schools and communities I believe they are still doing well; however, more and more people are in alternative schools and programs, and I believe they are cut off from the mainstream of community.	Jan 25, 2011 10:50 AM
52	We need to make computers available and web access a key to support. Great things happen when people connect!	Jan 25, 2011 8:36 AM

Page 3, Q12. Overall, how is Vermont doing locally and state-wide in reaching out to and including those with developmental disabilities in recreation, social, and other aspects of community life?

53	There is a long way to go. More training is needed by all Medical staff everywhere, the greater public needs more information about disabilities for there to be acceptance and that should start within our schools and public forums. More recreation (not only sports) need to be made available and we need more teen and adult services. Schools need to be monitored for their treatment of students with disabilities and this means that there should be people talking one on one with parent and not just the ones that the schools selected.	Jan 25, 2011 7:36 AM
54	access is much better with transportation that is now available for older people- we need to somehow extend down to little folks	Jan 25, 2011 6:15 AM
55	I can't answer this.	Jan 24, 2011 7:22 PM
56	Again this could be a N/A answer. We don't know.	Jan 24, 2011 6:40 PM
57	In general Vermont is very disability friendly	Jan 24, 2011 4:48 PM
58	See comments above. Overall, I have not felt at all that my local community has reached out to include my son in their recreation programs. We do like the handicapped recreation programs that we have used, but they are very expensive. I wish there were more opportunities for social and recreation programs for my son, particularly with dog training, caring for companion animals, bike riding, and swimming.	Jan 24, 2011 3:40 PM
59	GMSA does a great job of reaching out adn engaging.	Jan 24, 2011 3:32 PM
60	Social oppportunities are largely not inclusionary. There is a need for inclusion with typically developed peers in order to learn appropriate social skills.	Jan 24, 2011 3:06 PM
61	When you live in a rural area there are not many recreational or social activites available during the day and traveling becomes expensive especially for those with a small transportation budget.	Jan 24, 2011 2:11 PM
62	Parents have to do all the work.	Jan 24, 2011 1:58 PM
63	Not sure	Jan 24, 2011 1:52 PM
64	What is available as far as social oppportunities for college/high school aged kids with mental health issues?	Jan 24, 2011 1:34 PM
65	For the money and resources utilized terrible. But, better then other states	Jan 21, 2011 10:19 AM
66	There are few oppportunities and options.	Jan 19, 2011 2:09 PM
67	New to the state! (2 weeks)	Jan 19, 2011 12:39 PM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

1	At this time I would like to vent my frustration being a senior citizen with disabilities and needs and been pushed aside and forgotten since becoming legally disabled. [Specifics on lack of food and heat moved to topic sections.] . . . As far as the survey is concerned, I really do hope that whatever information is out there, that it actually does some help. . . I have worked all of my available years up to 3 jobs at a time and have given my share and taxed out of control but now that I have become a lesser member of society and have less that the state can take from me, I have fallen through the cracks.	Mar 26, 2011 1:27 PM
2	Many individuals who meet the federal definition of having a developmental disability find that their IQ measurement in the 70's-80's disqualifies them from receiving necessary supports and services. Families are stressed and ind/w/D not employed or underemployed. Thank you for all you do!!	Mar 26, 2011 1:05 PM
3	I am EXTREMELY worried that the only REAL choice I will have is DEATH. Eliminate the "useless" eaters. Their quality of life is not worth living. Make sure the satte workers get their high salaries & benefits for pushing papers & making life threatening decisions about my WORTHLESS life, which I love.	Mar 26, 2011 12:27 PM
4	Eligibility issues due to IQ scores are leaving several young adults to fall through the crack. It would be nice to have services for all individuals to meet all of their needs.	Mar 26, 2011 6:42 AM
5	VT excells in all of these areas. Agencies struggle to provide services now & do a wonderful job, but won't be able to if services are cut -- it's a "no-brainer"	Mar 26, 2011 6:33 AM
6	Excerpts from long handwritten statement: I am a widow. . . I have the hardest time fidning any one to do arrens [errands] for me. I don't have the proper food . . drug store does not always put all my prescriptions in the bag . .	Mar 26, 2011 6:26 AM
7	Get rid of automation of your telephone system for speed oolder people become lost in it. Who says everyone has a computer in this state?	Mar 26, 2011 5:53 AM
8	I am a single Disabled person in my mid 40's, and I don't qualify for any programs because I do not have any children or over the age of 65. I would like to see more benefits for folks stuck in the middle like me. P.S. I really enjoy this newspaper. Thank you.	Mar 26, 2011 5:51 AM
9	Enforcement, Enforcement, eEnforcement, Fines, Suit, Time on the Rocks ! Public Review: Advocate, Advocate, Advocate!	Mar 24, 2011 10:40 AM
10	more people needed better chcks and balance and more money to so	Mar 21, 2011 7:38 PM
11	I commend you for conducting a survey to find out how you are doing.	Mar 18, 2011 4:24 PM
12	What happens to my son when i die , who will be his advocate, will he be safe. will he have a home a job, access to the community. Those are the answers i need. Is unrelistic to expect or hope that schools would do more to educate are kids and better prepare them. Our kids can learn, if given the opportunity, its not how much you spend its how you teach, connect. Without funding they cant get training for jobs, w/o funding they stay at home, isolated margtnalized. Everything is connected, you cant be sucessful if you get all the pecies to fit. It needs to be early,longterm ,seamless thinking. less complicated, more flexiable. What does happen when i die, who does he turn to who will help??????	Mar 18, 2011 7:38 AM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

13	Supporting families to support individuals and reducing the over use of agencies is a good place to start. Creating easy avenues for clients and families and workers to connect is vital to efficient change. Allowing much more flexibility is also vital. Clients are so vastly different in needs from one another that the current model is not good enough.	Mar 16, 2011 9:20 AM
14	The visually impaired seen many cuts in services for social and recreation programs. The biggest issue is lack of transportation and especially in the NEK isolation.	Mar 15, 2011 6:05 PM
15	All the agencies and individuals working for and with individuals with disabilities appear to be doing the best they can under current circumstances and restrictions. More coordination of agencies and services, increased funding for practical and high impact on the quality of life for individuals with disabilities needs to improve.	Mar 15, 2011 7:43 AM
16	As a mother I am most concerned about the proposed budget cuts that will directly affect consumers like my son who depend 100% on the supports and assistance given within HCRS.	Mar 15, 2011 5:16 AM
17	Cost effective services are those that work. There need to be competent and effective programs for adults with autism. Listen to what the parents recommend. Have a competent outside person come in to evaluate adult autism services. There is absolutely no state management level expertise for adults with autism. Many parents who have adults with autism have given up on a totally unresponsive system. Why go to Care Plan meetings when nothing changes? It is a total waste of time to try to talk to Vermont autism specialists.	Mar 14, 2011 12:10 PM
18	I would like to suggest that everyone who is 'in charge' of policy making and decision process, be given a day or more to spend as though they have cognitive challenges, physical challenges, speech challenges or a combination of these. Get in a wheelchair and then try to shop or go to the park. Put on glasses that duplicate vision defects such as tunnel vision, near sighted, macular degeneration, etc. Go shopping, eat out, or go to a movie without the advantage of knowing how to read or write or speak and see how it feels to have people ignore you or worse, tell you to leave. Good luck. We do need changes and families and providers and consumers need to be heard.	Mar 13, 2011 3:20 PM
19	Don't have time or space to outline the agony of the past 25 years of trying to get assistance (sped, health care, community support, anything) for my son with multiple developmental and health issues. got no cooperation that I didn't bankrupt my family to sue for, and then it was promise only, no real help ever. He lives on the fringe now, unable (because undereducated and often ill) to get work good enough to afford the simplest health care for his lifelong needs, and I am working 3 jobs still to pay his medical bills. Please do not mistake my next statement for cynicism, bitterness, or twisted outlook, but a loving mother's long experience in today's world/society and a realist's viewpoint that has outlived idealism and hope: it seems sometimes that God would be kindest to take him before me because no one else can or will do the work it takes to understand his needs, navigate the health care maze, and protect him from the "system".	Mar 13, 2011 10:24 AM
20	More funding in all areas of recreation, daily services, including better wages for the people who give their time and effort to support folks with disability, more programs such as art, music dance sports	Mar 12, 2011 5:28 AM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

