Illinois Department of
PUBLIC HEALTH

Pat Quinn, Governor
LaMar Hasbrouck, MD, MPH, Director

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May 2014

TO: The Honorable Pat Quinn, Governor
The Honorable John J. Cullerton, Senate President
The Honorable Christine Radogno, Senate Minority Leader
The Honorable Michael J. Madigan, Speaker of the House
The Honorable Tom Cross, House Minority Leader

FROM: LaMar Hasbrouck, MD, MPH
Director, Illinois Department of Public Health

SUBJECT: Expert Review Recommendations regarding Conducting a Feasibility Study for the Construction of the Brain Medicine Institute and Education-Research Center of Excellence

At the request of the Governor's Office and the Office of the Speaker of the House of Representatives, the Illinois Department of Public Health convened an Expert Review Committee in 2013, to consider the question of whether or not the state of Illinois should pursue and fund a feasibility study exploring the construction of The Brain Medicine Institute and Education-Research Center of Excellence.

The committee included representatives with experience working with relevant patient populations and was drawn from numerous clinical and administrative disciplines, as well as representatives from related state agencies and the Illinois General Assembly. The committee met in January, July and September of 2013, and conducted a fact-finding survey among its members between its first and second meetings.

This report is available on the IDPH website at: http://www.idph.state.il.us/pub_home.htm. For additional copies of this report or for more specific information about any of the items, please contact IDPH's Division of Governmental Affairs, at 217-782-4977.

This report will also be shared with the Brain and Spinal Cord Injury Council within the Department of Human Services in order to further its mission which includes recommending appropriate preparation, training, retraining and distribution of manpower and resources in the provision of services to spinal cord and head injured persons; and recommending specific methods, means and procedures which should be adopted to improve and upgrade the State's service delivery system for spinal cord and head injured citizens of this State.

Enclosure

cc: Tim Anderson, Secretary of the Senate
Tim Mapes, Clerk of the House
Legislative Research Unit State Government Report Center

State of Illinois
Illinois Department of Public Health

Brain Injury Expert Panel Report to the Illinois General Assembly - Assessment of a Proposal to Conduct a Feasibility Study for the Construction of a Brain Medicine Institute and Education-Research Center of Excellence

May 2014

Illinois Department of PUBLIC HEALTH

Brain Injury Expert Panel Report: Assessment of a Proposal to Conduct a Feasibility Study for the Construction of a Brain Medicine Institute and Education-Research Center of Excellence

Executive Summary

At the request of the Office of the Governor and the Office of the Speaker of the House of Representatives, the Illinois Department of Public Health convened an Expert Review Committee to consider the question of whether or not the state of Illinois should pursue and fund a feasibility study exploring the construction of The Brain Medicine Institute and Education-Research Center of Excellence. The center, proposed by Dr. Ricardo Senno and state Representative Cynthia Soto, would combine clinical and research facilities dedicated to a wide- range of neurological issues, including acute brain injury; acute disorders, such as stroke and aneurism; progressive diseases, such as Alzheimer's and Parkinson's; and chronic neuropsychological conditions, such as autism.

The committee was appointed by Dr. LaMar Hasbrouck, state health director, and included three members recommended by Dr. Senno, with the balance of members representing a broad cross section of the provider and advocacy community versed in the subject matter. The committee included representatives working with relevant patient populations drawn from numerous clinical and administrative disciplines. The committee also included representatives from related state agencies and from the Illinois General Assembly. The committee met in January, July and September of 2013, and conducted a fact-finding survey among its members between its first and second meetings.

The committee opted to examine the question put before it using a needs-based framework: Identify the current deficits in care faced by relevant patient

populations and determine would the proposed facility address these deficits sufficiently to merit the use of state funding to conduct a feasibility study.

The committee identified a number of critical issues related to care in these patient populations, notably:

- **Poor infrastructure for continuum of care:** The committee explored numerous challenges related to coordinating care for this patient population as they moved among emergency, in-patient, outpatient and rehabilitative care settings. In general, the committee found existing mechanisms for handoff and maintenance of patient care to be inadequate and sometimes difficult to access.
- **Inadequate reimbursement:** The committee discussed numerous examples in which the existing payment system does not reimburse providers for aspects of care coordination and handoff critical to meeting the needs of patients. In addition, the committee discussed the ways in which federal patient-mix requirements for rehabilitation facilities provide a disincentive for those facilities to accept some patients within this population.
- **Access to information resources:** The committee discussed the challenges of finding appropriate facilities and services for patients given the lack of a centralized knowledge-base of available resources.

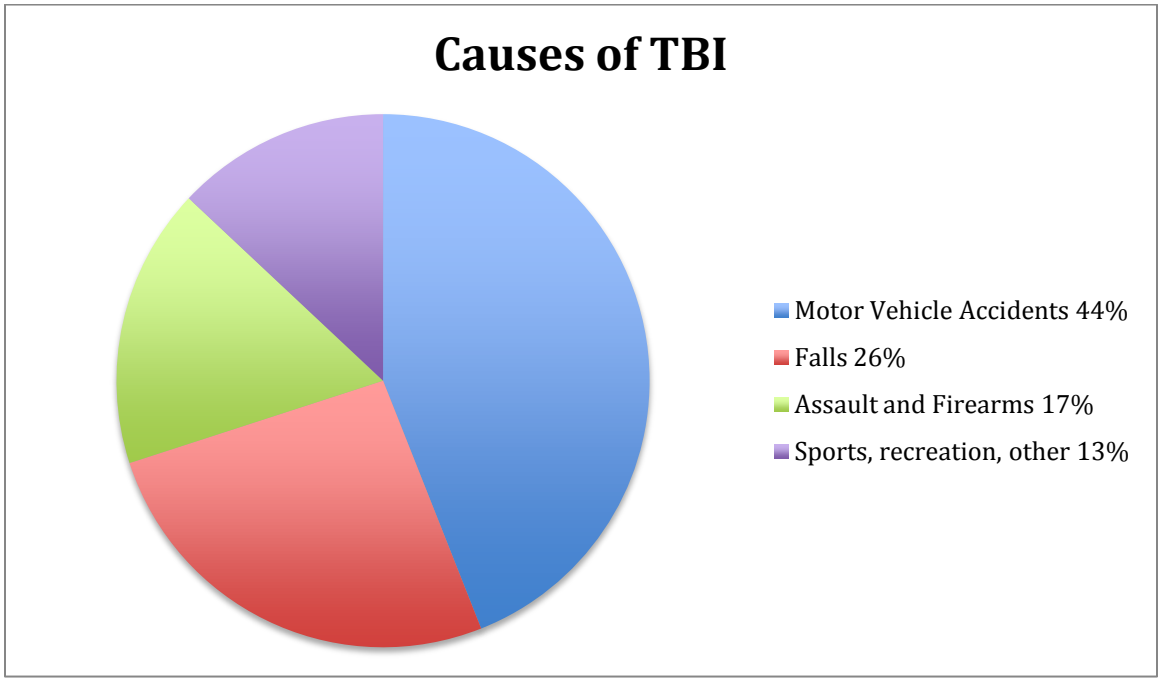
At this time, the committee finds the Senno/Soto proposal for a brick-and-mortar facility would do little to address these critical issues, and would be unlikely to succeed without the state first addressing them. However, if the state were to address the critical issues described above, the committee concluded

existing facilities would likely be adequate to meet the needs of the populations served. Therefore, the committee recommends the state direct its limited resources in this area towards addressing these broader gaps faced by brain-injured patients and their caregivers.

Background

Traumatic Brain Injury and Other Brain Disorders

Traumatic brain injury (TBI) affects nearly 1.5 million Americans every year, with approximately 50,000 annual related deaths, and 80,000 Americans developing a long-term disability each year as a result of TBI.



As of 2009, 3.2 million Americans — approximately 1 percent of the U.S. population — live with disabilities resulting from a brain injury. An estimated 200,000 children are hospitalized with TBI each year and, of those, approximately 30,000 suffer permanent disability. (1)

Veterans' advocates estimate 10 percent to 20 percent of service members have experienced a TBI, and 30% of patients admitted to Walter Reed Army Hospital are diagnosed as having a TBI. (2)

Symptoms from TBI can appear immediately or they may appear weeks, months or years after the time of injury.

