

NEW HAMPSHIRE BUREAU OF DEVELOPMENTAL SERVICES
HIGH COST REVIEW COMMITTEE
FINDINGS AND RECOMMENDATIONS
APRIL 5, 2010

INTRODUCTION

In New Hampshire, the Bureau of Developmental Services (the Bureau) within the Department of Health and Human Services oversees the provision of services to individuals with developmental disabilities or acquired brain disorders. The Bureau's responsibilities include both programmatic and fiscal monitoring of the state's developmental services system. As part of its budgetary oversight, the Bureau conducted a comparison of contracted high cost service arrangements (those whose annual cost for an individual exceeds \$100,000) for Fiscal Years 2004 and 2008. The Bureau found a 64% increase in the number of individuals with high cost service arrangements (433 individuals in FY 2008 as compared to 264 individuals in FY 2004)¹ and a modest increase of 7.6% in the average budgets for these services (\$123,696 per person cost in FY 2004 versus \$133,045 in FY 2008)².

The Bureau's findings served as the catalyst for establishing the **High Cost Review Committee** (the Committee). The Committee, which was formed in November of 2008, includes representation from area agencies, subcontract agencies, the Bureau of Developmental Services, and the Division of Community-Based Care Services. (See Appendix #1 for the list of Committee members.)

The purpose of the High Cost Review Committee was to:

- Gather detailed information on the needs and characteristics of individuals in high cost service arrangements.
- Identify the challenges - clinical, administrative, and fiscal - associated with providing supports and services to this group.
- Share identified best practices.
- Make recommendations to improve individual outcomes, efficacy of clinical services, and cost effectiveness of supports and services.

INITIAL SURVEY RESULTS:

At the outset, the Committee requested the State's ten area agencies to complete a survey for each individual with a high cost service arrangement. The survey asked for information on a number of issues potentially affecting budget costs. (See Appendix #2 for the complete survey.) Areas covered by the survey included:

¹ During this period BDS granted two rate increases; it appears these rate increases pushed the budgets for 8 individuals into the high cost category, which constitutes about 5% of the increase.

² Of the 7.6% increase in the per person average cost, 4.6% came from the two 2.3% rate increases that were approved by the legislative budget process.

- Medical issues (seizure management, tube feeding, turning, positioning)
- Behavioral issues (injuries to others or self, emotional outbursts, fire setting)
- Psychiatric issues (anxiety, depression, schizophrenia, personality disorder)
- Living situation (staffed residence, home provider, family home, number of people in the home)
- Institutional admission history (New Hampshire Hospital, Secure Psychiatric Unit)
- History of residential moves during the last 5 years.

Information was collected on 433 individuals. The results of the survey revealed that:

- The average age for individuals in the high cost group was 43 years.
- The average individual budget was \$132,944³.
- Sixty-one percent (61%) of these individuals lived in staffed settings, 18% in enhanced Family Care (EFC) settings, 13% in EFC settings with additional staffing, and 8% in other settings, such as the individual's family home.
- The average number of individuals being served in a residence was 2.7.
- On average individuals had experienced 2.4 moves within the last five years; only 39% of individuals had a stable living situation with no moves.
- More than half (55%) of these individuals were identified as having one or more medical issues. On average each individual had 2 medical issues. The average annual cost for individuals with medical issues was \$132,533.
 - The most frequently identified medical issues were:
 - Seizure Management (36%)
 - Lifting and transferring (36%)
 - Turning and positioning (28%)
 - The average medical score was 4 out of a possible 10.
- Eighty percent, (80%) of individuals, were identified as having one or more behavioral issues. On average each individual had 3 behavioral issues. The average annual cost for individuals with behavioral issues was \$134,889.
 - The most frequently identified behavioral issues were:
 - Emotional outbursts (70%)
 - Property destruction (49%)
 - Injuries to others (48%)
 - Injuries to self (45%)
 - Sexual aggression (21%)
 - The average behavioral score was 6 out of a possible 18.
- Seventy-five percent (75%) of the individuals were identified as having one or more psychiatric issues. On average, each individual was identified as having 3 psychiatric issues. The average annual cost for individuals with psychiatric issues was \$135,215.
 - The most prevalent psychiatric issues identified were:
 - Mood disorders/depression/bipolar (45%);
 - Anxiety disorders/Post Traumatic Stress Disorder (41%).
 - The average psychiatric score was 5 out of a possible 21.
- Of the total group surveyed:
 - 20% were identified as having one type of behavioral, psychiatric, or medical issue; the average annual budget for these individuals was \$128,073.
 - 52% were identified as having two types of issues; the average annual budget for these individuals was \$133,655.

³ This average cost of \$132,944 from the FY '09 budgets was slightly lower than the earlier cited FY '08 average of \$133,045 because some of the budgets had gone through adjustments.

- 28% were identified as having three types of issues; the average annual budget for these individuals was \$137,242.

IN-DEPTH REVIEWS OF A SAMPLE GROUP

As a follow up to the survey, the High Cost Review Committee conducted in-depth reviews for a selected group. In order to obtain a better understanding of the factors involved in high cost situations, each member of the Committee completed a comprehensive review of service arrangements for two individuals. For this review, a modified random sampling process⁴ was used to identify the 22 service recipients who were assigned to the 11 Committee members.

Each in-depth review included:

- Interviews with the individual and family/guardian, as appropriate;
- Interviews with service coordinator, direct service staff/providers, and management staff; and
- A review of the documents in the individual's file.

In preparation for the in-depth reviews, the High Cost Review Committee spent considerable time determining what information was needed and discussing how this could best be obtained. As a result, the Committee developed a review "checklist" that included:

- Individual Service Agreements
- Evaluations
- Hospitalizations
- Medical records and protocols
- Clinical services, current and past
- Behavioral plans
- Staff training information
- Incident reports, investigation results, and sentinel events
- Adult Outcome Reports
- Individualized budgets
- Legal history (arrests, incarceration, court orders, and conditional discharges)
- Information on social connections
- Employment

(See Appendix #3 for the complete review list)

SUPPORTS INTENSITY SCALE (SIS)

In conjunction with the individual reviews, each individual was administered the Supports Intensity Scale (SIS) by a staff member from Community Support Network Incorporated (CSNI)⁵. (See Appendix #4 for the SIS results.) SIS is a nationally recognized standardized assessment tool that evaluates practical support requirements of a person with an intellectual disability.

To determine whether there was any relationship between the service budgets for the 22 individuals in the sample group and their corresponding SIS scores, correlation coefficients were computed. Two of these correlation scores demonstrated statistically significant relationships between the individuals' budgets and their support needs. The following correlation values were calculated:

⁴ The initial random sample was modified in the following ways: a) At least two individuals from each region were included in the sample of 22; b) half a dozen individuals were from the ABD waiver; c) no Committee member reviewed a case with which he/she had any affiliation.

⁵ CSNI is the consortium for the 10 area agencies

- Correlation coefficient of **0.57** was found between the Overall SIS score and the budget amounts, which was statistically significant⁶.
- Correlation coefficient of 0.24 was found between the SIS Exceptional Medical Supports score and the budget amounts.
- Correlation coefficient of 0.36 was found between the SIS Exceptional Behavioral Supports score and the budget amounts.
- Correlation coefficient of **0.62** was found between the combined Exceptional Medical and Exceptional Behavioral Support scores and the budget values, which was statistically significant⁷.

While the budgets for the 22 individuals in the sample group had been created without the use of a formal assessment tool, there were significant correlation values of 0.57 and 0.62; indicating that the assigned budgets show a definite relationship to the individual's supports needs, as identified by the SIS assessments⁸.

In presentations before the full Committee, members shared the results of their in-depth reviews, providing specifics about the individual's situation, as well as the successes and shortcomings for each service arrangement. The presentations regarding individuals who receive high cost services typically resulted in extensive discussions of both the individual's personal circumstances, as well as the implications to the overall service system. There was consensus among the Committee that these discussions played an invaluable role in helping them to better understand and appreciate the complexity of serving people with extremely challenging needs.

REVIEWER RATINGS

In addition to sharing their findings in presentations before the Committee, each member completed an extensive on-line survey regarding the service arrangements for the two individuals in their sample group.

Based on the information obtained from the in-depth reviews, the High Cost Review Committee concluded that:

- In 86%⁹ of the cases the individual's medical needs were being appropriately met¹⁰.
- In 71% of the cases the individual's psychiatric needs were being appropriately met.
- In 50% of the cases the individual's behavioral needs were being appropriately met.
- In 61% of the cases the individual's clinical/therapy needs were being appropriately met.
- In 75% of the cases the individual's safety needs were being appropriately met¹¹.
- In 64% of the cases the needed staff resources were readily available.
- In 32% of the cases staff turnover had significantly impacted the care of the individual.
- In 81% of the cases staff and providers were appropriately trained.
- In 45% of the cases ongoing crises and the responses to these crises had produced a negative effect on the care and supports for this individual.

⁶ Significant at 0.01 confidence level

⁷ Significant at 0.01 confidence level

⁸ The above correlation values were calculated based on a very small sample size (i.e., the budgets and SIS scores for only 22 individuals.) Since correlation coefficients tend to be stronger viewed over a wider range of data it is possible that a larger sample size might demonstrate a more extensive relationship between the existing budgets and the SIS scores.

⁹ In calculating the percentages, responses of "not applicable" and "do not know" were excluded.

¹⁰ The membership of the Committee had diverse educational and professional backgrounds. In responding to some of the survey questions, members had to "step outside of their area of expertise" to render an opinion with respect to medical, behavioral or psychiatric issues based on the totality of information available to them.

¹¹ In cases where the reviewer concluded that there were issues with the individual's safety needs being met, the reviewer was asked to convey that information to the individuals' service coordinator for follow-up.

- In 57% of the cases the individual had enjoyed a stable living arrangement for the past five years.
- In 55% of the cases meaningful activities were a part of the individual's daily schedule.
- In 54% of the cases the individual was offered appropriate employment opportunities.
- In 58% of the cases the individual was offered appropriate volunteer opportunities.
- In 96% of the cases service coordination had been effective in regards to advocacy, facilitation, and oversight of services.
- In 80% of the cases assistive technology had been effectively utilized to enhance the individual's services and quality of life.
- In 60% of the cases budget elements were based on the individual's needs and desires and the budget amount seemed appropriate.
- In 100% of the cases the area agency's initial ratings regarding individual's medical and behavioral status were consistent with the reviewers' findings and observations.
- In 92% of the cases the area agency's initial rating regarding psychiatric status was consistent with the reviewers' findings and observations.
- In 86% of the cases the SIS score (based on maximum score possible) appeared to be consistent with the reviewer's overall findings and observations.
- In 65% of the cases the individual/guardian seemed to be happy with the service arrangement.

(See Appendix#5 for a complete summary of the survey results)

OVERALL FINDINGS, THEMES AND RECOMMENDATIONS

- A. *The initial survey completed by the area agencies for the 433 individuals with high cost budgets indicated that 80% of the individuals had challenges in more than one area (i.e., they had a combination of medical, behavioral, or psychiatric issues.) Nearly 30% of these individuals were identified as having needs in all three areas. These findings underscore the complexity of providing services to individuals who have critical and multifaceted clinical issues.*
- B. *The initial survey completed by the area agencies also made it clear that the overwhelming majority (80%) of these high cost service arrangements supported individuals with substantial behavioral challenges. In addition, in-depth reviews conducted by the Committee members concluded that in only 50% of these cases did the individuals' behavioral needs appear to be adequately met. Some reviews noted the contrast between service arrangements where clinical resources were readily and consistently available as compared to those where appropriate resources were not available; individuals who lacked appropriate clinical resources experienced frequent complications and personal crises.*

RECOMMENDATION #1

1-(a) The approval processes for service arrangements and individual budgets –both at the regional level and the state level- should insure that the proposals contain sufficient clinical resources. Accordingly, the Bureau should create a statewide ***Service Review Advisory Committee*** to facilitate the process for reviewing and approving proposals for high cost service arrangements. This committee membership should be interdisciplinary, with members who have expertise in clinical, administrative, and fiscal areas. In addition, the ***Service Review Advisory Committee*** should include representation from the area agencies, subcontract agencies, and the Bureau of Developmental Services.

1-(b) The area agencies, subcontract agencies, and the Bureau should work collaboratively to augment available clinical resources and to ensure that there are adequate supports for addressing challenging behaviors.

- For FY 2010, the area agencies and the Bureau have obtained consultations and trainings from the Institute on Disability's Center for START Services¹² to assist providers to better support individuals with challenging behaviors. In view of the positive feedback received regarding START, it is suggested that the area agencies consider increasing the number of these consultations to further improve the availability of behavioral resources within New Hampshire.
- In addition, three area agencies and the Bureau have begun to work with the START staff and consultants to establish regional clinical teams with interdisciplinary membership. The intent of this initiative is to provide opportunities for consultation, education, and individualized treatment planning. In addition, these efforts are expected to improve regional community linkages and collaborative relationships among clinical stakeholders. Upon completion of this pilot initiative, other area agencies will have the opportunity to create similar clinical teams within their region.

1-(c) The development of additional clinical expertise and resources should include the provision of orientation and training to service coordinators, family support coordinators, and mid-level program managers on how to better:

- Identify and address issues related to challenging behaviors;
- Coordinate efforts among multiple organizations; and
- Manage crisis situations.

The expansion and improvement of clinical resources is likely to improve outcomes not only for those with high cost service arrangements, but also will benefit those individuals with challenging behavioral needs who have more modest service budgets. In addition, providing adequate clinical supports for individuals with behavioral needs is likely to prevent future crises and the need for higher cost services.

C. In addition to behavioral challenges, psychiatric problems were identified as a prominent concern for individuals with high cost service arrangements; 75% of individuals in this group were reported to have psychiatric issues. Furthermore, 65 % of individuals were identified as having both psychiatric and behavioral issues. While the in-depth reviews found that in about 70% of the cases individuals' psychiatric needs appeared to be adequately addressed, obtaining appropriate psychiatric services for people with developmental disabilities or acquired brain disorders continues to be a considerable challenge.

RECOMMENDATION #2

2-(a) The Division of Community-Based Care Services (DCBCS) - which includes the Bureaus of Developmental Services and Behavioral Health - should create a statewide ***Dual Diagnosis Committee*** with membership from the developmental and mental health service systems. This Committee should be charged with further examining the issues related to accessibility and provision of psychiatric services to individuals with dual developmental and behavioral/mental health diagnoses.

¹² Center for START (Systematic, Therapeutic, Assessment, Respite, and Treatment) Services

2-(b) Several of the High Cost Review Committee members recalled previous efforts by the two service systems to create interagency agreements to improve psychiatric services to individuals with dual diagnoses. As part of its examination of issues concerning this population, the *Dual Diagnosis Committee* should review the status of these interagency agreements and make recommendations for improving the ability of the two systems to work collaboratively to provide psychiatric services for those with dual diagnoses.

2-(c) One of the important determinants of successful outcomes for those receiving psychiatric services is the availability of “good informants” during visits with the attending psychiatrist. When direct service staff, providers, and service coordinators who are familiar with the individual are able to provide meaningful information to the psychiatrist, the capacity for delivering effective psychiatric treatment increases significantly.

It is recommended that the *Dual Diagnosis Committee* establish a work group (whose members include psychiatrists, behavioral specialists, case managers, nurses, direct service staff, and home providers) to create best practice guidelines and make recommendations for improving services to those with dual diagnoses. A “family friendly” version of these guidelines should be available to assist families in their efforts to access appropriate psychiatric services for family members who have a dual diagnoses.

2-(d) The area agencies, subcontract agencies, and the Bureau should insure that staff and providers receive orientation and training on how to provide useful information during psychiatric visits and consultations. Currently, a few area agencies have created a “mental health specialist” position to support individuals served by their agency who have mental illness and who are seeking psychiatric services from the community mental health center or from a private psychiatrist.

2-(e) The general survey completed by the area agencies for individuals with high cost service agreements, as well as the 22 individual in-depth reviews, indicate that New Hampshire Hospital (NHH) is a critical clinical resource for individuals with psychiatric needs who receive supports through the area agency system. While the relationship between NHH and area agencies and their subcontractors has been primarily positive, unfortunately there also have been examples of significant difficulties. Staff members from the area agencies, subcontract agencies, mental health centers, and NHH have identified instances where there were breakdowns in planning, communication, and collaboration. These have resulted in frustration for both community providers and NHH staff and inferior outcomes for individuals. All sides agree that such problems must be addressed as they ultimately impact the service system’s ability to meet the psychiatric needs of vulnerable individuals.

The *Dual Diagnosis Committee* should establish a work group to review the access and availability of NHH services for individuals with developmental disabilities or acquired brain disorders and to make recommendations that will improve the ability of these individuals to receive NHH services and return to community-based programs in a timely manner. The findings and recommendations of this work group should be submitted to the Director of DCBCS for consideration and implementation.

2-(f) The recent closure of the NHH’s Neuropsychiatry Unit, due to funding shortages, has been a regrettable development. This program provided critical clinical resources for a number of individuals each year and was ultimately instrumental in enabling the system to support individuals with significant needs in community-based service arrangements. To address this gap in services, representatives from a number of organizations have formed a group to explore

possible alternatives. The **Dual Diagnosis Committee** should support these efforts to identify alternative settings and develop the clinical resources that were eliminated with the closure of the Neuropsychiatry unit.

- D. *More than half (55%) of those with high cost service arrangements had medical issues. Although the percentage of individuals with medical issues is smaller than those with behavioral and/or psychiatric needs, the High Cost Review Committee reviews found that the management of medical needs presented significant challenges, requiring frequent contact and coordination with health care providers.*

For the last several years, the area agencies and subcontract agencies have noted increased interactions with primary care physicians, specialists, and hospitals on behalf of the people they serve. In addition, there is a greater demand for nursing resources at the agency level. As individuals in the area agency system –with or without high cost budgets- live longer and have increased medical needs, greater efforts are required to secure and coordinate appropriate health care services.

There has been a growing consensus that New Hampshire’s area agency system should increase its nursing resources in order to better meet the health care needs for those they serve. While the area agency system presently employs a substantial number of nurses, their time is primarily dedicated to medication administration authorization of staff and providers. Agency nurses typically are not available to address the other medical needs of individuals.

RECOMMENDATION #3

3-(a) It is recommended that the Bureau create a **Health and Medical Care Task Force** to study the issue of accessing and coordinating health and medical services. Membership on the Task Force should include those who have expertise in clinical, administrative, and fiscal areas, as well as representatives from area agencies, subcontract agencies, and the Bureau of Developmental Services¹³.

3-(b) The **Health and Medical Care Task Force** should thoroughly review He-M 1201, the Bureau’s regulation regarding medication administration, to determine what modifications or changes are necessary in order to ensure that there are adequate nursing resources to meet the health care needs of those being served by the area agency system.

3-(c) Based on the recommendations of the **Health and Medical Care Task Force**, each area agency should review its regional nursing capacity and, if needed, work with the Bureau to develop a plan to enhance its nursing resources.

- One area agency has created a “nurse specialist/consultant” position that helps facilitate services for individuals who have significant medical needs and who require sophisticated medical services from a variety of health care providers and organizations. The nurse specialist/consultant has helped to improve outcomes for individuals served by this agency.

3-(d) The **Health and Medical Care Task Force** also should develop a best practices guideline for addressing health and medical needs of persons with developmental disabilities or acquired brain disorders.

¹³ The Board of Nursing should also be invited to participate on an ad hoc basis.

3-(e) The area agencies, subcontract agencies, and the Bureau should insure that staff and providers receive appropriate training, support, and supervision to implement the procedures and strategies identified in the best practices guideline.

E. *In conducting in-depth reviews, the Committee members looked at the effectiveness of the service coordination activities and concluded that in a great majority of the cases, the service coordination had been effective in regards to advocacy, facilitation, and oversight activities. However, discussions with individual service coordinators also highlighted the need for more comprehensive orientation and training specific to behavioral, psychiatric, and medical issues. In a few cases, the in-depth reviews found that the current regulatory restrictions on having “dual case managers” (one from the developmental services system and another from behavioral health system) created an obstacle for the coordination of clinical services.*

RECOMMENDATION #4:

4-(a) The Service Coordination Supervisors group and the Bureau staff should work with experts from the fields of psychiatry, behavioral supports, and nursing to create training modules to provide service coordinators with effective learning opportunities regarding facilitation of services for individuals’ behavioral, psychiatric, or medical needs.

- The yearly two-day conference for new service coordinators already contains the module *Health and Wellbeing*. This training could be improved through inclusion of new sections on behavioral and psychiatric needs and services.
- Two recent all-day conferences - *Mental Health Aspects of Intellectual Disabilities* and *Effective Crisis Prevention and Intervention Through Cross-System Collaboration and Community Support Planning* - were well attended and received high marks from service coordinators. The area agencies and the Bureau should take steps to build on these latest successes.

4-(b) The High Cost Review Committee agreed that the regulatory restrictions on accessing dual case management be re-examined by the ***Dual Diagnosis Committee***. Staff members who work in developmental services and mental health systems have different levels of clinical training, different skill sets, and unique areas of expertise. The current limitations on having dual case management seem to create gaps in clinical supports for individuals with psychiatric and behavioral issues. The ***Dual Diagnosis Committee*** should review this issue and make recommendations for improving service coordination for individuals who have dual diagnoses.

F. *There was clear consensus within the Committee that the in-depth reviews for a sample group of individuals with high cost service arrangements provided valuable information and insights, both at the individual and the systemic level. The in-depth reviews offered the following benefits.*

- i. *Having an objective third party review gave those who are providing support with another perspective on how services are proceeding and how the individual’s current service arrangement could be improved.*
- ii. *The leadership of the area agencies, subcontract agencies, and Bureau received information to help them identify and address the systemic issues involved in supporting individuals with very significant medical, psychiatric, or behavioral challenges.*

- iii. *Gauging the appropriateness of the individual's budget helped to inform decisions on continued funding, prior authorizations, and revisions for appropriate budget enhancements or reductions.*

RECOMMENDATION #5:

5-(a) Sample in-depth reviews of high cost service arrangements should be done on a regular basis in order to assess individual outcomes and improve the clinical, staffing, and financial aspects of these service arrangements. The statewide *Service Review Advisory Committee* should discuss this idea further and develop a plan for carrying out these reviews. Once the area agencies and the Bureau study and approve the plan the *Service Review Advisory Committee* should implement it.

5-(b) The *Service Review Advisory Committee* should work closely with the area agencies, subcontract agencies, and the Bureau regarding specific individuals with challenging conditions to ensure that supports are better tailored to the individuals' needs and provided within reasonable time frames.

- G. *In a small number of cases, Committee members reviewed arrangements for individuals who, because they posed a risk to community safety, had been placed in out-of-state treatment programs by New Hampshire's Division of Children Youth and Families (DCYF) and local school districts. It was the impression of the reviewers that while these placements had protected community safety, they had not provided the individuals with either effective treatment or the opportunities to developing vocational or other critical life skills.*

RECOMMENDATION #6:

It is recommended that a work group, with representation from the area agencies, subcontract agencies, DCYF, schools, and the Bureau be formed to jointly review the history of out-of-state placements and determine whether there are other alternatives that might yield better results. Some Committee members recommended establishing an in-state intensive treatment program for teens and young adults.

- H. *The Committee's discussion regarding the DCYF referrals highlighted the importance of providing an effective transition process for all young people with disabilities who are aging into the adult service system. Although there have been some improvements in this area, Committee members observed that a more timely and detailed transition planning process would be especially beneficial for individuals with significant needs.*

RECOMMENDATION #7:

A transition work group, consisting of the area agency Transition Coordinators, school personnel and DCYF staff, should review and make recommendations about how to best carry out the transition process from schools and DCYF into the adult service system. As part of its responsibilities, the work group should create a best practices guideline that could be a resource for area agency Transition Coordinators, Family Support Coordinators, and Service Coordinators; DCYF staff; and educators.

- I. *For the last two decades, New Hampshire's area agency system has been committed to supporting people in individualized or small service arrangements (one to three people) and has avoided creating congregate service settings. However, when serving people who have significant medical, behavioral, or psychiatric issues or who pose a risk to community safety, individual service arrangements may not be the most effective option either from a clinical or a financial perspective.*

RECOMMENDATION #8:

The *Service Review Advisory Committee* should examine the appropriateness of individualized and congregate settings when considering proposals for high cost service arrangements. This issue should be considered both at the time of initial approval for services and during periodic reviews of service arrangements.

- J. *In times of crisis individuals who have significant behavioral, psychiatric, or medical needs may need to be hospitalized. During these emergency situations agencies typically encounter a number of difficulties and complications that can be extremely challenging to address, especially if there is no crisis plan in place.*

RECOMMENDATION #9:

The *Service Review Advisory Committee* should require that a crisis plan be part of an individual's service proposal. The plan should provide detailed information about actions to be taken in the case of an emergency and identify the persons/agencies responsible for implementing the plan.

- K. *When the combined Exceptional Medical (EM) and Exceptional Behavioral (EB) SIS scores were arranged in relation to the average combined EM and EB SIS scores, two groupings emerged (See Appendix #6): In the cluster below the mean SIS score, there were three budgets¹⁴ that were higher than the mean budget value of \$146,835 but should have had lower budget amounts based on their associated SIS scores. In the second group, there were three budgets¹⁵ that were lower than the mean budget value of \$146,835 and yet should have had higher budget amounts based on their associated SIS scores.*

During the in-depth reviews, the Committee members identified five situations (out of the total 22 reviewed) where the budget for the individual did not appear to be appropriate for the individual being served.

RECOMMENDATION #10:

It is recommended that the budgets referenced above be carefully reviewed to ensure that they are in line with the needs of the individuals.

- L. *A recent national survey by the Human Services Research Institute (HSRI) looked at high cost developmental services, specifically the percentage of total State funds needed to support the*

¹⁴ These budgets were for individuals with ID codes of 11133185, 11128436, and 11124364.

¹⁵ These budgets were for individuals with ID codes of 11136935, 11134597, 11131098

most costly 5% of service arrangements. (See Appendix #7) While only a small number of states responded to the survey, the results suggest that New Hampshire's cost allocations are in line with what is happening nationally. In New Hampshire 14% of the State's developmental services dollars are used to support this top 5%; for those states responding to HSRI survey, this figure ranged from a low of 13% to a high of 20%, with a median score of 14%.

- M. For the 22 service arrangements that were reviewed in-depth, the Committee found that only slightly more than half provided individuals with meaningful activities, such as employment, volunteer opportunities, constructive community experiences, and visits with family members and friends.

Historically, the lack of opportunities to engage in meaningful activities has been a significant issue for a majority of individuals with disabilities. Social isolation and lack of meaningful engagement is especially acute for individuals with behavioral, psychiatric, or medical challenges. In fact, the absence of meaningful activities in a person's daily life can be the cause of challenging behaviors and can exacerbate underlying psychiatric problems. In contrast, having the support to participate in meaningful activities can improve physical and mental health and reduce challenging behaviors.

RECOMMENDATION #11:

11-(a) In evaluating the proposals for high cost service arrangements, the *Service Review Advisory Committee* should pay particular attention to whether or not individuals are being offered opportunities to engage in meaningful and constructive activities. The *Service Review Advisory Committee* should take an active role to ensure that agencies include supports for the individual to have a productive and meaningful life.

11-(b) The area agency *Training Collaborative* should augment its trainings to assist staff and providers to better support individuals to engage in worthwhile activities and lead meaningful lives.

11-(c) For most adults, employment is a critical component of a meaningful life. The current *Employment Leadership Group* should develop and submit recommendations to the area agencies, subcontract agencies, and the Bureau regarding how to increase and improve employment opportunities and outcomes for individuals who are being served by the developmental services system.

- N. In its work, the High Cost Review Committee identified factors that are critical for successful service outcomes. These included:
- i. Hiring staff and providers, who have the disposition and aptitude to deal with challenges, who appreciate the individual's unique talents, and who have the commitment to work through difficult issues and situations.
 - ii. Providing relevant and ongoing training, support, and supervision for staff and providers.
 - iii. Having a strong family involvement that supports the individual and his/her staff and providers.
 - iv. Recognizing the individual, family, and/or guardian should be included in all aspects of service planning and delivery, and have a primary voice in decisions regarding where, when, and how services are provided.

- v. *Developing and fostering effective communication, collaboration, and trust within the individual's circle of support.*
- vi. *Creating expectations about the individual having a meaningful and productive life.*
- vii. *Providing useful opportunities for the individual to discover personal interests and capacities; learn life, vocational, and social skills; develop independence; and make a contribution.*
- viii. *Customizing supports and services to meet the needs of the individual and family.*
- ix. *Providing appropriate and accessible clinical services.*
- x. *Creating an individualized crisis plan that provides specific direction, information, and assistance to address emergency situations.*
- xi. *Helping those supporting the individual to maintain their persistence, patience, and creativity in the face of difficulties and disappointments.*
- xii. *Ensuring that all stakeholders - the individual, immediate and extended family, relatives, friends and neighbors, schools, community organizations, and government agencies - play a role in the attainment of desired outcomes. This will include blending a variety of personal, programmatic, and fiscal resources and include sufficient funding from the state and federal government.*

IN CONCLUSION

In its findings and recommendations the High Cost Review Committee has identified a number of key issues related to supporting people with significant medical, psychiatric, and/or behavioral needs. The Committee has outlined the critical elements of effective service arrangements for people with significant and complex needs. To attain meaningful outcomes for individuals with disabilities and to get better value from those resources that already have been dedicated, New Hampshire's developmental services system must invest the time, energy, and money needed to bring about the changes recommended in this report.

The Committee realizes that implementing these recommendations will not be a simple matter, as New Hampshire's developmental services system continues to face ongoing challenges, including significant funding limitations and difficulties with workforce recruitment and retention. Nevertheless, the Committee asks that the Division of Community-Based Care, the Bureau of Developmental Services, the area agencies and their subcontract agencies work together to create a detailed plan for improving services and supports to individuals with multiple and significant needs. This plan should include specific goals, timelines, and identify the parties responsible for implementation. In finalizing the plan the Bureau should also seek feedback and suggestions from individuals and families.

When New Hampshire's developmental services system closed the Laconia State School and Training Center almost two decades ago, it made a commitment to provide effective community-based services to *all* individuals with developmental disabilities or acquired brain disorders, including those with significant medical, behavioral, and psychiatric needs. Ensuring that these services are in place is a collective responsibility; policy makers, area agencies, service providers, families, and communities all have a role to play. The High Cost Review Committee is asking for a sustained collaborative effort to implement these recommendations and improve services for New Hampshire's most vulnerable citizens.

APPENDIX #1

Review Committee Membership

John Capuco, Administrator of Brain Injury Services, Bureau of Developmental Services

Brian Collins, Executive Director, Community Partners

Steve Colombo, Director of Nursing, Lakes Region Community Services

Matthew Ertas, Administrator, Bureau of Developmental Services

Alan Greene, Executive Director, Monadnock Developmental Services

Robin Kenney, Consulting Psychologist

Diane Langley, Deputy Director, Division of Community-Based Care Services

Joseph Smith, Director of Family Services, Pathways

Kathleen Stocker, Business Manager, Community Partners

Tim Sullivan, Director, The Institute of Professional Practice

Peter Van Voorhis, Vice President of Community Services, Gateways

APPENDIX #2

Initial Area Agency Survey Items

Demographic Information

Name:
Unique Client Number:
MID:
DOB:
Age:

Medicaid Waiver History

Date of Initial Services:
Initial Total Waiver Cost:
FY 2009 Total Waiver Cost:

FY 2009 Waiver Services Authorized

Day:
Residential:
Service Coordination:
Consolidated:
Specialty Services:
Crisis Response:
DD or ABD:

Provider Agency

Day Services Provider Agency:
Residential Services Provider Agency:

Medical Issues [1 = some supports needed; 2 = extensive supports needed]

Seizure management:
Tube feeding:
Oxygen therapy:
Turning and positioning:
Lifting and transferring:

Behavioral Issues [1 = mild; 2 = moderate; 3 = severe]

Property destruction:
Injuries to others:
Injuries to self:
Sexual aggression:
Fire setting:
Emotional outbursts:

APPENDIX #2

Risk to Community Safety

High risk:

Court order under RSA 171-B:

Psychiatric Issues [1 = mild; 2 = moderate; 3 = severe]

Adjustment disorders:

Anxiety disorders (e.g., PTSD):

Mood disorders (e.g., depression, bipolar):

Eating disorder:

Personality disorder:

Psychosis/Schizophrenia:

Substance abuse disorders:

Other:

Living Situation

Staffed Residence:

Enhance Family Care:

Enhance Family Care with staff:

Other:

Number of individuals living in residence:

Staff Ratios

Residential staff ratio during non-sleep hours:

Residential staff ratio during sleep hours:

Staff ratio during day services:

Institutional Admissions

NHH:

SPU:

SNF:

NF:

Jail/prison:

Hospital:

History of Residential Moves

Number of moves past 5 years:

APPENDIX #3

SERVICE REVIEW CHECKLIST

The following areas/elements are to be looked at as a part of the review:

I. INDIVIDUAL FILE

1. Individual Service Agreement (ISA)
 - Goals related to individual needs and preferences
 - Goals successfully met
 - Progress notes
 - Service satisfaction
 - QA monitoring
2. Evaluations (medical, psychiatric, behavioral, assistive technology, etc.)
 - Yes/No
 - How often done
 - Recommendations
 - Yes/no
 - Implemented
 - Results obtained
3. Medical documents
 - Health record/history
 - Diagnoses
 - Allergies
 - DNR orders, as applicable
 - Advance directives
 - Physicals
 - Medication review list
4. Medical/nursing protocol
 - Procedures/activities staff are directed to perform (e.g., catheter flush)
5. ER visits
 - Number
 - Nature
 - Discharge summaries
6. Hospitalization (Medical/psychiatric)
 - Number of admissions
 - Staff needed during the stay
 - Yes/No
 - Results (better, worse)
 - Needed follow-up has happened
 - Yes/No
7. Behavioral plans
 - Yes/No
 - Human Rights Community approval (HRC)
 - Related HRC minutes/notes
 - How many different plans tried
 - Results of the behavioral plan
8. Staff Training provided
 - Core training

APPENDIX #3

- Behavioral, psychiatric, medical, other (employment, assistive technology)
- Any and all other trainings
- 9. Staffing schedule
- 10. Weekly activity schedule
- 11. Incident reports/investigation results.
 - Including client rights investigations
- 12. Sentinel/high profile event reports
 - Nature of events
 - How many
 - Needed follow-up has happened
 - Yes/No
- 13. Workman's comp frequency
- 14. Results of the adult outcome reports
 - Issues identified for follow-up
 - Closure on the issues
 - Yes/No
- 15. Legal section
 - 911/police calls
 - Number
 - Nature
 - Arrest reports
 - Jail or prison time
 - Number of incarcerations
 - Duration
 - Court orders
 - RSA 171-B petition/commitment
 - Conditional discharges
- 16. Correspondence
- 17. Guardianship
 - Family member or public
 - How active
- 18. Case management notes
- 19. Other items

II. MEDICATIONS

1. Medication List
2. Does it match diagnosis
3. Reviews
 - How often
 - By whom
 - Required follow-up
 - Yes/No
4. Changes
 - How often
 - Results (better, worse, no change)
 - Tracking system
5. How often seen by the MD/ARNP

APPENDIX #3

6. Problems/errors
 - Type
 - Number
 - Required follow-up
 - Yes/No
 - How do nurses deal with errors
7. Other issues

III. CLINICAL RESOURCES

1. Current clinical services
 - Type (OT, PT, etc.)
 - Purpose
 - Frequency
 - Results (better, worse, no change)
 - Who is involved
 - Provision
 - Oversight
 - Local Mental Health
 - Yes/No
 - Accessibility/barriers
 - What is missing
 - How is it paid
2. What has been tried before
 - Type
 - Purpose
 - Frequency
 - Results (better, worse, no change)
 - Who is involved
 - Local Mental Health
 - Yes/No
 - Accessibility/barriers
 - What was missing
 - How was it paid
3. Programs developed by healthcare professions and carried out by DSPs or families
 - Yes/No
 - If yes
 - Describe program
 - Who is involved
 - Who monitors
 - How is it paid
 - Accessibility of services
4. Interventions recommended but not tried
5. ISA references to clinical services
 - Required follow-up
 - Yes/No
6. Other issues

APPENDIX #3

IV. COMMUNITY MENTAL HEALTH CENTER

1. How responsive/helpful regarding
 - Routine requests
 - Crisis situations
2. Interagency agreement
 - Yes/no
 - Working well
3. How often do the leaders from the AA and CMHC meet
4. Barriers
5. What kind of changes would be beneficial
6. How things are different compared to 5/10 years ago.
7. How things have improved
8. How things have deteriorated
9. Other issues

V. OTHER

1. Utilization of generic/natural supports (Family/non-family).
2. How many different agencies serve/have served the person
 - Time frame
3. Number of staff/providers, who have worked with the person during the last 12 months
 - Number of case managers
4. Does the person have alone (unsupervised) time
5. Level of
 - Stability
 - Number of moves
 - Number of DSP turnover
 - Number of EFC provider turnover
 - Number of SC/CM turnover
 - Social connections
 - Productivity
 - Happiness
6. Home and/or vehicle modifications
 - Results
7. Special equipment/Assistive technology
 - Type used
 - Results
 - Needed but not purchased
8. Certification results [last report to BDS liaisons]
9. Being served out of region
 - Reasons
10. Can the person be served in a different service arrangement
11. Individualized budget
12. PA history [from BDS]
13. Acute care costs [from EDS]

APPENDIX # 4

Results of the Support Intensity Scale (SIS) Assessments

DUCK #	DOB	AGE	Lifting Factor	Exceptional Medical Supports Needed	Exceptional Behavioral Supports Needed	Home Living Score	Community Living Score	Lifelong Learning Score	Employment Score	Health and Safety Score	Social Activities Score	Activities Standard Score Total	SIS Support Needs Index
11133120	1/3/1963	46	0	1	2	8	11	8	11	7	9	54	93
11123712	8/17/1965	43	2	4	2	11	13	8	11	9	5	57	96
11128000	10/4/1967	41	2	6	1	15	11	9	9	10	6	60	100
11133185	6/2/1961	48	2	5	2	13	11	10	10	11	9	64	105
11133806	11/6/1985	23	0	3	21	10	12	12	11	10	11	66	107
11134597	7/5/1982	26	2	17	0	13	12	10	10	13	9	67	108
11144469	8/17/1981	27	0	1	11	9	12	12	14	11	12	70	111
11125727	5/11/1943	66	0	2	8	13	10	13	14	11	10	71	113
11128489	12/4/1991	17	0	3	9	12	12	12	12	11	12	71	113
11141368	8/30/1978	30	2	7	8	11	14	13	12	12	10	72	114
11128436	7/15/1954	54	1	4	6	13	11	11	14	12	12	73	115
11127685	8/2/1958	50	0	2	16	12	12	13	13	12	12	74	116
11133368	10/15/1953	55	2	12	0	15	11	13	12	12	12	75	117
11131098	11/11/1968	40	0	0	18	13	12	12	14	13	12	76	118
11131944	3/17/1973	36	0	2	8	13	14	14	13	13	10	77	120
11122481	2/16/1975	34	0	2	18	12	13	13	14	12	14	78	121
11125590	8/2/1978	30	0	3	26	10	14	15	12	14	14	79	122
11136935	6/22/1961	47	2	8	6	12	11	13	14	15	14	79	122
11126209	3/14/1980	29	0	2	14	12	14	15	14	15	14	84	128
11124364	6/4/1923	86	2	10	2	15	14	16	14	15	15	89	133
11141234	11/2/1946	62	1	12	10	16	14	16	14	15	15	90	135
11129255	5/8/1984	25	2	24	0	15	16	16	14	16	15	92	137

APPENDIX # 5

Reviewer Survey

1. The individual's MEDICAL needs are being appropriately met.

Disagree 0.0% 0
Somewhat Disagree 7.7% 1
Somewhat Agree 15.4% 2
Agree 76.9% 10
Don't Know 0.0% 0
Not Applicable 0.0% 0

2. The individual's MEDICATION needs are being appropriately met.

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 0.0% 0
Agree 100.0% 13
Don't Know 0.0% 0
Not Applicable 0.0% 0
If you disagree, please explain. 0

3. The individual's PSYCHIATRIC needs are being appropriately met.

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 15.4% 2
Agree 61.5% 8
Don't Know 0.0% 0
Not Applicable 23.1% 3
If you disagree, please explain. 0

4. The individual's BEHAVIORAL needs are being appropriately met.

Disagree 0.0% 0
Somewhat Disagree 7.7% 1
Somewhat Agree 7.7% 1
Agree 61.5% 8
Don't Know 0.0% 0
Not Applicable 23.1% 3

5. The individual's CLINICAL/THERAPY needs (OT, PT, etc.) are being appropriately met.

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 15.4% 2
Agree 69.2% 9
Don't Know 0.0% 0
Not applicable 15.4% 2
If you disagree, please explain 0

6. The individual's SAFETY needs are being appropriately met.

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 7.7% 1

APPENDIX # 5

Agree 76.9% 10

Don't Know 15.4% 2

Not Applicable 0.0% 0

7. The needed staff resources are readily available.

Disagree 7.7% 1

Somewhat Disagree 0.0% 0

Somewhat Agree 23.1% 3

Agree 69.2% 9

Don't Know 0.0% 0

Not Applicable 0.0% 0

8. Staff turnover has NOT significantly impacted the care of this individual.

Disagree 0.0% 0

Somewhat Disagree 0.0% 0

Somewhat Agree 0.0% 0

Agree 92.3% 12

Don't Know 7.7% 1

Not Applicable 0.0% 0

9. Staff and providers are appropriately trained.

Disagree 0.0% 0

Somewhat Disagree 0.0% 0

Somewhat Agree 7.7% 1

Agree 84.6% 11

Don't Know 7.7% 1

Not Applicable 0.0% 0

10. Ongoing crises and the responses to these crises have NOT had a negative effect on the care and supports for this individual.

Disagree 0.0% 0

Somewhat Disagree 15.4% 2

Somewhat Agree 23.1% 3

Agree 61.5% 8

Don't Know 0.0% 0

Not Applicable 0.0% 0

11. The individual has enjoyed a stable living arrangement for the past five years.

Disagree 7.7% 1

Somewhat Disagree 15.4% 2

Somewhat Agree 7.7% 1

Agree 69.2% 9

Don't Know 0.0% 0

Not Applicable 0.0% 0

12. Meaningful activities are a part of the individual's daily schedule.

Disagree 0.0% 0

Somewhat Disagree 8.3% 1

APPENDIX # 5

Somewhat Agree 25.0% 3
Agree 66.7% 8
Don't Know 0.0% 0
Not Applicable 0.0% 0

13. The individual is offered appropriate employment opportunities.

Disagree 15.4% 2
Somewhat Disagree 0.0% 0
Somewhat Agree 7.7% 1
Agree 30.8% 4
Don't Know 15.4% 2
Not Applicable 30.8% 4

14. The individual is offered appropriate volunteer opportunities.

Disagree 7.7% 1
Somewhat Disagree 7.7% 1
Somewhat Agree 7.7% 1
Agree 30.8% 4
Don't Know 15.4% 2
Not Applicable 30.8% 4

15. Service coordination has been effective in regards to Advocacy, Facilitation, and Oversight.

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 0.0% 0
Agree 100.0% 13
Don't Know 0.0% 0
Not Applicable 0.0% 0

16. Assistive technology has been effectively utilized to enhance the individual's services and life.

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 15.4% 2
Agree 69.2% 9
Don't Know 0.0% 0
Not Applicable 15.4% 2

17. Budget elements are based on the individual's needs and desires and is appropriate.

Disagree 7.7% 1
Somewhat Disagree 15.4% 2
Somewhat Agree 7.7% 1
Agree 61.5% 8
Don't Know 7.7% 1
Not Applicable 0.0% 0

APPENDIX # 5

18. The area agency's initial rating of the individual's MEDICAL status is consistent with my findings and observations.

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 0.0% 0
Agree 100.0% 13
Don't Know 0.0% 0
Not Applicable 0.0% 0

19. The area agency's initial rating of the individual's BEHAVIORAL status is consistent with my findings and observations.

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 0.0% 0
Agree 100.0% 13
Don't Know 0.0% 0
Not Applicable 0.0% 0

20. The area agency's initial rating of the individual's PSYCHIATRIC status is consistent with my findings and observations

Disagree 0.0% 0
Somewhat Disagree 0.0% 0
Somewhat Agree 0.0% 0
Agree 92.3% 12
Don't Know 7.7% 1
Not Applicable 0.0% 0

21. The SIS score (based on maximum score possible) appears consistent with my overall findings and observations.

Disagree 0.0% 0
Somewhat Disagree 7.7% 1
Somewhat Agree 0.0% 0
Agree 84.6% 11
Don't Know 7.7% 1
Not Applicable 0.0% 0

23. The individual/guardian seems to be happy with the service arrangement.

Disagree 0.0% 0
Somewhat Disagree 7.7% 1
Somewhat Agree 15.4% 2
Agree 76.9% 10
Don't Know 0.0% 0
Not applicable 0.0% 0

APPENDIX # 7



INFORMATION BRIEF

**What Percentage of the Waiver Budget Do
The 5% Most Expensive People Require?**

December 18, 2009

Prepared by:

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7420 SW Bridgeport Road (#210)
Portland, OR 97224

On Behalf of:

2009 NASDDDS Annual Conference

Summary

HSRI asked the question of states with no one or less than 100 people in residential institutions what percentage of their waiver budget in FY09 the 5% more expensive individuals required. We will update these results whenever possible.

Results

HI 20%

WI 18%

WY 15%

VT 14%

NH 14%

NM 13%

ME 13%

MI 13% (1/4 of state)

DC 13%