21	Routines are so important for many folks with developmental disabilities. i'm worried about what influence budget cuts have on these routines and how they will affect clients and providers	Mar 11, 2011 2:39 PM
22	Keep on funding parents for education opportunities about their children's disabilities.	Mar 7, 2011 10:29 AM
23	I think there need to be more collabaration between DAIL, DOE, VTDDC, VFN, VT support groups. SU need support from VTDDC (Goal #4) Develop statewide programs for employments and employers large and small, and transitions to colleges. Still many needs and goals out there, awarenes is getting better at least with ASD. ASD is the fastest growing DD, changes need to start showing up with programs and make autism spectrum disorders a higher funding priority.	Feb 21, 2011 2:44 PM
24	With the way the state has cut budgets it is incredibly important for VTDDC to be a voice for people with developmental disabilities at the statehouse. Support for the Coalition for Disability Rights is more important than ever since they can bring a variety of groups and individual into the advocacy picture!	Feb 21, 2011 11:49 AM
25	I really hope I am welcome to come live in the Burlington area. I have never been able to "escape" this CT hell (financial imprisonment saga) and I am debilitated for lack of ability to understand and reach those dedicated to the field of research that might or might not acutally make sense to anyone reading this (Sorry). Am interested in European travel for reasons of scientific research community ... these efforts (my independent research efforts which are not and never have been independent as all this is the continuation of my father's everything) have failed miserably in the past and I really am hoping to find a niche in the academic/social/living community of people up there.Thanks	Feb 18, 2011 7:25 PM
26	It's an impossible task. You can't meet everyone's needs. Ideally, all disabled individuals should receive the help and training they need to be successful, independent adults. The reality is that there are not enough funds to do so. Education and training as well as funding for recreational/social support are the areas I would concentrate on.	Feb 14, 2011 3:11 PM
27	More funding is needed so that quality staff and management are available for children with severe disabilities that need more than a babysitter and continual learning opportunities.	Feb 10, 2011 9:08 PM
28	1. We need acute care for children/adults on the autism spectrum. We've had to send our son out-of-state three times for acute care. Medicaid does not cover this. 2. Pay parents as PCAs 3. Get more services in southern Vermont - why cut the one position when it's all we had (re: Holly Beatty's job). This was highly insensitive to the families in southern Vermont. 4. Offer more services such as those in the northern areas - I don't understand why southern Vermont is the ugly step-child, so to speak.	Feb 8, 2011 2:01 PM
29	i think its disgusting that the people who care for our developmentally challenged persons are the who get the cuts. these people shouldn't be asked to do what they do and have money taken from them. our consumers need to have people care for them and help them access the community. when they lose hours it effects everyone in a negative way.	Feb 8, 2011 10:47 AM
30	I hope that I was able to relay the advantages that we feel living in this State with a child with disabilities and to describe some of our challenges. Thank you for reaching out.	Feb 7, 2011 2:40 PM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

31	I appreciate the services my son utilizes, as they allow him more independence and for me to do my own job. I can't say enough about Howard Center and SSTA because I rely on these two agencies to assist me in providing my son with a more full and rewarding existence. Please make sure the funding is not cut for either of these agencies, as we would be unable to manage without them!	Feb 7, 2011 12:22 PM
32	No final comments.	Feb 7, 2011 8:29 AM
33	At our shelter and our soup kitchen we find many who have been lost in the crowd so to speak,they don't know their rights or where to go . many end up in trouble with the law and have not a clue at what they did wrong. One such incident was a man who spit on the bus and it hit a women who also ate at our soup kitchen ,he was told he could not be around her so he was unable to come for meals. we finally sent one of our staff to court and the judge heard him but for 6 months we had to have him come at a differant time as he could not be in the same building with her. When my staff went to court for the hearing they had intended to put him in jail for 60 days until they realized he didn't understand and he could neither read or write. this is just one incident	Feb 7, 2011 7:40 AM
34	We need SRV! Social Role Valorization trainings in VT. Wolf Wolfensberger	Feb 5, 2011 8:58 AM
35	Many people with DD are not eligible for vermont dd services and this creates many folks that are underserved or not servered at all Vermont services are not always accesable or do not meet ADA stantards for access This is a severe weakness in serving the dd Population	Feb 2, 2011 2:10 PM
36	I am a special educator as well as a parent of an 11 year old girl with PDD-NOS. I called the correct place for finding out about how to get a PCA, was told to call someone else, called someone else who informed me to call back to the first place. My lower functioning parents would have given up after the first phone call. I also don't want to hear when I call that a county is overworked right now...I am a special educator and I can't use that as an excuse and don't expect others to use it.	Feb 2, 2011 1:36 PM
37	Funding cuts are making a "fair" system into a "not so good" one.	Feb 2, 2011 10:33 AM
38	Thank you for wanting to hear about our concerns as parents of children with disabilities and allowing us to participate via this format.	Feb 1, 2011 10:20 PM
39	I am a COS and I love my job. Though it is hard to look towards any kind of future in this field for there doesn't seem to be any room for financial growth and promotion. Its hard to find outstanding employees and keep them without giving them the room for advancement.	Feb 1, 2011 1:43 PM
40	Fire the incompetent autism "experts" and hire someone who knows what they are doing. Start providing competent services for transition and beyond through adulthood.	Feb 1, 2011 1:19 PM
41	I would say that it depends on who the person is connected with will depend on what type of services that they area able to access, utilize etc.	Feb 1, 2011 12:49 PM
42	I probably said too much - and I'm not sure we are the population you are targeting. I often feel like her/our needs are under the radar... but, I hope some of my comments assist you in this effort.	Feb 1, 2011 11:14 AM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

43	I think the supports/services are available- I think that they are easier to access if an individual has a higher level of education and most certainly access to a computer. Unfortunately I worry about the rural, perhaps indigent population with special needs not having the same access to the information that I may.	Feb 1, 2011 10:45 AM
44	Thank god VTDDC is advocating for our loved ones. We all do what we can, but it is a huge relief that you guys are out there helping lobby/advocate. Keep up the great work!	Feb 1, 2011 8:20 AM
45	We need one network for parents to access. I belong to a Down Syndrome Support group and people share information at each meeting that many of us don't know exists from VFN, I-Team, CSHN clinic to VT adaptive ski, special olympics, and theraputic riding. It is just very hard to find out about all that is available to our children.	Feb 1, 2011 7:12 AM
46	Some how find a way to let parents know what is out there	Jan 31, 2011 5:06 PM
47	Making sure that our GOP members know that we in the state of Vermont need more money for our programs because we are so small and rural. I feel that the VTDDC is really trying to help in all area's. As you know Vermont is small and our population is not big. I can say this about Vermont it's ahead of most states. Let people know in Washington that Vermont is a leader and we can get things done.	Jan 31, 2011 9:03 AM
48	VCDR needs to have full funding and we need to stop day programs from popping up as a result of budget cuts. Home Providers need to treat people like adults and not use the term foster daughter etc. This state needs to be the model of Inclusion not segregation for the rest of the country!	Jan 30, 2011 3:45 PM
49	I don't see the state agencies that are responsible for the delivery of services to the disabled public with any internal committees that are comprised of parents and people with disabilities who actually offer insight and direction for the Board of Directors and the local agency to learn from and follow. Standing committees seem to have no authority to direct any agency or board on ANY issue. Each committee can only "recommend" to the board any requests. No structures or checks that I can see.	Jan 29, 2011 4:54 PM
50	I have never met a service provider that did not want to be helpful during my tenure as a special needs parent.	Jan 28, 2011 3:15 PM
51	We are lucky we got our son into the program he is in. Lluck shouldn't have played a part in it, the services he was provided are hard to find out about and receive and more support and money needs to go to young autism intervention. If 1 and 140 children are born autistic, how come my son only had 4 other 2 yearolds in his program?	Jan 27, 2011 4:28 PM
52	Would like to see more flexablity in useing medicare waiver funds. Would like to see more self (family) directed care , more options, more choices in service providers.	Jan 26, 2011 4:44 PM
53	Thanks for valuing my input!	Jan 26, 2011 1:30 PM
54	I understand the fact that there is only so much money but its to easy to cut programs from people who can't stand up for themselves. It will save money in the long run if we spend it now to help these children grow up to be self supporting adults.	Jan 26, 2011 12:46 PM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

55	<p>Service agencies when faced with a budget shortfall routinely cut direct services to clients. In the same time span these service agencies have expanded their management and increased management salaries, often freezing direct staff salaries at the same time. This is a non-client oriented approach and is an abuse of funding. Serious scrutiny should be paid to management salaries and management-to-staff ratios. State mandates on funding reductions should stipulate reductions in management salaries to avoid the erosion of client services and adequate direct staff personnel-to-client ratios. This issue has come about due to a non-fiscally minded approach to client services and poor business practices in regard to overhead and salaries. Though this is a problem endemic of social services and non-profits in general responsibility dictates a new approach should be pursued. Budget oversight from outside sources should be considered.</p>	Jan 26, 2011 12:17 PM
56	<p>ARIS is excellent, and takes the most difficult part of self managed programs, the payroll part, to a workable level. The rewarding work online program works too in linking people who want to work with the programs who need people. HCRS Springfield is excellent and responsive to needs and emergencies. Parent/HCRS shared management is a great model for young adults to keep them near family and in the community. Parents must stay involved so they are part of the problem solving and goal setting plans. We have tried many models over the past 20 years and this one works the best for us.</p>	Jan 26, 2011 11:57 AM
57	<p>It would be nice to hear from Families First occasionally so I know my options</p>	Jan 26, 2011 11:19 AM
58	<p>Special educational money should be designated to school districts with a follow up on exactly what they can be used for and an accounting. It's not necessarily more money we need to throw at the problem, it's accountability. Programs that enhance the chances of a person with developmental disabilities to become independent should be a priority. Many times, with a successful support team, that would involve a job coach/mentor, a young adult could be successful.</p>	Jan 26, 2011 10:39 AM
59	<p>I would like all Vermonters and especially those who shape policies to recognize how important and core employment is as human beings. Most clients I work with would identify their jobs as the number one thing in their life that they value as would most of us. It defines us as who we are, it is the opportunity to connect with peers and socialize, and it is the biggest way to be a contributing member of society. Taking anything away or reducing employment services shouldn't come into the equation. Not only is it the best (and most natural) way for adults with disabilities (and everyone) to be an integral and included part of their community, but it sends a message of equality and human worth to our community members. It is the best advertisement of inclusion and human services in our community- seeing someone be successful and competent in their job.</p>	Jan 26, 2011 9:27 AM
60	<p>I feel it is extremely important for staffs working with people with disabilities to receive a higher rate of pay; a livable wage. Perhaps this means cutting positions in leadership roles across agencies. It is a challenge to recruit and retain quality, knowledgeable, caring staff at current pay scales and the turn over rate is costing agencies more and more money. The key is quality and you know the saying - you get what you pay for.</p>	Jan 26, 2011 8:30 AM
61	<p>For every state DS funding cut there is an individual who is falling through the cracks not getting the services he or she may need to be successful at home, work, or in the community. In the end they become a much higher financial burden to our community. Give funding to each individual at the beginning and give them the services to become independently successful.</p>	Jan 26, 2011 7:24 AM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

62	I'm not 100% sure my "disabled" loved ones have the type of problems this questionnaire is really about, but it was sent to me by someone who knows our situation and is in the business, so I erred on the side of completing it.	Jan 25, 2011 5:10 PM
63	How come the state will pay for someone to come into your home and take care of a disabled child, but they won't give a dime for a parent to do the work when the parent knows the most about their child.	Jan 25, 2011 4:50 PM
64	We have a very long way to go. It seems like the system of care and culture of DS is very bureaucratic and any success an individual has is based upon a service system that is a help your self to our excellent self service.... I am often handed brochures, links, phone numbers only to be lacking in time or opportunity in business hours to pursue them. When I have time to phone, its 7am or 9pm... It would be great to have a mobile information unit that could visit communities and be available to answer questions for folks in their neighborhood. There is a great dependency on computers, television etc when many rural places have only dial up and some families still don't have a computer to access that. Many people are being left out and isolated. I don't want more links and articles; I want face-time with knowledgeable people who can help me when I ask a question.	Jan 25, 2011 4:13 PM
65	In these very difficult times, Vermont just needs to continuing to do the best it can.	Jan 25, 2011 12:22 PM
66	We need to restore the System of Care funding to levels that were in place before the economy went south. We had the types of funding choices for both adult and children that were making a difference. We have been forced to be flexible and creative to make supports work at reduced levels and we should still strive to be creative and flexible and that includes the decision makers at the state level as well.	Jan 25, 2011 12:02 PM
67	VTDDC is helping sponsor our after-school program for students with autism in 2011--we look forward to increasing our partnership as we work together to provide resources for the special needs community	Jan 25, 2011 11:20 AM
68	We need to have a good old-fashioned PASS Training for the new generation of individuals, families, and service providers, including top leaders. The solid values of normalization and social role valorization are still around in the old-timers in the system, but they are aging out. We have lost our values base. We need to reestablish Summer Inclusion Institutes (and invite back Rich Villa and Jacque Thousand to run them). Most teachers now haven't had the experience of good team building and inclusion, and don't know how to do it anymore.	Jan 25, 2011 10:53 AM
69	Families should be seen as a whole. With that in mind supports should be in place for the parents and siblings to help ease the stress and time demands. I also believe strongly that single parent households should have more child support relief. Absent parents who have limited contact with their children should have a higher financial burden. Often the custodial parent is left in an extremely poor financial situation and is often torn between employment and the needs of their child. This really should a Federal legislation.	Jan 25, 2011 10:01 AM
70	Vermont has excellent schools that provide special ed to those children in need. My only gripe is that VT. needs to have psychiatric hospital closer than 2 1/2 hours away in Brattleboro.	Jan 25, 2011 9:25 AM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

71	We need to have more funding, more respect and more room at the table so Voices of people with disabilities can be heard at the State Government and local levels.	Jan 25, 2011 9:01 AM
72	Funding is hard in this state. It needs to be easier to access with a quicker time frame to receive it. VTDDC's application process isn't clear to whom should be completing the form and who can obtain money.	Jan 25, 2011 7:37 AM
73	I feel that most basic needs are being met, however the quality of life could be improved by better social focus. Most of my clients and their familie feel that this is the area they are lacking most. The funding for these activities as well as a community focus to bring them together has not been met.	Jan 25, 2011 7:35 AM
74	ARIS Solutions can be diffiult to work with. Many of the employees ar unfriendly and borderline rude. They seem to frequently misplace paperwork and timecards resulting in employees not being paid which seems like might open up a liability given the fact that they refuse to cut an immediate check to fix mistake. PCAs and respite workers are paid so little, it is horrible for an error to cause then to wait two more weeks to be pd what they are rightfully due. Sorry for all the erors--typing one handed while holding a child.	Jan 25, 2011 6:37 AM
75	I think we keep striving to do better and something new and good is happening all the time, but there is always something to work at. Access to mental health services for families in distress when not eligible for sp ed or Head Start as well as a guarantee of transportation so that all families can access preschool and other services that other families can access.	Jan 25, 2011 6:19 AM
76	I don't feel I was really ever given and overview. It seemed to me from my limited experience that we weren't very important. I think the school system easily took advantage and was never held accountable to really help my son. Your staff at the office was always very kind, I think Donna Gillen wo I met at the conference was awesome.	Jan 24, 2011 7:27 PM
77	Tell us what you think you've been doing in these categories. Then we can tell you if its trickled out to a meaningful result. Thank you!	Jan 24, 2011 6:41 PM
78	I stumbled across your organization via a web search. I wish I had learned about you in a more systematic way. Why can't pediatricians, EEE, public schools, and VT CSH routinely provide parents with information about your organization and others that advocate for those with developmental disabilities? Everything seems so disjointed and so many parents are spinning wheels trying to do everything on their own, instead of coming together via organizations like your own.	Jan 24, 2011 3:46 PM
79	Caring for a person with a developmental disability falls often falls to mom. And moms here are pretty overburdened and need more supports (better paid PCAs, respite money to take a day off becasue there are none for some of us, case mgmthelp for moms who work but don't get benefits but have to do tons of paperwork for everything, help getting to dr appts 56 times per year) to raise healthy independent HOPEFUL people. IT is winter, transportation and cold and snow are huge obstacles. Surgery on son had me out of work caring for him and now I am also broke but not eligible for any benefits becuase I do work FT. If moms are not being supported and they are teh only ones caring, if there are gone, institutional living is only option left.	Jan 24, 2011 3:38 PM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

80	Families need support. There have been countless committes, surveys, studies done. We need action.	Jan 24, 2011 3:07 PM
81	When it comes to individualized services I firmly believe that Vermont is the best!	Jan 24, 2011 2:12 PM
82	I would like the post-school coordination of benefits to be much better. During school years, there is usually one case manager who coordinates and tracks all services. Outside school, it feels very disorganized and not coordinated at all, even when the separate agencies are all under the same umbrella. It feels like no one is coordinating the different supports or looking at the person with a disability as a whole entity. It all breaks apart into little separate pieces that need to be tracked and handled individually, very inefficient and confusing.	Jan 24, 2011 1:38 PM
83	Not being able to invest in the stock market due to the \$2000 cap on assets hurts all disabled Americans... Reform must happen eventually to fix this injustice to disabled Americans (successful & wealthy people without disabilities are free to invest their money as they see fit; it's not fair to say the disabled Americans should be treated any differently from able bodied Americans...).	Jan 21, 2011 8:15 PM
84	DD waiver services for children are very limited and although avaiable to children in DCF custody currently these services do not extend beyond DCF custody and prevent children from being adopted.	Jan 21, 2011 2:13 PM
85	We need to develop best practices, oversight, and trained professional. We need to develop services and professional out of the current network of mental health agencies and schools. No alternatives. No oversight except the schools and mental agencies themselve.	Jan 21, 2011 10:20 AM
86	Let's keep track of what the new administrative order proposes	Jan 20, 2011 9:38 AM
87	It would be great that once a child is given a diagnosis that the parent's are immediatly provided with a resource guide that addresses contact persons and available programs. It would be great for more holistic or alternative programs to be offered to persons with DD. For example, sensory intergration programs (Philo.....no longer in existence.....used to provide sensory evaluations, again a private agency.....), or alternative therapies as many "traditional" therapuetic services just aren't appropriate. There also needs to be more consultants who are able to attend meetings, such as school meetings. Funding, it is rather expensive to support a child with DD interms of household accomodations (alarms, fencing, and sensory materials like weighted blankets or special lighting). Modificaitons need to be made to bikes or pools. There really needs to be a general funding option for parents to tap into.	Jan 19, 2011 2:23 PM
88	While it is appreciated that services for people are ideally individualized, it is also important to recognize that in tough economic times, safety should be be prioritized above all else. For example, it is time to relook at congregate settings where appropriate. I say this having a brother with DD who has lived at home his entire 50 years with very minimal supports and funding. As he ages, while ideally he would have one on one supports in the community, if to support him living where he chooses, at home, means he may have to join a group setting in some sort of a day program then so be it. Developmental Services has had over the last 20 years many advantages that other groups have not had, and Challenges for Change is an idea whose time has come.	Jan 19, 2011 2:14 PM

Page 4, Q1. Please add anything else you think is important for VTDDC to know:

89	The current system of care is not working for children with developmental disabilities in the St. of VT. The funding priorities for children are not supportive of children or their families.	Jan 19, 2011 1:10 PM
90	Overall I find the services to be inconsistent and complicated for our consumers. There seems to be more barriers then supports. I have been given many examples of kids that have had to come into DCF custody in order to get services. This just isn't right. At the same time it shouldn't be the case that kids aren't adopted so they won't lose their funding/services. The definition for permanency needs to be the same no matter what agency you are working with. I would see a lot of reorganization necessary to get DD services up to speed with the other agencies.	Jan 19, 2011 12:53 PM
91	So much trauma could be prevented if services, supports, parenting advise, skill building respite, develomental resilyency were part of each child/youth's care.	Jan 19, 2011 12:30 PM