Other types of brain disorders also contribute an oversized share of the disease and disability burden in the United States:

- Each year, nearly 800,000 Americans suffer a stroke and, of these, about 140,000 will die. Stroke is the leading cause of long-term disability in the United States. (3)
- Each year, about 30,000 Americans experience a ruptured brain aneurysm. Of these, approximately 40 percent will die. Among the survivors, approximately 66 percent will experience some kind of disability. (4)
- Alzheimer's disease is the most common form of dementia. One in eight older Americans has Alzheimer's dsease, and Alzheimer's is the sixth leading cause of death. As the U.S. population ages, rates of Alzheimer's are expected to increase. (5)
- More than 500,000 Americans have Parkinson's disease. The risk for Parkinson's increases as a person ages, so as with Alzheimer's disease, population prevalence is expected to increase as U.S. demographics skew older. (6)

- An estimated 1 in 88 children in the United States is diagnosed with a disorder along the Autism Spectrum. Of these, 38 percent are estimated to have an intellectual disability. (7)

Sources:

1. http://www.biail.org/whatis.htm
2. https://www.braintrauma.org/tbi-faqs/tbi-statistics/
3. http://www.strokecenter.org/patients/about-stroke/stroke-statistics/
4. http://www.strokecenter.org/patients/about-stroke/stroke-statistics/
5. http://www.alz.org/downloads/facts_figures_2012.pdf
6. http://www.ninds.nih.gov/disorders/parkinsons_disease/detail_parkinsons_disease.htm
7. http://www.cdc.gov/ncbddd/autism/documents/ADDM-2012-Community-Report.pdf

Senno/Soto Proposal

Dr. Senno and Rep. Soto have proposed the creation of a new institution in metro Chicago to be known as The Brain Medicine Institute and Education-Research Center of Excellence. As envisioned, the institute would incorporate multiple elements into a single facility for patients with TBI and other brain disorders:

- In-patient clinical services
- Out-patient clinical services
- Prevention and awareness programs
- Educational programs

- Research and investigations
- Advocacy and empowerment programs
- Community involvement

In 2012, Dr. Senno and Rep. Soto approached government leaders in both the executive and legislative branches of Illinois government and the federal government seeking assistance with their proposal. Specifically, they requested the state fund a feasibility study about this proposed facility. The feasibility study would take into account both the physical and environmental requirements of the proposed facility, as well as the market suitability of the institute given the current resources available in metro Chicago and other parts of the state.

Subsequently, the Office of the Governor and Office of the Speaker requested the Illinois Department of Public Health (IDPH) evaluate the proposal to determine whether or not a feasibility study was warranted. Acting on this request, IDPH convened an Expert Review Committee, drawing members from state government and local institutions working with related patient populations. Dr. Senno also was invited to nominate three members to serve on the committee.

This report details the committee's operations and findings during 2013. A minority response, authored by Rep. Soto and Dr. Senno, is included in Appendix C.

Expert Review Committee

Members

The Expert Review Committee consisted of clinicians, administrators, state government representatives and others whose work intersects with this patient population.

Expert Review Committee	
Voting Members	Julian Bailes, MD *Northshore University Health System (resigned; replaced by Dr. Sandin in July 2013)* Kenneth Bowman *Van Matre HealthSouth Rehabilitation Hospital* Philicia Deckard, BSW, LSW, CBIST *Brain Injury Association of Illinois* Michael DiDomenico, PsyD *Midwest Consultants for Cognitive Medicine* Allen Heinemann, PhD *Rehabilitation Institute of Chicago* Tona Kohn, MSE *Neurorestorative* Douglas Koltun, MD *Advocate Christ Medical Center* Charulatha Nagar, MD *Northwestern Memorial Faculty Foundation* Shaun O'Leary, MD, PhD *Northshore University Health System* Elliot Roth, MD *Rehabilitation Institute of Chicago* Karl Sandin, MD, MPH *Schwab Rehabilitation Hospital* Lawrence Singer, JD *Loyola University of Chicago School of Law* Honorable State Representative Cynthia Soto Kathleen Yosko, RN, MSN *Marianjoy Rehabilitation Hospital*
Non-Voting Members	Ricardo Senno, MD, MS *SennoGroup*

Ex-Officio Members	Matt Abrahamson *Illinois Department of Human Services* David Carvalho, JD *Illinois Department of Public Health* Craig Conover, MD *Illinois Department of Public Health* Kimberly Egonmwan, JD *Illinois Department of Public Health*

Operations

The Expert Review Committee was conducted in accordance with the Open Meetings Act. Notices of meetings were posted in accordance with the requirements of the act and all meetings were open to the public.

The bylaws adopted by the committee included provisions permitting the committee to meet via video- or teleconference and allowing members to send designees to meetings. Designees were permitted to vote in place of an absent member.

Timeline and Summary of Activities

The Expert Review Committee met three times and conducted one survey to provide additional environmental information for its discussions.

First Meeting

The committee first met January 28, 2013. During the first meeting, the committee approved its bylaws, received a presentation by Dr. Senno about the proposal, and had the opportunity to begin asking questions and formulating a framework for additional discussions. The committee also determined the need to survey its members and other knowledgeable meeting participants to develop an environmental scan of resources and gaps for this patient population in Illinois.

Environmental Scan Survey

In the Spring of 2013, IDPH developed and released its survey in conjunction with assistance from the University of Illinois at Chicago (UIC) School of Public Health. The survey went to committee members and other attendees from the committee's first meeting. When closed, IDPH summarized the results of the survey, again with assistance from UIC. A description of the survey and its results may be found in this report under "Environmental Scan Survey."

Second Meeting

The committee met for the second time on July 17, 2013. The committee received an update from Dr. Senno, the results of its survey, and brief presentations about the statuses of the Illinois Brain Injury Waiver Program and the Illinois Brain and Spinal Cord Injury Advisory Council (IBSCIAC). The advisory council was formed in 1989 in accordance with Public Act 86-510 with the mission to make recommendations to the Governor for developing and administering a comprehensive state plan to

provide services for individuals with brain or spinal cord injuries and to prevent new injuries from occurring.

Regarding the Illinois Brain Injury Waiver Program, Matt Abrahamson of the Illinois Department of Human Services (DHS) informed the committee the program was fully functional, with no waiting list as of the time of the meeting.

Regarding the Illinois Brain and Spinal Cord Advisory Council, Philicia Deckard advised the committee the Brain Injury Association of Illinois was working in conjunction with the Office of the Governor to reconstitute the council, with the goal of restarting meetings in late 2013. However, it was acknowledged that the council had not met since October 2009.

After concluding discussions around these issues, the committee agreed to meet for a third time in order to finalize discussions and develop consensus statements outlining its recommendations.

Third Meeting

The committee met for the third time on September 11, 2013. Synthesizing the discussions from prior meetings, IDPH presented a series of statements for consideration and voting. The final approved statements and the vote counts may be found in this report under "Committee Findings."

Environmental Scan Survey

About the Survey

At the direction of the committee, IDPH conducted a non-scientific survey to provide an environmental scan of the resources and gaps encountered by this patient population in Illinois. The survey was conducted online using Fluidsurveys.com. IDPH sent the participation link to members and others who had attended the first committee meeting.

The survey received a total of 13 responses. Of these, 11 were from members or ex-officio members, one was from a member delegate, and one was from a non-member. The responses came from 13 unique IP addresses, indicating that all 13 responses were from unique individuals.

Survey respondents were asked to answer questions based on their personal knowledge and expertise, so not every respondent answered every question.

Survey Highlights

The results below highlight key findings from the Environmental Scan Survey. A complete set of survey findings may be found in Appendix A.

Areas of major concern about adequacy of care for BI patients among >33% of question respondents	
Area of Concern	*% of respondents*
Acute hospital care, adults	45%
Rehabilitation hospital care, adults	55%
Outpatient rehab care, adults	55%
Outpatient rehab care, children	36%
Physician office care, adults	55%
Nursing home care, adults	64%
Nursing home care, children	36%
Residential facility and group home care, adults	55%
Residential facility and group home care, children	36%

Areas of major concern about adequacy of substance abuse related care for BI patients among >33% of question respondents	
Area of Concern	*% of respondents*
Outpatient settings, adults	36%

Areas of major concern about adequacy of mental health related care for BI patients among >33% of question respondents	
Area of Concern	*% of respondents*
Outpatient settings, adults	45%

Areas of major concern about adequacy of community-based supports and services for BI patients among >33% of question respondents	
Area of Concern	*% of respondents*
Assistance with management of finances	45%
Support groups	36%
Transportation services	36%
In-home services	64%
Assistive technology availability	36%
Education/school issues	55%
Community living schools training	45%

Areas of major concern about adequacy of coordination of care for BI patients among >33% of question respondents	
Area of Concern	*% of respondents*
Acute care discharge planning	56%
Rehabilitation hospital discharge planning	33%
Assistance for patients and their families to navigate the system	56%
Information and referral services for patients and families	56%
Resources to help physicians and other providers to obtain needed referrals and placements of patients in a timely manner	67%
Areas of major concern about insurance coverage/third-party coverage/benefit ability for BI patients among >33% of question respondents	
Area of Concern	*% of respondents*
Ability to obtain brain injury waiver	78%
Ability to obtain housing assistance funds	78%
Ability to obtain Social Security Disability Income	44%

Better insurance/third-party coverage needed for necessary care, services and support	89%

How important are new efforts/investments directed at the following:		
Area of Focus	*Not a Priority or Low Priority*	*Moderate Priority or High Priority*
Better case management/care navigation for patients	16%	84%
Training for community-based health care professions and others about brain injury	0%	100%
More efficient processes for referral of brain injury patients to available and needed care, services and supports	17%	83%
Better insurance/third-party coverage	0%	100%
Better availability of community-based care, services and support	8%	92%
Better availability of information for brain injury patients and their families	16%	84%
Working towards creation of a Brain Medicine Institute and Education Research Center located in metropolitan Chicago, as proposed by Dr. Senno	75%	25%
Working towards creation of a Brain Medicine Institute and Education Research Center as proposed by Dr. Senno, but located outside of metropolitan Chicago	75%	25%
Ensuring the Illinois Brain and Spinal Cord Injury Advisory Council has full membership and meets regularly (last meeting was October 2009)	8%	92%

Committee Findings and Recommendation

At its final meeting, the committee considered, discussed and revised a series of "consensus statements" regarding its findings prepared by IDPH. The findings below represent the broad consensus of the committee and include additional notes where appropriate.

Environmental Scan

The committee finds that:

1. **Illinois has many high quality providers and facilities serving persons with brain injuries.**
2. **Illinois does not have an adequate continuum of care for persons with brain injuries.**
3. **Third-party reimbursement issues are problematic for brain injury care. In addition to non-reimbursed care, the current design of the payment system also may be a contributing factor to issues in continuity of care for patients in this population.** The committee notes payment reform is part of the Illinois State Innovation Models currently under development by the Office of the Governor.
4. **Providers and facilities related to all facets of care exist in Illinois. However, patients may be unable to access these resources due to issues of geography, transportation, technology, advocacy, third-party reimbursement and payment system design. In particular, not**

all categories of care providers have access to reimbursement for the same services.

5. **Coordination of care along the full continuum is inadequate, due to third-party reimbursement issues, inadequate information about the availability of provider and facility resources, and maldistribution of resources. Coordination of care is further affected by the lack of structural and financial support for patient "handoffs" both within and among institutions and community-based resources.**
6. **Community-based resources are inadequate, in part, due to third-party reimbursement issues, and, in part, due to lack of awareness and expertise related to brain injury issues. These issues may be more pronounced outside of the Chicago metropolitan area.** The committee also notes the IDPH director is leading the Healthcare Reform Implementation Council Core Workgroup on Workforce and their work may address some of these issues.
7. **There exists a lack of recognition within the medical community and among the broader public about the causality of brain injuries, as well as the short- and long-term consequences, which in some cases may not appear for months or years after the initial trauma.**

Recommendations

The committee recommends:

1. **The state should undertake payment reform and changes to payment system design and incentives with the potential to lead to markedly improved delivery of brain injury care, services and supports.**
2. **Outpatient and community-based supports for brain-injury patients should be expanded and improved.**
3. **Coordination of care and case management for brain injury patients should be improved.**
4. **Brain injury professionals should have better access to information about the availability of specific services and supports for the wide spectrum of patients with brain injury based on their specific needs, geographic location, third-party coverage and other individual considerations.** The committee notes one proposal discussed at its third meeting: The Virtual Case Manager Search Engine (see Appendix B). While the committee does not endorse any particular solution, this proposal provides an example of the type of tool that could be developed in conjunction with other reforms outlined in these recommendations.
5. **Individuals with brain injury and their families should have better access to information and resources regarding brain injury.** The committee notes a version of the type of resource discussed in Recommendation #4 also could be made available to patients and to families.

6. **Community-based health professionals and others should receive more training about brain injury detection, care and management.**
7. **Additional research should be conducted to develop evidence-based standardized protocols for dealing with acute brain injury and these standard protocols should be widely disseminated.** The committee notes the current standard of care for cardiac events provides an instructive example of the types of standardized protocols needed in this area.
8. **The committee should transmit its findings and recommendations to the Brain and Spinal Cord Injury Advisory Council for further consideration of how to address the issues identified in the environmental scan.** The committee notes some members expressed concern this body, which last met in October 2009, might not be an effective vehicle for action. The committee also notes that, in part, due to its deliberations, the Advisory Council is reconstituting as of this writing and its first meeting will be publicized by the Brain Injury Association of Illinois. (Philicia Deckard, personal communication).

ON THE QUESTION: Should the state proceed with commissioning a feasibility study for the proposal of Dr. Senno and Rep. Soto for a Brain Medicine Institute and Education Research Center?

The committee voted 8-4 in opposition to the state proceeding with commissioning a feasibility study.

Discussion

Through discussions and discovery, the Executive Review Committee explored numerous aspects of the environment faced in Illinois by brain-injured patients, their families and their caregivers.

In terms of assets, Illinois has several high quality care providers and other community supports specializing in different aspects of brain injury treatment and rehabilitation, with a particularly heavy concentration in the Chicago metropolitan area.

Through the Illinois Department of Rehabilitation, Illinois provides a Brain Injury Waiver Program offering additional support to persons with disabilities resulting from brain injuries and for their families. This waiver program supports in-home help, transportation assistance, employment services, specialized medical equipment and other forms of assistance. At present, there is no waiting list for qualified individuals to enter the Department of Human Services brain injury waiver program.

Illinois state government also receives guidance from the Governor-appointed Brain and Spinal Cord Injury Advisory Council, which works closely with the Illinois Brain Injury Association. The advisory council suspended operations in 2009, but is anticipated to be reconstituted by the time of this report's delivery.

Nonetheless, brain injured patients, their families and their caregivers face numerous challenges when seeking and providing care and support. The bulk of

these issues fall into two broad categories: reimbursement issues and knowledge deficits.

Current third-party reimbursement policies and payment system design dis-incentivize a fully integrated continuum of care that provides high-quality "handoffs" among different providers, such as hospital emergency departments, nursing facilities, rehabilitation centers, community supports and others. The current system also creates barriers for providers seeking to help patients navigate these myriad resources and systems with different rules for different categories of patients and payers.

Patients, their families and their caregivers also encounter barriers caused by lack of knowledge. At a clinical level, brain injuries and their long-term consequences may not be properly diagnosed and treated. The clinical protocols for dealing with acute brain trauma lag behind those found in some other areas of medicine, such as cardiac care. Because a brain-injured patient may require resources from a wide variety of clinical and community resources, few individual care providers have access to a comprehensive knowledge-base of available supports and eligibility criteria.

The issues uncovered by the committee relate to broader deficits in the systems and policy landscape as related to brain injury care. These issues require serious consideration and reform to improve the environment for brain-injured persons, their families and their caregivers in Illinois.

The majority of the committee stated the brick-and-mortar facility described in the proposal would not address these broader issues. Indeed, without such

consideration and reform of these broader issues, the proposed facility would face challenges to its operation that might prove insurmountable.

The committee applauds Dr. Senno's and Rep. Soto's efforts to improve the lives of brain-injured patients and their families, and acknowledges the support for their proposal among some of its members. However, the committee's findings suggest at the present time, the state should devote its limited resources to addressing these broader systemic and policy issues to strengthen Illinois' infrastructure to the benefit of the maximum number of stakeholders.

Acknowledgements

This report represents the contributions and expertise of many individuals. IDPH gratefully recognizes the service of the Brain Injury Expert panel members, and the efforts of all who have provided input, commentary and guidance. Jason Rothstein, MPH, drafted this report on behalf of IDPH. Selma Hudson provided technical support.

Appendix A: Environmental Scan Survey Summary Report

1. Are you a professional that practices or has expertise in the field of brain injury?

Response	Chart	Percentage	Count
Yes		75%	9
No		17%	2
Other		8%	1
	Total Responses		**12**

2. What age groups do you focus on in your brain injury work?

Response	Chart	Percentage	Count
Children		64%	7
Adults--younger than age 65		91%	10
Adults--age 65 and older		91%	10
Other		0%	0
	Total Responses		**11**

3. What is your involvement with the IDPH Brain Injury Expert Panel that met on 1/28/2013?

Response	Chart	Percentage	Count
I am a member or ex-officio member of the panel		85%	11
I am not a member of the panel, but I attended the first meeting as a substitute for a member		8%	1
I attended the first meeting, but am not a panel member or substitute		8%	1
None of the above		0%	0
Other		0%	0
	Total Responses		**13**

4. Please indicate your overall level of concern about the adequacy of medically-related care (medical care, surgical care, PT, OT, etc.) provided to brain injury patients in the care settings and regions of the state listed. Choose N/A if don't have sufficient knowledge to answer any item. You also may provide comments and observations.

	N/A	No concerns	Minor concerns	Major concerns	Total responses
EMS care , adults	1 (9%)	3 (27%)	4 (36%)	3 (27%)	11
EMS care, children	3 (27%)	2 (18%)	4 (36%)	2 (18%)	11
Acute hospital care, adults	1 (9%)	3 (27%)	2 (18%)	5 (45%)	11
Acute hospital care, children	3 (27%)	2 (18%)	3 (27%)	3 (27%)	11
Rehabilitation hospital care, adults	1 (9%)	3 (27%)	1 (9%)	6 (55%)	11
Rehabilitation hospital care, children	3 (27%)	3 (27%)	3 (27%)	2 (18%)	11
Outpatient rehabilitation care, adults	1 (9%)	3 (27%)	1 (9%)	6 (55%)	11

Outpatient rehabilitation care, children	3 (27%)	3 (27%)	1 (9%)	4 (36%)	11
Physician office care, adults	1 (9%)	2 (18%)	2 (18%)	6 (55%)	11
Physician office care, children	3 (27%)	2 (18%)	4 (36%)	2 (18%)	11
Home health care, adults	1 (9%)	2 (18%)	5 (45%)	3 (27%)	11
Home health care, children	3 (27%)	1 (9%)	5 (45%)	2 (18%)	11
Nursing home care, adults	1 (9%)	1 (9%)	2 (18%)	7 (64%)	11
Nursing home care, children	4 (36%)	0 (0%)	3 (27%)	4 (36%)	11
Residential facility and group home care, adults	2 (18%)	1 (9%)	2 (18%)	6 (55%)	11
Residential facility and group home care, children	4 (36%)	1 (9%)	2 (18%)	4 (36%)	11
Correctional facility care, adults	7 (64%)	1 (9%)	2 (18%)	1 (9%)	11
Correctional facility care, children	7 (64%)	1 (9%)	2 (18%)	1 (9%)	11
Psychiatric hospital care, adults	5 (45%)	1 (9%)	2 (18%)	3 (27%)	11
Psychiatric hospital care, children	7 (64%)	1 (9%)	1 (9%)	2 (18%)	11

4a. Based on your knowledge, what regions of the state are you mostly concerned about?

	Metro Chicago	Outside metro Chicago	Both	Total responses
EMS care , adults	1 (12%)	2 (25%)	5 (62%)	8
EMS care, children	1 (12%)	0 (0%)	7 (88%)	8
Acute hospital care, adults	1 (12%)	1 (12%)	6 (75%)	8
Acute hospital care, children	1 (12%)	2 (25%)	5 (62%)	8
Rehabilitation hospital care,	1 (14%)	0 (0%)	6 (86%)	7

adults				
Rehabilitation hospital care, children	0 (0%)	1 (17%)	5 (83%)	6
Outpatient rehabilitation care, adults	1 (14%)	0 (0%)	6 (86%)	7
Outpatient rehabilitation care, children	1 (14%)	0 (0%)	6 (86%)	7
Physician office care, adults	1 (14%)	0 (0%)	6 (86%)	7
Physician office care, children	1 (14%)	1 (14%)	5 (71%)	7
Home health care, adults	1 (14%)	0 (0%)	6 (86%)	7
Home health care, children	1 (12%)	1 (12%)	6 (75%)	8
Nursing home care, adults	1 (14%)	0 (0%)	6 (86%)	7
Nursing home care, children	1 (14%)	0 (0%)	6 (86%)	7
Residential facility and group home care, adults	1 (14%)	0 (0%)	6 (86%)	7
Residential facility and group home care, children	1 (17%)	0 (0%)	5 (83%)	6
Correctional facility care, adults	1 (17%)	0 (0%)	5 (83%)	6
Correctional facility care, children	1 (17%)	0 (0%)	5 (83%)	6
Psychiatric hospital care, adults	1 (17%)	0 (0%)	5 (83%)	6
Psychiatric hospital care, children	1 (17%)	1 (17%)	4 (67%)	6

4b. Comments/observations

See Comments section

5. Please describe your level of concern about the adequacy of SUBSTANCE ABUSE related care for individuals with brain injury in the settings and regions listed. Choose N/A if you don't have sufficient knowledge to answer any item.

	N/A	No concerns	Minor concerns	Major concerns	Total responses
Inpatient settings, adults	2 (18%)	2 (18%)	4 (36%)	3 (27%)	11
Outpatient settings, adults	1 (9%)	1 (9%)	5 (45%)	4 (36%)	11
Inpatient settings, children	3 (27%)	1 (9%)	5 (45%)	2 (18%)	11
Outpatient settings, children	3 (27%)	1 (9%)	4 (36%)	3 (27%)	11

5a. What regions of the state are you mostly concerned about?

	Metro Chicago	Outside metro Chicago	Both	Total responses
Inpatient settings, adults	1 (14%)	0 (0%)	6 (86%)	7
Outpatient settings, adults	1 (14%)	1 (14%)	5 (71%)	7
Inpatient settings, children	1 (14%)	0 (0%)	6 (86%)	7
Outpatient settings, children	1 (14%)	0 (0%)	6 (86%)	7

5b. Comments/observations

See Comments section.

6. Please describe your level of concern about the adequacy of MENTAL HEALTH related care for individuals with brain injury in the settings and regions listed. Choose N/A if you don't have sufficient knowledge to answer an item.

	N/A	No concerns	Minor concerns	Major concerns	Total responses
Inpatient settings, adults	1 (9%)	2 (18%)	5 (45%)	3 (27%)	11
Outpatient settings, adults	0 (0%)	1 (9%)	5 (45%)	5 (45%)	11
Inpatient settings, children	4 (36%)	1 (9%)	4 (36%)	2 (18%)	11
Outpatient settings, children	4 (36%)	1 (9%)	3 (27%)	3 (27%)	11

6a. What regions of the state are you mostly concerned about?

	Metro Chicago	Outside metro Chicago	Both	Total responses
Inpatient settings, adults	1 (14%)	0 (0%)	6 (86%)	7
Outpatient settings, adults	1 (12%)	0 (0%)	7 (88%)	8
Inpatient settings, children	1 (14%)	0 (0%)	6 (86%)	7
Outpatient settings, children	1 (14%)	0 (0%)	6 (86%)	7

6b. Comments/observations

See Comments section

7. Please describe your level of concern about the adequacy of community-based supports and services and what region(s) of the state you are mostly concerned about. Choose N/A if you don't have sufficient knowledge to answer any item.

	N/A	No concerns	Minor concerns	Major concerns	Total responses
Legal services	4 (36%)	1 (9%)	5 (45%)	1 (9%)	11
Recreation services	2 (18%)	0 (0%)	6 (55%)	3 (27%)	11
Assistance with management of finances	2 (18%)	0 (0%)	4 (36%)	5 (45%)	11
Support groups	1 (9%)	2 (18%)	4 (36%)	4 (36%)	11
Transportation services	2 (18%)	0 (0%)	5 (45%)	4 (36%)	11
In-home services	2 (18%)	0 (0%)	2 (18%)	7 (64%)	11
Assistive technology availability	1 (9%)	1 (9%)	5 (45%)	4 (36%)	11
Education/school issues	2 (18%)	1 (9%)	2 (18%)	6 (55%)	11
Community living skills training	2 (18%)	1 (9%)	3 (27%)	5 (45%)	11

7a. What regions of the state are you mostly concerned about?

	Metro Chicago	Outside metro Chicago	Both	Total responses
Legal services	1 (20%)	0 (0%)	4 (80%)	5
Recreation services	1 (14%)	0 (0%)	6 (86%)	7
Assistance with management of finances	1 (14%)	0 (0%)	6 (86%)	7
Support groups	1 (12%)	0 (0%)	7 (88%)	8
Transportation services	1 (14%)	0 (0%)	6 (86%)	7
In-home services	1 (14%)	0 (0%)	6 (86%)	7
Assistive technology availability	1 (14%)	0 (0%)	6 (86%)	7
Education/school issues	1 (14%)	0 (0%)	6 (86%)	7
Community living skills training	1 (17%)	0 (0%)	5 (83%)	6

7b. Comments/observations – See Comments section

8. Please describe your level of concern about the adequacy of coordination of care for individuals with brain injury and what region(s) of the state you are mostly concerned about. Choose N/A if you don't have sufficient knowledge to answer any item.

	N/A	No concerns	Minor concerns	Major concerns		Total responses
Acute care hospital discharge planning	0 (0%)	2 (22%)	2 (22%)	5 (56%)	0 (0%)	9
Rehabilitation hospital discharge planning	0 (0%)	3 (33%)	3 (33%)	3 (33%)	0 (0%)	9
Assistance for patients and their families to navigate the system	0 (0%)	0 (0%)	4 (44%)	5 (56%)	0 (0%)	9
Information and referral services for patients and families	0 (0%)	1 (11%)	3 (33%)	5 (56%)	0 (0%)	9
Resources to help physicians and other providers to obtain needed referrals and placements of patients in a timely manner	0 (0%)	1 (11%)	2 (22%)	6 (67%)	0 (0%)	9

8a. What regions of the state are you mostly concerned about?

	Metro Chicago	Outside metro Chicago	Both	Total responses
Acute care hospital discharge planning	1 (12%)	0 (0%)	7 (88%)	8
Rehabilitation hospital discharge planning	1 (12%)	0 (0%)	7 (88%)	8
Assistance for patients and their families to navigate the system	1 (11%)	0 (0%)	8 (89%)	9
Information and referral services for patients and families	1 (12%)	0 (0%)	7 (88%)	8
Resources to help physicians and other providers to obtain needed referrals and placements of patients in a timely manner	0 (0%)	0 (0%)	7 (100%)	7

8b. Comments/observations

See Comments section

9. Please indicate your concerns about insurance coverage/3rd party coverage/benefit availability for patients with brain injury. Choose N/A if you don't have sufficient knowledge to answer an item.

	N/A	No concerns	Minor concerns	Major concerns	Total responses
Ability to obtain brain injury waiver	0 (0%)	1 (11%)	1 (11%)	7 (78%)	9
Ability to obtain housing assistance funds	2 (22%)	0 (0%)	0 (0%)	7 (78%)	9
Ability to obtain Social Security disability income	1 (11%)	0 (0%)	4 (44%)	4 (44%)	9
Better insurance/3rd party coverage needed for necessary care, services and support	1 (11%)	0 (0%)	0 (0%)	8 (89%)	9

9a. Comments/observations

See Comments section

10. In order to improve outcomes for individuals with brain injury, how important are new efforts/investments directed at each of following?

	Not a priority	Low priority	Moderate priority	High priority	Total responses
Better case management/ care navigation for patients	1 (8%)	1 (8%)	5 (42%)	5 (42%)	12
Training for community-based health care professionals and others (e.g., teachers and law enforcement) about brain injury	0 (0%)	0 (0%)	5 (42%)	7 (58%)	12
More efficient processes for referral of brain injury patients to available and needed care, services and supports	0 (0%)	2 (17%)	4 (33%)	6 (50%)	12
Better insurance/3rd party coverage	0 (0%)	0 (0%)	2 (17%)	10 (83%)	12
Better availability of community-based care, services and supports	0 (0%)	1 (8%)	1 (8%)	10 (83%)	12
Better availability of information for brain injury patients and their families	1 (8%)	1 (8%)	6 (50%)	4 (33%)	12
Working towards creation of a Brain Medicine Institute and Education-Research Center located in metropolitan Chicago, as proposed by Dr. Senno	8 (67%)	1 (8%)	0 (0%)	3 (25%)	12
Working towards creation of a Brain Medicine Institute and Education-Research Center as proposed by Dr. Senno, but located outside metropolitan Chicago	7 (58%)	2 (17%)	0 (0%)	3 (25%)	12
Ensuring that the Illinois Brain and Spinal Cord Injury	1 (8%)	0 (0%)	6 (50%)	5 (42%)	12

Advisory Council has full membership and meets regularly (last meeting was October 2009)	

10a. Comments/observations

See Comments section.

11. Please provide any additional comments or observations you wish to make.

See Comments section.

Comments
Note: Some comments have received light editing for legibility and clarity, as well as to preserve anonymity.

4b. Comments/observations
4b re: EMS care, adults

#	Response
1.	I am concerned that there are inappropriate strategies used at the beginning (acute), which causes long-term problems with recovery.
2.	Largely as no established consistent guidelines or used universally, or prevention of second impact or availability of limited services, not comprehensive to encompass, return to baseline.
3.	There is a need to ensure first responders are adequately trained in recognizing brain injury.

4b re: EMS care, children

#	Response
1.	Children often suffer multiple undetected brain injuries that have long-term cumulative effects.
2.	There is a need to ensure first responders are adequately trained in recognizing brain injury.

4b re: Acute hospital care, adults

#	Response
1.	Considered about dc destination and if people make it to the next appropriate level of care - SNF vs rehab.
2.	There are high differences in the quality or even presence of care at various facilities. Major hospitals (NMH, Rush, UIC, UCH, NorthShore, Christ, Cook County, Alexian Bros) are sufficiently staffed with highly skilled MDs/PhDs. Many other hospitals in the area lack clinical excellence in acute/long-term care for brain injured patients.
3.	Trauma Center Care is adequate. i.e., [REDACTED] psychiatrists consult in ICU's at 5 major hospitals to initiate the rehabilitation process. The same was true when I [REDACTED].
4.	Recognition and Funding for length of stay and insurance/funder coverage of cognitive rehabilitation.
5.	Need to be brought to acute (level 1) trauma or stroke centers. Time delayed leads to loss of brain function.

4b re: Acute hospital care, children

#	Response

1.	Recognition and Funding for length of stay and insurance/funder coverage of cognitive rehabilitation.
2.	Need to be brought to acute (level 1) trauma center. Time delayed leads to loss of brain function.

4b re: Rehabilitation hospital care, adults

#	Response
1.	Major rehabilitation centers (RIC, Schwaab, Marianjoy, etc.) are sufficiently staffed with highly skilled practitioners but could likely not absorb a higher admissions rate and are financially inaccessible to some at a time when we face a local influx of returning veterans and increasing awareness of brain injuries. These factors, as well as the increasing at-risk population for stroke and dementia, suggest a need for additional neurological rehabilitation services.
2.	There is concern for that here is not enough beds and treatment appears to be outdated .
3.	There are 3 major rehabilitation hospitals in the designated service area with specialized teams trained to care for head injury, as well as Lutheran and Christ hospitals.
4.	Recognition and funding for length of stay and insurance/funder coverage of cognitive rehab.
5.	Regarding funding for rehabilitation care.

4b re: Rehabilitation hospital care, children

#	Response
1.	Often not properly diagnosed.
2.	All 3 rehabilitation hospitals now and in the past have professionals who can and do treat pediatric rehabilitation cases.
3.	Recognition and Funding for length of stay and insurance/funder coverage of cognitive rehabilitation.
4.	Children can qualify more easily than adults for state funding if needed.

4b re: Outpatient rehabilitation care, adults

#	Response
1.	Medicaid is limiting the number of outpatient therapy visits...concern about potential impact.
2.	Major rehabilitation centers (RIC, Schwaab, Marianjoy, etc.) are sufficiently staffed with highly skilled practitioners but could likely not absorb a higher admissions rate and are financially inaccessible to some at a time when we face a local influx of returning veterans and increasing awareness of brain injuries. These factors, as well as the increasing at-risk population for stroke and dementia, suggest a need for additional neurological rehabilitation

	services. Limitations in availability and variability in quality may lead to poorer prognosis and under-treatment for the most vulnerable populations.
3.	Follow-up does not always happen.
4.	Again all of the providers above mentioned hospitals have professionals treating outpatient adults.
5.	Recognition and funding for length of stay and insurance/funder coverage of cognitive rehab.
6.	Concerned about referral for appropriate care and funding for care.

4b re: Outpatient rehabilitation care, children

#	Response
1.	Same as for adults.
2.	Continuity of care.
3.	Major providers follow pediatric patients in outpatient.
4.	Recognition and funding for length of stay and insurance/funder coverage of cognitive rehab.
5.	Concerned about referral for appropriate care.

4b re: Physician office care, adults

#	Response
1.	PCP usually not aware of bi issues and complications.
2.	Excluding neurologists, physiatrists, and some psychiatrists, most general practitioners have less than optimal knowledge of brain injuries. Their attempts to treat brain injured patients may lead to critical delays in assessment/diagnosis/interventions for brain injured patients.
3.	Treatment is often too brief and not consistent. The average physician spends less than 15 minutes with their head injury patients.
4.	Most physiatrists specializing in head injury follow their patients in office settings throughout their life. Additionally major rehab providers like [REDACTED] see post-concussive patients. i.e., sports-related injury.
5.	There is a need for the PCP to make BI resources/education available to the patient.
6.	Lack major knowledge and recognition of brain injury and appropriate treatment.

4b re: Physician office care, children

#	Response
1.	Pediatric physiatrists follow their children for many years.

2.	There is a need for the PCP to make BI resources/education available to the patient.
3.	Lack major knowledge and recognition of brain injury and appropriate treatment.

4b re: Home health care, adults

#	Response
1.	Unable to provide many services unless it is private pay due to limitations on visits and lack of funding towards this.
2.	Services are spotty. Workers may be largely unskilled. Issues of neglect/exploitation can abound undetected. It would be beneficial for a brain center of excellence to offer certified training to HHC staff or to maintain a department to provide this service while maintaining a high standard of quality of care.
3.	Very limited service provided in the home, which would be part of our vision statement.
4.	Referrals are made as appropriatee.
5.	Often times staff don't have adequate training related to brain injury and cognitive/behavioral needs.

4b re: Home health care, children

#	Response
1.	Same as above.
2.	This is a rarely used service for children.
3.	Oftentimes staff don't have adequate training related to brain injury and cognitive/behavioral needs.
4.	Limited availability of pediatric home care therapists.

4b re: Nursing home care, adults

#	Response
1.	Not trained in BI care.
2.	Very limited services if any in this type of setting.
3.	Unfortunately if needed these patients are housed long term with non-head injury elderly patients.
4.	Increased funding for adequate BI programming and cognitive/physical rehabilitation; more placement resources needed.
5.	This may be an overutilized and inappropriate resource to meet needs__especially for behavior.

4b re: Nursing home care, children

#	Response
1.	HH not skilled in Tx of children with BI and those that are medically complicated
2.	We have not needed these referrals.
3.	Increased funding for adequate BI programming and cognitive/physical rehab; more placement resources needed.
4.	Kids do not qualify for nursing home care. The burden falls on the families.

4b re: Residential facility and group home care, adults

#	Response
1.	Need for more residential facilities that accommodate people with BI more community homes vs nursing homes/SNF.
2.	I don't have the background to be able to comment.
3.	Inadequate funding to make placements possible, which makes providers not able to make placements available; increased funding for adequate BI programming and cognitive/physical rehab; more placement resources needed.
4.	Few in number and gross lack of funding for this.

4b re: Residential facility and group home care, children

#	Response
1.	See above.
2.	I am not knowledgeable about this level of care.
3.	Inadequate funding to make placements possible, which makes providers not able to make placements available; increased funding for adequate BI programming and cognitive/physical rehab; more placement resources needed.
4.	Not available unless in vegetative state or can be accessed as school behavior problem. Limited bed availability and funding.

4b re: Correctional facility care, adults

#	Response
1.	Little medical and psychological support for people in correctional facilities in general. For BI population there is nothing that I know of. Services only for medical issues.
2.	Very limited, if any, follow-up.

3.	No knowledge in this area.
4.	Staff need brain injury specific training to identify needs and to provide services to assist someone with a brain injury.
5.	Suspect a high incidence of undiagnosed brain injury in this population.

4b re: Correctional facility care, children

#	Response
1.	See above.
2.	No knowledge in this area.
3.	Staff need brain injury specific training to identify needs, and to provide services to assist someone with a brain injury.
4.	Suspect a high incidence of undiagnosed brain injury in this population.

4b re: Psychiatric hospital care, adults

#	Response
1.	BI and psych issues are not always identified and differentiated. Many times BI is mistaken for psych issues unless the person is trained in this. Many BI Dx are not detected in this population.
2.	Often unintentionally misdiagnosed.
3.	Short term intervention for suicidal patients is only available.
4.	Admissions often relate to increased medications without addressing the issues as related to the brain injury; brain injury training for staff would be beneficial.
5.	Suspect too few beds and poor funding to manage the magnitude of patient needs.

4b re: Psychiatric hospital care, children

#	Response
1.	Many BI Dx are not detected in this population.
2.	No knowledge in this area.
3.	Admissions often relate to increased medications without addressing the issues as related to the brain injury; brain injury training for staff would be beneficial.
4.	Suspect limited number of facilities and funding for services.

4b re: Other

#	Response

1.	I am in support of further exploring the development of a brain center of excellence in the Chicago area, as proposed by Dr. Senno. We should further determine the level of need through a feasibility study to objectify our impressions beyond the expert opinions of the task force team members, some of whom may be motivated by a desire to minimize competition with existing programs.
2.	I believe the scope of rehabilitation services in the designated service areas are currently optimal and do not need to be duplicated.
3.	There is a solid community of medical care for the individual who has sustained a brain injury in and outside the Metro area of Chicago, but what is missing is the funding for this care. Funders are not covering an adequate number of therapy days, and also not covering cognitive rehabilitation. Services are available to the individual who has sustained a brain injury at the acute, sub-acute and community settings. The issue is that funding sources will often not recognize cognitive rehabilitation for this patient, nor fund cognitive rehabilitation. Additional training and resources should be available for the first responders, physicians, and the psychiatric hospital and correctional settings. There is always a need for continued community education.

5b. Comments/observations

5b re: Inpatient settings, adults

#	Response
1.	Inpatient programs but are not able to also accommodate for the BI. This is a large issue in this population that needs to be addressed
2.	Psychiatry and psychology are available in the aforementioned rehabilitation hospitals.
3.	This is usually detected and addressed acutely but problem with post-acute care.

5b re: | Outpatient settings, adults

#	Response
1.	We work with the [REDACTED] to provide outpatient services so for us this is not an issue in the metro area.
2.	Lack comprehensive education about meds that may impair cognition in tbi patient along with substances of abuse potential.
3.	Poor counselling and follow-up management.

5b re: | Inpatient settings, children

#	Response
1.	I am unaware of any programs that will also take someone with a BI.
2.	This is usually detected and addressed acutely.

5b re: Outpatient settings, children

#	Response
1.	I am unaware of any programs that will also take someone with a BI.
2.	Poor resources availability and funding.

5b re: Other

#	Response
1.	Substance abuse treatment is traditionally difficult to obtain. Specific programs for those dealing with neurological comorbidities are nearly non-existent. A brain center of excellence could uniquely address this gap by hiring psychologists and addiction therapists with a background in the neurological sciences and substance abuse to integrate empirically support treatment options for this population.
2.	Oftentimes, the person who sustains a brain injury has issues relating to substance abuse, and these issues can continue after the injury and can worsen. Substance abuse treatment should be made available to the patient, but funding becomes an issue. It is frequently not covered by the funder. Treatment staff need to be educated about brain injury and the impact the injury may have on the person's treatment plan.

6b Comments/observations

6b re: Inpatient settings, adults

#	Response
1.	Recently became aware of a patient with frontal lobe pathology that lead to sexual disinhibition having the police called to his bedside at a hospital after a nursing assistant complained that he had been sexually inappropriate toward her. In a center with a focus on neurological patients, I doubt that this would have occurred due to better staff training and specific protocols for addressing neurologically-induced behavioral disturbance.
2.	Lack of adequate resources such as psychiatrists, psychologists, especially underinsured indigent patient groups.
3.	Resources are often available in the hospital but not for outpatient follow-up.

6b re: Outpatient settings, adults

#	Response
1.	As above.
2.	Community behavioral issues can occur with limited outpatient psychiatric services.
3.	Lack of referrals, resources, and funding.

6b re: Inpatient settings, children

#	Response
1.	Resources are usually available in the hospital but no availability or funding for outpatient services.

6b re: Outpatient settings, children

#	Response
1.	Lack of resources, availability, and funding.

6b re: Other

#	Response
1.	In general I am not aware of programs that specialize in BI and mental health issues. Many mental health services are not available in general for the Medicaid population
2.	I can't begin to describe the horror stories that my patients have shared with me regarding their difficulties in locating appropriate services following their discharge from acute care and sub-acute rehabilitation facilities. They and their families face daunting challenges in addressing their long-term needs and emerging disabilities in a decentralized environment with high disparity in access to care.
3.	Too often focus is placed on the person's behavior, emotional status and medications without considering the impact of the brain injury on the patient's functioning. Staff should be adequately trained in brain injury, identify brain injury, and be able to develop a treatment plan addressing the patient's functioning as related to the brain injury. There is a need for staff training and discharge planning.

7b Comments/observations

7b re: Legal services

#	Response
1.	By the time that they need legal intervention, many brain injured patients are unable to afford it.
2.	An attorney may not be aware of the individual's long term needs, and that cognitive skills can decline with age.

7b re: Recreation services

#	Response
1.	In general not many recreation services for people with disabilities. And little for BI specifically.
2.	Needs to be a better differentiation for those who have cognitive impairments, as opposed to

	including them within a developmental delay group.

7b re: Assistance with management of finances

#	Response
1.	Who does this now? No one.
2.	Financial exploitation is particularly high in this patient population. Errors in judgment are compounded when patients attempt to manage their finances independently but can also be worsened when they cede authority to exploitative parties.
3.	Training should be provided to the individual and caregiver by qualified persons, and resources be made available.

7b re: Support groups

#	Response
1.	Good BI support group resources in both areas
2.	Recently heard complaints from family members who have been unable to locate a stroke support group in their area. Online options may be helpful here.
3.	These are very limited
4.	There are several ongoing, well established support groups including Marianjoy that I am aware of.
5.	There is an ongoing need for new support groups around the state.
6.	Brain Injury Association and Midwest Brain Injury Clubhouse are great resources but need funding.

7b re: Transportation services

#	Response
1.	PWD RIDE FREE BUT THE PROCESS OF REQUESTING AND RECEIVING SPECIAL SERVICES IS DIFFICULT AND TIME CONSUMING.
2.	More difficult in outlying areas than within the city itself.
3.	Limited and costly.
4.	Transportation venues need to be increased and more readily available. Staff should be required to complete a brain injury education course.

7b re: In-home services

#	Response

1.	Need more in home services that provide for longer hours vs having someone placed in a NH because the services are not available at home.
2.	Limited and transient.
3.	There is a need to revise/update the screening to determine the individual's personal care attendant needs.
4.	Supportive care services needed.

7b re: Assistive technology availability

#	Response
1.	Takes funding and a lot of time to receive approval and the technology.
2.	Too often individuals aren't aware that technology services, programs and equipment are available. Increased funding is needed to ensure individuals' needs are met.

7b re: Education/school issues

#	Response
1.	Transitional services in CPS are non-existent. Outside of CPS, there is always advocacy that is needed to make sure the person receives what they are entitled to.
2.	Need for increased transitional programming from the school setting to community/secondary classes. Parents would benefit from having training addressing their rights in the school process and with the IEP.
3.	Many schools lack understanding of brain injury and appropriate accommodations.

7b re: Community living skills training

#	Response
1.	Very little support for this. This is an ongoing need that requires financial support with outcomes that will take time to accomplish.
2.	Increased funding and availability of services is needed.

7b re: Other

#	Response
1.	Community living skills training, community resources and access to those community activities and programs are very much needed. We have great resources for the patients regarding medical and rehabilitation programs, but once the individual is returned to his home setting his access to community resources and services can be limited due to funding.

8b Comments/observations

8b re: Acute care hospital discharge planning

#	Response
1.	Acute care facilities operate under an assumption that follow-up will be made by down-line providers. There are many patients who simply fall through the cracks after acute care and miss critical therapeutic junctures for intervention.
2.	They get discharged to inappropriate facilities.
3.	Providers are well equipped
4.	Recognition of and funding for appropriate care needs

8b re: Rehabilitation hospital discharge planning

#	Response
1.	Continued access to information and services needs to be more readily available.
2.	Funding of and proximity to appropriate follow-up care

8b re: Assistance for patients and their families to navigate the system

#	Response
1.	Patients and their families are justifiably confused by the decentralized services provided locally. A brain center of excellence should offer a centralized approach for patient/family education and continued assistance in navigating the system over longer periods of time than are feasible for acute care and rehabilitation centers.
2.	Due to limited knowledge and finances, but the family can be the strongest link. Sometimes the family knows more than the treatment professionals.
3.	Illinois Head Injury provides good supplemental support post discharge.
4.	Hospital social work and Brain Injury Association are good resources.

8b re: Information and referral services for patients and families

#	Response
1.	Patients and their families don't seem to know what is out there or how to access it personally. By the time that their questions arise, they are often outside of the formal system. Simply providing a continuing resource liaison service could reduce unnecessary re-admission and/or treatment delays.
2.	Lack of outpatient resources.
3.	As stated above.
4.	This has been readily available but patients and families are so overwhelmed by acute care

	needs initially that they cannot process this.

8b re: Resources to help physicians and other providers to obtain needed referrals and placements of patients in a timely manner

#	Response
1.	This varies hugely between and within facilities. Centralized services with a goal of educating physicians and other providers of the available resources appears to be greatly needed.
2.	As stated above.
3.	Education to recognize the problem and need for care is one aspect. Knowledge about appropriate referrals and funding are other aspects.

8b re: Other

#	Response
1.	The issues of care coordination are great for this and other people with disabilities. The coordination needs to start at the acute care hospital and continue through the community setting. This rarely happens. When it does there are barriers that need to be identified and systems changed.
2.	Discharge plans are identified, but are often finalized due to the patient's funding status. Illinois is fortunate in having strong acute hospital programs and rehabilitation programs, but the course of treatment, length of stay and/or discharge site are based on funding and availability. We need more funding streams and funding authorization for patients to continue receiving services. The services are present, but often not able to be accessed due to funding.

9b Comments/observations

9b re: Ability to obtain brain injury waiver

#	Response
1.	4-6 months before this starts--and this is upon discharge from a rehab hospital
2.	My understanding from patients is that they have found it difficult to engage with the brain injury waiver programs or have experienced substantial delays. We are now making alternative recommendations.
3.	Illinois Brain Injury Waiver needs to be reviewed and updated. The program was intended to prevent nursing home placements and to keep an individual in their home setting. This isn't often possible because the waiver dollars are decreased, and the individual's personal attendant hours are limited.

9b re: Ability to obtain housing assistance funds

#	Response
1.	I did not realize there were housing funds. Section 8 vouchers are not being given out and low-income accessible housing is scarce. People go to nursing homes because there are no housing resources.
2.	Too many people are on waiting lists for apartments to become available. More units are needed, but housing assistance funds are limited.

9b re: Ability to obtain Social Security disability income

#	Response
1.	If you are in a rehabilitation hospital the process is quicker. If you are in the community without a good connection to a competent physician that can complete the paperwork necessary you are in trouble.
2.	Patients with severe disabilities are being routinely turned down 2-3 times before securing benefits. This causes major distress for the patients and their families as well as service delays.
3.	It is often difficult for a person with a brain injury and little/no physical impairments to receive benefits. The cognitive impairments are often more difficult to document and to be recognized by the reviewer.

9b re: Better insurance/3rd party coverage needed for necessary care, services, and support

#	Response
1.	Better insurance in general that consistently pays for services that are needed in a timely

	manner.
2.	There needs to be a recognition of cognitive rehabilitation, and it needs to be covered by the funder. Community based programs need to be covered for the patient's continued rehabilitation.
3.	It is frequently a struggle to advocate for appropriate benefits on behalf of patients.

9b re: Other

#	Response
1.	Barriers to service set by insurance companies limit the ability of uninsured patients to receive the level of care offered to insured patients. However, being insured is not a guarantee that patients will have appropriate service access, to appropriate specialists, for the medically indicated duration.

10a Comments/observations

#	Response
1.	I feel that a creation of a brain medicine institute is not necessary. We need to coordinate existing services and ensure continuity of care. This is a priority.
2.	The Illinois Brain and Spinal Cord Injury Advisory Council has long since dropped the ball. The needs of neurological patients are too great to place in the hands of the advisory council. A brain center of excellence, whether located within or outside of metropolitan Chicago, would formally address the needs of this population. Clearly, the mission of such a center would include continued advocacy dedicated to this vulnerable patient population. Although I believe that having the center located within metropolitan Chicago, I would strongly advocate for a feasibility study to determine the most appropriate location based upon the services needs of patients in Illinois.
3.	Again, I am aware of Dr Senno's passion for head injured patients during his employment at RIC and at Marianjoy. However, these inpatient/outpatient resources are already in place at 3 major rehabilitation hospitals equipped with teams of experts. There is a need for more resources to support community re-entry of head injured patients. Additionally, if there are available funds for more clinical research, why not have Dr. Senno work with existing providers, who already treat the majority of cases.
4.	The priority should be at making funding available for the programs and services already in place. Increased funding would allow current providers to expand their programs and services. Illinois has cutting edge brain injury providers providing a continuum of care. We need to make funding available to them for cognitive rehabilitation, and to make funding available for community-based programs.
5.	I strongly believe that a lack of community supports for all individuals with disabilities, including persons with traumatic brain injuries, is the greatest obstacle we face towards

	maximizing the independence and opportunities for all individuals to live in and contribute to their communities.
6.	Availability of and funding for cognitive rehabilitation and community reintegration (including vocational, educational, and family counselors) are key needs. Chicago is already endowed with many excellent medical institutes to manage medical and therapy care for patients with a brain injury. Publically funding one seems like a misplaced use of resources which could be better targeted to more urgent areas of need as above. Most of these areas of need are not well funded--even for those with insurance. Funding support for organizations already in place (such as the Brain Injury Association of IL, the Brain Injury Clubhouse) may be cost effective ways to augment educational resources and community services.

11. Please provide any additional comments or observations you wish to make.

#	Response
1.	This project should be given full consideration and a feasibility study should be undertaken. We face increasing need for brain injury services given an aging population of less-than-healthy individuals, increasing awareness of the impact of brain injuries, longevity of brain injury survivors (including those who would not have survived without recent advances in the neurosciences), and the return of veterans who may present with atypical neurological injuries (i.e., chronic traumatic encephalopathy). I felt that there were great attempts by some members of the task force to protect their turf. I would be far more interested in protecting this vulnerable patient populations, reducing the utilization of long-term care services, encouraging and maximizing opportunities to re-engage in the work force, and improving the quality of life for patients/families affected by brain injury. The status quo is unacceptable and too frequently lamented (among our peers and patients) for us to miss this valuable opportunity. We are locally blessed to have many of the best training institutions in the country within our service region. Our ability to identify and acquire the most talented doctors, allied clinicians, and supporting staff should be very high. By centralizing services, advocacy, education, and rehabilitation, the center of excellence should reduce the burden on patients, their families, and even their clinicians in providing for their needs for the duration necessary.
2.	Patients with brain injury are often called the "walking wounded" because physical skills may be relatively preserved while cognitive skills are profoundly disrupted. Illinois already has many wonderful acute and rehabilitation brain injury care facilities and professionals so I believe Dr. Senno's proposal should not be the focus. Instead, the priority should be on funding care, community-based resources, and education to utilize and expand the excellent resources already present.
3.	State resources should not be devoted to this proposal.

Appendix B: Virtual Case Manager Search Engine Proposal

Submitted by Lisa Thornton, MD

The optimal care of a patient who has sustained a brain injury or any other disability requires the coordination of multiple services. These include:

- Medical care –Physiatry, Neurosurgery, Neurology, Orthopedics
- Therapy services – Physical therapy, occupational therapy, speech therapy, assistive technology, etc.
- Vocational services
- Psychological services – adjustment counseling, neuropsychological testing
- Educational services for children
- Equipment/DME Vendors – wheelchair, orthotics, etc.
- Home modification specialists – contractors/architects who are knowledgeable about ADA regulations
- Recreation services – park districts, adapted sports, accessible health clubs, etc.
- Transportation companies
- Home health care companies
- Case management companies

This is an incomplete list, but begins to illustrate how many different services are needed. These services function in silos and so each patient or health care coordinator must find the services that are available and that serve the specific need. Identifying these service providers is arduous and time consuming. In general, practitioners develop relationships with a few vendors and consistently refer to them because identifying others requires so much time and often includes multiple phone calls to assure the appropriate fit. It becomes a "needle in a haystack" endeavor FOR EACH SERVICE NEEDED. Currently, providing the most effective care coordination for a patient with a disability requires resourcefulness, tenacity, and UNREIMBURSED TIME! This challenge probably leaves many patients sub-optimally managed.

In a large service area like Chicago, it would be much more efficient to refer patients to the vendor closest to them who can provide the service, and accepts their funding source.

A POTENTIAL SOLUTION: A Virtual Case Manager Search Engine:

The development of a statewide search engine that specifically addresses these needs.

Providers would need to complete an online questionnaire about the service they provide, the insurance they will accept, the ages of patients they will accept, their

areas of specialization, etc. This could be easily edited as businesses expand their services or change contractual agreements with insurance companies.

This service has obvious benefit to the patient as it simplifies the acquisition of the appropriate provider quickly and accurately.
It will improve efficiency for the care provider (physician, nurse, case manager, etc)
It will also benefit the vendors by driving business to them.

EXAMPLE A: A 7-year-old boy who sustained a traumatic brain injury. His recovery has been good, but he still has difficulty walking, has issues with communication, and has cognitive decline. He lives in Kankakee. He is funded by IHFS. He attends public school. His mother does not own a car.
At minimum he needs the following services:

- Outpatient pediatric physical therapy in Kankakee who will accept IHFS funding
- Outpatient pediatric speech therapy in Kankakee who will accept IHFS funding
- Cognitive testing by a pediatric neuropsychologist who will accept IHFS
- An orthotic vendor to build his brace to support his walking
- Transportation to and from these appointments and his doctor's appointments

NOTE: I have worked in Pediatric Rehabilitation for almost 20 years and I am continually challenged to find all of these services especially outside of Chicago.

With the Virtual Case Manager Search Engine:

- Enter child's age, location (within xx miles), diagnosis, funding source, service needed:
- 7yo
- Kankakee
- Brain Injury
- IHFS
- Physical therapy or Occupational therapy or Cognitive testing, etc.

The providers who meet those criteria would be presented. If there were no one within the requested geographic area then the closest provider would be presented.

EXAMPLE B: A 54-year-old man who sustained a traumatic brain injury in a car crash. He is left quadriparetic and uses a wheelchair for all mobility. He requires daily assistance with his care. He has speech difficulties. He lives in Evanston in a two story home with his wife who can assist with his care, but cannot transfer him because of his size. He has private insurance and has significant personal resources so money is not a barrier for him. The wife has purchased a van for transportation.
At minimum he needs the following services:

- Outpatient Physical, Occupational, and Speech therapists who specialize in brain injury
- Wheelchair and equipment vendor
- Orthotic vendor
- A contractor who can do home modifications for a barrier free lift for transfers, a stair lift to access the upstairs, a ramp for home access, bathroom modifications.
- An auto dealer who can provide van modifications
- A homemaker to assist with daily living skills for a few hours a day.

With the Virtual Case Manager Search Engine:

- Enter age, location (within xx miles), diagnosis, funding source, service needed:
- 54yo
- Evanston
- Brain Injury
- BC/BS PPO or Self Pay
- Home contractor, home health provider, etc.

The providers who meet those criteria would be presented. If there were no one within the requested geographic area, then the closest provider would be presented.

Appendix C. Minority Response (attached)

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CYNTHIA SOTO
STATE REPRESENTATIVE
4th DISTRICT

COMMITTEES:

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- Appropriations Higher Education Vice Chairperson
- Appropriations Elementary & Secondary Education
- Health Care Availability & Accessibility
- Human Services

BRAIN MEDICINE INSTITUTE & EDUCATION - RESEARCH CENTER OF EXCELLENCE

NEEDS ASSESMENT & FEASIBILITY/FRAMEWORK STUDY PROPOSAL

MINORITY RESPONSE

February 10, 2014

First and foremost, our deepest appreciation to the Governor's Office, The Office of the Speaker the House of Representatives and the Illinois Department of Public Health (IDPH) for convening the Expert Review Committee to consider pursuing a feasibility study for the proposed Brain Medicine Institute & Education - Research Center of Excellence. This center of excellence would be a first, of its kind, in both service and scope. It will combine clinical, research and education programs dedicated to treating a wide range of neurological disorders of the human brain. These include: anoxic and traumatic brain injuries, Parkinson's and Alzheimer's disease, multiple sclerosis and cerebral palsy, stroke and brain tumors, Lou Gehrig's disease, autism and many others. