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**THE NEW HAMPSHIRE BRAIN AND SPINAL CORD  
INJURY ADVISORY COUNCIL**

2011 ANNUAL REPORT TO THE GOVERNOR,  
LEGISLATURE, AND THE DEPARTMENT OF HEALTH AND HUMAN SERVICES



November 2011

**The New Hampshire Brain and  
Spinal Cord Injury Advisory Council  
2011 Report to the Governor and Legislature**

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## EXECUTIVE SUMMARY

The Advisory Council is charged by the New Hampshire Legislature with investigating the unmet needs of New Hampshire residents with brain and spinal cord injuries. See RSA 137:K. It is comprised of a diverse group of professionals, legislators, and survivors or relatives of survivors of brain and spinal cord injuries. Public hearings are held by the Advisory Council each year pursuant to its statutory charge for the purpose of identifying gaps in services that cause these unmet needs for the subject population.

Brain injuries can be devastating life altering events that cause such things as cognitive deficits, physical weakness or paralysis, and communication deficits which in turn can result in joblessness and homelessness. It can further put a strain on family relationships due to the overall mental impact of such an injury. Similarly, spinal cord injuries can have a devastating effect on the life of a survivor of such an injury and the family members. The devastating effects of these types of injuries and the plethora of new needs that arise after such injuries were the two main bases for creating the Brain and Spinal Cord Injuries Statute. See RSA 137-K: 1-a (detailing statutory purpose).

The Advisory Council held two public hearings for purposes of identifying unmet needs. The first hearing was held on May 19, 2011 at St. Joseph's Hospital in Nashua. The second public hearing was held on October 18, 2011 at Granite State Independent Living in Concord, New Hampshire.

The testimony at the public hearings indicated that there are several areas of the service system that raise concerns. These areas included the improper reduction of services that have resulted from NH Medicaid's recent use of managed care for prior authorizations, the lack of quality primary care for the subject population, the lack of adherence to patient rights by the medical profession, the insufficient numbers of post-injury centers, insufficient transportation for the subject population and the overall insufficient funding for services for individuals with brain and spinal cord injuries.

Based upon its 2011 investigation, the Advisory Council recommends:

- **Reexamine the efficacy of implementing a managed care model;**
- **Increase funding for services through a trust fund;**
- **Improve the quality of discharge/transition services and information provided to patients;**
- **Improve medical professionals' knowledge of the medical issues faced by individuals with brain injuries and spinal cord injuries;**
- **Improve professionals' and survivors' understandings of patient rights and strengthen rights;**
- **Improve informed consent procedures and/or application of informed consent procedures;**
- **Create a fund for post-injury centers that would operate similar to the Krempels Center in Portsmouth, NH; and**
- **Examine the efforts to improve public transportation and why those efforts have failed.**

## **I. Brain and Spinal Cord Injuries**

In 1997 the legislature enacted Chapter 137-K in the New Hampshire Revised Statutes Annotated, titled “Brain and Spinal Cord Injuries.” As stated in RSA137-K:1

“The purpose of this chapter is to support injury prevention efforts and to help meet the needs of individuals who have sustained brain and spinal cord injuries, who would otherwise be dependent on the public for their care and rehabilitation.”

That legislation created the New Hampshire Brain and Spinal Cord Injury Advisory Council. RSA137-K:2. In 2002, the legislature created a brain injury program. RSA 137-K:9.

### **A. The Advisory Council**

The Brain and Spinal Cord Injuries statute created the New Hampshire Brain and Spinal Cord Advisory Council within the Department of Health and Human Services. RSA 137-K:2. The Advisory Council is the mechanism established by the legislature for implementing the purpose of the statute.

The Advisory Council began because individuals and families who experience brain injuries and spinal cord injuries almost always know very little about how to live a life with such a devastating injury. In 1997, the issue of how to approach moving forward with one’s life after such an injury was a black hole. Thus, the Advisory Council was formed to obtain input about where needs were not being met or were being insufficiently met.

### **B. Advisory Council’s Charge**

The Advisory Council is charged with the following primary functions:

- Meet at least quarterly;
- Investigate and identify the unmet needs of citizens with brain and spinal cord injuries, including identifying gaps in services;
- Hold a minimum of two public hearings annually in different regions of the State to generate input on unmet needs;
- Issue a yearly report on unmet needs to the Governor, the Speaker of the House, the Senate President, and the Commissioner of the Department of Health and Human Services;
- Consider the feasibility of establishing a brain and spinal cord injury trust fund; and
- Review the status of the brain injury program and make recommendations to the Commissioner.

## **II. Advisory Council Membership**

A. The Advisory Council is made up of the following voting members:

- One Senate member appointed by the Senate President;
- One House member appointed by the Speaker of the House;
- Four members appointed by the Governor, two of whom are survivors, and two of whom are family members;
- Two members appointed by the Governor, from the professional community, one of whom shall be in a neurological specialty;
- One member representing the bureau of vocational rehabilitation, appointed by the Commissioner of Education;
- One member appointed by the Commissioner of the Department of Health and Human Services who is involved in injury prevention;
- Two members appointed by the Brain Injury Association of New Hampshire;
- Two members appointed by the Spinal Cord Injury Association;
- One member appointed by the Commissioner of Education, who is an educator.

**B. The current voting membership includes:**

- Senate representative: vacant.
- House representative: vacant.
- Survivor and family representatives: Newton Kershaw, James Fox, Thad Mandsager and Jenifer Evans.
- Vocational Rehabilitation representative: James Piet.
- Professional Community representatives: Debbie Krider, and neurological specialty is vacant.
- Injury prevention representative: Rhonda Siegel.
- New Hampshire Brain Injury Association representatives: Laurie Boyce and Brandy Rhorer.
- New Hampshire Spinal Cord Injury Association representatives: Mark Race and Clement Izzy.

**C. Ex-Officio non-voting members of the council include:**

- Commissioner, Department of Health and Human Services, or any division administrator.
- Chief, Special Education Bureau, Department of Education.
- Administrator, Division of Vocational Rehabilitation, Department of Education.
- President or Executive Director, Brain Injury Association of New Hampshire, currently Steve Wade.
- President or Executive Director, New Hampshire Spinal Cord Injury Association.
- Administrator, Brain Injury Services, Division of Developmental Services, Department of Health and Human Services, currently John Capuco, Ph.D.

- Administrator, HCDC/ECI Waiver, Division of Elderly and Adult Services, Department of Health and Human Services, currently Diane Langley.
- President or Executive Director, Granite State Independent Living, currently Clyde Terry.
- President or Executive Director, New Hampshire Developmental Disabilities Council.
- Representatives of related agencies or organizations, as approved by the Council, currently Paul Van Blarigan, chair of the Governor's Commission on Disability; Julia Freeman-Woolpert, representing the Disabilities Rights Center; Ellen Edgerly, representing the New Hampshire Brain Injury Association.
- Others, not in any official capacity: Brant Elkind, past president of the Advisory Council; Ted King, M.D.

### **III. Brain Injury and Spinal Cord Injury in New Hampshire**

#### **A. Definition and effects of brain injuries**

##### **1. Definition of Brain Injury**

Acquired brain disorder is the term used in New Hampshire in connection with the establishment and operation of the New Hampshire area agencies. That term is defined in State Regulation He-M505.02(a). That definition provides that an acquired brain disorder (ABD):

- cannot be congenital or caused by birth trauma;
- must present a severe and lifelong disabling condition which significantly impairs a person's ability to function in society;
- must occur prior to age 60;
- must be manifested by significant decline and cognitive function or ability and/or deterioration in personality, impulse control, judgment, modulation of mood, or awareness of deficits;
- ABD must be attributable to
  - external trauma (a traumatic brain injury or TBI);
  - anoxic or hypoxic injury to the brain such as from cardiopulmonary arrest, carbon monoxide poisoning, airway obstruction, hemorrhage, or near drowning;
  - infectious diseases such as encephalitis and meningitis;
  - other neurological disorders such as Huntington's Disease or Multiple Sclerosis which predominantly affect the central nervous system;
  - brain tumor;
  - intracranial surgery;
  - cerebral vascular disruptions such as a stroke, or
  - toxic exposure.

ABD can result in short or long-term problems with independent function. 1.4 million people sustain traumatic brain injuries each year in the United States.

The leading causes of traumatic brain injury include falls (28%), motor vehicle accidents (20%), struck by/against events (19%) and assaults (11%). Blasts are a leading cause for TBI in military personnel. Children between the ages of 0-4 and teens between 15 and 19 years old are at the highest risk of sustaining TBI's. Americans paid approximately \$60 billion in 2000 for medical and disability-related costs related to traumatic brain injury.

A stroke, or cerebrovascular accident (CVA), occurs when the blood supply to part of the brain is disrupted, or there is a bleed in the brain, causing brain cells to die. Strokes may be caused by a blockage of an artery (ischemic

stroke) or the rupture of a blood vessel (hemorrhagic stroke). About 795,000 Americans each year incur a new or recurrent stroke. On average, a stroke occurs every 40 seconds in the U.S. Stroke kills more than 137,000 people a year, and accounts for about 1 of every 18 deaths in the U.S. Stroke is the third leading cause of death and the leading cause of disability in the U.S. Someone dies of a stroke, on average, every 4 minutes in the U.S. Americans will pay about \$73.7 billion in 2010 for stroke-related medical costs and disability.

## 2. **Effects of Brain Injury**

- **Physical** – May include paralysis or weakness (often on one side of the body only), reduced joint mobility, changes in muscle tone, difficulty swallowing (dysphagia), decreased sensation, poor balance, difficulty with mobility such as walking and getting out of bed, physical fatigue, seizures and other physical deficits.
- **Cognitive** – May include difficulty with thought processes such as impaired memory, difficulty problem-solving, impaired attention, impulsivity, delayed processing skills, mental fatigue, loss of previous personal identity and more.
- **Communication** – Some brain injury survivors experience difficulties with communication. These problems may be related to aphasia, a communication disorder that impairs the ability to speak and/or understand others and may also affect one's ability to read and write. Dysarthria (muscle weakness in the orofacial muscles) may also affect one's ability to speak clearly.
- **Visual-Perceptual** – May include double vision, visual field cuts, one-sided neglect, impaired senses (hearing, taste, smell, touch etc.) etc.
- **Emotional and Social** – May include loss of employment, homelessness, financial hardship, low self-esteem/confidence, depression, social isolation, difficulty controlling emotions (liability), anxiety, difficulty with social interactions and relationships, loss of independence etc.
- **Family** – Financial hardship, loss of employment because of caregiving roles, caregiver fatigue and stress, emotional and mental health impacts on caregivers.

## B. **Definition and Effects of Spinal Cord Injuries** (Source: Information Provided by the National Institutes on Health; Foundation for Spinal Cord Injury Prevention, Care, and Cure; and National Spinal Cord Injury Statistical Center.)

### 1. **Definition of Spinal Cord Injury**

Although the hard bones of the spinal column protect the soft tissues of the spinal cord, vertebrae can still be broken or dislocated in a variety of ways and cause traumatic injury to the spinal cord. Injuries can occur at any level of the spinal cord. The segment of the cord that is injured, and the severity of the injury, will determine which body functions are compromised or lost. Because the spinal cord acts as the main information pathway between the brain and the rest of the body, a spinal cord injury can have significant physiological consequences.



Most injuries to the spinal cord don't completely sever it. Instead, an injury is more likely to cause fractures and compression of the vertebrae, which then crush and destroy the *axons*, extensions of nerve cells that carry signals up and down the spinal cord between the brain and the rest of the body. An injury to the spinal cord can damage a few, many, or almost all of these axons. Some injuries will allow almost complete recovery. Others will result in complete paralysis.

## 2. Effects of Spinal Cord Injury

- **Total Number of Injured:** A quarter of a million Americans are currently living with spinal cord injuries.
- **Number Injured Each Year:** There are an estimated 10,000 to 12,000 spinal cord injuries every year in the United States.
- **Yearly Cost:** The cost of managing the care of spinal cord injury patients approaches \$4 billion each year.
- **Occupational status:** More than half (57.5%) of those persons with SCI admitted to a Model System reported being employed at the time of their injury. At post injury year 1, 11.5% of persons with SCI are employed. By post injury year 20, 35.4% are employed and a similar level of employment is observed through post injury year 30.
- **Residence:** Today 87.8% of all persons with SCI who are discharged alive from the system are sent to a private, noninstitutional residence (in most cases their homes before injury.) Only 5.7% are discharged to nursing homes. The remaining are discharged to hospitals, group living situations or other destinations.
- **Marital status:** Considering the youthful age of most persons with SCI, it is not surprising that most (52.3%) are single when injured. Among those who were married at the time of injury, as well as those who marry after injury, the likelihood of their marriage remaining intact is slightly lower when compared to the general population. The likelihood of getting married after injury is also reduced.
- **Lifetime costs:** The average yearly health care and living expenses and the estimated lifetime costs that are directly attributable to SCI vary greatly according to severity of injury.

Severity of Injury	Average Yearly Expenses (in 2008 dollars)		Estimated Lifetime Costs by Age At Injury (discounted at 2%)	
	First Year	Each Subsequent Year	25 years old	50 years old
High Tetraplegia (C1-C4)	\$801,161	\$143,507	\$3,160,137	\$1,860,390
Low Tetraplegia (C5-C8)	\$517,356	\$58,783	\$1,786,836	\$1,131,560
Paraplegia	\$292,740	\$29,789	\$1,055,869	\$720,169
Incomplete Motor Functional at Any Level	\$236,109	\$16,547	\$704,344	\$510,452

These figures do not include any indirect costs such as losses in wages, fringe benefits and productivity which average \$64,443 per year in December 2008

dollars, but vary substantially based on education, severity of injury and pre-injury employment history.

- **Life expectancy** is the average remaining years of life for an individual. Life expectancies for persons with SCI continue to increase, but are still somewhat below life expectancies for those with no spinal cord injury. Mortality rates are significantly higher during the first year after injury than during subsequent years, particularly for severely injured persons.

		Life expectancy (years) for post-injury by severity of injury and age at injury									
		For persons who survive the first 24 hours					For persons surviving at least 1 year post-injury				
Age at Injury	No SCI	Motor Functional at Any Level	Para	Low Tetra (C5-C8)	High Tetra (C1-C4)	Ventilator Dependent at Any Level	Motor Functional at Any Level	Para	Low Tetra (C5-C8)	High Tetra (C1-C4)	Ventilator Dependent at Any Level
20	58.8	52.6	44.8	39.8	35.3	18.1	53.0	45.5	40.8	36.9	25.1
40	39.9	34.1	27.3	23.1	19.6	8.0	34.5	27.9	23.9	20.8	12.2
60	22.5	17.7	12.7	9.8	7.6	1.8	18.1	13.1	10.3	8.4	3.6

- **Cause of death:** In years past, the leading cause of death among persons with SCI was renal failure. Today, however, significant advances in urologic management have resulted in dramatic shifts in the leading causes of death. Persons enrolled in the National SCI Database since its inception in 1973 have now been followed for 35 years after injury. During that time, the causes of death that appear to have the greatest impact on reduced life expectancy for this population are pneumonia, pulmonary emboli and septicemia.

#### **IV. Public Hearings in 2011**

The Advisory Council held two public hearings for purposes of identifying unmet needs. The first hearing was held on May 19, 2011 at St. Joseph's Hospital in Nashua. Council member Clem Izzi was the public hearing coordinator. Mr. Izzi is a paraplegic and is also blind. There were 17 attendees at the Nashua Public Hearing, 6 of whom were from the Council and 2 of whom were from the Governor's Commission on Disability.

A second public hearing was held on October 18, 2011 at Granite State Independent Living in Concord, New Hampshire. Jenifer Evans was the public hearing coordinator. She is an active member of the Brain and Spinal Cord Injury Advisory Council and the Concord area brain injury support group. At the Concord Public Hearing there were 29 attendees, 8 of whom were from the Council. The following public hearing notices were disseminated to advertise the public hearings. The two public hearing notices are attached as Exhibit A.

At the public hearings, there was wide ranging discussion, including significant discussion of The Krempels Center at the Concord hearing. The following items are an attempt to articulate and highlight issues presented at the hearings along with issues known to council members.

##### **1. Lack of Discharge Planning at Medical Facilities and Lack of Coordination of Information Among Providers.**

Individuals with both brain injuries and spinal cord injuries felt that they were not provided with sufficient discharge planning by rehabilitation facilities and acute care facilities in regard to services that are available post-discharge.

One participant stated that there was a problem with the lack of awareness on the part of professionals and rehabilitation centers on the need to relay information on available services to individuals with brain injuries. This particular individual only found out about New Hampshire's Krempels Center when he happened to meet a University of New Hampshire student on a walk and the student informed him of the existence of the Krempels Center which is a center devoted to supporting individuals with brain injuries by assisting with post-rehabilitation needs. The center is a non-profit organization that was started by a brain injury survivor, David Krempels, and provides a model of what can be done post-rehab to assist individuals with brain injuries. Another participant stated that he was told to just do what he wanted.

Further, once a survivor or survivor family is able to locate some services, there is a perception that there is a proprietary mentality in New Hampshire which results in organizations being resistant to sharing information. There was also a concern that some of the information that was shared as to other possible providers of services wasn't quality information and/or that due to a lack of resources individuals are simply directed from one agency to another without obtaining any actual assistance. This lack of quality information would result in survivors and survivor families making a plethora of phone calls that would result in little useful information or in unreturned calls.

## **2. Patient's Rights**

Participants indicated that physicians are not receptive to providing medical care to a brain injury survivor once the physician becomes aware the person is a survivor of a brain injury. The physicians became intolerant of behavioral issues and move to discharge the person as a patient. One participant indicated that he had been through several physicians and keeps getting dropped due to intolerance. The physicians do not appear to have accommodated behavioral issues that arise out of a brain injury. This is the case even though physicians' offices are subject to Title III of the Americans with Disabilities Act and Section 504 of the Rehabilitation act of 1973. They have been subject to the latter for almost forty years. Participants further indicated that they were concerned about bringing up protected rights because "[t]he more rights you bring up the dirtier you get treated."

## **3. Quality of Primary Care Physician Services**

The input received by the Advisory Council was that there is a lack of knowledge in the medical community as to the issue of both brain injuries and spinal cord injuries.

As one participant stated, "my husband was hit in the head, leg and shoulder by a tree branch. The medical professionals spent all their time on the leg and shoulder and totally ignored the head." There were many similar statements regarding the lack of medical knowledge among physicians in terms of brain injuries. One participant put it bluntly as to the need for increased awareness in the medical profession about brain injuries by stating "people in the medical field need to understand that we are a different bunch."

It was felt that this potential lack of knowledge regarding the best medical practices in the area of brain injuries resulted in such things as: (1) lack of proper diagnosis of brain injury; (2) overmedication of individuals with brain injuries; (3) the misdiagnosis of mental illness; and/or (4) the failure to diagnose any injury.

Participants felt that they would be misdiagnosed with depression and prescribed antidepressants. Overmedication and improper medication was a concern of all present. As one participant stated "I can't tell you how many medications that I have been on. After looking at them I realize that I should not be on them. I feel that I might be overmedicated." This statement at a minimum indicates a lack of communication from physician to patient on what is being prescribed and for what reason. It has been documented that overprescribing medications can cause a decrease in life expectancy and quality.

This knowledge based problem is also present as to spinal cord injuries. One participant stated that his primary care physician did not realize that individuals with complete injuries do not have reflexes in the affected area. This demonstrates the lack of basic knowledge of spinal cord injuries. There is further a lack of knowledge on how to address such things or provide guidance on simple things such as pain management for post-paralysis pain. There is also a lack of upfront information regarding potential medical issues that can be faced by individuals with paralysis and ways to prevent those issues from causing devastating injuries such as skin sores.

#### **4. Difficulty Enforcing Patient's Bill of Rights as to Home Health Care Services.**

A participant brought up a concern regarding protections for survivors of both brain injuries and spinal cord injuries as to home health care providers. The New Hampshire Patient's Bill of Rights provides certain standards that home health care providers must meet. For example, it provides that a facility shall not transfer or discharge a patient except for a limited number of reasons. It goes on to provide procedural requirements that must be followed prior to discharging or transferring a patient. All facilities must abide by these requirements. Facility is defined as any hospital, or other facility, building, residence, or other place or part thereof, licensed under the provisions of RSA 151:2. RSA 151:2 provides that the following facilities shall not be established, conducted, or maintained without acquiring a license under this chapter: . . . (b) home health care providers. Thus, home health care providers are facilities for purposes of the Patients' Bill of Rights and home health care providers should comply with such things as discharge standards. Unfortunately, there are some home health care providers who do not adhere to the discharge standards. This puts severely disabled individuals with brain injuries and spinal cord injuries at risk for being abandoned and facing either severe medical risk or having to be institutionalized in a nursing home.

#### **5. Krempels Center**

There was unanimity among participants that the post rehabilitation programs offered by the Krempels Center in Portsmouth, New Hampshire are an invaluable asset to individuals with brain injuries. The Krempels Center was founded by David Krempels. Mr. Krempels was injured in a motor vehicle accident and received a damages award from a jury in Maine federal court. Mr. Krempels provides the following description of the Krempels Center.

Welcome to the Krempels Center. My name is David Krempels, and like many of you, I survived a severe traumatic brain injury. I am honored to have my name attached to this organization that four friends helped me start in 1995. It is something really good that came out of the incredible heartbreak of my own experience with traumatic brain injury.

If you are in the Portsmouth, NH area, please visit us. If you are part of the larger brain injury community of survivors, families, caregivers, and friends everywhere, we hope you will stay in touch online. We're all in this together. I want to share my story as a message of hope. Every story is tragic. Life will never be the same. But it can be good again.

For 15 years, I poured a ton of money and all my passion into building this organization. Our mission mirrored my own needs after my brain injury. At first, we made small grants to help relieve immediate financial crises. Gradually we realized that there were even more lasting and paralyzing needs of survivors and their families – isolation, depression, despair. The Krempels Center evolved to provide a physical space where survivors and families could come together for companionship, encouragement, opportunities, and hope.

The organization has flourished beyond my wildest dreams. We are a close, honest, vital, heart-driven community that draws energetic interns from area universities and dynamic volunteers from the region. Our programs and research are pushing the frontiers of what's possible post rehab. Everyone associated with the organization – our team of staff, volunteers, consultants, the Board of Directors – brings exceptional compassion, enthusiasm, and professionalism.

With our programs well-established, my last years as Board President were focused on securing our future. It's a huge challenge: how can we guarantee that these essential services are available to the next generation ... and the next? So much depends on public understanding and support. Over time, we've attracted funders and community leaders to establish a solid financial base and strengthen our team. It has been a relief and a pleasure to pass this sound and vibrant organization to new, capable leadership.

Participants overwhelmingly indicated that the Krempel Center's model is one that provides invaluable assistance to individuals with brain injuries in the Portsmouth, New Hampshire area. The frustration among the participants is that the Krempel Center's model is not available in any other part of New Hampshire and survivors who are unable to drive have a difficult time accessing the Center's programs.

## **6. Managed Care**

New Hampshire is moving more-and-more to a managed care system. There was a fear among participants that the increased use of managed care in New Hampshire will result in an increase of improper denials of essential services and the corresponding need to engage in legal battles to keep essential services. Some participants indicated that they had never received the hours of care they were entitled to and, if anything, hours have already been reduced. The fear is that managed care will result in further reductions.

New Hampshire Medicaid's prior authorization system is already using a managed care system. The implementation of that system resulted in the New Hampshire Medicaid hiring Schaller Anderson as its third party administrator to determine whether to authorize service requests that require prior authorization. Schaller Anderson has reduced Medicaid costs by denying valid claims that provide services to the most severely disabled in the name of reduced costs. [footnote?] There was a justifiable fear that managed care will result in an expansion of this practice.

New Hampshire has passed a new law regarding Medicaid managed care, sometimes referred to as Senate Bill 147. The prospect of the new law has generated significant concerns that these changes may result in cost management that deteriorates outcomes. As may be evident from the above discussion, the Advisory Council is particularly concerned to make sure that brain injured individuals are enabled to be cared for in the communities and not in an institutionalized setting, nor with resulting homelessness. The Advisory Council's concerns are especially heightened by its realization that the brain injured constituency is exceedingly vulnerable, and particularly subject to discrimination when they do not appear to be disabled.

## **7. Lack of Effective Communication**

Regardless of the topic discussed, there was a common thread of a lack of information being available. As one participant stated “my main concern . . . is not getting information.” This concern was part of a frustration with everyone from medical providers to potential employers in regard to the issue of effective communication. It involved such things as not being informed of when programs would end to not being provided assistance with filling out employment applications that a survivor of a brain injury could not fill out without assistance. This communication gap exemplifies the need for more public awareness of the need to communicate effectively with individuals with cognitive deficits and also of the legal requirements under the Americans with Disabilities Act and Section 504 of the Rehabilitation act of 1973 that most entities interacting with individuals with disabilities provide effective communication.

## **8. Transportation.**

The lack of transportation was discussed as a persistent problem. There is simply little to no viable public transportation for the substantial population of individuals with brain and spinal cord injuries who are not able to drive due to their cognitive and physical limitations. When one participant was asked what he does all day due to the lack of transportation, he stated, “I sit in my house all day.” Thus, the results of the lack of transportation are that a lot of individuals who have fought to recover to the point of being able to be contributing members of society are homebound. They are unable to take advantage of many of things in a community that most of people take for granted like going for groceries or going out for dinner.

And in places where accessible public transportation does exist, the bus schedules are not always written in an easy to understand format. Such a basic formatting problem can result in individuals with cognitive impairments not being able to use the public transportation system at all.

## **9. General Lack of Funding**

The other common thread in terms of unmet needs is the simple lack of funding for essential programs from needed Medicaid services to places such as the Krempels Center. A lack of financial support is a major hurdle faced by both individuals with brain injuries and individuals with spinal cord injuries.

## V. Recommendations

- A. **Reexamine the Efficacy of Implementing a Managed Care Model.** The consensus among participants was that the managed care model is likely to result in the loss of needed services for individuals with disabilities, including brain injuries and spinal cord injuries. The negative effects of managed care are already being seen in Schaller Anderson's administration of prior authorizations for New Hampshire Medicaid. The State should reexamine whether the managed care model is consistent with right to medically necessary treatment for this vulnerable population.
- B. **Improved Systems for Acute Care and Rehabilitation Facilities to provide Quality Transition Information.** An important step in returning to society as quickly and successfully as possible is knowledge of assistance that is available. There should be a uniform system that provides this valuable information at the early acute care and rehabilitation stages.
- C. **Improved Knowledge by Medical Professionals of Medical Issues Faced by Individuals with Brain injuries and Spinal Cord Injuries.** Medical personnel should be encouraged to improve their knowledge in the area of brain injury and spinal cord injuries to understand things like the fact that a brain injury is not a mental health issue. The lack of understanding of the medical issues surrounding brain injuries and spinal cord injuries can lead to disastrous medical complications, whereas improved knowledge can facilitate effective treatment and community integration.
- D. **Increased Funding for Services through the Establishment of a Trust Fund.** Many of the needs of individuals with brain injuries and spinal cord injuries require funding. One of the Advisory Council's charges is to evaluate the feasibility of a trust fund to assist individuals with brain injuries and spinal cord injuries. The need for such a fund has never been greater as budgets of state agencies are being reduced.
- E. **Improved Understanding By Professionals and Survivors of Patient Rights.** The Americans with Disabilities Act and similar laws have protected individuals with disabilities against discrimination for decades. Yet some professionals in the medical industry still fail to adhere to these protections. Thus, there needs to be increased efforts to raise awareness, particularly in the medical field. This may require legislative action to amend New Hampshire's law against discrimination to address these important issues.
- F. **Improved Informed Consent Procedures and/or Application of Informed Consent Procedures:** All medications have risks and these should always be explained and monitored by medical professionals for any individual who is being asked to begin taking a medication.



- G. Funding for programs similar to Krempels Center.** As detailed above, the Krempels Center is a valuable resource post-rehabilitation to help improve recovery of individuals with brain injuries. State funding of similar Centers throughout New Hampshire likely go a long way toward ensuring that the unique needs of individuals with brain injuries are met.
- H. Examination of Efforts to Improve Transportation and Why Those Efforts have Failed.** The transportation problem has yet to be resolved. The issue of why things have not progress more quickly should be examined.

## **VI. Brain and Spinal Injury Advisory Council Meeting Minutes**

Meeting minutes for meetings which took place December 13, 2010, March 14, 2011, June 13, 2011, and September 7, 2011 are attached as Exhibit B.

## **VII. Conclusion**

On behalf of the Brain and Spinal Cord Injury Advisory Council, this report is submitted with respect to the Advisory Council's work up to November 1, 2011.

Newton H. Kershaw, Jr., Co-Chair

James Fox, Co-Chair

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