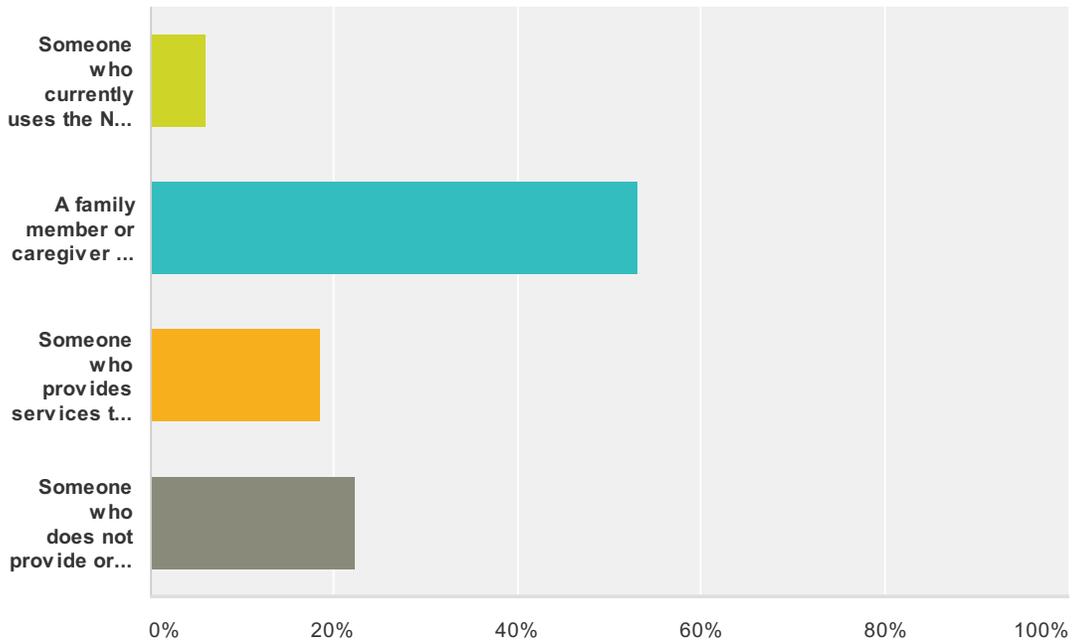


NH Medicaid Long-Term-Care Program Survey

Q1 Would you describe yourself as:

Answered: 892 Skipped: 0

Please note before printing:
this document is 155 pages long.

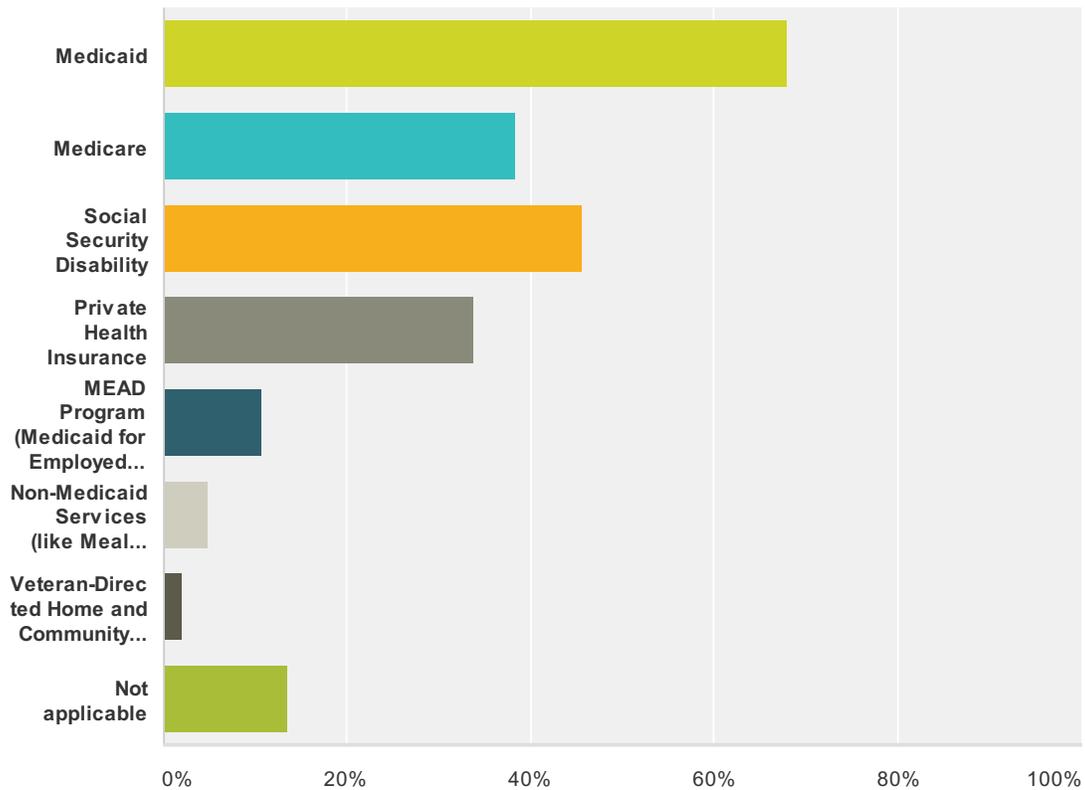


| Answer Choices | Responses |
|--|------------|
| Someone who currently uses the NH Medicaid Long-Term-Care system | 6.17% 55 |
| A family member or caregiver or guardian of someone who uses the Medicaid Long-Term-Care system | 53.03% 473 |
| Someone who provides services to people who use the Medicaid Long-Term-Care system | 18.50% 165 |
| Someone who does not provide or receive Medicaid Long-Term Care services or supports but who has an interest in how the NH Medicaid program operates | 22.31% 199 |
| Total | 892 |

NH Medicaid Long-Term-Care Program Survey

Q2 Do you or your family member currently use (please check all that apply)

Answered: 809 Skipped: 83



| Answer Choices | Responses |
|--|------------|
| Medicaid | 67.86% 549 |
| Medicare | 38.44% 311 |
| Social Security Disability | 45.49% 368 |
| Private Health Insurance | 33.75% 273 |
| MEAD Program (Medicaid for Employed Adults with Disabilities) | 10.75% 87 |
| Non-Medicaid Services (like Meals on Wheels or non-medical Adult Day Care) | 4.94% 40 |
| Veteran-Directed Home and Community Based Services | 2.10% 17 |
| Not applicable | 13.47% 109 |
| Total Respondents: 809 | |

| # | Other (please specify) | Date |
|---|--|-------------------|
| 1 | care provider through volunteer services-mostly transportation/visiting/telephone reassurance | 12/9/2013 9:27 AM |
| 2 | I observe many users of most of the above services and think I have valuable input based on those observations. You should consider a survey for persons such as myself. | 12/7/2013 4:23 AM |
| 3 | family member is applying for SSDI | 12/6/2013 4:33 PM |
| 4 | my adult son uses SSI, Medicaid, Food Stamps, Food pantry in Michigan. we want to move him to NH | 12/6/2013 3:34 PM |
| 5 | Champva | 12/6/2013 2:27 PM |

NH Medicaid Long-Term-Care Program Survey

| | | |
|----|--|--------------------|
| 6 | Son is being treated for a mental illness; Insurance is not covering it although it is a covered service. Receiving very little financial coverage. We cannot understand how families can remain financially secure when they are paying hundreds of thousands of dollars in medical health care that should be covered. | 12/6/2013 2:25 PM |
| 7 | Provider | 12/6/2013 12:42 PM |
| 8 | No insurance | 12/6/2013 12:09 PM |
| 9 | Uninsured | 12/6/2013 11:53 AM |
| 10 | out of pocket for mental health services because providers don't accept health insurance | 12/6/2013 11:24 AM |
| 11 | my son will need medicaid in his future due to his autism/adhd. He is 18 and we support him now | 12/6/2013 11:14 AM |
| 12 | Local church minister who interacts with people with various mental health needs. | 12/6/2013 10:01 AM |
| 13 | public assistance for mental health and other health care | 12/6/2013 9:55 AM |
| 14 | fuel assistance food stamps | 12/6/2013 9:23 AM |
| 15 | Local food pantry weekly food basket, Keene Community Kitchen evening meals 3 to 5 times a week (open 6 days for one meal a day) | 12/6/2013 9:18 AM |
| 16 | I work in health care and do assist people (mostly youth) in accessing services | 12/6/2013 9:12 AM |
| 17 | I arrange discharge services for patients with NH LT Medicaid | 12/6/2013 8:52 AM |
| 18 | I do have a sister in law who does use Medicare Services | 12/6/2013 7:58 AM |
| 19 | As a County Corrections facility we incarcerate individuals who are or were on these types of services. | 12/6/2013 7:49 AM |
| 20 | Unemployed - No Insurance | 12/6/2013 12:28 AM |
| 21 | section eight | 12/5/2013 10:56 PM |
| 22 | charitable care | 12/5/2013 9:33 PM |
| 23 | Work opportunities for my disabled teen | 12/5/2013 7:54 PM |
| 24 | Will be applying shortly for social security disability for a loved one | 12/5/2013 7:50 PM |
| 25 | applied discount at Hospital and Doctor for low income with no insurance | 12/5/2013 6:31 PM |
| 26 | no, but I have a child with a mental health disability and in the future she might need Medicaid insurance | 12/5/2013 6:19 PM |
| 27 | SSI | 12/5/2013 6:12 PM |
| 28 | Local hospital's financial assistance | 12/5/2013 5:56 PM |
| 29 | Family member | 12/5/2013 4:08 PM |
| 30 | Social Security under parents retirement, use to be SS Disability, but more under parents retirement | 12/5/2013 11:08 AM |
| 31 | Healthy kids | 12/5/2013 7:29 AM |
| 32 | Healthy kids gold | 12/5/2013 7:23 AM |
| 33 | SSI | 12/5/2013 5:11 AM |
| 34 | medicaid spenddown | 12/4/2013 9:35 PM |
| 35 | SSI | 12/4/2013 2:51 PM |
| 36 | Waiver Programs | 12/4/2013 1:51 PM |
| 37 | (This is more than one person.) Also, I am both a family member AND a service provider of Medicaid recipients. | 12/4/2013 12:09 PM |
| 38 | I also have some family members who are using Medicaid services. | 12/4/2013 11:38 AM |
| 39 | ANB | 12/4/2013 10:05 AM |
| 40 | I am a provider who assists people with these programs | 12/4/2013 9:12 AM |
| 41 | cash benefits, food stamps | 12/3/2013 8:15 PM |
| 42 | ssi | 12/3/2013 7:26 PM |
| 43 | Railroad retirement for disabled children | 12/3/2013 3:23 PM |

NH Medicaid Long-Term-Care Program Survey

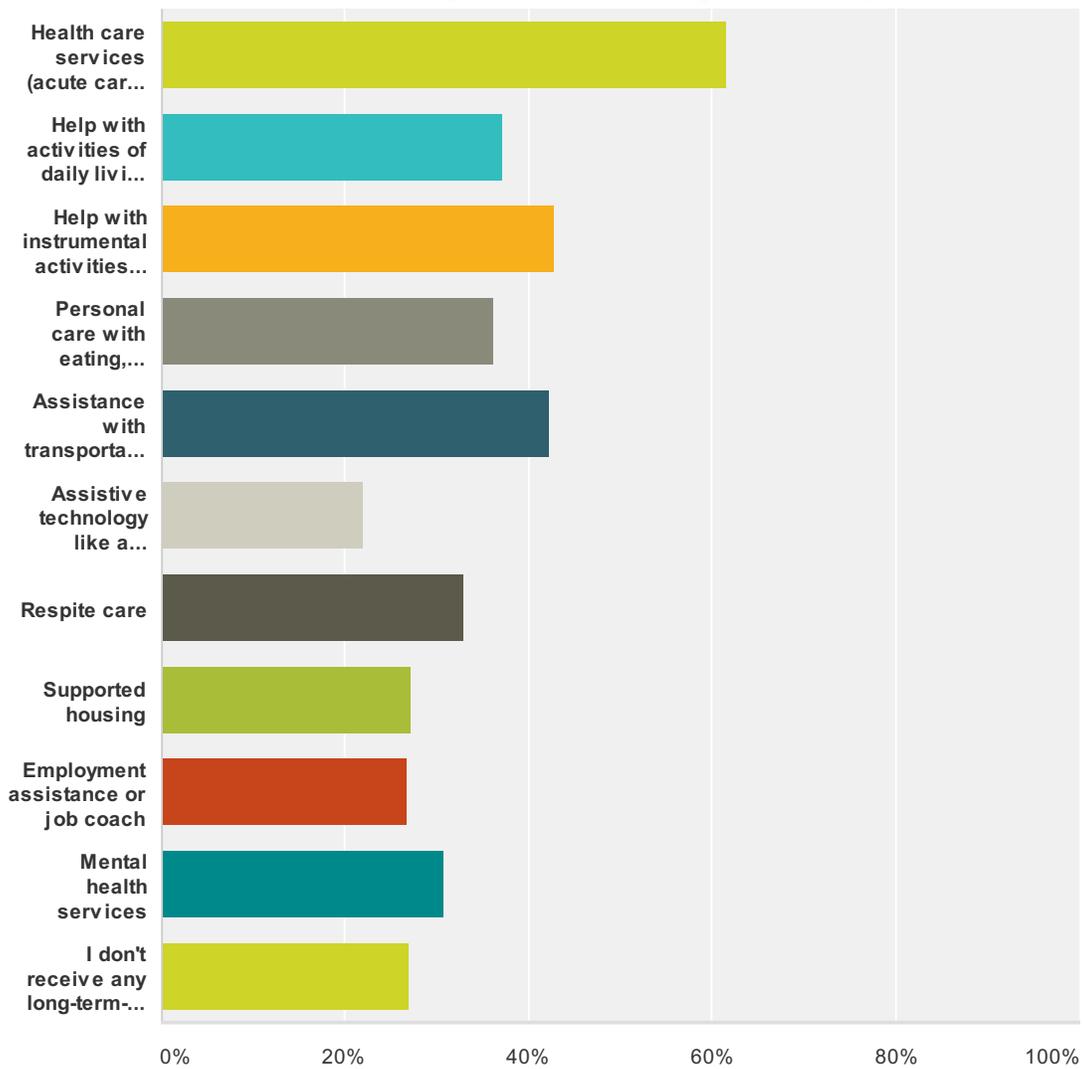
| | | |
|----|---|---------------------|
| 44 | SSI | 12/3/2013 11:30 AM |
| 45 | I consult with families applying for Medicaid and actually apply for them | 12/3/2013 10:50 AM |
| 46 | service provider of Medicaid | 12/3/2013 10:43 AM |
| 47 | Long term residential school | 12/3/2013 9:23 AM |
| 48 | I work with clients that use all of the above services | 12/3/2013 9:05 AM |
| 49 | DD Waiver Services | 12/3/2013 8:14 AM |
| 50 | Voc rehab | 12/2/2013 10:50 PM |
| 51 | Self pay dental | 12/2/2013 3:07 PM |
| 52 | SSI | 12/2/2013 2:22 PM |
| 53 | SSI | 12/2/2013 1:58 PM |
| 54 | I am a case manager for clients that utilize all of the above | 12/2/2013 1:55 PM |
| 55 | private dental insurance | 11/30/2013 1:46 PM |
| 56 | railroad retirement for disabled children | 11/30/2013 1:01 PM |
| 57 | have to pay privately if want assistance/respite from 24/7 care of totally disabled adult | 11/29/2013 7:11 PM |
| 58 | Medicaid Waiver for residential & day support from my Area Agency. I most strongly encourage the continuation of the Area Agency system, and that people with long term disability needs be exempted from Phase Two of the Medicaid Managed Care. | 11/29/2013 10:56 AM |
| 59 | Medicaid-funded community-based services and supports for individuals with developmental disabilities, administered through my area agency | 11/27/2013 8:47 AM |
| 60 | Deceased | 11/26/2013 10:14 PM |
| 61 | Will likely use other services as my child progresses into adulthood | 11/26/2013 12:14 PM |
| 62 | In Home Supports | 11/26/2013 8:01 AM |
| 63 | work with resources for people that may have above programs | 11/25/2013 1:49 PM |
| 64 | Community Bridges | 11/25/2013 12:32 PM |
| 65 | Area Agency, 525 Supports, Home Health Services | 11/25/2013 8:54 AM |
| 66 | son | 11/25/2013 8:40 AM |
| 67 | SSI | 11/23/2013 10:47 AM |
| 68 | I have staff in my home and they take me out to community services and events I volunteer at | 11/23/2013 8:30 AM |
| 69 | Section 8 housing and SSI | 11/23/2013 12:26 AM |
| 70 | Sec. 8 housing | 11/22/2013 11:49 PM |
| 71 | Yet, my 17 year old daughter with Down Syndrome whom is graduating next year(2014) is in need of supports, medically, socially, emotionally and educationally. | 11/22/2013 10:15 PM |
| 72 | social security under Father's benefit & Tricare | 11/22/2013 6:35 PM |
| 73 | In home supports, nursing support, day program support | 11/22/2013 6:04 PM |
| 74 | not sure which she has medicare or medicad | 11/22/2013 12:25 PM |
| 75 | work with people who use all of the above | 11/22/2013 12:09 PM |
| 76 | waiting for SSDI determination and need to apply for medicaid | 11/22/2013 11:56 AM |
| 77 | Area Agency services | 11/22/2013 11:34 AM |
| 78 | housing voucher Section VIII | 11/22/2013 10:14 AM |
| 79 | My MR grandson is waiting for his Medicaid card so he can be covered | 11/22/2013 10:12 AM |
| 80 | SSI | 11/22/2013 10:03 AM |

Q3 Medicaid long-term care services are different than the "acute care" or health care services that Medicaid also pays for.

Long term care services are used by people with developmental or physical disabilities, mental health needs or older adults who need assistance to stay in their homes. Long-term-care services include assistance with services like: - Activities of daily living (ADLs) - Instrumental activities of daily living (IADLs) - Personal care - Respite care - Supportive housing - Transportation - Assistive technology - Mental health services - Employment assistance - Transportation assistance
Please check any services you may receive with support of the Medicaid program.

Answered: 727 Skipped: 165

NH Medicaid Long-Term-Care Program Survey



| Answer Choices | Responses |
|---|------------|
| Health care services (acute care) like doctor's visits and medications | 61.49% 447 |
| Help with activities of daily living like eating, dressing, grooming, bathing | 37.14% 270 |
| Help with instrumental activities of daily living like shopping, laundry, housekeeping, handling finances | 42.78% 311 |
| Personal care with eating, dressing, shopping or other daily activities | 36.18% 263 |
| Assistance with transportation to where you need to go like doctor's appointments, shopping or work | 42.23% 307 |
| Assistive technology like a wheelchair or screen reader or another adaptive device | 22.01% 160 |
| Respite care | 32.87% 239 |
| Supported housing | 27.10% 197 |
| Employment assistance or job coach | 26.69% 194 |
| Mental health services | 30.67% 223 |
| I don't receive any long-term-care services | 26.96% 196 |
| Total Respondents: 727 | |

| # | Other (please specify) | Date |
|---|------------------------|------|
|---|------------------------|------|

NH Medicaid Long-Term-Care Program Survey

| | | |
|----|---|--------------------|
| 1 | We operate Caleb Caregivers out of Whitefield serving 7 other surrounding towns. | 12/9/2013 9:28 AM |
| 2 | I don't at this time but in the near future may | 12/8/2013 4:55 PM |
| 3 | Day Service Providers (ie - Easter Seals, Lutheran's) | 12/8/2013 3:18 PM |
| 4 | Developmentally disabled adult who resides at congregate living facility (Famsteads of New England, Hillsboro) | 12/7/2013 4:11 PM |
| 5 | Specially qualified SIGNING (ASL Interpreter) Support Person/Intervenor at all times | 12/7/2013 9:06 AM |
| 6 | Services available in the rural northern part of the state are much fewer and much farther apart. Transportation is ALWAYS an issue, Respite care as far as formal and not a family member or friend is hard to find (one adult day care one day a week in our area) | 12/7/2013 4:27 AM |
| 7 | adult son has bi-polar disorder; anxiety; self-medication issues; need for bi-polar meds, and both physical and mental health care | 12/6/2013 3:36 PM |
| 8 | I support and assist consumers in hiring their own workers. | 12/6/2013 1:21 PM |
| 9 | My child may need services at sometime due to mental health issues. | 12/6/2013 1:20 PM |
| 10 | I am a provider working with folks who would be using most of these services | 12/6/2013 12:44 PM |
| 11 | My child receives long-term mental health services | 12/6/2013 11:29 AM |
| 12 | these will be what he will need | 12/6/2013 11:14 AM |
| 13 | My son will be eligible for partial disability in the near future. | 12/6/2013 10:59 AM |
| 14 | The above are the ones I think my family member receives not me. | 12/6/2013 10:35 AM |
| 15 | Though my work, I find that there are layers of need with regard to these services. Often, age-related mental health needs are seen first as simply elderly care, and the mental health component is seen as secondary. | 12/6/2013 10:04 AM |
| 16 | I have checked the areas that I am aware of and that I may help or recommend people to potentially receive assistance | 12/6/2013 9:14 AM |
| 17 | Rely on these services for patients being discharged for a tertiary care hospital and these services enable them to return to the community rather than a nursing facility or group home | 12/6/2013 8:53 AM |
| 18 | Again as a County Corrections facility we have many incarcerated offenders who are or have been using various services as indicated. | 12/6/2013 7:51 AM |
| 19 | My sister uses some of these services and could use more - I do not use them | 12/6/2013 6:15 AM |
| 20 | Day Program Services, None traditional Counseling Services, Case Manager, Physical and Occupational Therapy as needed, Evaluations, daily medical treatments, 24 hour care, supervision and supports, eye exams, dental extractions, specialized Physicians, such as endocrinologist, neurologist, dietician, other specialized services, as needed | 12/5/2013 8:32 PM |
| 21 | I am currently waiting to find out If the financial has been approved and waiting on medical. | 12/5/2013 7:51 PM |
| 22 | Yet | 12/5/2013 7:51 PM |
| 23 | PROVIDER | 12/5/2013 7:14 PM |
| 24 | I can see my daughter needing these services in the future | 12/5/2013 6:20 PM |
| 25 | my sister is in the Glencliff Home. She is schizophrenic and has Parkinson's disease | 12/5/2013 6:14 PM |
| 26 | Supported employment and daily supervision. | 12/5/2013 5:57 PM |
| 27 | Project SEARCH | 12/5/2013 5:47 PM |
| 28 | all these answers are based on the services my family member receives | 12/5/2013 5:34 PM |
| 29 | My mother is my legal guardian/care giver. I live at home and I am 100% dependant. I am blind and in a wheelchair. TBI | 12/5/2013 2:36 PM |
| 30 | I evaluate many people who use many, if not all but respite care. | 12/5/2013 11:55 AM |
| 31 | We receive a daily program in the community for 6 hours per day. | 12/5/2013 8:32 AM |
| 32 | Currently transition services moving into job coaching services | 12/5/2013 5:14 AM |
| 33 | In my current work position I work with seniors. | 12/4/2013 11:39 AM |

NH Medicaid Long-Term-Care Program Survey

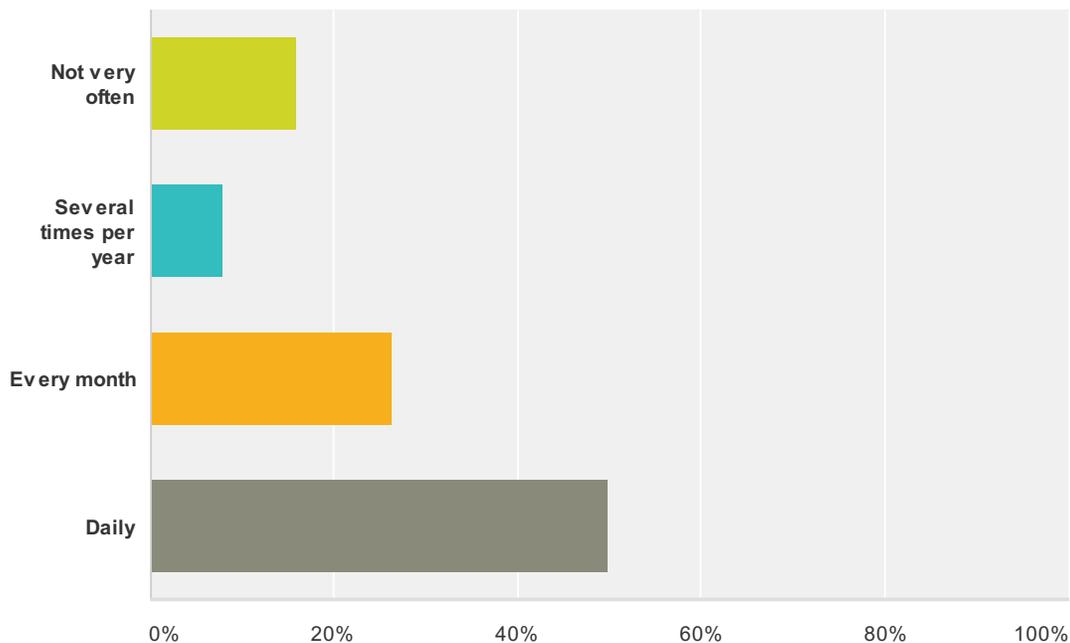
| | | |
|----|--|---------------------|
| 34 | 20 hours of a day program per week | 12/4/2013 10:59 AM |
| 35 | I work in a hospital with patients and families who use and need long term care. | 12/4/2013 9:42 AM |
| 36 | not applicable | 12/4/2013 9:22 AM |
| 37 | Provider who assists people with these services | 12/4/2013 9:12 AM |
| 38 | Group living on farm 25 other residents in 4 person apts EXCellent care Farmsteads of N E in HillsboroNH Model is perfect for my daughter . she is so happy and too difficult behaviorally for single home . loves contact with other residents and constant community opportunities. | 12/4/2013 9:09 AM |
| 39 | Child is 9 but want info on where Nh is going with OTC program. | 12/4/2013 8:34 AM |
| 40 | Prior to my retirement, I had the opportunity to provide services to older adults with mental health needs. Regardless of their insurance coverage, MANY of them could have benefitted from an array of these services as needs changed. The challenge was a system that encouraged transitioning in/out services as individual needs changed. This becomes even more of a challenge when the focus is on supporting the choice to remain at home. | 12/3/2013 5:19 PM |
| 41 | Although eligible for the program, we do not accept the charity since there is no financial need. We believe the funds should be allocated to the needy. | 12/3/2013 12:16 PM |
| 42 | Very necessary for the Emotionally Disabled folks. We need to keep these services | 12/3/2013 11:31 AM |
| 43 | service provider of long term care | 12/3/2013 10:44 AM |
| 44 | Son is resident of Crotched | 12/3/2013 9:32 AM |
| 45 | Again, my clients receive all of the above services | 12/3/2013 9:06 AM |
| 46 | I support families and individuals who receive long-term-care services | 12/2/2013 4:14 PM |
| 47 | These services are received by my son. | 12/2/2013 3:09 PM |
| 48 | medicaid is our secondary insurance but will become the primary at some point | 12/2/2013 2:24 PM |
| 49 | I work for a provider | 12/2/2013 1:56 PM |
| 50 | I coordinate the care and services. | 12/2/2013 1:55 PM |
| 51 | I do not receive any long-term care services personally with the support of the Medicaid program. However, I have received long-term care services through insurance, and members of my family have received Medicaid services. | 12/2/2013 11:59 AM |
| 52 | Receives day hab services and residential services | 12/2/2013 11:52 AM |
| 53 | My daughter, for whom I am answering this questionnaire, receives a 24/7 model of "home provider" which can be called "life sharing model". Her mentor/home-provider provides day programming/activity/support as well as evening & night. In this model, my daughter is seamlessly integrated into a family, rather than segmented into day support and night support. This model has improved both her mental health as well as her physical health - markedly. | 11/29/2013 11:00 AM |
| 54 | MEMBER OF BOARD OF DIRECTORS FOR A DIRECT CARE ORGANIZATION | 11/27/2013 1:10 PM |
| 55 | My son is school-aged. I expect he will receive employment assistance in the future. We have received some in home behavioral supports in the past. | 11/27/2013 8:49 AM |
| 56 | Family Support Program through my area agency | 11/26/2013 3:00 PM |
| 57 | Ina services, home infusions | 11/25/2013 10:23 PM |
| 58 | Day Program at Lakes Region Community Services | 11/25/2013 7:39 PM |
| 59 | I work with clients that receive elder care services and with others with handicapping conditions. A barrier for these people is transportation esp to medical appointments, appointments out of their living area. There are people e.g. elder Nepali or other refugees that need more personal care than any programs allow. Housing is also a big need with unrealistic waiting lists. What does one do with a pregnant 24 year old, couch surfing/homeless. If I refer to FIT the day I see the client, there will not be any housing available for 12 months. | 11/25/2013 1:54 PM |
| 60 | work with users of these services | 11/25/2013 11:22 AM |
| 61 | Long term medical supports for Seizures and Breast Cancer. Support to maintain social and recreational connections, case management through AA, Nursing Plan of Care through Home Health Agency | 11/25/2013 8:59 AM |

NH Medicaid Long-Term-Care Program Survey

| | | |
|----|--|---------------------|
| 62 | Son is applying for medicaid inNH previously received in VT | 11/25/2013 8:41 AM |
| 63 | My son is 15 and is under the Katie Beckett waiver. He will be in need of these adult services when he transitions from High School. | 11/24/2013 1:23 PM |
| 64 | cooking, budgeting | 11/23/2013 9:33 PM |
| 65 | income restrictions | 11/23/2013 4:17 PM |
| 66 | not myself, but my family members. adult Brother (developmentally delayed), adult sister (mentally ill), father (Alzheimers), son (pdd-nos). My mother has been doing most of the support for the first three but soon it will be falling to myself & another sister. The selected are services that some of the individuals currently receive | 11/23/2013 9:48 AM |
| 67 | They take me to recreation activities and volunteer jobs | 11/23/2013 8:31 AM |
| 68 | I've been paying out of pocket for all services through Children's hospital. Was denied in past for services. | 11/23/2013 6:24 AM |
| 69 | She does not receive any yet, but will need the above checked within the year. | 11/22/2013 10:17 PM |
| 70 | Adult Incontinence Products Medication | 11/22/2013 6:24 PM |
| 71 | Assistance in recreational activities Assistance in community involvement | 11/22/2013 6:06 PM |
| 72 | She can not be left on her own for safety reasons. | 11/22/2013 3:40 PM |
| 73 | I am disabled and have my health care through Medicaid. I live in an elderly/disabled apartment building with financial support through NH Housing. I don't know if that qualifies as Supported Housing or not. Never thought of my housing as being through Medicaid. | 11/22/2013 3:30 PM |
| 74 | In home support waiver | 11/22/2013 2:28 PM |
| 75 | There are those that may truly benefit from any of the above services, yet as an employee I also see a waste of taxpayer dollars. | 11/22/2013 1:51 PM |
| 76 | Self-directed services that encompass the options above with the exception of acute care | 11/22/2013 1:49 PM |
| 77 | Adult day services | 11/22/2013 1:35 PM |
| 78 | Day program | 11/22/2013 1:07 PM |
| 79 | in a 24/7 supervised home setting with a family | 11/22/2013 12:26 PM |
| 80 | I don't have medicaid yet | 11/22/2013 11:59 AM |
| 81 | My daughter has a Katie Beckett waiver. | 11/22/2013 11:26 AM |
| 82 | Goals under the self-directed services through the area agency to work on activities of daily living, but they do not occur every day. | 11/22/2013 11:03 AM |
| 83 | use of a cane | 11/22/2013 10:48 AM |
| 84 | fuel reimbursement | 11/22/2013 10:12 AM |
| 85 | Recreation is very important | 11/22/2013 10:05 AM |

Q4 How frequently do you use services paid for by the NH Medicaid program?

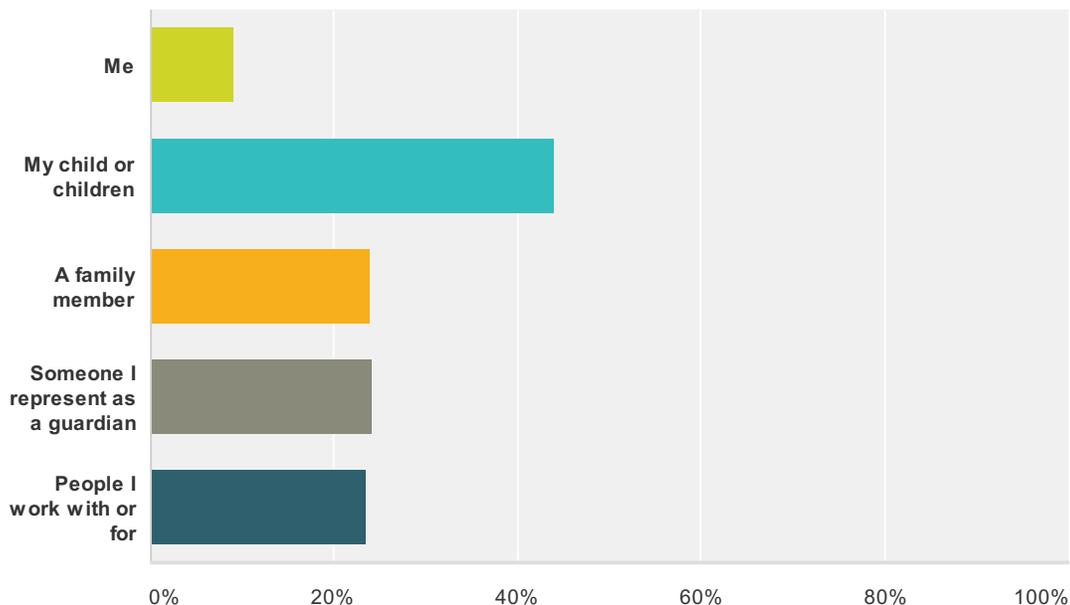
Answered: 613 Skipped: 279



| Answer Choices | Responses |
|------------------------|------------|
| Not very often | 15.82% 97 |
| Several times per year | 7.99% 49 |
| Every month | 26.43% 162 |
| Daily | 49.76% 305 |
| Total | 613 |

Q5 Who uses services paid for by the NH Medicaid program?

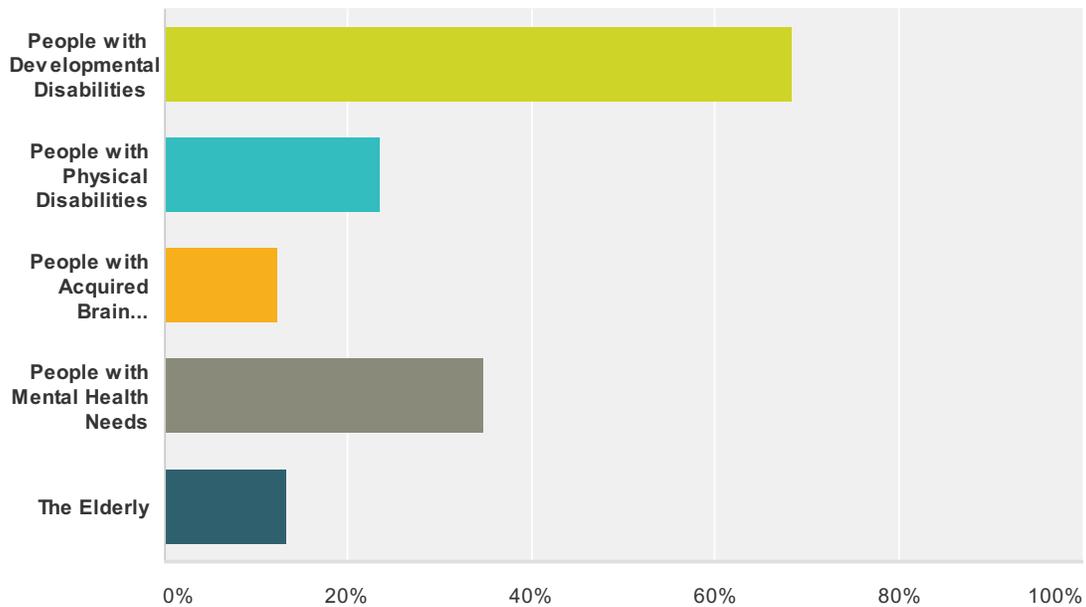
Answered: 666 Skipped: 226



| Answer Choices | Responses |
|-----------------------------------|------------|
| Me | 9.01% 60 |
| My child or children | 43.99% 293 |
| A family member | 24.02% 160 |
| Someone I represent as a guardian | 24.17% 161 |
| People I work with or for | 23.57% 157 |
| Total Respondents: 666 | |

Q6 Which Medicaid Long-Term-Care consumer population do you or your family member represent?

Answered: 675 Skipped: 217



| Answer Choices | Responses |
|--|------------|
| People with Developmental Disabilities | 68.30% 461 |
| People with Physical Disabilities | 23.56% 159 |
| People with Acquired Brain Disorders | 12.30% 83 |
| People with Mental Health Needs | 34.81% 235 |
| The Elderly | 13.33% 90 |
| Total Respondents: 675 | |

| # | Other (please specify) | Date |
|----|--|--------------------|
| 1 | Persons with disabilities also | 12/7/2013 4:28 AM |
| 2 | none | 12/6/2013 8:20 PM |
| 3 | The Poor | 12/6/2013 1:55 PM |
| 4 | schizoaffective disorder | 12/6/2013 12:04 PM |
| 5 | anticipate needing medicaid long term care for 19 year old daughter with mental health needs | 12/6/2013 11:25 AM |
| 6 | Our child may have an acquired brain disorder, but it has not yet been diagnosed. | 12/6/2013 10:33 AM |
| 7 | More often elderly, and the broader mental health needs of middle age, and teens. | 12/6/2013 10:05 AM |
| 8 | including substance abuse | 12/6/2013 9:30 AM |
| 9 | Mostly youth | 12/6/2013 9:15 AM |
| 10 | Mixed population with multiple needs as listed above | 12/6/2013 8:55 AM |
| 11 | mental health needs, who may have physical or developmental disabilities | 12/6/2013 8:54 AM |
| 12 | family members with mental health issues | 12/6/2013 7:59 AM |

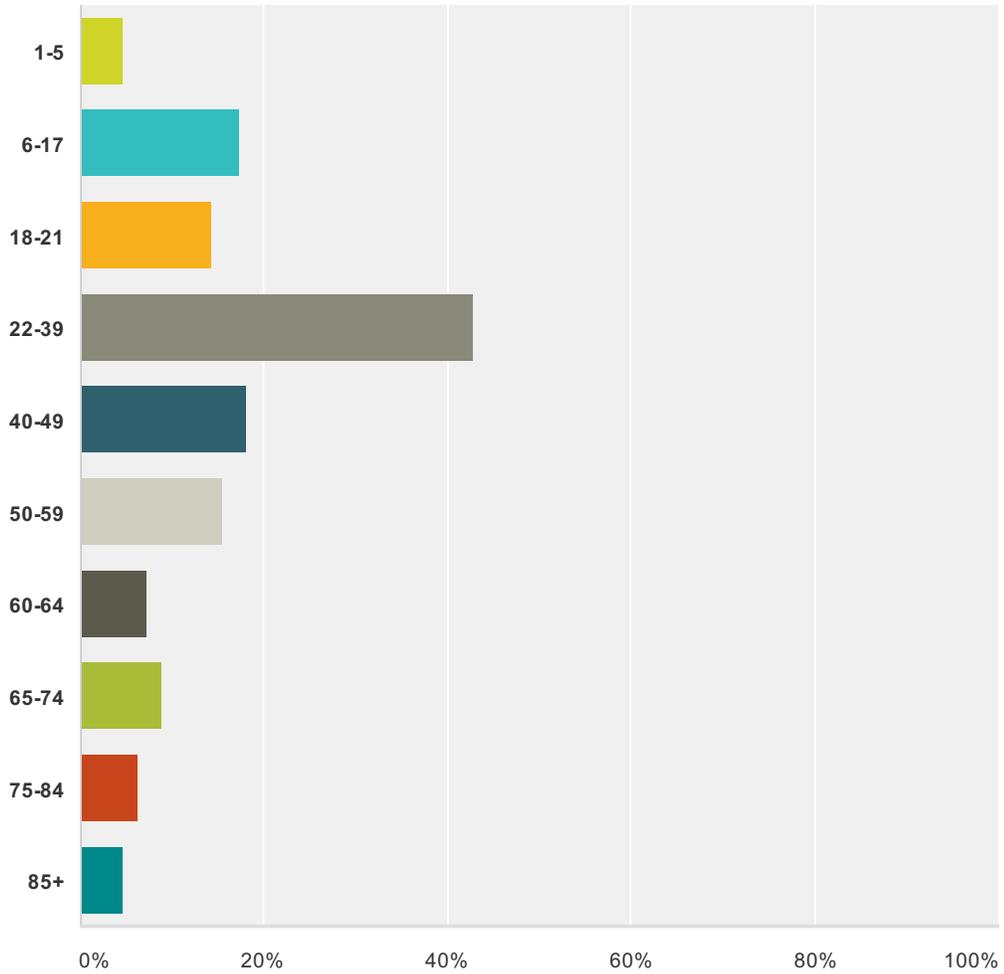
NH Medicaid Long-Term-Care Program Survey

| | | |
|----|--|---------------------|
| 13 | In the County Corrections system it could be any of these. | 12/6/2013 7:52 AM |
| 14 | schizophrenia | 12/6/2013 7:23 AM |
| 15 | My Mom wants to stay in her home. | 12/5/2013 7:51 PM |
| 16 | None | 12/5/2013 7:15 PM |
| 17 | Foster Care | 12/5/2013 6:25 PM |
| 18 | my daughter is diagnosed with a serious mental illness | 12/5/2013 6:21 PM |
| 19 | Autism, retardation | 12/5/2013 2:43 PM |
| 20 | as a service provider | 12/5/2013 8:47 AM |
| 21 | Austistic | 12/4/2013 9:04 PM |
| 22 | N/A | 12/4/2013 12:48 PM |
| 23 | All of the above in work position | 12/4/2013 11:39 AM |
| 24 | People with Addiction | 12/4/2013 9:28 AM |
| 25 | smith-Magenis syndrome -autistic like -neurological behavioral -requires24/7help | 12/4/2013 9:11 AM |
| 26 | Both physical and developmental disability; do you really think folks have only one? | 12/4/2013 6:50 AM |
| 27 | autism | 12/3/2013 8:17 PM |
| 28 | I do not get/use Medicaid | 12/3/2013 12:16 PM |
| 29 | over 65 | 12/3/2013 12:05 PM |
| 30 | All of the above, but mostly people with developmental disabilities | 12/3/2013 9:07 AM |
| 31 | seizures | 12/2/2013 6:16 PM |
| 32 | I work with allthe above consumer populations | 12/2/2013 4:12 PM |
| 33 | All of the above | 12/2/2013 1:55 PM |
| 34 | People with Chronic Health Conditions | 12/2/2013 12:00 PM |
| 35 | People with chronic health | 12/2/2013 9:14 AM |
| 36 | Prenatals, individuals with MS | 11/25/2013 1:56 PM |
| 37 | all the above | 11/25/2013 12:13 PM |
| 38 | My sister/ward is in need for medical support throughout every day | 11/25/2013 9:01 AM |
| 39 | Deaf and Hard of hearing; speech and language delays | 11/23/2013 10:20 PM |
| 40 | Also many medical problems | 11/22/2013 5:04 PM |
| 41 | I work with all of the above but elderly predominantly | 11/22/2013 12:10 PM |

NH Medicaid Long-Term-Care Program Survey

Q7 What age is the person (either you, your family member or your ward) who receives Long-Term-Care services through the Medicaid program?

Answered: 626 Skipped: 266



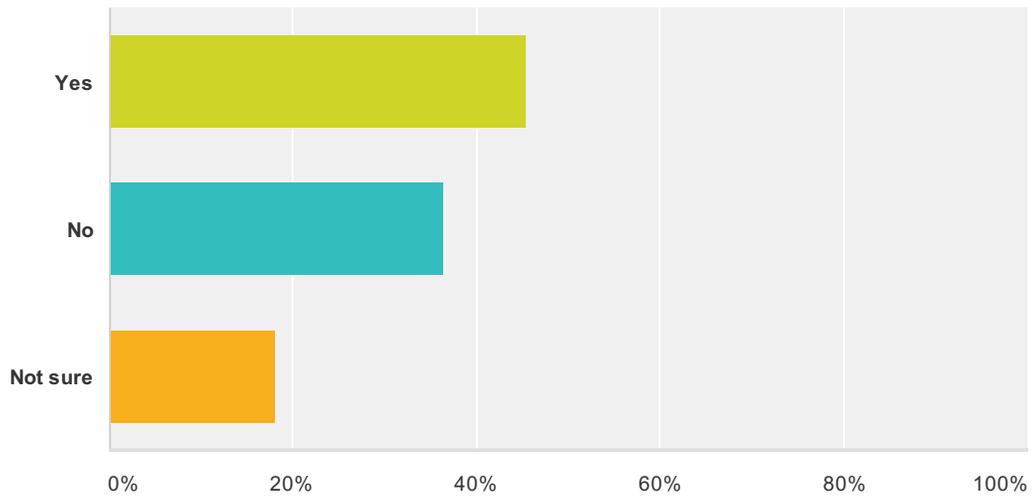
| Answer Choices | Responses |
|----------------|------------|
| 1-5 | 4.63% 29 |
| 6-17 | 17.25% 108 |
| 18-21 | 14.38% 90 |
| 22-39 | 42.81% 268 |
| 40-49 | 18.21% 114 |
| 50-59 | 15.50% 97 |
| 60-64 | 7.35% 46 |
| 65-74 | 8.95% 56 |
| 75-84 | 6.23% 39 |
| 85+ | 4.63% 29 |

NH Medicaid Long-Term-Care Program Survey

Total Respondents: 626

Q8 Have you ever been on a waiting list for services?

Answered: 645 Skipped: 247

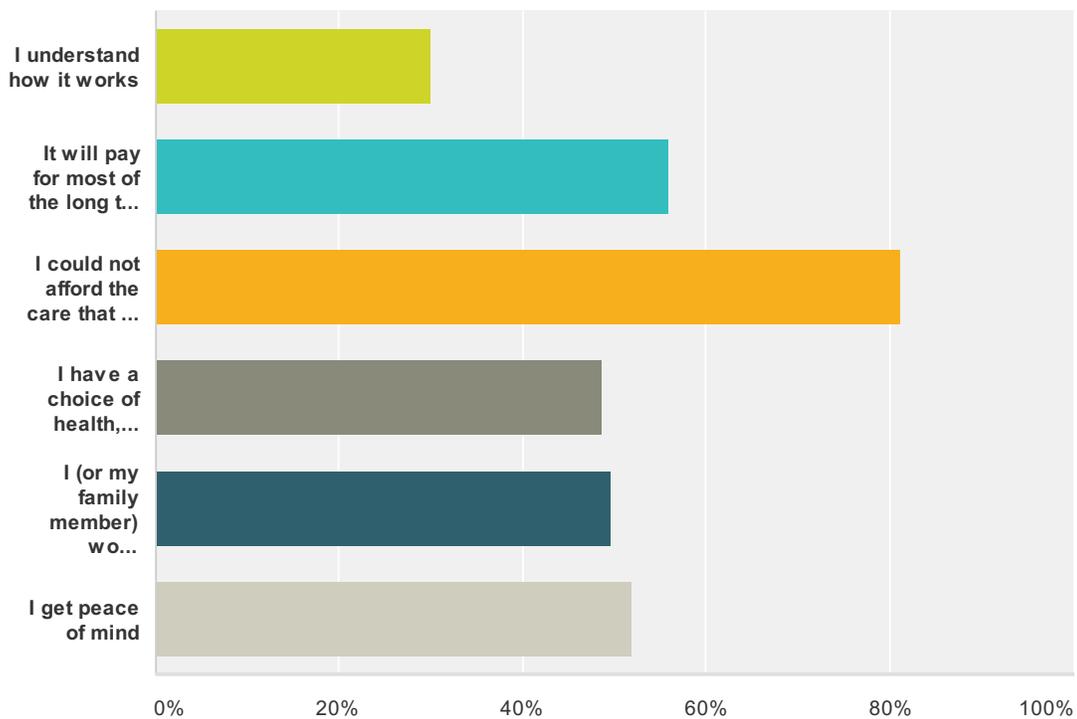


| Answer Choices | Responses |
|----------------|------------|
| Yes | 45.43% 293 |
| No | 36.43% 235 |
| Not sure | 18.14% 117 |
| Total | 645 |

NH Medicaid Long-Term-Care Program Survey

Q9 What do you like about the current NH Medicaid Long-Term-Care program? (Choose all that apply)

Answered: 579 Skipped: 313



| Answer Choices | Responses |
|--|------------|
| I understand how it works | 29.88% 173 |
| It will pay for most of the long term care services that I (or my family member) needs | 55.79% 323 |
| I could not afford the care that I (or my family member) needs without it | 81.00% 469 |
| I have a choice of health, in-home or direct support providers | 48.53% 281 |
| I (or my family member) would not be able to stay in my (their) home without it | 49.57% 287 |
| I get peace of mind | 51.81% 300 |
| Total Respondents: 579 | |

| # | Other (please specify) | Date |
|---|---|---------------------|
| 1 | MEAD is a wonderful program. this program has provided me the motivation to work. providing my daily PCA personal care attendences allows me to live and work as independent as possible. | 12/10/2013 10:24 AM |
| 2 | I wish the State would accept group homes as a WONDERFUL alternative to private homes . . . | 12/8/2013 4:59 PM |
| 3 | I do not utilize the program, but think it is important that individuals have a choice in providers and venue | 12/7/2013 8:25 AM |
| 4 | Most of the above apply for the people I have observed: the elderly, disabled and their family members. | 12/7/2013 4:30 AM |
| 5 | We are able to think "outside the box" to provide the services that will best help my daughter and meet her needs. | 12/6/2013 10:49 PM |
| 6 | section 8 housing | 12/6/2013 12:05 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|--|--------------------|
| 7 | I can't afford health care, yet don't qualify for assistance. | 12/6/2013 11:57 AM |
| 8 | My sister is 81 and is in a LTC facility and has benefit of Medicare LC services. | 12/6/2013 11:49 AM |
| 9 | Really do not have enough information to respond. | 12/6/2013 10:06 AM |
| 10 | My brother is a developmentally disabled person (down's syndrome), he has lived at home with my elderly parents for 42 years and continues to do so today. He receives support for many activities that have helped him remain living with my parents for a lot longer than they would have been able to manage this situation otherwise. As a society we have a responsibility to care and provide for individuals who are unable to care for them selves and help families with that care. Surely a society we have to provide a reasonable amount of care for these individuals. | 12/6/2013 9:49 AM |
| 11 | I get SOME peace of mind..because it feel like its another service going to be ripped away from me, AND, not only do I NOT understand how it works, MOST people I KNOW DON'T UUNDERSTAND..seems like there are any ways to interpret rules & money allocation..VERY CONFUSING... | 12/6/2013 9:23 AM |
| 12 | This program often allows the youth I deal with to request services that their families cannot afford. | 12/6/2013 9:16 AM |
| 13 | I receive all of the above from patients in the acute care setting transitioning to home in their community | 12/6/2013 8:56 AM |
| 14 | Re: clients | 12/6/2013 8:55 AM |
| 15 | Mental health services could not be provided at a reasonable cost. | 12/6/2013 8:19 AM |
| 16 | LTC Program does assist the tax payers intially upon incarceration of offenders covered as costs related are not paid for by the County. But more important is that these services serve to assist the individual (offenders) upon release back into the community thus assuring a continuity of care. | 12/6/2013 7:55 AM |
| 17 | Would be on the streets and very ill without it. | 12/5/2013 10:02 PM |
| 18 | It allows for the individuals dignity and is set up to meet the individuals Human and Civil Rights. It gives the opportunity to meet The Right to Pursuit of Happiness. It opens opportunities for employment and for the individuals to be an active, productive and contributing member of society. It allows for the individual to remain living at home with the proper supports and is more cost effective than previously undignified institutions. Within that taking into consideration that, without the supports, presently in place, for individuals with developmental disabilities, families would and will not be able to continue to support the individuals. This would require a reopening of institution. Taking into consideration inflation and present cost of institutionalization, without the current NH Medicaid Long-Term-Care program, in the way in which it exists for people with Developmental Disabilities and/or other Disabilities, without experienced and trained case managers, Medicaid waivers for day program, respite, residential staff, cost of care for the individuals will be by far greater. This is not factoring in the stress level for family members who, without these necessary supports for their family member, will suffer stress related illnesses and round and round it goes. There is a great deal more to be said for the current NH Medicaid Long-Term-Care Program. Let us move forward, not back to the old days, that did not work then, it will work even less now! | 12/5/2013 8:55 PM |
| 19 | It is the difference of my family member living a 'normal' life, where he is able to work, have supports to succeed and feel like he is a success . He is able to get the medication that he is stabilized on, not the generic that did not work well for him! | 12/5/2013 8:26 PM |
| 20 | Having choice is very important. If my daughter can be kept out of an institution and get care, all the better. This way her dignity is respected and she will have more opportunity | 12/5/2013 6:23 PM |
| 21 | N/A | 12/5/2013 5:39 PM |
| 22 | service provider not recipient | 12/5/2013 11:55 AM |
| 23 | I am not familiar with the details. | 12/5/2013 8:34 AM |
| 24 | The assistance from OneSky Services Coordinator has been great. I was lost trying to help the recipient prior to having them. | 12/5/2013 5:16 AM |
| 25 | The only thing I like about NH Medicaid is the MEAD program. | 12/4/2013 7:37 PM |
| 26 | not using yet | 12/4/2013 3:22 PM |
| 27 | N/A | 12/4/2013 12:49 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|---|---------------------|
| 28 | My mother-in-law and father-in-law provide 24/7 care for their son. My mother-in-law died in April 2011 and we requested long-term-care because my 67-yo father-in-law cannot physically or emotionally provide the level of care his son needs. We've been "waiting", now for 2.5 years, with continuous promises of "in a few months". The check marks above indicate what I WOULD like about it if we could access the level of care and support needed. | 12/4/2013 12:20 PM |
| 29 | I can go to work | 12/4/2013 11:27 AM |
| 30 | My son's program is inadequate for his needs as we would like a residential placement and have not received it. | 12/4/2013 11:01 AM |
| 31 | Provides this for my pt.s | 12/4/2013 9:44 AM |
| 32 | N/A | 12/4/2013 9:28 AM |
| 33 | thank you so much for these services. my daughter was in Easter Seals group home from age 12. Easter seals group home was not ideal and greatly needs improvement but no where else option. farmsteads of New England in Hillsboro NH is her adult placement and an answer to My prayers. if I had to design a place myself I wouldn't change one thing. thank you for supporting her in this amazing life. she feeds baby goats and her team has gone above & beyond to work with her intense behavioral challenges. pathways in Claremont has been excellent as has been the Stars evaluations which recommendations are already helping. | 12/4/2013 9:21 AM |
| 34 | without the services provided for and reimbursed for by Medicaid I would be unemployed and without private health insurance for myself and my adult child. | 12/3/2013 10:21 PM |
| 35 | With the help and support of the team at the Moore Center we were able to develop a plan that would best benefit Megan. Help her with daily living, medical and physical care as well as being a good citizen in her community. | 12/3/2013 4:18 PM |
| 36 | Don't use, but see the need for it. | 12/3/2013 3:18 PM |
| 37 | I value the personalized and community based support our Area Agency offers. The have a long history of supporting our child through eary intervention, school age years and now as an adlt so have a solid sense of her needs, and our priorities for support as a family. Our area agency has a keen understanding of the local resources available to us in our community. | 12/3/2013 2:34 PM |
| 38 | Under my guardianship and with your help my sister has the feeling of living independently for the first time in her life and she is thriving. | 12/3/2013 12:40 PM |
| 39 | It should assist the truly needy. Those with family who can afford it should pay their own way. It is their responsibility. | 12/3/2013 12:18 PM |
| 40 | This keeps up skills already obtained in Special Ed. Very important to these folks. My boys would just rot away in their rooms laying on their beds watching TV without these very important services. I especially know we need to keep our area agency in tact: Community Crossroads. Great help whenever you need it | 12/3/2013 11:35 AM |
| 41 | it can be very frightening and lonely and the support and kindness is increadably helpful | 12/3/2013 8:44 AM |
| 42 | It allows my loved one to get to and from work, have social interaction and daily living skills support and education. | 12/3/2013 8:17 AM |
| 43 | Before my son qualified, we were on the brink of losing our home because his services to care for him were astronomical. Medicaid long term care allows me to be able to work and take care of him. Before, I could not do both. We almost lost everything. | 12/2/2013 7:56 PM |
| 44 | All the people I serve depend on Medicaid Long-Term-Care to support them in their daily activities and personal needs. | 12/2/2013 4:19 PM |
| 45 | If it weren't for the assistance we get, I would not be able to work and would have to stay at home to care for my son. We would both have to be on public assistance and health insurance if I could not work. | 12/2/2013 2:04 PM |
| 46 | This is an extremely challenging position to be in as a parent. It stresses the family to the max even with help. | 11/29/2013 5:52 PM |
| 47 | See an answer given above about the "life share" home-provider model she receives. | 11/29/2013 11:02 AM |
| 48 | Provides my family member the least restrictive and most normalcy in quality of life within her capacity. | 11/28/2013 3:05 PM |
| 49 | This program is facilitating my daughter's quest toward independent living. | 11/28/2013 2:27 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|--|---------------------|
| 50 | I like the local/direct/decision-making control we have with the family-governed Area Agency System. I appreciate the non-profit Area Agencies' mission-based approach to care and much prefer it over the for-profit system of the MCOs. | 11/27/2013 10:42 PM |
| 51 | I know my son's case manager. She lives in my community. She is familiar with our needs. We are not just a number or a voice on the phone. I want my area agency to remain intact and able to meet his needs through the transition from school to community-based adult services. | 11/27/2013 8:55 AM |
| 52 | Each area agency gets to know their clients and the challenges they have individually so that the money is spent in the way that best utilizes the funds based on need and geography and availability | 11/26/2013 3:02 PM |
| 53 | I have a say in what and how the services are delivered. I am able to be involved with the oversight of the organizations that provide the services. | 11/26/2013 10:45 AM |
| 54 | It is important to for the person who experiences disabilities to be able to participate in choosing who helps them so they can succeed in the community | 11/26/2013 10:24 AM |
| 55 | I do not have a choice of providers. My area agency, community bridges told me who my provider would be. There were no "choices". I had to research myself to find out what other options were available for my child with autism | 11/26/2013 6:28 AM |
| 56 | My son would not be able to use the services of Lakes Region Community Services - he would not have a job or the support for that job. | 11/25/2013 7:41 PM |
| 57 | Looking toward the future...difficult situation | 11/25/2013 3:24 PM |
| 58 | It is not easy to understand, and all of a families options are funneled through area agencies, who often do not present ALL options, present incorrect information, and families are still required to do a LOT of the organizing and the work. In addition, the current system is underfunded, and completely out of balance where some people have HUGE budgets and others have pittance. | 11/25/2013 1:37 PM |
| 59 | My husband (my sister's brother in law and guardian) is able to provide for my sister's daily needs. We are able to accommodate Holly's daily schedule, according to how she is feeling for the day (medical and emotional.) My sister resided with our paternal grandparents for 25 years, resided in their home for 35 years and as of this year will move to a new home. As of yet, this adjustment is successful because we go according to Holly's needs-for the day. | 11/25/2013 9:23 AM |
| 60 | There is never any piece of mind. Every two years during the budget process there is the potential that the NH legislature will not allocate the necessary funds and my daughter's budget may be reduced. The other reality is that there are many children and adults that are currently under served. Every day is a struggle. If my daughter is placed on a waitlist again when she turns 21 she would no longer be able to live in her local community with her family and siblings in a loving, familiar, and supportive environment- I will have to hand her over to the state of NH. I have to work and cannot quit my job to be her caregiver full-time. Ironically enough if that happens it will cost the state of NH far more. I believe turning LTSS over to Managed Care Organizations is the WRONG thing to do. NH already ranks 2nd in the nation (2013 Cerebral Palsy Institute Study) in highest quality services and in the lower third for dollars spent. Why on earth would we hand over our system to MCOs that have little to NO experience?! This SIM grant money should have been utilized to further improve our current person-centered locally controlled DD system. We are moving from a bottom-up system where the users of the system have a direct say about how and what services are utilized to a top-down system where the MCOs have final say... where they will create new and more complicated processes for approvals, appeals, etc. further burdening families and individuals beyond the very unique and complicated challenges we face every day. I have already been informed of this for Step 1 (acute medical)... there will be a new telephone approval process for all 3 MCOs to participate in the Medicaid mileage reimbursement program. Using a Managed Care model and lens to deliver LTSS is NOT appropriate. This is the worst thing to happen to NH. This is being forced upon the stakeholders. This will destroy the partnership families and individuals have with the Bureau and put these already extremely vulnerable citizens at risk. The commissioner, legislature, and Governor state that Medicaid is unsustainable... that the managed care model will save money while maintaining quality of care (for Step 2), but to date we have not been provided with any objective data, information, and evidence to prove that it will. Heck we don't even have a plan yet. If we want to have a serious national discussion about reducing Medicaid costs then we should be talking about utilizing the current NH DD system in the US and carrying that into the elder baby-boomer population, but it would appear that with the wealthy special interest of health insurance companies and nursing home companies that private special interest wins over what is actually more appropriate for our citizens. I'm very disheartened and disappointed with the process and the key people who have been charged with safe guarding this system. | 11/25/2013 8:39 AM |
| 61 | My son does not receive adequate services through this program. | 11/23/2013 9:58 PM |
| 62 | CDS | 11/23/2013 9:35 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|---|---------------------|
| 63 | W/o consumer directed services my son would not be able to live independently, He currently works a p/t jobs, takes community transportation every where and essentially have a life he enjoys and feels like part of his community. He requires assistance with job coaching (minimal hours), transportation, frequent safety checks, social skills and MH services. I would most likely need to quit my job if the service we have currently work so hard to create were no longer available to him. | 11/23/2013 7:49 AM |
| 64 | Just was approved... Been struggling without it. | 11/23/2013 6:26 AM |
| 65 | Area agency and their contractor Chesco are local and work closely with our family. | 11/23/2013 12:19 AM |
| 66 | I don't have enough information about it yet. | 11/22/2013 10:19 PM |
| 67 | The current NH system has been in place for 30 years. The Area Agencies located in NH's counties, know their areas, connections, resources, businesses, etc. They have long standing working knowledge of how to help the individuals within their particular area 24/7. | 11/22/2013 9:55 PM |
| 68 | without the services provided my guardian would have to be in a locked setting | 11/22/2013 6:27 PM |
| 69 | He is able to be active in his home community, access recreation, supplemental services, we meet and work with a team regularly | 11/22/2013 6:10 PM |
| 70 | Many of the families I work with share with me that these are the things they most value about the current system. | 11/22/2013 5:50 PM |
| 71 | He has the support he needs to stay safe 24 hours/day. | 11/22/2013 3:32 PM |
| 72 | Not sure if I am in the Long Term Care Program | 11/22/2013 3:31 PM |
| 73 | I know the people who provide services to my sister and can call on them at any time, night or day, midweek or weekend, emergency or unexpected change of plans. My sister also has a personal relationship with the local area agency employees. | 11/22/2013 3:28 PM |
| 74 | there are a number of consumers that are quite happy with what the state "gifts" them. And have no intention of even trying something different. | 11/22/2013 1:53 PM |
| 75 | I can contact local and state personnel if I have an issue. | 11/22/2013 1:52 PM |
| 76 | very cumbersome, overly regulated and difficult to deal with | 11/22/2013 1:49 PM |
| 77 | Choice for those receiving services | 11/22/2013 1:45 PM |
| 78 | I like that fact that we have access to some funding but I do not like the way the system is laid out. | 11/22/2013 1:40 PM |
| 79 | she doesn't understand the question & would not know what to answer even if she did | 11/22/2013 12:28 PM |
| 80 | without the benefit many people would be without services needed to meet basic daily activities, whether at home or in a placement | 11/22/2013 12:11 PM |
| 81 | don't have it yet | 11/22/2013 12:00 PM |
| 82 | It is consumer driven and directed, and community supported by consistent, personally hired and selected support staff and providers who value and fully understand the benefits to ALL involved of long-standing, trusted relationships with local, community-involved people and organizations. | 11/22/2013 11:42 AM |
| 83 | It would be nice to have a choice of providers to receive mental health care from instead of one provider per region. | 11/22/2013 11:37 AM |
| 84 | The question is what I like about it. Well I can't answer that because the people that handle the programs are not reliable. still need to have a babysitter because they don't find someone to cover when that person do not go in and they always tell you last min. we work and have to travel to get home and they never give enough time to be there when the disabled person is dropped off and can not be home alone. some of the long term programs he only gets once a week for a couple of hours. Do you think a person who has MR is going to learn life skills in a couple of hours a week. They need it every day. | 11/22/2013 10:17 AM |
| 85 | it is better than nothing but inadequate | 11/22/2013 10:16 AM |
| 86 | There are really no other choices to "like" it could be improved | 11/22/2013 10:14 AM |
| 87 | Although support does pay most of the needs, it does NOT pay for all and the family has to make up the difference. What will happen when we die? | 11/22/2013 10:08 AM |
| 88 | Ability to customize non-traditional, complementary therapies that enhance traditional therapies -- much more effective outcomes, progress. | 11/22/2013 8:48 AM |

NH Medicaid Long-Term-Care Program Survey

Q10 Is there anything else that you like about the current Medicaid Long-Term-Care program that you would like to tell us about?

Answered: 254 Skipped: 638

| # | Responses | Date |
|----|--|---------------------|
| 1 | I think it is important for individuals with disabilities to live as independent as possible. the MEAD program gives people the resources to go out and work. it is important for me and i'm sure others with disabilities to have a purpose in life and working is a wonderful option for us. MEAD allows individuals to actively participat in work and community environments without losing essential medical services that Medicaid provides. thank you please keep this option for us! | 12/10/2013 10:31 AM |
| 2 | It is community based and accessible. The current program is based around the needs of the individual. | 12/9/2013 7:33 PM |
| 3 | I have applied for medicare for my family member and was denied. I have time and again tried to get assistance for my family member with no results. I don't know what else to do as my family member can't find a job. I feel your agency has not helped in any way. | 12/9/2013 12:31 PM |
| 4 | Don't know the plan but wold hope it builds off Vt.'s SASH program which is structured first around the state's Senior Housing facilities to group services | 12/9/2013 9:31 AM |
| 5 | I am very concerned about the future of my family members Long Term Care Medicaid benefits under Step 2 of the Medicaid Managed Care program. I have no idea what Step 2 includes. | 12/7/2013 4:15 PM |
| 6 | It is vital for consumers to receive needed services for their own welfare and to reduce the overwhelming burden on their families | 12/7/2013 11:49 AM |
| 7 | As a guardian, I am able to work directly with the service provider and area agency when there are changes in the needs of my sister, who has Downs Syndrome and dementia. | 12/7/2013 10:34 AM |
| 8 | People generally do not apply until their living situation is on the cusp of becoming unsafe. It takes 90 days or more for an application to be completed. Often times this gap leaves the family in limbo waiting and not knowing if they will receive the requested help. The number of Nursing Facility beds are frozen and there are long wait lists so individuals in need are at risk for a period of time and there are no services to fill this gap especially if the client cannot afford to pay which Medicaid Long Term Care applicants cannot because they have low income and assets. | 12/7/2013 4:37 AM |
| 9 | Although some of the services my daughter receives are called a program, they don't neatly fit into a prescribed "program" that might only be available through our local area agency. These are people my daughter and I know, who also know and understand her unique needs. | 12/6/2013 10:51 PM |
| 10 | It helps many different types of people and populations in this area including the poor and the elderly | 12/6/2013 10:13 PM |
| 11 | It is vital for persons living with mental illness | 12/6/2013 9:40 PM |
| 12 | It keeps my young adult son safe and medically stable. | 12/6/2013 5:30 PM |
| 13 | My son get all he needs. I wish however that he could get some preventative dental care. | 12/6/2013 3:18 PM |
| 14 | There is a severe lack of step down Mental health services for patients discharged from the State hospital in Concord. As a result Pts have to stay longer in the State Hospital, until the community outpatient services can begin. Residential programs are BADLY NEEDED. If nothing else to save taxpayer dollars. These patients would not need to stay at the State Hospital if there were residential (cheaper) SERVICES. | 12/6/2013 1:40 PM |
| 15 | Waiting time for assessment is too long! | 12/6/2013 1:03 PM |
| 16 | accessing crisis services including telephone crisis line has literally saved my daughter's life many times - from attempted suicide three times, plus other crises that would have led to more serious events if not for the earlier intervention. | 12/6/2013 12:11 PM |
| 17 | I worry for my son's future. My husband and I will not live forever and I want to go knowing that he is taken care of. | 12/6/2013 11:16 AM |
| 18 | ServiceLink has been a positive part of the system to help connect older adults to available services. | 12/6/2013 11:13 AM |

NH Medicaid Long-Term-Care Program Survey

| | | |
|----|--|--------------------|
| 19 | The flexibility of choices and being able to run the program services in behalf of my adult children. | 12/6/2013 11:09 AM |
| 20 | VITAL IN NH | 12/6/2013 11:00 AM |
| 21 | It provides me choice of providers. My daughter needs 24 hour support from developmental services as well as support for her mental health issues. Medicaid supports her long term care needs in both systems. | 12/6/2013 10:50 AM |
| 22 | We are hoping that our child can get some kind Long Term Care with a mental health problem disability that is not Schizophrenia or Bipolar Disease. She is very much affected by some brain disorder that keeps her from being able to get out into the work place. | 12/6/2013 10:36 AM |
| 23 | DD services do have some problems | 12/6/2013 9:27 AM |
| 24 | I am concerned about added administrative costs related to Managed Medicaid and how those funds will go to out of State Profits and administrative overhead. I am also concerned about added administrative burdens on providers. I am especially worried about plans to include people with developmental disabilities in this system. | 12/6/2013 9:27 AM |
| 25 | It really helps and DOES provide some peace of mind.... | 12/6/2013 9:23 AM |
| 26 | I believe there is a need for this program for the youth who do not have access to their own financial stability so they can receive these services. By receiving these services hopefully in most/some cases they will gain the opportunity to improve their personal situations in order to become active members of society. Mental health is a very necessary factor in normal development and success in life. The people with long term disability also need these services in order to function to the best of their ability. | 12/6/2013 9:20 AM |
| 27 | It prevents abject poverty and human suffering. Please consider funding it adequately. | 12/6/2013 9:00 AM |
| 28 | It is crucial to the support of our loved one who presents with mental health issues and other health issues | 12/6/2013 9:00 AM |
| 29 | It provides extra services from personal care attendants that VNA cannot provide and enables people to meet their needs in the community. There are waits in some areas due to the rural setting and limited creproviders | 12/6/2013 8:57 AM |
| 30 | Adult mental health services for the not seriously and persistently mentally ill do not provide for enough sessions. Frequently they don't receive the services they need and deserve because of the spenddown and the \$1,800 limit. | 12/6/2013 8:57 AM |
| 31 | It would nice if this kicks in to help families of the disabled between the ages of 18 and 21. It is a "dead zone" and families are in horrible shape to care for children that are in that age group. | 12/6/2013 8:28 AM |
| 32 | think it has always been responsive in a positive way to help meet my brother's needs | 12/6/2013 8:09 AM |
| 33 | It helps individuals who need mental health services obtain counselling, respite and nursing home care that they otherwise would be unable to obtain. | 12/6/2013 8:01 AM |
| 34 | Any services and assistance that impacts direct cost reductions to the County Corrections system such as LTC is important to the tax payers of our County. | 12/6/2013 7:57 AM |
| 35 | Our family has had to go through many obstacles to get our son what he needs and being able to maintain that has been almost impossible. Our family along with many others need help with respite services and it seems as though when we get one the system cracks again. I also do not believe that these children should have to end up in the juvenile system to get the help they need. Also let's work to save the group homes we have or work with them to get new | 12/6/2013 7:57 AM |
| 36 | I should mention my answers are retrospective. My son, while in the care of NH Mental Health System, was killed by a delusional fellow sufferer of schizophrenia. In a major way no one was guilty of a crime. In fact that is what the court decided "No guilty by reason of insanity." It has been many years. The intensity of my belief in the necessity for an effective Mental Health System is unwavering. | 12/6/2013 7:30 AM |
| 37 | with a diagnosis of bipolar mood disorder and Schizophrenia he would not survive on his own. He would be living on the streets with no medications. | 12/5/2013 11:10 PM |
| 38 | ACT team services provided through Medicaid are critical to my loved one's ability to live in the community. | 12/5/2013 10:59 PM |
| 39 | Without Medicaid I would be unable to pay for my medical or psychiatric care. I would not be able to pay for my medicine and would be unable to live independently. | 12/5/2013 10:36 PM |
| 40 | Trust | 12/5/2013 10:12 PM |
| 41 | Medical care is important | 12/5/2013 10:08 PM |

NH Medicaid Long-Term-Care Program Survey

| | | |
|----|--|--------------------|
| 42 | Provides case management services that have been critical at some points in my family member's history. | 12/5/2013 9:44 PM |
| 43 | I have a spend down that is unrealistically high and I often don't seek medical care when needed because of this. | 12/5/2013 9:26 PM |
| 44 | I just out laid this under # 9. Yes, anything less than that which this program supports will be a violation of basic Human and Civil Rights. Anything less prevents these individuals who are in need of these supports and services from their pursuit of happiness. Additionally, do the math at the level of cost of institutions these days and you will find that the current Medicaid Long-Term-Care Program, as it is set up, at present, for people with D.D., brain injuries and such remains most cost effective, by far. Take away this program and you affect not only this population, but their family members, care givers, people who know what they are doing, who've been doing it for years. You'll be affecting efficiency, cost effectiveness, jobs (many will be lost), the economy as a whole will be affected, Constitutional Rights will be under violation and this state, this country will have joint into third world country movements. This country has been established under God, with Liberty and Justice for ALL ! | 12/5/2013 9:09 PM |
| 45 | Please increase your attention to the mental health issues in our state. | 12/5/2013 8:49 PM |
| 46 | Family member has a lot of medical issues that we would not be able to cover the cost. If not for medicaid family member would end up in a facility needing 24/7 nursing care. I estimated that it would cost the state half a million dollars a year. It is more cost effective for our family member to stay home with us but the love and care we provide is so much better than any facility could ever give. For this we are thankful. | 12/5/2013 8:45 PM |
| 47 | I think expansion is important! Perhaps that won't include housing or food stamps, but integrated health care is vital for our families, the community and the state. | 12/5/2013 8:27 PM |
| 48 | I get support from others, which help me as my sisters caregiver and guardian. | 12/5/2013 8:13 PM |
| 49 | That a basic model exists at all is appreciated. Yet a tremendous amount of improvement needs to take place. | 12/5/2013 8:10 PM |
| 50 | Have not used the services yet. Still waiting for approval. Very long wait. | 12/5/2013 7:53 PM |
| 51 | More hospitals that can take long term mental health patients to avoid the long stays in the ER | 12/5/2013 7:34 PM |
| 52 | I would need to know more information about the Medicaid Long-Term-Care program before I answer this question. | 12/5/2013 7:31 PM |
| 53 | Regular supportive services are less expensive than crisis driven care and is more humane for the individual | 12/5/2013 6:27 PM |
| 54 | Medicine, housing, job training and on job assistance are very important. | 12/5/2013 6:20 PM |
| 55 | It will become the vehicle for introduction of medical homes in NH. It is essential that people with mental health issues have coordinated care. For too long, the PCP has been left out of the communication loop. | 12/5/2013 6:14 PM |
| 56 | It provides flexibility so our son can have the services he needs now and I hope, when we aren't able to care for him, he will be able to get more services as needed. | 12/5/2013 6:10 PM |
| 57 | They are community members. I know them. We function well as a team. | 12/5/2013 6:02 PM |
| 58 | Project SEARCH is an excellent program for young adults with developmental disabilities and mental health challenges. | 12/5/2013 5:50 PM |
| 59 | That I direct the services that best suit my son. | 12/5/2013 5:14 PM |
| 60 | We are thankful for all the help and support that we receive... | 12/5/2013 2:48 PM |
| 61 | I like the fact that Medicaid supports programs that give people with disabilities the opportunity to be included in their communities and in the society at large. | 12/5/2013 1:09 PM |
| 62 | People with disabilities should receive more money in their allowance rat \$600.00 a week You cannot live under \$600.00 just to get by today especially the high cost of food and other goods and services. There should be changes in the Consumers with disabilities who lives in the community. Consumer with disabilities deserves to live a better life in the Community. Jocelyn Gallant, Salem, NH | 12/5/2013 1:01 PM |
| 63 | The case manager was invaluable in understanding and helping my family member to access services and help us find staff that fit with our family. Our family deals directly with one person for everything and keeps us well informed. | 12/5/2013 12:39 PM |
| 64 | That it provides quality of life and community inclusion for people with acquired brain injury. | 12/5/2013 11:57 AM |
| 65 | nope | 12/5/2013 11:55 AM |

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| 66 | More housing options need to be made available and funded. Better pay and training for help needs to be in place. | 12/5/2013 11:12 AM |
| 67 | The choices we get to make to personalize my daughters care and support. | 12/5/2013 10:58 AM |
| 68 | Local control. | 12/5/2013 10:16 AM |
| 69 | It is extremely important that I have the ability to hire the support staff for my child. They are an integral part of her care as well as our family. In addition, when an issue arises, I need the ability to speak with someone local to help we resolve the issue. | 12/5/2013 9:14 AM |
| 70 | We eventually will need to use it and would like details. | 12/5/2013 8:35 AM |
| 71 | It is helping the recipient maximize her potential that i otherwise would not be able to do. | 12/5/2013 5:17 AM |
| 72 | I like the fact that it is handled locally. I don't want any third party insurance company that is located out of state handling this for my family member. It is crucial that it remain locally controlled. No out-of-state company needs to take this over. | 12/4/2013 10:10 PM |
| 73 | It provides the services needed to not only keep my daughter in our home and community but also keeps her healthy and able to maintain acquired skills through on-going therapies as needed. | 12/4/2013 9:39 PM |
| 74 | My son needs eye glasses, because of his autism sometimes his behavior is off color and he breaks his glasses. This is very expenses behavior for the family. His medication to adjust his attitude is very costly and it is very nice that these things are covered so that he can be involved with society and handle overwhelming situations better. | 12/4/2013 9:08 PM |
| 75 | no | 12/4/2013 9:06 PM |
| 76 | My daughter Monica has Aicardi Syndrome, rare disorder that leaves her physically, mentally and visually challenged. She is fed with a feeding tube, has seizures everyday and is totally non verbal and incontinent. Total Care. When she was 22 she moved in to a group home staffed by medically trained caring people who care for her as much as we do. It has been a blessing to have her in a home that has 24-7 care and it is her home as we use her social security check to pay for her rent there. Medicaid pays for the rest. It has been a life saver for Monica as she is very happy there with her two roommates and the staff it is a very busy house that has lots of activity unlike her life at home which was quiet as her parents worked all day and her brother was at school | 12/4/2013 9:06 PM |
| 77 | I want to be assured of my health needs being assured in my old age, not being required to auction everything I have to fund it. I have contributed enough to the economy of this country for it, in turn, to care for me. | 12/4/2013 9:05 PM |
| 78 | My spendown is too high for Medicaid to be helpful at this time (I am not currently working so am not eligible for MEAD). I suppose it would be helpful if I became very ill, and for ER and hospital coverage (I have not been in the hospital for over 7 years and haven't gone to the ER for several years). | 12/4/2013 7:41 PM |
| 79 | We are very appreciative of the services we receive through Katie Beckett/HKG/Medicaid program. Thank you so much! | 12/4/2013 6:27 PM |
| 80 | It gives me the support I need for my 36 yr old developmentally disabled son. | 12/4/2013 3:03 PM |
| 81 | The ABD Waiver Program under Medicaid and managed by the Dept of Developmental Disability Services who contract with the local Area Agency(s) is a quality program with case management and accountability for delivering appropriate LTC services | 12/4/2013 2:37 PM |
| 82 | no co-pays | 12/4/2013 2:05 PM |
| 83 | The Waiver Programs allow individuals that cannot be properly cared for in a traditional nursing home to find a non-Medicaid provider that can meet their medical, social and individualized care needs. | 12/4/2013 1:59 PM |
| 84 | Our daughter has a Self-Directed-Services Program funded by Medicaid that allows us to design her program and choose her support professionals as her needs dictate within her funding allotment. As her developmental disability is complex and severe, it is critical that the model is sensitive to her individual medical and developmental profile. The SDS program gives her the opportunity to strive toward her potential, while improving functional/daily living skills, increasing cognitive growth, contributing to the community through volunteer work, and addressing specific medical and personal needs. It allows her to remain at home (her least restrictive environment) with a positive quality of life among family members and friends. As we (her parents and guardians) age, the SDS Program will allow her to continue living at home. The support services offered through our Lakes Region Community Services team allows for a smooth and efficient operation/coordination of her individualized program. In short, it works! | 12/4/2013 1:16 PM |
| 85 | the ServiceLink agency is very helpful | 12/4/2013 11:49 AM |

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| 86 | Maintain the consumer-directed options for community-based care | 12/4/2013 11:48 AM |
| 87 | Medicaid Client services has been helpful to assist in finding providers of Medicaid services. Service Link can also be helpful with providing resources for Medicaid recipients. | 12/4/2013 11:42 AM |
| 88 | Need help before child reaches 21. Maybe at age 12 start with plan that can develop person's ability to be somewhat self sufficient, develop job skills that notes person's abilities, develop daily living skills etc. | 12/4/2013 11:31 AM |
| 89 | wished it help with dental | 12/4/2013 11:27 AM |
| 90 | We only have to deal with one entity as opposed to multiple entities. | 12/4/2013 11:02 AM |
| 91 | Any pending changes is cause for extreme stress for both the client and family. Not knowing what services will be covered going forward makes it difficult to plan ahead. | 12/4/2013 10:29 AM |
| 92 | Having the system run by local area agencies and having family members serving on the governing Boards of Directors | 12/4/2013 10:22 AM |
| 93 | There should be better housing options in NH. People should be allowed to live in group settings (not institutions) to share providers and have "friends" to live with. | 12/4/2013 9:49 AM |
| 94 | It is very poorly managed. Patients and families wait inordinate amounts of time for approval from the state for placement and/or services which would prevent having to move to a local facility | 12/4/2013 9:47 AM |
| 95 | Why are people trying to fix something that is not broken? We are bombarded with pseudo-information, but never are we told WHY the 2nd rated system in the country which is in the lower half of cost / capita is being "fixed". We don't really want to provide information, we want to know WHY. Why? | 12/4/2013 9:35 AM |
| 96 | I like the fact that it is available for our daughter. The Respite is especially appreciated by us. | 12/4/2013 9:33 AM |
| 97 | N/A | 12/4/2013 9:28 AM |
| 98 | all I can say is thank God we live in America where our citizens who cannot care for themselves are given what they need. thank you for your long term care program without which I would be unable to meet her needs and her quality of life would plummet. jillian Lee 39 Bay point rd newbury nh 03255 603-763-0385 jillclee@icloud.com | 12/4/2013 9:27 AM |
| 99 | My sister (I am her guardian, as well.) receives excellent care because of these services. She has recently been diagnosed with Alzheimer's and will require more care in the future. Thank you. Ed Allard. | 12/4/2013 8:40 AM |
| 100 | Long term care funding. Customize program that fits individual needs not one program that fits all. Use funds prudently but should look at spending needs now that would save funds in the long term. For example, paying for preventative dental care and not wait till emergency dental work is required. | 12/4/2013 8:38 AM |
| 101 | More should be done for the at-home long term care and consideration focussed from institutional care to support for at home care with more dollars available for this purpose. | 12/4/2013 8:13 AM |
| 102 | I love that I can go to my local area agency for any obstacles I may encounter and they assist in finding a solution and that families are helping families, even though it may not cost anything, there is the connection to others going through similar obstacles and we can learn from each other and have local control | 12/4/2013 7:08 AM |
| 103 | Easter Seals of NH is responsive, caring and takes a personal interest in my son's long term care while constantly working with him to advance his own abilities and capabilities. | 12/4/2013 2:07 AM |
| 104 | It would cost the State of NH significantly more than the stipend I receive to provide services to my sibling. | 12/3/2013 11:10 PM |
| 105 | I am kept informed by Area Agency about services and options for my DD adult child. It is client based and serves the clients with WHAT they need...NOT directed by a panel of non-medical MBA people who focus solely on numbers, checks and balances. The rights of the person with the disability are honored and respected with the "hands-on" support people. With a remote panel of strangers making financially-based decisions for this population it would turn back the hands of time, back to the 80's when HMO's first appeared on the scene. Many people needlessly suffered, endured untoward outcomes...and many died waiting for a financial decision and this is unacceptable. Managing one's healthcare efficiently will automatically manage the associated costs...but the decision making must be ethically done and appropriate for the client. | 12/3/2013 10:33 PM |
| 106 | My client is able to have a family like atmosphere, where as a non-verbal client he is understood due to the consistency with staffing, the individualized treatment. | 12/3/2013 9:25 PM |

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| 107 | I would like to explore creating a small community of people that my adult son already knows- and whose families he already knows- from the last 10 years of his life. The families are all committed and involved with their person... and this is the only scenario I can think of that would be in my son's best interest. | 12/3/2013 8:20 PM |
| 108 | No | 12/3/2013 8:11 PM |
| 109 | Needs much more publicity. What are the qualifications for getting into the program? Currently Medicaid clients get full health care including nursing home care. Is not this considered long term care? Personal knowledge: In a nursing home, roommate paying private pay at close to \$330 a day while other on Medicaid, which pay between 100 and 200 a day. Absolute no difference in care...rightly so. | 12/3/2013 5:24 PM |
| 110 | Keep the community based area agencies | 12/3/2013 4:49 PM |
| 111 | The fact that it is tailored to meet my son's specific needs which change literally on a daily basis and that it is consumer/family directed, not a cookie cutter approach. | 12/3/2013 4:39 PM |
| 112 | the waiting period and the transition to services was confusing and frustrating at times. But now that her plan is in place it works really well. There is a good system of checks and balances and good communication between the Moore Center, Megan's provider and myself. | 12/3/2013 4:19 PM |
| 113 | I like the fact that everything is done locally. Everyone knows everybody else. Knowledge of the local communities, business partners, employment and social activities seems to make it work. The relationships which develop increase the understanding of my sons needs, and a genuine interest in meeting them. | 12/3/2013 3:52 PM |
| 114 | The Gateways program has always been there to meet any need or provide information about the best way to meet the need. | 12/3/2013 3:27 PM |
| 115 | Takes care of those in need. | 12/3/2013 3:19 PM |
| 116 | I like the personalized and local support offered by our Area Agency. They have longevity in providing support to our severely disabled child from early intervention, through school age, and into adult services. They know her needs well, they know our family and our priorities for our child's care and they have a solid understanding of local resources and supports that can help provide care for our child in her community. | 12/3/2013 3:07 PM |
| 117 | We recently went through the process of transitioning from school age supports to adult services when my child turned 21. At times it was very frustrating because despite best efforts, the process was not seamless. The support staff who would support my young adult once she turned 21, were not able to overlap with support staff from our child's school age program to benefit from their expertise and training because of lack of funding. There are federal mandates in place to provide for transition services before a child turns 21, but really no accountability to these transition goals once the child turns 21. | 12/3/2013 2:41 PM |
| 118 | I like that my son's services are overseen by an Area Agency. I like the local control and having someone (who understands my son's complex needs) available to support him and our family. It's working well under the current Long Term Care Program. | 12/3/2013 1:48 PM |
| 119 | Community-based and individualized | 12/3/2013 12:36 PM |
| 120 | Improved access to needed services is essential. More and frequent options for in home care must be developed at the soonest possible. Longevity coupled with debilitation is definitely not a privilege for most people. | 12/3/2013 11:37 AM |
| 121 | Has to be kept in place for these people. These are human beings, not animals. We cannot let our Mentally Challenged folks down. These services need to be kept in place as a human rights issue. My sons love going to school and to his program everyday. One son is now coming of age and will need services. This is the second one we have under Legal Guardianship. Wait list needs to be fully funded | 12/3/2013 11:37 AM |
| 122 | My children's medications are very costly and Medicaid pays what my private insurance does not. Without it I would not be able to afford their monthly prescriptions. | 12/3/2013 10:56 AM |
| 123 | My day program. And having a home. | 12/3/2013 10:35 AM |
| 124 | No not at this point... | 12/3/2013 9:22 AM |
| 125 | Job development for a person with MR | 12/3/2013 8:48 AM |
| 126 | I don't know what I would have done if there wasn't help out there | 12/3/2013 8:45 AM |

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| 127 | I like that my loved one can continue to work and receive supports. This helps my family out as the caregiver of the Medicaid recipient ages. Worry about what happens when older parent can't take care of love one or needs more help. What happens then if it is not in their plan? | 12/3/2013 8:19 AM |
| 128 | We finally have continuity in services between all his providers. It took him getting long term care for that to happen. Before I had to call every doctor to relay information, now his case worker co-ordinates that. | 12/2/2013 7:57 PM |
| 129 | Too much staff turn over | 12/2/2013 6:19 PM |
| 130 | Without the support, these individuals would be lost and accomplishing little or nothing. They depend on the support for their survival. | 12/2/2013 4:20 PM |
| 131 | It helps my family member so that he is able to live a good life and accomplish things that he would not be able to do with out it. He would be the homeless bum on the streets without the support he receives. | 12/2/2013 4:05 PM |
| 132 | Providers that know my son and take a personal interest in his wellbeing. An agency that has a proven track record of successful case management, home care providers, and community integrators with a team approach that includes my son as well as me. | 12/2/2013 3:15 PM |
| 133 | The process for applying is simple, the process of acceptance takes a long time. If there could be something done to speed the process up for services would be great. Currently we attend an appointment requesting services and the actual services don't start until 2+ months down the road. | 12/2/2013 2:18 PM |
| 134 | Local control; priority of client choice; focus on quality of life, dignity and opportunity for the individual | 12/2/2013 1:58 PM |
| 135 | Services when available are not limited | 12/2/2013 1:53 PM |
| 136 | Very responsive - like they are part of my family | 12/2/2013 1:53 PM |
| 137 | Needs to be locally controlled with minimum of overhead: That's the way it works now | 12/2/2013 12:40 PM |
| 138 | Ease of use of providers & specialized support | 12/2/2013 12:06 PM |
| 139 | I no where and who I need to speak with if there is a issue, I have some choices as to where our son lives and hopefully where he is now is where he will continue to be for the rest of his life. | 12/2/2013 11:55 AM |
| 140 | It is very difficult to understand Many people will not participate due to the property lien process | 12/2/2013 10:31 AM |
| 141 | Local Area Agency - knowing I have someone I can call to ask questions and assist me if needed. | 12/2/2013 8:58 AM |
| 142 | Its supports have given my self and son a life that I don't know what we would do without it. | 12/1/2013 10:09 PM |
| 143 | it is administered by local gateways which knows the needs and is very available | 11/30/2013 1:09 PM |
| 144 | I think with the current budget the Area Agencies manage things fairly and should be commended for balancing costs and services. Managed care will not be able to duplicate this for less unless they cut costs. The quality of care will suffer if they are allowed to do this. Happy to talk with any of you any time. Thanks, Bill Doherty, 58 Davis Rd. Merrimack, NH. 424-1944 or 440-3993 | 11/29/2013 6:05 PM |
| 145 | We need to be people not numbers. You need to have representatives that work closely with you and know who you are. They need to be able to see what issues you have and where they can help. Being a number in any system will NEVER work. As parents grow old, our love doesn't change, but our energy gets low. The hardest part of raising a child with challenges is that we don't live forever. | 11/29/2013 5:55 PM |
| 146 | The person receiving the services gets to receive their services in their community from someone in or near their community. When ever a crisis arises I know that I can call someone at my Area Agency and they can help because they know my child and what the issues are. There is no need to read a file and no flow chart to follow because the case manager knows the child. | 11/29/2013 4:01 PM |
| 147 | It is most important that my son can stay at home and that we have choices, although choices are few. | 11/29/2013 1:21 PM |

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| 148 | It is necessary that any program providing "life building", or "life supporting" services that are not medical, but are programming the daily living supports for individuals with developmental or mental disabilities be provided 1) locally, and 2) by a non-profit agency. Regarding #1, my local Area Agency knows my daughter personally; she can visit them (accessibility) any time she needs to have questions answered, assistance, through her care coordinator. Her care coordinator is familiar with community resources because she lives in the community where she works for the area agency. And, by extension, the area agency knows the community. It is not located in another part of the country. Even in a rural state like NH, there are still issues of the agencies needing to be closer to their clients; but at least they are within an hour's drive for most clients. #2 – NON-PROFIT is essential because any private managed care will definitely reduce the quantity and quality of care for clients in order to make a profit – off them. The current system at least is not taking away money that could be spent on clients. NH is one of the most financially efficient DD systems in the country. | 11/29/2013 11:11 AM |
| 149 | My child receives the IHS waiver; I like that I can develop his service agreement, supports and budget based on his needs. | 11/29/2013 8:29 AM |
| 150 | I like that my local area agency "Gateways Community Services, Inc." has partnered with me and my family member for 25+ years. They know the life style my family member is accustomed to and I am confident in the quality of services that would continue to be provided thru them when I am unable to do so. | 11/28/2013 3:13 PM |
| 151 | I like the Self-Directed Services option | 11/28/2013 2:28 PM |
| 152 | I like how the State (BDS), the Area agencies and the individual/families work in collaboration to help people follow their bliss and live good lives. I like that the current system we have does NOT employ services through a medical model, but instead seeks to help people identify their hopes and dreams then connect to them as closely as possible. | 11/27/2013 10:46 PM |
| 153 | The area agencies are uniquely qualified to deal with the array of disabilities and to deliver supports. I have great concern that the programs will be moved into some sort of "managed care" process which will do nothing more than skim money off the top, leaving less for client support. | 11/27/2013 5:56 PM |
| 154 | No. | 11/27/2013 11:42 AM |
| 155 | Online renewal. Application assistance from Servicelink. Not having to worry about shelter & food for my family member. | 11/27/2013 11:22 AM |
| 156 | The developmental disability system in NH is # 2 in the country according to UCP. It has a degree of built-in local control and consumer input (in addition to consumer directed services on the individual level) that is unusual and important to its success. | 11/27/2013 11:13 AM |
| 157 | This whole program has been a life savor for me(my husband is the one who gets the services) Without this program I feel he would be in a nursing home or if he is at home he wouldn't be getting the care that he needs without you folks. THANK YOU!!!! | 11/27/2013 8:44 AM |
| 158 | They are doing a good job and keep up the good work. | 11/27/2013 8:33 AM |
| 159 | Not a lot of options | 11/26/2013 10:16 PM |
| 160 | it works, it allows my sons to live in the least restrictive options possible and participate in community life. | 11/26/2013 4:00 PM |
| 161 | Family Support system..... | 11/26/2013 3:02 PM |
| 162 | The long term care program was developed by people who are in our communities, know our family members and what is best for them, has advisory councils of individuals who know how to develop and oversee the needs of our family members and therefore can do it in a cost effective way. | 11/26/2013 11:21 AM |
| 163 | It's a not for profit system so no one at the top is making big bucks off of my family members needs. The system is "NH grown" and runs fairly smoothly. Having spoken with families across the country I am well aware that we have one of the best systems in the country! | 11/26/2013 10:46 AM |
| 164 | supports and services provided to help people with disabilities work and live in the community | 11/26/2013 10:25 AM |
| 165 | It is community based which is important for the people that receive the benefits. It's important that they are part of the community. | 11/26/2013 8:04 AM |
| 166 | i like everything about medicaid, because it helps people who need help with their health. not everybody has what some people have and this is how it's we can help our self. | 11/25/2013 10:51 PM |
| 167 | My daughter sees specialist in 3 different states, multiple hospitals and she sees who she needs to without question or waiting for approval. | 11/25/2013 10:28 PM |

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| 168 | Is very helpful. I get some time away while paying for someone to watch my two developmental disabled children. I would not be able to get my peace without the funding. Thank you! | 11/25/2013 8:36 PM |
| 169 | I want my area agency to stay like it is. Keep the mcos out of my childs long term care! | 11/25/2013 3:58 PM |
| 170 | Access to people to talk with about options and knowing they are from our area and aware of our community. | 11/25/2013 3:24 PM |
| 171 | I like that the waitlist is much shorter than in other states. | 11/25/2013 1:57 PM |
| 172 | Long term care in NH should embrace all of the options that are available and effective in other states. It could be done at far less cost and far more effectively... especially for people with autism. | 11/25/2013 1:38 PM |
| 173 | The people I have talked with in reference to my nephew have all been very supportive and helpful. | 11/25/2013 12:36 PM |
| 174 | Day as well as Residential services. Day services site seen by families and guardians as a safe place for their individuals to see friends, participate in activities, and base their "community participation". | 11/25/2013 11:05 AM |
| 175 | I like that there was an option of a vendor service for my Uncle, because he needed to be in a place that was his home with staff coming in and out. I didn't want his caregiver to burn out and then he be the one who had to move again. The home care provider model is a wonderful option for some people, but having choice is important. I would also like to see more supported living options for people, especially all of the young people coming out of school with Autism who could really benefit from an independent, social environment with just enough oversight to keep them safe. The state of NH does well, and I hope that it keeps exploring new models to give everyone the options that can work for them. | 11/25/2013 9:43 AM |
| 176 | 525 services has allowed my family to stay in tact. My husband was forced to resign from his job, and the Area Agency made Holly's changes (medically, emotionally, and physically) possible. My husband receives Adult Foster Care stipend, I work full time, and my sister's quality of life is two-folded because financial needs (mortgage, utilities, insurances, etc.) are met, all while my sister is happy and cared for. | 11/25/2013 9:30 AM |
| 177 | yes, the direct support personal that deliver the daily services should be required to get certification. The state of NH should adopt the practices and standards of the NADSP. Today, though the DSP individuals are sensitive and responsive to these populations, they lack the necessary training and skills to deliver the services. | 11/25/2013 8:56 AM |
| 178 | The individuals at our local Area Agency, Community Partners, understand my son's needs. They know our family and seek to provide the services that will allow my son to remain at home and in our community. | 11/25/2013 8:53 AM |
| 179 | Delay implementation... of Step 2. This is complicated... very complicated. More complicated than anyone could have predicted. It's reasonable and appropriate to delay. Let's further analyze and develop a plan to ensure the welfare and safety of the individuals who utilize LTSS. If we have a solid plan that proves how we will maintain care while cutting costs then we can move forward. We must be very thoughtful, cautious, and careful as this significantly impacts your fellow citizens. The legislature and executive council made a hasty decision. Time to step back and rethink things. | 11/25/2013 8:49 AM |
| 180 | It is consumer directed, community based, and focused on the needs of the individual rather than the "group" | 11/25/2013 6:50 AM |
| 181 | Need to work closely with those that need it and it needs to be better funded to reach all who need it. | 11/24/2013 7:24 PM |
| 182 | People know my adult son and his family. They understand the community we live in. If services turn into anything like when you call the insurance company? we are all done! | 11/24/2013 7:16 PM |
| 183 | Local control, area agencies | 11/24/2013 2:39 PM |
| 184 | I like the system the way it is. I hope there will not be much change for my son since he has private insurance through my husband's employer and then Medicaid second. Medicaid only picks up what my son's primary private insurance does not cover. | 11/24/2013 1:26 PM |
| 185 | I love working with my area agency. They have known my son since he was 3 years old. My son would not be able to get a lot of the assistance he needs in life without Medicaid long term care. | 11/24/2013 8:00 AM |
| 186 | No referrals needed | 11/23/2013 10:21 PM |
| 187 | We very much like working with the people in our Area Agency because they take the time to get to know my son and his needs personally. They come to the house to help establish a budget that addresses his individual needs. We are then able to manage his budget in ways that best meet his needs. This family control is important to us. The people in the Area Agency are a wonderful resource for us and we'd be lost without them. | 11/23/2013 7:48 PM |

NH Medicaid Long-Term-Care Program Survey

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| 188 | it too complicated | 11/23/2013 4:18 PM |
| 189 | I am concerned about what my child will do when she ages out of the school system and if local agencies will have the money to provide any services. I have been waiting for a year to get respite care for her. | 11/23/2013 3:52 PM |
| 190 | I like the ability to choose the types of services and providers for my children | 11/23/2013 11:58 AM |
| 191 | My child gets care provider services through the LRCSC for 20 hours a week. I appreciate this program as it gives her activities outside of the home that are enjoyable for her and valuable to a local restaurant. | 11/23/2013 10:08 AM |
| 192 | The people in the agencies my family deals with understand the difficulties. When a family member drops the ball and doesn't do what needed to be done they try to help pick up the pieces. i.e Sister lost mead because although she was able get her documents together (filled out forms, sent to employer for documentation, and picked them up) she fell into a depression/anxiety attack (during which she can't leave her house or even take care of her own basic hygiene needs) off and on and didn't deliver them on time. When she finally showed up her case worker helped get her back on. 35 yr old brother who has been living with Parents became impossible to live with (abusive to father, who is in midstage of Alzheimers) and mother called for help and they were able to find him a place that day. Not ideal and he won't be able to keep it without close supervision, but they were able to help in the emergency. When father called about a possible alternative solution. ie finding an apartment for he and his friend (who are both in this rooming house individually paying 475) to pool resources and be in a better environment. The idea was considered as a possible option and not summarily dismissed. The willingness to keep the families in the loop and look for options to keep the disabled people part of society. | 11/23/2013 10:04 AM |
| 193 | I can go to legislative meetings, actions, massage, gym, scouts, bike riding, skiing because I have in home supports that let me go out of my home | 11/23/2013 8:34 AM |
| 194 | His CM has been with him he was 15 years old. She advocates for what he wants, his program is Person Center, as it should be. My son want a life of his own, one he can feel safe and successful in be a responsible young adult. For this he needs oversite and the Consumer Directed Program through Medicaid funds provides this for him. | 11/23/2013 7:52 AM |
| 195 | Provided services are managed by a community org planning mtgs are at my home I get to know the case manager they know the community resources and respond quickly when needed | 11/23/2013 7:46 AM |
| 196 | I thank God daily that Community Bridges and NH Health and Human services are available to us as a family. Life is hard but they help a lot. | 11/23/2013 7:44 AM |
| 197 | Should not be so difficult to get children approved. We are still waiting for services. Takes too long. | 11/23/2013 6:27 AM |
| 198 | The application process is far too cumbersome for the elderly population to navigate. | 11/23/2013 5:38 AM |
| 199 | the services my son receives from Community bridges have been fantastic due to the direct support staff. Everything should be done to support the direct support workers to increase their pay, benefits, and satisfaction with their work, so that they remain on the job. thank you. | 11/23/2013 12:30 AM |
| 200 | Beacuse of the services my family member receives, she is able to work part-time, which pays taxes as well as paying into medicaid. | 11/22/2013 10:32 PM |
| 201 | Leave what works alone! Chaos within the system or a new system will gravely affect individuals and their families! This system works and the people running the current system are passionate about what they do and have a lot of knowledge in doing it! | 11/22/2013 9:58 PM |
| 202 | none | 11/22/2013 8:58 PM |
| 203 | The job supports, without which, my son would be unable to work | 11/22/2013 6:40 PM |
| 204 | His team both medical and in home community supports really listens to my concerns for him and acts on those concerns to make his life very worthwhile and enjoyable for him. | 11/22/2013 6:11 PM |
| 205 | Family directed services interviews, hires, and trains their own staff. Many are afraid this will no longer exist with Phase 2 implementation. | 11/22/2013 5:51 PM |
| 206 | It works as a non profit. More resources go to those in need, rather than lining the deep pockets of for-profit organizations. | 11/22/2013 5:32 PM |
| 207 | While it is clear to me that the companies providing direct service to us are profiting from the provision of this service, I do not feel like there is an /additional/ layer of people in between (aka, some rapacious health insurance company) attempting to skim even more profit off the top. | 11/22/2013 5:25 PM |

NH Medicaid Long-Term-Care Program Survey

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| 208 | Very difficult working with the state employees. Seldom do they return phone calls, often rude and not helpful. Most employees from the state lack knowledge of how to make the system client friendly. Seldom do they understand how difficult it is to care for a disabled and medically needy person. Some of the regulations are not geared to making the life of the client or family easy. | 11/22/2013 5:10 PM |
| 209 | At this time the long term supports are provided by the Area Agency system and they do an outstanding job at it They also perform in a very cost effective manner. If it ain't broken don't "fix" it! | 11/22/2013 3:50 PM |
| 210 | It cannot be replaced and there's no more efficient alternative. | 11/22/2013 3:41 PM |
| 211 | The area agency system in this state has been amazing. They have been able to provide necessary services and support with very limited funds. They know my daughter and her needs intimately and truly stay involved with our lives | 11/22/2013 3:40 PM |
| 212 | Personalized service with regular checks on efficacy | 11/22/2013 3:39 PM |
| 213 | Local control of services received. | 11/22/2013 3:39 PM |
| 214 | I am a caregiver for a person with DD, 24/7 personal care required, also pureed feed for eating, non verbal, could never live on her own.... | 11/22/2013 3:38 PM |
| 215 | It is locally controlled with people who know the individual who is being cared for. | 11/22/2013 3:37 PM |
| 216 | Confused if there is a program, or just a collection of services that are cobbled together to help support people with long-term- complex needs. | 11/22/2013 3:34 PM |
| 217 | no | 11/22/2013 3:33 PM |
| 218 | The current non-profit area agency system is local and is experienced in providing the long-term services needed by my sister. Money provided by the state and federal governments for services for all individuals with developmental disabilities or acquired brain injuries goes to services versus being syphoned off to provide a profit for large corporations. Money that will go toward profit means fewer and/or diluted services for individuals. | 11/22/2013 3:32 PM |
| 219 | wish the budget was bigger | 11/22/2013 3:06 PM |
| 220 | personal choice of providers, and type of care provided. | 11/22/2013 3:01 PM |
| 221 | the dedication of the caregivers and the communication on a daily basis if requested | 11/22/2013 2:53 PM |
| 222 | As a participant in Family Directed Services, I am able to make choices about how my sibling's budget should be spent. | 11/22/2013 2:50 PM |
| 223 | I appreciate that it can be used for equipment that our private insurance will not cover. | 11/22/2013 2:32 PM |
| 224 | When my family member needs help or answers. We get it. | 11/22/2013 2:15 PM |
| 225 | no | 11/22/2013 2:11 PM |
| 226 | The ability to have consolidated funding that allows us to have an holistic approach to the services my daughter needs. It is flexible and not tied to task analysis and predetermined unit funding. We have been able to use the same funding to support our daughter when she lived with us, then lived with someone else, then lived on her own...we didn't need additional funding as her circumstances changes since we had the DD consolidated funding approach. | 11/22/2013 1:55 PM |
| 227 | It does give my son a better opportunity for him to live as independently as possible and has allowed us to have him secured and adjusted while we are still alive. Though that has come at a very high cost to us financially and emotionally. | 11/22/2013 1:54 PM |
| 228 | plenty of waste now on the backs of tax payers. Not very much that I like. | 11/22/2013 1:53 PM |
| 229 | we are very concerned in changes to the system and how we receive services. It would be a financial, emotional and physical detrement to our lives if there were negative changes. | 11/22/2013 1:52 PM |
| 230 | Area agencies are HORRIBLE. There are no options and if you advocate or questions anything you are then punished. | 11/22/2013 1:41 PM |
| 231 | I have excellent support from Community Partners. They are a god send. | 11/22/2013 1:29 PM |
| 232 | There is a strong family/consumer presence in the governance of the system. My area agency is local and has built relationships in my community. | 11/22/2013 1:06 PM |
| 233 | The quality and benefit to recipients of care cannot be replaced or replicated by non-local, non-community based personnel or systems. The personal relationships and local networks of support throughout a community (where people actually know everyone) is what makes the care provided appropriate, accessible, affordable, and have meaning. | 11/22/2013 11:46 AM |

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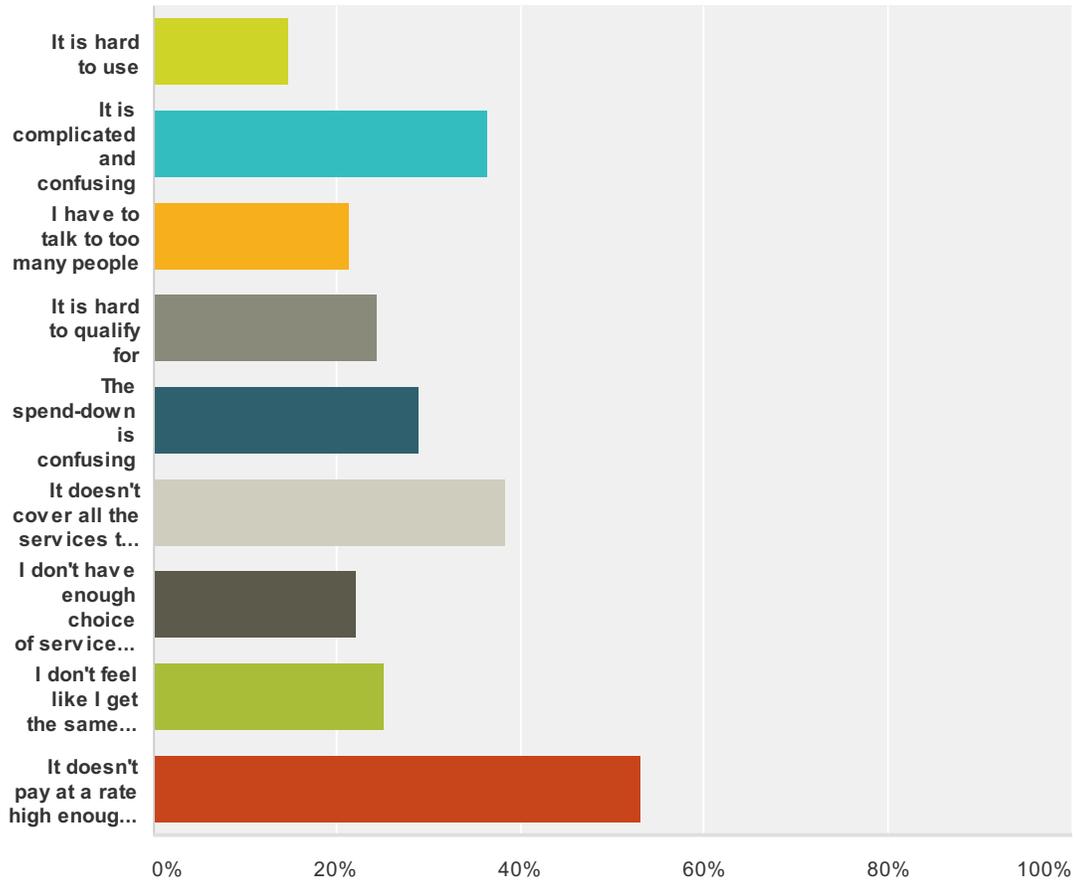
| | | |
|-----|--|---------------------|
| 234 | Yes! The local area agency engages me and my ward in planning and budgeting. We are very much involved and part of the process. We receive stellar, personalized services and supports. The area agency is able to respond to us. The vendor is able to engage with us. Any issues are dealt with expediently because this is a long term relationship network. | 11/22/2013 11:33 AM |
| 235 | Individualized support provided to families. | 11/22/2013 11:29 AM |
| 236 | I value the relationship that we have developed with the local Area Agency who administers and oversees the supports my daughter receives. I like the fact that we have choice and control over her services. I like the fact that the services are provided for and managed locally by people/agencies who are local and familiar with our community. I like the fact that my opinion is valued by the local providers. | 11/22/2013 11:18 AM |
| 237 | There are others ways to cut back without effecting the needed direct care | 11/22/2013 11:11 AM |
| 238 | The freedom it gives me knowing my daughter is "where she wants to be and has friends," as well as the wonderful round-the-clock staffing who's able to assist her better than I ever could. It was extremely difficult for her to see her younger siblings grow up and move on with their life. Now, she feels she has grown up, has her own apartment on a farm and she's happy. And I have the peace of mind knowing I don't need to worry 24-7 about meeting those needs. | 11/22/2013 11:10 AM |
| 239 | I can adjust the budgeted amounts if I need to use more services in one area due to increased need using self-directed services. | 11/22/2013 11:07 AM |
| 240 | As parents we would find a way to take care of our daughter, but the program has helped us establish a long-term approach that we feel fairly confident will give our daughter the ability to live fairly independently with necessary supports without becoming a nameless dependent of the state, even after we are gone. | 11/22/2013 11:02 AM |
| 241 | Thank goodness for it! | 11/22/2013 10:53 AM |
| 242 | My area agency helps or son and us navigate the system and take care of many of the details | 11/22/2013 10:50 AM |
| 243 | Help organizations make it to hard to get services. ie...Riverbend | 11/22/2013 10:18 AM |
| 244 | The ability to manage the funds so services are tailored to the needs of my son. | 11/22/2013 10:17 AM |
| 245 | people are friendly | 11/22/2013 10:16 AM |
| 246 | It is important to help people who can't make enough money to live on. | 11/22/2013 10:15 AM |
| 247 | I like the ability to select the area agency we work with. We have used this ability to choose one agency over another and fear that we will no longer have this vital choice of long-term-care provider, but will rather be "stuck" with one, good or bad. | 11/22/2013 10:10 AM |
| 248 | Very concerned that step two is going to limit services - what do insurance companies know about FC and respite and community inclusion? | 11/22/2013 10:01 AM |
| 249 | Within our family member's budget, we have the freedom to create a program of services and to choose the providers we feel will best meet our needs. We have specific goals for our family member, as she has for herself, and currently have the ability to make them happen. | 11/22/2013 9:51 AM |
| 250 | Very complicated system, and time intensive. My uncle almost ended up in a NF because it took so long to get services. | 11/22/2013 9:48 AM |
| 251 | I believe the amount of paperwork to is needed to keep long term care available to the people that have it and have had it becomes very tedious and fatiguing. Especially when I have the fatigue syndrome to begin with, that goes with my condition | 11/22/2013 9:45 AM |
| 252 | It's a system that works well with excellent response time from current, local case managers that have worked with my family member for 11 years. | 11/22/2013 9:45 AM |
| 253 | Care management through the department of special medical services – this is essential to keep maya in the preventive care doctors and out of emergency/hospitalization type services. The nursing support (LNA) that we receive on a daily basis allows me to work; without it I couldn't work and with a disabled husband I would likely be on welfare. Transport reimbursement is available though I wish it were easier to access (lots of paperwork – very particular about how it is filled out, etc). Choice of doctors to see is also very important – while the majority of her services are at DHMC – she has doctors in Boston and Vermont as well. | 11/22/2013 9:32 AM |

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| 254 | Ability to receive support from my local, community agency over the phone or in person. I receive personal help for almost any question, concern, situation that comes up. They are proactive, keeping me informed of pertinent information and suggestions that relate to my child/family needs, as well as reactive, responding when I contact them. They are community based, know the needs of those they serve. | 11/22/2013 9:29 AM |
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Q11 What don't you like about the current NH Medicaid Long-Term-Care program? (Choose all that apply)

Answered: 476 Skipped: 416



| Answer Choices | Responses |
|--|------------|
| It is hard to use | 14.71% 70 |
| It is complicated and confusing | 36.34% 173 |
| I have to talk to too many people | 21.43% 102 |
| It is hard to qualify for | 24.37% 116 |
| The spend-down is confusing | 28.99% 138 |
| It doesn't cover all the services that I, or my family, needs | 38.45% 183 |
| I don't have enough choice of service providers or specialists | 22.06% 105 |
| I don't feel like I get the same quality of care as other people who have private insurance or who can afford to pay for services themselves | 25.21% 120 |

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| It doesn't pay at a rate high enough to keep good personal care attendants or direct support providers | 52.94% 252 |
| Total Respondents: 476 | |

| # | Other (please specify) | Date |
|----|---|--------------------|
| 1 | It doesn't pay at a rate high enough to keep good personal care attendants or direct support providers . times 1,000 | 12/8/2013 5:00 PM |
| 2 | The issue of the rate of pay for providers is huge. We have a hard time getting LNA's due to the LNA's being able to get higher pay for doing staff relief and/or getting benefits through nursing homes and hospitals. This has been an ongoing problem for quite a few years now. For instance, for the hours we need an LNA for - which we are allotted 40 hrs/wk - I'm lucky to be able to be staffed for 30hrs. I'm aging and I'm getting very tired. I also think that somewhere along the lines - Medicaid or someone should pay us parents to care for our adult children. We are burdened by not having a normal life once our kids are grown. Some are burdened by having to live off the system and come retirement age - we have nothing. We live on a tight schedule and if someone doesn't show for a shift - we are that someone. And should we want to place our individual elsewhere, we are required to prove that we can no longer care for them (even though we are told otherwise that's not true as many families have had to do so in order to do out of home placement). I don't mind doing my share but I would like the states/government to understand that once our children turn adult that that's a different ballgame. | 12/8/2013 3:54 PM |
| 3 | Calls for information are handled rudely and abruptly by office staff | 12/8/2013 6:19 AM |
| 4 | I have not complaints at this time. | 12/7/2013 4:15 PM |
| 5 | Not enough services in a timely fashion to keep clients safe in their home. | 12/7/2013 4:41 AM |
| 6 | getting started | 12/7/2013 4:08 AM |
| 7 | There is a very limited pool of mental health personnel available and currently no psychiatrists available in our area. I firmly believe the dedicated, caring, compassionate people who provide services to my daughter are severely underpaid for all they do. | 12/6/2013 10:54 PM |
| 8 | N/A | 12/6/2013 3:39 PM |
| 9 | I know I can speak for many of my consumers when I say that it doesn't pay a rate high enough to keep good personal care attendants or direct support providers. | 12/6/2013 1:23 PM |
| 10 | I cannot reply to the above because I am not responsible for her care, her son is. | 12/6/2013 11:52 AM |
| 11 | Also, my adult child is reluctant to use these services due to the stigma attached to having a long-term mental illness. | 12/6/2013 11:32 AM |
| 12 | MEAD works very well for my mentally ill son and neither he nor I find it difficult to use. | 12/6/2013 11:30 AM |
| 13 | Although I don't use the system personally, the feedback I get from family members and clients is that most of these (pretty much all of them) apply. Individuals in the throws of a crisis related to mental illness, or for older adults dealing with the complexities of multiple medical conditions, dementia, depression, etc., it is next to impossible to navigate the system smoothly and with a sense of control. On a good day it is complicated and confusing. | 12/6/2013 11:17 AM |
| 14 | I don't help my family member with this so I'm not sure which apply. | 12/6/2013 11:01 AM |
| 15 | I currently don't have any issues with the current system. While not perfect, it provides my daughter with the supports she needs. | 12/6/2013 10:52 AM |
| 16 | I anticipate one of more family members needed to access these services when ready for treatment but I don't have experience with how the services are currently implemented. | 12/6/2013 9:32 AM |
| 17 | I worry about Managed Medicaid. Current system currently works. | 12/6/2013 9:28 AM |
| 18 | It FEELS complicated to use...I feel very dependent on other to interpret my benefits with NH Medicaid and I am one of a few people that understands these things, as a mental health client because I worked for a while as a claim adjuster for an insurance company with timelines rules & regulations... | 12/6/2013 9:26 AM |

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| 19 | Again, I have not used this service personally but have heard the above comments. One issue I do not see addressed in here is in the North Country we are a direct border with Vermont and I feel that we should be able to receive services in either state. For example if someone lives in Guildhall, VT and goes to school in Groveton, NH and needs mental health services it would be easier for them to receive these services in Groveton but instead they must travel about 1 hour to be seen in Canaan, VT or St. Johnsbury, VT. I also know of some adult home providers who would be a great match for the disabled NH adult but cannot take them in due to Medicaid guidelines. | 12/6/2013 9:25 AM |
| 20 | At first it was confusing to get his medication. But it is easier as I understand the timing is important. One had to make sure that medication was in place before the 1st of the month. | 12/6/2013 9:15 AM |
| 21 | Abject poverty is still a reality even with benefits. | 12/6/2013 9:01 AM |
| 22 | I have heard all of the above from people using these services and could use more for safety or complicated home situations. | 12/6/2013 8:58 AM |
| 23 | long wait for services | 12/6/2013 8:29 AM |
| 24 | As with most services payment to the individuals stops or are placed on hold normally past thirty days of incarceration. This serves to be problematic to those incarcerated in receiving needed services and retaining those services once released. | 12/6/2013 7:59 AM |
| 25 | I am not familiar with the current system. Probably any of the above is relevant. The WORST might be having to wait for service while in a CRISIS mode. | 12/6/2013 7:33 AM |
| 26 | I don't have enough personal experience to specify. | 12/5/2013 9:44 PM |
| 27 | The NH Bureau for Developmental Disabilities does designate Area Agencies to oversee services. However, the Bureau does not always oversee Area Agencies very well and Area Agencies are given too great a "power" and monopoly. There are a number of conflicts of interest. This can be limited by use of independent case managers, as well as by having individual vendors compete for the funding for individuals they serve, eliminating the middle man and creating competition is more cost effective, as is independent case managers who can assist in overseeing this as well. There are some improvements that can be made, as suggested above. However, the managed health care system is not the way to go about this, that's for sure!!! Managed Health Care requires MEDICALLY TRAINED Personal that alone will drive up cost for services, as medically trained persons are also by far better paid. | 12/5/2013 9:22 PM |
| 28 | The services my son receives are long overdue and were the result of consistent, vigorous advocacy by my husband and me. We have gone through several life-or-death situations prior to receiving the services he now has in place. I wish I could admit to being overly dramatic, yet I am not.. | 12/5/2013 8:13 PM |
| 29 | Not enough staff to assist those of us who are waiting for approval. Calls go unanswered. | 12/5/2013 7:54 PM |
| 30 | More information is needed before I can begin to really understand the complexity of the program. | 12/5/2013 7:32 PM |
| 31 | The items checked are ones that I have heard families talk about many times. | 12/5/2013 6:25 PM |
| 32 | I don't feel like I understand it very well. | 12/5/2013 5:50 PM |
| 33 | time for application processing | 12/5/2013 5:37 PM |
| 34 | one sky services is great and always very helpful | 12/5/2013 2:38 PM |
| 35 | limits on transportation and activities | 12/5/2013 1:40 PM |
| 36 | Very True!!! | 12/5/2013 1:03 PM |
| 37 | It took us too long to find the right agency to help us but once we did it has been fine. | 12/5/2013 12:41 PM |
| 38 | There is a long wait time for ABD funds for supported living that keep people in nursing homes and hospitals too long | 12/5/2013 12:00 PM |
| 39 | Currently my daughter has and LNA through an agency. The In Home Support current model would allow us to manage her budget and hire staff which would SAVE so much money but the funding for this waiver has been decreased over the years leaving us with no choice but to use Medicaid. Please look into IHS waiver for this is the model that works very well and can save money. | 12/5/2013 9:17 AM |
| 40 | Over the years the recipient would have been able to get more assistance making transitioning and medical care more effective however no one in the offices ever told me these services were available to her. | 12/5/2013 5:18 AM |
| 41 | I feel that the local control, through the area agency, addresses my concerns very well. If I have questions or concerns, they are addressed immediately. | 12/4/2013 10:11 PM |

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| 42 | I never knew that the Aid to the Permanently and Totally Disabled and the In-Home Supports we receive through Gateways Community was considered NH Medicaid Long-Term Care program. I am still in the dark and about this program and the best explanation I have received so far is that medicaid has different "bucket" of monies that pay for different services under "waivers" - all of which is very confusing and difficult to navigate. I am also very discouraged that it doesn't cover compounded medicines and specialized nutrition needs and other over the counter medicines needed for her bowl regime and incontinence due to her disabilities. I pay over \$400 a month for these items. | 12/4/2013 9:59 PM |
| 43 | The quality of eye glasses makes them break easy. Myraflex frames can be chewed, but they do not break and so a better quality metal frame and myraflex frames should be able to be replaced and repaired when needed. | 12/4/2013 9:11 PM |
| 44 | SPENDOWN! NH's community mental health services are horrible (I can't emphasize this enough!!!!!!!!!!!!). Lack of choice in mental health services. | 12/4/2013 7:43 PM |
| 45 | the annual forms/reports that we have to complete can be tedious, especially if there haven't been any changes since the previous year. | 12/4/2013 6:29 PM |
| 46 | no experience | 12/4/2013 3:22 PM |
| 47 | does not cover dental | 12/4/2013 2:06 PM |
| 48 | The quality of caregivers who are willing to provide services at the rate offered is very low and difficult to trust. | 12/4/2013 12:20 PM |
| 49 | Transportaion services for MD appointments are needed for ambulatory residents of assisted living facilities/nursing homes who cannot drive. | 12/4/2013 12:13 PM |
| 50 | The individual budgets have not increased in MANY years which results in a decrease of services each year due to increased program costs | 12/4/2013 11:49 AM |
| 51 | See previous | 12/4/2013 9:47 AM |
| 52 | While I think the system should have a more formal system of Continuous Improvement (via metrics, measurements, etc), I don't have any specific complaints. All I am saying is that no system is perfect and ANY system should have a formalized set of checks/balances/improvement process. | 12/4/2013 9:37 AM |
| 53 | I would like to be able to take my daughter to any doctor but I appreciate the fact that I can take her to some doctor. It would be easier for us if more doctors would accept Medicaid. | 12/4/2013 9:36 AM |
| 54 | I am a bit concerned about having to choose different insurance vendor recently. also dental care is absolutely a service that requires coverage. I cover Jess under my dental plan but without it it would be hard to pay out of pocket. | 12/4/2013 9:30 AM |
| 55 | N/A | 12/4/2013 9:29 AM |
| 56 | This population finds change difficult, but the caregivers cannot exist on the low pay, and they leave... | 12/4/2013 6:53 AM |
| 57 | I am a family member that provides in-home personal care and direct support to a sibling. The required paperwork has little significance. | 12/3/2013 11:13 PM |
| 58 | Durable medical equipment is difficult to obtain, and at times not preventative. | 12/3/2013 9:27 PM |
| 59 | Too much of a person's budget is kept by area agencies for administrative costs.. (and I am not talking about case managers). The people/staff that families MOST rely on are paid way too little for the work they do. Case managers are getting more and more clients, with NO RAISE in financial compensation for this, and the amount of time they can support families is drastically reduced. Also, many families get differing information about programing and options. | 12/3/2013 8:25 PM |
| 60 | No vision or Dental care available. Costly transportation. | 12/3/2013 6:13 PM |
| 61 | As in many programs people complain but with no documentation. Is this another survey that just assumes people are being truthful? Good decent care is a must...but to have the choices that private pay has is not part of it. | 12/3/2013 5:30 PM |
| 62 | I have no complaints | 12/3/2013 5:10 PM |
| 63 | Until and unless you really dig in and learn the system it's confusing. Honestly I still don't understand where all the pieces come from and some of the plan seems 'patched' together so Megan gets what she needs but the Moore Center folks really have done a great job in getting done what needs to be done. | 12/3/2013 4:21 PM |
| 64 | So far I have no complaints | 12/3/2013 4:09 PM |

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| 65 | I feel there are limited expectations for continued growth and development for disabled individuals once they become adults at age 21, especially in the area of functional literacy and learning. This is evidenced by lack of funding and quality programs available to disabled adults. The rigors of learning should continue for these individuals, especially young adults age 21-26 as their trajectory for learning is a longer curve. I understand that to maintain an intensity in services which includes functional literacy learning over the lifetime of adults with disabilities is very expensive, but I wonder if a tiered approach to funding could be adopted? For individuals age 21- 26 there is a portion of funding available for continued literacy learning (most 21-26 year olds go on to higher education). This might help increase the numbers of these individuals who actually get employed once they are 26 and keep a job....and ultimately lower cost of their care as older adults. Additionally because of the current expectation for custodial care vs. ongoing learning, expectations for service providers shifts to caretaker or "babysitter" and this is reflected in the rates of pay for personnel working with disabled adults. This mindset is also reflected in the very limited availability of service providers who have expertise in providing ongoing learning and behavioral support to adults with disabilities. | 12/3/2013 3:23 PM |
| 66 | There isn't anything I don't like about it. It's not broken and doesn't need to be fixed. | 12/3/2013 1:49 PM |
| 67 | I would like help with dental. Everything else is wonderful. | 12/3/2013 12:41 PM |
| 68 | Gateways is a poor administrator. | 12/3/2013 12:19 PM |
| 69 | There is no choice in autism services in my area agency. | 12/3/2013 11:47 AM |
| 70 | Good people need to be hired and paid well. They need benefits: health insurance, vacation pay, good hourly pay, sick time etc. Many great people have left due to low payment. The higher ups get all the money from our funding and they get a lousy \$10 \$11 hr. These folks are not easy to handle in some circumstances. We entrust our folks to their care. Change for these folks is very difficult and challenging but happens often due to low pay and not benefits. This needs to be changed. | 12/3/2013 11:41 AM |
| 71 | Availability of qualified providers has been a problem. IF I can find a trained professional, I am unable to pay them at the rate commensurate with their experience. Also, as I work outside the home, it becomes difficult for me to perform the duties of finding a caregiver, training them, reporting monthly on progress, ensuring they are being paid, performing yearly reviews, providing merit increases, etc.. | 12/3/2013 9:04 AM |
| 72 | Lack of communication/knowledge sharing between DHHS departments providing services to the disabled individual | 12/3/2013 8:55 AM |
| 73 | Serious challenges in accessing acute psychiatric services/NHH or similar beds. | 12/2/2013 10:56 PM |
| 74 | Not knowing all the services that are available and we are eligible for - until speaking with a variety of people at conferences or other events. | 12/2/2013 8:17 PM |
| 75 | As a support staff, there are many rules and regulations that people do not understand and the requirements are many. | 12/2/2013 4:22 PM |
| 76 | Many, many providers won't accept you as a patient if you are on Medicaid. You are treated as a second class citizen. | 12/2/2013 4:09 PM |
| 77 | Puts a lien on any property owned | 12/2/2013 10:32 AM |
| 78 | Rules on what can be paid can be difficult to interpret. | 12/2/2013 9:00 AM |
| 79 | It is a challenge to find help and staffing. | 11/29/2013 5:57 PM |
| 80 | We have not had a "raise" in ten years therefore I can buy fewer service. And there is not enough money for the durable goods needed in home modification specifically. | 11/29/2013 1:23 PM |
| 81 | The current Phase Two has not been definitely implemented yet. I fear, however, that if it should be that I would be checking all the above boxes, for the reasons I previously described. | 11/29/2013 11:13 AM |
| 82 | I don't have any complaints. Any time I call for assistance from the staff of my local area agency "Gateways", any & all concerns have been answered and resolved. | 11/28/2013 3:17 PM |
| 83 | I don't like that we need to go and fight every two years for adequate funding for Developmental Services. Rather than continue to make cuts in the budget, the legislature needs to explore new sources of revenue. | 11/27/2013 10:48 PM |
| 84 | There is no annual adjustment. If you have a budget in 2011...it will be the same budget in 2014. Costs change - we want to keep good people (they only pay \$14 per hour and offer no insurance) and it is difficult to do if there is no COLA available. | 11/27/2013 5:58 PM |
| 85 | I have no dislikes | 11/27/2013 11:23 AM |
| 86 | As a service provider who has worked in two states, it is an excellent program. | 11/27/2013 11:14 AM |

NH Medicaid Long-Term-Care Program Survey

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| 87 | My family is happy with the program. No complaints. wait they did cut the hours my husband was getting. It is only 3 hours but it does make a difference | 11/27/2013 8:45 AM |
| 88 | Doesn't cover applied behavior analysis therapies | 11/26/2013 12:17 PM |
| 89 | Not enough doctors who take it. | 11/26/2013 11:01 AM |
| 90 | I have heard that the waitlist can be frustrating but we have not gotten there just yet. | 11/25/2013 3:25 PM |
| 91 | Limited choices, and MANY of the people making decisions about what is available and supported (i.e. the IOD and area agency administrators) have NO IDEA what would be the best choice for DD individuals, but continue to live in a box and tow the party line from 40 years ago about living "independently". | 11/25/2013 1:41 PM |
| 92 | Not in the program yet, but am getting great services from Community Bridges for my nephew. | 11/25/2013 12:38 PM |
| 93 | Too much money goes to the area agency that could be spent on the child. Cut out the middle man and have it be managed by the recipient or guardian. | 11/25/2013 10:40 AM |
| 94 | The wait list is frustrating for many people. There should be enough money to care for our friends, families and neighbors when we can seemingly easily afford to spend billions killing people in foreign countries. Our community should be our number one financial priority. The lack of manufacturing/production and agricultural jobs in our state hampers how self sufficient many people with disabilities could be, as routine, step by step jobs are often ones they can manage and excel at. | 11/25/2013 9:47 AM |
| 95 | 525 budgets are overseen by the area agencies. This is the state budget my sister receives through the AA. As the supervisor, my husband oversees the budget. Unfortunately, the area agency can go months without providing us an updated budget. As a result, this makes monitoring the monies difficult. | 11/25/2013 9:33 AM |
| 96 | I think this is an inappropriate question. What should have been asked is how user-friendly is the current system and respondents could have rated each category. This would have provided valuable information about the areas that are working well and where we need to improve. Uninformed folks who don't understand the potential differences for a managed care system and what we stand to lose may check off multiple boxes here. Step 1 has already forced people to sever trusted long-term relationships with doctors/specialists, created more complicated approval processes, and if the appeals process is similar to my HMO it will also be exhaustive and time-consuming for individuals. The reality is that I fear ALL of the above will be worse once Step 2 managed care is in place. Private health insurance companies worry first and foremost about making their profit and would view my daughter and others like her as a commodity. The system will be designed to protect their bottom line. This question won't provide the information we really need. | 11/25/2013 9:04 AM |
| 97 | To-date, there is nothing negative I can say about long-term care program. I believe this is a direct result of our Area Agency, Community Partners. The entire staff are committed to make the lives better for those with disabilities. | 11/25/2013 8:55 AM |
| 98 | on a wait list -- got nothing | 11/24/2013 6:45 PM |
| 99 | This really hasn't affected us much yet as my son is only 15 and does not use much of the services. He will have a strong need for these services to be available to him when he turns 21. I am afraid those services will no longer be available then. | 11/24/2013 1:28 PM |
| 100 | Music Therapy etc. is under the Recreational benefits cap but if we are working on specific goals should be covered as Therapy. Social Skills, Music therapy are not covered expenses but are proved effective under the National Autism Center project | 11/24/2013 9:58 AM |
| 101 | Many doctors do not accept it because Medicaid does not reimburse them at a rate that is sustainable - this forces me to go to a lesser quality doctor | 11/23/2013 10:22 PM |
| 102 | Your budget gets set, and then mid way during the year things that were in the Budget like phone assistance, dental are then not eligible expenses. You want your child to be able to enjoy social events, but then you say we can't reimburse the care provider for their movie ticket? Who do you know wants to earn 12/ hr and then have to pay \$8 out of their own pocket to take a client to the movie? I get that I as a parent should pay for my child to go to a movie or an event, but respite should provide for the out of pocket providers cost. | 11/23/2013 9:43 PM |

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| 103 | <p>The first 5, I checked, are all tied together. It takes years & years to get the needed help. Many factors involved: recognizing there is a problem, finding out that help exists, understanding & completing the documents to gain access; ditto the documents to keep access; finding the time to do all that and still do what is needed and to provide for the rest of the the family. I happen to come from a family that although riddled with mental illness is very intelligent. Comprehending words and numbers are a strength (weakness organization), we have a strong family and the able help the disabled and we struggle to cope, I don't know how anyone manages. My mother did not have an easy time when she was learning the ropes with 5 difficult children. However, at the time it was more possible to support a household on one income. We can not survive on my husbands income and the issues my children have (along with the emergency calls to help the brother, sister) prevent me from working a regular job. Same issues make childcare impossible. After 2 years of trying I have an aide for 10 hours a week. However, I or another adult has to be home because if there is a meltdown (not unlikely) someone else has to be there. Medical bills after insurance are a minimum of \$10,000. I have to work. Therefore my options are very limited as to where. When I am not doing damage control, I am working. It doesn't leave time to attend informational meetings, make telephone calls or fill out reams of paperwork. I do so when I can, but getting to completion is not happening. Now with parents declining how do we keep the disabled adults from becoming homeless? The quality of care issue is real, I can see the difference between what my family gets and what my brother & sister do is significant. It has more to do with the people providing the care than the actual services. They do get what is needed but, sometimes are treated horribly while getting it. Sometimes just tone face & words, sometimes rough handling of the injured site. Because the provider assumes the person is lying about the pain. There are also very good providers that do not behave this way.</p> | 11/23/2013 10:49 AM |
| 104 | <p>I want to work for pay and my day program and team haven't been able to find me paid work in years I have a hard time with people changing and too many go away too fast even when I liked them</p> | 11/23/2013 8:37 AM |
| 105 | <p>When someone works it is so complicated with having to send pay stubs to SS, Medicaid, Housing, His payments constantly changes. All this for working 3-6 hours a week. To keep my son busy he volunteers at the local Soup Kitchen. He enjoys this because feels like he is giving back.</p> | 11/23/2013 7:55 AM |
| 106 | <p>I don't get paid for the care I provide for a family member who has a disability living in my house. Transportation is minimal my family can not travel together. No good placement out of family home for housing young adult with dd and physical disability</p> | 11/23/2013 7:50 AM |
| 107 | <p>there just is not enough money for respite care.....I sure could use more.</p> | 11/23/2013 7:46 AM |
| 108 | <p>There aren't enough people that provide services in my area for respite care.</p> | 11/23/2013 7:40 AM |
| 109 | <p>My son is isolated socially, and more should be done to integrate his support services with some of the social groups the area agency runs.</p> | 11/23/2013 12:31 AM |
| 110 | <p>waiting list</p> | 11/23/2013 12:20 AM |
| 111 | <p>Although I don't use the "system" yet, the above is what others I know have faced and I hope I don't have to in the future.</p> | 11/22/2013 10:21 PM |
| 112 | <p>The area agency system is faulty. Too much power sits with the area agency which believes that it can dictate everything about my family member's life. The AA is too intrusive, extremely unhelpful and takes forever to respond to any request.</p> | 11/22/2013 10:10 PM |
| 113 | <p>It is sometimes very confusing. My brother and I are Rep Payees and Guardians for our brother... but my brother's care is managed by MDS and we have had several issues dealing with Medicaid/Medicare not allowing MDS to handle what needs to be handled - even with all the correct forms to be signed (according to Medicaid, they still tell us that MDS cannot act as our brother's representative.) I fear that he will need emergency medical care and they will delay because they decide that MDS cannot represent him. It's just getting more and more confusing. It used to be pretty straightforward and easy but now it is not and the person who is being impacted is my brother!</p> | 11/22/2013 6:53 PM |
| 114 | <p>n/a</p> | 11/22/2013 6:30 PM |
| 115 | <p>The home care program is inflexible. It would be nice to be able to use as many hours as I need up to a given amount, but to choose not to use all of the hours when we are home as a family without being concerned about losing those hours. Respite doesn't allow for any carry over. Our son receives \$300/quarter. That isn't enough for a weekend away. It would be great if we could save it up to have an actual break.</p> | 11/22/2013 6:29 PM |
| 116 | <p>High turnover of in home support personnel due to low wages</p> | 11/22/2013 6:13 PM |
| 117 | <p>Please reference to question 9 response. Very difficult contacting government employees. They have no understanding of our situation.</p> | 11/22/2013 5:12 PM |
| 118 | <p>It does not always provide medical equipment that would make a person's life more safe.</p> | 11/22/2013 3:56 PM |

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| 119 | unknown, unsure | 11/22/2013 3:39 PM |
| 120 | I didn't even know it existed. | 11/22/2013 3:35 PM |
| 121 | It doesn't pay at a high enough rate to cover mental health services such as Hampstead Hospital and therapies such as hypnotherapy and autism services such as ABA limits make it impractical to peruse on a limited budget. | 11/22/2013 2:36 PM |
| 122 | it doesn't cover dental services | 11/22/2013 2:12 PM |
| 123 | AA's have too much power imposing their philosophies and policies on those that need services with little regard and respect to families and vendors. As long as you agree with what they tell you and don't challenge anything you're a good customer. | 11/22/2013 1:57 PM |
| 124 | I have checked the items that apply to my family but could really check all of the above, based on what I have heard from others. | 11/22/2013 1:56 PM |
| 125 | but plenty of money not spent wisely. but spent to use it up. | 11/22/2013 1:54 PM |
| 126 | It can be confusing and bureaucratic. Funding can be hard to get. It can be difficult to find specialists that take Medicaid | 11/22/2013 1:47 PM |
| 127 | Legislature has gradually eroded funding, which stresses staff at all levels. While I am fortunate to have the care I need for my son, individuals with a higher level of need and/or challenging behaviors are not sufficiently supported. Also, there is not enough choices about supported housing. There is an overemphasis on "adult foster care," which is not necessarily a good fit for some individuals. | 11/22/2013 1:10 PM |
| 128 | The application process is lengthy and cumbersome, especially for families in crisis, length of time for appts and approval take too long which delays pts ability to access appropriate care, spenddowns are hard to meet and when met the delay for being open often means that needed meds are not covered, | 11/22/2013 12:13 PM |
| 129 | don't have it yet | 11/22/2013 12:00 PM |
| 130 | Can't think of anything at the moment that I don't like about the current program... | 11/22/2013 11:47 AM |
| 131 | The Area Agencies do not like the 24-7 model of care that and make it very difficult. | 11/22/2013 11:12 AM |
| 132 | Recently I went from having private health insurance with Katie Beckett Medicaid as a backup for my son to strictly KB Medicaid. His therapist discharged his speech services when he has not mastered the goals. I believe the reason for this is the decrease in the amount of reimbursement that she receives now and the number of sessions being limited. | 11/22/2013 11:10 AM |
| 133 | I rate the program as moderately successful. The programming is heavily weighted with administrative costs and is not transparent. | 11/22/2013 11:08 AM |
| 134 | All the components of the program seem well thought-out yet flexible. We have a case worker and a team of experts to answer our questions and keep us on top of issues that could affect us. Our daughter got a great education in the schools, training for a meaningful job and the opportunity to pursue her interests. We can't think of much more that could be done to help us and help our daughter. | 11/22/2013 11:07 AM |
| 135 | Redetermination forms are confusing and have to be completed so often. Sometimes approval is slow.. | 11/22/2013 10:55 AM |
| 136 | We think it works rather well | 11/22/2013 10:51 AM |
| 137 | I don't like the fact that the people that you count on don't show up and last min they call to tell you. as a worker it hard to leave work last min. to get home before the school bus drops off the teen who can not be left home alone as he has MR. | 11/22/2013 10:28 AM |
| 138 | You don't get enough time for it. I am not asking for help on someone normal teen who can do things for them self. I am looking for help for a teen who has MR and can not do things for them self. the older he gets the harder it gets to take care of him. At his age he should be doing so much more for him self. | 11/22/2013 10:20 AM |
| 139 | If my son was only on Medicaid & not covered by my health ins. company I most likely would have checked many more boxes | 11/22/2013 10:19 AM |
| 140 | too much paperwork | 11/22/2013 10:17 AM |
| 141 | Service providers are considerably further away than for private plans. Little knowledge of services available, | 11/22/2013 10:16 AM |
| 142 | direct support providers need to be paid a living wage! This directly impacts the support services. An Asperger's individual is often smarter than the direct support providers, who have no computer skills or vision, their own lives are often very compromised. I am however delighted to see them hiring refugees, they are often much higher caliber individuals | 11/22/2013 10:16 AM |

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| 143 | It is hard to find and keep qualified care providers as well as qualified care providers to temporarily fill in when regular providers are unable to work due to their personal needs (vacation, doctor appts, sick kids, etc.) | 11/22/2013 10:14 AM |
| 144 | As with most things in life, those who have money can pay for and receive the best of services. We have to keep a tight reign on the budget and some providers we've approached would not take the position due to the low wages we are able to offer. | 11/22/2013 9:54 AM |
| 145 | I work well within these guidelines to have my daughters needs met | 11/22/2013 9:47 AM |
| 146 | I do supplement out of pocket my personal care attendant to give her a livable wage. | 11/22/2013 9:33 AM |

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Q12 Is there anything else that you don't like about the current NH Medicaid Long-Term-Care program that you would like to tell us about?

Answered: 177 Skipped: 715

| # | Responses | Date |
|----|---|--------------------|
| 1 | No | 12/9/2013 4:49 PM |
| 2 | I guess I'd have to say it is not better than nothing. Not for us. | 12/9/2013 12:32 PM |
| 3 | For individuals who are severely disabled and are on medications and whom we advocate for as parents or guardians - it's extremely frustrating to be told that we have to start at square one with certain meds. For instance, my son has a gagging problem which is treated by Protonix or Nexium. Both work real well except for when he has a lot of changes happening which creates more gagging. Changing meds has been proven to work in calming down the food that comes up when he gags. That said, in order to have a different med prescribed - the doctor is always told he has to have an upper GI which will NEVER happen....he can't follow directions. That is followed by having to take Zantac 2X's a day - which doesn't work - before we can be prescribed what we DO KNOW works. This has been the procedure over and over again and it's very frustrating. Another time - we were told he had to switch to Crystalose for constipation - Medicaid wouldn't pick up Miralax any longer. The Crystalose did NOT work - he was having to be given suppositories and enemas frequently which didn't always work. After hearing him scream one night in trying to have a BM - I had enough. I emailed the doctor telling her something had to be done. Come to find out - Medicaid had started paying for the Miralax again - WHO knew though? Not us - not the doc. In addition, Medicaid will reimburse for transportation of pharmacy pick ups. However, that system is flawed. They will only pay for the trip to a pharmacy nearest your home. For us - we utilize a pharmacy that can do his medical supplies and his meds - however NH Medicaid won't pay for us to use this pharmacy as it is 2 miles further from our home's nearest pharmacy. Another issue with transportation reimbursement - I send in the forms to only have many be returned for trips to the pharmacy as whomever is processing them - states the date on the form is not in their system. And that may be for the reason that just because a prescription is filled on a certain date - that I don't get to the pharmacy to pick it up DAYS later. There are times when I don't leave the house for a week simply because I cannot get out due to my son being ill, LNA's not showing, etc. I think after saying all this - that somewhere someone needs to look at the fact that families that have long-term care individuals in their home need to be allowed special circumstances from the get-go. Our lives need to be made simpler. | 12/8/2013 5:18 PM |
| 4 | No | 12/7/2013 4:16 PM |
| 5 | There appears to be conflicts of interest, since the area agencies are able to also be service providers. | 12/7/2013 10:37 AM |
| 6 | The five year look back is taxing for most applicants. The amounts of paper is ridiculous. Banks and other providers of verifications would like to produce electronic records for this purpose but the local offices, I am told, do not have a way to read the CDs or whatever is produced. | 12/7/2013 4:43 AM |
| 7 | My spouse is in a nursing home and I on MEAD and our cases are often mixed up | 12/6/2013 11:00 PM |
| 8 | It would be beneficial to have stable functional support services and general wrap around care devoted to the "long term" outcomes. | 12/6/2013 3:48 PM |
| 9 | Current laws do not hold insurance companies accountable for parity in Mental Illness coverage. Insurance companies do not pay for quality mental health services unless forced to by a lawsuit. And if families don't have insurance or the ability to self-fund care for the mental illness, preventative care is difficult to access and families are left to watch their loved one's illness deteriorate until the person is suicidal or psychotic. | 12/6/2013 2:31 PM |
| 10 | Because there are no step down facilities, Private insurers DENY services out of state for step down services. Then they Deny services provided at the state hospital because the patients should be in outpatient settings. As a result the BILLS fall directly to the taxpayers when the Insurers should be covering services if they were available in state. Basically every pt who stays longer than the insurance company "precertifies" for in the state Hospital, is paid for by the state - either through the Medicaid program, or due to Direct expense because the patients never pay. The state need to FORCE insurance companies to pay for covered mental health services is they don't want the State hospital to cause bankruptcy of the system. | 12/6/2013 1:45 PM |

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| 11 | no | 12/6/2013 11:30 AM |
| 12 | There are not enough community based services, and the payment system the way it is makes accessing the services challenging. For example, it is often easier for an older adults to go to a nursing home than to stay in the community, even though the majority of older adults, when asked, indicate that they would prefer to stay in the community. In addition to increasing community based supports, individuals with mental illness and older adults and their families need added support and counseling to help them set up and maintain long term care services. | 12/6/2013 11:22 AM |
| 13 | Upper Valley of NH & VT do not have adequate Psychiatric services combined with the Dartmouth Hitchcock medical center that are covered by Medicaid or Green Mountain Care of VT. Psychiatrists charge out of pocket for services in this area, making support for family members almost impossible to locate in this rural area. | 12/6/2013 10:00 AM |
| 14 | Wish it paid all the therapies my son need, like ABA. | 12/6/2013 9:42 AM |
| 15 | YES: Clear up the confusing....keep all benefits consistent and clear...figure payouts within 15 days...counting on getting money and then either having to wait makes it hard to plan a budget and we, the poorest people, need to know our monthly budgets as quickly if not more quickly than regular folks, because we have to know exactly where we'll need to spent each penny from first to last...if we need to pay our rent, have enough food, but last month we we're able to pay for a haircut, too, if our monthly income changes 2 months later because of what we did last month, we have to know NOT to plan on getting that haircut...AND there is NO MONEY to SAVE...and when we do save money, it is counted against us TWICE when it comes to figuring out our rents...nothing is fair in life, but how would you like it, if your income figured double because your landlord saw some of it as savings and he added THAT to your income AGAIN ????? | 12/6/2013 9:33 AM |
| 16 | Get rid of Spend Downs / Cost of Care. It is barrier to treatment. | 12/6/2013 9:29 AM |
| 17 | Case managers do not often communicate | 12/6/2013 9:28 AM |
| 18 | NH legislators are not aware of the suffering they induce by not taxing capital gains. | 12/6/2013 9:03 AM |
| 19 | There is too long a wait for many people who needs services at the time of discharge for a safe setting. | 12/6/2013 8:59 AM |
| 20 | As a professional who works with consumers trying to access long term care services, I frequently hear comments that it is confusing, families don't know who to call, and specifically with CFI it takes too much time to access services often causing the nursing home placement the family did not wish to occur because supports were not available for 6-8months. | 12/6/2013 8:50 AM |
| 21 | Not at this time. | 12/6/2013 7:59 AM |
| 22 | Help! Help! | 12/6/2013 7:58 AM |
| 23 | direct support staff are the KEY to provision of quality services and yet get the least pay and benefits of anyone in the service delivery system...they also get next to no training to do their jobs. How could/would a system work given these basic facts? | 12/6/2013 7:40 AM |
| 24 | Again, my knowledge is not current. | 12/6/2013 7:33 AM |
| 25 | The poverty level needed is just high enough so that I only qualify for the spend down program and with the money that I do make, it makes it very hard to make ends meet. | 12/6/2013 6:42 AM |
| 26 | It is not flexible enough. | 12/5/2013 11:01 PM |
| 27 | The spend down system | 12/5/2013 10:35 PM |
| 28 | It is still a medical model and is moving towards data to define quality of Life. | 12/5/2013 10:15 PM |
| 29 | When there is a problem the system is difficult to navigate and sometimes people over the phone give you incorrect information which can then lead to more problems. | 12/5/2013 9:31 PM |
| 30 | I've said all that needs saying in the aforementioned questions. | 12/5/2013 9:24 PM |
| 31 | No | 12/5/2013 8:46 PM |
| 32 | Sometimes, it feels like our family member is 'kicked' out as he has missed a deadline. I understand deadlines are important. But there is always the balance as a family member, to let them 'do it themselves' fearing it will be done wrong , simply to try to preserve dignity. With mental illness, why don't you know it is the brain that is damaged, and have a bit of leeway? | 12/5/2013 8:30 PM |

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| 33 | Minimal services. Someone with a mental illness often doesn't have the strength or understanding to maneuver through our complex system. As it is, mental illness is stigmatized in our society. Our own state's health care system shouldn't follow suit, by treating citizens with mental illness with less dignity than those with a physical health ailment. | 12/5/2013 8:16 PM |
| 34 | Long waits Forrest approval. Poor communication for those of us who need answers. | 12/5/2013 7:55 PM |
| 35 | More information is required . | 12/5/2013 7:33 PM |
| 36 | Inadequate funding for services. CMHCs provide NH Medicaid Long Term Care Services yet were lumped in with acute care Medicaid services in step 1 of MCM implementation. | 12/5/2013 7:06 PM |
| 37 | Staff may spend too much time trying to keep eligible people from getting services. It creates a threatening rather than supportive environment. | 12/5/2013 7:06 PM |
| 38 | I am collecting my SSDI, but have to wait 2 years for Medicare and am not eligible for Medicaid, so 2 years without proper medical attention, are they hoping I die in the mean time? | 12/5/2013 6:35 PM |
| 39 | Program can be cut off suddenly without prior warning. Several times my daughters benefits have been stopped, only to be reinstated after providing information a second or third time. | 12/5/2013 6:25 PM |
| 40 | Reimbursement is too low to attract quality, experienced mental health professionals to the state. | 12/5/2013 6:15 PM |
| 41 | It requires the assistance of someone very functional and knowledgeable to navigate it; I worry about those who haven't family members to advocate for and assist them; it is so bare bones that there's no capacity to spend extra dollars that might save money in the long term. While vigilance to protect against abuse is needed, it can translate into a sense of persistent distrust of those in the system. As if anyone on medicaid is trying to rip off the system where instead I'd like to see a compassionate attitude that says we must do what we can for those who can't manage for themselves. I do find the people working for DHHS in NH to be generally kind and caring. | 12/5/2013 6:14 PM |
| 42 | No, it works well for me. | 12/5/2013 6:14 PM |
| 43 | My son lives on his own and needs more services but his yearly budget hasn't changed since he turned 21. It would be nice to have periodic "needs" reviews. Since he's on his own I pay for much of what he needs to be successful. What happens when I go? | 12/5/2013 5:16 PM |
| 44 | no | 12/5/2013 2:38 PM |
| 45 | It doesn't cover dental for adults. Information and transition services especially are lacking in support and direction for caregiver/parent/guardian. | 12/5/2013 1:41 PM |
| 46 | Because it's lacks funded in Community-Bases Services Medicaid funds less in Community-Base Services. Medicaid funds more for people with disabilities who living in State Run, Private Run, nursing home. Medicaid gives very little to Community-Base Services | 12/5/2013 1:07 PM |
| 47 | It's too hard to get good mental health services. What can be accessed is barely adequate. | 12/5/2013 12:42 PM |
| 48 | The current approval and case management system through the area agency service coordinators works well, service coordinators actually know the person they are representing, unlike other states where people managing waiver services do not. | 12/5/2013 12:01 PM |
| 49 | You shouldn't have to live in poverty before you can qualify for services. | 12/5/2013 10:17 AM |
| 50 | Turn over of staffing is difficult for everyone involved | 12/5/2013 9:33 AM |
| 51 | It is vital that we continue to manage the staff for our family members. | 12/5/2013 9:17 AM |
| 52 | The current system works just fine...let's leave it the way it is. | 12/4/2013 10:12 PM |
| 53 | The quality of eye glasses makes them break easy. Myraflex frames can be chewed, but they do not break and so a better quality metal frame and myraflex frames should be able to be replaced and repaired when needed. | 12/4/2013 9:12 PM |
| 54 | no | 12/4/2013 9:07 PM |
| 55 | It is being held hostage by politicians that only look at "the bottom line" instead of the human side of care. | 12/4/2013 8:10 PM |
| 56 | I feel the reimbursement rate for Elderly Long Term Care Services in nursing homes is inadequate to provide proper care. The homes can not afford the level of staffing they need to even give more than one or two baths per month. The average person takes a bath or shower daily | 12/4/2013 2:58 PM |
| 57 | does not cover dental | 12/4/2013 2:06 PM |

NH Medicaid Long-Term-Care Program Survey

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| 58 | The waitlist for the Waiver Funding has put many compromised individuals in unsafe circumstances where their medical needs are not being met while they await funding approval. | 12/4/2013 2:01 PM |
| 59 | Transportation services continues to be a large problem because it is not always covered by Medicaid or is not available. Also, poor coverage in areas of dental and eye and hearing services and costs for assistive devices. | 12/4/2013 11:50 AM |
| 60 | no | 12/4/2013 11:29 AM |
| 61 | Being on a Waiting List!!!!!! | 12/4/2013 10:23 AM |
| 62 | It would be very helpful if this Medicaid would cover dental and peridental expenses for older clients. Our daughter is 54 and we pay \$204.00 for her dentist and \$240.00 for her peridental. I had to cut down to once a year for the dentist and peridental instead of every six months because it was too expensive for us. We are retired and live on a fixed income. I think everyone should be encouraged to have good dental care. | 12/4/2013 9:39 AM |
| 63 | See comments provided on other questions. | 12/4/2013 9:38 AM |
| 64 | no - Thankyou for this much needed service!! | 12/4/2013 9:32 AM |
| 65 | It is not well managed. | 12/4/2013 9:14 AM |
| 66 | Please keep funding for these programs. | 12/4/2013 8:41 AM |
| 67 | Need for long term planning by age 12 not when person is ready to graduate from ugh school. | 12/4/2013 8:39 AM |
| 68 | I appreciate so much the support my son is currently getting, thank you! ,! | 12/4/2013 7:09 AM |
| 69 | no | 12/3/2013 10:34 PM |
| 70 | The focus on individuals living by themselves and "independently" is antiquated and was created by people who have no idea what adults with DD and now ASD want and need to be happy and successful. There should be a clear focus on going forward to create cooperative situations that combine people who fit well together and who have different skills that can balance and compliment one another. (This will be easier for people with autism.) The budgets for individuals that own homes or condos and need 24/7 care is not only ridiculous, but is keeping others from accessing what they need. The state needs to look at what is successful in other states and work with families to create more logical and reasonable solutions... this is the first generation of families who have had their DD/ASD person live WITH them- attend public schools and thus have created a network of connection in the community that should be leveraged in sustaining our loved ones. No one knows them better or can decide what they need to be successful than the primary caregivers for their entire lives. | 12/3/2013 8:34 PM |
| 71 | I don't like the fact that people who have nothing can't be penalized financially for services paid for by the Medicaid program but people who have worked all of their lives but acquire a brain injury has to let the state put a lien on their house to try and recoup monies that were spent on caregivers coming into the home to care for the brain injured person while the spouse works a full time job | 12/3/2013 8:29 PM |
| 72 | No | 12/3/2013 8:12 PM |
| 73 | No | 12/3/2013 5:10 PM |
| 74 | No | 12/3/2013 4:50 PM |
| 75 | no | 12/3/2013 4:22 PM |
| 76 | Not yet. | 12/3/2013 4:09 PM |
| 77 | There isn't enough emphasis and value placed doing the work of a DSP for DD individuals in the schools. It should be presented as an option for those interested in nursing or social work. There is a big difference in working with DD folks and changing diapers at a nursing home. It can be a lot more fun and rewarding, and should be presented that way to encourage kids who can't or don't want to make it as nurses. | 12/3/2013 3:52 PM |
| 78 | Some of the people have such large client case loads (Plus co) that they do not see us for months at a time. | 12/3/2013 3:30 PM |
| 79 | The delay in receiving funding support for those with severe disabilities transitioning from school base program to adult services. There should be a better way to bridge the supports so that the expertise and training of the school based staff can extend to the adult service program and staff. Many school districts will not back in services from an adult service provider as it is an extra cost and they offer transition services in their high school programs which they fell are sufficient to meet IEP transition goals. | 12/3/2013 2:47 PM |

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| 80 | Nothing. It's one of the best in the nation. Leave it alone! We don't want to go back to the Laconia State School Days. | 12/3/2013 1:50 PM |
| 81 | It is difficult to find a place for my sister to get hearing tests/ hearing aids. All but one location in Manchester says they won't take anyone on Medicare/ Medicaid as they don't get reimbursed enough. | 12/3/2013 12:43 PM |
| 82 | Concerns about the quality and competence of the staff at Gateways. Concerns about the quality and competence of the "Family Managed Employees" selected by Gateways. | 12/3/2013 12:21 PM |
| 83 | I feel that the providers that are available to me are unqualified and not knowledgeable in the treatment of autism. | 12/3/2013 11:48 AM |
| 84 | Client Providers need better pay and benefits to keep them employed. Also if situations change and more needs are needed as these folks age, I understand that once your budget is set, it cannot be changed. I would like to see changes allowed when necessary for folks as situations change in the households. We save the state millions of dollars taking care of our own at home yet that is not taken into consideration. | 12/3/2013 11:44 AM |
| 85 | Not all of our service providers accept NH Medicaid, according to the providers it is too frustrating for them and they did not get paid in a timely manner. They also do not cover some necessary medical testing cost. I just received a large bill for an EEG that my son needed because they thought he was having seizures caused from his medication. My private insurance paid some and Medicaid refused to pay anything. | 12/3/2013 11:00 AM |
| 86 | Almost every time I pick up my son's prescription, the pharmacy tells me that the medication is not covered when in fact, it is covered. I can't send my son to pick it up because the pharmacy will charge over \$200 per month for something that should be no charge. The employees at the state and local level are uncaring and, at times, nasty. These are people I have spoken with on the phone. The employees who are at the local level that you see at the front desk couldn't be nicer and more helpful. | 12/3/2013 10:41 AM |
| 87 | Home care providers and direct support professionals do not earn enough money and go for years without pay increases. Obviously, this affects the quality of services being provided to recipients. | 12/3/2013 10:37 AM |
| 88 | I worry about when we (I) am not around as to how he will manage... | 12/3/2013 9:23 AM |
| 89 | THE MEDICAID RATES HAVEN'T CHANGE IN MANY YEARS, THUS IMPEDING OUR ABILITY TO COMPENSATE CAREGIVER APPROPRIATELY. | 12/3/2013 9:04 AM |
| 90 | Lack of communication/knowledge sharing between DHHS departments providing services to the disabled individual | 12/3/2013 8:55 AM |
| 91 | The medication / having scripts filled and being approved has been difficult | 12/3/2013 8:49 AM |
| 92 | Everyone at the state has a different answer and doesn't address the family needs and changes, only the Medicaid client/loved one. | 12/3/2013 8:21 AM |
| 93 | It is extremely difficult to get someone the MH care needed, even with guardianship status. | 12/2/2013 10:57 PM |
| 94 | The only thing I don't like is the response time to the billings for his services. I have had providers who dropped taking the insurance because they were not paid fast enough. But I have no complaints at all about my son's insurance. | 12/2/2013 7:58 PM |
| 95 | Paperwork | 12/2/2013 6:17 PM |
| 96 | The system looks good on paper but the lack of finding does not allow it to help all that need help. | 12/2/2013 4:10 PM |
| 97 | Doesn't provide respite services or substance abuse services | 12/2/2013 1:54 PM |
| 98 | n/a | 12/2/2013 11:56 AM |
| 99 | the spend down amount is too high for me. | 12/2/2013 11:02 AM |
| 100 | Process is much too long to get on CFI program. No reasonable explanation as to why it takes so long (months). No responses from OLTC when inquiries are made. | 12/2/2013 10:33 AM |
| 101 | We are currently in the IHS program and not sure what will happen when my son turns 21. Would be a comfort knowing that he would be assured quality services at this time. | 12/2/2013 9:02 AM |
| 102 | budget cuts that take away from the services that we have . | 12/1/2013 10:12 PM |
| 103 | the person who conducted the initial interview was in such a hurry she put down incorrect information. if I had not corrected the mis information my child would have been denied services. | 11/30/2013 1:16 PM |
| 104 | I have three children with Autism, ages 17, 19 and 22. They could use more direct care services, but that's a funding or budget problem. The money simply isn't there. I get that. They agencies do the best with what they have. I know this! | 11/29/2013 6:10 PM |

NH Medicaid Long-Term-Care Program Survey

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| 105 | It doesn't prepare parent for when they are gone. You have to work really hard and not take No for an answer when you need something for your loved one. You must learn to be an advocate who has broad shoulders. | 11/29/2013 6:00 PM |
| 106 | There is a fear of what will happen to him when I can no longer care for him physically and no long term plan available. And in our area no real choices between in home care and group homes if necessary. | 11/29/2013 1:26 PM |
| 107 | Once again, I believe that for-profit management is not ethically or financially appropriate. I urge that DD services be exempted from NH Medicaid Long Term Care, and that the present system be continued. | 11/29/2013 11:15 AM |
| 108 | It does not provide dental care which my sister is in great need of. She has extremely poor oral care at this time. | 11/28/2013 8:23 PM |
| 109 | No, in fact it concerns me that if I have to deal with new providers outside of my local community that my family member's QUALITY of services may be jeopardized. | 11/28/2013 3:21 PM |
| 110 | I | 11/27/2013 10:48 PM |
| 111 | Not really - just the lack of some sort of a COLA - keeping our mentors is VERY important and becoming more difficult. | 11/27/2013 6:00 PM |
| 112 | No. | 11/27/2013 11:43 AM |
| 113 | No | 11/27/2013 11:14 AM |
| 114 | There is often disparity across the state and much of what people receive for services depends on the ability of the guardian or family member to advocate for needs. However, I am not convinced that any other system would be different. Much of it is human nature and we are still all humans.. | 11/26/2013 10:48 AM |
| 115 | Wait list not a lot of information on how to access services I usually hear through the grape vine | 11/26/2013 10:26 AM |
| 116 | It took too long to receive it. | 11/26/2013 8:05 AM |
| 117 | Most of my complaint lies with the area agency (community Bridges) and the lack of understanding of the current best practice approach to autism treatment in addition to the under-qualified staffing | 11/26/2013 6:30 AM |
| 118 | too much paperwork | 11/25/2013 3:30 PM |
| 119 | Not enough options for residential services. Adult foster care is not appropriate for many and thus parents are left to deal with very challenging disabled adult children on their own. Group villages and communities should be created. | 11/25/2013 2:56 PM |
| 120 | I don't like dealing with the area agency | 11/25/2013 1:58 PM |
| 121 | Families do not get the same information from area agency to area agency- there should be ONE place that gives ALL the information and that would allow families to connect and work together to create what would be best for their person. | 11/25/2013 1:42 PM |
| 122 | NA | 11/25/2013 12:38 PM |
| 123 | I don't know of anyone who speaks well of BEAS Adult Protective Services; including police, EMS, social workers, friends, colleagues, coworkers, lawyers, etc. | 11/25/2013 11:39 AM |
| 124 | Same as previous....dealing with the area agent is a challenge at best and a nightmare at worst. I don't know why money has to go to a middle man when it could be easily managed by the recipient or the guardian. | 11/25/2013 10:42 AM |
| 125 | Let's be more thoughtful & delay implementation. | 11/25/2013 9:05 AM |
| 126 | More housing options | 11/24/2013 7:02 PM |
| 127 | FUND THE WAIT LIST!!! Governor Hassan signed the bill, but the backdoor budget cuts are crippling | 11/24/2013 6:46 PM |
| 128 | This is a vital program to keep children out of facilities and at home. Kids at home cost the state less than if in a facility. Without the block time nurses and LNAs, these families will not be able to achieve this. | 11/24/2013 5:21 PM |
| 129 | Private agencies are soaking up tax payer dollars that could be better managed by the state government. | 11/24/2013 4:11 PM |
| 130 | I didn't even know it existed, or how to get access to it. This is actually the first I've heard of it. | 11/24/2013 1:51 PM |

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| 131 | Not many dental providers in NH accept it. I paid a lot of money for my sons teeth which were coming in behind others and he can't simply wiggle them out or wouldn't let us so I had to have them extracted and needed to pay in full. Also, he needed to be put under anesthesia which was another expense because he was a risk to himself and the dental team because he swings his arms and tries to push the mask off | 11/24/2013 10:01 AM |
| 132 | Offer a higher reimbursement so that more medical physicians and facilities will accept NH Medicaid | 11/23/2013 10:23 PM |
| 133 | Too many hands on the pie. Area Agency gets a cut for their overhead, then Easter Seals takes their piece, and then your vendor such as plus company gets their piece. If a parent is willing to do CDS, then Gateways/Area agency should not be getting two separate line items out of the budget to administer writing one check per month? This means less and less money for the client who is the one who needs the funds and the one intended to get all the services they need. | 11/23/2013 9:47 PM |
| 134 | The rules that prevent the disabled from saving money. If they should ever get a windfall we can't save it for them to use in future. That means the money gets spent on frivolities (perhaps nice & functional but not necessary at the time) and when later the money could have been used to repair a car, pay for food or gas, there is none. So it comes out of the rest of the family who are also struggling to make ends meet. | 11/23/2013 10:52 AM |
| 135 | I want to use FC to communicate but there is not enough people to do that in my program | 11/23/2013 8:38 AM |
| 136 | Dental and ABA service are not covered. My son like so many others has sensory issues and brushing his teeth is difficult for him. Currently we carry him on our private dental plan, however that will change when he turns 27 and can no longer be on my plan. Currently he sees the dentist 4 times a year and for 2 of those visits we pay out of pocket. Dental issue lead to all types of Medical issues, it does not make sense for medicaid to stop paying for Dental at age 19. The other issue I have MH services. TRY to find a a long term provider for someone with developmental disability. My son suffers from anxiety and finding a MH providers was time consuming and unsuccessful. With the provider did not take my primarily insurance, did not take Medicaid, did not work with the DD population and only took on short-term clients. For someone living with a DD MH services are long-term. | 11/23/2013 8:01 AM |
| 137 | Hb528 prohibits income from child support for a person over 21 who has a disability. Living at poverty level is not good. Family Care providers are saving the state a lot of money how can they get more supports. Able families should support their family members when able. Why would the state want persons with disabilities on state programs and absent parents not held responsible for financial assistance when able and for physical assistance | 11/23/2013 7:55 AM |
| 138 | I'm worried that my son will age out and not be cared for. | 11/23/2013 7:41 AM |
| 139 | Takes too long. | 11/23/2013 6:28 AM |
| 140 | No. | 11/23/2013 12:31 AM |
| 141 | I appreciate any help for my family member. However, when she has money in her fund I don't like that it can't be used for dental work or vision care. | 11/22/2013 10:34 PM |
| 142 | Families should have the option of choosing their own agency instead of an area agency for a budget home. | 11/22/2013 10:10 PM |
| 143 | Sometimes I feel like people get "burnt out"... | 11/22/2013 10:00 PM |
| 144 | no | 11/22/2013 8:59 PM |
| 145 | The constant need to re-authorize hours is draining. If no change in status has occurred, why is it necessary to continually go over the same information every 90 days? | 11/22/2013 5:26 PM |
| 146 | All in all it's not a bad system. Sometimes one case worker will say something and another says something else. They all should be on the same page and not be afraid to say "I'm not sure but let me find out and I'll be right back with you". | 11/22/2013 4:01 PM |
| 147 | unknown | 11/22/2013 3:39 PM |
| 148 | Too much emphasis on employment for people who really don't have the attention span and skills to be employed. Too little diversification of service venues. One model does not work for everyone! | 11/22/2013 3:35 PM |
| 149 | I don't like the idea that the current system will change. The area agency system already provides managed care in a cost-effective manner. | 11/22/2013 3:35 PM |
| 150 | Not enough respite available. I take care of my disabled sister by myself. We have no family to help out and I work 50 hours a week and take care of her in addition. I don't have anywhere near enough respite. | 11/22/2013 3:25 PM |
| 151 | no | 11/22/2013 2:54 PM |

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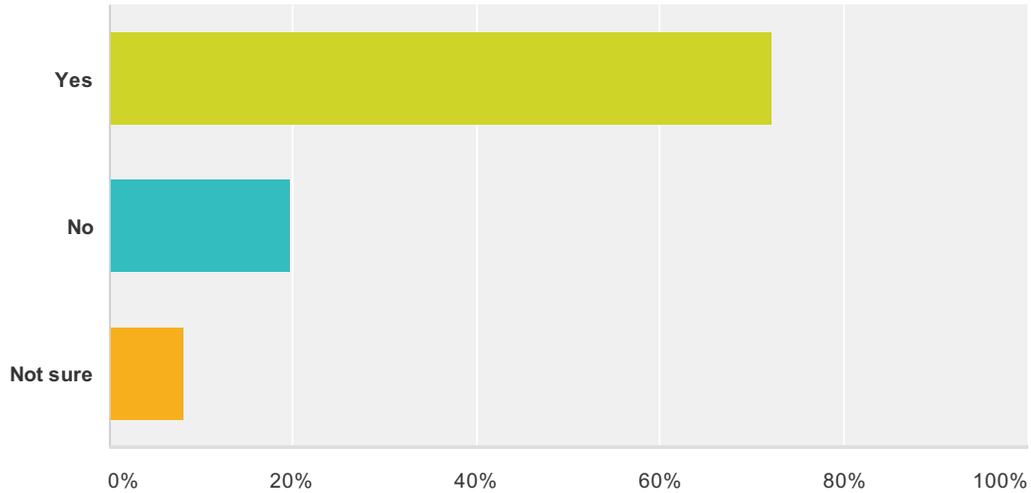
| | | |
|-----|--|---------------------|
| 152 | When we first received our in home support waiver we could use most of the budget to cover therapies that were extremely beneficial to our son. Now with the \$1200.00 limit we have had to pull him out of sensory, social, hypnotherapy and music therapy. Most of his budget is never used because there just isn't the staff available to do respite. I also don't understand why sanitary products like overnight bladder control underwear that my son needs because of cerebral palsy aren't covered. | 11/22/2013 2:43 PM |
| 153 | I have been trying to get my daughter a new Medicaid card for more than 2 years and it never comes no matter how many times I have requested! | 11/22/2013 2:38 PM |
| 154 | assistance in purchasing handicap van with wheel chair lift. Even if it was a used one. help in this area would greatly be appreciated. | 11/22/2013 2:19 PM |
| 155 | no | 11/22/2013 2:12 PM |
| 156 | The paper work..yearly requalifying. The poor communication from the Medicaid office. Having an Area Agency structure that I know is there to help us if we need it. I have seen them jump into action and take individuals they serve into their homes when there was an extended power outage. It is a personal connection and right now the comfort is ... if my husband and I should have an accident and no survive the Area Agency would step in right away to be sure our daughter is safe. I would hate to see this structure broken down. I have seen first hand the benefit of consumer directed services and would like to see this carried over for other populations in need of long term supports. I have seen this work for someone on the CFI waiver and their quality of life improved once they could have a flexible (consolidated budget) and select the individuals to work with them and also use the funding to purchase products that work for them and cost less than the required Medicaid product. I don't like when rules are established based on distrust rather than setting guidelines from a trust perspective. It does not provide preventative coverage for dental care and has limited Mental Health services. | 11/22/2013 2:07 PM |
| 157 | Support and educate families right from the beginning and help them to do the best job with their family member as possible would save lots of heartache and lots more money. Helping them with what they need builds a better foundation for success, rather than it being such a hardscrabble system. You don't know what you don't know and when no one tells you or no one can tell you, it's very frustrating. | 11/22/2013 2:02 PM |
| 158 | The wait list for additional needed services. | 11/22/2013 1:49 PM |
| 159 | It would be much better if the money followed the person no matter what the age so that people will have real choices. Making families accept services they don't need or want is a waste of money that the state doesn't have. People should be able to choose any approved vendor agency and not have to work with the area agencies if they don't want to. | 11/22/2013 1:44 PM |
| 160 | We are back on the wait list | 11/22/2013 1:37 PM |
| 161 | nothing - I'm very happy | 11/22/2013 1:30 PM |
| 162 | Lack of consistency across the state drives me crazy! Quality assurance is slipping because staff at the state level have been drastically cut. The system relies more and more on the good will (and money) of family members. Why is there an assumption that my son will live with me forever? If he does, why can't the State offer me something in return – tuition break at state university for my other kids? Lower real estate taxes? Something! | 11/22/2013 1:14 PM |
| 163 | My daughter receives LNA services at home after school. Unfortunately, due to the way the State of NH interprets the federal guidelines, the LNA cannot accompany my daughter and myself to doctor's appointments, dance, gymnastics class or shopping. My daughter requires 1:1 assistance due to her lack of fine, gross motor skills and speech. It is imperative that she have an aide to accompany her for assistance. She is confined to the four walls of her home after school and not able to participate in after school activities as her peers do. If I take her myself (which I have done), the aide still can't go with me and the aide then loses a day of pay, and I may lose my slot to have the services continue, | 11/22/2013 12:23 PM |
| 164 | delay in approval for snf, ltc through state nurse is too long and means that pt who under other ins would be able to access appropriate care, instead are kept at the hospital for too long, feel that they are forgotten and are placed at increased risk for infection due to increased exposure to acute care facilities. | 11/22/2013 12:14 PM |
| 165 | No! | 11/22/2013 11:48 AM |
| 166 | The current system does not put enough emphasis on direct supports in terms of pay, benefits or a comprehensive training opportunity (and ongoing). All services lead to who is going to perform them and leadership in this state does not focus their time and money in making sure the direct workforce is prepared to deliver quality services. If this was more of a concentration of all service agency providers I believe the outcomes for the people receiving services would have better health, safety and overall quality of life. And more cost effective and natural community resources would be utilized therefore lowering some costs. Direct support workers need a lot of attention and they can make or break any system. | 11/22/2013 11:18 AM |

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| 167 | The way the funding trickles down ..to much funding goes into overhead | 11/22/2013 11:12 AM |
| 168 | no | 11/22/2013 10:56 AM |
| 169 | No | 11/22/2013 10:52 AM |
| 170 | It's to hard to use | 11/22/2013 10:24 AM |
| 171 | It feels fragile and changeable. Families need to be certain supports will be there for the long term. Parents will not always be here and proper supports & services are always a concern | 11/22/2013 10:21 AM |
| 172 | there is no program that helps with finding jobs in a realistic way - compared to other job-seekers, our population is not going to be chosen for a job | 11/22/2013 10:18 AM |
| 173 | Inadequate level of program funding, inadequate pay for providers. There should be no or a VERY short wait list. Fearful of my son's good life when I am gone... | 11/22/2013 10:16 AM |
| 174 | This is such a highly regulated program, and I can understand the need for it, but it would be wonderful if some of the red tape and paperwork could be dropped. Perhaps its time to review the process and remove outdated policies that no longer make sense. | 11/22/2013 10:00 AM |
| 175 | I don't know why you have to have the same paperwork filled out your early if there has been no changes I would say take and make changes to the paperwork that was previously handed to you like some of the doctors offices do. You create so much more paperwork for yourself | 11/22/2013 9:46 AM |
| 176 | Case managment services totally suck. | 11/22/2013 9:42 AM |
| 177 | Reapplication process is paper work for little purpose. The issues Maya has will not resolve in her lifetime. Why do I have to keep reapplying? Also the total amount of paper work -- respite, reapplication, transport forms, etc -- take time I don't have. There is no easy, online way to do it. There have been times when the paper work burden has meant that I missed out on service that I was entitled for. I just couldn't get the applications, etc, out on time. | 11/22/2013 9:37 AM |

Q13 Have you, or your family member, ever had experience with a team of service providers or professionals who meet on a regular basis to review your (or your family member's) progress and help set new goals?

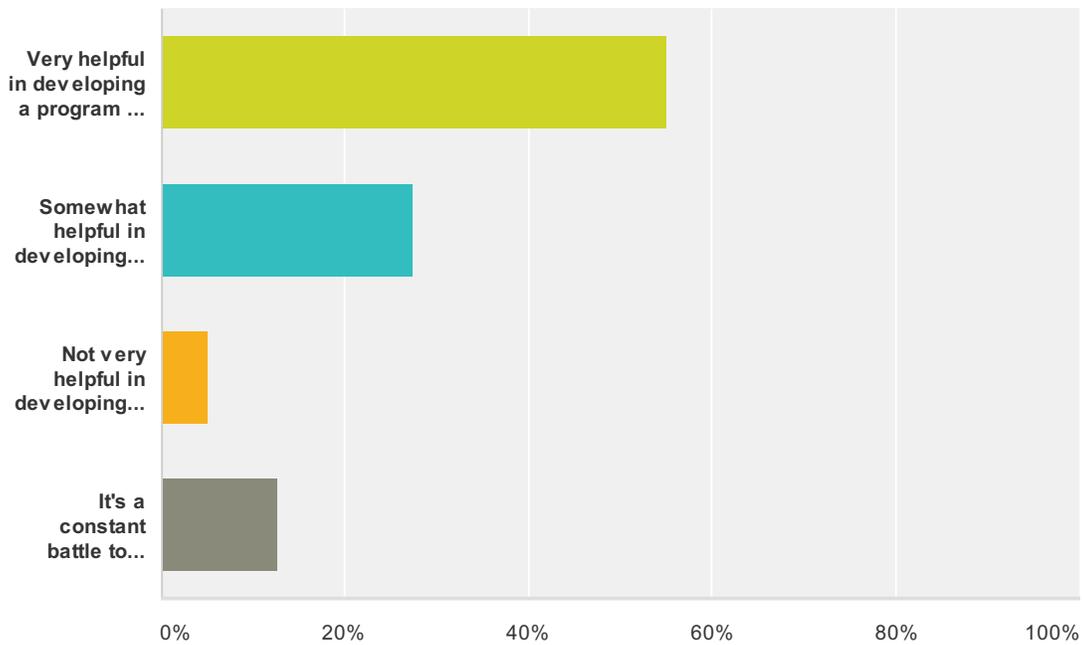
Answered: 610 Skipped: 282



| Answer Choices | Responses | Count |
|----------------|-----------|------------|
| Yes | 72.13% | 440 |
| No | 19.67% | 120 |
| Not sure | 8.20% | 50 |
| Total | | 610 |

Q14 What statement comes closest to your general experience with these teams of service providers?

Answered: 433 Skipped: 459



| Answer Choices | Responses |
|--|------------|
| Very helpful in developing a program of services and supports to meet my (our) needs | 54.97% 238 |
| Somewhat helpful in developing a program of services and supports to meet my (our) needs | 27.25% 118 |
| Not very helpful in developing a program of services and supports to meet my (our) needs | 5.08% 22 |
| It's a constant battle to advocate for the services and supports I (we) need | 12.70% 55 |
| Total | 433 |

| # | You are welcome to comment if you would like | Date |
|---|---|--------------------|
| 1 | This has always been a team effort where everyones opinions and knowledge are respected. | 12/9/2013 7:36 PM |
| 2 | It seems difficult to get everyone together and when it happens, it is difficult to reach consensus | 12/9/2013 4:51 PM |
| 3 | Way too often our case workers are switched from the cases they are on. Have you any idea what it's like to have to fill in a new case worker? Then there are the times when we get the "new" ones that just don't know what they're doing. That's extremely frustrating. | 12/8/2013 5:39 PM |
| 4 | They help me meet the goals I want for myself. They don't tell me what I can and cannot do. They treat me like an adult. | 12/8/2013 11:05 AM |
| 5 | A local team of professionals who know the resources available in our area, know my daughter and the culture of our family is extremely important in developing and implementing services to best meet her needs. | 12/6/2013 10:56 PM |
| 6 | It has been a battle to ensure the services are carried out for the long term versus the immediate acute period of a month. If my son did not his family to advocate for him, I truly feel that he would fall through the cracks. | 12/6/2013 3:50 PM |

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| 7 | It is 99% family-paid even though I have insurance and was told it would be covered. Our family member has received residential treatment, is now in out-patient treatment. He is now a working member of society who continue to receive treatment from an Outpatient team that helps him manage his symptoms and communicate with his employer about his illness. | 12/6/2013 2:33 PM |
| 8 | dont let you know when they have to miss an appointment | 12/6/2013 12:50 PM |
| 9 | No matter how good the team and the programs/activities suggested or arranged for, the person with mental illness is usually unable to actually do the things provided. Newly discovered: there is a part of the brain that controls whether the person can perceive the things they themselves are doing. | 12/6/2013 12:15 PM |
| 10 | My son meets with a meds coordinator at The Bedford Clinic (Manchester Mental Health) each month and I have participated in those meetings. Leslie Clokay does an excellent job, but my son needs more attention and services than MMH can provide, given the funding issues and growing numbers they must serve. Funding is greatly needed! | 12/6/2013 11:34 AM |
| 11 | Feedback from family members is that the general experience is overwhelming and confusing. More support is needed. | 12/6/2013 11:24 AM |
| 12 | It is VERY frustrating, since our child's counselor will not speak with us. We realize she can't say anything about her patients without being released to do so, but we have some information she could take into account and we would appreciate being advised about what we can best do to be a help. We are supporting our child and paying all the doctors' bills and it is such a missing link not to allow our input. | 12/6/2013 10:41 AM |
| 13 | As a mental health client using my local county mental health clinic, getting my services met is very dependent on who my case manager is and that is constantly changing...they get burnt out and are willing to change jobs for better money or because they get burnt out...you must ALWAYS consider the EXTRA constant change we mental health clients are under...YOU MUST !!! | 12/6/2013 9:36 AM |
| 14 | The meetings I am familiar with are a Core Team meeting for youth with mental health services | 12/6/2013 9:35 AM |
| 15 | the degree of coordination and communication among the various providers is inconsistent | 12/6/2013 9:33 AM |
| 16 | I have heard any and all of the above depending on where the patient resides and what the needs are. some are unrealistic but many have no other source for support. | 12/6/2013 9:00 AM |
| 17 | I believe getting all stakeholders involved and communicating with each other for the interest of the individual requiring services is a solid approach to obtaining and maintaining services needed or in some case discontinuing services not needed. | 12/6/2013 8:02 AM |
| 18 | Essential for both humanitarian and cost saving service. "Essential" puts it mildly. | 12/6/2013 7:35 AM |
| 19 | Community mental health Special education And now the courts - it's been and still is a constant battle | 12/5/2013 11:40 PM |
| 20 | My Social Worker is so helpful in being my advocate for me. She knows the "in's and out's" of the system and knows how to get the services I need. | 12/5/2013 10:38 PM |
| 21 | Limited choice in medical providers. | 12/5/2013 10:04 PM |
| 22 | A happy or unhappy experience depends a great deal on the individual service provider/vendor Many more such specialized vendors are needed, to create competition. Stop assigning Area Agencies who are given power to monopolize. Step up to implement that which NH has had a pilot program for, years ago, stop talking, but do that which you've "TALKED ABOUT" regarding independent case managers to keep oversight. Giving INDEPENDENT CASE MANAGERS greater authority over Agencies will make things work better and more effectively. Most case managers are great, less costly than medically trained and they work hard to get the most services possible out of the individuals' fundings. Separate them from the AA's, give them authority and we'll get a better "Bang" out of the tax dollar spend !!!!! | 12/5/2013 9:50 PM |
| 23 | Hasn't happened recently, but we met annually for this type of review early in my son's illness. | 12/5/2013 9:46 PM |
| 24 | We had one counselor who lied, in writing about our family member. We didn't learn about it until she left and he got a new clinician. I'm the guardian, I was never shown this information- why not? It is now in his permanent record. That shouldn't be allowed and there should be recourse when it occurs. | 12/5/2013 8:32 PM |
| 25 | The system creates treatment providers that are overloaded, overworked, underpaid and under appreciated . They need more tools to better serve this population. Need to look at improving efficiencies, reporting, billing just as a start. | 12/5/2013 6:30 PM |
| 26 | My daughter lacked medication management services for most of last year because her community mental health center could not replace a prescriber who had left for another job. She ended up having an exacerbation requiring a 15 day hospitalization and has not fully recovered from that experience 7 months ago. | 12/5/2013 6:17 PM |

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| 27 | Pathways has been excellent; less impressed with West Central. While there are excellent people at West Central, there are also some who are woefully uninformed and not well trained for their work. People seem burned out and not capable of handling their work. | 12/5/2013 6:15 PM |
| 28 | We have had a few team meetings, but not enough, and there has not been very good follow-through after the meetings. | 12/5/2013 5:52 PM |
| 29 | The team is effective in developing programs, but there is no follow-up and oversight. | 12/5/2013 1:12 PM |
| 30 | All seem to have recipients best interest at heart | 12/5/2013 9:33 AM |
| 31 | OneSky Transition Coordinator Karen Tellier was a life saver and the recipient would not be where she is now if it were not for Karens hard work. | 12/5/2013 5:20 AM |
| 32 | My area agency was a bit "secret society" when we first started adult services but once we got placement in to the group home they have been nothing but wonderful. The Bureau of Special Medical Services was one of the best resources we used and was sad to leave them at the age of 21 years. | 12/4/2013 9:27 PM |
| 33 | We are currently in school but are starting the transition period soon. | 12/4/2013 9:13 PM |
| 34 | I participated in ONE team meeting between 2007-2013 and that only happened because I advocated and worked very hard for it to happen. | 12/4/2013 7:45 PM |
| 35 | Heidi Jackman with One Sky is fantastic, she is so helpful with certain state forms and giving guidance when needed. | 12/4/2013 6:30 PM |
| 36 | We go through Area Agency and they tell you one thing you get the agreement and budget and it does not look anything like what was put collectively together for state review. | 12/4/2013 2:54 PM |
| 37 | Our team meets a few times a year and works together to identify and coordinate goals and objectives. The meetings provide an opportunity for questions and future concerns. The team is knowledgeable in terms of monetary allocation and flexible enough to make program changes as are necessary to meet our daughter's changing needs. There is always someone available from Lakes Region Community Services to answer our questions, including Medicaid issues. Most importantly, the present service model is made up of individuals/professionals in close proximity to our daughter/family, who understand her individual case and are closely involved with it. As a result, the most cost effective yet appropriate decisions can be made to address her needs in a timely manner. | 12/4/2013 1:27 PM |
| 38 | The team (albeit with high-turnover) is very kind and understanding. They agree with our sense of urgency and they explain things in a way that is understandable. But the bottom line is: we're still WAITING for services. 2.5 years of waiting. | 12/4/2013 12:22 PM |
| 39 | This varies with different towns, organizations, clients...Some Care Plan Teams are excellent and some are useless. | 12/4/2013 11:51 AM |
| 40 | This only became the case once we had the opportunity to participate in a consumer directed program where we could choose all of our providers (area agency for fiscal services, case management, home/day services, etc). Before it was a much more challenging process and did not necessarily meet our needs. | 12/4/2013 11:51 AM |
| 41 | But once things are put in place no one sticks to them. | 12/4/2013 11:30 AM |
| 42 | They try, but there is inadequate funding so what can they do? | 12/4/2013 11:03 AM |
| 43 | Case Managers at Community Crossroads are skilled and knowledgeable, but it is not fair to have been on the Waiting List for additional services for 8 months now, even though Waiting List funding passed in the budget in July and have had NO communication from Community Crossroads as the IF or WHEN the needs of my daughter on the Waiting List for add'l supports might be addressed | 12/4/2013 10:25 AM |
| 44 | Primarily this occurred during transition from High School. The overall experience was wonderful in lowering the stress of what is otherwise a very scary, stressful period. This part of the system should NOT be altered significantly! | 12/4/2013 9:39 AM |
| 45 | Jess urinates at night and refused to get cleaned up she refused her day program so farmsteads wasn't getting paid for those hours. We were able to get urgent funding from pathways area agency through Medicaid. she is currently going through the STARS eval process and there have been great improvements. We are meeting frequently to implement all the recommendations. her team is very dedicated to improving quality of life and solve difficult issues. | 12/4/2013 9:37 AM |
| 46 | Our case worker is very responsive to our needs. | 12/4/2013 9:34 AM |
| 47 | The Moore Center has provided so much for her. | 12/4/2013 8:42 AM |

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| 48 | I end up doing most of the research and footwork when a change in services is needed. There is frequent turnover of personnel which makes any continuity in services very difficult. | 12/3/2013 11:15 PM |
| 49 | It seems there needs to be more nursing or rehabilitative participation on the treatment teams. | 12/3/2013 9:30 PM |
| 50 | At some point, the focus on "goals" and a person with DD achieving the next step is annoying... I now it needs to be framed in a constructive way- but a DD person is an adult individual that needs to be accepted and celebrated for who they are- and not expected (unrealistically) to continue to do things or learn things that are not possible for them. An adult needs to be a valid and contributing member of their community using whatever gifts they have... keeping 'goals' set up as when they were in school is patronizing, and a waste of time. The focus should be on how they are part of a community that supports and honors them. | 12/3/2013 8:40 PM |
| 51 | the only thing that is a bit frustrating at times is the amount of paperwork involved to be done by our case worker, our provider and myself. It seems to me that we NEED a checks and balance system but sometimes the information needed is just too repetitive. | 12/3/2013 4:23 PM |
| 52 | I greatly appreciate all the assistance Gateways has given us. | 12/3/2013 12:44 PM |
| 53 | Gateways implements a cookie cutter approach for the population it "serves." For example, nearly everyone was recommended to take an expensive music "therapy" class regardless of their ability to participate meaningfully - a financial windfall for the Community Music School of Manchester - and an expensive imposition on the citizens of N.H. and the U.S. so that Gateways can spend the time of their "clients" and appear to be "doing good." The individual client's needs were NOT taken into account when planning "services" which could more appropriately be described as very expensive "approved" time-fillers. | 12/3/2013 12:37 PM |
| 54 | On the State level we are required to fight and fight and fight for the disabled. This should not happen. This should be covered and covered right without the year to year fight for funding. Like I said before, these are human being not animals we are talking about. Sometimes I feel the animals are given more care than the disabled when it comes to funding and services in place. Like any budget it should be automatically covered without all this yearly aggregation. I am 68, my husband is 81 and we are tired of this yearly fight. | 12/3/2013 11:47 AM |
| 55 | This was for my Dad who has since passed away. | 12/3/2013 11:02 AM |
| 56 | My experience on these teams is that goals for clients are being written to accommodate the requirements of the State, rather than written to accommodate the clients' actual wishes. | 12/3/2013 10:39 AM |
| 57 | I wouldn't call it a "team" that we meet with but as my son has a consumer directed care plan in place we do meet annually with his "care manager" at our area agency to review/develop his annual care plan. Additionally his care mgr meets with him a couple of times a year to check in and see how he is doing..... | 12/3/2013 8:58 AM |
| 58 | In the beginning, it was hard to coordinate services, but once my son got a caseworker, things smoothed right out. | 12/2/2013 7:59 PM |
| 59 | The providers would like to outline an all inclusive program but can't because the resources are simply not available. You can't advertise a Lexus and then provide a Ford and not expect criticism. | 12/2/2013 4:17 PM |
| 60 | I am invited to attend and participate in every annual ISP meeting as well as quarterly review for my son. His home care providers also attend. | 12/2/2013 3:21 PM |
| 61 | It takes a very long turn around time to receive a response. | 12/2/2013 1:57 PM |
| 62 | Local Gateways helps take care of all of that | 12/2/2013 12:42 PM |
| 63 | Service availability and satisfaction vary by population type. | 12/2/2013 12:25 PM |
| 64 | There have been times when you feel like the service providers are working against you and you never get resolution. | 12/2/2013 11:58 AM |
| 65 | No response from individuals that are supposed to be helping These programs are supposed to be client driven, but I find the services are at the convenience of the agencies and the workers involved | 12/2/2013 10:36 AM |
| 66 | one was very helpful a other one was not very helpful. | 11/30/2013 1:18 PM |
| 67 | This was done when my child was using Early Supports and Services. This is not currently done in our situation. | 11/29/2013 4:03 PM |
| 68 | Even though I prefer the current area agency system, it is not funded sufficiently. My daughter regressed for 10 years because her capacity for self-care was over-estimated. She finally went into two crises before being considered for a home-provider. | 11/29/2013 11:18 AM |
| 69 | Would like to meet more than once per year. | 11/28/2013 8:24 PM |

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| 70 | The Winnisquam School District did not do its job in preparing my daughter for transition from high school. The IEP team was not anxious to recognize the extent of her disability and services while she was in high school were marginal. Our experience with Lakes Region Community services has restored our faith that our daughter's needs can be met and exceeded. | 11/28/2013 2:34 PM |
| 71 | The Area Agency system is the best because it is governed by its users - people with disabilities and family members. | 11/27/2013 10:50 PM |
| 72 | My experience is school-based around developing and implementing my son's IEP. All of the players work on site and are expected to show up at these meetings. I don't know how realistic it is to expect that all team members (especially doctors and mental health professionals who are already taxed and receiving low reimbursement rates) are going to be able to participate in such team meetings. | 11/27/2013 8:58 AM |
| 73 | Some have been extremely helpful and others extremely difficult. | 11/26/2013 11:53 AM |
| 74 | The program that we have developed is very good - the frustration arrives when people interpret the rules as requiring that there be a change in a program - even when the program and individual do not wish to have a change. | 11/26/2013 10:50 AM |
| 75 | Providers are still based in a medical model rather than person centered too much of the time | 11/26/2013 9:37 AM |
| 76 | School program | 11/25/2013 3:26 PM |
| 77 | The private providers are great but the community bridges staff are very difficult to deal with. | 11/25/2013 1:59 PM |
| 78 | Our first meeting will be in Dec. | 11/25/2013 12:39 PM |
| 79 | Team members from the area agency hesitant to place people on the wait list for services, even when family, guardian, and other team members feel increase in services are required. | 11/25/2013 11:08 AM |
| 80 | School and direct support providers are awesome and invaluable and do not cost additional funds for the input. The area agency, which takes funds away from the recipient is a nightmare to deal with. They do not add value to the process. | 11/25/2013 10:44 AM |
| 81 | After ten years of struggling to secure the right supports, the area agency proposed that our family implement 525 supports. We combine AA services with Home Health Services. This combination of supports has benefited my sister because her quality of life has two-folded and our family can still function with our day-to-day needs. | 11/25/2013 9:37 AM |
| 82 | The Area agencies service agents/case coordinators are very helpful... as much as they can be. They can't provide anything beyond what the NH legislature has allocated in the budget. So again I think this question is somewhat inappropriate. You are somewhat leading uninformed folks to come to the conclusion that if they don't have adequate supports and services that the area agency is at blame. If folks say they have a constant battle it doesn't necessarily mean it's the area agency's doing. | 11/25/2013 9:12 AM |
| 83 | i believe the service providers are profit centers and do not invest and provide the necessary training for their staff. As well, i believe the state could take on the service delivery, make it a state job, and save millions of dollars. | 11/25/2013 9:00 AM |
| 84 | It was a pilot project through Hood House. We had one meeting and the funding was pulled, so nothing ever came of it. I was very discouraging, because it required a bit of prep work on my part and then it stopped without ever starting. | 11/24/2013 2:41 PM |
| 85 | area agencies are very helpful in helping to explain services, find resources and information and help set goals for clients. they are aware of changes and share information to families. | 11/24/2013 1:25 PM |
| 86 | I need to be involved a lot because the BCBA doesn't get enough covered service hours to help oversee all the programs. We get 10 hours of ABA a week and she comes 1 hour | 11/24/2013 10:02 AM |
| 87 | First, it is difficult to get these teams to meet and for them function well all the representatives/providers (including school and health care) should be present. But there is no way to reimburse many of these providers for their time if they are willing to participate in such a team, thus their input is usually not available. Second, the teams only work if the consumer or consumer's caretaker comes to the table with a good understanding of the needs that exist and the services that are available and is capable of advocating for themselves. It also helps if the consumer/caretaker is able to "think outside the box" in order to creatively design services to meet complex multiple needs. I fear that too often consumers and their families are unable to do this for themselves and fall victim to a "rigid" matching of services to needs in an inflexible manner - sort of taking of taking "square peg" needs and shoving them into "round hole" services. That doesn't work. Sometime existing services need to be re-interpreted or their design needs to be tweaked to meet the individual needs of a consumer with multiple complex disabilities. | 11/24/2013 8:02 AM |
| 88 | Area agency extremely helpful in working with us on goals and providers. | 11/24/2013 8:01 AM |

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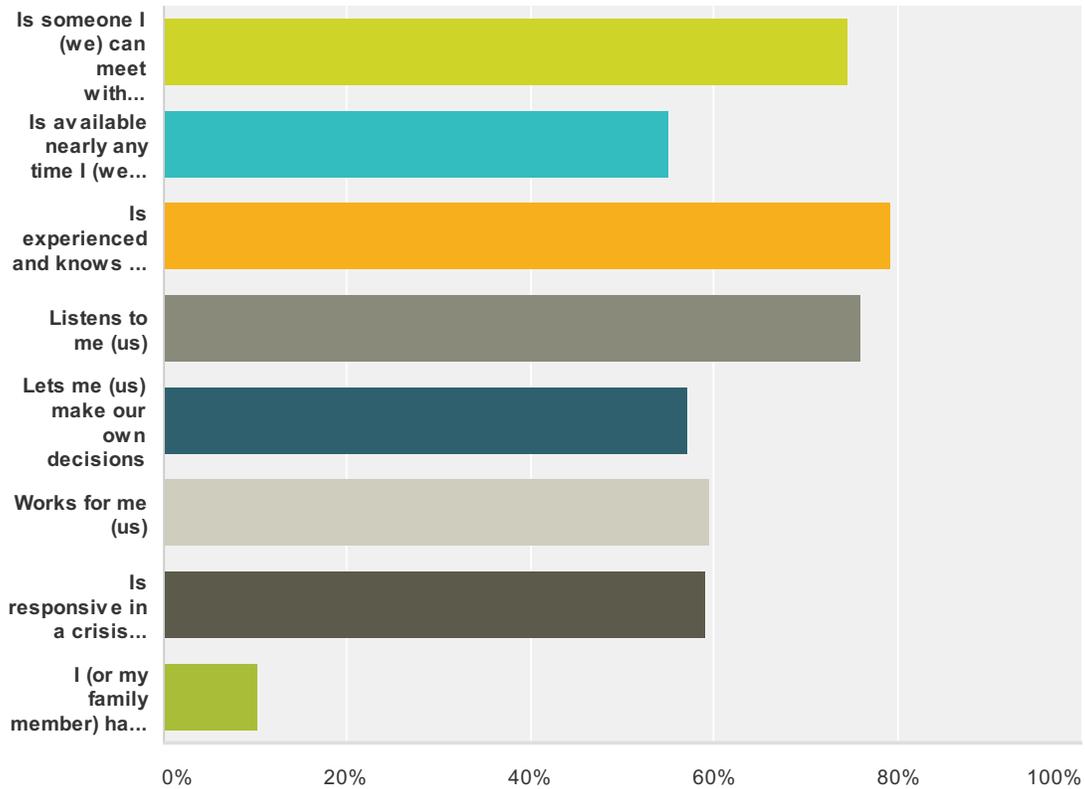
| | | |
|-----|---|---------------------|
| 89 | Community Partners has been a tremendous resource | 11/23/2013 10:24 PM |
| 90 | Gateways staff are very dedicated and caring individuals and is a wonderful organization. I just think that their overhead rates and percentages should match the services they provide to each client individually. When you have a parent who is hiring, preparing payroll and quarterly reports their budget should not be charged the same overhead rate as a client that Gateways is doing all of this work for! | 11/23/2013 9:51 PM |
| 91 | My brother has that service. I have only been to two meetings and they were helpful. But my mother has done most of this and I don't know her feelings. I think they are generally positive. | 11/23/2013 10:54 AM |
| 92 | But they say not enough money for what I need. A tech said I shouldn't use FC. That's not ok. I use it a lot. | 11/23/2013 8:40 AM |
| 93 | Only issues I run in to is when my son needs something that is not support by BDS, like dental. | 11/23/2013 8:03 AM |
| 94 | Angel has been wonderful to deal with and I don't know where I would be without her. When she says she will look into or do something she does it. Not enough people take pride and show so much compassion as this wonderful person. | 11/23/2013 7:48 AM |
| 95 | We have the special medical services with Katie Lajoie and she has been wonderful in helping us navigate through the system | 11/23/2013 4:31 AM |
| 96 | In my experience, these teams meet and say lots of things about what they are doing but spend little to no time listening to the concerns of the individual or family. It ends up being a reporting time instead of a person centered session. The focus should be, "what can we do to make this person's life better, " and not - this is what I am doing and this is what the individual did. These meetings need to be a dialogue. The family and individual need to be listened to. If they say - I need more hours or a ride to church or anything like that, then that should be the focus. Make this process individual-centric. | 11/22/2013 10:14 PM |
| 97 | The people I deal with are very helpful and receptive to any concerns and we all try to come up with ideas and possible solutions. They always will call back and talk with me at any time I feel the need. | 11/22/2013 10:02 PM |
| 98 | The team of professionals we work with for our son has been exceptional. | 11/22/2013 6:43 PM |
| 99 | These teams were always associated with school. Now we have a rep from Community Bridges that meets with us periodically. She has been helpful in brainstorming when we needed something. | 11/22/2013 6:30 PM |
| 100 | Most of our direct providers are fine. Some of the companies the state has contracted to (such as Schaller-Anderson) employed extremely obnoxious personnel who were rude and hostile during evaluations. | 11/22/2013 5:27 PM |
| 101 | My sister's resource coordinator assists the family by advocating for my sister and, along with or in the absence of family members, helping my sister make wise decisions so she can maintain a safe, independent life. | 11/22/2013 3:39 PM |
| 102 | I checked off Somewhat helpful, but it's a tie between that and a Constant Battle. There is no where near enough help for families. It's all about giving support and money to paid home providers and that is just wrong. | 11/22/2013 3:27 PM |
| 103 | The case manager from our area agency is a great help but some of those who work with my daughter do not follow through with plans or cite money as an impediment. | 11/22/2013 2:44 PM |
| 104 | Daughters IEP mtgs | 11/22/2013 2:39 PM |
| 105 | Meetings are not well facilitated, it is about meeting the regulation process of completing a service agreement. Meetings are generally not creative due to the process. Most of the time as a family we manage what needs to be done and use the 'professional' sources for education on what the regulations say we can and cannot do with the Medicaid funding. | 11/22/2013 2:07 PM |
| 106 | It is a constant battle that wears you down and burns you out. So many more family's could do and would do a better job if things were set up to help everyone equally. When you find out years later that there was something that could have helped out and no one told you about it is a set up for failure. We don't really want to be burdens on the system, but I've know many families that have gotten so frustrated trying to be honest or work hard and end up losing benefits or not getting them at all and see others that do things the "other way" and get everything they need and more. | 11/22/2013 2:06 PM |
| 107 | Teams vary in their effectiveness. | 11/22/2013 1:48 PM |
| 108 | My experience has been with school teams that are supplemented by medical, VR, and human services providers. Generally, the problems have been: (1) Lack of respect/trust among professionals from different systems; (2) Tention over who will pay for what. Also, I am a strong advocate, but I wonder what happens to parents who are less well informed. They are at a significant disadvantage and there are really no affordable advocacy services in NH -- Even PIC charges parents. | 11/22/2013 1:17 PM |

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| 109 | My son's service providers are very helpful. However, sometimes it seems hard to find a plan that will improve his long term outcome to meet the goals that are reimburseable through Medicaid. For example, due to autism he is in need of significant community services to get him to learn to deal with others, read social cues, engage in social activities, etc., but some of the suggestions I have made are not reimburseable though Medicaid. Such services are necessary for these young adults as they learn to maneuver independent life and move forward. | 11/22/2013 11:41 AM |
| 110 | See earlier comment. Also, Gateways actively encourages and promotes programs, vendors and service organizations in the community so that there are lots of choices and opportunities for people with disabilities to find activities and social groups that are suited to their interests. That encouragement is as important as developing an individual program to take advantage of those opportunities. | 11/22/2013 11:26 AM |
| 111 | I value the in-person, face-to-face interactions and support we receive to help in planning, problem-solving and implementation. | 11/22/2013 11:23 AM |
| 112 | Truth, someone like myself who works with individuals 24 hrs ,365 days ..knows their needs more than someone who sees them once and awhile. The saying ...To "Many Hands In One Pot".. is a given. I am their best advocate | 11/22/2013 11:17 AM |
| 113 | The people have been very helpful in trying to obtain appropriate supports, however, are sometimes limited because something is not covered through Medicaid. The two things that I have been desperate for is 1. A service dog that would alert me when my son elopes in the middle of the night 2. A cabinet that has locks on the doors and drawers as recommended by his behaviorist. Neither is reimbursable - they don't reimburse for service dogs or "furniture". Both of these things would be an incredible relief to me - especially as a single mother because I just can't be one-on-one 24/7. | 11/22/2013 11:17 AM |
| 114 | Certain past experiences have been very unprofessional. | 11/22/2013 11:11 AM |
| 115 | Comunity Bridges has been great! | 11/22/2013 10:57 AM |
| 116 | Having the option to self-direct or family-direct is the reason the team and supports work. | 11/22/2013 10:24 AM |
| 117 | My grandson has been MR all his life, including bipolar, ADHD, back curvature and Alcohol and drug fedal syndrome. He has seen doctors and had meds all his life. Now the guy at Riverbend say he is only ADHD and age 19 which they do not treat. | 11/22/2013 10:24 AM |
| 118 | Our current area agency is extremely helpful. We selected our current area agency after having a very bad experiences with our local area agency. Having this choice is vital and more families need to be aware they have this choice. With any change to NH's long term care system, I fear this choice will be lost and this is a very bad thing. | 11/22/2013 10:19 AM |
| 119 | the team is always suggesting generic suggestions. Over time these have been tried. With the large tum over, much time is spent with these individuals just getting acquainted with the client | 11/22/2013 10:18 AM |
| 120 | Some providers are so invested in maintaining the status quo its difficult for them to see "outside the box" when it comes to service choices. | 11/22/2013 10:11 AM |
| 121 | always needing to keep up on them so the job gets done | 11/22/2013 9:47 AM |

Q15 If you have had experience with a case manager, service coordinator, or someone who serves in that role, what is important to you about that person's ability to help you meet your needs?

Answered: 563 Skipped: 329



| Answer Choices | Responses |
|---|------------|
| Is someone I (we) can meet with face-to-face | 74.42% 419 |
| Is available nearly any time I (we) need him or her | 55.06% 310 |
| Is experienced and knows how the system works | 79.04% 445 |
| Listens to me (us) | 75.84% 427 |
| Lets me (us) make our own decisions | 57.02% 321 |
| Works for me (us) | 59.33% 334 |
| Is responsive in a crisis situation | 58.97% 332 |
| I (or my family member) has never had a case manager or service coordinator | 10.30% 58 |
| Total Respondents: 563 | |

| # | You are welcome to comment if you would like | Date |
|---|---|--------------------|
| 1 | Every case worker has sounded encouraging but nothing happens as a result of their visit. | 12/9/2013 12:34 PM |
| 2 | Great Bay is a wonderful place it is to bad they and one sky can't work together | 12/8/2013 5:02 PM |
| 3 | I like not having my service coordinator change every year. I like Tanya. | 12/8/2013 11:08 AM |

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| 4 | Can't say. Case manager did not return call | 12/8/2013 6:21 AM |
| 5 | I worry that my disabled child will need a case manager when I can no longer fill that role. I don't know how my child would qualify for one or how to go about getting one. | 12/7/2013 11:52 AM |
| 6 | My sister's case managers from Great Bay Services have been very helpful in meeting when needed and knowing (and understanding) the system and my sister's needs. | 12/7/2013 10:40 AM |
| 7 | Having someone who is knowledgeable and readily available in a crisis situation has been invaluable, not just to my daughter but to our whole family. These dedicated professionals have stepped in, not taken over and have provided us with peace of mind during these exceptionally trying times. | 12/6/2013 11:02 PM |
| 8 | Our son's case manager is excellent - knowledgeable, accessible, helpful and professional. The only complaint is that he, or another person, is may not be available when a crisis develops, ie. nights, weekends, & holidays, in particular. | 12/6/2013 4:30 PM |
| 9 | Our family member receives great care. It is a tragedy that many individuals with mental illness and their families cannot afford the services needed to restore and maintain their health. | 12/6/2013 2:35 PM |
| 10 | A attentive case manager can make all the difference, from what I hear from other families in my support group. Or they can be a total zero or perceived as controlling by the mentally ill person. | 12/6/2013 12:18 PM |
| 11 | I would want the coordinator to offer all these all of the above. | 12/6/2013 11:55 AM |
| 12 | My son needed a case manager but didn't access services due to the stigma and the complex nature of the system. Because he was an adult it was difficult for us to help him. | 12/6/2013 11:34 AM |
| 13 | Family members have reported that trust and confidence in the case manager is very important. All of these selections would apparently be significant traits and relationship components with a case manager. | 12/6/2013 11:28 AM |
| 14 | these are all important qualities! | 12/6/2013 11:27 AM |
| 15 | We have been blessed to work with some wonderful individuals affiliated with the Moore Center, I don't know where we would be without them. Melissa Jarvis our current contact is outstanding, she has been a wonderful, caring and supportive advocate for my brother Jamie and an incredible resource for our family. This is a vital service that needs to be sustained. | 12/6/2013 9:52 AM |
| 16 | and that they can think out of the box, rather than put me in a circle where I am back where I started with the first person, not having my problem solved or even connected to someone willing to solve it with out of the box, or rather circle, thinking.. | 12/6/2013 9:38 AM |
| 17 | I find this to be a very beneficial service and helps to complete the home/services gap. | 12/6/2013 9:37 AM |
| 18 | all are important but these 3 areas stand out as highly important | 12/6/2013 9:34 AM |
| 19 | Our experience has been excellent with the case manager. | 12/6/2013 9:19 AM |
| 20 | If NH invests short term funding adequately we would save billions in long term costs | 12/6/2013 9:04 AM |
| 21 | Essential for successful home management of longterm need. | 12/6/2013 9:01 AM |
| 22 | I am a provider, not someone who utilizes long-term medicaid | 12/6/2013 8:59 AM |
| 23 | I believe service providers such as Case Managers provide essential functions for those requiring services and facilitate moving through various systems much easier than trying to do it on their own. Always more personal and provides a direct link of support often needed by the individual or their families. | 12/6/2013 8:04 AM |
| 24 | All the qualities listed are very needed! | 12/6/2013 7:36 AM |
| 25 | These are aspirational and not the reality of what we experienced | 12/5/2013 11:41 PM |
| 26 | The case manager is the most important service provider my loved one has. | 12/5/2013 11:02 PM |
| 27 | I have had a case manager for over twenty years. Having a responsive treatment team helped me be able to raise a daughter as a single parent despite having a serious mental illness. | 12/5/2013 10:41 PM |
| 28 | Is some one who can be creative, think "outside of the box", is knowledgeable regarding resources, will have direct contact with family and individual, oversees the individuals' services provided, for quality assurance, helps the individual and family/care-giver to apply for necessary services, coordinates services, refers, assists, supports, communicates with all team members, assists to develop a plan, writes service agreements specific to the individuals needs, knows the individual and his/her needs, assists in identifying the individuals' needs, follows through and follows up. I'm sure that there is much more that our case manager does, aside for the aforementioned and the checked off. We would be lost without her ! | 12/5/2013 9:59 PM |

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| 29 | We are truly great full for the person who supports us. I have no idea what I would have done the past 19 years. | 12/5/2013 8:19 PM |
| 30 | Imperative - Having the client, mental health providers, AND guardians/family members all be considered valuable parts of the "treatment team". I have been told by my son's doctor that my husband nor I (we are also legal guardians), that we are not part of the treatment team. Very insulting in my humble opinion. We should all be working together in support of the client/family member. Not in a confrontational manner. | 12/5/2013 8:19 PM |
| 31 | most are new to the system and have limited education or experiences for case management | 12/5/2013 6:57 PM |
| 32 | Supportive, educated families should be a part of a successful treatment team. Hipaa should not be mis used as a barrier. Supportive family members can help alleviate a burdened provider community. | 12/5/2013 6:32 PM |
| 33 | This sounds like a good thing. It has been brought up several times, but never comes to fruition. Maybe because case managers caseloads are overloaded. | 12/5/2013 6:29 PM |
| 34 | The current case manager suggested to my daughter that if her medication management through the community mental health center was inadequate she could always go to the hospital for a tune up. | 12/5/2013 6:19 PM |
| 35 | It's not enough for a case manager to mean well. They need to know a lot and be creative problem solvers with the maturity to advocate for those in need. | 12/5/2013 6:16 PM |
| 36 | It's important that a case manager see the "big picture" -- the different aspects of the person's life, and all the different service providers involved -- and stay on top of it as things change. | 12/5/2013 5:54 PM |
| 37 | it's awful when they leave and you get a new one | 12/5/2013 5:36 PM |
| 38 | The only coordinator we have had has been through our Agea Agency. They have been kind but not generally knowledgeable of how the system works. | 12/5/2013 1:43 PM |
| 39 | These services through the area agency work very well now. Please don't change the current system. | 12/4/2013 10:13 PM |
| 40 | I have been very lucky with my case workers. | 12/4/2013 9:14 PM |
| 41 | From 2007-2011, when I was a client at Riverbend, I had a case manager- actually, I had 5 different ones during that time. Other than Eric, my first case manager, the only purpose they served were: transportation, getting out of the house/socialization, someone to talk to. From 2011-2013, as a client at Manchester Mental Health, my therapist also served as my case manager. I had three therapist/case managers in 2 years and none of them did any case management- I did it all myself. | 12/4/2013 7:50 PM |
| 42 | I am the Guardian of a person and they don't return my calls, I would like to speak with a person not someones voice mail who doesn't return calls. | 12/4/2013 6:57 PM |
| 43 | knowledgeable in working with care givers in making realistic goals that meet the individuals needs and not what they (case manager) like or think would be fun for someone | 12/4/2013 3:02 PM |
| 44 | We have been able to meet with our case worked, but I don't feel that our current worker really listens or truly understands the need for services to be regular. I feel that I depend on my family member's services so that I can go to work on a regular basis and keep a roof over our heads, food on the table, and the car in operable condition. When I have already worked a 50 hour week, I hate to have to call around for a respite worker because the regular person is unavailable, I believe that the case manager should have a list of subs that she can contact during a regular business day to cover for my family member. | 12/4/2013 2:27 PM |
| 45 | Our case manager/service provider during our daughter's school years was available to meet with her Pupil Placement Team each month. The result was an intimate knowledge of her programming and medical needs. She was involved in program development and transition and was present to guide us through the Medicaid process. The case manager directed the family through the transition process from elementary to high school to post graduate phases of her life seamlessly and without negative incident. As she left the school and entered the SDS Program, the case manager overlapped services with the new case manager in charge of SDS Programs to assure as little disruption as possible. Because of these efforts, our daughter's life was not disrupted and she received the continuous care she needed. | 12/4/2013 1:35 PM |
| 46 | Is inexperienced and never has an answer right away, having to ask someone else for answers. Poor quality case manager! | 12/4/2013 12:49 PM |
| 47 | Have a QUALIFIED and CONSISTENT case manager. We were tossed around to different case managers every few years (not because they left the agency) before consumer directed care. | 12/4/2013 11:52 AM |

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| 48 | pathways 603-542-8706 case mgr Kaitlyn Mack is the best because she is organized and goal oriented. She responds to each issue I bring up in a methodical way. Jody fennessey there is running the Stars eval team -we went to UMass team Jody is very good at making things happen. very happy - can be difficult jumping through all the State hoops to get her the help she needs. | 12/4/2013 9:43 AM |
| 49 | Any service provider we have spoken to has been very helpful and has been very reassuring that help is there should we need it. | 12/4/2013 9:42 AM |
| 50 | Jade is exceptional in all of the above categories. | 12/4/2013 8:43 AM |
| 51 | Our Service Coordinator is extremely interested in our input and is willing to enact steps to meet our mutual goals. | 12/4/2013 2:14 AM |
| 52 | Again, the frequent turnover and inexperience of case managers makes progress difficult. | 12/3/2013 11:17 PM |
| 53 | I have always had outstanding case managers, but I believe that the time is coming when some families will be more knowledgeable about our system... and great for them, but for those who do NOT understand... those staff with the most knowledge will leave or lack of financial compensation, politics, being bumed out, or all three. Jan Larsen has yet to be replaced! | 12/3/2013 8:44 PM |
| 54 | Our current case worker, Lisa, gets back to us quickly and is always looking for ways she can help us. I'm not sure that there could be a better connection for our situation. My only frustration with the Moore Center in case worker regard is that we have had several... so we hope we can keep Lisa for a good long while. | 12/3/2013 4:25 PM |
| 55 | I assume case manager is like a resource coordinator. It seems to me that a lot of time is spent on few individuals who don't have adequate services, and the resource coordinator acts like a fill-in. Then others who manage ok, or don't complain, don't get the attention they need or want from the resource coordinator. Definitely good people and experienced, but overwhelmed with paper work and a few very needy individuals. | 12/3/2013 4:02 PM |
| 56 | Gateways case managers and service coordinators I experienced were poorly informed, appeared to be poorly educated, and were more concerned with pleasing their bosses rather than with giving their clients the attention they dearly require and doing the job which Medicaid expects them to do. Gateways employees represent an "us against them" system where Medicaid clients have to please and flatter the Gateways "gatekeepers of funds" to get what they need. The entire disability care system would better served, much more efficient, and considerably less expensive were Gateways and similar area agencies simply and immediately cut off from the process and a knowledgeable and professional organization such as Blue Cross/Blue Shield hired to administer Medicaid funding. | 12/3/2013 12:49 PM |
| 57 | Most of the above. Listens to our concerns and incorporates into the plan developed. Helped me extensively with Social Security and setting up Special Needs Trusts the right way. Decisions are made by both parties in the best interest of our clients. We have a case manager and a service coordinator who I can call anytime I have questions or concerns | 12/3/2013 11:50 AM |
| 58 | It is important to have a person in this role help us navigate through the system(s). I want this person to tell us what they would advise for their own loved one (I.e., put themselves in our shoes). | 12/3/2013 11:04 AM |
| 59 | Case manager from Community Bridges is wonderful. Case management at Crotched as much to be desired. | 12/3/2013 9:43 AM |
| 60 | Works for OR with us to achieve goals and to help with establishing those goals | 12/3/2013 9:24 AM |
| 61 | I am a case manager/service coordinator | 12/3/2013 9:11 AM |
| 62 | Face to face is not necessary on a daily, or even weekly basis, but the ability to do so when needed is preferable. Daily/weekly correspondence via e-mail is VERY important, especially for that person to help me remember when things need to get done. | 12/3/2013 9:06 AM |
| 63 | I often times struggle with timeframes in which our case mgr is able to get back to me with information requested. Often times the issue is that he/she is dependent on gathering information from others withing the DHHS/Medicaid/State systems and the lack of communication and lack of shared knowledge between all of these "players" makes it very difficult to move something forward! | 12/3/2013 9:01 AM |
| 64 | meet with coordinator 1 or 2 times since assigned. Not sure what services they can provide or assist with | 12/2/2013 8:19 PM |
| 65 | People want to be listened and understood in their efforts to be a productive community member. | 12/2/2013 4:26 PM |
| 66 | The individual should listen and get to know the patient and the patient's need. The individual must do what they say they are going to do and not just say all the right words and fill out the paper work to satisfy State requirements. The paper works is the tail, that wags the dog. | 12/2/2013 4:22 PM |
| 67 | The Area Agency is very responsive, helpful and efficient. | 12/2/2013 2:07 PM |

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| 68 | I am the case manager. | 12/2/2013 1:58 PM |
| 69 | We have had service coordinators that are useless and do not take their jobs very seriously. If we call with a concern about how our son is being treated or how something can be funded we expect at least a phone call back in a timely manner. I know that they are supposed to make quarterly visits to my son's program that doesn't happen with any regularity. | 12/2/2013 12:02 PM |
| 70 | There are case managers who refuse to meet w/their clients other than what is required by the CFI program. There are many case managers who only provide a medical model of social work and do not provide holistic and comprehensive case management. | 12/2/2013 10:39 AM |
| 71 | We have a Service Coordinator in our IHS program but it isn't a team. We do have an IEP team at my son's school. | 12/2/2013 9:04 AM |
| 72 | This works! | 11/29/2013 6:12 PM |
| 73 | Someone who is good at communicating. Someone who works on any and all issues that arise. They need people and dollar resources to help make things work. Nothing is worse than someone that is unresponsive. | 11/29/2013 6:03 PM |
| 74 | Lakes Region Community Services has case managers that go the extra mile to ensure that my daughter is reaching her potential in a supported atmosphere. | 11/28/2013 2:35 PM |
| 75 | I can reach our case manager or the agency CEO any time of day or night and they are available - going above and beyond if there's a crisis. We have their cell numbers. The MCOs will be reachable via a call center M-F, 9-5. We won't be able to reach the CEO of Centene on a weekend! (or ever) | 11/27/2013 10:53 PM |
| 76 | As a service provider, I believe the level of quality & responsiveness of service coordinators is high. Our families tell me they have a high degree of satisfaction. | 11/27/2013 11:17 AM |
| 77 | Keep up the good work! | 11/27/2013 8:36 AM |
| 78 | Not very experienced but tries very hard and is under paid for the work he does | 11/26/2013 12:18 PM |
| 79 | Our service coordinator for our daughter knows her as well as we do and is therefore very effective in helping us with all aspects of her program. | 11/26/2013 11:26 AM |
| 80 | Helps us make difficult decisions and gives us options | 11/26/2013 10:27 AM |
| 81 | My experience has been that my community bridges case manager is not knowledgeable in the area of autism treatment for young children. | 11/26/2013 6:32 AM |
| 82 | I wish we we didn't have a case manager shes awful. | 11/25/2013 2:00 PM |
| 83 | Empathy to what we family members (who are doing all of the work supporting our adult child) go through, and being non-judgemental. | 11/25/2013 1:45 PM |
| 84 | I am extremely pleased with Community Bridges and our case manager....even the receptionist who answers the phone is pleasant and helpful. The same goes for the people at Voc Rehab. | 11/25/2013 12:41 PM |
| 85 | I do not believe I need this person. I am able to coordinate my son's care without a middle man. If I need help there are plenty of volunteer advocates and non profits that are willing to help. In addition, his school team is an excellent resource. | 11/25/2013 10:45 AM |
| 86 | Through the area agency system my sister had about five service coordinators in a ten year period. Most recently, she was matched with a service coordinator which is proven to be a good match. | 11/25/2013 9:40 AM |
| 87 | For this question it would have been helpful to define 'case manager/service coordinator' for the respondents. I interpreted it as the person from my area agency who sits down with me to develop my daughter's budget and goals... the main point of contact. I know that the commissioner and other representatives from DHHS have played up the concept of a 'care coordinator/manager' in the July 2012 informational sessions. I asked Nancy Rollins specifically about how many folks are expected to receive a care coordinator/manager and she emailed me back, "From DHHS past experience with a pilot, it was found that 5-10% of the consumer population would need more active outreach and activity in order to assure access to care and quality health outcomes. Thus there is a role for a care manager." That's a very low percentage. As a mom I currently do that and envision filling this role until I am no longer able. This is certainly a valuable and needed service for an individual who doesn't have a family member who can take that role. So instead of changing the system we should be thinking about how we can implant that in our high-quality current system. | 11/25/2013 9:28 AM |
| 88 | Every individual at Community Partners has understood my son's needs from age 3 until present (age 21). | 11/25/2013 9:01 AM |
| 89 | helps me see that sometimes my own decisions are not the best and is able to work with me to help me understand the best decisions | 11/24/2013 7:27 PM |

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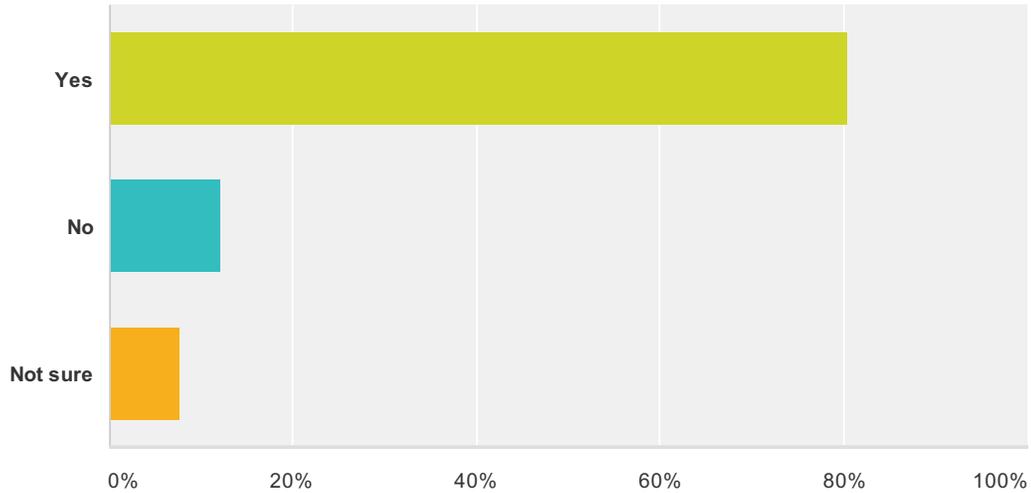
| | | |
|-----|---|---------------------|
| 90 | nobody contacts us - it is up to me to keep advocating for my family member - very frustrating | 11/24/2013 6:47 PM |
| 91 | I am not sure if the region services (One Sky) applies to this. | 11/24/2013 1:52 PM |
| 92 | Our service coordinator has been very helpful and has some experience. I like the fact that if she does not know the answer to our questions, she can get them from others in her office. | 11/24/2013 1:30 PM |
| 93 | case managers are crucial in providing much needed support, information and services to families. They are important in helping to knit the plans and services to families on a state and federal level. | 11/24/2013 1:26 PM |
| 94 | Most important they are experienced with services delivered across the spectrum - we have multiple "case managers" (4 at present - but have had more in the past) all working in different State or publicly funded agencies. Yet, it is a private therapist who we rely upon most for "case management" because she is the only one who will consistently make herself available to contact, communicate with and attend meetings with other providers. Yet, since this is not considered "therapy" services so we have to private pay for her to do this. To the credit of many of the providers - at least the schools, they have observed the value in this and have opted to contract with her at the beginning of each school year to provide training and consultation services to their staff who work with our child. A true case manager has to be willing to manage services from a variety of different providers and across many different silos. Even with the support of our child's therapist, I average 4-10 hours per week providing case management services for our child, sometimes even more when she is in crisis. This is time taken away from providing direct care and meeting the needs of other family members. | 11/24/2013 8:12 AM |
| 95 | Community partners has been crucial in supporting my sons needs in a very personal way. I can call anytime and will get a prompt call back. I have worked with many people there who have been there since my son was 3. This is important to work with consistency in staff and really know your child/adult. They know me and my son very well. This is important in a relationship you need in a situation like ours. They have been helpful more than I could put into words. | 11/24/2013 8:05 AM |
| 96 | Understands the complexities, speaks to you with compassion and understanding, is responsive to emails/calls, advocates on your behalf when needed. | 11/23/2013 10:25 PM |
| 97 | Consistency with your service coordinator. There is a high turnover rate. | 11/23/2013 9:53 PM |
| 98 | na | 11/23/2013 4:18 PM |
| 99 | The one I got last year is changing again. I hate that | 11/23/2013 8:40 AM |
| 100 | Our CM is very responsive to our needs. We know we have the right to choose a CM, we have had the same CM for the past 9 years. | 11/23/2013 8:05 AM |
| 101 | Angel works miracles...for us | 11/23/2013 7:49 AM |
| 102 | We did have some care coordination, and I do have an advocate to help me, but right now the focus is mainly about school. | 11/23/2013 7:42 AM |
| 103 | The case manager must have experience with the population or some type of personal involvement - otherwise there is no credibility. The case manager must do better than just using the yellow pages and saying "oh, try this place and that." The case manager needs to have a relationship with providers in the area. | 11/22/2013 10:18 PM |
| 104 | These answers are relating to our Resource Coordinator at our Area Agency that is assigned to us. | 11/22/2013 10:04 PM |
| 105 | This person also must have empathy for the client. | 11/22/2013 6:44 PM |
| 106 | Other than turnover of personnel all these things do happen now. | 11/22/2013 6:15 PM |
| 107 | Comments from families I work with | 11/22/2013 5:53 PM |
| 108 | Person needs to be understanding, intelligent and available. | 11/22/2013 5:15 PM |
| 109 | Service facilitators change far too often. | 11/22/2013 3:37 PM |
| 110 | Often I feel like I have to train new case managers who lack experience. I don't believe I have had a case manager for more than a two year period. They often move on due to the low wages and burnout from workload. Therefore, they often don't have the expertise to help me with a problem. | 11/22/2013 2:54 PM |
| 111 | Theres not a lot to do in our family as Daughter is only 16 and theres only respite available | 11/22/2013 2:48 PM |

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| 112 | I thing LTSS needs more than the traditional Case Manager approach. They get so focused on regulations they often lose site of how to involve community members in supports. It is not all about more money and more programs. Being able to pay a neighbor, without having to put them on payroll for providing transportation would be a good thing but not often thought about or suggested due to the Medicaid regulations. Services therefore end up costing more, Being able to use Medicaid funds to by a gas card every now and then to say thank you is a lot more cost effective that builing an hourly wage for someone to provide transportation. Service Coordinators often don't think beyond programs. Some do but they are rare. | 11/22/2013 2:12 PM |
| 113 | My experience is if I have had a good case manager who goes the extra mile or actually supports the family, that is frequently not looked upon favorably by the AA. | 11/22/2013 2:09 PM |
| 114 | We have had several case managers they were completely useless in every sense of the word. It is a giant waste of money. There is no difference between the general account management and service coordination and I hate that I have to spend half of my daughters budget on those two services. | 11/22/2013 1:47 PM |
| 115 | None of these fit my experiences. I have a case manger who is unwilling to advocate for my child needs. She feels her job is to make me do as the day provider wants even when they refuse to comply with the contract that they were hired to do. | 11/22/2013 1:44 PM |
| 116 | It has always bothered me that I have to pay for case management out of my son's waiver money (CIHS Waiver). I do the vast majority of care coordination myself. | 11/22/2013 1:18 PM |
| 117 | I am dysarthric, ataxic, and use a wheelchair. I am 49 and on CFI, Medicaid has been very good to me. | 11/22/2013 11:47 AM |
| 118 | Kendra is fabulous! | 11/22/2013 11:39 AM |
| 119 | Never had a crisis, fortunately. | 11/22/2013 11:26 AM |
| 120 | This has historically been a high turnover position maybe due to having too many people on their caseloads. This position is very helpful in accessing benefits and maybe facilitating meetings that can arrive at person centered thinking, planning and action. Again, historically not all service coordinators are up on best practices of supporting people in the community and can do more harm than good. Sometimes they become agents of the agencies and not for the people they serve. Who is paying them? That is where their allegiance stands. | 11/22/2013 11:23 AM |
| 121 | Having experience in the System can be helpful ..however knowing the person .is the most important factor . | 11/22/2013 11:20 AM |
| 122 | Is available to attend IEP meetings for support for me as well as offering options that the IEP team may not be aware of that could be coordinated by the area agency. | 11/22/2013 11:19 AM |
| 123 | We love our cars manager | 11/22/2013 10:54 AM |
| 124 | It would be nice if they would tell us what programs are out there for this teen. Why is everything a secret or when you read about it it makes your head spin. Why do you have to wait to be 21 for adult day care to kick in. Where all the other rules in the world you are an adult at the age of 18. Why do you have to be disable for two year before you can be on Medicare?????. When you were born disabled | 11/22/2013 10:32 AM |
| 125 | You can never find anyone to help when needed. | 11/22/2013 10:27 AM |
| 126 | See Riverbend complaint. | 11/22/2013 10:25 AM |
| 127 | This group varies wildly. The Client needs to be able to shake loose of an case manager, etc. who is not compatable with them and the family | 11/22/2013 10:20 AM |
| 128 | is proactive with suggestions | 11/22/2013 10:20 AM |
| 129 | All the above pertains to our current area agency case manager. When we were with our local area agency, very little would have been checked off! | 11/22/2013 10:20 AM |
| 130 | knows what services are available. We did not know about certain Medicaid plans until we had accumulated a considerable amount of medical debt for our child and had to constantly choose between getting basic needs vs therapies that could change his life. | 11/22/2013 10:18 AM |
| 131 | Although all items on the list are important, for me the most import item on this lis is "Works for me (us). It seems to be difficult for some to relinquish authority to families. | 11/22/2013 10:11 AM |
| 132 | very frustrated at times and have good had to go up the ladder to get the results needed | 11/22/2013 9:48 AM |

Q16 Have you or your family member ever had a care plan or services plan (IEP, wrap around plan, service agreement, etc.) that outlines your goals and the services and supports that are needed to help accomplish them?

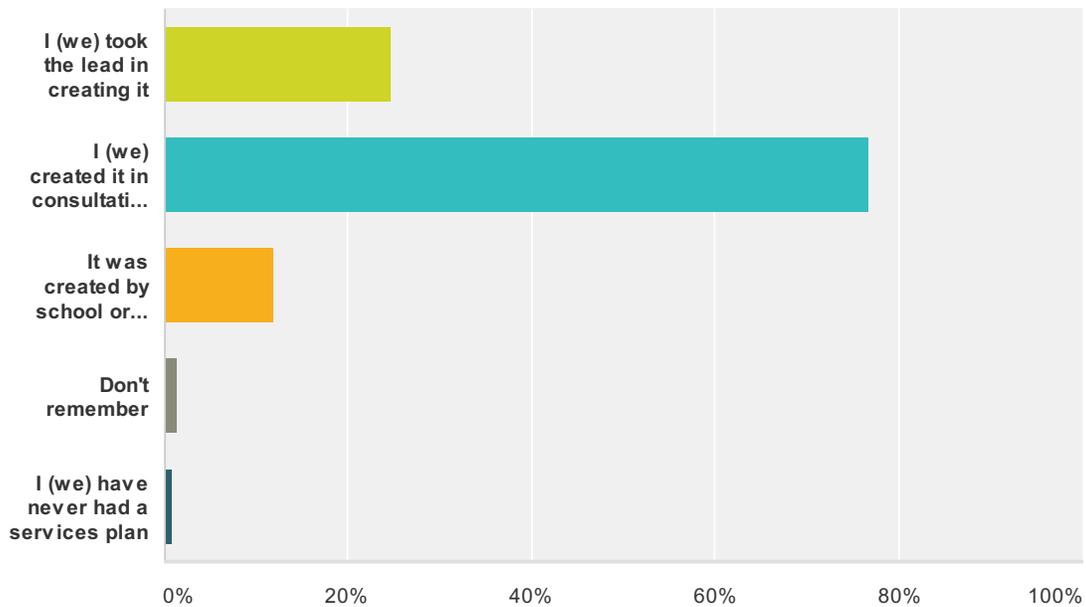
Answered: 586 Skipped: 306



| Answer Choices | Responses | Count |
|----------------|-----------|------------|
| Yes | 80.20% | 470 |
| No | 12.12% | 71 |
| Not sure | 7.68% | 45 |
| Total | | 586 |

Q17 If you or your family member have had, or currently have, a care or services plan, what was your role in developing it?

Answered: 463 Skipped: 429



| Answer Choices | Responses |
|--|------------|
| I (we) took the lead in creating it | 24.84% 115 |
| I (we) created it in consultation with school or agency staff members, a case manager or other professionals | 76.67% 355 |
| It was created by school or agency staff members, a case manager or other professionals and I (we) did not have much input into it | 11.88% 55 |
| Don't remember | 1.51% 7 |
| I (we) have never had a services plan | 0.86% 4 |
| Total Respondents: 463 | |

| # | Other (please specify) | Date |
|---|--|--------------------|
| 1 | once again One Sky and Great Bay do not play well in the sand box . and that makes it very hard for the families | 12/8/2013 5:04 PM |
| 2 | The ISA is created by the case manager from an annual meeting with my sister (client), 2 guardians, case manager, and other staff members working with my sister. | 12/7/2013 10:44 AM |
| 3 | While we enjoy the option of creating my daughter's service plan, it is very helpful to have the input of knowledgeable staff who make suggestions, which leads us to the best outcome. | 12/6/2013 11:05 PM |
| 4 | I worked with other care professionals to help the families develop a plan | 12/6/2013 2:09 PM |
| 5 | MEDICAL PROFESSION HAS BEEN INVOLVED | 12/6/2013 11:02 AM |
| 6 | Mostly, my case manager does not have enough time to really develop it much from the last time, although change does come slowly...and usually I am not told ahead of time enough to really have time to think about it...they come in and say it's time to do this and we do it on the spot...I rarely get a copy or time to check it out once it is written & signed.. | 12/6/2013 9:40 AM |

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| 7 | We had an IEP until my child turned 21 . He now receives services through my husband's social security as a disabled child, and also has Medicaid health insurance. He has a case manager through West Central Services. they manage his meds. He has been working with voc rehab but as yet only not had any employment opportunities through either. He lives with us currently. He is not able to live on his own at this time. He does not drive. He can stay alone but follows us around when we are home. I prepare his meds. He takes them himself, but I check to make sure he does. We are working with people that we know in the community and our family to get him out. He will go with me to run errands. He will not leave the house on his own. | 12/6/2013 9:37 AM |
| 8 | I did not have a role in developing it | 12/6/2013 9:35 AM |
| 9 | I believe the member requiring services should always be involved in the development of any service plan. | 12/6/2013 8:05 AM |
| 10 | School has been very hard to get on board to do anything to help our son. Multiple people have been involved but again it seems to feel like jumping through hoops to get the right things. | 12/6/2013 8:01 AM |
| 11 | We tried to have input but they didn't listen much | 12/5/2013 11:42 PM |
| 12 | It is created with the input from all team members, that includes the individual, family/guardian, providers, staff , vendors and case manager. Input prior to a meeting is requested, to expedite the actual service agreement and to address the needs and provisions necessary to best support the individual. Case manager coordinates to have all or the majority of the team members present at the meeting and to have their input, reminds to come prepared and might meet with the individual, and or various team members (family and/or guardian included) to assist in the individuals' input as services and or improvements needed. After the service Agreement meeting, Case manager writes the ISA, with every once input, presents it to guardian. It is then presented to guardian for correction, approval/or rejection. Usually it is approved or else team meets again and tries to reach an agreement to best serve the individual. It must be guardian approved. This is also followed up, by, Case manager, face-to-face meetings to assure service satisfaction, quality and delivery, as well as follow up progress on goals. This also allows case manager to determine if a change of/in services or level of service would be appropriate for the individual and more cost effective. Seeing and knowing the individual person, allows for better determination of needs the individual might have or progress that might have been made, determine the appropriateness of services and levels thereof necessary for the individual . | 12/5/2013 10:27 PM |
| 13 | Not mych input but are a significant role | 12/5/2013 10:13 PM |
| 14 | We had to work as a family to get the IEP correct since the school system's bigger interest was getting him out of the school not the quality of the education he received. Every child especially the children who need larger support systems should be able to have teams for them that actually care and do their job. Several IEP meeting we attended at the school only the case manager was there and none of the teachers. We as a family felt slighted by the fact that there is such little disregard for the student since there are too many students in the Nashua school system. There are too few teacher and too many students. It also took 3 meetings to get any sort of answers. | 12/5/2013 8:45 PM |
| 15 | Through out the whole process we fought and were never given all options available until threats of lawyers getting involved and it dragged on so long our son lost out and was damaged even more by this process. | 12/5/2013 8:02 PM |
| 16 | Not as many community programs for adults with mental health issues | 12/5/2013 7:37 PM |
| 17 | We were consulted, but it was created by a case manager. | 12/5/2013 5:55 PM |
| 18 | Not enough funding to have a complete plan | 12/5/2013 11:14 AM |
| 19 | It is an IEP for school | 12/5/2013 8:52 AM |
| 20 | It was created with the input of the whole team that is involved with my son. | 12/4/2013 3:10 PM |
| 21 | Although the plan is in place, it is not always followed. | 12/4/2013 2:28 PM |
| 22 | Throughout our daughter's life, we (family) has played a strong role in creating her programs, but with the support of and in consultation with other educational and medical professionals, including agency staff members. | 12/4/2013 1:38 PM |
| 23 | awesome team includes me and my daughter | 12/4/2013 9:44 AM |
| 24 | It was totally a "team" effort! | 12/4/2013 2:15 AM |
| 25 | Service plans do not always seem to reflect the vast array of services which are provided to assist the client with 24/7 services. but seem to be focus on more simple goals: it seems the interpretation of the guidelines is a new goal needs to be added to the care plan, where often times the activities of daily living are still a major challenge and very time consuming for the client and providers, particularly as my client ages or when there is an acute health issue. | 12/3/2013 9:48 PM |

NH Medicaid Long-Term-Care Program Survey

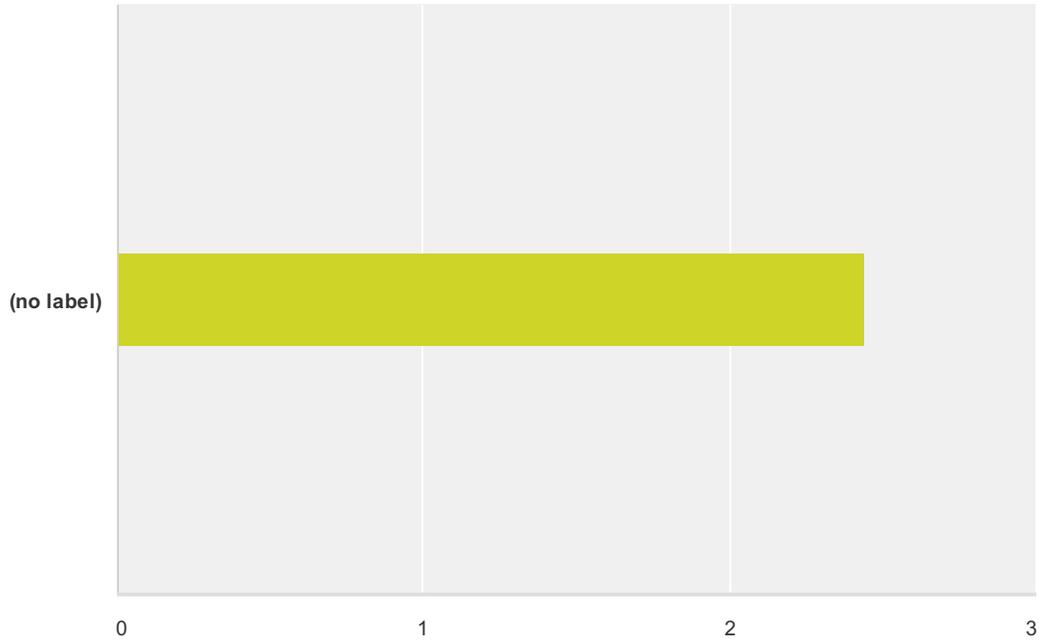
| | | |
|----|---|---------------------|
| 26 | I had all the ideas and the work situations set it was a matter of collaborating with the Moore Center to fund the program and to continue to manage it together. | 12/3/2013 4:27 PM |
| 27 | Specifically, it was made to appear in early meetings at Gateways that our family was the decision-making entity. However, when the final document was presented by Gateways, it represented wasteful, meaningless, and unnecessary services Gateways wanted rather the services and needs individually designed for the family. This was unlike our excellent experience with a local high school. | 12/3/2013 12:53 PM |
| 28 | Decisions were made by both in what would be in the best interests of our boys | 12/3/2013 11:51 AM |
| 29 | No options were presented to us. We were assigned services. When our child reached school age there was no choice. We were assigned to a 'behaviorist' who is contracted with many schools in the area. His services and knowledge are sorely inadequate | 12/3/2013 11:50 AM |
| 30 | Again, goals are frequently written to the requirements, rather than the actual wishes of the client. | 12/3/2013 10:41 AM |
| 31 | We develop service plans with the team approach | 12/3/2013 9:11 AM |
| 32 | It was created and then reviewed with us to change or modify if we wanted. It was presented to us | 12/3/2013 8:24 AM |
| 33 | With School for IEP multiple times a year as we drive the program with the school coordinators. | 12/2/2013 8:20 PM |
| 34 | I develop the ISA with the family and or individual receiving services | 12/2/2013 1:58 PM |
| 35 | Individual and family didn't have a strong voice in the process | 12/2/2013 1:57 PM |
| 36 | The state dictates much of what we can or can't do. The service plans are becoming IEP's for adults rather than life plans. Example: One of the goals we have is that we must cut vegetables 3 times a week. It must be a measurable goal. So now I am logging when we cut vegetables. Really now! | 11/29/2013 6:06 PM |
| 37 | Again, service from the Winnisquam School District was poor. Lakes Region Community Services has given us great direction and we are a team that is seeing success! | 11/28/2013 2:37 PM |
| 38 | Personal experience with two sons with IEP's in public school setting. | 11/27/2013 11:18 AM |
| 39 | While we had input in consulting with the school in what my child needed, it did not give us everything that was needed and getting through that process came with an undue burden of hiring an IEP advocate at the expense of several thousands of dollars. | 11/26/2013 12:22 PM |
| 40 | We were sent directly from unsatisfactory early supports and services to the schools contracted 'behavior specialist' who is not versed in best practice treatment of children with autism. No other options were presented to us. | 11/26/2013 6:34 AM |
| 41 | I do care plans with elders | 11/25/2013 1:58 PM |
| 42 | Typical experience has been that families often do not have much input when offered opportunity to help create goals and objectives. Would like them to be more involved but they often feel that's what vendor agency are being paid to create. | 11/25/2013 11:11 AM |
| 43 | The home health agency provides a Nursing Plan of Care. This addresses my sister's medical needs. Where as the agency promotes supports that allow my sister greater independence, supports in the community/neighborhood, that are a good match for her specific interests, likes, etc. (unlike when she attended a day rehabilitation) | 11/25/2013 9:44 AM |
| 44 | an IEP is only good until your family member ages out | 11/24/2013 6:48 PM |
| 45 | We also sought the assistance of Parent Information Center (PIC) in developing the IEP. | 11/24/2013 1:30 PM |
| 46 | Discussions with agency staff assisted us by thinking about our sons goals. It was very new to us and they were extremely helpful. | 11/24/2013 8:07 AM |
| 47 | Depends on the year. | 11/23/2013 9:54 PM |

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|----|---|---------------------|
| 48 | <p>It varies by school and case worker. With my oldest, in highschool, we created the IEP very collaboratively and it was great. On paper. However, he refused to do anything in it and so it was not implemented. I also have been unable to get him to comply with any requests at home either. Soo very intelligent boy does not graduate highschool, even though he has more than enough credits and can achieve an A in honors class when "he is interested". Even though I saw the train wreck coming, beginning in 9th grade, and actively tried to stop it; through school, mental health professionals, primary care doctor and the medical specialists (genetic disorder that affects heart & lungs)... I failed. Sorry just a slightly irrelevant rant, apparently I'm not over it yet. Youngest the school develops IEP and I tweaked it. Since his issues are so severe and no one knew what was wrong, I had no idea if what they wanted was appropriate or not. In any case it wasn't working and by the time he got home he'd reached saturation and would spend the rest of the day in a fullblown tantrum. He is now homeschooled and the tantrums no longer take up the entire time he is home. The best service plan was during the preschool years. When easter seals dropped us and we got moved to the school system all helpful info stopped. And schools do not facilitate connecting with other parents in a similar boat, even when asked. In my current town one particular woman fought this and got the district to allow space for & post a parent support group. Hugely helpful, but because of my schedule I can only make ~ 2 per yr.</p> | 11/23/2013 11:16 AM |
| 49 | It doesn't say let me use FC or get me a job | 11/23/2013 8:41 AM |
| 50 | I had to take the initiative to organize a team, find the resources, and make sure that developmental goals were set. It took nearly 5 years. | 11/23/2013 7:44 AM |
| 51 | The service plan is mostly filled out when the SC comes to the house, and they just ask us to sign it. | 11/22/2013 11:02 PM |
| 52 | The latest plan was ridiculous. It was formatted with the generic expectation of work, job etc for someone unable to hold a job. It listed lots of functions that fell to the family. In short, it was just a document that made the area agency feel like it was doing something, when in reality - the family was doing all the work. | 11/22/2013 10:21 PM |
| 53 | Whenever we meet to prepare a new ISP it always takes longer than we anticipate, primarily because we all want my sister to have a voice in the plan's design. Sitting around a table with experienced resource coordinators and direct service providers leads to a stronger, more comprehensive plan. | 11/22/2013 3:44 PM |
| 54 | coordinator does it and sends it to me to sign | 11/22/2013 2:49 PM |
| 55 | My Son, Doctors, Gateway and ourselves discuss plan and activate my son's care of services. | 11/22/2013 2:25 PM |
| 56 | Mostly we've been told this is what there is take it or leave it. If we needed or wanted anything over and above it usually took legal action to get it. | 11/22/2013 2:11 PM |
| 57 | They include me and ask me for input and respect my contributions. | 11/22/2013 11:39 AM |
| 58 | I can 't say I agree with it. They treat him like a baby when they should be doing life skills with him. Not reading math. He will never work but he should be doing things on his own. | 11/22/2013 10:35 AM |
| 59 | as time goes on, these tend to be repetitive and geared to be very flexible | 11/22/2013 10:21 AM |
| 60 | Does not matter, it's never followed and no resources to have them follow it | 11/22/2013 10:19 AM |
| 61 | have had my son without an aid which is needed for 4 months out of the year this should tell you something | 11/22/2013 9:50 AM |

Q18 How satisfied are you with your current care or services plan, if you have one, or plans you have had in the past if you do not have one now?

Answered: 482 Skipped: 410

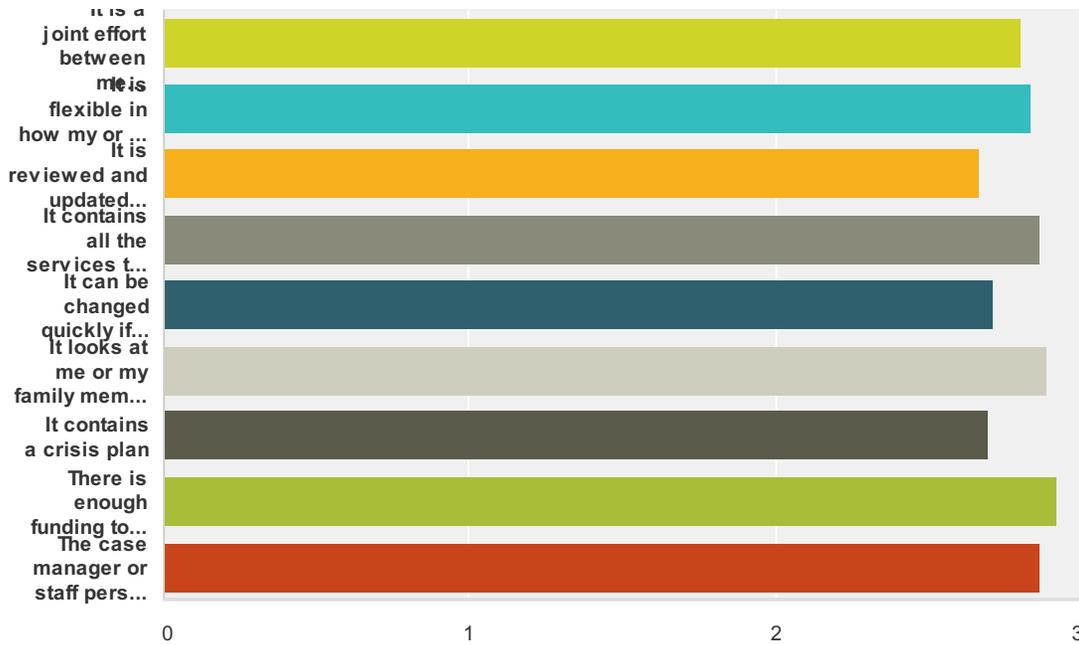


| | Dissatisfied | It's okay | Very satisfied | N/A | Total | Average Rating |
|------------|--------------|---------------|----------------|-------------|-------|----------------|
| (no label) | 7.05% 34 | 38.17% 184 | 48.96% 236 | 5.81% 28 | 482 | 2.44 |

NH Medicaid Long-Term-Care Program Survey

Q19 In your view, what makes a good care or services plan? Or would make a good one if you have not had one? Please rate all that apply.

Answered: 602 Skipped: 290



| | Not important | Important | Very important | N/A | Total | Average Rating |
|---|---------------|---------------|----------------|-------------|-------|----------------|
| It is a joint effort between me and the school or agency that I work with | 1.21% 7 | 16.75% 97 | 79.10% 458 | 2.94% 17 | 579 | 2.80 |
| It is flexible in how my or my family member's needs are met | 0.85% 5 | 15.06% 89 | 82.74% 489 | 1.35% 8 | 591 | 2.83 |
| It is reviewed and updated regularly | 2.21% 13 | 29.42% 173 | 67.01% 394 | 1.36% 8 | 588 | 2.66 |
| It contains all the services that I/we need | 0.17% 1 | 13.27% 78 | 85.37% 502 | 1.19% 7 | 588 | 2.86 |
| It can be changed quickly if needed | 1.36% 8 | 26.24% 154 | 71.38% 419 | 1.02% 6 | 587 | 2.71 |
| It looks at me or my family member as a whole person | 0.68% 4 | 10% 59 | 87.80% 518 | 1.53% 9 | 590 | 2.88 |
| It contains a crisis plan | 3.10% 18 | 22.76% 132 | 66.90% 388 | 7.24% 42 | 580 | 2.69 |
| There is enough funding to pay for the services I/we need | 0.34% 2 | 7.90% 47 | 90.59% 539 | 1.18% 7 | 595 | 2.91 |
| The case manager or staff person who helps create the plan knows how the system works | 0.33% 2 | 13.04% 78 | 85.12% 509 | 1.51% 9 | 598 | 2.86 |

| # | Other (please specify) | Date |
|---|------------------------|------|
|---|------------------------|------|

NH Medicaid Long-Term-Care Program Survey

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| 1 | As important as a crisis plan is in place - this still hasn't happened 29yrs.later. Neither has future planning happened either - in the event that something were to happen to me. There is no family that can care for my individual in an emergency. In addition, (and I apologize if this is not the place in the survey to say this), but - why isn't it that there options available where as a caretaker needs surgery and recovery - that there aren't enough places and funding to send their individual for this period of time? These places need to have wheelchair accessibility, lift systems, hospital beds, access to bathing facilities (tub - shower accessibility) and 24/7 care. Even if one could do this in their home with extra care from LNA's - this isn't a solution as we can't count on LNA's showing up for their shifts. For us families that don't have a good family support system in our family - that doesn't work for us either. It's not like every caregiver would be having surgery all the time - but there needs to be funding and places for our individuals to go if we are unable to continue with the caregiving during this time. | 12/8/2013 6:20 PM |
| 2 | area agencies working together would help even more | 12/8/2013 5:06 PM |
| 3 | The case manager gets to know my family member as a whole human being, not just a disability Plans and decisions are made jointly | 12/7/2013 11:54 AM |
| 4 | It is truly person centered and not just the available program(s) | 12/7/2013 4:47 AM |
| 5 | Crisis response is key and in need of improvement in our situation, both at the local community mental health center level and the state level. | 12/6/2013 4:34 PM |
| 6 | eval based on adult son's program in Mchigan. we hope to get at least equal service if son moves to NH | 12/6/2013 3:42 PM |
| 7 | Again, our family member is fortunate enough to have all of this, but its only because WE are paying for 99% of the cost. Neither insurance not managed care is assisting. | 12/6/2013 2:37 PM |
| 8 | My daughter with schizoaffective feels that social workers do not understand mental illness, psychiatry. Has no use for social workers for that reason | 12/6/2013 12:23 PM |
| 9 | I am unable to respond due to lacking direct involvement. | 12/6/2013 11:58 AM |
| 10 | It allows those who are close to the individual in need of help to be in contact with the doctors. | 12/6/2013 10:43 AM |
| 11 | This is a vital communication tool for all the support individuals in the community that are involved in some aspect of my brothers care, it is vital to have a plan that everyone involved is aware of and working towards. My brother has a very hard time communicating these things himself which requires all of us to work together to provide the best environment possible for him during his time with us | 12/6/2013 9:55 AM |
| 12 | Professionally, all of these aspects are important when working with individuals and/or their family members toward identifying needs, prioritizing needs within the funding available and ensuring the implementation of the care plan. It should be an ongoing and fluid process. | 12/6/2013 8:57 AM |
| 13 | Helps children between 18 and 21 years of age! | 12/6/2013 8:34 AM |
| 14 | Agencies that provide services (stakeholders) need to know there is a plan in place and respect (honor) that plan on an equal basis. These agencies or service providers must be willing to communicate with each other for the better treatment of the member requiring services. | 12/6/2013 8:08 AM |
| 15 | Dream on . . . One hopes . . . | 12/6/2013 7:38 AM |
| 16 | It includes best practices. My family member with private insurance is eligible for the same in home supports they would get if they had Medicaid | 12/5/2013 11:45 PM |
| 17 | It allows to function as a valued, productive member in society. It is written to promote growth and, thereby, the possibility for the individual to function as independently as possible. It integrates and is community and home based, it is least restrictive environment. It covers the individuals needs and protects the individuals' basic human rights to health, safety, well-fare, wellbeing and pursuit of happiness. It protects from abuse, it is specific to meet the individuals' needs | 12/5/2013 10:39 PM |
| 18 | It would be great if the area agency had the staff to provide the service. Also the staff needs to be well trained and educated..it seems the only places available to us in the past had long wait list and sub standard staff.. | 12/5/2013 9:48 PM |
| 19 | Rose Meadow farm and Lake regions community center is awesome and take a personal interest in my brothers needs. | 12/5/2013 9:34 PM |

NH Medicaid Long-Term-Care Program Survey

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| 20 | There is a minimal wait in local emergency rooms. Minimal implying less than 24 hours. Also E.R.'s would be designed to allow a patient in crisis to be treated with respect and not placed in isolation. The room should allow for the lighting to be altered and not constantly be turned on. The area where the patient should wait should include a window to the outdoors (with protective glass), the ability for the patient to see other people even if its behind a protective glass, and consistent reassurance they are valued and respected. (These suggested conditions are all listed due to several horrific E.R. experiences my own son endured.) | 12/5/2013 8:28 PM |
| 21 | Need help to find a job, and help on the job. Many times services are cut or reduced if a person is considered to be doing "well," instead of realizing the person is doing well because of the services. | 12/5/2013 6:37 PM |
| 22 | I feel we have this at Pathways. I'm not as confident about West Central. | 12/5/2013 6:18 PM |
| 23 | All these elements exist currently....please do not change it! | 12/4/2013 10:16 PM |
| 24 | It sets realistic goals that can be met in the time allotted. | 12/4/2013 9:59 PM |
| 25 | I don't like drastic changes | 12/4/2013 9:12 PM |
| 26 | The staff at Riverbend worked actively with me to create a service plan that met my needs. The problem was that once it we finished with it, it was filed away, and not looked at again until the next year. Manchester Mental Health did not work actively with me to create a plan. The whole process is a joke! | 12/4/2013 7:54 PM |
| 27 | All of the above statements are necessary to create an effective services plan. | 12/4/2013 1:41 PM |
| 28 | The checkmarks above are for a service plan that we've created but has not yet been implemented, because we're WAITING. | 12/4/2013 12:23 PM |
| 29 | Honestly, I wanted to rank all of the listed items as Very Important. I am sure if one did the research on any single line item, there would be lengthy written accounts of the benefits to the individual being served, the family, the local community, and thus the State for each one. The crisis plan is a trivial example, if such a plan exists and as such prevents a crisis from happening, an entire family's future can be saved without anyone ever even realizing it. | 12/4/2013 9:52 AM |
| 30 | I really don't understand anything about the funding. No one ever mentioned that funding was not available. | 12/4/2013 9:45 AM |
| 31 | It is a very cooperative effort. They listen! | 12/4/2013 8:46 AM |
| 32 | the current plan has no back-up plan (crisis) as no resources are available | 12/3/2013 10:39 PM |
| 33 | It is logical and not based on the school day schedule. It sets out to create an environment that our loved ones can be celebrated and accepted in, that uses their gifts and skills as they are, rather than continuously focusing on ways to make the person look, act and function like a neuro-typical person. | 12/3/2013 8:49 PM |
| 34 | actually is done | 12/3/2013 7:17 PM |
| 35 | this one doesn't work | 12/3/2013 5:26 PM |
| 36 | We have had a family situation change during the first year of our plan and the Moore Center was quick to help us. It did take quite a while for the state to agree to the new plan and to get us the funding we needed but the Moore Center was also pretty quick in helping us with funding so that Megan's plan was almost seamless. | 12/3/2013 4:29 PM |
| 37 | Not sure what is meant by whole person. If it means including medical issues, then not important. If it means my home, work and social life, then very important obviously. | 12/3/2013 4:11 PM |
| 38 | It is created and supported with expectations for continued functional literacy learning and behavioral support for those that require this to continue to be integrated into their communities and world of employment. | 12/3/2013 3:26 PM |
| 39 | It should be administered by insurance health care professionals such as well-known and highly regarded health insurance companies with decades of public experience, not a charity organization such as Gateways operating without public scrutiny with poorly informed employees imposing unneeded services and denying meaningful ones. | 12/3/2013 12:58 PM |
| 40 | Not sure what you mean by crisis plan | 12/3/2013 12:46 PM |
| 41 | My experience has been that autism and it's treatment are not an area that is understood by the staff at Community Bridges. There are evidence based data driven proven interventions that are NOT utilized by Community Bridges. An ' eclectic' approach is ineffective in autism treatment, and it is ill advised for the staff there to recommend interventions which are not the best treatment. Especially when treatment is time sensitive and families are relying on these folks to be trained professionals. I found myself educating them. | 12/3/2013 11:56 AM |

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| 42 | FUNDING without fighting with congress. Automatic funding should happen Yearly updates except in case of crisis | 12/3/2013 11:53 AM |
| 43 | It pays service providers in a timely manner...would attract and keep more service providers. | 12/3/2013 11:04 AM |
| 44 | Poorly worded question. Who wouldn't want all of these things? | 12/3/2013 9:27 AM |
| 45 | I want it to also include what it important to him and his cirle of support and what is important for him and his cirle of support | 12/3/2013 8:26 AM |
| 46 | One of the issues with my son that we run into often is that his plan is not always followed because there is not enough funding. It is a huge frustration that he can not always get the services he needs because of that. | 12/2/2013 8:02 PM |
| 47 | It is my observation that these elements are important to people I support | 12/2/2013 4:29 PM |
| 48 | The plan must be tailored to the individual and not just a boiler plate to satisfy legal requirements. | 12/2/2013 4:27 PM |
| 49 | It needs to have continuity. | 12/2/2013 3:28 PM |
| 50 | This survey is not allowing me to enter any answers... | 12/2/2013 1:59 PM |
| 51 | Case managers that are skilled and knowledgeable | 12/2/2013 1:59 PM |
| 52 | Application is done in a timely manner - it should not take 3-9 months to get onto the CFI program Being able to contact OLTC and obtain a response in a timely manner. | 12/2/2013 10:41 AM |
| 53 | I am a person not a number. | 11/29/2013 6:08 PM |
| 54 | That the plan be responsive more to the individual's own adult needs, and not use the parent's as support & residential resources just because they are available. Parental support, however well-meaning, is not always in the best growth interests of the adult child. Our daughter could have become healthier emotionally & physically had she been with a home provider sooner instead of being expected by the area agency to live alone. | 11/29/2013 11:28 AM |
| 55 | A good service plan is one where the family is the ultimate decision-maker, without interference and with maximum choice from all life has to offer. | 11/27/2013 10:57 PM |
| 56 | We don't so much need a concrete crisis plan. Yet it is good to know who to turn to and the steps involved in addressing a crisis should one arise. | 11/27/2013 9:02 AM |
| 57 | More residential options would helpful. | 11/25/2013 2:56 PM |
| 58 | It is directed by me and NOT an area agency. | 11/25/2013 10:47 AM |
| 59 | The last statement is important to me and my family. My sister is part of our family. Our immediate family (me, my husband, adult sister/client) need to function just like any other family that includes work, rest, play, etc. In order to address Holly's needs our lives are affected. With the current supports in place we are able to meet the needs for the entire family not just Holly's needs. | 11/25/2013 9:50 AM |
| 60 | I am happy with our plan, services, and agency staff. I would not be pleased if there were major changes to this relationship and funding. | 11/24/2013 8:09 AM |
| 61 | It gets me a job and people I can FC with | 11/23/2013 8:43 AM |
| 62 | All is needed. We just don't have it. | 11/23/2013 6:33 AM |
| 63 | Not sure what you mean by a "crisis plan." | 11/23/2013 12:26 AM |
| 64 | As noted before - these plans are useless documents that end up sitting in a file folder and taken out once a year so that area agency parties can point to something that demonstrates involvement with a family. In reality, most staff at area agencies have no involvement and have never met the families. | 11/22/2013 10:24 PM |
| 65 | It is responsive to the needs of the individual and respects their right to change and grow. | 11/22/2013 6:18 PM |
| 66 | There should be one person you can contact for answers and changes/updates, who will not refer you to 12 different people/departments/agencies to call. Also be sure there are answers. I have called the 800 number and been told there is no answer and we don't know who you shuold talk to, or when there might be an answer | 11/22/2013 4:03 PM |
| 67 | See previous comments. | 11/22/2013 3:45 PM |
| 68 | Not much thought is put into the goals that are established each year. I create and follow through with the home goals. The goals during day program are so generic that not much effort has to be afforded them. It bothers me that if a goal is not met by the end of the year, you cannot continue working on that goal. You must create a new goal. That is counterproductive. | 11/22/2013 3:00 PM |

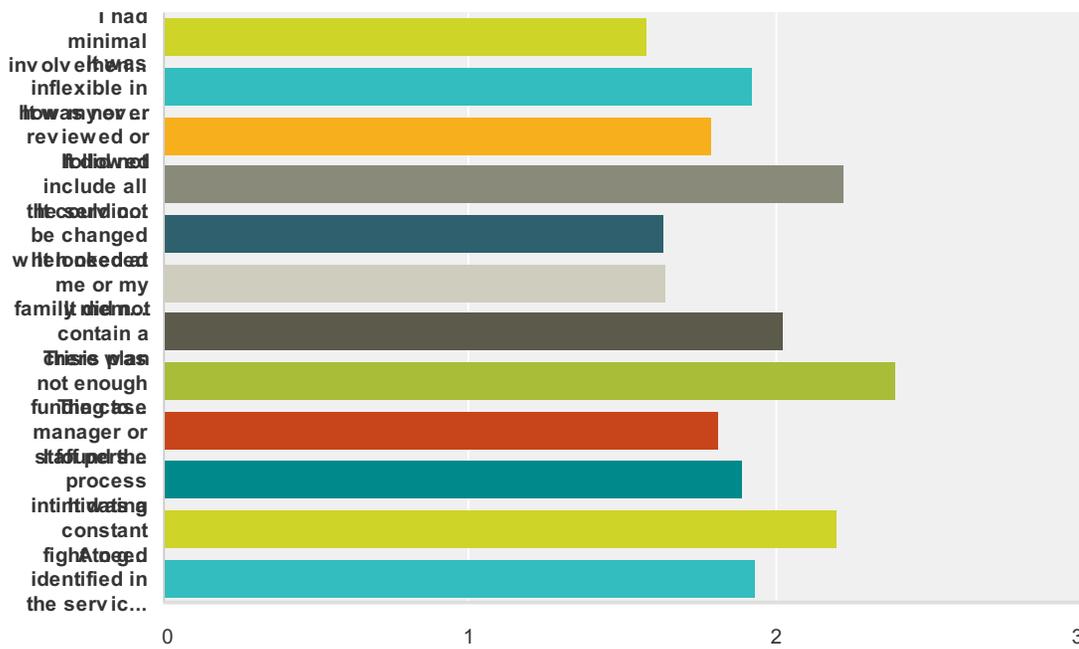
NH Medicaid Long-Term-Care Program Survey

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| 69 | Theres just not enough services for kids. Its exhausting at times | 11/22/2013 2:51 PM |
| 70 | I think today the service plans are too long. I think it should be a plan that is matched to budget. to spend time placing in the plan services that the funding source will not pay for does not make sense, unless it is clearly seperated out. Not knowing what a crisis might be in a non-medicald model I don't know what I would put in a plan. Having backup services for someone who might not be able to deliver critical services would be important. A lot of services may be needed but some are provided through natural community supports I don't know that they all need to be listed in the plan, or at least how much detail needs to be in the plan. Right now folks could have several plans and they are not always well connected. They are usually per funding stream. You could have one for Developmental disabilities (ISP), at the same time you have a school plan (IEP) and a Vocational Rehabilitation and Edcuation Plan (IWP). Not sure if that will every change. Makes sense if someone is footing the bill they need to know what they are paying for...many families look at them as contracts. | 11/22/2013 2:21 PM |
| 71 | Regs need to be more "individual" focused and flexible. | 11/22/2013 2:14 PM |
| 72 | That providers are trained for there jobs and are held accountable | 11/22/2013 1:46 PM |
| 73 | I listed flexibiity and a wholistic response as not important because these strike me as just jargon. What matters is that my son is safe, that I am involved because I know him best, and that there is enough money. | 11/22/2013 1:28 PM |
| 74 | Your system would not accept a check mark next to every question, much as I tried. | 11/22/2013 12:59 PM |
| 75 | She has had an ISP for many many years | 11/22/2013 12:45 PM |
| 76 | It is important for the majority of these folks that there is consistency in their plan/staff person. What I've found in the last year that my adult son has received services, is that the staff persons hired to assist him as needed are very underpaid for the services they provide which leads to significant turnover resulting in chaos for the person receiving services. Also need back up plan so that when that staff person is out unexpectedly there is someone to take over. | 11/22/2013 12:12 PM |
| 77 | The service plan should completely reflect the person at the center, what their hopes, dreams and vision is for their life, using culturally valued analogues to make the plan (ie. at 21 year old should be looking at further education or employment - not day wasting programs where people sit around and color or an elder who wants to pursue hobbies and interests and not necessarily be grouped with other elders just because they are all old). the service plan should reflect the level of care that is needed to support the highest level of integrity to the person and the overall plan should be flexible and creative - not a box type of agreement where the person is only offered this or that. | 11/22/2013 11:40 AM |
| 78 | The only things it has not provided that is disappointing is: 1. A service-dog 2. A cabinet with locks on the doors and drawers | 11/22/2013 11:23 AM |
| 79 | We currently don't have a crisis plan, that I know of, but could have used one previously when a crisis took over 2 months to rectify. | 11/22/2013 11:16 AM |
| 80 | I checked of very important for containing a crisis plan although my son's plan does not have one. I will address this over site. Thank you! | 11/22/2013 10:23 AM |
| 81 | it has to factor in the abilities of the workers which is often a limiting factor. | 11/22/2013 10:22 AM |
| 82 | Great plans are only good if followed. In 10 years, it has never been followed aggravating our son's condition | 11/22/2013 10:21 AM |

NH Medicaid Long-Term-Care Program Survey

Q20 Have you ever had a bad experience with a care or services plan? Please rate all that apply.

Answered: 511 Skipped: 381



| | Never happened to me | Has happened once | Has happened a few times | Often happens | Total | Average Rating |
|---|----------------------|-------------------|--------------------------|---------------|-------|----------------|
| I had minimal involvement in creating the plan | 67.08% 324 | 13.25% 64 | 13.87% 67 | 5.80% 28 | 483 | 1.58 |
| It was inflexible in how my or my family member's needs are/were met | 52.61% 252 | 13.15% 63 | 23.59% 113 | 10.65% 51 | 479 | 1.92 |
| It was never reviewed or followed | 58.00% 279 | 13.51% 65 | 20.37% 98 | 8.11% 39 | 481 | 1.79 |
| It did not include all the services that I/we need | 38.48% 187 | 16.87% 82 | 29.01% 141 | 15.64% 76 | 486 | 2.22 |
| It could not be changed when needed | 65.96% 312 | 11.42% 54 | 16.07% 76 | 6.55% 31 | 473 | 1.63 |
| It looked at me or my family member as a number, not a person | 65.24% 321 | 13.41% 66 | 13.41% 66 | 7.93% 39 | 492 | 1.64 |
| It did not contain a crisis plan | 50.22% 230 | 16.81% 77 | 13.76% 63 | 19.21% 88 | 458 | 2.02 |
| There was not enough funding to pay for the services I/we need | 33.95% 164 | 14.91% 72 | 29.81% 144 | 21.33% 103 | 483 | 2.39 |
| The case manager or staff person who helped create the plan did not know how the system works | 54.96% 266 | 17.98% 87 | 18.60% 90 | 8.47% 41 | 484 | 1.81 |
| I found the process intimidating | 52.16% 253 | 17.32% 84 | 20% 97 | 10.52% 51 | 485 | 1.89 |
| It was a constant fight to get the right services | 41.36% 201 | 15.64% 76 | 24.49% 119 | 18.52% 90 | 486 | 2.20 |

NH Medicaid Long-Term-Care Program Survey

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| A need identified in the service plan was not available locally | 50.41% 243 | 18.05% 87 | 20.12% 97 | 11.41% 55 | 482 | 1.93 |
|---|----------------------|---------------------|---------------------|---------------------|-----|------|

| # | Other (please specify) | Date |
|----|--|--------------------|
| 1 | In addition to last question's comment - there needs to be more places in the community for out of home respite and more funding to be able to make that happen....for those in wheelchairs who need 24/7 care. It was really nice when we could utilize Crotched Mountain many years ago...of course, I don't believe that would be even an option at this point and time because my then child, is now a 29yo adult. | 12/8/2013 7:14 PM |
| 2 | things change from the state and are NOT COMMUNICATED properly from the area agencies to the providers | 12/8/2013 5:08 PM |
| 3 | Still waiting for a therapist. | 12/6/2013 5:36 PM |
| 4 | We are pleased with the care under the Manchester Mental Health Center, however we had very different experiences, both negative when our son was under the Nashua and Dery mental health agencies. | 12/6/2013 4:37 PM |
| 5 | My family member was going to have to go more than 60 miles away in a different State for residential treatment. This removes the person from the supports in the community and family. These supports are critical to that person when outpatient services start and ultimately when the person returns to a job or school. This was unacceptable. We found an excellent residential treatment center here in NH, but it is not covered. Our family member participates in the in-State outpatient treatment now and has the support of family, friends, and the community where he has lived his whole life. | 12/6/2013 2:43 PM |
| 6 | only had a case manager early in her illness. No case manager since. | 12/6/2013 12:24 PM |
| 7 | no plan in effect that I am aware of for my son, though he is monitored and his medication is provided through MMH | 12/6/2013 11:37 AM |
| 8 | This area of questioning is hard to rate on the above scale. I do feel though that funding is often an issue in what can be done. Finances are always discussed in what plans are made, which isn't always a bad thing if appropriate treatment can be done cheaper it should be, but sometimes knowing that funding is available for those cases that have not responded to the alternatives. | 12/6/2013 9:46 AM |
| 9 | With people entering & leaving my local mental health clinic/center constantly, it is hard to keep some services steady & methods to do services are constantly changing..I had a job coach, then she just disappeared & I haven't heard back despite a phone call leaving a message to that group of people at my Menal health agency | 12/6/2013 9:45 AM |
| 10 | We had a great plan when my son was in school up until age 21. Now we are pretty much on our own in terms of a plan. We sought out West Central & voc rehab. Voc rehab appointments are 6 weeks apart and can only work on one goal at a time. So far they have found out that my son has no interests. We have a young case manager who visits with my son once a week. Other than that, there is no plan that I can tell. | 12/6/2013 9:42 AM |
| 11 | I have not been an active participant in a plan. | 12/6/2013 9:37 AM |
| 12 | Does not apply to providers | 12/6/2013 9:00 AM |
| 13 | My child's service plan has never been implemented. we get no help from SMS even after having meeting at my home after needing to fight for an appointment... Our worker left 6 months ago with a whole page of things she was going to work on for us and haven't heard a word since. | 12/6/2013 8:36 AM |
| 14 | I have seen care plans not work well for all kinds of reasons but overall I have seen that they work very well for a majority of people. | 12/6/2013 8:19 AM |
| 15 | My sister has a guardian, so I do not get included in service planning typically. Although, if I ask they are always willing to include me. They just do not think to let me know when these things are being reviewed/updated. There are insufficient resources/ services for people with mental health disabilities. | 12/6/2013 6:20 AM |
| 16 | I have been scolded (bullied) by team leaders for trying to advocate for my child | 12/5/2013 11:48 PM |
| 17 | the case manager is trying to get him to come to the appointment. | 12/5/2013 11:16 PM |
| 18 | The above are things that have occurred while the, by the state designated AA did provide the services, under their day program *(when more conflict of interest is present, we leave opening for less protection , abuse of certain privileges, lack in services and such). Since moving to an outside vendor, there is greater satisfaction, better communication, better access, less issues, illumination of conflict of interest, better cooperation and accommodation, well improved service overall. | 12/5/2013 10:48 PM |

NH Medicaid Long-Term-Care Program Survey

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| 19 | Plan was created but the staff turn over rate did not help with carry over.. Long periods of time would pass with no replacement staff | 12/5/2013 9:50 PM |
| 20 | They don't know what services are available and some parts of the state have good programs others have none!! Need transition or group home options | 12/5/2013 7:41 PM |
| 21 | See previous note. | 12/5/2013 6:39 PM |
| 22 | When my daughter's IEP update was presented to the special education steering committee at Hollis Brookline High school, the response was "This kid just needs and needs and needs" and requested services were denied. My daughter ended up leaving the school district and graduated from high school in another town 8 years later at the age of 25. | 12/5/2013 6:25 PM |
| 23 | I dont know if I even have a service plan. This is something that has not been made clear to me. | 12/5/2013 6:18 PM |
| 24 | I have seen many service plans created and area agencies are thorough in their requests for rehabilitative and supported living goals for each person based on their abilities. | 12/5/2013 12:04 PM |
| 25 | not involved with NH Medicaid Long-Term Program | 12/5/2013 10:56 AM |
| 26 | This was at newfound school district. They do not offer enough assistance for every special need. Quite often their classroom aids have a cup of coffee in their hand and weren't available to intercept a bad behavior. Job training wasn't available, summer school hours were three hours four days a week for I think five weeks. Just enough to completely throw an autistics person of a schedule. And cause chaos. Luckily they currently pay for him to attend Spaulding youth center which is fabulous! My case worker helped tremendously with this. | 12/4/2013 9:24 PM |
| 27 | If you're unable to help people with the biggest barriers in moving forward that they are facing it's a waste of time. For me the following barriers were not addressed: lack of transportation, employment discrimination, helping me with paperwork | 12/4/2013 7:59 PM |
| 28 | NA | 12/4/2013 3:23 PM |
| 29 | I feel that our voice is often lost because what we need is not available or is expensive. The lack of a crisis plan drives me wild...my family member is an insulin dependent diabetic and I can not tell you how many times I have had to leave work in the middle of the day to do the noon insulin run because our regular mentor is out sick or on vacation and there is no replacement for him qualified to give a shot. | 12/4/2013 2:32 PM |
| 30 | A school superintendant brushed aside my concerns regarding my foster son's IEP plan not being utilized. The supintendant did not agree that had the two teachers involved followed the IEP plan that my foster son's reaction to the teachers verbal and intimidating behaviors would have been different and not resulted in out of school suspension. The superentendan also would not consider providing a different consequence to my foster son. My foster son loved not going to school, and saw it as a reward. Every night before school my foster son would ask me if he had to go school the next day, and I said yes. Every morning he would ask again and I said yes. Giving him a three day out of school suspension was a plus not a minus as far as my foster son was concerned. What is the point of an IEP plan if it is not going to be followed by the teachers or upheld by the superintendant? | 12/4/2013 12:01 PM |
| 31 | The first time though was, of course, intimidating. With the amount of change, all the new people, I'm not sure how this could or should be avoided. Via the benefit of 20-20 hindsight, it could have been overwhelming and it wasn't because the existing process works so very well. | 12/4/2013 9:55 AM |
| 32 | If state were to make a site visit they would say farmstead had a deficiency if Jess's room smelled like urine but hers is a unique case where she has such noncooperative behavior and is a big girl you cannot get her to cooperate with hygiene. Farmsteads has gone to incredible lengths to address health issues and is in no way at fault. It is important to take individual cases and see the context and not just the rules. farmstead and pathways have made great improvements in Jess health and safety issues but it is very challenging. | 12/4/2013 9:53 AM |
| 33 | Some of these questions are difficult to answer. I only answered the ones I felt comfortable with. | 12/4/2013 9:48 AM |
| 34 | N/A | 12/4/2013 9:31 AM |
| 35 | The agency has been great, such a difference from the school years which were so stressful. It went from battling with the school district, to the agency allowing us total control of what happens daily for our son and support with every challenge or new idea we have, such an enormous difference and such a blessing! ,! | 12/4/2013 8:07 AM |
| 36 | Not included in all development of day program and inflexiablity and not caring what the family or individual needed | 12/3/2013 7:19 PM |
| 37 | this one doesn't work | 12/3/2013 5:27 PM |

NH Medicaid Long-Term-Care Program Survey

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| 38 | As I said previously, we had some wait list issues but the communication between the Moore Center and my family was open the whole time. | 12/3/2013 4:31 PM |
| 39 | I really can't answer all of these. Within the confines of budgetary constraints and my energy to make things happen, all is well. | 12/3/2013 4:25 PM |
| 40 | No | 12/3/2013 3:20 PM |
| 41 | My only bad experience has been years of advocacy with the state to keep the services in tact - fighting and testifying everytime a legislator presents a bill that could possibly harm the services that my son and our family rely on. At 60 years old, I am getting tired. | 12/3/2013 1:57 PM |
| 42 | Every bad experience was the result of the unprofessional staff at Gateways treating us as if we should be grateful to them personally for receiving the funds our disabled family member qualified for from Medicaid by virtue of permanent and total disability. Gateways behaved as if it were their own funds to distribute as they saw fit. Their unprofessional participation did not merit the large percentage of Medicaid funds they took off the top for administration. Gateways was condescending and bullied us. Fortunately, after learning what Gateways actually did, in virtually appropriating the entire Medicaid system and pursestrings for their own, and trying to keep us in the dark concerning the relevant state and federal laws, we had the personal funds available to reject any involvement with them. They should be ashamed of their behavior. | 12/3/2013 1:09 PM |
| 43 | The area agency in Concord would not allow us to spend our budget in an autism treatment program of our choice. We had to fight and fight and fight to have this permitted. A lot of valuable time in my son's life was spent with unqualified personnel when qualified providers were available around the corner. | 12/3/2013 12:00 PM |
| 44 | I do feel we are underfunded for the 24/7 care my son will need for the rest of his life. He will need to always be in a home with family or a group home at some point. Us taking care of him saves the state megabucks yet we continue to fight for funding year after year | 12/3/2013 11:57 AM |
| 45 | Need funding for Rose Meadow | 12/3/2013 9:46 AM |
| 46 | If the service for a need was not available it was not identified in the plan | 12/2/2013 2:00 PM |
| 47 | I am not able to check the boxes in this survey, it is not recording what I am checking | 12/2/2013 1:59 PM |
| 48 | An issue never reviewed or followed up upon is a HUGE issue, not only with the OLTC, but also with some case managers. | 12/2/2013 10:44 AM |
| 49 | Do not have access to appropriate services that would benefit my son. We used to be able to have weekly Speech Therapy and Occupational Therapy from providers we selected but now that we must use providers who accept Medicaid, he no longer receives these services because there aren't enough providers who accept Medicaid. The quality and consistency of the services he used to receive were wonderful and we saw progress. He does receive these services at school but they are not the same quality or consistency which is key to my son making improvement. | 12/2/2013 10:21 AM |
| 50 | one person seldom checks to see how things are going | 11/30/2013 1:25 PM |
| 51 | The only time I remember problems was in the early years when the kids were little. Some of this was on the school district not telling us about other services we needed or could use and some of it was our perception. When your new at this stuff everything is daunting. As we became educated about the system we became better advocates. Being better advocates enhanced our relationships with the school district and Area Agency, which led to more comprehensive plans and care. | 11/29/2013 6:22 PM |
| 52 | Case manager/support brokers staff turnovers create havoc and have often been under trained or have been not a good fit for the job at all. it is very frustrating when we know more than our support broker does. It feels like there is no support at all and we have little confidence that they would be able to help if we needed it. I have gone to supervisors in the past when this has happened. | 11/29/2013 1:32 PM |
| 53 | See #19 | 11/29/2013 11:33 AM |
| 54 | Again, the Winnisquam School District Special Education Department did not meet my daughter's needs. There were teachers along the way that made soe successful attempts, but in high school, the team downplayed her disabilities and did not form a transition plan until she was 18 years old and I asked about it. My daughter's father raised her as a single parent for 14 years after her mother died and was overwhelmed. When I came into the picture and started asking questions about her services, they were begrudgingly provided, but it was already very late in the game. As a result, she spent time on the wait list and her forward progress stalled. When we connected with Lakes Region Community Services, her situation began to improve. Now we are involved with self-directed services and feel that we have excellent support. | 11/28/2013 2:44 PM |
| 55 | Massage therapy | 11/28/2013 5:37 AM |

NH Medicaid Long-Term-Care Program Survey

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| 56 | Again, we have a mentor that is wonderful - but I fear that we won't keep her due to the inability to reward her great contributions. These folks don't get insurance or retirement - all we can do is give them some sort in increase in salary. training a new person is just NOT in the best interest of anyone. | 11/27/2013 6:07 PM |
| 57 | Personal: Have not had a service plan in adult system, just IEP's in school. | 11/27/2013 11:20 AM |
| 58 | When my son turned 3, we developed his first IEP. Soon after, we moved to another town within the state. After going through the process in our new home, I realized that the services he was offered initially were completely inadequate. | 11/27/2013 9:05 AM |
| 59 | While we had the ability to provide input in the IEP process and also pushed to address issues with it as school year progressed, little to nothing was done to address it in a meaningful manner. | 11/26/2013 12:26 PM |
| 60 | The director of our agency adult services was incredibly difficult. We had to fight her or go above her to get what we needed for our sons. | 11/26/2013 11:58 AM |
| 61 | i once went two months without service because my spend down had gone over the limit. | 11/26/2013 11:51 AM |
| 62 | When there was a crisis the system was responsive but there was no "plan" prior to the crisis. | 11/26/2013 10:54 AM |
| 63 | Some professional services are not readily available in our area | 11/26/2013 8:09 AM |
| 64 | When I was with a different management company, the case manager NEVER came and discussed any- thing with my husband & me. He always talked the talk, but did absolutely nothing more than the barest minimum for us. When we actually discovered misconduct by our assistance provider, he contacted the company manager and they "investigated it themselves," spoke to the provider before speaking to us and then swept it under the table instead of notifying the proper authorities. We both got a different case manager, partially because he didn't want to face us! And we were disgusted with him. | 11/25/2013 9:15 PM |
| 65 | this page wont let me answer any of the questions | 11/25/2013 8:21 PM |
| 66 | Don't need the area agency. Plan can be developed by me, healthcare providers and school staff without middle man. | 11/25/2013 10:50 AM |
| 67 | Fortunately, I have always worked in the area agency system. I believe without this experience my sister would not be where she is today. My grandparents went years without having an area agency service coordinator. Their belief was to allow someone else the help because our family could provide for all of Holly's needs. This proved to be difficult because as my grandparents aged their personal needs increased. We did not have the support from our relatives (bio parents.) At one point, my husband and I provided all personal care for my sister and both grandparents. The tipping point was when my sister received service coordination from the workshop where she attended and was financially exploited. | 11/25/2013 9:57 AM |
| 68 | The budget that is determined by the NH legislature is the largest determining factor as to how adequately the area agencies can meet the needs of the individuals they serve. While we have had to 'fight' for services it's because the NH legislature does not allocate adequate funding... forces individuals on wait lists. NH Medicaid does not ABA services. So again this question is somewhat inappropriate and may suggests to folks that any challenges they have had is the sole responsibility of the area agencies. We have never had a crisis situation, but if we did we do have a number to call a person from our area agency to get an immediate response/support outside of the normal business hours. | 11/25/2013 9:40 AM |
| 69 | My family has only been residents of NH for 4 years. When we lived in Rhode Island, we also had private primary insurance and my son was covered by the Katie Beckett waiver. We had services for my son where a staff person came out to the house 2 - 3 times per week and did homework with my son, helped with ADLs, chores, took him on social outings, etc. I have not had those types of services for my son in NH. I was always told by our area agency that those types of services were only available for adults AND that there was a waiting list to get those types of services and there may not be money available to pay for the services. I am not sure if this is in fact the case in NH but I feel as though I had better services for my child when we lived in Rhode Island. | 11/24/2013 1:38 PM |
| 70 | Can't say enough good things about community partners. | 11/24/2013 8:10 AM |
| 71 | It is called "self directed" but the name is not accurate. | 11/23/2013 11:20 PM |

NH Medicaid Long-Term-Care Program Survey

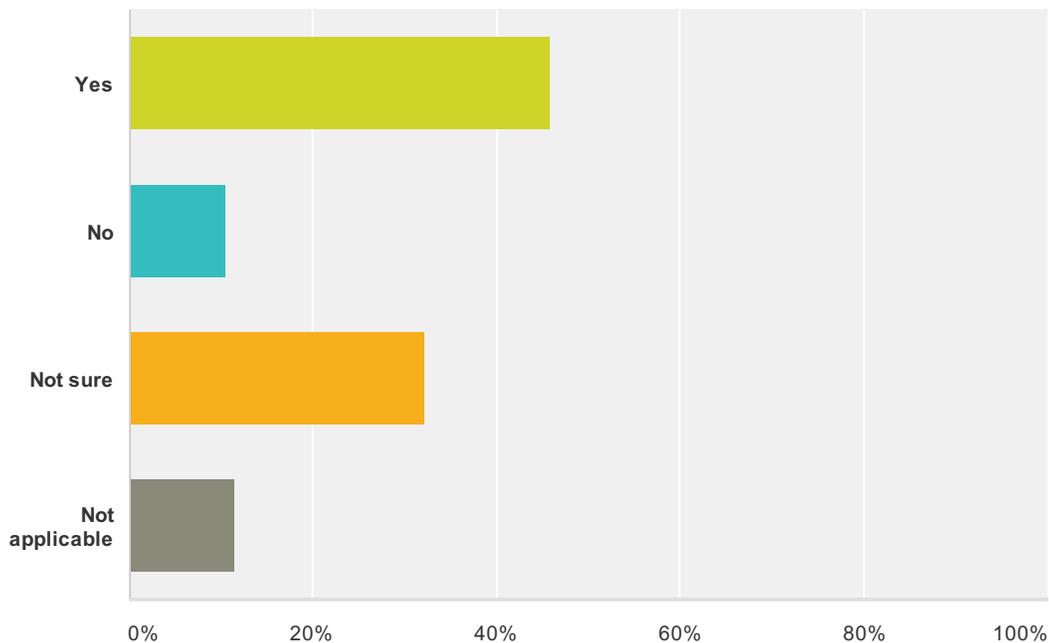
| | | |
|----|---|---------------------|
| 72 | <p>First few years I didn't know what we needed, so did not ask. My assumption had been that if they knew what was needed they would tell me and if they could not provide it they would tell me why. If there were alternative options they did not alert me. I have no idea if school had a funding issue. And since if you can't attend functions where parents congregate, can't go on field trips, can't go to afterschool activities because they always serve things your child can't eat, then you do not hear from the other parents about the less common options that might have been available. Services I needed were beyond the scope of the school, since they happened at home. After 3 years of requests youngest was added to PASS program and they did assign someone to meet with us (parents) and come to the house. She was helpful, after 2 years she did recommend homeschooling him (off the record). At the time I was already homeschooling oldest two. The oldest was too smart to get help in gradeschool, and middle child was and is thriving as a homeschooler, so I never bothered to send her to school. I don't know what a crisis plan is, in this context is. Youngest never melted down at school, simply shut down. Oldest child had a medical crisis plan with nurse, but not on IEP. In grade school it took active effort on my part to get the plan tweaked till it worked. It would take till April before he began to progress and then every single year it would be a brand new team that would dismiss my concerns, ignore what worked last year and use "their program" and so it began again. In highschool it took months to realize that the IEP wasn't being followed or implemented. No one bothered to tell me that Nathan was not implementing any of the supports provided. When 18 months in (and every 3 months from then on) I asked for a truant officer the team would say that's a last resort lets do x, y, or z. So we did and every quarter 1 week before marks close the boy would habd in enough work to go from D or F to A, B or C and they would assume it was working. At the final meeting 6 weeks before graduation they bring in the Truant officer and he says I wish you'd brought me in 2 yrs ago. At that point the boy stops showing up altogether. In all cases (both children) in these mtgs there was never any antipathy, just simply didn't believe me. So as the months march on the plan gets reworked. Soo much wasted time and energy.</p> | 11/23/2013 11:54 AM |
| 73 | My son and family are very ionvolved in creating teh Service Agreement. | 11/23/2013 8:09 AM |
| 74 | once we started with Angel our life changed for the better....she cares and works hard for the whole family | 11/23/2013 7:56 AM |
| 75 | Been working with IEP only by myself. | 11/23/2013 6:35 AM |
| 76 | It is no fault of the case manager when certain services could not be funded. It was that the "plan" would not allow payment for a specific need. | 11/22/2013 10:39 PM |
| 77 | I wouldn't say there was ever a "fight" but the services were very basic, the casemanager did not listen to what the individual wanted and the services were token offerings compared to needs. | 11/22/2013 3:48 PM |
| 78 | The narrative service plan was often just cut and pasted into the new service plan. Some case managers do not take the time to get to know the client. Often the once-a-month meeting is just an email sent to the provider saying "how's it going?" | 11/22/2013 3:08 PM |
| 79 | The school plan can never meet his needs because of his multiple diagnosis there isn't a facility or program that covers them all. The plan through the area agency can not provide the services needed because most of the programs are only for adults. The mental health plan can only cover what is available through their services. It would be good to have someone to coordinate all these plans as well as his medical team to identify his needs and come up with a cohesive plan. | 11/22/2013 2:57 PM |
| 80 | respite pool would be greatly appreciated but that doesn't exist | 11/22/2013 2:54 PM |
| 81 | We have had mostly success with our plans in LTSS DD services because we have been fortunate enough to self-direct. My IEP experiences were very different in the school system. | 11/22/2013 2:24 PM |
| 82 | I've been left to either handle things on my own or not given the support and direction that I've needed. | 11/22/2013 2:16 PM |
| 83 | The needs that were not addressed were pre-vocational readiness (VR is an inflexible and unhelpful partner in youth transision.) The "fight" for services was not at the area agency but at the school district -- We always had to push the district to do more. | 11/22/2013 1:32 PM |
| 84 | Again, your system would not allow me to answer all questions, much as I tried. By the way, all my answers are that it never happened to me. | 11/22/2013 1:08 PM |
| 85 | Problems in staffing. | 11/22/2013 1:02 PM |
| 86 | The second question that states "It was a constant fight to get the right services." I would definitely not use the word fight. It was more in how I approached and how I kept approaching, asking for what I needed in different ways. Again the services that are billable, need to include additional services that will assist autistic persons more in the social aspect of life and in living a healthy lifestyle. | 11/22/2013 12:20 PM |

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| 87 | It contained a crisis plan that was ridiculous. "If you feel yourself getting agitated try to do some deep breathing or listen to music." This when my son was being hospitalized for a mental illness episode for the 4th time in a three month period. He also has developmental disabilities and it was clear after the second time that "deep breathing....." was not going to work nor was he capable of accessing that skill in a time of crisis. But as long as he signed the right forms and said he understood his crisis plan he was let go. Only to return again, and again, and..... | 11/22/2013 12:20 PM |
| 88 | Sometimes the agencies agenda was trying to trump the person's agenda so the number of agency personnel around the table out numbered the direct care team. Power struggles. | 11/22/2013 11:43 AM |
| 89 | Staffing of a DSP was challenging in the beginning because we are located in a more rural area. | 11/22/2013 11:26 AM |
| 90 | We were on a wait for early intervention services when my daughter was a toddler, but not for very long. | 11/22/2013 11:26 AM |
| 91 | To be honest, we didn't know all the services we needed and the Area Agency prefers to keep you in the dark to what's available and helpful. We've learned the most from other families and parents with children with developmental needs and from the yearly conferences held at Attitash & Mt Washington. | 11/22/2013 11:22 AM |
| 92 | In the past there have been many contradictions regarding funding, especially where we are told something that later is different. | 11/22/2013 11:16 AM |
| 93 | Robin Hill Farm is an excellent placement for our family member. | 11/22/2013 11:02 AM |
| 94 | Our area agency does a great job on this issue | 11/22/2013 10:58 AM |
| 95 | This page pertains to a former area agency. I would say I was not intimidated, but rather frustrated and angered as I knew what my adult son required. I had the benefit of leadership training (first graduating class), week long PLAN workshop, TASH and parent meetings, difficult and challenging public school IEP meetings resulting in successfully navigating my son through graduation of his local high school. I was experienced. My son and I changed area agency. | 11/22/2013 10:40 AM |
| 96 | My family member was on the wait list for services for 12 years and we believed we couldn't do anything about it. We had an awful time getting any services at all during that time. We are educated about our choices now and advocate for what we feel is best for our family member. | 11/22/2013 10:19 AM |

Q21 Does your services plan have an annual, individualized budget or some type of annual services account? (Or did it if you do not have a plan now?)

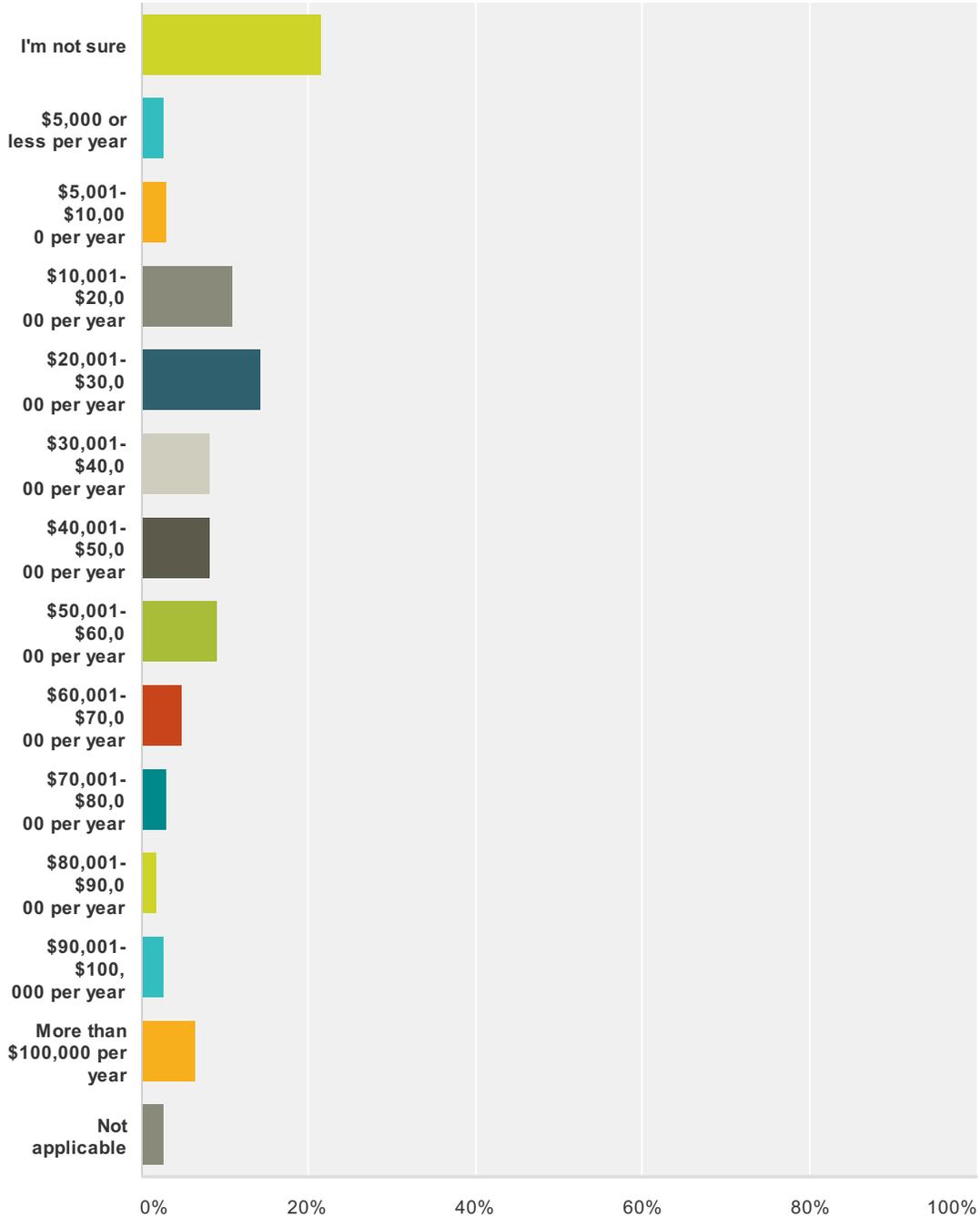
Answered: 565 Skipped: 327



| Answer Choices | Responses |
|----------------|------------|
| Yes | 45.84% 259 |
| No | 10.44% 59 |
| Not sure | 32.21% 182 |
| Not applicable | 11.50% 65 |
| Total | 565 |

Q22 What do you estimate the annual budget is for the services in your plan? (Or for the annual services you receive through Medicaid.)

Answered: 264 Skipped: 628



| Answer Choices | Responses |
|---------------------------|-----------|
| I'm not sure | 21.59% 57 |
| \$5,000 or less per year | 2.65% 7 |
| \$5,001-\$10,000 per year | 3.03% 8 |

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|------------------------------|--------|------------|
| \$10,001-\$20,000 per year | 10.98% | 29 |
| \$20,001-\$30,000 per year | 14.39% | 38 |
| \$30,001-\$40,000 per year | 8.33% | 22 |
| \$40,001-\$50,000 per year | 8.33% | 22 |
| \$50,001-\$60,000 per year | 9.09% | 24 |
| \$60,001-\$70,000 per year | 4.92% | 13 |
| \$70,001-\$80,000 per year | 3.03% | 8 |
| \$80,001-\$90,000 per year | 1.89% | 5 |
| \$90,001-\$100,000 per year | 2.65% | 7 |
| More than \$100,000 per year | 6.44% | 17 |
| Not applicable | 2.65% | 7 |
| Total | | 264 |

| # | Feel free to comment if you would like | Date |
|---|--|--------------------|
| 1 | <p>Although this seems like a lot of money - it doesn't meet the needs of the individual or those caring for their individual. In comparison to what it would cost to house these individuals in private homes in the community OR in a facility vs. at home we still save the state a LOT of money - help us out by being able to offer higher wages for those who work with individuals requiring more care than those who don't (walking vs. wheelchair and often severely developmentally disadvantaged) so that people will want to work and stay on with these individuals. Give us more respite funding. Treat parents who have their adult individuals at home the way the providers in the community (private homes, group homes) are treated compensation wise. I for one, am unable to work. I'm a single mom and my adult requires 24/7 care for which I can NOT count on LNA's. I need to sleep while he's at day programming and the most sleep I get at one time is 4 hrs max and that's while he attends day program. I'm getting older and I feel it. I also feel resentment of how I will be of retirement age - have no social security benefits to draw from, have no IRA's to draw from (because I can't afford to contribute money to one) because I already live off the system and get nothing monetarily to care for my individual. Put families like mine, out of such severe poverty. Don't penalize those who've stepped up to the plate...we didn't ask for our situation to be like it is.</p> | 12/8/2013 7:42 PM |
| 2 | This is just for the community support budget | 12/8/2013 11:13 AM |
| 3 | For the total of the services provided. Medicaid also receives \$ for \$ Federal monies to match their fundings, as I understand it. Never-the-less, these services necessary, the amounts spend for this individual would reach a far greater level of cost, if this individual were to be in an institution, where the individual would regress and at today's level of cost of care this approximated annual budget is a fraction of what it would cost under a different setting. Again, the above asked for the Medicaid \$ amount, not for the \$ by \$ match. | 12/5/2013 10:54 PM |
| 4 | Not realistically sure. But it is expensive | 12/5/2013 10:19 PM |
| 5 | As with any medical care all the costs should be known by providers and recipients. I've never been told the cost of services provided. Although some services are expensive, they can result in less costs in the future. | 12/5/2013 6:43 PM |
| 6 | I know my IHS budget but not the Medicaid limits or any Limits of the IEP. | 12/5/2013 1:49 PM |
| 7 | The budget was always a secret, when we were looking for adult services we were told to look at all these places and then when we picked one, it was not the most favorable to the area agency at first. That's like a sales man in a car parking lot to pick a car you like and then after you pick it tell you it is too expensive for you because you didn't know your budget. Very frustrating. In the end we are happy but the initial experience was daunting | 12/4/2013 9:34 PM |
| 8 | I do not understand how my daughters budget keeps getting cut. We waited for this budget and plan for years we finally receive it and it has been cut every year since. Nursing homes do not get their budgets cut. When she was in nursing home they never touched the amount they were allot a year. Every year ours gets cut and the Moore Center gets more money out of her budget. | 12/4/2013 3:05 PM |

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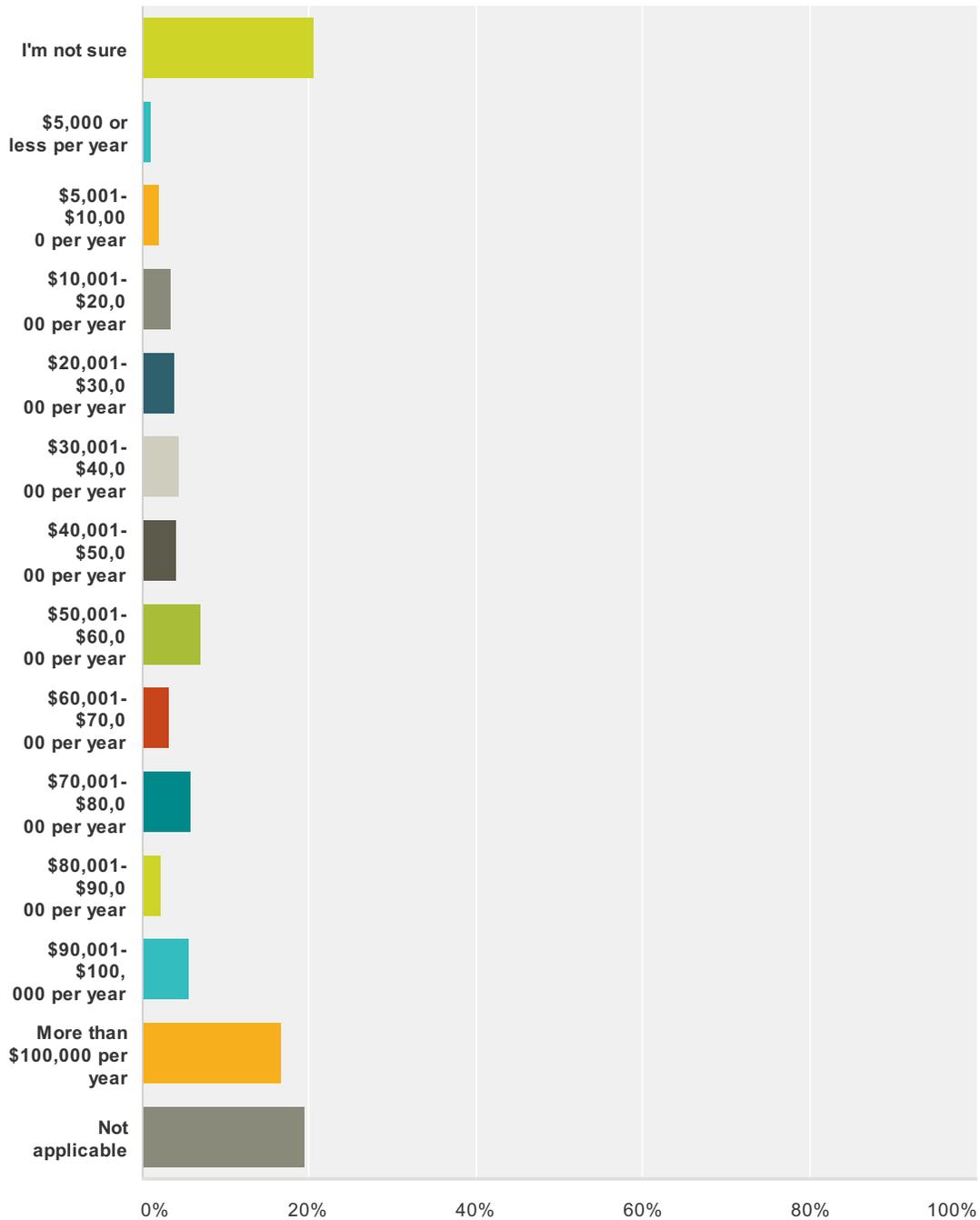
| | | |
|----|---|---------------------|
| 9 | For someone who resides in an assisted living home or nursing home, this budget includes cost of prescriptions and medical appts. | 12/4/2013 12:01 PM |
| 10 | Jess requires 24/7 supervision and teams and specialists to maintain her good quality of life. Farmsteads at one point was going to ask Jess to find another placement because of the intensity of her challenges and not being reimbursed when Jess refused day program. Her funding needs to be more residential than vocational due to her unique issues | 12/4/2013 9:57 AM |
| 11 | However, I really am not certain. | 12/4/2013 8:49 AM |
| 12 | This does not include supported housing. | 12/3/2013 8:51 PM |
| 13 | My son is in a residential placement due to his complex needs. He was placed out of his school district at age 12 and transitioned into a group home at age 21. This is a bit more costly. Most individuals live with their parents which keeps costs down. His annual budget is around \$140,000. We contribute to his care. He comes home every other weekend. He pays rent every month out of his SS Income. We pay his dental bills, buy clothing, provide money for recreational activities, etc. | 12/3/2013 2:03 PM |
| 14 | I feel more funding will need to happen. Paying the Direct care providers a better pay would also keep good people working for our folks | 12/3/2013 11:58 AM |
| 15 | Since a transition to a residential school. these numbers have changed (and funding sources changed a bit) | 12/3/2013 9:28 AM |
| 16 | Not sure what the current amount is, at one time several years ago it was slightly over \$53,000 | 12/2/2013 2:34 PM |
| 17 | Each budget is specific to the needs of the individual receiving services | 12/2/2013 2:00 PM |
| 18 | This doesn't include further planning for when we (the parents) are gone. | 11/29/2013 6:11 PM |
| 19 | Just over \$40k including region 10's cut. | 11/29/2013 1:33 PM |
| 20 | Daughter lives with a 24/7 model home-provider. She uses PDMS with Area 5. | 11/29/2013 11:36 AM |
| 21 | This is my budget - I have no idea if it comes completely through Medicaid or not. | 11/27/2013 6:08 PM |
| 22 | Does not include basic Medicaid | 11/26/2013 8:09 AM |
| 23 | I have never been told how much my budget is | 11/25/2013 8:22 PM |
| 24 | I consider myself and my adult son VERY VERY lucky to have a reasonable budget. | 11/25/2013 1:49 PM |
| 25 | Too varied by individual. | 11/25/2013 11:16 AM |
| 26 | The range above does not include pure medical. I am not sure what the total of that is at this point. | 11/25/2013 11:05 AM |
| 27 | This does not include the straight Medicaid dollars that are charged by the home health agency through my sister's Medicaid. She receives 17 1/2 hours per week from the HHA. | 11/25/2013 9:59 AM |
| 28 | There are additional health care costs and perhaps some school related services also covered by Medicaid, but I am unsure of the \$ value. But I am sure they are considerable. | 11/24/2013 8:18 AM |
| 29 | In the family members case I think there may be a budget I do not know what it is. In my sons case if their FSP, IEP, or ISP had budgets I do not know what it was. When I was getting Family Support my youngest's budget was \$330 either annually or every 6 mo. I remember the number but not what it reflected. Unfortunately, although the idea of the support is wonderful and I really need it, I have been increasingly unable to utilize it. I have been trying to complete the renewal package since last year. I am no longer able to get to the office between 2 and 4pm on a Monday to pick up tickets for movie tickets. While still enrolled and when Once my oldest's health issues cropped up in 2009 I have been increasingly unable to keep up with paperwork to request reimbursement for an aide for my youngest. | 11/23/2013 12:09 PM |
| 30 | This amount is for 1 Child enrolled in In Home Supports and 1 Adult in CDS | 11/23/2013 12:06 PM |
| 31 | they all vary | 11/22/2013 5:56 PM |
| 32 | This is the first time we are in a PDS.....historically there was one class the individual attended. So this is progress as we've taken over from the traditional casemanager. | 11/22/2013 3:50 PM |
| 33 | I do not know the precise amount of money dedicated to my sister's services. When she required additional hours of service, however, it was possible to incorporate that time and money into her plan. | 11/22/2013 3:49 PM |
| 34 | \$360.00 per quarter | 11/22/2013 2:54 PM |
| 35 | I've know of several circumstances that budgets are awarded on very innocuous circumstances, some being almost identical but vary by 10s of thousand of \$\$. | 11/22/2013 2:46 PM |
| 36 | Budget is not only for individual services but also includes all of the overhead costs. | 11/22/2013 2:25 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|---|---------------------|
| 37 | there are some large budgets that probably could be scaled down. | 11/22/2013 1:57 PM |
| 38 | The agreement is per year but the area agency breaks it down per month and will not allow you to utilize the funding unless you have enough in the year to date column. | 11/22/2013 1:50 PM |
| 39 | The CIHS waiver. No idea what the school-based services cost. | 11/22/2013 1:33 PM |
| 40 | This is for 24/7 care of the person with all costs of food, clothing, shelter, entertainment, respite, meds, transportation, included. | 11/22/2013 11:46 AM |
| 41 | My annual budget is roughly \$17,000.00, however, that does not include all of Medicaid covered services like medical, dme, etc. | 11/22/2013 11:28 AM |
| 42 | Our need for certain services is sporadic, such as respite. We can't always use the funds because we sometimes can't get time to use the service. We give up the unused budget funds whenever possible, but it is important for us to have the ability to use it when we can. | 11/22/2013 11:27 AM |
| 43 | Not Sure | 11/22/2013 11:24 AM |
| 44 | Our most recent budget provides \$24,700 for direct support plus an additional unknown amount for admin. costs. Last year, that amount was somewhere around \$10,000. | 11/22/2013 11:19 AM |
| 45 | That is a guess. | 11/22/2013 11:04 AM |
| 46 | There is never enough money for all needed services so we have to carefully pick and choose them. | 11/22/2013 10:20 AM |

Q23 What would you estimate that you or your family save the state of NH by caring for yourself or your family member in your home and avoiding institutionalization, out-of-home placement or placement in a hospital or nursing home? This might include the value of the direct care you provide, services and supports provided by other family members, friends, volunteers, etc.

Answered: 571 Skipped: 321

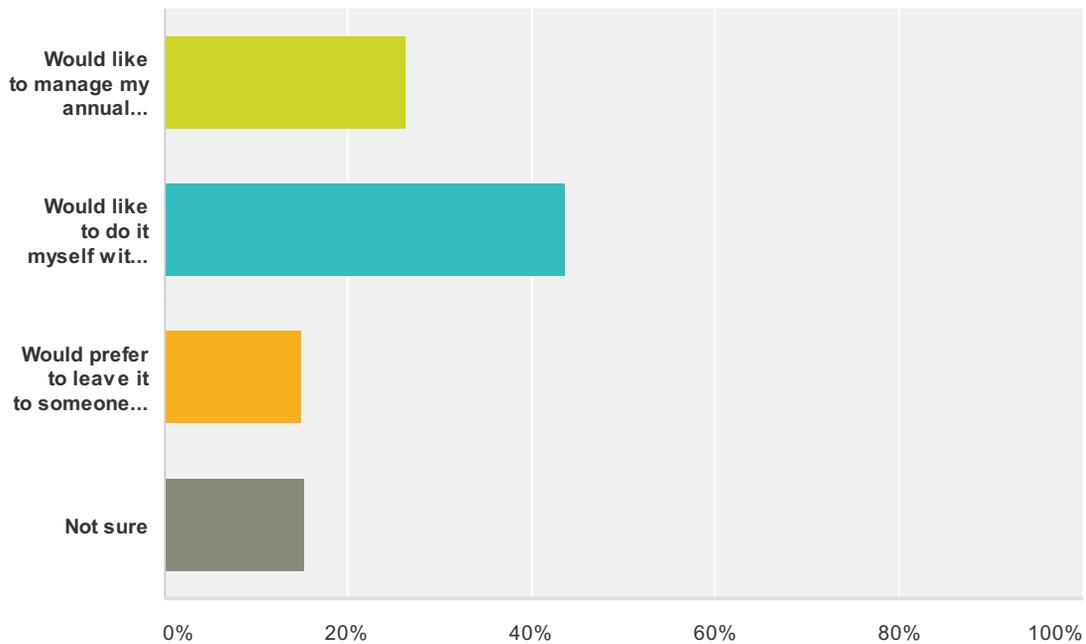


NH Medicaid Long-Term-Care Program Survey

| Answer Choices | Responses | |
|------------------------------|-----------|------------|
| I'm not sure | 20.49% | 117 |
| \$5,000 or less per year | 1.05% | 6 |
| \$5,001-\$10,000 per year | 2.10% | 12 |
| \$10,001-\$20,000 per year | 3.50% | 20 |
| \$20,001-\$30,000 per year | 3.85% | 22 |
| \$30,001-\$40,000 per year | 4.55% | 26 |
| \$40,001-\$50,000 per year | 4.03% | 23 |
| \$50,001-\$60,000 per year | 7.01% | 40 |
| \$60,001-\$70,000 per year | 3.33% | 19 |
| \$70,001-\$80,000 per year | 5.95% | 34 |
| \$80,001-\$90,000 per year | 2.28% | 13 |
| \$90,001-\$100,000 per year | 5.60% | 32 |
| More than \$100,000 per year | 16.81% | 96 |
| Not applicable | 19.44% | 111 |
| Total | | 571 |

Q24 If you were to have a flexible annual services account and budget through Medicaid, would you prefer to have the ability to manage it yourself and move money around in the account to spend more on services which are more important to you and less on services that are not as important? Or would you rather leave that to someone else and perhaps have less flexibility?

Answered: 537 Skipped: 355



| Answer Choices | Responses | |
|---|-----------|------------|
| Would like to manage my annual services account and budget myself | 26.26% | 141 |
| Would like to do it myself with help | 43.58% | 234 |
| Would prefer to leave it to someone else | 14.90% | 80 |
| Not sure | 15.27% | 82 |
| Total | | 537 |

| # | If you answered "Leave it to Someone Else" or "Not Sure," what might make you comfortable in managing it yourself? | Date |
|---|--|------|
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NH Medicaid Long-Term-Care Program Survey

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| 1 | Okay - so this is a loaded question. I already can and do manage the budget to a POINT. However, I will not compromise services my individual NEEDS for my own needs...ie: more respite funding line item vs. therapies, day services etc.). Consistency is HUGE for my individual. I refuse to go totally self-manage by doing his day programming hiring etc., because when I was told that he would get more from my doing so and I had had enough of his day services provider - he was going to get LESS. Yes, you read that right - less. Not to mention that I would be then doing EVERYTHING and getting nothing for doing it except MORE stress. Plus - how ironic it is that if one goes completely self managed - that money is TAKEN away from the budget for doing so...really? And yet, I'd get no compensation for taking over the added burden. | 12/8/2013 8:13 PM |
| 2 | Knowing there would be enough money to provide all the services she currently has. | 12/7/2013 6:13 PM |
| 3 | Frequent checkups that I am staying within budget | 12/7/2013 11:57 AM |
| 4 | Afraid that I wouldn't have all the money that I would need. Life changes and so does needs. | 12/6/2013 11:10 PM |
| 5 | My sister is my guardian and she and PathWays manage it. It works well that way. | 12/6/2013 6:07 PM |
| 6 | I don't feel that I have the clarity of mind to do this myself. As I get older I find myself getting more scattered. | 12/6/2013 3:32 PM |
| 7 | My family member is an adult, unable to do this himself. It would be best if someone else was able to do it for him. | 12/6/2013 2:45 PM |
| 8 | not sure we will be able to manage for our child by the time it is needed - when we are older | 12/6/2013 1:25 PM |
| 9 | SOME input/guidance from someone else, who actually understands mental illness and can be firm but sympathetic. | 12/6/2013 12:29 PM |
| 10 | The clients and family members I work with indicate they would be very interested in managing their account, but would need support and guidance since this is completely new to them | 12/6/2013 11:36 AM |
| 11 | Because of the volatile nature of my daughter's mental health issues, I do not want to be responsible for hiring and managing staff. I want to be involved in the planning, I want to understand the costs, but I do not want to be responsible for the day to day management of her program. | 12/6/2013 10:59 AM |
| 12 | a case manager assigned to those under psychiatric care is necessary. HIPPA is not helpful when dealing with a mentally ill person who manages their own accounts and own care without a family member being involved with the plan. | 12/6/2013 10:05 AM |
| 13 | I am not an expert at providing care through our patch work system of services and organizations. I am a computer professional with deep expertise in that area, when I need legal assistance I go to a lawyer, when I need financial assistance I go to a financial planner... this is no different and I would argue more important since we are dealing with individuals who do not have the ability to advocate for themselves and need more assistance | 12/6/2013 10:00 AM |
| 14 | Documentation is a big issue. I pay for everything for my son while he is with me. Trying to separate out and document how I spent the money would be cumbersome. For instance, a previous care provider saw my son when visiting and they discussed a movie. She said they might make plans some day to see it together. I suggested that if they went together, I would pay for it. They made a date for this Saturday night when I will be out of town. By my volunteering to pay for the movie tickets, I got my son out of the house with a person I did not have to pay other than the movie ticket. I found a course in video game design which was just starting. It is the only thing my son has show. An interest in. I explained the mental health issues of my son & asked if they could tutor him. Since it is a start up and no one else is in the advanced class, I got my son to agree to go to the studio twice a week. Another son who works said he would change his work's heddle and take it with him offering him transportation and insuring that he overcomes his fear of leaving the house when I offered to pay for him to take the course as well. | 12/6/2013 9:52 AM |
| 15 | As a knowledgeable outsider looking in I feel that having that checks and balance person would be good. Allow people to express what the money should be spent on but have someone readily accessible to discuss whether this is the best option. Hopefully by doing this the money would last and be used most effectively. | 12/6/2013 9:49 AM |
| 16 | I just saw this survey yesterday, 24 hrs before the closing of this survey & I do not have time to think...wondering about the choice of doing it myself with help but just not sure..wondering if some of my services would be cut if things were simply allocated by money needs evaluation..Pleasure is a NECESSITY in life...and that IS NOT CONSIDERED when a person is on any benefits. | 12/6/2013 9:48 AM |
| 17 | Don't have the time and we need something in place when we're gone | 12/6/2013 9:34 AM |
| 18 | My son only gets food stamps and case managent. Not sure what Medicaid pays for. | 12/6/2013 9:15 AM |

NH Medicaid Long-Term-Care Program Survey

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| 19 | i think that since i am at the end stage of life-do not think there is anything that the state of new hampshire could do to make me comfortable in managing a budget for my brother from the area agency set up. | 12/6/2013 8:34 AM |
| 20 | Wouldn't know what I should spend my account on.. medication, doctors, infusion, psych services...what is more important??? | 12/5/2013 10:47 PM |
| 21 | My age makes it difficult to be as involved as I would like | 12/5/2013 10:45 PM |
| 22 | I can't manage it. With severe mental illness it's too stressful and confusing. Additionally, my family might try to take it from me. | 12/5/2013 10:10 PM |
| 23 | Not sure this exists for my son in the mental health area. | 12/5/2013 9:50 PM |
| 24 | Lakes region community services does an excellent job ensuring my brother is taken well care of and finances are so organized | 12/5/2013 9:37 PM |
| 25 | Nothing would make me comfortable. It is hard enough each and everyday to care for my sister. Stress levels are very high and I do not need any extra stress worrying about the money and what else I need to do. I really like things the way they are. | 12/5/2013 8:29 PM |
| 26 | I am a case manager and social worker myself and have concern about the quality or services available at this time due to budget cuts and experienced workers retiring/leaving the system--I would need to be involved to monitor effectiveness and progress of worker and plan. | 12/5/2013 7:02 PM |
| 27 | Neither. How do you quantify when the need has volatility? | 12/5/2013 6:39 PM |
| 28 | I am not over loaded with time as I work and take care of my daughter. | 12/5/2013 11:19 AM |
| 29 | Supported decision making. | 12/5/2013 10:21 AM |
| 30 | I have this method now working with the Area Agency. | 12/4/2013 10:19 PM |
| 31 | Now that my daughter does not live at home after 22 years of total care which would have cost the state over \$100,000/ year to have her in Crotched Mountain from birth I prefer to let her case manager and the manager of her home manage her services as they are the ones providing it to her now. Due to her medical needs she became too much for our family to manage on our own at home | 12/4/2013 9:37 PM |
| 32 | The help I would need would be in doing spread sheets and the math, but I would definitely know how to move the money around to suite my needs. | 12/4/2013 9:18 PM |
| 33 | I budget funds for transportation so that I could get to medical appointments, apply for jobs, pick-up my prescriptions, do my grocery shopping, volunteer, as well as attend advocacy meetings in Concord. | 12/4/2013 8:02 PM |
| 34 | I do not live in NH so would not feel easy about it | 12/4/2013 5:24 PM |
| 35 | I spend my days working on federal forms for homeless students, Title I, Title II, Title IX and Rural/Low income grants. I am responsible for writing Federal Focus School Plans and managing the accountability piece of education for a moderate sized school district. The last thing that I want is to come home and deal with more complicated paperwork and budgeting that is strict. Nothing would make me happy with needing to manage yet another federal account. | 12/4/2013 2:38 PM |
| 36 | We did have a flexible situation which was managed by my mother-in-law. When she died, my father-in-law (who speaks English as a second language) could not manage it, so now I would prefer to leave it to someone else, but we are having a hard time "enacting" this plan. | 12/4/2013 12:27 PM |
| 37 | I don't have time to learn how everything works and work my job and take care of my daughter too. | 12/4/2013 12:10 PM |
| 38 | Would not be able to manage money for programs what would be needed the most or how to apply. | 12/4/2013 10:50 AM |
| 39 | If I knew how much would be available in time of crisis? If you have a budget and are managing it yourself what happens if a crisis occurs and there is nothing left in the budget? | 12/4/2013 10:00 AM |
| 40 | Team could help | 12/4/2013 9:58 AM |
| 41 | Some individuals and families do need assistance with developing realistic priorities | 12/4/2013 9:52 AM |
| 42 | N/A | 12/4/2013 9:31 AM |
| 43 | I have a combination that works for us, day program we utilize staff at the agency but have an individualized program which is great and I do not manage the money for that, but do manage the money and respite people for the care of our son as parents/ guardians as his home providers. | 12/4/2013 8:31 AM |
| 44 | I do not have the knowledge our case manager has, and the family members are now in our 60s and dealing with our own aging issues. | 12/4/2013 6:59 AM |

NH Medicaid Long-Term-Care Program Survey

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| 45 | it should not be expected that a family member would manage the individual alone. That in and of itself is a full time job. speaking for myself there would be no way that I could work my current FT and part time jobs AND manage my child's living arrangements / coordinate his daily care and remain intact myself. It does take a village to raise an individual with disabilities..... | 12/3/2013 11:10 PM |
| 46 | My client is legally incapacitated and managing a budget would be beyond my training and experience. | 12/3/2013 10:08 PM |
| 47 | Does the person creating this survey have any idea the amount of knowledge, organization, and time it takes to manage a service budget, run a program, find providers, fill out paperwork, evaluate, assess and create changes where and when necessary for our loved one??? I would definitely prefer to leave it to someone else, because I am exhausted and old and held hostage by my adult son's disability. | 12/3/2013 8:55 PM |
| 48 | Nothing. As a legal guardian, I do not wish to oversee my ward's budget. | 12/3/2013 8:18 PM |
| 49 | have done it, takes a team | 12/3/2013 7:21 PM |
| 50 | I like how it is now. I gave the information that I felt Megan needed for her plan, provided the jobs and goals etc and the Moore Center staff helped create the budget to get Megan what she needs | 12/3/2013 4:34 PM |
| 51 | The Person Centered Plan (525) offers this ability already.. with oversight from the area agency. | 12/3/2013 3:29 PM |
| 52 | Due to the fact that my husband and I are aging, it gives us peace of mind to know that this is managed by someone at our Area Agency and the vendor who knows and cares about his needs. We are unable to care for him 24/7. It's impossible. Also, it gives us peace of mind about his future when we will no longer be here to watch over him. We had a say in how he will live out the rest of his life. Someone else, possibly a stranger, won't be making the decision of where he will live upon our passing | 12/3/2013 2:11 PM |
| 53 | Taking Gateways completely out of the picture would considerably more efficiently utilize Medicaid funds from the state and the federal government in a more individualized and meaningful way. Right now, the entity receiving the most benefit from the current NH Medicaid system is Gateways - and similar entities throughout the state - together with their "preferred vendors" from which Gateways clients are forced to purchase their services rather than more professional or more individually appropriate vendors selected by families of the disabled. | 12/3/2013 1:16 PM |
| 54 | The agencies that provide services take the major part of the budget which really gets me irritated while those people who directly take care of our folks get crap pay. Like I said before more of our budgets should go to the Direct Care Staff instead of making the CEOS and higher ups rich. This is just wrong. I would need help if I were to manage it myself. I got a copy of my budget and I was so angry at where my money is going. Sure not going to Direct Staff Providers where it should be going. These people should be making \$15 to \$20 an hr with benefits They have a lot of responsibility daily. | 12/3/2013 12:02 PM |
| 55 | I would need to see how the system would work and what it would take to manage the account before i would answer this question | 12/3/2013 11:02 AM |
| 56 | We donot have the ability to get to talk wih agencies etc. as nither of us drive so we would have dfficulty managing it ourselves. | 12/3/2013 10:26 AM |
| 57 | I want to comment here anyway. I think more families should be REQUIRED to manage their own account. If they can't, then they should receive help to teach them how to do it – and audit them as frequently as needed. Too much overhead to people pushing papers - use the money for the individual. Too much worry about fraud. Families are more fiscally responsible than some for-profit organizations. | 12/3/2013 9:31 AM |
| 58 | As a staff who support families and individuals direct their services, it is important that they have the flexibility to move the fund to where they need most in their situation. It is important to assess the whole picture of the person's needs, including their families with which they live with. | 12/2/2013 4:33 PM |
| 59 | I prefer to have the area agency manage it with my input. They have the experience and expertise not to mention the time involved to coordinate all facets of required services. | 12/2/2013 3:51 PM |
| 60 | If I didn't have a full-time job outside the home and then have to provide the evening and weekend coverage for our son I wouldn't mind trying to manage the funds with help. | 12/2/2013 2:36 PM |
| 61 | I think that some individuals may have the ability to manage a budget themselves, whereas others would not have the capability. Also there would need to be oversight so that abuse of the system does not take place. | 12/2/2013 10:46 AM |
| 62 | I like being able to manage it myself but it can be difficult to do since it can take a lot of time. Do other populations (other than individuals with developmental disabilities) have the accountability tied to receiving Medicaid funds? If not, is this a fair practice? As a parent/family member, we do the best we can everyday to use these funds to promote growth, does accountability need to be so stringent? | 12/2/2013 10:42 AM |

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| 63 | Nothing. I want Gateway's help with this. I still have control on where and how to use it. I can't be doing payroll, taxes, benefits for my direct support providers. I can't and shouldn't be doing supervision. I can't be objective - It's my home, my kids! We need a third party (Gateway's). This system works very well and it's very efficient. Don't Screw It UP!!! | 11/29/2013 6:31 PM |
| 64 | But... need to have someone in place to take over when we are not able to do this anymore. | 11/29/2013 6:12 PM |
| 65 | We already use the PDMS model with support from MDS. | 11/29/2013 11:38 AM |
| 66 | Deeper understanding of the Medicaid system. | 11/28/2013 8:31 PM |
| 67 | I am already getting help thru local area agency "Gateways" | 11/28/2013 3:38 PM |
| 68 | Could use some money on a therapy that actually has shown good results; massage therapy. | 11/28/2013 5:40 AM |
| 69 | I have no complaints with the current arrangement | 11/27/2013 11:27 AM |
| 70 | N/A | 11/27/2013 11:21 AM |
| 71 | I would blow it all, it is better that I get the help. | 11/27/2013 8:44 AM |
| 72 | Unable to afford continued care at home--not enough services! Parent was institutionalized and died as a result of a Stage 4 pressure ulcer | 11/26/2013 10:21 PM |
| 73 | My husband and I are elderly and my health is not good so would find it stressful to handle more than we already are. There can be a burnout point with parents as they age. Our family is small and our only other child has health issues of his own. | 11/26/2013 11:34 AM |
| 74 | I currently manage the funds myself and it works until the agency realizes we have been able to save funds so they want to reduce my budget for the following year. It is fine with me if they want to take the funds that I have saved to help another family with a one time expense but I cannot guarantee that I will be able to save funds the following year - this then becomes a punishment for having been careful with taxpayer dollars. | 11/26/2013 10:57 AM |
| 75 | I would want to be able to confer with trained people to help me budget, plan and prepare for the unexpected problems that arise. | 11/25/2013 9:15 PM |
| 76 | I have a monthly budget not an annual budget. | 11/25/2013 2:04 PM |
| 77 | Many families do not have the time, energy, or desire to be this involved with care needs of their adult in care. many want to move on with their own lives and assist the individual to move on as an independent (as possible) adult. | 11/25/2013 11:18 AM |
| 78 | Please, please, please....I am begging for this option. Children with autism are so unique and no two kids require the same services. An area agency and the current system is unable to accommodate these differences. By the time you get the 20 people in the middle to agree to your child's needs, the need or the opportunity has passed. We all take advantage of the generosity of others in the way of grants/gifts so being able to move previously budgeted money to an area you thought you wouldn't be able to accommodate is invaluable. The management is best handled as close to the recipient as possible. This option does not mean someone CAN'T get help it just leaves the option to NOT have help open. | 11/25/2013 11:09 AM |
| 79 | It's essential to have a contact person who is reachable to receive guidance and support when needed. We currently have this. | 11/25/2013 9:43 AM |
| 80 | learning to make good choices on how to spend money the right way. | 11/24/2013 7:32 PM |
| 81 | If the funding was equal to or greater than our son receives now and no restrictions on the programs, transportation or service agency we choose to use | 11/24/2013 6:03 PM |
| 82 | Would want the area agency case manager to assist with this to keep families updated on policies and procedures that are new or coming in the future. | 11/24/2013 1:29 PM |
| 83 | We currently have self-directed services and can do this. It works well when you have a knowledgeable staffer supporting you who can help identify allowable versus ineligible services and costs in a timely manner when asked. It is complicated, though, and requires a lot of reporting and record keeping. It should be an option but might not be best for all families who do not want to be responsible for the administrative management of services. | 11/24/2013 8:22 AM |
| 84 | Could save me a lot of money since there are many that take "pieces" of funding out now and it is not necessary. | 11/23/2013 11:22 PM |

NH Medicaid Long-Term-Care Program Survey

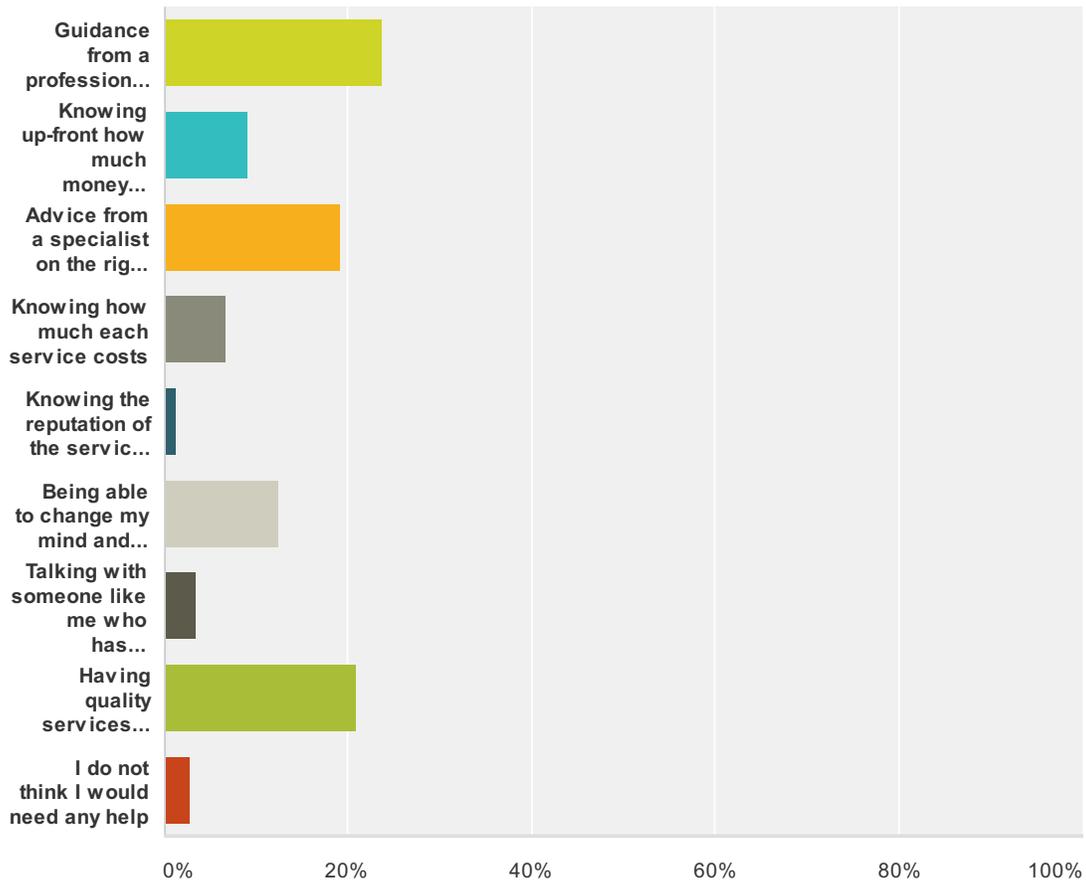
| | | |
|-----|---|---------------------|
| 85 | Regarding my children. If this meant I had a budget with a list services and constraints (a check book or debit card) and only had to send copies of the statements to someone (via email). I would be comfortable doing it myself. Or something like it. In other words if I could do it in the middle of the night without reams of paper needing to be filled out. Ex online forms like this, webpages to read. Someway to ensure that the relevant information is accessible and there is a minimum amount of paper to lose track of. I am not afraid of the math part. If it meant I had to fill out forms & statements and then mail or deliver them then I would need help. I would only be able to either talk the info over the phone or send answers to questions via email. I just can not manage the paperwork on top of everything else I am already doing. Regarding the adults siblings, they do not want their big sister or daughter telling them what to do. In that respect a third party would be very helpful. And although I would like to do it I do not know how I am going to fit anything more in. I think more flexibility is better, but I need more information on how to implement. More flexibility is no good, if services are lost because you don't file paperwork on time. | 11/23/2013 12:52 PM |
| 86 | Education of how to budget and account for all the money, with a project plan and annual goal setting. A list of service providers and assistance for over-all plan. | 11/23/2013 7:51 AM |
| 87 | 1. Since I am not my adult son's legal guardian, it would be he who would "manage" the account. I would be concerned about the choices he may make or be encouraged to make (he is very susceptible to "guidance"). With the area agency, I trust our service coordinator and feel that we as parents are appropriately involved along with our son in making decisions. 2. The area agency's contractor has done a great job recruiting DSPs. I don't want to have to find my own DSPs. 3. I don't understand why flexibility is given only to those who manage their own programs. | 11/23/2013 12:39 AM |
| 88 | A huge part of services for my son is knowing that, if something happened to his father and me, a system would be in place. Plus, not having to manage his services now is a huge relief, as we both work, have other children, and cannot continue to provide care now that he is an adult, and has to be on his own. We wouldn't want to have to manage our typical children's finances throughout their adult lives, either, nor, we assume, would most parents. | 11/23/2013 12:38 AM |
| 89 | Would like to make sure that I am fully prepared and educated in what is allowed to be covered by the plan and know of any changes coming ahead of time. Also, I have many commitments already, I may not have the time or knowledge to handle all the services. | 11/22/2013 10:42 PM |
| 90 | I am much more comfortable managing the budget myself. | 11/22/2013 10:26 PM |
| 91 | This sounds like a tricky way to make less money available, by giving us a set amount and expecting us to haggle as individuals with service agencies. I do not like that plan AT ALL. If services are determined to be needed, they should be provided. Period. | 11/22/2013 5:31 PM |
| 92 | I would need a lot of training. I'm 74 years old and feel someone else should handle it with oversight and input from guardians. | 11/22/2013 4:19 PM |
| 93 | I find the prospect of hiring and firing staff undesirable. It is more comfortable for me to work with and through the area agency. I know the area agency would guide me toward mastering the process if we moved to SDS, but that still doesn't make me want to take on the task. | 11/22/2013 3:56 PM |
| 94 | Training regarding how the various choices might effect the services | 11/22/2013 3:53 PM |
| 95 | Its just not enough money to help us. \$360.00 per quarter doesn't even work if I cant find respite. Would help if I could use the money for her after school program that's outrageous in cost | 11/22/2013 2:57 PM |
| 96 | Been there done that, both ways and found out the hard way that to much of the pie does not go to the ones that it is intended for. I realize that there are expenses, but know that much is wasted on things that really do should not be supported on the backs of our annual budgets. Would like to be able to eliminate the area agency from the management process or at least reduce their "take" from the budget. | 11/22/2013 2:46 PM |
| 97 | This would be a dream. The are agencies have too much power and low quality employees | 11/22/2013 1:51 PM |
| 98 | Things are going well - why change? | 11/22/2013 1:34 PM |
| 99 | I would be more comfortable managing the funds myself, if I knew what was involved. Also, simplified benefits filing. | 11/22/2013 1:20 PM |
| 100 | I currently am not involved in self-directed services. The main reason is that I must continue to work full time out of the home and hiring his staff, monitoring the services given, dealing with personnel issues, etc., is just too much. When I'm not working, I'm focusing mostly on working with my adult son and reminding him to take care of his ADLs, follow up on necessary paperwork for SSI, Medicaid or his job, etc. There is just not enough time in the day to add managing his annual services account. | 11/22/2013 12:23 PM |
| 101 | Prefect example Day ProgramMandatory 30 a week... Not something everyone wants | 11/22/2013 11:35 AM |

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| | | |
|-----|---|---------------------|
| 102 | Having the education & knowing all the right people to assist me to make it happen. | 11/22/2013 11:27 AM |
| 103 | We are told that we currently have this ability. | 11/22/2013 11:21 AM |
| 104 | We don't have an in depth knowledge of the system and feel that we get optimal services when managed by a professional that will provide life long continuity | 11/22/2013 11:04 AM |
| 105 | more work for me to do. With all the paperwork that needs to be filled out. No time to do it, But how can I trust someone to do it how do they know wht is needed or not needed | 11/22/2013 10:40 AM |
| 106 | I don't want to do MORE work. The agency needs to do the hiring and supervising. I see this desire to "manage services" as a way for the Agency to do less. They need to do more. | 11/22/2013 10:26 AM |
| 107 | paperwork is daunting wouldn't know how to go about finding people to help don't want to be my child's provider forever (dependence) | 11/22/2013 10:24 AM |
| 108 | We currently manage our budget and it aligns with services we receive | 11/22/2013 9:57 AM |
| 109 | I have chronic conditions so that's why I have done it this way, and that way if something should happen to me at least things are a little in place | 11/22/2013 9:56 AM |

Q25 If you could only choose one thing, what would help you the most in developing and managing a flexible, annual Medicaid services account and budget for yourself or your family member?

Answered: 517 Skipped: 375



| Answer Choices | Responses |
|---|------------|
| Guidance from a professional who knows how the system works | 23.79% 123 |
| Knowing up-front how much money I have to work with | 9.09% 47 |
| Advice from a specialist on the right mix of services and supports for me or my family member | 19.15% 99 |
| Knowing how much each service costs | 6.77% 35 |
| Knowing the reputation of the service providers I have to choose from | 1.35% 7 |
| Being able to change my mind and change my plan and budget whenever I need to | 12.57% 65 |
| Talking with someone like me who has more experience in this than I do | 3.48% 18 |
| Having quality services available locally | 20.89% 108 |
| I do not think I would need any help | 2.90% 15 |
| Total | 517 |

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| # | Other (please specify) | Date |
|----|--|--------------------|
| 1 | I think it's important to note that even though we were only able to select the most important to us - that there are several things mentioned that follow the most important issue to me. | 12/8/2013 8:15 PM |
| 2 | I think all of the above would be important, but I suppose knowing up front the amount of money to work with would be the most important first step | 12/7/2013 8:29 AM |
| 3 | How can you choose only one when they all apply | 12/6/2013 11:18 PM |
| 4 | In our case the services were fragmented because of our son's denial and avoidance of what care we were trying to set up for him. | 12/6/2013 11:41 AM |
| 5 | ALL OF THE ABOVE...if someone is working for their paycheck, don't they need ALL OF THE ABOVE ? Why do Money situations seem different for us of lower means who get benefits ? Are we NOT REGULAR HUMAN BEINGS in this difficult society ?? | 12/6/2013 9:50 AM |
| 6 | N/A | 12/5/2013 9:51 PM |
| 7 | Persons with ABI and their families are often overwhelmed by the process of planning a return to the community and require professionals knowledgeable about their family members needs and the systems in NH to make educated decisions. Not everyone with ABI can go home or their families do not have the ability to manage an account like this on their own. | 12/5/2013 12:07 PM |
| 8 | understanding choices available | 12/5/2013 8:51 AM |
| 9 | We also have problems with qualified people to care for our son in home for respite. This does not include his daily program. We are very happy with his daily caregiver. | 12/5/2013 8:43 AM |
| 10 | All these are important, I can not choose one of the above that would help me the most. I need to know the amount of money I have to work with, but also need to know what the services cost and also need to know the reputation of the providers and of course the nature of disabilities requires the flexibility to change a plan as needed. I also need guidance from a professional who knows the system as well as advice from specialists on the right mix of services and supports needed. I can not pick one. | 12/4/2013 10:09 PM |
| 11 | I understand budget development and cost planning | 12/4/2013 3:12 PM |
| 12 | In addition to having the flexibility to change when necessary, it would also be important to maintain a team, which would include guidance from a professional who truly understands how the system works. | 12/4/2013 1:50 PM |
| 13 | Actually several of these services would help. | 12/4/2013 10:02 AM |
| 14 | Farmsteads is only 45 minutes away!!! | 12/4/2013 9:59 AM |
| 15 | Since such a plan already exists and is in-place, again, what would help most is to know WHY? | 12/4/2013 9:57 AM |
| 16 | I do like to know what we are working with, as I do for the home provider provision, I think I know as before I did what the cost of day programming personnel costs so, it's good! | 12/4/2013 8:33 AM |
| 17 | still would not be enough to provide for the individual(s). | 12/3/2013 11:11 PM |
| 18 | These are odd choices and each person or family needs access to ALL of them. | 12/3/2013 8:56 PM |
| 19 | its a very difficult process that takes a team, or if the person taking care of it is retired and that is there whole life | 12/3/2013 7:22 PM |
| 20 | Having the ability to develop the budget based on actual needs and associated cost of service rather than on available funding. Most of the statements are important, and some equally so. | 12/3/2013 4:39 PM |
| 21 | And having folks with more experience to be sure all Megans needs are met | 12/3/2013 4:35 PM |
| 22 | Options for quality service providers are very, very limited in NH. I believe this is a function of low hourly reimbursement for direct service providers, limited incentives to work with adults with disabilities, limited training workshop opportunities for those wanting to work with adults with disabilities, lack of positive behavioral support and training for those supporting adults with disabilities, and also lowered expectations for continued growth and development of adults with severe disabilities. | 12/3/2013 3:33 PM |
| 23 | This doesn't seem like a fair question. It's never only one thing in our situation. | 12/3/2013 2:12 PM |
| 24 | I have already created a strong and supportive team of doctors and teachers who have known our family for many years and whom I trust to make professional recommendations - unlike the unqualified and condescending staff at Gateways. | 12/3/2013 1:20 PM |
| 25 | Gateways in Nashua has been exceptional | 12/3/2013 12:51 PM |

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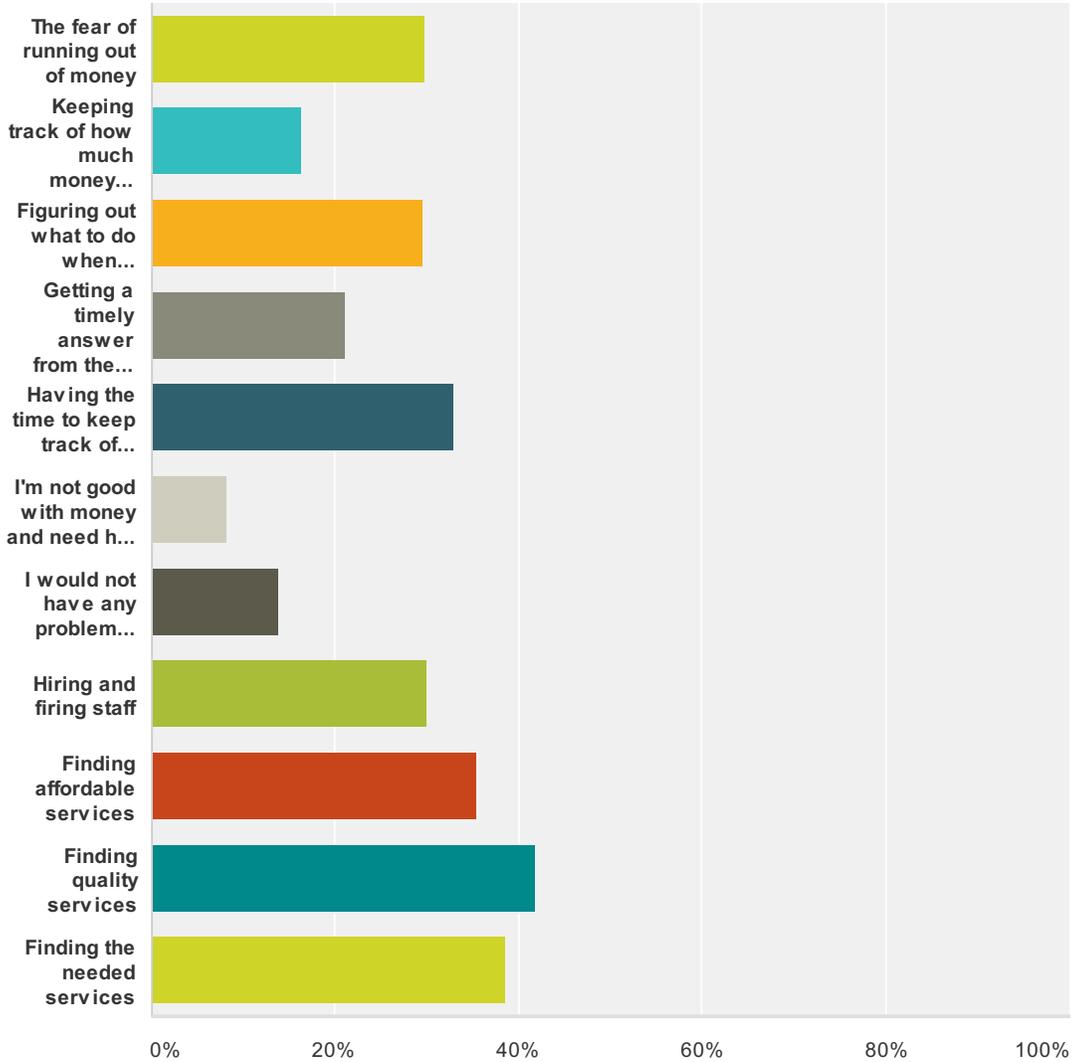
| | | |
|----|--|---------------------|
| 26 | We need to keep our local agencies open. I never knew how important their needs were until my son reached 21 then oh boy, I do not know how I would have made it without them. Budget is so important also and being able to change it if necessary. We gets peanuts compared to others with disabilities. | 12/3/2013 12:04 PM |
| 27 | Not having to change the providers we currently have. | 12/3/2013 11:09 AM |
| 28 | Being able to adequately compensate them wouldn't hurt either. | 12/3/2013 9:16 AM |
| 29 | We fell in with an OT service provider who suddenly closed her office, leaving us without warning or notice. It took over a year to get my son's records. Turns out she was being investigated by the Atty. General's office. Horrible experience. In the meantime, his skill level deteriorated because we had no written plan to work from. | 12/2/2013 5:09 PM |
| 30 | Families need the support to accomplish their goals their the son/daughter needs to be successful and have a valuable day. | 12/2/2013 4:35 PM |
| 31 | & ability to change it. | 12/2/2013 12:43 PM |
| 32 | would not do it | 12/2/2013 12:05 PM |
| 33 | Difficult to choose only one thing. | 12/2/2013 10:43 AM |
| 34 | Nothing. Don't want this! Bad idea | 11/29/2013 6:33 PM |
| 35 | Knowing the system is very important. But...having someone to guide you through all of the above is necessary. | 11/29/2013 6:14 PM |
| 36 | And having an increase each year as the costs of services and equipment increases each year. | 11/29/2013 1:36 PM |
| 37 | N/A | 11/27/2013 11:22 AM |
| 38 | The answers to this question aren't framed the way I would answer. You can't develop a plan without knowing what each service costs, and equally critical knowing what services are available, and also having input on which ones are best overall and which ones are going to get the most value in terms of supporting IEP goals and other developmental progress milestone. | 11/26/2013 12:35 PM |
| 39 | I would like to manage the account myself so I don't have to fight with my area agency every week. It would be much better if I had the ability to get all of the expenses approved at the beginning of the year and not have to deal with the area agency every time my child needs something. | 11/25/2013 2:07 PM |
| 40 | I'm assuming that the up-front how much money available is a given. No budget works without this as a starting point. | 11/25/2013 11:11 AM |
| 41 | My husband needs to receive the monthly budget on a monthly basis. | 11/25/2013 10:02 AM |
| 42 | Ridiculous... can't choose just one thing... all of these categories (except for the last option) are necessary to have a high quality system. When it comes to this small part of humanity I am the expert on my child/family member... even the most experienced 'specialist' isn't as knowledgeable as me... currently I educate our specialists about our daughter's needs and they help point us in the right direction. The specialists need to listen to the individuals/families they serve. Bottom line though... individuals and families need to have flexibility and the power to make the most informed decisions based upon their needs. | 11/25/2013 9:49 AM |
| 43 | The Area Agency model works extremely well and should not be changed. | 11/25/2013 9:10 AM |
| 44 | I do not do math well and couldn't manage the account alone. | 11/24/2013 7:33 PM |
| 45 | A streamlined reporting process which would cut out all of the middle people, who are eating away at the budget, so that my child would have more of the funds and be able to do more things. Have those families who use CDS have Gateways available for consultations and charge the budget per hour for their services only when needed. | 11/23/2013 10:09 PM |
| 46 | Things change, people change, especially when a crisis occurs. ALL of these things are important to a degree. Some days i just need to role with it. | 11/23/2013 8:13 AM |
| 47 | All of the above, given the amount of paperwork and lack of help finding the right programs with a very medically complex child, I am burnt out and have very little time to invest in more paperwork, scheduling and other tasks | 11/23/2013 4:38 AM |
| 48 | I don't believe this applies to my son's situation. | 11/22/2013 6:51 PM |
| 49 | There are many things involved at different times in any budget process. Services/needs/costs are in constant flux. No one "specialist" could cover it all. We need (and have) a team approach | 11/22/2013 6:25 PM |
| 50 | I do not want to have to find, locate, budget, interview or any other individual management of the Medicaid portion of my daughters care. I prefer to work with our case manager to craft this program | 11/22/2013 5:20 PM |

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| 51 | There are actually several things but you only allow 1 choice. | 11/22/2013 4:21 PM |
| 52 | I don't think there can be just 1 from this list: You need to know total budget and cost of each to plan, you need to have advice from someone with experience and you need to have guidance from a professional who knows how the system works. Advice about the right mix, and having high quality local services are all required to make a successful plan | 11/22/2013 4:08 PM |
| 53 | I think you need all the pieces above to develop and manage a flexible annual Medicaid services account. Knowing I could call on someone with experience, at any time, to direct me to quality, local services is critical. | 11/22/2013 4:03 PM |
| 54 | unknown | 11/22/2013 3:43 PM |
| 55 | What is needed is objective advice about what services are available (including a list of vendors, respite providers,etc.) and help making those contacts | 11/22/2013 3:13 PM |
| 56 | I have learned the most from those that have the least to gain over the years and the least from those that have the most to gain. Not only is it important to know how all the services cost and what all the available services are, and where it comes from so that we can be responsible stewards of public monies. | 11/22/2013 2:46 PM |
| 57 | You need to know the governing rules about what funding can cover. And the approach should be a budget that is consolidated not so many units authorized for this and for that. I don't expect the system to pay for everything but would like a system that would allow paying for more 'normal' 'natural' supports. A thankyou gift for a co-worker who provides supports on the job - \$25/yr is much more cost effective than \$20/hr for 10 hrs a week for 50 weeks a year. | 11/22/2013 2:32 PM |
| 58 | this is something that I am not interested in doing this I find this just places more stress and tension on families. This is why area agency are in place. This choice is unacceptable for my family, I can make more money working within my career than doing this. I need my child to get more than 30 hours of services a week so that I can work | 11/22/2013 2:00 PM |
| 59 | although I do not think that cost matters very much to most individuals | 11/22/2013 1:58 PM |
| 60 | When it comes to formulating a plan for my son, all the best advice I have received has come from other parents -- not from professionals. | 11/22/2013 1:36 PM |
| 61 | working with someone who knows my child | 11/22/2013 1:35 PM |
| 62 | none verbal and serve MR w/ Autism | 11/22/2013 12:48 PM |
| 63 | Again while I work full time outside of the home, unless more hours could be added to a day, I would not be able to do this. | 11/22/2013 12:25 PM |
| 64 | I don't think you can have one without the other. | 11/22/2013 12:07 PM |
| 65 | Larger budget and higher pay for dsp workers | 11/22/2013 11:36 AM |
| 66 | Working full-time and part-time to keep our lives afloat, I don't have the time, knowledge or skill set needed to do everything myself for her, nor would she be as happy as she currently is. When she was home, she receiving services her socialization was minimal, she was unhappy and depressed. Now she has a reason to live, loves her life, friends, staff & lifestyle. | 11/22/2013 11:31 AM |
| 67 | My grandson would like his own place to live but with support system for everything. | 11/22/2013 10:32 AM |
| 68 | I would have no problem if things we're set up in a manner but they should be and follow through | 11/22/2013 9:57 AM |

Q26 What do you find difficult about managing a services account (if you have had one), or do you think would be difficult if you did have one?

Answered: 513 Skipped: 379



| Answer Choices | Responses |
|---|------------|
| The fear of running out of money | 29.82% 153 |
| Keeping track of how much money I have spent during the year | 16.37% 84 |
| Figuring out what to do when unexpected expenses come up | 29.63% 152 |
| Getting a timely answer from the professional who is helping me manage the budget | 21.05% 108 |
| Having the time to keep track of everything | 32.94% 169 |
| I'm not good with money and need help managing it | 8.38% 43 |
| I would not have any problem managing an annual services budget | 13.84% 71 |
| Hiring and firing staff | 30.02% 154 |

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| Finding affordable services | 35.28% | 181 |
| Finding quality services | 41.72% | 214 |
| Finding the needed services | 38.60% | 198 |
| Total Respondents: 513 | | |

| # | Other (please specify) | Date |
|----|--|--------------------|
| 1 | If this were to ever happen - maybe there could be a ledger book to help us keep track - something that has already been proven to work that wouldn't require us knowing spreadsheets etc. | 12/8/2013 8:19 PM |
| 2 | Budget reports are not sent out every month as they are supposed to be, so it is hard to check my account with my mom | 12/8/2013 11:16 AM |
| 3 | The nature of my disability makes it extremely difficult, if not impossible to initiate contact/ask questions/self-advocate, so having someone willing and able to take the time to know me and support me in such things would be immensely helpful. It is, really, essential. | 12/7/2013 10:54 AM |
| 4 | Being controlled in what I want to do. | 12/6/2013 12:33 PM |
| 5 | Juggling all of this. | 12/6/2013 11:37 AM |
| 6 | NH REALLY NEEDS A HALF-WAY PROGRAM FOR PEOPLE WHO COME OUT OF THE HOSPITAL, WITH ENOUGH STAFF SO THERE IS NOT A WAITING LIST. | 12/6/2013 11:08 AM |
| 7 | WE ARE NORMAL HUMANS IN THIS DIFFICULT SOCIETY. | 12/6/2013 9:51 AM |
| 8 | At this time I am not managing services | 12/5/2013 6:31 PM |
| 9 | I would like to see hiring and firing staff but there not been staff is ever gotten fired they they need to be held accountable there no accountable actions against Services Providers today | 12/5/2013 1:16 PM |
| 10 | completing all the paper work involved. | 12/4/2013 10:11 PM |
| 11 | never had one | 12/4/2013 9:43 PM |
| 12 | I would find it difficult to keep track of money spent during the year IF my case manager did not quarterly send me information on what the status of the budget is. Because I receive the regular updates, I can cross-check my records with the records from the Agency. This is an important service for me. | 12/4/2013 1:53 PM |
| 13 | Will not do don't know and want some one locally and prof | 12/4/2013 10:56 AM |
| 14 | Right now we don't know how much services for our daughter costs. How can we give an accurate answer if we don't know the costs and how much money is available and what happens in time of Crisis? | 12/4/2013 10:05 AM |
| 15 | I am not qualified but pathways and famsteads are. please just let me be the Mom!!! | 12/4/2013 10:00 AM |
| 16 | I did do this for a while, but was really doing half and half as I did utilize service costs from the agency which was a Hugh help to us, but the arrangement we have now works well with the agency controlling the day program monies and us as a family managing the home care and respite and other needed expenses with the help of the AA to find caregivers to help with respite/ recreational needs. | 12/4/2013 8:36 AM |
| 17 | poor question | 12/3/2013 6:41 PM |
| 18 | If the services in the agreement were all being fulfilled, then some of the others would come into play perhaps, such as running out of money or being able to access real time budget information. | 12/3/2013 4:45 PM |
| 19 | I think the current choice to families for Participant Directed and Managed Services is a very good option (He M 525) but that there needs to be continued support and oversight from the area agencies to assist in this process. Hiring staff is difficult because the pool of qualified candidates, and the rate of pay for these providers is too low. | 12/3/2013 3:38 PM |
| 20 | This would not work for us. We are aging. Can't do it. | 12/3/2013 2:13 PM |
| 21 | For those who need assistance, a professional health care staff with a proven track record of financial prudence and appropriate care recommendations should be available for consultation - such as Blue Cross/Blue Shield, NOT Gateways. | 12/3/2013 1:23 PM |
| 22 | Most of the above would be difficult without my area agency. They currently manage my sons budget and his services received and it works well. Should not be changed. | 12/3/2013 12:06 PM |

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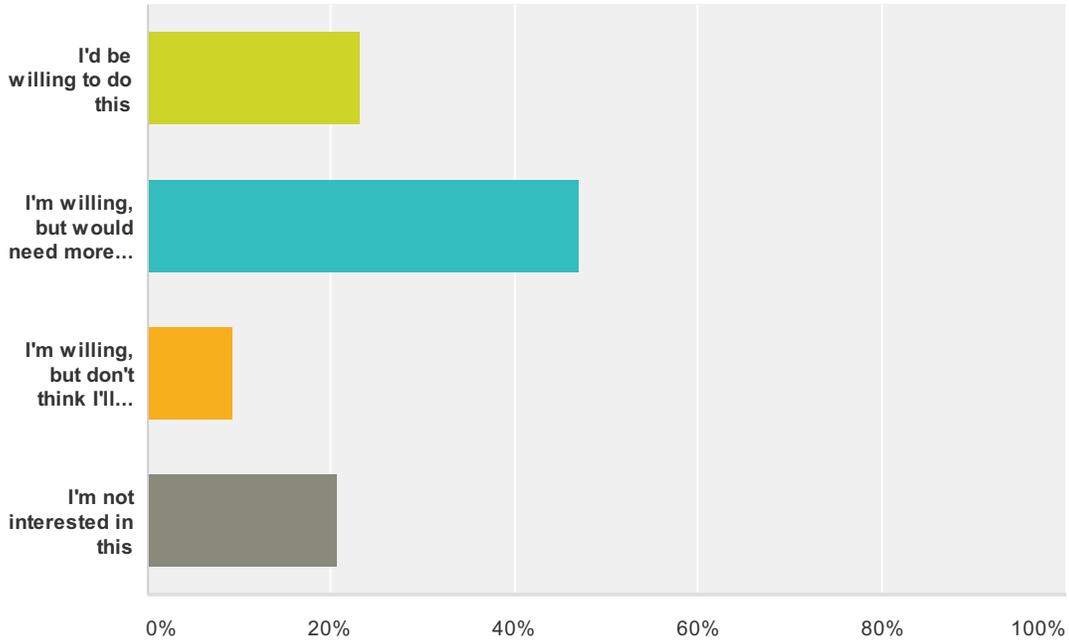
| | | |
|----|--|---------------------|
| 23 | Too much % taken out for overhead for a bureaucrat to manage the account. That \$ should go to client. Audit our family once or twice a year -- offer help if need be. | 12/3/2013 9:32 AM |
| 24 | Families need support and guidance in directing their services | 12/2/2013 4:36 PM |
| 25 | Too much paperwork. Limitations set on mileage. Workman's compensation. Receiving a 1099 form at the end of the year. | 12/2/2013 2:52 PM |
| 26 | All of the above apply when coordinating the services in different ways for each individual | 12/2/2013 2:01 PM |
| 27 | None anticipated. Of course, not being full time, assistance in finding services and seeing how to get what is needed is always required. I.e., a plan that just deposits a check in an account wouldn't work. | 12/2/2013 12:48 PM |
| 28 | n/a | 12/2/2013 12:06 PM |
| 29 | Changing rules. | 12/2/2013 10:44 AM |
| 30 | Finding staff!!! | 11/29/2013 6:15 PM |
| 31 | Fortunately, I do not have to manage multiple staff because my daughter's residential program is "wrap around". My MDS PDMS coordinator & MDS fiscal assistant help me manage the expenses. The PDMS program has made it possible to find a home-provider who is contented with her reimbursement and with working directly with me & with the assistance of the area agency in making the annual ISP. | 11/29/2013 11:43 AM |
| 32 | N/A | 11/27/2013 11:22 AM |
| 33 | These are the problems we currently deal with. | 11/26/2013 10:59 AM |
| 34 | We are just now receiving In Home Supports. Not enough experience yet | 11/26/2013 8:11 AM |
| 35 | The day to day stuff I think would overwhelm me. | 11/25/2013 9:15 PM |
| 36 | Again, not operating with a current budget adds unneeded stress. My husband can not tell where the budget amount reflects for that period of time. | 11/25/2013 10:07 AM |
| 37 | Yes it does require a substantial amount of time managing things, but it's worth it to us to maintain that control of who works with our daughter. It's challenging finding and retaining quality staff that will stick around because we are forced to compensate them so poorly (in order to stretch our budget). I could opt to use a vendor agency, but that is too costly given my daughter's support needs and the size of her budget. | 11/25/2013 9:54 AM |
| 38 | I don't need to know how much money is available in the budget at any given point because I can track that myself. But it be helpful both at the beginning of the year when the budget is created as well as throughout the year when unexpected needs might arise to know what can and cannot be paid by funds in the budget. | 11/24/2013 8:25 AM |
| 39 | In real life I hate hiring & firing staff. In my home life I have never had enough money to hire staff. I pay my unreliable disabled family members to help when they can and work ridiculous hours to compensate. | 11/23/2013 12:56 PM |
| 40 | Currently if I would like to know what we have spent on my son's budget, I have to call Gateways, ask and report is run. Would be nice if it was real-time and I check myself. Also, transportation is a serious and expensive concern. Hard to find and when you do the pricing is very high and unaffordable. | 11/23/2013 12:12 PM |
| 41 | Finding good reliable direct support staff is challenging. Getting my son involved in social outing is even harder... | 11/23/2013 8:14 AM |
| 42 | na | 11/22/2013 10:32 PM |
| 43 | I care for a spouse with alzheimers and my developmentally delayed 30 year old daughter and I work full time. I cannot do all of this | 11/22/2013 5:24 PM |
| 44 | N/a | 11/22/2013 3:53 PM |
| 45 | Individual cannot read nor write, 24/ assistance with all things | 11/22/2013 3:44 PM |
| 46 | getting the support and knowledge to know how to manage a service account, it is a full-time job on top of being the off-hour care givers. | 11/22/2013 2:46 PM |
| 47 | Under my current methodology the Area Agency handles the physical money...payment is based on invoice for services, receipts and payroll. I do not manage direct cash and do not have to get involved in filing taxes and workman's comp etc. | 11/22/2013 2:43 PM |
| 48 | The biggest problem I had with my son's CIHS waiver was the fact that I had to pay money up front and then wait to be reimbursed by the agency. I was essentially giving the State of NH an interest free loan for as much as \$2,000. | 11/22/2013 1:38 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|--|---------------------|
| 49 | doesn't understand | 11/22/2013 12:49 PM |
| 50 | I could check off most of the items above. | 11/22/2013 12:25 PM |
| 51 | Currently have a client directed plan. | 11/22/2013 10:49 AM |
| 52 | I need services done for my grandson, not me to manage | 11/22/2013 10:34 AM |

Q27 How willing would you be to use the Medicaid funds in your annual services account as if it were your own money in order to get the best value for the dollar?

Answered: 520 Skipped: 372



| Answer Choices | Responses |
|---|------------|
| I'd be willing to do this | 23.08% 120 |
| I'm willing, but would need more information on service costs and quality than I have now | 46.92% 244 |
| I'm willing, but don't think I'll get the opportunity | 9.23% 48 |
| I'm not interested in this | 20.77% 108 |
| Total | 520 |

| # | Feel free to comment if you would like | Date |
|---|---|--------------------|
| 1 | I'm concerned with this idea - would we get the total amount that is NOW in the budget or would the state take away funding in the budget like they already do if one goes completely self-directed? I'm not willing to get less of services for my son and me having more stress by doing this. | 12/8/2013 8:22 PM |
| 2 | What services and management are satisfactory as is | 12/8/2013 6:26 AM |
| 3 | Since I already have a full time job, have extensive care giving responsibilities and other time-consuming responsibilities, I am not interested in taking on this task. | 12/6/2013 11:17 PM |
| 4 | not sure how it will affect my income. | 12/6/2013 2:37 PM |
| 5 | Communication problems would be a difficult issue because my son is mentally ill. It works better for him to deal directly with professionals and for my role to be advisory. | 12/6/2013 11:43 AM |
| 6 | VERY very unsure, because who decides how much money I get, AND I have have spending problems like most people in this service category from deprivation of a very difficult past..my mind knows what to do correctly, but I cannot control my habits because of past deprivation and our society always finding ways to trick us into spending money in worthless ways.. | 12/6/2013 9:54 AM |

NH Medicaid Long-Term-Care Program Survey

| | | |
|----|--|--------------------|
| 7 | I think this program would take a lot of education and continued education as services and expenses changed and may in turn cost more money. | 12/6/2013 9:53 AM |
| 8 | Not applicable to providers | 12/6/2013 9:02 AM |
| 9 | I am answering as the mother of a long deceased son. I would have an did spend to help him in whatever way. | 12/6/2013 7:44 AM |
| 10 | I don't want health care vouchers as the conservative political party would like I don't believe healthcare is a entitlement, we should have a national health insurance system as every other western country has. | 12/5/2013 10:54 PM |
| 11 | but need to know that appropriate services would be available and a comprehensive plan agreed upon by each provider. | 12/5/2013 7:04 PM |
| 12 | Currently the state has rules about how much money can be spent on respite, assistive technology, and activities. Sometimes we're willing to give up some staff support and fill in ourselves so our family member can benefit from an activity that goes over the that part of the budget but we aren't allowed to do that. | 12/5/2013 12:56 PM |
| 13 | This concept would be very difficult for most folks receiving the ABD waiver to do, some guardians and family members may want the responsibility but they already manage so much if the person in their family is in supported living, or at home. | 12/5/2013 12:09 PM |
| 14 | Needs too great for family to handle. Had ihswaiver and staffing was always an issue and it often fell to family to cover services Ndle | 12/5/2013 9:39 AM |
| 15 | I am willing to do this but would need more funding based on daughters needs. If the system doesn't get fixed, in the long term, it is going to cost the state more money to support their individuals. It's a lot cheaper for us to assist but soon that is not going to be the case if you don't fix it funding. | 12/5/2013 9:37 AM |
| 16 | I like the system as it works now and don't want to change. | 12/4/2013 10:21 PM |
| 17 | As the account stands now there are line items in the budget that do not get used on a monthly basis and I feel ties up money that could be used for other items BUT those other items are not funded by the service plan so even if the money was released from the line item it can not be used for the current need. To be able to use the medicaid funds as if it were our own money would be helpful to pay for unexpected needs as they arise. | 12/4/2013 10:14 PM |
| 18 | Due to my daughter in the wonderful group home she is in, her annual services are billed by her home for her care. I would not want to presume I would know better than the staff at her home on how to bill Medicaid for their services which are so important | 12/4/2013 9:41 PM |
| 19 | This is what I will be doing over the next year. I want a fulfilled work week for my son. Something that keeps him busy, mind stimulated, safe, and happy. So I will need transportation, care provider, job training for him., and probably stuff I haven't even thought of. | 12/4/2013 9:31 PM |
| 20 | I can not imagine a situation where the most knowledgeable persons (my wife and I) about our sons needs would be given the funds to provide for him. If we left his care totally up to the state it would cost ~\$10,000 per month for his care/protection/housing. | 12/4/2013 9:19 PM |
| 21 | It's about time for consumers to have control of how and where their Medicaid funds are spent!!!!!!! | 12/4/2013 8:05 PM |
| 22 | See previous comment. I don't think my father-in-law (the main guardian) could do this adequately. | 12/4/2013 12:28 PM |
| 23 | I do a lot I would prefer her area agency handle this. It scares me | 12/4/2013 10:02 AM |
| 24 | I don't really get the point of this question - this has been examined, studied, and reported upon Nationally, if not internationally. Families_tend_ to treat such funds as if the money was their own and spend it wisely. Again, there should be a system of checks and balances as there are always exceptions. | 12/4/2013 10:00 AM |
| 25 | The system seems to work fine most of the time. | 12/4/2013 8:52 AM |
| 26 | See previous answers | 12/4/2013 8:37 AM |
| 27 | it is a full time job to manage individuals with a lot of needs....unreasonable to expect a family member who already works 2 jobs to keep a roof overhead and primary private healthcare insurance...way too much to expect of 1 individual. | 12/3/2013 11:16 PM |
| 28 | Way too vast a responsibility for families. | 12/3/2013 8:58 PM |
| 29 | I have managed before difficult process | 12/3/2013 7:23 PM |
| 30 | I already do this. There really isn't much more to do. Aside from some small admin expense, most of the budget is used for DSP. The DSP gets no significant benefits, so it's pretty bare bones now. | 12/3/2013 4:48 PM |

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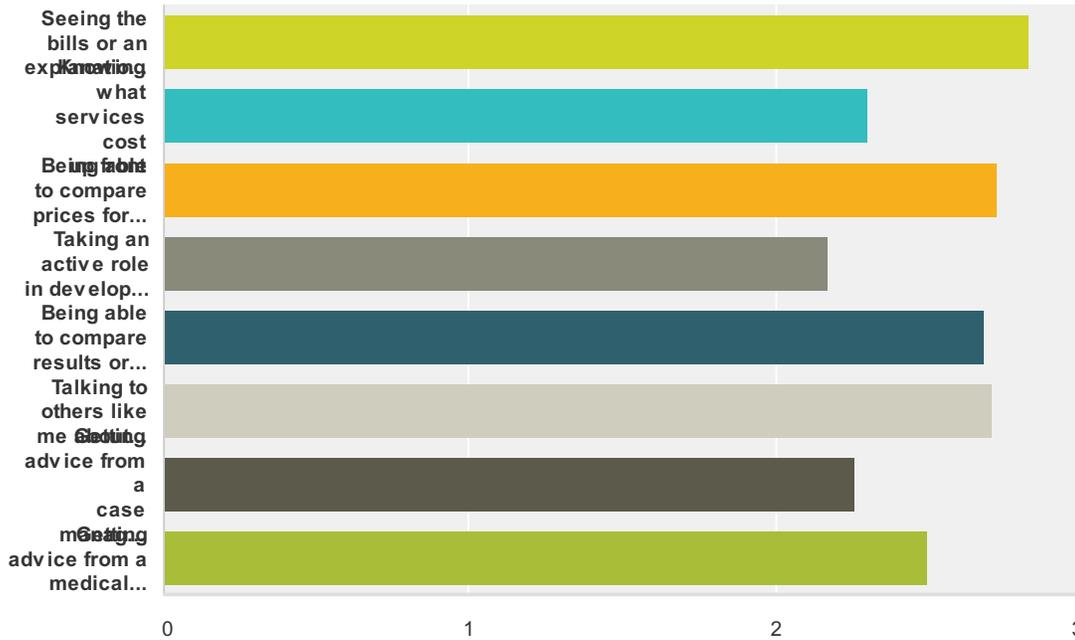
| | | |
|----|---|---------------------|
| 31 | In preparing a budget for our young adult's annual plan, I already approached it as if it were my money. I was not extraneous in requesting what was needed. | 12/3/2013 3:40 PM |
| 32 | That is exactly what I do now with my own funds for the benefit of my disabled family member. The best decision I have ever made for the benefit of my disabled family member was to reject the interference of Gateways. | 12/3/2013 1:25 PM |
| 33 | I already do this. | 12/3/2013 12:52 PM |
| 34 | I think more people should be REQUIRED to work this way. If they can't, they can opt out. Too many intermediaries! | 12/3/2013 9:33 AM |
| 35 | As I mentioned earlier, I also do not have a lot of time to manage this budget and services due to the need to work outside the home. | 12/3/2013 9:18 AM |
| 36 | More and more families want the control over their services and manage it. | 12/2/2013 4:37 PM |
| 37 | I would not want to receive a 1099 form!! | 12/2/2013 2:52 PM |
| 38 | Most people would be interested in this; however do not have a strong understanding that Medicaid is an insurance plan and does not pay for luxury items | 12/2/2013 2:02 PM |
| 39 | I get the best services for the least amount of dollars that I can. You must pay staff well to get quality people. | 11/29/2013 6:17 PM |
| 40 | I wonder how this might reduce the amount in daughter's budget that is required to be paid to MDS as the fiscal agent? | 11/29/2013 11:46 AM |
| 41 | already doing this under the DD 525 Waiver - participant managed services | 11/27/2013 11:04 PM |
| 42 | N/A | 11/27/2013 11:22 AM |
| 43 | I am willing to do this with assurances that the care and provider choose will be good quality | 11/26/2013 10:36 AM |
| 44 | Right now I have a lot on my hands, in the future I might be interested, but I have been extremely lucky to have found a truly dedicated case manager who treats me as a person and is instantly "there" when I have a problem of just need a sounding board or any type of problem at all. | 11/25/2013 9:16 PM |
| 45 | Our experience as a vendor agency has been that families with PDMS budgets do not realize how much work it will be and get very frustrated with the system overall as they do not know all the things that vendors do behind the scenes that are now their responsibility. | 11/25/2013 11:20 AM |
| 46 | I believe it is my duty to manage these funds well so that it is there for the future needs of my child and others like him. | 11/25/2013 11:12 AM |
| 47 | I am not capable | 11/24/2013 7:34 PM |
| 48 | I feel we already do this with the self-directed services budget. First and foremost, we set priorities regarding service needs. Then we attempt to make sure that those services needed the most which we cannot afford to private pay for are funded through the budget. If the services are unique, rare or far away but of high priority, they might be at a higher cost. But we are aware that means their will be less Medicaid funds available to meet other needs of lesser priority. So obviously, the goal is to get as many service needs covered as possible; but given the shortage of certain services in some locales, we are willing to travel or pay more for the "right service." We have all too frequently "spun our wheels" accepting local services from less skilled providers only to see no progress being made. In the long run, if the services are properly delivered and needs are met, you have less costs because most likely less direct and ancillary services will be needed. | 11/24/2013 8:33 AM |
| 49 | I am assuming the costs of services will be transparent. Curious as to the question, there never seems to be enough money to go around. Why wouldn't one be careful with it? | 11/23/2013 1:02 PM |
| 50 | Even though I would be willing, how do I manage to find the time to get the proper training necessary without losing my job? I have already taken FMLA, all my vacation time and sick days are reserved for medical issues and emergencies; so, great, you give me a budget to help manage my son's life...what do I live on? | 11/23/2013 7:55 AM |
| 51 | I do not have the time to add the job of being my son's case manager. | 11/23/2013 12:40 AM |
| 52 | At my advanced age and medical condition would not be helpful. | 11/22/2013 4:24 PM |
| 53 | I don't understand the question. | 11/22/2013 4:10 PM |
| 54 | this is a guardian question | 11/22/2013 3:44 PM |
| 55 | There are no services available for my daughter. I do it all. | 11/22/2013 3:00 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|---|---------------------|
| 56 | I believe that is how I treat the funds now. I have to manage to changes and needs and live withing the budget I have been allocated, just as I do for my own salary and household expenses. I know if a crisis occurred I could ask for some 1 time help or look for an annual increase but I accept that this money comes with responsibility. I can shop where I want an I don't have to live withing preset rates. If I want to pay my woker \$20/hr and have to adjust something else in my budget I am willing to do that. I can prioritize and shop where I want based on my sense of quality and price. | 11/22/2013 2:48 PM |
| 57 | I think families should be able to be compensated for their time and energies that go into managing services. If we didn't do it someone else would have to do the job with a salary, benefits, retirement and days off. Everything I "had" to give up to care for our child and keep him out of an institution. | 11/22/2013 2:46 PM |
| 58 | This is not a good idea. | 11/22/2013 1:59 PM |
| 59 | We have solid recommendations for medical professionals and great therapists to implement the recommendations but you have to jump through hoops to access the funding that has already been allocated for approved services. It makes the whole process much more difficult. | 11/22/2013 1:55 PM |
| 60 | doesn't understand any of this. talk with her Guaidian for more info | 11/22/2013 12:49 PM |
| 61 | If we were allowed to be more flexible with each individuals needs, as we should be . and drop all the overhead , the funding go to better meet their needs and offer better pay for direct care personal | 11/22/2013 11:43 AM |
| 62 | If you are suggesting that we pay staff directly or other professionals, I am not on board with this. There is so much stress on a family with a child who has a developmental disability, that putting more burden them is unfair and very realistically could cause harm with the added stress. We want to be a parent, and already in many instances have to be a case manager, researcher, physical therapist, occupational therapist, speech therapist, behaviorist, pharmacist and doctor/nurse in addition to parent that adding more roles would be overwhelming. | 11/22/2013 11:40 AM |
| 63 | Right now, we're content with the way things are; unfortunately the Area Agency isn't. | 11/22/2013 11:33 AM |
| 64 | With payroll handled by a third party as the area agency now does. I do not want to be responsible for payroll and related filings | 11/22/2013 10:51 AM |
| 65 | We have been in the CDS program for apx 3 years and find it to be the best service model we've experienced to date. We have help from our area agency advertising and interviewing provider's and setting the budget. It allows us greater freedom of choice when choosing providers and programs. | 11/22/2013 10:32 AM |
| 66 | this needs to be flexible; the ability for the Agency to do the parts I don't want to do | 11/22/2013 10:29 AM |
| 67 | I currently do this successfully | 11/22/2013 10:01 AM |

Q28 What are the top 4 things that would help you shop more effectively for the long-term-care services and supports Medicaid pays for? What would help you get the best services for the money you spend?

Answered: 495 Skipped: 397



| | 1 | 2 | 3 | 4 | Total | Average Rating |
|--|---------------|--------------|--------------|--------------|-------|----------------|
| Seeing the bills or an explanation of benefits for services I use | 14.44% 27 | 24.06% 45 | 26.20% 49 | 35.29% 66 | 187 | 2.82 |
| Knowing what services cost up front | 30.95% 78 | 28.17% 71 | 21.03% 53 | 19.84% 50 | 252 | 2.30 |
| Being able to compare prices for services from several service providers | 13.36% 35 | 27.48% 72 | 32.82% 86 | 26.34% 69 | 262 | 2.72 |
| Taking an active role in developing a care plan or services plan | 40.27% 118 | 21.16% 62 | 20.14% 59 | 18.43% 54 | 293 | 2.17 |
| Being able to compare results or outcomes from service providers | 20.10% 42 | 22.01% 46 | 27.75% 58 | 30.14% 63 | 209 | 2.68 |
| Talking to others like me about their experiences with providers | 15.43% 27 | 25.71% 45 | 32.57% 57 | 26.29% 46 | 175 | 2.70 |
| Getting advice from a case manager or other professional | 36.28% 115 | 22.40% 71 | 19.87% 63 | 21.45% 68 | 317 | 2.26 |
| Getting advice from a medical specialist | 24.19% 30 | 30.65% 38 | 16.94% 21 | 28.23% 35 | 124 | 2.49 |

| # | Other (please specify) | Date |
|---|---|--------------------|
| 1 | Dont know if the above options have "best to worst". They aare all equally important to me. | 12/6/2013 12:38 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|--|---------------------|
| 2 | Health care is paramount. I am eligible for Medicare but have maintained private health insurance at great expense because my son has not been able to receive some services through Medicaid . I can't keep doing this. He lives with me now. He could not afford to live on his own, but I won't be here forever. | 12/6/2013 9:59 AM |
| 3 | THIS IS WAY TO COMPLICATED A QUESTION TO ANSWER AT THE LAST MINUTE...WEHO KNOWS, UNTIL THE SYSTEM IS IMPLIMENTED ?? | 12/6/2013 9:55 AM |
| 4 | Don't want to do this | 12/6/2013 9:39 AM |
| 5 | Being able to pay for the services and medications I have now | 12/5/2013 10:56 PM |
| 6 | all the above | 12/5/2013 7:05 PM |
| 7 | I would like guidance from a case manager or professional who actually knows something. | 12/5/2013 6:24 PM |
| 8 | NOT sure | 12/5/2013 1:53 PM |
| 9 | my daughter is in a group home so I don't have to shop for services as she is getting them every day and the home is the service | 12/4/2013 9:43 PM |
| 10 | It would help if the community mental health services weren't monopolies! CHOICE! | 12/4/2013 8:07 PM |
| 11 | Very difficult question to answer. | 12/4/2013 10:12 AM |
| 12 | Do not need medical aspect in any of these matters no serious health care needs medically | 12/4/2013 8:39 AM |
| 13 | does not work | 12/3/2013 5:29 PM |
| 14 | Case management needs to be local with an understanding of the process and educational/medical history of those being supported and priorities of the family. | 12/3/2013 3:42 PM |
| 15 | Being able to compare prices for services from several service providers is also an important factor. | 12/3/2013 1:28 PM |
| 16 | I would need help managing this and would probably want and need an area agency to help out or hire someone to keep up with all the things the state requires. Many people do not have the skills necessary to do this.as | 12/3/2013 12:12 PM |
| 17 | As an individual outside of the state funding system (Medicaid/DHHS/Area Agency, etc.) I also think that getting advice from a case mgr/other professional is vital in putting together an effective LTC service agreement. | 12/3/2013 9:11 AM |
| 18 | being able to negotiate price and or find an alternative that might include informal/non traditional ways of getting needs met at a better cost. | 12/3/2013 8:35 AM |
| 19 | These are the top 4 things that I see families needing. | 12/2/2013 4:40 PM |
| 20 | This form is not allowing me to check boxes | 12/2/2013 2:03 PM |
| 21 | "Getting advice" ?? - Talking to people highly knowledgeable in the feild and services. | 12/2/2013 12:57 PM |
| 22 | I run my son's accounts like a home health care business. I stretch the dollars as far as they can go. | 11/29/2013 6:19 PM |
| 23 | This question is not applicable to my situation | 11/27/2013 11:30 AM |
| 24 | N/A | 11/27/2013 11:22 AM |
| 25 | Develope a better way to find/choose health care professionals. Right now it is hit or miss. Even if you like your physician, that doesn't mean that he/she is the right one for you and your needs. Sometimes that knowledge comes at a very high price...when it's too late. | 11/25/2013 9:16 PM |
| 26 | I can't answer any of the questions on this page either | 11/25/2013 8:26 PM |
| 27 | This question is confusing... is '1' the top... or did you want us to select 4 items and rate them? I already know upfront the cost of my daughter's support services and sign off on time sheets. I already play the key role in developing her care/services plan. I already recruit, hire, and train support staff and determine their hourly wage (within the means of my budget... they deserve to be paid more, but I have to be extremely frugal in order to ensure I don't exceed my budget). I do this because of my daughter's very unique and individual needs and to save money. You could pay me for my services... that would be nice. I am the most qualified and experienced person for my daughter. | 11/25/2013 10:02 AM |
| 28 | more support in hiring dsps | 11/24/2013 7:28 PM |

NH Medicaid Long-Term-Care Program Survey

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|----|---|---------------------|
| 29 | The problem with comparing outcomes or results from service providers is that the data can be "cooked." Bigger institutions can afford to dedicate time and money to collecting and reporting outcomes that make themselves appear successful while smaller providers may not have the administrative time or resources to do so. Yet, in my experience, some of the smaller providers offer a more comprehensive and personalized approach, which is needed when working with individuals with complex and multiple disabilities. It isn't always fair to burden these small providers who focus more on service delivery with more administrative work and can actually detract from the quality of their services. | 11/24/2013 8:39 AM |
| 30 | If I had 1 through 4 I am assuming I would have an active role. Getting advice is number 1 as I can't know what I do not know. I don't necessarily know what is available or what is appropriate to the individual. All I might know is that there is a problem I need help with, I would hope that if the case manager suspected a medical specialist would help they'd refer us. | 11/23/2013 6:10 PM |
| 31 | Not a fair question. Many things go into planning and at any given time all of these things are important. | 11/23/2013 8:17 AM |
| 32 | Knowing that the service providers were reputable, thoroughly checked, and tops in their field. I would like to know that the person caring for my child actually wants to be in their chosen profession, and cares about the out-come. They shouldn't be burned out or just serving their time to move up the ladder. | 11/23/2013 8:01 AM |
| 33 | I had to take care of my mother in the last years of her life, and the only important ting is dealing with the lack of quality staff. .A stressful nightmare, | 11/23/2013 12:42 AM |
| 34 | I don't think I could handle this. | 11/22/2013 4:26 PM |
| 35 | 1. Taking an active role in developing a services plan AND being INVOLVED in ENSURING the plan is CARRIED OUT AS INTENDED. | 11/22/2013 4:14 PM |
| 36 | Having services available there is nothing available | 11/22/2013 3:02 PM |
| 37 | I do not want to have to select from pre-determined providers. I don't have to do that know. I can hire my neighbor, a friend, relative or stranger...I would not at all like that to be taken away – so I do not know how to answer your questions where you use the term provider, as if it was a preexisting entity. | 11/22/2013 2:50 PM |
| 38 | In order (1-4), Knowing what services cost up front., Being able to compare prices for services from service providers., Being able to compare outcomes from service providers., Getting advice from a case manager or other professional. Of course, being dysarthric, I would need to do this on line. | 11/22/2013 1:44 PM |
| 39 | Family member is not able to do this on their own because of developmental disabilities | 11/22/2013 12:24 PM |
| 40 | Having the time to do all of this, work more than full-time and have some semblance of life to my life | 11/22/2013 11:36 AM |
| 41 | Prepare my grandson to live on his own | 11/22/2013 10:36 AM |

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Q29 What Long-Term-Care services and supports should be added to the NH Medicaid program that are not available to you now?

Answered: 286 Skipped: 606

| # | Responses | Date |
|----|---|--------------------|
| 1 | Knowing what my total budget is and where the money is going. | 12/9/2013 6:43 PM |
| 2 | they probably already have the services. I just have never been able to get any. | 12/9/2013 12:41 PM |
| 3 | Being paid. | 12/8/2013 8:30 PM |
| 4 | if people were paid a decent wage they may stay and our loved ones would not see so many people come and go . . .people with developmental disabilities should be treated with respect it is hard for them to accept change and that is what happens because of the low wage | 12/8/2013 7:40 PM |
| 5 | Transportation | 12/8/2013 7:18 PM |
| 6 | Community meeting and living places where one can go and feel comfortable. Not a mall or church basement. | 12/8/2013 4:30 PM |
| 7 | Not sure | 12/8/2013 9:55 AM |
| 8 | Increase in supports to more readily ensure a positive outcome in meeting goals. | 12/7/2013 4:30 PM |
| 9 | The most important thing is a good case manager who sees the whole picture so my child's services are not fragmented | 12/7/2013 12:02 PM |
| 10 | Dental care is a gaping hole in the current service system. By neglecting this aspect of a person's well-being, many other health issues are created, costing more money in the long term. This is a very short-sighted policy and should be remedied sooner rather than later. There is a grave lack of funds for clothing available to people with disabilities. Although my daughter is middle-aged, I continue to contribute heavily toward her wardrobe, long past the time I would expect to do this with a typical adult child. We are encouraged to treat our adult children who have disabilities as typically as possible, and rightly so. Yet they are living in poverty with few options for employment or ability to provide their own clothing. How can we expect a poorly dressed person with dental issues to be offered a job and thus work toward self-sufficiency? | 12/6/2013 11:28 PM |
| 11 | respite care for people with mental health | 12/6/2013 11:23 PM |
| 12 | Intergrated care with other medical providers such as a specialist as needed | 12/6/2013 10:27 PM |
| 13 | Respite for families | 12/6/2013 5:39 PM |
| 14 | I am not sure, in particular because I do not know what is not available to us now. | 12/6/2013 4:42 PM |
| 15 | more functional support as well as Acute care service interventional services | 12/6/2013 4:03 PM |
| 16 | ease in transferring my adult son currently living in MI with SSI, Medicaid, food stamps and food pantry to similar services in NH | 12/6/2013 3:47 PM |
| 17 | Preventative Dental Care | 12/6/2013 3:35 PM |
| 18 | my mom does not need these services right now but will need them shortly. More help is needed to keep my loved one home longer. Like more adult medical day programs with flexibility. More respite care. | 12/6/2013 2:57 PM |
| 19 | residential services - group home for stepdown until ready for community based services | 12/6/2013 1:50 PM |
| 20 | Adult day program | 12/6/2013 1:16 PM |
| 21 | wlder public Information about THE EARLY SIGNS OF MENTAL ILLNESS WHEN PERSON IS CHILD OR UPPER TEEN! | 12/6/2013 12:39 PM |
| 22 | Mental health services need to be strengthened and increased. Our mental health system is "broken" and struggles valiantly to provide the basic services. | 12/6/2013 11:46 AM |

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|----|--|--------------------|
| 23 | A mental health case management system geared toward individuals who are reluctant to seek help through the current system. For example, having the Riverbend counselors meet clients at medical offices rather than at the Riverbend office. Maybe this concept could be expanded toward case management. | 12/6/2013 11:45 AM |
| 24 | Non medical services that help keep people at home, such as grocery shopping, pharmacy delivery, personal care, etc. | 12/6/2013 11:39 AM |
| 25 | Transportation costs are not realistic for people who live in rural areas. Adjustments to funding based on location(s) of client and services provided to them. | 12/6/2013 11:29 AM |
| 26 | better mental help coverage | 12/6/2013 11:21 AM |
| 27 | HALF WAY GROUP COUNSELING, JOB ASSISTANCE. | 12/6/2013 11:10 AM |
| 28 | Transportation for aging. More employment supports. Consumer Direction for aging. More family support/respite care. | 12/6/2013 11:02 AM |
| 29 | Psychiatric Services for brain injuries and resulting mental illness that affects families - legal representation when necessary, and financial management assistance. | 12/6/2013 10:09 AM |
| 30 | I could find an apartment for my son in my town within walking distance, but he would have nothing to do all day and no where to go. He has schizoaffective disorder and works well with one other person who is non threatening. He could follow someone around and help them, or could use someone to get him into a slow paced part time situation where he could work side by side with someone. He is of average intelligence and has aptitudes in visual areas. He is also logical, kind, and has an interesting sense of humor, but afraid of his own shadow. He needs someone to check to be sure he takes his meds, which he usually does, but when he forgets just one course either morning or evening, it really throws him off. | 12/6/2013 10:06 AM |
| 31 | Medicaid Benefits should not depend on a partners money, esp. in long term nursing home care. There should be NO SPEND DOWNS...this ??money allocation problem ?? should be handled in a different way....people go without needed medications & all kinds of health services because of this. ALL DENTAL & EYECARE Health SHOULD BE INCLUDED in Medicaid services. | 12/6/2013 9:58 AM |
| 32 | ABA therapy. | 12/6/2013 9:56 AM |
| 33 | A small group home (about 3 residents) with drop-in services for around the dinner hour | 12/6/2013 9:40 AM |
| 34 | NHH | 12/6/2013 9:35 AM |
| 35 | financial help, local activities that my whole family can participate in. IEP assistance and more options for my disabled child. | 12/6/2013 8:42 AM |
| 36 | Care for those that are incarcerated. | 12/6/2013 8:22 AM |
| 37 | Help with providing quality care as well as help with respite care. He may also be a person to benefit from job coaching and indepent living. | 12/6/2013 8:09 AM |
| 38 | Support groups | 12/6/2013 6:52 AM |
| 39 | not familiar with all the options now...need more education. | 12/6/2013 6:24 AM |
| 40 | none | 12/6/2013 12:37 AM |
| 41 | Individualized and in home supports. Crisis and respite. Family supports | 12/5/2013 11:53 PM |
| 42 | long term institutionalization in concord state hospital | 12/5/2013 11:25 PM |
| 43 | Mental health should have the same level of supports available as other illnesses and disabilities. | 12/5/2013 11:09 PM |
| 44 | Psych services should be paid in total. Too many things happen to psych patients when they don't get the services they need. It's expensive to have mental illnesses and not to be able to get help | 12/5/2013 11:00 PM |
| 45 | dental care for cleanings, xrays and fillings. | 12/5/2013 10:48 PM |
| 46 | Consistent medical care | 12/5/2013 10:27 PM |
| 47 | Dental | 12/5/2013 10:26 PM |
| 48 | Transportation, someone to help with Adl's | 12/5/2013 10:14 PM |
| 49 | Day programs or club house for mental health recovery/reintegration into community. | 12/5/2013 9:54 PM |
| 50 | More available agency's for mental illness.. | 12/5/2013 9:54 PM |
| 51 | supported affordable housing | 12/5/2013 9:44 PM |

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| 52 | Registered nurse to accompany my brother home for visits that are funded. We have no way to care for him during visits | 12/5/2013 9:41 PM |
| 53 | Vision and dental care | 12/5/2013 9:39 PM |
| 54 | Dental care and wellness services such as "In Shape" and Nutrition counseling. | 12/5/2013 9:24 PM |
| 55 | Mental health services | 12/5/2013 8:55 PM |
| 56 | ADL support, certified clubhouse support | 12/5/2013 8:49 PM |
| 57 | Dual-Diagnosis Treatment programs. There are none in our state. We traveled to Boston to receive these services for our son. Research shows there is a high rate at which mental and substance-use disorders occur together. Yet our state has no programs to support this vast client base. Also again, Emergency Rooms must be better prepared and designed for patients experiencing a mental health crisis. In my opinion, our current system exacerbates the situation. Support needs to be ready once a patient is released from the state hospital. Unfortunately for our family, that has not been the case, even with a more than reasonable lead time prior to discharge. | 12/5/2013 8:41 PM |
| 58 | Support for the client who wants to remain functioning at a high level associate with others of similar capabilities | 12/5/2013 8:39 PM |
| 59 | Shower chair for adults not only pediatric patients. We were denied on recently, which makes it much harder to care for my sister. | 12/5/2013 8:34 PM |
| 60 | What is out there? | 12/5/2013 7:48 PM |
| 61 | Group homes for mental health patients who end up at state hospital a lot and need a transitional option | 12/5/2013 7:46 PM |
| 62 | 1. independent living/ apartments with services such as, onsite manager and case managers. 2. mental health inpatient care in local hospitals or facilities that provide comprehensive discharge planning with patient and family for outpatient services and case management. | 12/5/2013 7:08 PM |
| 63 | Need more help for supported employment. | 12/5/2013 6:50 PM |
| 64 | Interagency interface. Integrated supportive services. | 12/5/2013 6:43 PM |
| 65 | Make sure the services are integrated so that there are mental health, health and rehabilitation services coordinated into on holistic plan | 12/5/2013 6:34 PM |
| 66 | I use mental health hospitalizations in crisis, help paying for prescriptions and counseling services. All of these are covered for me at this time. | 12/5/2013 6:25 PM |
| 67 | Support from someone who can help make long term plans and guide a family to a plan that cares for the disabled person and makes sure the caregivers are not so overburdened that they cannot continue to provide care. | 12/5/2013 6:25 PM |
| 68 | Leave the current system alone. | 12/5/2013 6:17 PM |
| 69 | Reevaluations and post mortem analysis' | 12/5/2013 6:15 PM |
| 70 | Help with independent living skills, supported housing options. | 12/5/2013 6:01 PM |
| 71 | Bigger budgets! | 12/5/2013 5:24 PM |
| 72 | Don't seem to | 12/5/2013 3:09 PM |
| 73 | visiting nurses several times a week. | 12/5/2013 2:06 PM |
| 74 | Coverage of dental costs for individuals who require anesthesia and hospital services in order to receive dental care. | 12/5/2013 1:28 PM |
| 75 | House keeping. Sometimes it's impossible to do everything when caring for someone with a disability and our family would prefer to provide the care ourselves and not worry about cleaning the bathroom or washing the floors. Our friends in another state used to have this service and it was a good send. | 12/5/2013 1:01 PM |
| 76 | Transitional apartment settings and the availability of specialized outpatient day programs for people with ABI/TBI like exist in Maine, so more folks could get intermittent supports and clinical oversight, not just outpatient services just post ABI and then it is over. | 12/5/2013 12:12 PM |
| 77 | More registered nurse hours for those who need more help at home, including day services and respite. More decent long term care homes for those unable to remain in their family homes. | 12/5/2013 11:26 AM |
| 78 | Dental | 12/5/2013 11:07 AM |
| 79 | Eliminate the asset cap. If you need the services, you get in. | 12/5/2013 10:23 AM |

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| 80 | Dental care into adulthood. Child needs to go into outpatient for cleanings. | 12/5/2013 9:41 AM |
| 81 | Having the ability to hire someone to bring my daughter into the community. Having her be part of society is key for everyone. She should be given the same opportunity to live a good life just like you and I. | 12/5/2013 9:39 AM |
| 82 | Group homes or staffed apartments available in the seacoast area for intellectually and mentally challenged young adults. | 12/5/2013 8:51 AM |
| 83 | More respite---there should NOT be a cut off in dollars spent. We have a budget but are allowed a limited amount of dollars from that budget for respite. It should be up to us how much we spend on respite from that budget as long as we stay within the budget. This also applies to recreation. | 12/5/2013 8:49 AM |
| 84 | We are lucky to have everything covered:-) | 12/5/2013 7:41 AM |
| 85 | Transportation to and from paid employment as the recipient has come so far and may have to quit the job. This job has increased the recipient's independence and sense of responsibility far past what she was ever capable of prior. | 12/5/2013 5:30 AM |
| 86 | coverage for compounded medications, coverage for any doctor prescribed nutrition, vitamins and supplements. All incontinence supplies, including creams and cleansers and especially more absorbent products not just the approved list that often fail. Speech, OT, PT, Vision and any other Therapies for people over 21 years of age to maintain acquired skills from childhood. Full Dental (cleaning as needed, extractions and fillings) for people over 21 years of age. | 12/4/2013 10:28 PM |
| 87 | Residential | 12/4/2013 10:23 PM |
| 88 | Help with finding and financially affording an apartment so that person can live independently. | 12/4/2013 9:53 PM |
| 89 | I am one of the blessed ones who has their child who needs so much medical and physical support to be in a wonderful active group home. A group home is so much more like home than an institutional model like Cedar Crest or Crotched Mountain. Both are important for acute cases but for the multiple disabled and medically fragile a group home is a much better model for long term care. Having medically certified people with one nurse overseeing the staff seems more cost effective too. We as parents are not nurses and doctors but we can change g tubes, monitor seizures, change diapers, dressings etc. so I see a group home as a wonderful example of long term care services so I feel I get the best support at this time. | 12/4/2013 9:47 PM |
| 90 | I will let you know once I'm in full time. | 12/4/2013 9:35 PM |
| 91 | More flexibility and better funding for respite and other services that allow family care providers to take a break. | 12/4/2013 9:23 PM |
| 92 | Transportation | 12/4/2013 8:08 PM |
| 93 | Physical Therapy, Occupational Therapy, equipment when needed, shouldn't have to wait 5 years to get a new w/c that you've outgrown 2 years ago. | 12/4/2013 7:13 PM |
| 94 | I honestly don't know, but something like the extra PT/OT which Easter Seals provides (used to provide us before scheduling conflicts) would come in very handy for my daughter - she currently gets some of this with school but she really needs more. | 12/4/2013 6:39 PM |
| 95 | Professional outreach help for support, encouragement. Emergency phone access to help talk through crises times. Professionals to help navigate the complexities of the system. Community mental health centers are extremely important to the individual in diagnosing, treatment, recovery and services for those inflicted with a lifelong chronic mental illness. | 12/4/2013 4:03 PM |
| 96 | Music therapy, Per deim or some kind of place to be able to go to hire trained aides to work with my Daughter. I have been looking for months for an aide that is qualified to work with my daughter at the rate of pay that I can afford. Adaptive equipment for speech. Home modifications, wheelchair vans, Volunteer work for my daughter part of her service agreement, a goal actually but no one can seem to help me with this. Not Dept of ED, Voc rehab, Moore Center, Independent Living, Dev dis council. | 12/4/2013 3:22 PM |
| 97 | Dental preventative care | 12/4/2013 3:15 PM |
| 98 | Someone to assist with hygiene and daily care activities. | 12/4/2013 2:40 PM |
| 99 | home care provider funds | 12/4/2013 2:10 PM |
| 100 | finding out how much services cost. | 12/4/2013 12:55 PM |
| 101 | A pool of respite providers who are trained in disability issues available and familiar with clients | 12/4/2013 12:53 PM |

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| 102 | Better dental and eye care including being able to replace eye glasses after so many years and dentures as well as Medicaid paying for the cost of batteries for hearing aids, and also for Medicaid to widen the parameters for paying for transportation, ie. transportation to and from dialysis. After dialysis seniors for the most part are not able to drive after the treatment but are having to pay upwards of \$100.00 to be transported back to their home/facility. | 12/4/2013 12:02 PM |
| 103 | dental | 12/4/2013 11:51 AM |
| 104 | None | 12/4/2013 11:51 AM |
| 105 | Preventative dental care | 12/4/2013 11:39 AM |
| 106 | Residential placement where we want our son and where he wants to be. | 12/4/2013 11:10 AM |
| 107 | 1. More choices in mental health services. 2. After hours phone number for the region agency in case of emergencies. | 12/4/2013 10:45 AM |
| 108 | Dental care, more funding for transportation, better wages for direct support providers | 12/4/2013 10:32 AM |
| 109 | Dental services for adults so they don't lose their teeth. Good teeth are important for a person's overall health. | 12/4/2013 10:13 AM |
| 110 | Dental. And dividing the money in a way that meets the individuals needs not automatically giving most of it to day services | 12/4/2013 10:04 AM |
| 111 | Stability. Don't summarily dismiss the one word answer. Instead, think about its ramifications... | 12/4/2013 10:03 AM |
| 112 | better housing options | 12/4/2013 10:02 AM |
| 113 | More money allocated to education/physical activities/daily community involvement activities and the transportation to get to these activities. | 12/4/2013 9:47 AM |
| 114 | I am not certain. I would like to see dentures included. | 12/4/2013 8:53 AM |
| 115 | Not sure. | 12/4/2013 8:48 AM |
| 116 | More respite people available and trained properly | 12/4/2013 8:39 AM |
| 117 | decent dental insurance | 12/3/2013 11:25 PM |
| 118 | Continuing education | 12/3/2013 10:30 PM |
| 119 | Dental services | 12/3/2013 9:19 PM |
| 120 | Logical, safe and effective congregated communities for my son to be a part of and to live in. | 12/3/2013 9:00 PM |
| 121 | I am not sure. | 12/3/2013 8:22 PM |
| 122 | Vision & dental. | 12/3/2013 6:46 PM |
| 123 | family providers | 12/3/2013 5:45 PM |
| 124 | More crisis MH beds & intermediate care options. | 12/3/2013 5:18 PM |
| 125 | Not sure if it is available or not, but we are not going to be able to care for our son forever. There may come a time when we need help ourselves. Providing around the clock care for our son will be necessary within probably 10 years for us as we won't be able to physically attend his needs. Suppose we don't want him to go to foster care or group home, providing around the clock care at home would be nice and possibly cost effective. | 12/3/2013 5:05 PM |
| 126 | Not sure | 12/3/2013 5:00 PM |
| 127 | More integrated mental health services, more supportive job opportunities | 12/3/2013 4:49 PM |
| 128 | n/a | 12/3/2013 4:37 PM |
| 129 | I don't know. | 12/3/2013 4:29 PM |
| 130 | Preventative dental care for adults... or at least an extension of preventative dental care to age 26 to follow in sync with Healthcare act. This may provide more time for improved oral hygiene and less problems down the road as an older adult , hence less cost long term. Increased funding for consultation for OT, Speech and PT support as an adult. Direct service is not necessarily beneficial at this point, but consultation and training to staff would be. | 12/3/2013 3:45 PM |
| 131 | I don't know | 12/3/2013 3:42 PM |
| 132 | Home assistance | 12/3/2013 3:23 PM |

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| 133 | My mom should be paid whatever another family housing provider should get for taking care of me. It's not fair to force her to work so hard just because we want to stay together. My mom has to work to pay the bills as well as juggle my 24/7 care. This is very stressful because she can't do either very well in this scenario. She has lost many jobs because my care needed priority sometimes. If she got paid what you would pay a stranger to take care of me, she wouldn't have to work outside the home and I would be better taken care of and she would be less stressed. This includes giving her free health insurance as this is very expensive and caregivers need mental health support, etc. | 12/3/2013 1:13 PM |
| 134 | Dental and locating hearing aid specialists that you work with | 12/3/2013 12:54 PM |
| 135 | Individualized housing options | 12/3/2013 12:42 PM |
| 136 | The ability to see monthly bills as to where my money is going. Many folks would be horrified if they saw their actual breakdown and who is getting the money from their budget. The ability to change a budget if needed due to unforeseen circumstances. | 12/3/2013 12:14 PM |
| 137 | qualified providers of autism treatment | 12/3/2013 12:10 PM |
| 138 | Continued, reliable, and competent in home care. | 12/3/2013 11:48 AM |
| 139 | better transportation assistance | 12/3/2013 11:47 AM |
| 140 | DONT KNOW WHAT IS AVAILABLE TOME NOW | 12/3/2013 11:19 AM |
| 141 | Specialized medical testing like EEG. Expand on dental care and add ortho care. | 12/3/2013 11:13 AM |
| 142 | I think spouses should be able to be paid to provide some services. | 12/3/2013 11:09 AM |
| 143 | dental | 12/3/2013 10:08 AM |
| 144 | I need to know how and where I will transition my son when I am no longer able to care for him myself. What residential services are available? I've heard of very little being available. | 12/3/2013 9:36 AM |
| 145 | additional education support, both credit and non credit as well as more help with jobs (inquiry and placement) | 12/3/2013 9:33 AM |
| 146 | The one thing I can think of that seems to be lacking is services in more areas for individuals with brain injuries. There may also be a lack of local services for other disabilities however my experience is with TBI. Outside of a monthly meeting at our area agency, there are virtually NO activities/services in southern NH for my son to take part in. | 12/3/2013 9:13 AM |
| 147 | more programs for the clients who are not working and have MR.. Since Jan 1 focusing more on employment seeking.. | 12/3/2013 9:00 AM |
| 148 | A menu of services that cover my loved ones needs as they get older without having to change or drastically alter the plan of care. For example his needs are not medical or functional at this time so his plan does not have this. If he does need these things and they are not in his plan we have to be on a waiting list. | 12/3/2013 8:38 AM |
| 149 | no idea | 12/2/2013 10:59 PM |
| 150 | Unfortunately not sure all of what is available now! | 12/2/2013 8:26 PM |
| 151 | not sure | 12/2/2013 8:10 PM |
| 152 | Dental | 12/2/2013 6:24 PM |
| 153 | Being able to see the specialists I need to see without a prior authorization that is denied based on money. For once it would be nice to get the right diagnosis and treatment to make me feel better. regardless of money. | 12/2/2013 6:04 PM |
| 154 | The system allows for the services that my family member needs but the funds are not available to pay for them so they can't be provided. Except for the current budget, the State has for several decades annually reduced funds for the social service programs. | 12/2/2013 4:44 PM |
| 155 | Dental | 12/2/2013 3:56 PM |

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| 156 | When a family cares for their child/adult child/ward both residentially and for day services, they are paid a lower stipend than the Home Care Providers are paid. They also receive less Social Security for Room and Board, as the standard of need is decreased when an individual resides at home. This is not right! Families are more inclined to spend the funding on their disabled family member and their family members needs. Parents/Family Guardians love their family member and are connected to the individual with disabilities emotionally. They truly want the very best care for them and will not settle for substandard care, just so that they could get more money for themselves. Families make sacrifices every day to insure that the individual is well cared for. This is not the case with Home Care Providers, who wouldn't do it without the paycheck, and who would feed them cheap lousy foods, or not take them anywhere, just so that they could make more money for themselves! | 12/2/2013 3:06 PM |
| 157 | Substance use treatment Respite | 12/2/2013 2:04 PM |
| 158 | dental | 12/2/2013 1:58 PM |
| 159 | - Instrumental activities of daily living (IADLs) - Respite care - Supportive housing - Employment assistance | 12/2/2013 1:03 PM |
| 160 | Transportation; Dental; increased community involvement beyond specialized providers; | 12/2/2013 12:53 PM |
| 161 | pt,ot,sp | 12/2/2013 12:09 PM |
| 162 | Help to set up a budget | 12/2/2013 11:28 AM |
| 163 | Payment for Emergency expenses like fuel, food, utilities Chore services I like snow removal, lawn care, plumbing repairs, household repairs | 12/2/2013 10:52 AM |
| 164 | More providers available and not so many rules and limits. | 12/2/2013 10:51 AM |
| 165 | We don't get anything. We're not eligible. | 11/29/2013 7:18 PM |
| 166 | Easier access to what to do to ease into having your child move out into the world. | 11/29/2013 6:20 PM |
| 167 | In case of a medical emergency for the care provider there is no "placement" that could kick in short term. And there is not enough money in the budget to take 24/7 care in case the primary provider (me) is in the hospital. | 11/29/2013 1:39 PM |
| 168 | Annual training for providers. | 11/29/2013 11:52 AM |
| 169 | Dental care | 11/28/2013 8:38 PM |
| 170 | None needed at this time | 11/28/2013 3:46 PM |
| 171 | Massage therapy. It has been the most effective therapy that keeps my client mobile and comfortable | 11/28/2013 5:48 AM |
| 172 | some sort of stipend/salary or other benefits (family caregivers being offered health insurance, car insurance, dental, etc) in appreciation of all they donate to the state by keeping adult family members with DD/ABD at home. | 11/27/2013 11:10 PM |
| 173 | Group housing | 11/27/2013 1:41 PM |
| 174 | I do not know of any in our current situation | 11/27/2013 11:30 AM |
| 175 | dental coverage | 11/27/2013 11:23 AM |
| 176 | preventative dental care. I would like to see that available to my son once he transitions to adult Medicaid. | 11/27/2013 9:11 AM |
| 177 | not sure | 11/27/2013 8:50 AM |
| 178 | dental services | 11/27/2013 8:49 AM |
| 179 | services for 18-21 yrs old. quality care and group housing or assistance for housing etc. qualified good staff incomes to be able to keep staff. | 11/26/2013 5:34 PM |
| 180 | Applied Behavioral Analysis | 11/26/2013 12:40 PM |
| 181 | more support for employment opportunities | 11/26/2013 12:06 PM |
| 182 | dental | 11/26/2013 11:56 AM |
| 183 | More home care providers for the families who find themselves in the position of having to have their family members live outside their home due to health issues or aging. | 11/26/2013 11:41 AM |
| 184 | More professionals who accept Medicaid | 11/26/2013 11:11 AM |

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| 185 | Transportation - we purchase a vehicle for our family member which allows him to lead an active and full life. Without our ability to do that he would be severely limited. We receive assistance with the day today costs of transportation but the largest cost is the purchase of the vehicle with we fund. It would also be helpful to have access to individuals for short term back up when staff are ill/vacationing, etc. It is not possible when running your own budget to have "staff on call" for these instances. This places a significant burden on the family acting as caretaker and trying to maintain employment themselves. | 11/26/2013 11:04 AM |
| 186 | more knowledge about how to access services while keeping cost in mind more education on the process and what parents can do to help | 11/26/2013 10:39 AM |
| 187 | Respite care for families of children and youth with emotional and behavioral disorders. Short term intensive treatment home options for children and youth who do not need hospital level care but do need a brief intervention/break. Youth peer to peer supports. | 11/26/2013 9:44 AM |
| 188 | social transportation - grocery shopping, errands, visits | 11/26/2013 7:52 AM |
| 189 | Osteopathic services have been cut back on, so by the time I'd be making headway, I wouldn't be able to go anymore. Also, this is one of the things I don't know enough about, is acupuncture covered. I can't help thinking that there has to be a way without narcotics to control pain/symptoms. Sometimes taking meds. brings on other problems or dependency, both are equally unacceptable. | 11/25/2013 9:20 PM |
| 190 | Help with emergency fuel for home heating oil, especially with kids with chronic health issues. | 11/25/2013 8:52 PM |
| 191 | do not know | 11/25/2013 5:39 PM |
| 192 | Appealing residential care; more day time activities for disabled adults who cannot work. | 11/25/2013 3:02 PM |
| 193 | ABA for kids with autism. | 11/25/2013 2:09 PM |
| 194 | I would like the supported option of creating a community of my son and his well-matched peers (from attending public school) to live together in a congregated living facility like a small fraternity house that could be supported by all of the families that already know each other. | 11/25/2013 1:58 PM |
| 195 | Dental Care! Prevention, Maintenance, and supplies. | 11/25/2013 11:22 AM |
| 196 | ABA Therapy for Autism...this must be a standard of care for children with autism. Sensory equipment, swimming pools and alternative therapies like Horseback riding, gymnastics, art and music. Children with autism are so different in their needs that it is difficult to fit them in the current mold. | 11/25/2013 11:17 AM |
| 197 | none noted | 11/25/2013 10:10 AM |
| 198 | 1. ABA/behavioral services... objectively proven treatment for individuals who experience Autism. This should be provided especially since Connors Law was enacted. The NH medicaid (Step 1) should provide access to these services. 2. Preventative adult dental and oral health care... we could utilize the new model- 'mid-level dental providers' other states and countries utilized successfully to meet the needs in our state and cut costs. We all know that your oral health impact your over general health. It's shocking that we don't already provide this. Mid-level providers would be key in serving individuals who live in areas where we have extreme shortages of dentists. Overall I find that because NH has one of the lowest medicaid reimbursement rates doctors and specialists don't want to be hassled by serving this population. | 11/25/2013 10:10 AM |
| 199 | My uncle recieves the services he needs right now. We have no concerns about the quality of his care or supports and have been very pleased since he moved into his home 7 years ago. | 11/25/2013 9:56 AM |
| 200 | i cannot answer this, since my son just entered into the adult services program. | 11/25/2013 9:16 AM |
| 201 | A network of social opportunities for adults with disabilities to add meaning to their lives. | 11/25/2013 9:14 AM |
| 202 | individualized housing that is not like adult foster care, but rather giving the person the ability to live on his own with the supports necessary to do so, even if it is with full-time assistance. | 11/25/2013 6:59 AM |
| 203 | housing with supports and training as part of the program. | 11/24/2013 7:36 PM |
| 204 | Better housing options to develop friends, independence and the home is stable and long term. | 11/24/2013 7:20 PM |
| 205 | Mentors trained in he Social Thinking methodology to help adults understand expected behavior in community situations | 11/24/2013 6:57 PM |
| 206 | In-home supports. My son has been on the wait list for 8 years. | 11/24/2013 2:46 PM |
| 207 | Respite Provider List, Hippotherapy, Self Defense Training, Income Loss reimbursement (for caregivers), conflict coaching (mediation) for social situations | 11/24/2013 2:01 PM |
| 208 | I would love to be able to get the type of supports that are available for adults for my son like we had in Rhode Island. | 11/24/2013 1:51 PM |

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| 209 | Give the client control and keep services at a local level. More funding for education and training | 11/24/2013 1:32 PM |
| 210 | Person centered transitioning planning (child to adult) done at the Area Agency level should be better integrated with Voke Rehab and the school's IEP transition planning process. There is currently no coordination across these areas and, as a parent, I was left trying to have all these separate groups develop separate plans that went in the same direction without a duplication or conflict in services. My guess is that some families who are more passive about participating in the delivery of services may not see a need to integrate these plans or have the time or ability to do so. | 11/24/2013 8:44 AM |
| 211 | not sure | 11/24/2013 7:17 AM |
| 212 | Residential Dental Currently the family has two dental plans out to help the cost of his dental, but have been told cannot take the weekly fees for the cost of the dental out of his plan. We also have him living in our home without a 521 paid home like others in the community. We were told the area agency frowns on this. | 11/23/2013 11:27 PM |
| 213 | Ongoing transportation funding for those with critical health care needs (instead of submitting forms constantly); coming to your home for meetings; less paperwork to obtain services | 11/23/2013 10:33 PM |
| 214 | The ability to purchase a smartphone and pay for the monthly cost there are so many time mgmt functions that would help my child be more independent. Paying for the providers out of pocket cost for social and respite care events. Dental expenses being covered. | 11/23/2013 10:16 PM |
| 215 | Mobile Phlebotomy | 11/23/2013 10:06 PM |
| 216 | I am not managing my siblings care yet and my kids are not on medicaid. I do not know the answer to this. | 11/23/2013 6:10 PM |
| 217 | Would be nice to have a "family friendly" website to go to see what services, equipment, providers..etc are eligible through Medicaid and the prices/amounts/caps. For instance my daughter needs a communication device. Would like to be able to go to the website, click on communication devices, see what qualifies through Medicaid and how much they will pay for. Would also be great to have the ability to have a "Live Chat" at anytime. As a single mom taking care of 2 children with Special Needs, by the time I have a chance to research or talk to someone it's 8:00 - 10:00 p.m. at night. No one is available. | 11/23/2013 12:21 PM |
| 218 | My dentist I want my drs to talk to each other and treat all of me. I'm more than a collection of pieces. | 11/23/2013 8:49 AM |
| 219 | Dental, transportation to medical appointment. The current transportation for medical appointment is a joke. There are caps as part of the BDS's considerations on what can and cannot be paid for. If you can find a private ABA therapist that charges \$80 per hour, however you are forced to use one from an established business who charges \$120 per hour, and the end result is the same, why should I have to pay more? | 11/23/2013 8:20 AM |
| 220 | back up provisions for when you are ill and cannot provide care for your child or invalid. There are times you just cannot do it.....even if you WANT to. | 11/23/2013 8:08 AM |
| 221 | Better transportation assistance to screen hired help PAC In a pcp. Insurance for personal care providers pool of personall to use when people call out sick. Payment to families who care for family members | 11/23/2013 8:06 AM |
| 222 | Respite care providers and specialized tutors on this side of the state. Also, specialized, field specific psychologists that accept Medicaid. | 11/23/2013 8:02 AM |
| 223 | Autism support in nashua including behaviorist. | 11/23/2013 6:41 AM |
| 224 | More appropriate organized group activities to reduce social isolation, including shared living arrangements. | 11/23/2013 12:43 AM |
| 225 | Vocational rehab for blind teen | 11/22/2013 11:18 PM |
| 226 | Chiropractic Supplements Naturopaths and Massage Therapy | 11/22/2013 11:11 PM |
| 227 | Not sure....but wonder about speech pathology or OT/PT services for long term. | 11/22/2013 10:48 PM |
| 228 | More respite monies, mental health services that arise with individuals with disabilities that may not have been prevalent in the younger years. | 11/22/2013 10:35 PM |
| 229 | Mental health providers, respite providers and mental health in patient stays. | 11/22/2013 10:30 PM |
| 230 | Applied Behavioral Analysis (ABA) | 11/22/2013 10:24 PM |
| 231 | None that I can think of. | 11/22/2013 6:55 PM |
| 232 | Dental Funeral services If syndrome is rare add the ability to connect with conferences/groups for rare syndrome support | 11/22/2013 6:31 PM |

NH Medicaid Long-Term-Care Program Survey

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| 233 | Well funded system that can hire qualified people. | 11/22/2013 5:52 PM |
| 234 | The home and vehicle modification amounts available are completely unrealistic in terms of their maximums. | 11/22/2013 5:34 PM |
| 235 | Neuro-Resource Facilitation | 11/22/2013 5:30 PM |
| 236 | Clients should be allowed to remain in their homes and receive adequate amounts of care without the state trying constantly to place them in a nursing home. | 11/22/2013 5:25 PM |
| 237 | A willingness to provide useful appliances and DME rather than just looking at a list and saying "no". | 11/22/2013 4:28 PM |
| 238 | - Dental care - A vastly improved mental health provider system, with less staff turnover. Dedicated, qualified providers don't stay with the community mental health system very long, hindering progress that might be made | 11/22/2013 4:17 PM |
| 239 | more transportation, RN training for individual's blood sugar testing, more employment programs and vocational education with tuition paid, more independent living help | 11/22/2013 3:56 PM |
| 240 | I do not know. | 11/22/2013 3:56 PM |
| 241 | Adequate budgets for people with intense needs. | 11/22/2013 3:53 PM |
| 242 | unknown | 11/22/2013 3:46 PM |
| 243 | dental, mental health services. vision | 11/22/2013 3:23 PM |
| 244 | dental, mental health services, vision | 11/22/2013 3:22 PM |
| 245 | Dental coverage, long term speech and physical therapy | 11/22/2013 3:20 PM |
| 246 | LNA service to be provided outside of home. | 11/22/2013 3:18 PM |
| 247 | opportunity to have physical therapy on occasion | 11/22/2013 3:09 PM |
| 248 | A larger budget allowance for therapies that are beneficial. | 11/22/2013 3:05 PM |
| 249 | Respite used to help offset afterschool programs. A pool of respite people to choose from. Teen groups with similar issues. Teen activities in community with kids of similar issues | 11/22/2013 3:03 PM |
| 250 | Behavioral and speech therapy | 11/22/2013 2:54 PM |
| 251 | Dental prevention for Adults, Mental Health and substance abuse supports, Consolidated budgets for all populations as in the DD system. The ability to pay for things -- not just 'staff' | 11/22/2013 2:51 PM |
| 252 | Increased funding for cost of living raises and to pay a living wage to support personal. | 11/22/2013 2:47 PM |
| 253 | Home care provider money | 11/22/2013 2:18 PM |
| 254 | you need to end the wait list , you need to have providers held accountable fiscally for the lack of services and bad services they provide | 11/22/2013 2:03 PM |
| 255 | As a taxpayer, I need a break. There needs to be more oversight and looking for some lower cost alternatives. There should not be a never ending pocket. | 11/22/2013 2:01 PM |
| 256 | Get rid of the wait list. Add respite care to outreach clients. Improve mental health funding. Improve funding for DD clients. | 11/22/2013 1:57 PM |
| 257 | Applied Behavior analysis. ABA | 11/22/2013 1:56 PM |
| 258 | DENTAL - Other than extractions. Having ataxia, I can't handle dentures without breaking them. | 11/22/2013 1:48 PM |
| 259 | vocational and pre-vocational services for youth in transition are so poorly provided by VR and by school districts that there should be an alternative from Medicaid. With support for a few years, I believe my son could be employed, drastically reducing his lifetime cost to "the system." Coaching services for an adult with autism, who needs assistance decoding work situations. (This is different from traditional job coaching. | 11/22/2013 1:43 PM |
| 260 | Dental | 11/22/2013 1:37 PM |
| 261 | Staff for back up.....maybe agencies with back up staff. | 11/22/2013 1:25 PM |

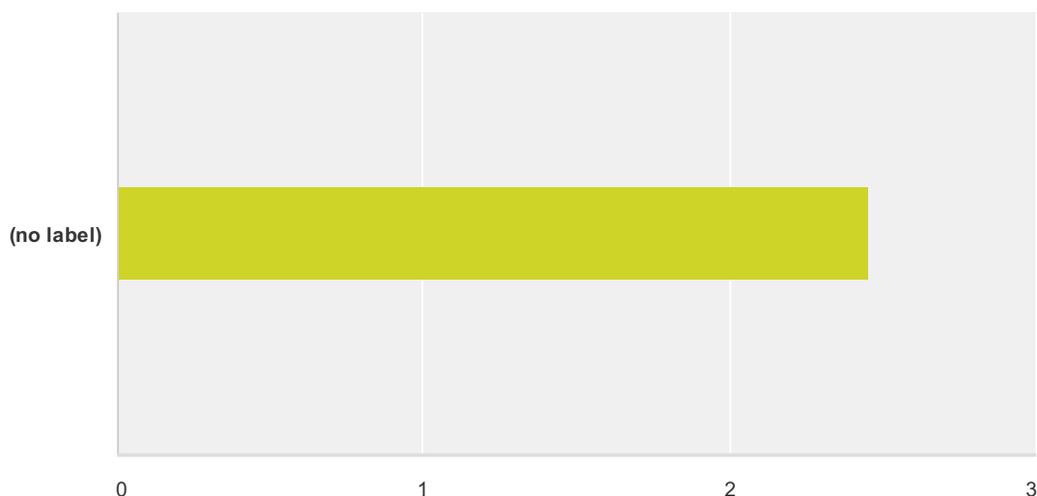
NH Medicaid Long-Term-Care Program Survey

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| 262 | Coverage of items needed to continue improving the person's ability to progress. For example, some young adults need assistance in living a healthy lifestyle, including exercise. Taking hikes and other types of physical activity would be of benefit. The more physically fit and healthy a person is, the actual long term costs in medical care are decreased. Begin to add services earlier in a young person's life, like while still in school so that all partners in the continuing care of a person know the goals and can begin to work earlier on them. Pay a living wage to care providers as they are the ones that must provide the one on one services to the person. They are underpaid now. Remember the old saying you get what you pay for. This is true with staff as well. There are some very dedicated people doing this difficult job and should be compensated appropriately for it. | 11/22/2013 12:31 PM |
| 263 | A PCA vs. LNA that could provide transportation as well as administer medications. | 11/22/2013 12:29 PM |
| 264 | housing options for those who are both developmentally disabled and mentally ill. | 11/22/2013 12:25 PM |
| 265 | Not sure what is available now. | 11/22/2013 12:10 PM |
| 266 | In home LNA services | 11/22/2013 11:47 AM |
| 267 | A service dog and the cabinet with locks on it. Also iPads for verbal kids with Autism. It is extremely helpful for communication even when your child is verbal and is also necessary for writing, behavior modeling, and much much more. | 11/22/2013 11:44 AM |
| 268 | Funds for extras or travel & staffing funds to be able to do the extras that we're able to provide. | 11/22/2013 11:39 AM |
| 269 | More staff and respite hours. More money for communication services | 11/22/2013 11:39 AM |
| 270 | A hotline (phone or email) that could give specific answers to questions about filling out Medicaid/Medicare/SSA program requirements and forms. The recent changeover to Medicare was confusing and time-consuming. | 11/22/2013 11:32 AM |
| 271 | The ability to utilize funds for more staff recruitment and retainment initiatives. | 11/22/2013 11:30 AM |
| 272 | Psychiatry Rx Mgt | 11/22/2013 11:25 AM |
| 273 | Robin Hill provides needed care. | 11/22/2013 11:10 AM |
| 274 | More group facilities for those with disabilities - requiring some but not all total care services...and more transportation services for people who need them | 11/22/2013 11:04 AM |
| 275 | More social activities and supports in the community. Increased units in certain services such as augmentative communication, physical therapy, computer skills beyond the basics. | 11/22/2013 10:56 AM |
| 276 | Transportation for NON medical. the fact that he is an adult now. Who can not drive and want to go see his mother. I always hear that you want them to have a normal life. why isn't there any transportation for them to go out to do things??????? | 11/22/2013 10:46 AM |
| 277 | We live in a rural area and transportation is always a concern. Currently we pay an individual for transportation but if he was suddenly not able to continue, it would be difficult finding a replacement. Increased funding would be great. | 11/22/2013 10:37 AM |
| 278 | Independent living but supervised for safety | 11/22/2013 10:36 AM |
| 279 | computer training | 11/22/2013 10:31 AM |
| 280 | Despite being approved for respite, we were never able to find a provider. Screened providers would be great (too late for us though), when determining eligibility, look at the whole family budget, not just the basics and use common sense. E.G., someone making \$30,000 a year and \$30 in gas a week has more money left over than someone who makes \$50,000 a year but commutes at a cost of \$30 per day! | 11/22/2013 10:30 AM |
| 281 | group housing for young adults | 11/22/2013 10:28 AM |
| 282 | Complementary therapies need to be fully supported. Also, chiropractic services need to be reinstated as a medical therapy as well. | 11/22/2013 10:04 AM |
| 283 | Respite homes | 11/22/2013 10:03 AM |
| 284 | Respite services that do NOT include placing my ward into a nursing home. | 11/22/2013 9:53 AM |
| 285 | Some alternative therapies like music therapy, aqua therapy, and hippotherapy. | 11/22/2013 9:50 AM |
| 286 | Adult dental benefit, ABA for autism, more quality mental health services including counseling | 11/22/2013 9:42 AM |

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Q30 How willing would you or your family member be to do something to add a small reward of funds to your annual services account -- like participating in a health screening or fitness program or volunteer work -- if it were something that it was within your (their) ability to do?

Answered: 507 Skipped: 385



| | Would not | Might | Would | Total | Average Rating |
|------------|-------------|---------------|---------------|-------|----------------|
| (no label) | 8.68% 44 | 38.07% 193 | 53.25% 270 | 507 | 2.45 |

| # | Feel free to comment if you would like | Date |
|----|--|--------------------|
| 1 | Volunteer work is already being done and is very important to the individual volunteering. | 12/9/2013 7:54 PM |
| 2 | This would all depend on what it is specifically and how time consuming it would be. Some things just can't be counted on especially if our individual is sick, the weather is bad, the time of the year it is, or if we have alternate care for our individual etc. | 12/8/2013 8:33 PM |
| 3 | I do it all the time volunteer take the penguin plunge . maybe the state workers who get an awful lot of sick and vacation time should consider giving some up to help others in need | 12/8/2013 7:42 PM |
| 4 | We do enough already to provide for our member 24/7 for 32 years. | 12/7/2013 6:17 PM |
| 5 | Great Idea! Beneficial and creates ownership and a sense of worth for my child | 12/7/2013 12:03 PM |
| 6 | I might be able to get time to do this. The other guardian works full-time and has a family so would be less likely to be able to do this. My sister (client) with Downs Syndrome and dementia is increasingly less able to. | 12/7/2013 11:00 AM |
| 7 | This question is too poorly worded for me to attempt to answer. | 12/6/2013 11:29 PM |
| 8 | What does that mean, small reward of funds? | 12/6/2013 6:17 PM |
| 9 | Greg does all of the above | 12/6/2013 3:36 PM |
| 10 | I am the soul caregiver in my family. The question is time. Right now it is 24/7 | 12/6/2013 2:59 PM |
| 11 | Sounds like a marvelous idea! | 12/6/2013 1:43 PM |
| 12 | Definitely would if volunteer work. I have no funds to help financially. | 12/6/2013 12:40 PM |

NH Medicaid Long-Term-Care Program Survey

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| 13 | He likes monetary rewards and I pay him often for doing things by having him put the money on a pay sheet in our kitchen cupboard. He can then use that money to buy what he wants, like video games or gifts for birthdays or Christmas. Something like a points account. When he wants something, I pay for it, and he takes the money off his pay sheet. | 12/6/2013 10:10 AM |
| 14 | It must also be clear that I am TRYING TO LIVE a REGULAR HEALTHY LIFE, and access to this should not be deprived to me, even if I am part of a rewards program..a healthy life includes a variety of people & activities & focuses, not just ONE.. | 12/6/2013 9:59 AM |
| 15 | Good idea | 12/6/2013 9:25 AM |
| 16 | not applicable to providers | 12/6/2013 9:03 AM |
| 17 | I think this is a very good idea. | 12/6/2013 8:22 AM |
| 18 | Happily! | 12/6/2013 7:52 AM |
| 19 | Shouldn't need to "jump through more hoops" for additional funds. Somehow "special rewards" don't seem fair. We are not dogs looking for an extra biscuit. We're human beings in need of care! Funds should be evenly dispersed. Thank you. | 12/6/2013 12:52 AM |
| 20 | I volunteer now | 12/5/2013 11:01 PM |
| 21 | I absolutely would help. We all need to support each other to move forward. It benefits everyone. | 12/5/2013 8:43 PM |
| 22 | Participating is very important. | 12/5/2013 6:51 PM |
| 23 | Prevention counts but participation should not be tied to getting other services | 12/5/2013 6:35 PM |
| 24 | I'm not sure what this means. Our son already tries to participate in a fitness program that has proven essentially useless in motivating him. And I volunteer a lot with efforts to assist those with disabilities. I'm exhausted. I don't think I have it in me to do more. Caring for someone with disabilities is a huge task in and of itself. | 12/5/2013 6:26 PM |
| 25 | Money should not be tied to specific programs. My son receives regular medical, vision, and dental care. We already make sure he exercises regularly. We work very hard caring for our son and find a question like this one insulting. | 12/5/2013 6:23 PM |
| 26 | I believe most folks on the ABD waiver already do these things through their family supports or service providers. | 12/5/2013 12:13 PM |
| 27 | As I am near 70 and still working, I do not think I am going to be overloaded with extra time and energy myself. My daughter has tried volunteer work, but it is hard to find such that has appropriate bathroom facilities and actual needed work. Some of the volunteer jobs she has had were moving papers from here to there and doing the same each time. She is much too smart for this type of work. | 12/5/2013 11:31 AM |
| 28 | my family member is profoundly disabled so it would greatly depend on the activity. | 12/4/2013 10:30 PM |
| 29 | I think belonging is a very important part in all of our lives, so clubs and volunteer are a healthy thing to do. | 12/4/2013 9:37 PM |
| 30 | Money is a great incentive! | 12/4/2013 8:09 PM |
| 31 | excellent idea and would love to participate! | 12/4/2013 12:56 PM |
| 32 | I'm assuming this means the recipient of funds, and my brother-in-law (recipient) would not be appropriate for these programs. | 12/4/2013 12:30 PM |
| 33 | My family suffers from high anxiety. Never worked or learn to drive. For her it would be very difficult to do this, however, with baby steps and lots of support she may succeed in doing something. I have met with over a hundred residents and I would say at least 25% would love to have some type of volunteer job, especially if it meant more money to go to the cost of their care services. | 12/4/2013 12:02 PM |
| 34 | Great idea! | 12/4/2013 11:52 AM |
| 35 | If there would be transportation provided for our daughter she could participate in this. My husband and I are older and do not drive that much any more. | 12/4/2013 10:15 AM |
| 36 | Work full time and want to be a mom not superwoman | 12/4/2013 10:05 AM |
| 37 | All three of those items are already part of our CDS plan. | 12/4/2013 10:04 AM |
| 38 | does not work | 12/3/2013 5:30 PM |
| 39 | Not sure this applies in my case. | 12/3/2013 2:17 PM |
| 40 | No strings should be attached. | 12/3/2013 1:28 PM |

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| 41 | Glad to help even if not for a reward. The benefit is already like a reward. It is very much appreciated. | 12/3/2013 12:56 PM |
| 42 | I do it now. I work with the Parent Partnership in Concord. I go to Community Crossroads meetings as much as possible. Due to age some things would be very difficult. | 12/3/2013 12:16 PM |
| 43 | Ineffective and prejudiced use of this (often money rewarded) personal information. | 12/3/2013 11:49 AM |
| 44 | My children participate/involved in so many meetings, therapies, etc. that they need time to be kids too. I would not want them to have to participate in any more required attendance type items/work. | 12/3/2013 9:18 AM |
| 45 | I would join a health club as long as they agreed to pay for it. | 12/2/2013 6:05 PM |
| 46 | My family member currently participates in a healthy living program run by the Greater Nashua Mental health center. | 12/2/2013 4:47 PM |
| 47 | I would be happy to do whatever I could to help my son and anyone else. | 12/2/2013 3:07 PM |
| 48 | I feel that most people would participate in this | 12/2/2013 2:03 PM |
| 49 | YEs, but what does health screening or fitness that have to do with long term support? I can see the example being suitable for the acute side of care; There are already hour-for-hour volunteer programs that are handled off-medicaid books and, other than funding the coordination person for that, medicaid should stay out of it. | 12/2/2013 12:56 PM |
| 50 | We are fully involved in a fitness program and volunteer weekly. | 11/29/2013 6:21 PM |
| 51 | We are limited in what we can physically do to volunteer, although we would like to find a good volunteer fit. | 11/29/2013 1:41 PM |
| 52 | Since my daughter has not been able to find suitable employment, volunteer work is especially important, especially if it added some funds or benefits to her annual account. | 11/29/2013 11:54 AM |
| 53 | We already volunteer and go to the health club...can't imagine what else this would bring. | 11/27/2013 6:16 PM |
| 54 | N/A | 11/27/2013 11:23 AM |
| 55 | I am already an active volunteer in my community. | 11/27/2013 8:50 AM |
| 56 | We have explained to our sons that giving back to the community and helping others in any capacity is very important to themselves and those they help. | 11/26/2013 12:09 PM |
| 57 | My daughter already does all these things. She volunteers in a daycare kindergarten class, takes a modified karate class and is always up-to-date on all her health screenings. | 11/26/2013 11:43 AM |
| 58 | I currently do volunteer work through ABLE and would love to be able to do more. I enjoy helping other people, because I know how it feels to have to finally admit that I needed help and the negative feelings that I learned to endure. The price of losing your pride. That is why I think everyone should try it, if they can! | 11/25/2013 9:24 PM |
| 59 | can't answer on this page either can't click on the answer I want | 11/25/2013 8:27 PM |
| 60 | Again more work for them when they would prefer less responsibility. | 11/25/2013 11:23 AM |
| 61 | My son is young but I believe in volunteerism. It should be a reward/addition for doing the work and not necessarily a requirement. | 11/25/2013 11:18 AM |
| 62 | I believe these 'screenings' are an invasion of privacy. We do live a very healthy life-style and are a healthy family, but I believe these 'screenings' are a serious invasion in my personal and private life. | 11/25/2013 10:12 AM |
| 63 | depends on what you are asking for my sister to do | 11/25/2013 10:10 AM |
| 64 | medically fragil | 11/24/2013 7:29 PM |
| 65 | No time | 11/24/2013 5:26 PM |
| 66 | We often do these things anyway, it would be great to be recognized for it | 11/24/2013 2:02 PM |
| 67 | I do this all the time with my people who know me | 11/23/2013 8:49 AM |
| 68 | Most definately! | 11/23/2013 8:21 AM |
| 69 | Feel this question is inappropriate. Discriminates, unfair, and should not be part of this survey. | 11/23/2013 7:47 AM |
| 70 | We do | 11/22/2013 6:31 PM |
| 71 | My daughter is completely disabled. She can't do anything like this. | 11/22/2013 5:34 PM |
| 72 | Would not apply to my son's situation | 11/22/2013 5:26 PM |

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| 73 | Need to think long and hard first. | 11/22/2013 4:29 PM |
| 74 | not really relevant; my son would not likely participate | 11/22/2013 3:54 PM |
| 75 | Would very much welcome a fitness program | 11/22/2013 3:21 PM |
| 76 | volunteer | 11/22/2013 2:55 PM |
| 77 | What if they already do these things –what would be the incentive for them... seems like rewards are to correct bad (sorry not the best word but all that comes to mind this moment) and not the good things folks already do. | 11/22/2013 2:53 PM |
| 78 | I have served on boards, councils given free advise over the past 30 years. During that time I gave up a career (\$30,000 per yr. x 30 yrs. = \$900,000 not including raises, benefits, etc.) income, friends, family free time. Not that I wouldn't do anything for my son still, but I don't believe it is fully realized what we sacrifice to care for our children through no fault of our own. We still support many of his needs to give him the quality of life that he deserves. I would get involved if it actually was productive and positive outcomes. | 11/22/2013 2:48 PM |
| 79 | You have rushed into a plan that you have no idea how it will impact families. You are using families as cheap labor. Many families use CDS as means to provide need money to the households. However, this impacts my family by not allowing a highly trained person to work outside of the home. | 11/22/2013 2:08 PM |
| 80 | WOULD | 11/22/2013 1:50 PM |
| 81 | We have individuals in our system that are homebound ..without visitors. Volunteering to do home visits is a wonderful way to give back . | 11/22/2013 11:50 AM |
| 82 | It depends. I am bringing my son to therapy 2 times a week outside of school and I already do a TON of volunteer work in the disability world. I would love to be compensated for the work I already do by facilitating a support group- soon to be two support groups and everything else I do! | 11/22/2013 11:47 AM |
| 83 | All depends on the time commitment, spread rather thin 3/4 of the year! | 11/22/2013 11:40 AM |
| 84 | Our daughter is very dedicated to personal fitness. Learning more about different ways to stay healthy and fit would be very effective for her. | 11/22/2013 11:34 AM |
| 85 | We currently advocate for doing these things and our family member receives ongoing medical attention and also we ask him to volunteer where appropriate. Also, a physical fitness component has always been part of his individual service plan. | 11/22/2013 11:32 AM |
| 86 | Even discounted rates of the local health club facilities are out of our budget but I would gladly pay for these services if more affordable and he would healthier as well | 11/22/2013 11:06 AM |
| 87 | Who is going to take them to the GYM? I would like to see them get some pay if they do volunteer work not a lot. They know that they are working and they know that people get paid to do a job. | 11/22/2013 10:48 AM |
| 88 | Not sure because he dreams of many things he really can't do, and being lazy and stubborn as he is, the 3 things above would ware off right away and he would want something else. | 11/22/2013 10:39 AM |
| 89 | volunteer work, not interested in health screening or fitness program because of confidentiality | 11/22/2013 10:31 AM |

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Q31 What activities that would increase your health or quality of life (or your family member's) should be considered for rewards to add funds to your annual services account if you had one?

Answered: 314 Skipped: 578

| # | Responses | Date |
|----|--|--------------------|
| 1 | Additional recreational opportunities. | 12/9/2013 7:54 PM |
| 2 | Health club membership to increase exercise. | 12/9/2013 6:44 PM |
| 3 | something physical | 12/9/2013 12:41 PM |
| 4 | I have no idea. Relieving stress would be nice but not sure how that could come about. | 12/8/2013 8:34 PM |
| 5 | why do we need rewards??? why not do it because they deserve it ? | 12/8/2013 7:43 PM |
| 6 | Not sure | 12/8/2013 7:19 PM |
| 7 | Nutrition education to include cooking classes. Hiking/walking events. Gym memberships with trainer guidance. | 12/8/2013 4:33 PM |
| 8 | Exercising and eating healthy,,,quitting smoking | 12/8/2013 9:56 AM |
| 9 | Being able to leave the facility with support staff occasionally on weekends. | 12/7/2013 4:31 PM |
| 10 | diet and nutrition budgeting/money management exercise opportunity for service to others | 12/7/2013 12:04 PM |
| 11 | volunteering health check ups visits to others similarly situated (if possible) attendance at educational seminars/activities to remain updated about program | 12/7/2013 8:32 AM |
| 12 | weight watchers, gym, volunteer work, participating in my care | 12/6/2013 11:25 PM |
| 13 | Volunteer work | 12/6/2013 10:28 PM |
| 14 | Physical activities (like YMCA membership) | 12/6/2013 9:52 PM |
| 15 | Education and Physical Activity | 12/6/2013 6:05 PM |
| 16 | Exercise. Learning medication management. | 12/6/2013 5:40 PM |
| 17 | Adherence to IEP, efforts to improve fitness, would be positive reinforcements. | 12/6/2013 4:44 PM |
| 18 | volunteering in the community in a structured setting | 12/6/2013 4:43 PM |
| 19 | I am not sure at this time | 12/6/2013 4:03 PM |
| 20 | fitness; appropriate social interactions with others: mental health diagnosis often has stigmas attached | 12/6/2013 3:48 PM |
| 21 | light exercise & semi social engagements such as dog walking, gardening, simple building/painting projects with others in program; nutrition course that includes helpful shopping & food prep tips/recipes; encouragement to participate in the community, and feel accepted & valued i.e. reading to young or elderly, assisting at soup kitchen, tending shared garden plot... and help with facilitation of/transportation to these activities | 12/6/2013 3:38 PM |
| 22 | More socialization and interaction for my mom. I would like more discussion with other caregivers. I'm new at this level of care for my mom. | 12/6/2013 3:07 PM |
| 23 | For my family member: Exercise, adequate sleep, healthy foods, AA participation, meeting goals or commitments. For family members: Al-anon participation, Family-to-Family training through NAMI. | 12/6/2013 2:51 PM |
| 24 | not sure how it works | 12/6/2013 2:40 PM |
| 25 | membership at health fitness clubs | 12/6/2013 1:51 PM |
| 26 | seeing a professional!! | 12/6/2013 1:31 PM |
| 27 | Therapy | 12/6/2013 1:19 PM |

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| 28 | Arrange volunteer activities the mentally ill person ight want to do: Have place where tasks are brought in. Person shows up (gets refreshment) and helps for an hour or two - sticking labels on for public service mailing, counting out somethings, assembling packets for a program or nonprofit oprganization) and the like. | 12/6/2013 12:44 PM |
| 29 | The activities provided by Granite Pathways (Manchester NH) and other peer support groups are tremendously valuable to mentally ill individuals. Funding is needed to make these programs possible and to support their activities and staffing. | 12/6/2013 11:50 AM |
| 30 | Comprehensive care for patients with co-occurring mental illness/substance abuse. For example, support to encourage regular participation in AA, counseling, medication management. | 12/6/2013 11:47 AM |
| 31 | Home based mental health supports for older adults; Transportation | 12/6/2013 11:40 AM |
| 32 | Physical activities, finding program services that are comparable to the individuals needs at a lower cost. (ie. the YMCA compared to a health club) | 12/6/2013 11:32 AM |
| 33 | volunteer activities participating in long term mental health studies | 12/6/2013 11:32 AM |
| 34 | Daily exercise. | 12/6/2013 11:26 AM |
| 35 | health assessments, gym memberships, healthy behaviors | 12/6/2013 11:03 AM |
| 36 | For our child to have some kind of occupation, either paid or volunteer. I am very interested in IPS and the services they provide. | 12/6/2013 10:50 AM |
| 37 | Volunteer work would be nice. There is no where for,him to volunteer that I know of... He would need to be brought there with someone and they would have to volunteer together at least at first. After that he would need transportation. Exercise. Taking a class. | 12/6/2013 10:13 AM |
| 38 | respit | 12/6/2013 10:09 AM |
| 39 | More Money rewards, access to entertainment, like movies, local shows that cost money, free & better transportation, memberships in healthy organizations with admissions with sliding scales for low income people...there should be NO EMPTY SEATS ANYWHERE ANYTIME..there are plenty of low income people who'd pay PLAN a dollar rather than leave that \$15 seat empty..and a working word is PLAN..if we don't & cannot know our budgets, we CANNOT PLAN, LIKE ANY OTHER PERSON to be part of an event..and sometimes events in this economy, you only hear about, less than a week before...how can a person on a MONTHLY budget plan for THAT ?? | 12/6/2013 10:04 AM |
| 40 | Play therapy. | 12/6/2013 9:57 AM |
| 41 | participation in heath education, fitness, and recreational activities | 12/6/2013 9:42 AM |
| 42 | ?? | 12/6/2013 9:41 AM |
| 43 | Gym or cooking | 12/6/2013 9:37 AM |
| 44 | Volunteer work attending educational programs excercise programs | 12/6/2013 9:36 AM |
| 45 | Exercise | 12/6/2013 9:18 AM |
| 46 | Not applicable to providers | 12/6/2013 9:04 AM |
| 47 | pool memberships, outings (movies or parks) | 12/6/2013 8:44 AM |
| 48 | Gym or activite lifestyle rewards, rewards of staying out of hospital or having regular health appointments. | 12/6/2013 8:10 AM |
| 49 | exercise | 12/6/2013 6:53 AM |
| 50 | Annual Physical, attending peer support programs, participation in a relevent education program | 12/6/2013 6:17 AM |
| 51 | a gym membership | 12/6/2013 12:37 AM |
| 52 | Exercise and nutrition programs | 12/5/2013 11:54 PM |
| 53 | housing, food , utilities, cable, internet, phone, transportation, medications,medical care, long term hospitalization for mental disorders. | 12/5/2013 11:28 PM |
| 54 | Smoking cessation | 12/5/2013 11:09 PM |
| 55 | Help in paying for membership in our community center for swimming and a walking tracked | 12/5/2013 11:03 PM |
| 56 | I participate in the INSHAPE program and exercise four times a week at the YMCA. This is improving my mental health as well as my physical health-I am preventing diabetes through exercise and a change in diet.. It would be great to have this add funds to my services. | 12/5/2013 10:51 PM |

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| 57 | Exercise and nutrition | 12/5/2013 10:50 PM |
| 58 | Activities and help with daily living | 12/5/2013 10:29 PM |
| 59 | Adaptive sports | 12/5/2013 10:27 PM |
| 60 | Exercising, community service | 12/5/2013 10:16 PM |
| 61 | Exercise | 12/5/2013 10:14 PM |
| 62 | Volunteer to speak to mental health providers on what's important to the mentally ill.. | 12/5/2013 9:56 PM |
| 63 | Weight loss. Exercise/fitness activities. | 12/5/2013 9:55 PM |
| 64 | Exercise nutrition preventive care financial for completing these activites | 12/5/2013 9:51 PM |
| 65 | nutrition info, fitness/social activities, job skills | 12/5/2013 9:46 PM |
| 66 | Gym/Yoga membership, Granite Pathways/Clubhouse membership, Healthy eating programs. | 12/5/2013 9:26 PM |
| 67 | Become a member to the YMCA for exercise. | 12/5/2013 9:08 PM |
| 68 | Education funding., Help getting funding for transportation, such as a car. Financial assistance for gym memberships and/or other wellness activities. Believe it or not, but I believe certificates for reduced meals at restaurants, movie theaters, bowling alleys, sporting events, etc. would be phenomenal. People with a mental illness often feel self-conscious and lack confidence. Social anxiety is a tremendous issue. Having the opportunity (and reduced financial concern) to experience activities, that most people take for granted, could contribute to improved mental health. The socialization aspect is so important in recovery and stabilization., | 12/5/2013 8:50 PM |
| 69 | Going to the movies, out door activities like walking or going to the beach, grabbing something to eat, new board game we all could play... | 12/5/2013 8:41 PM |
| 70 | having a support group | 12/5/2013 8:36 PM |
| 71 | Member to a gym | 12/5/2013 7:50 PM |
| 72 | Fitness programs, volunteer programs | 12/5/2013 7:47 PM |
| 73 | social outings | 12/5/2013 7:14 PM |
| 74 | support group for family members support group for patients with similar issues or needs active involvement in patient's care--treatment planning. | 12/5/2013 7:10 PM |
| 75 | Supported employment. | 12/5/2013 6:52 PM |
| 76 | physical fitness, nutrition and diet and transportation subsidy | 12/5/2013 6:36 PM |
| 77 | Nonsmoker Weight loss goals Physical activity | 12/5/2013 6:35 PM |
| 78 | Socially based physical activities -- there's little of supported social options. These need the guidance of professionals and should not be left to peers. These should be community based, easy to get to, and appealing to all ages -- particularly young adults. | 12/5/2013 6:28 PM |
| 79 | Any form of exercise including walking. Any adaptive sport activity. | 12/5/2013 6:27 PM |
| 80 | fitness program | 12/5/2013 6:26 PM |
| 81 | meaningful employment or service possibilities | 12/5/2013 6:18 PM |
| 82 | Exercise, volunteering. | 12/5/2013 6:02 PM |
| 83 | membership to a local gym with a personal trainer | 12/5/2013 5:24 PM |
| 84 | None at this time | 12/5/2013 3:13 PM |
| 85 | More social interactions for my son with supports other than myself. | 12/5/2013 1:54 PM |
| 86 | Additional respite services. Adequate training of direct support providers. | 12/5/2013 1:30 PM |
| 87 | Going swimming. The pool is the best for our family member but the one in our area is too expensive for us to afford. | 12/5/2013 1:03 PM |
| 88 | Fix her disability. What a stupid question. | 12/5/2013 11:32 AM |
| 89 | Exercise | 12/5/2013 11:07 AM |
| 90 | n/a | 12/5/2013 11:00 AM |

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| 91 | Screenings, doing activities in the community, continuing education | 12/5/2013 10:24 AM |
| 92 | Adaptive therapies and fitness program | 12/5/2013 9:40 AM |
| 93 | Physically involving outings like hiking, snowboarding, swimming or team sports: basketball, volleyball, etc. My daughter has become obese while in the program and there is next to nothing for activities that might help in weight management. Eventually, her weight may impact her health and lead to avoidable health issues. | 12/5/2013 8:57 AM |
| 94 | Good qualified respite providers | 12/5/2013 8:50 AM |
| 95 | I would like a special Olympic activities involved in our schools | 12/5/2013 7:42 AM |
| 96 | Tutoring funds | 12/5/2013 5:41 AM |
| 97 | gym membership | 12/5/2013 5:31 AM |
| 98 | bowling, going out side for a walk, going to the YMCA, swimming, cooking/baking | 12/4/2013 10:32 PM |
| 99 | membership in a local gym. | 12/4/2013 10:24 PM |
| 100 | Physical Therapy for stretching | 12/4/2013 9:48 PM |
| 101 | not sure | 12/4/2013 9:45 PM |
| 102 | Snowshoeing, bowling, skiing, waterskiing, canoeing, kayaking, hiking, rock climbing, fishing, ice fishing, swimming, gardening, basketball, baseball, golf, archery, biking, walking, running, kite flying, skating, hockey, floor hockey, tennis, ping pong. I could go on! | 12/4/2013 9:43 PM |
| 103 | Visits to rehab pool (which we now pay for out of pocket). | 12/4/2013 9:25 PM |
| 104 | gym membership | 12/4/2013 8:15 PM |
| 105 | Quit smoking, increase exercise, lose weight, work or volunteering. | 12/4/2013 8:10 PM |
| 106 | Make my day more meaningful in doing more hands on hands things with me. | 12/4/2013 7:16 PM |
| 107 | volunteering, fitness evaluation/program involvement | 12/4/2013 6:41 PM |
| 108 | yoga classes silver sneakers free flu shots | 12/4/2013 3:27 PM |
| 109 | Swimming, or gym membership, Music classes or therapy, Maybe a ski program like they have a Crotchet Mountain. | 12/4/2013 3:25 PM |
| 110 | Small increase in monthly personal needs allowance | 12/4/2013 3:17 PM |
| 111 | My family member is pretty sedentary, and likes it that way! We could probably participate in screenings or outings that didn't require much effort. | 12/4/2013 2:43 PM |
| 112 | recreation | 12/4/2013 2:11 PM |
| 113 | Music therapy, therapeutic riding, travel (Is this what is meant by reward???) | 12/4/2013 2:00 PM |
| 114 | nutrition & exercise | 12/4/2013 12:57 PM |
| 115 | Fitness programs, Community Service | 12/4/2013 12:15 PM |
| 116 | Volunteer work. No missed medical appointments. If they are in a ltc home, doing their own room cleaning/bed making, (saves staff time from doing this work). After being trained, assisting other residents at meal times. One person I work with, has superb mechanical skills, and could perhaps assist with wheelchair adjustments and fixing wheelchairs. He set up a whole light system on his wheelchair so that when he went into town in his wheelchair, cars would see his lights and directionals. Walking or staying near a resident who tends to wander aimlessly and verbally direct them to not enter someone else's room ro leave the facility, and of course if the other resident did enter someone else's room or walked out of the facility, letting a staff member know immediately. If the person likes doing laundry, having them assist with laundry tasks or kitchen duties, etc. All of these things could raise the self-esteem of the person and free up staff time for other duties. | 12/4/2013 12:02 PM |
| 117 | More intensive job development and initial on-site support. | 12/4/2013 11:57 AM |
| 118 | paying for his gym membership | 12/4/2013 11:53 AM |
| 119 | Healthy nutrition and weight loss, classes on stress reduction, sleep classes, exercise and fitness | 12/4/2013 11:53 AM |
| 120 | Not sure | 12/4/2013 11:40 AM |
| 121 | Exercise program | 12/4/2013 11:11 AM |

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| 122 | 1. Tie performance to the service plan 2. Incentive to stay below budget 3. Be keenly aware of "cost of services" 4. Create a team mentality with other families to choose the best services available rather than "trial and error". | 12/4/2013 10:48 AM |
| 123 | volunteering | 12/4/2013 10:32 AM |
| 124 | I really don't know. | 12/4/2013 10:16 AM |
| 125 | physical activities to do with friends. | 12/4/2013 10:04 AM |
| 126 | Physical fitness activities eg: involvement in regular exercise programs or teams Community service/volunteering (library etc) | 12/4/2013 9:51 AM |
| 127 | Walking | 12/4/2013 8:54 AM |
| 128 | Physical activity and experienced in home support provider. | 12/4/2013 8:49 AM |
| 129 | Regular exercise program overseen by trainer or fitness club or staff trained to do and overview for accountability for peoples eating habits and healthy life choices and held accountable for their health outcomes and rewarded for their progress or continued fitness program | 12/4/2013 8:42 AM |
| 130 | I think people who smoke yet are on Medicaid and have their respiratory meds paid for need to stop smoking. people who are overweight need to lose weight...these are 2 prominent issues with many medicaid recipients. my situation is that my child is developmentally disabled...born that way...did not contribute to the disability. those with acquired (alleged) disabilities who actively participated in their outcome should be held accountable to some degree. Sadly millions of dollars are profoundly wasted on people who are NOT disabled...greed and corruption are rampant in the welfare system. Those on disability need to be reviewed every 6 months.....check DMV records for the kind of car(s) they drive, check personal possessions....72" screen TV, top of the line cable pkg., NorthFace, Ugg boots, 18k gold jewelry, fake fingernails, Coach bags, etc.....those wasted Medicaid / disability dollars can be and should be re-directed to those TRULY disabled..... | 12/3/2013 11:25 PM |
| 131 | Lowering cholesterol, blood pressure, clocking in a particular amount of exercise per week | 12/3/2013 10:32 PM |
| 132 | Physical exercise | 12/3/2013 10:31 PM |
| 133 | Healthy life style | 12/3/2013 9:19 PM |
| 134 | contributing to the community/society in a productive way | 12/3/2013 9:02 PM |
| 135 | Not sure | 12/3/2013 8:23 PM |
| 136 | providing control of funds for families unable to do so | 12/3/2013 7:25 PM |
| 137 | Diet or exercise programs, stress reduction programs | 12/3/2013 6:41 PM |
| 138 | diabetes program, nutrition counseling, exercise, personal trainer--health motivator. | 12/3/2013 5:47 PM |
| 139 | Gym membership Nutrition counseling Weight watchers type programs | 12/3/2013 5:19 PM |
| 140 | Regular exercise of any kind. | 12/3/2013 5:09 PM |
| 141 | Not sure | 12/3/2013 5:01 PM |
| 142 | volunteer or job opportunities | 12/3/2013 4:50 PM |
| 143 | Volunteering in the community - outside of Megan's regular service plan (she already does some) and maybe tracking her exercise/healthy program | 12/3/2013 4:39 PM |
| 144 | I do not know. | 12/3/2013 4:30 PM |
| 145 | a program for weight loss and proper nutrition | 12/3/2013 3:43 PM |
| 146 | Exercise program | 12/3/2013 3:24 PM |
| 147 | NA | 12/3/2013 2:17 PM |
| 148 | Have no idea. We're just trying to take it one day at a time as life is very hard when you have someone in your family with a disability. We're thankful for whatever support we can get and we do not want to abuse the system like some proclaim (republicans). We just want to be able to stay together and take care of each other and be happy. | 12/3/2013 1:16 PM |
| 149 | Involvement in smoking cessation and/or weight loss program. Participation in nutrition counseling. Receiving counseling support to promote self-awareness of the need to take responsibility for my life. Participation in approved job training. | 12/3/2013 1:13 PM |
| 150 | YMCA membership is awesome...but we already have that. | 12/3/2013 12:57 PM |

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| 151 | Exersize program costs covered. | 12/3/2013 12:24 PM |
| 152 | fitness programs | 12/3/2013 12:21 PM |
| 153 | Membership to a good health club with pool. My kids get weekly group pool therapy that they medically need. | 12/3/2013 12:17 PM |
| 154 | Access to a gym | 12/3/2013 12:11 PM |
| 155 | volunteering -meals on wheels-taking folks to appointments-home clean-up-etc. | 12/3/2013 11:50 AM |
| 156 | NO IDEA | 12/3/2013 11:21 AM |
| 157 | Family Membership to YMCA | 12/3/2013 11:14 AM |
| 158 | Fitness Stress management Healthy eating Safety | 12/3/2013 11:10 AM |
| 159 | Community volunteer work | 12/3/2013 11:09 AM |
| 160 | I don't know | 12/3/2013 9:37 AM |
| 161 | Fitness, socialization activities | 12/3/2013 9:34 AM |
| 162 | Membership to a gym; transportation to activities offered by Northeast Passage or New England Handicapped Sports Association | 12/3/2013 9:15 AM |
| 163 | Gym Memberships YMCA is a great program with lots of options however very \$\$\$ | 12/3/2013 9:00 AM |
| 164 | more physical activity, might purchase healthier food and meals since they are more expensive. | 12/3/2013 8:40 AM |
| 165 | not sure | 12/2/2013 11:02 PM |
| 166 | attendance at family support meetings and fitness activities | 12/2/2013 10:25 PM |
| 167 | Exercise program | 12/2/2013 10:09 PM |
| 168 | community involement! | 12/2/2013 8:27 PM |
| 169 | fishing or hiking..... | 12/2/2013 8:11 PM |
| 170 | Having adequate trained respite providers | 12/2/2013 6:29 PM |
| 171 | Join a health club at your expense. | 12/2/2013 6:05 PM |
| 172 | Participating in a regular exercise program. Maintaining a successful weight lose program. Participation in volunteer work. Offer courses in health life style and reward them for successful completion. Finding them employment and supporting them on the job. | 12/2/2013 4:53 PM |
| 173 | Smoking cessation | 12/2/2013 3:42 PM |
| 174 | Traveling, hiking, swimming, biking, skiing, snowshoeing, walking, running, fishing, and gardening. | 12/2/2013 3:09 PM |
| 175 | Exercise, volunteering, employment | 12/2/2013 2:04 PM |
| 176 | nutrition - walking | 12/2/2013 1:59 PM |
| 177 | Flexible funds - recreation, household, etc. | 12/2/2013 1:07 PM |
| 178 | Rewards? I'm not sure that has any bearing on us or even state benefit on this topic. If you are talking about physical, acute wellness, it makes sense (helping to stop smoking, fitness, etc.). Applying incentives it to long term care seems half-thought through, of trying to think of long term from an acute care perspective. | 12/2/2013 12:59 PM |
| 179 | dental services | 12/2/2013 12:09 PM |
| 180 | Health fitness | 12/2/2013 11:29 AM |
| 181 | Exercise equipment someone to exercise with | 12/2/2013 10:55 AM |
| 182 | Ability to truly direct services rather than need the assistance of the service coordinator. | 12/2/2013 10:53 AM |
| 183 | Fitness programs | 12/1/2013 8:08 AM |
| 184 | Community involvement;health screening | 11/30/2013 7:43 PM |
| 185 | nutrition for healthy weight management | 11/30/2013 1:35 PM |
| 186 | Chiropractic | 11/30/2013 11:14 AM |
| 187 | The state must put fitness at the top of the list along with food, and clothing. | 11/29/2013 6:23 PM |

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| 188 | For us it would be lack of skin breakdown. Healthy | 11/29/2013 1:42 PM |
| 189 | Physical activity Regular volunteering in local community Volunteering for the area agency Assistance in making a product | 11/29/2013 11:56 AM |
| 190 | Community based activities because this life can be isolating. | 11/29/2013 8:59 AM |
| 191 | volunteering | 11/29/2013 8:02 AM |
| 192 | No idea | 11/28/2013 8:39 PM |
| 193 | regulare exercisè, keeping a healthy wieght through nutrition education, attending adult ed classes for life skills improvement | 11/28/2013 2:49 PM |
| 194 | Good annual physical outcomes | 11/28/2013 5:51 AM |
| 195 | Serving on Area Agency Boards or Family Support Councils. Serving on the DD/ABD Quality Council, DD Council. Being a graduate of the NH Leadership series. Volunteering to help families learn how to manage their own services. | 11/27/2013 11:16 PM |
| 196 | fitness benefits well health check ups | 11/27/2013 10:32 PM |
| 197 | Local community center for social interaction...that would be wonderful. | 11/27/2013 6:18 PM |
| 198 | Not applicable | 11/27/2013 11:31 AM |
| 199 | N/A | 11/27/2013 11:23 AM |
| 200 | volunteering working | 11/27/2013 8:51 AM |
| 201 | exercise activities | 11/26/2013 3:12 PM |
| 202 | Fitness related | 11/26/2013 2:42 PM |
| 203 | Cooking classes - how to cook more healthy/clean (e.g. more organic) Family skills building (e.g. communications workshops, cognitive based therapies) Family outdoor [physical] activities (e.g. cycling, swimming, hiking, skiing, surfing, anything really) | 11/26/2013 12:43 PM |
| 204 | Volunteer in nursing homes or food shopping/errands for individuals unable to get out themselves. | 11/26/2013 12:11 PM |
| 205 | pool member | 11/26/2013 11:57 AM |
| 206 | Our daughter pays for her own karate lessons so would say help paying this would be nice. | 11/26/2013 11:45 AM |
| 207 | A place that is set up for swimming for the handicapped | 11/26/2013 11:13 AM |
| 208 | More doctors who accept medicaid | 11/26/2013 11:12 AM |
| 209 | I have not idea as his health is very good and his quality of life is also quite good. He is a member of a local gym (and attends) and he has routine health care. | 11/26/2013 11:05 AM |
| 210 | excecise community sercives getting the person who experiences involved in helping the community | 11/26/2013 10:40 AM |
| 211 | exeses | 11/25/2013 11:14 PM |
| 212 | meeting requirements of an individualized plan, possibly things as exercise, proper medication use, volunteering/ being socially involved. avoiding unnecessary hospital visits/ expenses | 11/25/2013 10:41 PM |
| 213 | A membership to the Community Center's aqua exercise program. It would allow for more mobility and more regular exercise. | 11/25/2013 9:25 PM |
| 214 | swimming | 11/25/2013 8:53 PM |
| 215 | volunteer work | 11/25/2013 3:58 PM |
| 216 | Recreational activities | 11/25/2013 2:10 PM |
| 217 | My son's quality of life would be improved (mine would too) if the had a living situation that was permanent and functioning and valued him as a wonderful person JUST THE WAY HE IS. But I think you mean exercise. | 11/25/2013 2:00 PM |
| 218 | WALKing | 11/25/2013 1:52 PM |
| 219 | exercise | 11/25/2013 1:34 PM |
| 220 | Joining an exercise program, volunteering | 11/25/2013 12:52 PM |
| 221 | Participating in benefit walks, community clean-ups.. | 11/25/2013 11:19 AM |

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| 222 | maintain medical needs, monitor health issues, and exercising | 11/25/2013 10:11 AM |
| 223 | civic involvement (food drive, volunteer at library, etc) swimming for flexibility and strength | 11/25/2013 9:58 AM |
| 224 | weekly gym, sponsor social events, health incentives such as be within your weight range, quit smoking. group walking / bicycle rides | 11/25/2013 9:20 AM |
| 225 | Community service. | 11/25/2013 9:15 AM |
| 226 | Individual-based, it is dependent on person's abilities as to what activities can be accessed. I feel this would need to be customized and determined based on the person's neurological, gross and fine motor physical and energy ability. | 11/25/2013 8:20 AM |
| 227 | swimming, danceing, gymnastics | 11/25/2013 2:08 AM |
| 228 | Exerise | 11/24/2013 9:29 PM |
| 229 | swimming, fishing | 11/24/2013 7:36 PM |
| 230 | Participate in any form of exercise. Advocacy programs. | 11/24/2013 7:23 PM |
| 231 | a gym buddy to excercise with my family member | 11/24/2013 6:58 PM |
| 232 | Using a health facility/gym/supervised excercise program Community service | 11/24/2013 6:17 PM |
| 233 | Fitness program. Regular nutritional guidance. | 11/24/2013 4:26 PM |
| 234 | Community-based activities, of course, these would require support | 11/24/2013 2:46 PM |
| 235 | Fitness classes such as yoga or pilates, martial arts classes, mental health counseling, weight loss programs | 11/24/2013 2:03 PM |
| 236 | Sporting events or a health/fitness club. | 11/24/2013 1:52 PM |
| 237 | unsure, education , training | 11/24/2013 1:33 PM |
| 238 | Music Therapy | 11/24/2013 10:12 AM |
| 239 | 1. Supported volunteer opportunities (that match the interests/skills of the consumer, not demean or exploit her/him as free labor). 2. Participation in physical fitness activities 3. Medical screenings (But given that the consumer population you are targeting probably receives a high level of specialty medical care, this may be unnecessary or difficult to coordinate with their exiting medical team.) | 11/24/2013 8:49 AM |
| 240 | exercise , emotional support from others | 11/24/2013 7:19 AM |
| 241 | letting the family be a real "self directed". Now there are many stipulations and caps on the funds that can be spent on one particular item/area. It is NOT meeting our needs that way. Every year, the rules change and our son/individual does not. | 11/23/2013 11:29 PM |
| 242 | exercise (but respite would need to be offered/provided while exercising) -- I am unable to maintain that consistency at a gym because I cannot secure care always while being away at the gym | 11/23/2013 10:33 PM |
| 243 | Going to a fitness program. Volunteering your time to charities. | 11/23/2013 10:18 PM |
| 244 | Access to a gym/trainer/nutritionist, access to money to help purchasing quality foods | 11/23/2013 10:07 PM |
| 245 | Volunteer work Getting out with friends for social activities on a regular basis | 11/23/2013 8:10 PM |
| 246 | activities/respite care | 11/23/2013 4:10 PM |
| 247 | Gym Memberships Activities where gross motor skills are utilized (dancing, gymnastics, sports complexes) | 11/23/2013 12:26 PM |
| 248 | I would be interested in finding out what the options would be. | 11/23/2013 10:32 AM |
| 249 | Don't know. | 11/23/2013 10:13 AM |
| 250 | Membership to swimming facility | 11/23/2013 9:11 AM |
| 251 | Skiiing, recreation, membership in organizations that provide conferences on my rare disability and staff expenses to go to their national conferences where I can be with people like me. There is only 200 of us just 5 in New England | 11/23/2013 8:52 AM |
| 252 | Changing caps for non traditional therapies, like cranial, reiki, massage, current cap is \$1,200, however some of these things help people like my son who suffer from anxiety. | 11/23/2013 8:23 AM |
| 253 | her being able to help with someone who cannot do things for themselves | 11/23/2013 8:10 AM |

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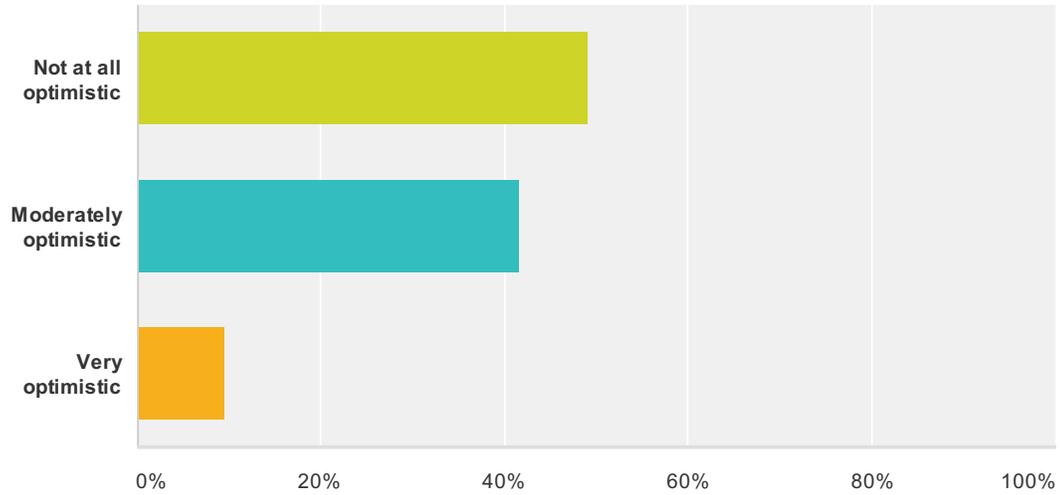
| | | |
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| 254 | Personal transportation funding. Payment for personal care provider. Good respite care to personally get to gym and take vacation and date night with spouse | 11/23/2013 8:09 AM |
| 255 | no clue | 11/23/2013 8:03 AM |
| 256 | More for families. A lot of services like respite excludes siblings when you need a sitter to go to meetings. Makes it more tough for planning. | 11/23/2013 6:43 AM |
| 257 | fitness activities (not just a fitness assessment, but actual activity) might make sense. He already has innumerable health assessments/treatments/appointments, so another "health assessment" would just be a bother with no real value. | 11/23/2013 12:49 AM |
| 258 | Not sure what this is getting at. | 11/23/2013 12:45 AM |
| 259 | Fitness commitment | 11/22/2013 11:19 PM |
| 260 | Provide respite for another family Volunteer to drive a family to an appointment | 11/22/2013 11:13 PM |
| 261 | Health club membership reimbursement may be one. Can't think of anything else at the moment but I am sure there are other things that would come to mind also. | 11/22/2013 10:50 PM |
| 262 | swimming, walking, gym memberships, etc | 11/22/2013 10:36 PM |
| 263 | any form of exercise; working with a dietician on eating healthy; preventive care medical appointments | 11/22/2013 6:59 PM |
| 264 | swimming in a heated pool massage | 11/22/2013 6:38 PM |
| 265 | We are active in health care, physical activity, community, local, state and national support groups. It would be nice to get a reward or bonus to cover these expenses. We also attend educational seminars related to his disability and we educate others in the community about disability. | 11/22/2013 6:36 PM |
| 266 | Volunteer work | 11/22/2013 6:02 PM |
| 267 | Health screening | 11/22/2013 5:53 PM |
| 268 | Respite care for the family that would allow the caregivers some alone time | 11/22/2013 5:27 PM |
| 269 | Don't know. Right now I think the more we do to help the state the more they would want me to do. Sounds like a bribe. | 11/22/2013 4:31 PM |
| 270 | joining the local YMCA | 11/22/2013 4:24 PM |
| 271 | - Participation in an exercise program - Visits to a dentist to maintain/improve oral hygiene - Participation in a nutrition program | 11/22/2013 4:23 PM |
| 272 | nutrition training for special diets....find the question hazy. | 11/22/2013 4:00 PM |
| 273 | A regular swimming program. | 11/22/2013 3:58 PM |
| 274 | Smoking reduction | 11/22/2013 3:54 PM |
| 275 | ? | 11/22/2013 3:54 PM |
| 276 | a gym attended now for ind with disabilities | 11/22/2013 3:47 PM |
| 277 | health club membership | 11/22/2013 3:25 PM |
| 278 | participation in a fitness program participation in a nutrition program | 11/22/2013 3:23 PM |
| 279 | being able to be out of the home and involved in the community! | 11/22/2013 3:19 PM |
| 280 | more opportunities to attend musical concerts, | 11/22/2013 3:12 PM |
| 281 | Any program that would help with exercise and nutrition that he was able to participate in taking into account his physical, emotional, psychological and developmental levels. Any health screenings that may benefit him. Volunteering would be a more difficult task to accomplish because of extremely low endurance and social anxiety. | 11/22/2013 3:12 PM |
| 282 | respite pool, teen programs with kids of similar issues, respite monies utilized for afterschool programs | 11/22/2013 3:05 PM |
| 283 | more community activities for my adult daughter | 11/22/2013 2:56 PM |
| 284 | not sure I have an answer for this one -- requires more thought than I have time for right now. | 11/22/2013 2:54 PM |

NH Medicaid Long-Term-Care Program Survey

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| 285 | Having being able to get regular time off to recharge, save marriages, mental and physical health, be productive members of our communities. Support. I was told many years ago (before Katie Beckett) when I looked for help for a short time that "because we were married" we didn't qualify for any assistance... | 11/22/2013 2:49 PM |
| 286 | wellness activities & practices | 11/22/2013 2:44 PM |
| 287 | money for a home care provider | 11/22/2013 2:18 PM |
| 288 | volunteer work, exercise, health screenings, healthy eating | 11/22/2013 1:58 PM |
| 289 | I'm not sure what this means but ABA would improve quality of life. | 11/22/2013 1:57 PM |
| 290 | fitness -- things like a gym membership. | 11/22/2013 1:44 PM |
| 291 | walking more, gym membership | 11/22/2013 1:38 PM |
| 292 | Volunteering Health screening | 11/22/2013 1:26 PM |
| 293 | Exercising (either at a formal gym or on their own). Incentives to follow up on preventative testing. | 11/22/2013 12:34 PM |
| 294 | gym membership | 11/22/2013 12:30 PM |
| 295 | Nutrition Classes | 11/22/2013 12:23 PM |
| 296 | Gainful, competitive employment in a job enjoyed | 11/22/2013 12:12 PM |
| 297 | Anything that would work and person would be capable of doing. | 11/22/2013 12:11 PM |
| 298 | YMCA Passes, Gym Passes , Movie Passes , Bus / Stepsaver Passes , Passes to Fairs and even Certificates to a go out for Dinner . | 11/22/2013 11:53 AM |
| 299 | Providing support to other families. The best supports are other families that have walked this road before us. | 11/22/2013 11:48 AM |
| 300 | good health outcomes, satisfaction and progress on goals | 11/22/2013 11:45 AM |
| 301 | Being able to travel to visit relatives over holidays or family events; being able to afford hippotherapy, art therapy, able to take her to a musical or play. | 11/22/2013 11:43 AM |
| 302 | More recreational sports | 11/22/2013 11:40 AM |
| 303 | Fitness measurements (height/weight ratio, cardio fitness) and fitness activities. Group walks, swimming, etc. | 11/22/2013 11:36 AM |
| 304 | Possibly better coordination through our area agency with other groups that are in need of volunteerism. | 11/22/2013 11:33 AM |
| 305 | Gift Cards | 11/22/2013 11:26 AM |
| 306 | Health club with a pool or exercise classes that was affordable...More transportation options - local buses don't run on weekends or later in the evenings and it limits options and cabs are ridiculously expensive | 11/22/2013 11:09 AM |
| 307 | Increasing computer skills beyond the basics, that is training in specific applications such as web or data base related. Physical fitness programs in the community. | 11/22/2013 10:59 AM |
| 308 | Gym memberships, quality relationships/memberships in groups of interest | 11/22/2013 10:52 AM |
| 309 | Our family member currently holds a volunteer position, a fitness program membership and has yearly medical screenings and visits if needed but volunteer work is great for anyone. | 11/22/2013 10:41 AM |
| 310 | Valuing the stay-at-home parent who sacrifices to do the work as opposed to having taxpayers pay for strangers to do only some of it despite all the research supporting the benefits of a stay-at-home parent | 11/22/2013 10:33 AM |
| 311 | meaningful volunteer work | 11/22/2013 10:32 AM |
| 312 | participation in fitness program | 11/22/2013 10:29 AM |
| 313 | Recreation accessible for all | 11/22/2013 10:05 AM |
| 314 | Travel | 11/22/2013 9:54 AM |

Q32 How optimistic are you that a redesigned Medicaid long-term-care system will be an improvement over the current service system that you use?

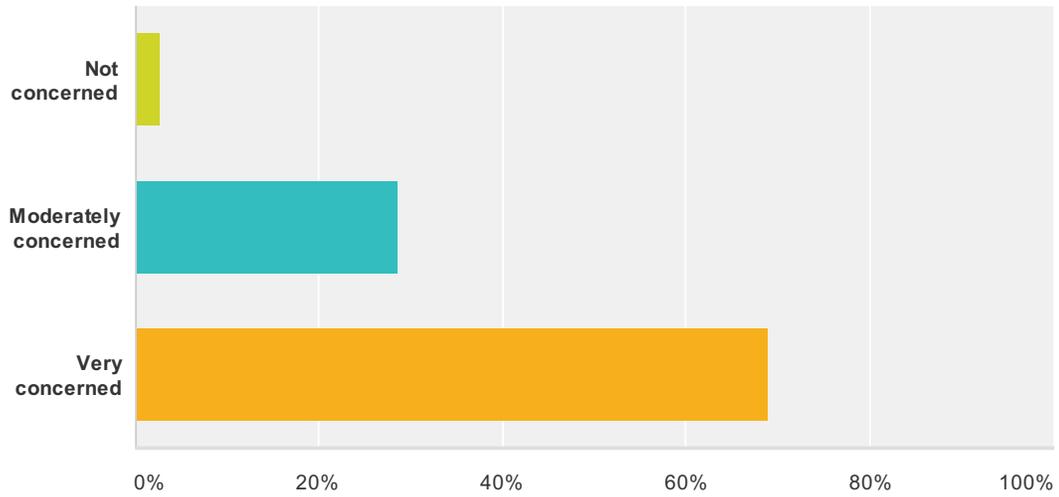
Answered: 530 Skipped: 362



| Answer Choices | Responses | |
|-----------------------|-----------|------------|
| Not at all optimistic | 49.06% | 260 |
| Moderately optimistic | 41.51% | 220 |
| Very optimistic | 9.43% | 50 |
| Total | | 530 |

Q33 How concerned are you about the State's ability to fund the Medicaid program?

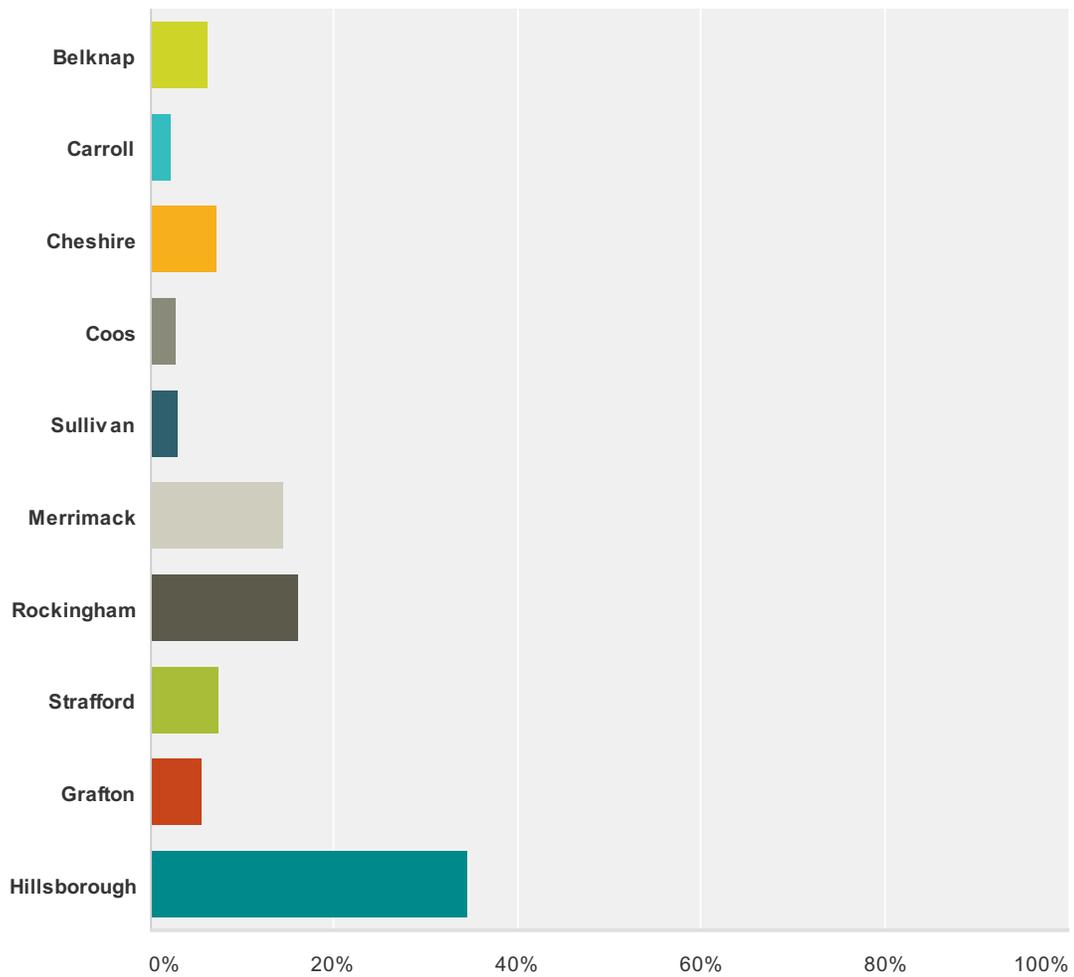
Answered: 547 Skipped: 345



| Answer Choices | Responses |
|----------------------|------------|
| Not concerned | 2.74% 15 |
| Moderately concerned | 28.52% 156 |
| Very concerned | 68.74% 376 |
| Total | 547 |

Q34 In which county do you live?

Answered: 560 Skipped: 332



| Answer Choices | Responses |
|----------------|------------|
| Belknap | 6.25% 35 |
| Carroll | 2.32% 13 |
| Cheshire | 7.32% 41 |
| Coos | 2.86% 16 |
| Sullivan | 3.04% 17 |
| Merrimack | 14.46% 81 |
| Rockingham | 16.07% 90 |
| Strafford | 7.50% 42 |
| Grafton | 5.71% 32 |
| Hillsborough | 34.46% 193 |
| Total | 560 |

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Q35 Is there anything else you wished we had asked or you would like to tell us?

Answered: 199 Skipped: 693

| # | Responses | Date |
|----|--|--------------------|
| 1 | The system in place is participatory and allows guardians and individuals the right to a good quality of life. | 12/9/2013 7:56 PM |
| 2 | I've been doing what I'm doing - caring for my disabled son alone - since he was two years old - he's nearing 30yo. I'm getting older and getting tired. Us older parents need to be taken into consideration more so than those who have children under 18/21. I am thankful that I do live in a State that has the services we do for our individuals - it's tops to other States...but there's always room for improvement. I'm also thankful that I saw this survey in the DRC email I receive. I think it's really important for law makers etc. to hear from families who live this life every day - years on end. | 12/8/2013 8:41 PM |
| 3 | I truly hope the state takes this seriously | 12/8/2013 7:44 PM |
| 4 | Families with DD children need your services to stay as a family. Put money with professional guidance into the family pockets. The State will save money and the quality of care and services will improve. Too much state money is skimmed before it reaches the intended target. | 12/8/2013 4:38 PM |
| 5 | It would be most helpful to have some idea of what direction Step 2 is headed. | 12/7/2013 4:33 PM |
| 6 | Thank you for taking this seriously and soliciting input from the consumers and their family. Makes me feel like there's hope yet for the NH system! | 12/7/2013 12:05 PM |
| 7 | I would like to see the program be very client and family centered and flexible. | 12/7/2013 11:03 AM |
| 8 | In response to your previous question, I am very concerned about the state's ability to pay a for-profit company to provide all of the necessary services to people who need them. As inflation causes rising prices and rising wages and the for-profit company continues to pay annual dividends to its stock holders, I fear the needs of the people will be backburnered. I fail to see the wisdom of inviting profit hungry strangers into our lives to provide intimate services to our loved ones. | 12/6/2013 11:35 PM |
| 9 | people are apt to do without care if they got to keep part of their budget. poeple's health changes and sometimes for the worst and they will run out of money. cost the state more in the end as most people arent able to manage it all by themselves. | 12/6/2013 11:31 PM |
| 10 | NH needs more services and more funding and better options for care and services altogether there needs to be a system that works together to intergrate services for each person and care professionals | 12/6/2013 10:32 PM |
| 11 | I currently use a single vendor, PLUS Company to provide life skills and voc. services in addition to mental health center. Hiring private staff to work with my child at another location would be tricky. He would have no services if an employee didn't work out. | 12/6/2013 5:43 PM |
| 12 | Thank you for conducting this survey. My list of things I would like to tell you is much too long for the space allocated. | 12/6/2013 4:45 PM |
| 13 | The states acute care services need to be revamped in order for Lang term care to be effective. The long term care plans must address the acute phases of the illness as there will not be a long term phase if the person cannot be managed through the acute phase. | 12/6/2013 4:05 PM |
| 14 | yes, but not time to answer. just rec'd this notice a few hours ago and it is due by 5 PM (now 4 PM). ironically, i have an appt with a psychiatrist concerning my son's status Pat Schumacher 2 Hollenbeck Lane Hanover, NH 03755 603 643-3440 patschu@comcast.net | 12/6/2013 3:51 PM |
| 15 | Thank you for asking. If you take such a survey again, please make more effort to get the word out and maybe distribute paper copies in low income housing developments where many of these patients reside. | 12/6/2013 3:41 PM |
| 16 | taking care of loved with demitia or alzhiemers is very hard alone. I isolates you and your loved one and you can fall into depression easily. Services need to be added and not taken away. We don't always now what we need but we need help. | 12/6/2013 3:13 PM |

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| 17 | Please hold insurance companies accountable. Help hospitals by providing beds for those in need of critical mental health services. Provide preventative care - - rather than hospitals turning people away because they are not suicidal enough or because they aren't going to hurt someone else, lets get resources to divert these people to the care they need. Preventative care works to prevent heart disease, and to reduce symptoms and outcomes for diabetes. Lets support preventative care for mental illness too. | 12/6/2013 2:55 PM |
| 18 | Anthem denies payment to the state hospital for all services provided. they use Horrible MD reviewers as case managers. They just deny outright with out careful consideration. This is the biggest provider of health care payment in NH, and they cover govmt workers, teachers, firefighters, police and other first responders. THEY DON NOT HAVE MENTAL HEALTH CARE COVERAGE BASED ON Antheims interpretation. You should investigate Anthem for their practices and Fine them for the denial of what should be appropriate payment. In our son's case alone they have cost the state \$ 130,000 for his hospitalization from 12/12 through 3/13. Just denials without careful consideration. These services should have been covered without having to have to go to second and third appeals and ultimately arbitration. If they get away with this pratctce on one patient then they are probably getting away with it on many costing the State Millions of dollars. Kermit Brunelle, MD Bedford NH 603-471-2537 I would LOVE to talk to someone about what Anthem is doing in this regard. | 12/6/2013 2:00 PM |
| 19 | Availability of emergency mental health services | 12/6/2013 1:07 PM |
| 20 | GET DEMOCRATS IN! | 12/6/2013 12:45 PM |
| 21 | I think proactive, early intervention and help with coordination of services for families who have children with mental illness is important. In our case, we worked very hard to help our son but the support was fragmented, he had an IEP and attended counseling but there was no connection between the two. As a parent I had to learn how to case manage my son's services. If more help was available earlier we may have been able to prevent the difficult and expensive road through his adolescent and early adult years. Perhaps this preventative support could be funded through the Medicaid Long-term program. | 12/6/2013 11:55 AM |
| 22 | Just that I checked Hillsborough County in the previous question because my son lives there. I live in Merrimack County. | 12/6/2013 11:52 AM |
| 23 | It may have been challenging for many behavioral health and elder clients and their representatives to take part in an on-line survey. My guess is that a significantly greater proportion of responses on this survey come from developmentally disabled representatives. Lower number of survey responses from behavioral health and elder populations may not reflect a lack of interest but rather limited access to or skills in responding to on-line surveys. | 12/6/2013 11:51 AM |
| 24 | I am sorry that we have no experience with Medicaid Long Term Care, but we are hoping that our child might qualify and get some better coordinated care, such as a case manager. | 12/6/2013 10:51 AM |
| 25 | Please do not let this burden fall on individual families and let us please do our part to help those members of our community that can not help themselves, this is as important to me as educating our youth. Societies are judged by how they take care of those who can't take care of themselves we have plenty of resources available surely we can make this a priority Please feel free to contact me Joseph Doucet, 603.865.5350 or jrd1260@yahoo.com | 12/6/2013 10:07 AM |
| 26 | YES...do what is needed to get ALL THE CONNECTING FEDERAL ACCESSIBLE & AVAILABLE HELP to match our Medicaid Dollar..otherwise, you are a WASTE as legislators to us low income folks..I MEAN IT !!! AND I VOTE !!!!! | 12/6/2013 10:06 AM |
| 27 | Why are you not seeking feedback on Managed Medicaid - Your survey is quite biased. | 12/6/2013 9:36 AM |
| 28 | I think it's a shame that the mentally ill or disabled between the ages of 18 and 21 have little to no support. This is a crucial time for families with children who are lost in the system for these years. What are they to do? Help is needed desperately! | 12/6/2013 9:21 AM |
| 29 | How much we value the social safety net. | 12/6/2013 9:08 AM |
| 30 | On behalf of all individuals and their families would very much like to see changes made to the long term care program (especially CFI) which are more person centered; flexible and perhaps "non-traditional" services that really meet the defined needs of the individual to stay in their home; and above all to be able to access these services in a timely manner not almost 8 months from the date of an application. | 12/6/2013 9:07 AM |
| 31 | I believe this survey is important and helpful. | 12/6/2013 8:23 AM |
| 32 | Just please help families that are struggling mental health is becoming a large need for us to start helping more. | 12/6/2013 8:12 AM |

NH Medicaid Long-Term-Care Program Survey

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| 33 | People with serious, long term mental illnesses need and deserve treatment. Money should not be a limiting option! | 12/6/2013 7:54 AM |
| 34 | As I said, if you are interested in providing quality services, you find good staff and offer a living wage, benefits, support, supervision and provide training along the lines that is currently offered via DSP Certificate Program www.dspcertificateprogram.com | 12/6/2013 7:45 AM |
| 35 | I am always concerned when state government starts to talk about redesigning services, as the motivation is always about money not quality of care of recipients. I understand the need to be fiscally responsible, but I would love to see honest concern about the day to day life of those who cannot care for themselves due to disability. | 12/6/2013 6:26 AM |
| 36 | Please, don't give up the fight! We need your help! Thank you... :-) | 12/6/2013 12:55 AM |
| 37 | There is no linkage between the court system and mental health system. No one cares about integrating back into the community and it results in recidivism. There are no substance abuse treatment available | 12/5/2013 11:57 PM |
| 38 | no | 12/5/2013 11:29 PM |
| 39 | Why don't we have a system like Vermont? Healthcare should be available for every citizen..not based on income or ability to pay.Get rid of the insurance companies. I lived in Europe for almost a decade. The healthcare was second to none. We didn't have all "bells and whistles" i.e.electric beds, cable television, interior designer lobbies what we did have was good medical care for EVERYONE!! | 12/5/2013 11:13 PM |
| 40 | How can we provide incentives to service providers to assist people to be less dependent on the Medicaid system? | 12/5/2013 10:31 PM |
| 41 | How grateful the state has a vested interest in mental Health and families that live with it | 12/5/2013 10:31 PM |
| 42 | I wish Medicaid in general was more excepted in the mental health world.. The only places that except Medicaid seem to be poorly staffed or under staffed..some of the providers are the worst therapist, counselor and doctors I have ever seen, completely incompetent .. I have frequently over the years have had to pay out of pocket so my child could see a mental health doctors to adjust her medication and get her stable. | 12/5/2013 10:05 PM |
| 43 | Medicaid expansion is a no brainer it is Needed | 12/5/2013 9:52 PM |
| 44 | The existing program my brother is in @ Rose meadow farm is excellent and the funding keeps him as comfortable and active. Please don't change his coverage or care. | 12/5/2013 9:43 PM |
| 45 | No | 12/5/2013 9:09 PM |
| 46 | Thank you for taking the time to ask our opinions. Our state could be a model for the rest of the nation in terms of how to best support our citizens in need. | 12/5/2013 8:52 PM |
| 47 | It is less expensive to support clients in their own homes than in institutions, which means the proper medication , services, and support are critical. Waive co-pays, because it is us paying for it, the family member barely has enough to get through the. Or they just won't go to the providers because of the obstacles. | 12/5/2013 8:44 PM |
| 48 | Nobody truly understand how very hard it is to care for people with severe disabilities. So when you start changing things it put a great deal of stress on people who already have a great deal of stress. All people want to care for their family members the best way they can, but most of the people who want to change things and those who make the laws do not get it!!!! | 12/5/2013 8:42 PM |
| 49 | What are the clients gaining not the state. | 12/5/2013 7:52 PM |
| 50 | Please have consumers, family members and workers (esp case managers and social workers in the system) be involved in developing a system and in assessing the effectiveness and quality of services being provided. | 12/5/2013 7:12 PM |
| 51 | People should work even if it is one hour per week or as a volunteer. Socialization skills are important and often lacking. | 12/5/2013 6:55 PM |
| 52 | We need more time.....for those that do not have advocates...the system is poor. It is a shame how these people are devalued. Our lawmakers need to walk in their shoes to gain insight, empathy and compassion. | 12/5/2013 6:47 PM |

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| 53 | I'm disheartened to hear that the legislature has not heard from mental health stakeholders. I testified several months ago about how important Medicaid expansion would be to people with mental health issues in NH. I told about being a nursing student needing to do mental health clinicals when SNHMC decreased available beds from 30 to 10 so that we lost their unit as a clinical site. We went instead to the state hospital where there was an empty unit attached to the one we were assigned to. It was vacant because of a lack of staffing, not a lack of patients. There was a three week waiting list while we were there. I'm sorry this testimony went unrecorded and unnoticed. | 12/5/2013 6:40 PM |
| 54 | This can work but must include the Medicaid expansion population. | 12/5/2013 6:37 PM |
| 55 | Our family is among the lucky. We are well educated, well connected and live in a compassionate community. I worry desperately about those in our state who do not have our advantages. New Hampshire, like so many states, has a terribly broken system for supporting those with developmental disabilities and mental health issues. The ways we are now responding are expensive, ineffective, and, at times, barbaric. We must make fundamental changes to how we respond to those in need. I do not believe we mean to be the society we have become in how we treat those with difficulties arising from brain disorders. | 12/5/2013 6:32 PM |
| 56 | Provide adequate funding and leave the current community based delivery model in place. It is simply disgraceful how this population is being treated by the state government. | 12/5/2013 6:30 PM |
| 57 | requirements for legal assistance | 12/5/2013 6:19 PM |
| 58 | Having insurance companies take over the long-term medicaid program is terrifying! | 12/5/2013 5:25 PM |
| 59 | I am very pleased with the services that the Area Agency in my county provides. I would not like to see that changed. They know the individuals and the families they serve and are committed to provide quality support services. | 12/5/2013 1:32 PM |
| 60 | I would like to see more consumers with disabilities like myself and my sister to have an increase in his or her allowance from their Services Coordinators. There allow people with disabilities earn very little money in his or her take home paychecks. It's hard to live on very little money a week. It's time for Real Changes in the current services system the Area Agencies has gotten too big that's why consumers with disabilities like me and my sister gets very little money in their weekly allowance. That is the problem many of consumers with disabilities faces for years since moved to the Community-Based Services from State institutional | 12/5/2013 1:28 PM |
| 61 | How about a state income tax or sales tax to help fund programs like those available in other states. | 12/5/2013 11:34 AM |
| 62 | Not at this time. | 12/5/2013 8:58 AM |
| 63 | We worry about what will happen to our son if something happens to us. We hope he would continue to have a happy and healthy life without us. | 12/5/2013 8:52 AM |
| 64 | I just feel that a lot of services are offered to people that are not willing to try and the ones in the middle who do try do not get any assistance at all. Basically if you try you are punished for it. | 12/5/2013 5:32 AM |
| 65 | I am not sure that the quality of care would be the same as it was before. | 12/4/2013 11:24 PM |
| 66 | Please don't change our current system.....If it's not broken, don't fix it!!! | 12/4/2013 10:25 PM |
| 67 | I think very few people in government (State & Federal) realize the savings that are obtained on the backs of family members who support their disabled family members. I think we provide a higher quality of life and much better care for our handicapped son, than could possibly be done by the state. SNF care in most places is in excess of \$10,000/month, we get less than \$1000/month from all sources, plus sporadic respite and in home services (no way to determine value because nobody knows or is willing to tell). | 12/4/2013 9:38 PM |
| 68 | You should be asking: How can we better involve consumers in being a part of the service delivery system in roles such as peer advocates and counselors? | 12/4/2013 8:13 PM |

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| 69 | I have had a lot of issues with my area agency. My daughter lived at Crotchet mountain and got a dislocated knee which went untreated because no one spoke up about it. Until I finally did and then Crotchet Mountain gave her 30 days to move out. They then palced her in another Nursing home that would not do anything for her but the State paid them \$400.00 a day for her to stay there temporarily until I could get my home ready for her. I told the State I thought 400.00 a day for her to just live there was very expensive and asked for a breakdown of the cost. Of course I was denied and told it is what it is and it will not change so no you can not have that information. They would not toilet her, take her out to the community. She pretty much just stayed in the house. They won't give her PT any more due to the severity of the knee. I was able to bring her home but she can no longer stand and pivot or bear weight anymore. The Moore Center did nothing about it. We are now without an aide in the afternoon and I have to leave work early to take care of her. I could lose my job. The Moore Center is suppose to help with this and is getting paid from my daughters budget to do this but it has been 6 months and no aide and my job is getting very aggitated at them and me but I can not leave her home alone. | 12/4/2013 3:40 PM |
| 70 | New Hampshire is very fortunate to currently be a model (#2 in the Country) for the management of the ABD Waiver program and the structure of the current Area Agency system that can contract with providers in the State that best meet the clients needs. | 12/4/2013 3:22 PM |
| 71 | I understand that this is a very difficult state for anyone trying to provide help to children, the elderly or the disabled. I wish that there was an unlimited pot of money for those of us who need services. There seems to be a scarcity of service providers in our area...my brother was without a mentor from mid September until Dec. 2nd. It would have been nice to be able to run an advertisement that offered a competitive wage and a decent number of hours per day to work with him. He keeps asking why no one likes him and I keep trying to explain that he is likable, but that most people need a job that pays more than we have to give. I am very worried that something will happen, and no medicaid will be available. At that point, I may have to quit my job to care for him and we will both be on the state roles for welfare. It would be good if the people who fund medicare realize that a more generous funding might prove to be a money saver in the long run. More disabled and elderly people would be able to remain at home, if their caregivers had adequate support. | 12/4/2013 2:51 PM |
| 72 | The present system has provided our daughter with a budget, program, and local personnel to meet her individual needs in a timely manner. We are happy with the present system and have concerns about dealing with people who are not involved with the developmentally disabled Medicaid recipients and their families on a regular basis. Presently, it is easy to get our questions answered or receive direction as needed. The local agencies know their clients unique status and understand the need for flexibility. We are hesitant to change a model that works in an efficient and effective manner. | 12/4/2013 2:12 PM |
| 73 | no | 12/4/2013 2:11 PM |
| 74 | I work mainly in Rockingham County and Strafford County, though I have also worked in other NH counties as well. I have also been a case manager for students with IEP's and have been involved with several NH school districts attending IEP meetings. It would be wonderful if Medicaid could broaden the guidelines on how to train people on how to safely assist someone to eat. The nursing homes or very strict on who they will allow to do this task and the needs of the residents to be assisted during mealtimes is still greater than the number of people who can assist them. In other words, residents are losing weight and jeopardizing their health because they are not able to eat their meals. | 12/4/2013 12:02 PM |
| 75 | no | 12/4/2013 11:54 AM |
| 76 | Presently very pleased with the services my daughter gets from pathways in concord. | 12/4/2013 11:54 AM |
| 77 | The Wait list stinks and having my adult child receiving inadequate services p;aces a stress on him and the entire family. Also, our limited experience with Medicaid managed care has not been positive. There is a mistake on my son's insurance card for his Medicaid managed care. WellSense tells us to go to DHHS and DHHS tells us to go to WellSense. Then what do we do? Sit on the phone arguing for hours? | 12/4/2013 11:14 AM |
| 78 | Do not change the system if it not broker don't fix it you will screw it up. | 12/4/2013 11:03 AM |
| 79 | Thank You and the Region 8 agency staff for all the support my family has received over the years. | 12/4/2013 10:50 AM |
| 80 | Looks like you have it pretty much covered. Thanks for the Respite program and as I mentioned before a Dental Program would be appreciated. Thanks for all you do right now. | 12/4/2013 10:18 AM |
| 81 | From the outside looking in, this "redesign" is virtually guaranteed to be a train wreck. Why? It goes against all lessons learned from a huge cross section of industry and history. First, the notion of "If it isn't broke, don't fix it" was created for a reason. Does anyone _seriously_ think that the second rated system in quality metrics in the country is going to be replaced with something "designed by committee" and NOT turn into a disaster? I guess I have answered my own question as to why we will never be told why... | 12/4/2013 10:09 AM |
| 82 | No thank you for your interest in improving | 12/4/2013 10:06 AM |

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| 83 | It is difficult to stay informed as a guardian, but I try. Simplification in communication could be helpful. | 12/4/2013 8:56 AM |
| 84 | How about partnering together the elderly with the disabled population in ways that can benefit both, like persons with disabilities helping the elderly in household tasks like laundry and cleaning, or grocery shopping and errands which would benefit both and save money! ,! , , | 12/4/2013 8:44 AM |
| 85 | I would like to know more about the proposed plan the group has come up with? Questions # 19, # 20 and # 28 would not allow me to choose an answer | 12/4/2013 7:22 AM |
| 86 | I would hope you would and could encourage young people to enter the field of caring for the disabled and pay them respectfully. And please do remember that many disabled folks are both physically and mentally disabled (my sister has cerebral palsy and mental retardation). | 12/4/2013 7:04 AM |
| 87 | As a Guardian I am extremely concerned about the ramifications of Obamacare on the individuals that are in need of benefits. | 12/4/2013 2:25 AM |
| 88 | acknowledge, accept and address the greed / corruption epidemic in the Medicaid system, address that effectively.....able bodied people are funded very well (in southern NH anyway) and are far too comfortable being welfare professionals. the erroneously directed funds need to be taken away from those who CAN do for themselves but CHOOSE not to.....and forwarded to those who cannot do for themselves. In my jobs I see abuse of the " system " every single day. people drive up to the facility in a new SUV BMW, dressed to the nines, jewelry, nails, hair, accessories, top of the line iPhone...yet wave the Medicaid card like a badge of honor. the system is very very broken and it appears that no effort is being taken to address the outrageous abuse and fraud. Make a reportable fraud phone number / systemreciprocity among ALL states so that out of state Medicaid cards are able to be tracked. expiration of welfare benefits after 18-24 months.....this will make the able bodied-but-lazy people motivated. Welfare is meant to be a short term assistance process, not a lifelong goal; to achieve yet NH is seeing 3rd generation welfare professionals.....it's a mindset, a way of life...because it has been acceptable and accommodated and should no longer be the case. Please address the root of the lack of funds for those who TRULY need the help.. . | 12/3/2013 11:36 PM |
| 89 | Adding another layer of management to the current system does not seem like a fiscally beneficial option. It only adds another party taking a piece of the budget pie. | 12/3/2013 9:21 PM |
| 90 | No | 12/3/2013 8:26 PM |
| 91 | I think you need to look at ways to improve the current system. I would rather see the State spend money on updating financial management software and consolidating business functions across area agencies than on MCO fees. Including commercial MCO's is not the answer and will only drive up costs over time. | 12/3/2013 5:17 PM |
| 92 | No | 12/3/2013 5:15 PM |
| 93 | Leave the community based area agencies in place and allow them to do their jobs, which they do well, more than well actually | 12/3/2013 5:04 PM |
| 94 | no | 12/3/2013 4:39 PM |
| 95 | No | 12/3/2013 4:31 PM |
| 96 | I think that the effectiveness of the current offering that He M 525 offers should be looked at closely. | 12/3/2013 3:46 PM |
| 97 | I am very concerned that the present system will be changed and that needs will not be met | 12/3/2013 3:45 PM |
| 98 | No | 12/3/2013 3:25 PM |
| 99 | Yes - please preserve the current services and my son's residential placement. It's working well the way it is. The greatest fear I have is having to die and leave him to the system. I want to know he will be okay. | 12/3/2013 2:19 PM |
| 100 | Please tell the Republicans who are against Medicaid and other social safety nets that without these benefits, many of us would simply fall apart and become homeless or die. The impact of having a family member with a disability is so profound that you have to live in our shoes before you can judge us. It is unbelievably difficult and stressful. Please try to make maintaining these benefits as easy on us as possible. There is so much paperwork, so many meetings. We understand that this is in place to prevent abuse; however, once you know us and you know that this disability is for the rest of our lives, please have mercy and minimize the red tape. | 12/3/2013 1:22 PM |
| 101 | Keep smiling... | 12/3/2013 12:58 PM |

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| 102 | I feel Managed Care for Long Term Care is not the way the state should go. Medicaid expansion I am for as it would give many people much needed health services The way Medicaid is managed has worked and our state as been looked at as having one of the best systems. Why change what is not broken. Being part of an HMO or Managed care in private life, I know it is much more difficult to obtain services in many instances. My kids have Boston Doc's. I do not want them to lose their Docs they have had all of their lives. Area Agencies are so important to us. I do not know how I would have managed without their help. Thank You | 12/3/2013 12:22 PM |
| 103 | I cannot stress enough the inadequate services available to children on the autism spectrum through the area agency | 12/3/2013 12:15 PM |
| 104 | just keep it working--do not let other ;not as important things; take away the funds that are necessary to keep helping those who need what these programs provide! | 12/3/2013 11:56 AM |
| 105 | Always patient and hopeful for needed improvement of effective service model. | 12/3/2013 11:51 AM |
| 106 | WE NEED MORE INFOMATION IN WRITTING, AND NOT ALL THE POLITICAL TALK THAT IS AROUND. | 12/3/2013 11:23 AM |
| 107 | It would have been helpful to know which questions allowed more than one choice and which ones allowed only one choice (a few did but all should have). | 12/3/2013 11:12 AM |
| 108 | Do not know if my grant for help is part of mdicaid or not. | 12/3/2013 10:32 AM |
| 109 | My son is an autistic young man who has a fair amount of capability, yet struggles with trying to get to a point where he can be self sufficient. We subsidize him to the tune of \$300/month plus unexpected expenses like, his car and its upkeep, insurance, etc.; utilities for his apartment, food, all the while he is working as much as he is capable of, 35-40 week in a hospital with little chance of upward mobility. Hence he makes enough to not qualify for SSDI (in fact he is paying \$3000 back for an overpayment-actually we're having to do that for him), and the because of a 12 cent raise, he now in unable to receive food stamps...this cycle seems never ending, in fact the system seems to perpetuate itself, not help those who might become independent, actually get to independence. | 12/3/2013 9:40 AM |
| 110 | I think that 90% of this survey was worded in a way to support existing expectations of a fully outsourced Step 2 plan (10% is fine). Pretty disappointed in the quality of listening from the department over the past 24 months. The consultant that was brought in to run the regional meetings was a bureaucratic slide pusher (good with statistics indeed). But what good are "statistics" when the data gathered is only partial? | 12/3/2013 9:36 AM |
| 111 | Thanks for allowing us the opportunity to take part in this survey | 12/3/2013 9:15 AM |
| 112 | no | 12/2/2013 11:03 PM |
| 113 | I wouldn't mind having to manage my son's account for his services, but what concerns me is who would do it if something happened to me. At this point in life, we are not sure if my son will ever be able to manage his own finances or even cook for himself. I would hope that something would be designed in the new system to account for this issue. I would do it as long as I can, but eventually, I would not be able to. | 12/2/2013 8:14 PM |
| 114 | The State of NH is not willing to raise the revenue necessary to provide the services needed by its residents. It has a penny wise and pound foolish mentality. If each individual/family were to provide an equal share, there is adequate dollars to get the job done. | 12/2/2013 5:01 PM |
| 115 | NH has one of the best, most cost effective DD service systems in the country. There is not an inability to fund, but an unwillingness to fund by the state legislature. | 12/2/2013 4:00 PM |
| 116 | I wish that the state would give families that care for their children with disabilities more flexibility and higher funding streams to at least match the funds that go to caregivers that do not have financial or an emotional interest in the individuals that they are caring for. They are doing it mostly for a check. It pays well and it is tax free money to them. They are not always providing as high a standard of care that a family would provide. Thank you! | 12/2/2013 3:14 PM |
| 117 | Ideally there would be the same level of professional expertise with simplified, flexible, and across the board access to services. If the networks for services are not at area agencies, community health centers, etc, there would need to be new locations/agencies to work with. | 12/2/2013 1:29 PM |

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| 118 | The prospect of turning Long term care for DD over to for-profit payor MCOs seems ill advised. It will add additional margin requirements and that has come out of services. Selected use of MCOs for particular issues ... lay processing billing or helping to normalize waivers in the state ... may yield savings. There is no experience of MCOs in Long term (They said so at a governor's council meeting and the national surveys confirm), have no track record nationally in patient -centered services (as national surveys/analysis confirm) and there has been no data exchanged to show any way to set or measure savings. I can see why DHSS wants to impact LTSS that uses institutional care, but why does DHSS insist upon change to DD when it has a system that has worked so well?? | 12/2/2013 1:20 PM |
| 119 | It would really help me if I could find a place in Lancaster to get fit. | 12/2/2013 11:33 AM |
| 120 | Too many people and agencies involved and the Medicaid Managed Care is just one more layer of bureaucracy to navigate. The typical lay person has no idea how to work through the system. The individuals and families that are being served by Medicaid already struggle with economic and health issues and may feel overwhelmed with trying to navigate the Medicaid system. They also may have aging and/or cognitive issues which limit their ability to understand this complicated system. My mother, who is a retired school teacher and very intelligent, but who is also 89 y.o., is not able to understand this system. | 12/2/2013 11:02 AM |
| 121 | What about housing? What choices does a parent or caregiver have once they are no longer able to provide care and services? | 12/2/2013 10:56 AM |
| 122 | Managing the daily living needs of DD people is not a science, or suitable to being managed by insurance companies. It is not cut-and-dried like medicine (and even that is an art, to a degree). This is about managing LIVES, not medical issues, although medical issues are a large part of the lives of many with developmental disabilities. This part of Managed Care is about their programming and residential needs, their quality of life determined by work, leisure, social life, recreation and living situation -- day, evening and night. It is about how they are helped to spend their time in ways that are individualized to their ability and interests. It is about the intangible thing called "quality of life." With the complex physical, social, psychological and intellectual needs of this population, from brain injury to autism spectrum to Down's syndrome, it is essential that there be local professionals who are personally acquainted with the persons they serve. It is essential that the umbrella funding source not need to make a profit, thereby inevitably decreasing the funds available for the people they are supposed to serve. Their mission should be only for the clients, and not at all for the bottom line of a private entity. | 11/29/2013 3:58 PM |
| 123 | We were automatically enrolled in a plan although we are exempt under qmby/slmby. It does not bode well for the new plan meeting our specific needs if the system did not even know we were an exception. | 11/29/2013 1:44 PM |
| 124 | It would be good if more non-traditional methods of care were considered for funding, especially in the area of pain and mobility management. | 11/28/2013 5:55 AM |
| 125 | I wish we were asked about the wisdom of hiring inexperienced MCOs to replace our family-governed Area Agencies before our LTSS were arbitrarily rolled into MC. The math doesn't bear out. If we are already so strapped for funding that there is a waiting list for services (even though RSA:171A states no one can wait more than 90 days), it doesn't make sense to hand over up to 20% off the top to the MCOs for their overhead and profits, before services even begin. They will not add any value nor savings to developmental services. They will kill it. | 11/27/2013 11:22 PM |
| 126 | Everyone thinks area agencies are good. They have mediocre leadership and are stuck in paradigms. They play favorites and run amok | 11/27/2013 1:44 PM |
| 127 | No. | 11/27/2013 11:46 AM |
| 128 | You should ask what kind of services we are currently getting. Many of these questions don't apply to our situation. | 11/27/2013 11:32 AM |
| 129 | I think the State has seriously erred in contracting with large, out-of-state MCO's to manage LTSS for people with developmental disabilities. | 11/27/2013 11:25 AM |
| 130 | How important is it to have the flexibility between regions of the state with regard to available services and travel needs and flexibility with creation of therapeutic activities because no traditional ones are available in the area. | 11/26/2013 3:14 PM |
| 131 | I wish this had asked where are you in the continuum of needing services from time of diagnosis or something since the survey feels like it's looking at people already well established in the system vs. those who are only a year or two (~4-5 years of age) into their programming through school and private insurance means. | 11/26/2013 12:46 PM |
| 132 | Instead of feedback on an agency as a whole, individual feedback for those in leadership should be part of a quality improvement survey or surveys for re-designation. | 11/26/2013 12:14 PM |

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| 133 | <p>My daughter has tried for years to work with Voc Rehab to find work and has been unsuccessful. It is her biggest disappointment so would like the state to continue its efforts to help the disabled become employed. The other difficulty she has is having a more normal social life. Socializing for people with developmental disabilities is very limited. Having services on the local level helps as much as possible. Our current system is constantly working on providing some social outlets with the help of Family Support programs. It is wonderful that young families are being trained to manage their services for their family members through Transition programs, etc. but for the elderly parents dealing with adult children it is difficult due to aging and health issues so I still feel it is a huge help to us to have options available that do not require us to handle everything ourselves. That is not to say we do not want or expect to be involved in decision making for our family members, or do not expect and want to support them in any way we are able to but complete management of their services seems overwhelming to us now.</p> | 11/26/2013 11:55 AM |
| 134 | <p>The concern over the states ability to fund Medicaid should really have been worded "willingness" to fund Medicaid. The funds exist in this state but we are not always "willing" to spend the money - especially via tax dollars.</p> | 11/26/2013 11:06 AM |
| 135 | <p>I am hopeful that the new managed care program will work more efficiently, be cost effective while providing the supports and services people who experience require to be successful in the community and at work.</p> | 11/26/2013 10:42 AM |
| 136 | <p>If a new program were to be implemented, how would the people using the program learn about alternative ways of getting not only the correct kind of care, but also what is available? Sometimes, it takes a group of qualified people to get us on the right path with the correct type of services.</p> | 11/25/2013 9:31 PM |
| 137 | <p>Leave the area agencies alone!</p> | 11/25/2013 4:04 PM |
| 138 | <p>Please give families the ability to choose who manages their services. Some area agencies are very good while others are very bad. If we could choose the bad one would go out of business.</p> | 11/25/2013 2:12 PM |
| 139 | <p>I am happy to discuss anything I have written in more detail or work at creating a more efficient system overall. My name is Elizabeth Webster- I have a 23 year old son with autism and bi-polar disorder. I can be reached at 603.785.2423 One other thing...I am the sole guardian of my son, and am completely responsible for every aspect of his care. His father, who takes him to McDonalds twice a month, has no responsibility for his care at all. WHY? He should be contributing toward his son's care, and toward compensating me for the time I spend and limited lifestyle I have to live because of our son's disabilities at the very least. This is something that MANY mothers are situated with, (and a few dads) and there should be some action by the state to have the absent parent continue some responsibility for their adult child.</p> | 11/25/2013 2:09 PM |
| 140 | <p>As a relative/care provider for a profoundly mentally retarded sister in law the most arduous or impossible thing to do in relationship to getting medicaid funding is the goals. My sister in law has the mental IQ of about a 2 year old and socially/emotionally probably that of a 12 year old. She is older and very set in her ways which are extremely if not impossible to retrain/comprehend new tasks or goals. I guess what I am trying to say is that I do think it is very important for monthly feedback and updates regarding the person receiving benefits. But to set goals at least for my sister in law is virtually impossible.</p> | 11/25/2013 1:58 PM |
| 141 | <p>Please eliminate the area agencies as a rule. They are a waste of money. There are so many wonderful non profit advocates and schools out there that offer their services at no cost that the money would be spent so much better without them. An area agency is NOT LEAN! Thank you for this opportunity.</p> | 11/25/2013 11:21 AM |
| 142 | <p>Again, recognizing that over the past ten years my husband and I cared for both grandparents and sister who lives with multiple disabilities. Both grandparents died at our home, and my family maintained a peaceful, secure home environment during this period. My grandparents did not receive Medicaid funding, where as my sister relies on Medicaid (and Medicare) funding.</p> | 11/25/2013 10:20 AM |
| 143 | <p>While I am very concerned with the states 'ability' to fund the medicaid services for individuals who experience a developmental disability/acquired brain injury, I want proof... objective evidence that this transition to a managed care model Step 2 will maintain local control, quality of care, and cut costs. Again I urge policy makers to delay the implementation of Step 2 so thought we can engage in a more thoughtful assessment of this type of transition.</p> | 11/25/2013 10:17 AM |

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| 144 | I've lived in several states and find the services in NH to be best so far. There were good points to services in California and Hawai'i, but California still has institutions and Hawai'i has a positive Aloha culture where people take care of each other based on that moreso than on a financial model. Florida's services were terrifying. I would prefer a national system that provided equal service opportunities to everyone so people could have mobility, and freedom to move around the country even if they have disabilities. The state by state model discriminates against people. I'm thankful that my uncle could come to NH and receive good services, but it shouldn't be based on the luck of being born in the right state. A federal system would be a beast, of course, but being able to have my uncle live across the border in Maine an hour away vs. a place in NH 3 hours away makes a big difference in how much I can visit him. | 11/25/2013 10:05 AM |
| 145 | What are your hopeful outcomes? How do you envision this helping a system that we don't perceive to be broken? | 11/25/2013 9:16 AM |
| 146 | I would like to see a plan that is incorporating, including current area agencies in this whole planning process. I feel they should be part of this plan. | 11/25/2013 8:24 AM |
| 147 | FUND THE WAIT LIST | 11/24/2013 6:59 PM |
| 148 | What assurance do we have that medicaid will cover all of the current services our son receives? | 11/24/2013 6:21 PM |
| 149 | There needs to be access to this information as part of the diagnosis process. There needs to be a centralized resource online that is easy to access and informational. | 11/24/2013 2:05 PM |
| 150 | Flexibility in choosing service providers (even Area Agencies), even if they are outside your region, is vital. Every agency has a certain culture or area of expertise. Given that the needs for this population of consumers can be complex and that multiple diagnoses can exist, families should be able to select an agency/provider whose culture and services matches their needs. Also, there is sometimes a hierarchy that exists within an agency's culture that identifies individuals with certain diagnoses as more needy than others and more services are designed with their needs in mind, thus making the services they provide less relevant to those with other diagnoses. Lastly, school officials should become more aware of what long-term care community-based services are available for families in need since they are often a point of first contact. | 11/24/2013 8:56 AM |
| 151 | Continuing the current services is most important aspect of services provided. Also continuing access to current providers with no lapse or interruption is key for my guardian's complex needs. | 11/24/2013 6:30 AM |
| 152 | My goal for my child is to make them as independent as possible, thus making them less of a burden on society. I will not be around for ever and time is ticking. Allow more funds to be used for creative adaptive equipment. | 11/23/2013 10:21 PM |
| 153 | Very glad you are exploring improvements. I skipped the earlier questions because I got bumped off the system ~80% of the way through ~1pm today. I'm hoping the part I previously filled made it through. If not, please email me jodiell@comcast.net. What does one do if a chronic health condition is discovered in a persons teens and it is not clear until after they have turned 18 that this will be lifelong, prevent physical labor (not mental labor), and results in procedures that your typical young person has no chance of absorbing the costs for? 1) The first major obstacle is to get information on what help is available and how to find it, out to the newly diagnosed or struggling but undiagnosed. Although I knew my youngest had a problem from birth it has taken thirteen years to get traction. I was unable to get my oldest the help he needed. I used to be a scientist before it became impossible to work the schedule required. I am used to doing research, I've researched, I network, I read everything I can get my hands on. I've asked for help, and we are drowning. I can't figure out why this is so hard? I can't figure out how anyone manages. I can't figure out how to fill out the forms with the required documentation when your children won't allow the specialists to do the required evaluations. When the young adult fires the child or the psychologist fires the child. 2) Safe adult housing options (not institutional) with the supervision needed, it seems impossible to find for the mentally ill, mildly mentally impaired or the autistic. Such fun when all of it runs in the same family. | 11/23/2013 6:55 PM |
| 154 | We are fairly new to CDS and In Home Supports. Not sure what families went through prior to the way it is now, but it currently works wonderful for us. Concerned that we are messing with something that is already working. Hard to believe we will improve on it given NH is rated as one of the top States in the country to live in for an individual who experiences a disability. The waiting list, which we were on and friends of ours are on is incredibly frustrating. A friend of mine may lose her job b/c there are no funds available for her son and she is forced to stay home as there is no one to take care of him. If we could fix that... GREAT! | 11/23/2013 12:33 PM |
| 155 | I think this is good step in reviewing options to improve the current system -- continuous improvement is a great idea. | 11/23/2013 9:12 AM |
| 156 | How can I get insurance companies, a tech , whoever works with me to see FC works for me and I can do this. Pascal says if I practice more I can do more myself. It's important. | 11/23/2013 8:55 AM |

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| 157 | This is scary. I do not know if with the new system that my son will have what he needs to continue to live independently. My husband I have worked really hard over the last 10 years to all to get our son where he is today. My son's dream is have his own place, have a good job and to some day have children. As a parent it my responsibility to ensure that all my children are given the opportunity to succeed in whatever their dream is. The future is uncertain for my youngest son. As a parent my biggest fear is what will happen to my son once I am gone. I have dedicated the last 10 years and will dedicate the next 30+ years advocating for his independence to the best of his ability. | 11/23/2013 8:28 AM |
| 158 | All autism spectrum disorders are on the rise, as well as auto-immune diseases. Combine the two and you have quite a cocktail of issues. There needs to be a board or panel that actually looks at both as a combined issue, not as individual issues. The two impact each other significantly, and navigating the system to address both of these is near impossible. Schools are the biggest issue, but my work and IEP will actually be a model for more children to come through. Hopefully, as these services become better, parents won't have to do all the work. I should never been given a diagnosis without also being given resources and a follow-up appointment. As a result, my son is significantly delayed because he didn't receive the services he should have gotten when he was young enough to be impacted by them. | 11/23/2013 8:11 AM |
| 159 | I am not at all optimistic that a redesign will improve the DD system, but I would be optimistic about a redesign to make elder care and services for people with severe mental illness more like the DD system. We have one of the best DD systems in the country yet spend far less than the national average - it ain't broke, don't fix it! I am not sure what you meant by whether I'm "concerned about the State's ability to fund Medicaid." I am certainly concerned about the State's WILLINGNESS to fund Medicaid. | 11/23/2013 12:55 AM |
| 160 | I think the area agency management, e.g., directors and top level staff should have their salaries reviewed, as it seems that salaries are high, given that the agencies frequently complain that funds are not available for clients. There should be serious questions raised about anyone who makes a six figure, or close to a six figure, salary, given that these agencies are nonprofits, and the mission is to serve people in need. | 11/23/2013 12:48 AM |
| 161 | The Medicaid Managed Care companies for acute care that are being implemented.....should NOT be the companies handling Step 2. Leave the current system in place. We do NOT want people who do not really know our situation with our loved ones deciding things for their program! They do not know our areas, our communities, the 24/7 things that may pop up at any time or hour etc. Their call centers are not local. (well...one is in Bedford but would not know the whole state area either) Let the MCO's handle the acute care issues if need be,....but do NOT let them handle Long Term care for our developmentally disabled or acquired brain injured individuals. Keep NH #1 in the WORKING system we currently have in place with our Area Agencies in each county. | 11/22/2013 10:58 PM |
| 162 | The process/transition of individuals coming out of school to the "work force" or area agency and not being "prepared" socially, emotionally, academically, because there has not been a "great" connection between providers and the school districts to help our children. | 11/22/2013 10:39 PM |
| 163 | For my family member, the current long-term-care program has and is working extremely well. I would be concerned if it was turned on its head. There is always fear of the unknown, particularly when it comes to providing appropriate care for our most vulnerable citizens. | 11/22/2013 7:02 PM |
| 164 | Why do you think insurance companies operating for profit will be better able to manage services than the current system which parents/providers/participants have built? How do we improve on being the best in the nation at service and among the lowest on cost? | 11/22/2013 6:40 PM |
| 165 | Dental Health is imperative for all adults and need to somehow be included in Medicaid benefits. | 11/22/2013 6:04 PM |
| 166 | Please do not out source to a for-profit company. | 11/22/2013 5:55 PM |
| 167 | The current model is working just fine. Our children should not be guinea pigs because someone in Concord is afraid to raise the gas tax to fill in budget holes. Fund the current program and leave it alone. | 11/22/2013 5:36 PM |
| 168 | I am very concerned about the prospect of Step 2 managed care and have many questions. A few are: How will MCOs work WITH local, experienced area agencies versus replace area agencies? MCOs have no long-term care experience. Why shouldn't I be concerned about the removal/dismantling (perhaps not immediately but within a few years) of the area agency system? What happens if the MCOs don't realize the savings they expected and leave the state after the area agency system has been deconstructed? Why COMMERCIAL managed care versus the managed care that has been in place for decades? | 11/22/2013 4:45 PM |
| 169 | You should have asked "how much do you trust the state?". | 11/22/2013 4:33 PM |
| 170 | No. | 11/22/2013 3:59 PM |
| 171 | no | 11/22/2013 3:55 PM |

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| 172 | I could not answer all these questions, but did what I could considering the person that lives with me. There is not much of anything that she can do for herself. | 11/22/2013 3:48 PM |
| 173 | More funding for families! Again, it's all about supporting financially those home providers who already receive a paycheck and then get additional money for food, fuel assistance, clothing, etc. Nothing comes out of pocket for them. While family members save the State of NH tens of thousands of dollars or more and we don't receive anywhere the financial support that home providers do. If I were to say I wasn't taking care of my family member any more, a program would have to be put in place and that would cost the state at least \$100,000 for 24 hour care. Dental bills should be covered, not out of pocket for families. More respite for families not home providers! | 11/22/2013 3:47 PM |
| 174 | I'm concerned that working with managed care organizations will be like dealing with an insurance company rather than with professionals with expertise in the I/DD world. While managed care may decrease the amount of expensive visits to the ER by regular Medicaid patients, I am not confident that they will be able to deal with the I/DD population effectively. | 11/22/2013 3:29 PM |
| 175 | my husband has been permanently disabled for over 30 years since his diagnosis and is in the severe progressive stage of his disease, but his community based home care has been his saving grace. | 11/22/2013 3:15 PM |
| 176 | The waiting list for adult services needs to be abolished. The state needs to fund these programs more responsibly. | 11/22/2013 3:14 PM |
| 177 | no | 11/22/2013 3:06 PM |
| 178 | Good survey questions! Thanks for asking. I hope people listen. | 11/22/2013 2:55 PM |
| 179 | How have the Area Agencies and schools helped or hindered our lives. I've known to many families that wouldn't take the stress and strain of the constant battles and many didn't make it. | 11/22/2013 2:51 PM |
| 180 | no | 11/22/2013 2:19 PM |
| 181 | Please give us freedom from area agencies. | 11/22/2013 1:58 PM |
| 182 | I have no confidence in how the State of NH has chosen to undertake Medicaid reforms. Payment reform is also a type of culture shift. There needs to be a gradual roll out of SIM funded pilot projects - not the 1 year timeline contemplated by DHHS. Moreover, success depends on having excellent IT and a clear and common appreciation for the quality metrics used to reward providers. NH is a long way from developing this infrastructure. I am also highly skeptical about the role of commercial insurance companies in this reform effort. The long term care system for people with developmental disabilities in NH is already very lean. I do not see where the MCO's will find money for a positive return on their investment. | 11/22/2013 1:51 PM |
| 183 | If you live in a rural community how likely to you think it is that you would or could receive services locally? The problem for us was that our son needed services for both his developmental disability and mental illness that were not accessible in a small rural town. So when NH looks at models that include community based programs they often model them around major city hubs - which are definitely not local. Support groups and peers for him were 30 miles away - so the state had the programs but they were not accessible to our child because of our geographic location - which has meant that in order to get him the services he needs, on the regular basis he needs, he had to move to a large city and group housing - which he had to wait for while our local police department acted as the "absentia" service while we waited for placement (over two and a half years). It just didn't seem humane, responsive or compassionate. | 11/22/2013 12:35 PM |
| 184 | A local, within 20 minutes, office accessible by public transportation is essential in providing the highly personal one-to-one consistent relationships that are required in the delivery of quality community based long-term care | 11/22/2013 12:15 PM |
| 185 | How would you change our System. I would need to eliminate the overhead of monies used within Our System. Use these monies to stop the cycle of constant turnover in Direct Care/ Providers. Increase Direct Care rate of pay, offer Medicaid to all Home Providers/ Families, after 3 years of Service for a buy in of 100-200 monthly Be flexible with Day Program Hours ..15 - 30 hrs a week . Not everyone Wants to be out in the community for 30 hrs a week !! Find a way to allow someone to purchase needed items without having to purchase through MEDICAID. A perfect example . I could have purchased a full electric medical Bed for 800 but no Medicaid would not approve so one was purchased for thousands of dollars . Qualify me for Medicaid purchases and I could save you lots of money and still earn a go living !! | 11/22/2013 12:12 PM |

NH Medicaid Long-Term-Care Program Survey

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| 186 | Any system has to understand the vulnerable position the people who are on the receiving end are in. We keep people in poverty, segregation, congregation and overall in devalued roles in our communities. Medicaid dollars could be used to elevate people in creative ways to be active participants in their communities as well as taking care of their health and safety needs. And the supports the people need must be given by competent staff who see the value and talents of the people they are serving. The staff need to be valued by the overall system through pay and benefits and ongoing training. Leadership should develop bottom-up practices and figure out how to best support and nurture both the people receiving and giving the supports. Let the resources get to the people closest to the situation. Bottom up and not top down. | 11/22/2013 12:00 PM |
| 187 | The Area Agencies need to know that what's best for one isn't necessarily best for all. Developmentally disabled also like to grow up and live on their own (or feel like they are); and getting stuck in a low-income/elderly apartment with a few hours of services a week doesn't work for many that are stuck with that model. I hear horror stories of the "caregivers/roommates" that take advantage of these adults. | 11/22/2013 11:48 AM |
| 188 | I do not want managed care taking over the local system. I believe that would be a huge error because the system now works very well. It's about money and politics and it should not be. | 11/22/2013 11:48 AM |
| 189 | Take phase two out of the picture!!!! | 11/22/2013 11:41 AM |
| 190 | I am concerned that the results of the hard work done by a group of dedicated families and professionals over the last 30 years may be discarded by a bureaucratic/business-oriented program that looks only at bottom line numbers (dollars) rather than the harder to define, but easily recognizable results. | 11/22/2013 11:40 AM |
| 191 | I feel strongly that long-term supports should not be included in the new Managed Care Model of Medicaid Services. I feel that the individuals receiving such services are going to be the ones to suffer from this decision and they are the ones who need to be protected by the State because many are not in a position to advocate for themselves. | 11/22/2013 11:33 AM |
| 192 | Community Bridges and admission to Robin hill Farm has been an answer to our prayers! | 11/22/2013 11:13 AM |
| 193 | Group home providers could save money and I would love to see someone (I would do it if I had the money and knew how to do it) get a government grant to buy some old mill building or vacant hotel and make more housing for disabled/handicapped citizens where services can be provided more efficiently or give options to have this type of housing to those who would benefit from this type of close monitoring but don't require full services...semi-independence for those living there - a safe place to be.. | 11/22/2013 11:13 AM |
| 194 | Choice, choice, choice and more choice with adequate funding. | 11/22/2013 11:01 AM |
| 195 | I don't think the state understand how hard it is to take care of a person who is disabled and how much help they need to do life skills. The fact that they are at home with their family as an adult why should it matter how much I make. The programs should be based on the disabled person income which is not a lot of money. We are talking about someone who will NEVER be able to be left alone. | 11/22/2013 10:56 AM |
| 196 | We are extremely concerned that if stage 2 of managed care takes effect, all of our efforts and gains will deteriorate as none of the mco's have experience with this population. We believe the mco's will use it to balance their budgets and pay shareholder's and that profit will be their top priority while our families will become a distant second place. | 11/22/2013 10:44 AM |
| 197 | red flags should go up when someone has been out of service is for 4 months out for a month that's when the flag should go up. And then it should forward right to someone that will help if it hasn't been taken care of. I was lucky I got the name of someone to use and I forwarded everything that I forwarded to the area agency that got people hoping | 11/22/2013 10:04 AM |
| 198 | I wish this survey focused more on making the application process to access LTC services more accessible and quicker. People are waiting in excess of 3 months to find out if they are eligible for services, and then it can several more months to get services in place. | 11/22/2013 9:58 AM |
| 199 | Please be VERY careful when trying to change what is a very frugal approach (in the US NH is in the lowest 3rd spent per capita on services) with high quality outcomes (2nd in the nation according to the CP group) like we have now. There is a lot that I am giving to the state free of charge that I might not be able to give without some of the supports I get. Do not dismantle family support councils and area agencies in the new system. These are highly effective organizations that work to provide good outcomes for families. I wish that Medicaid would work more like an IRS model where there is trust with periodic audits. You tell the government what they owe you, they pay assuming that you are honest. It is a good assumption in my case because I am honest. Then every once in a while people would be audited to see if they are actually honest. | 11/22/2013 9:57 AM |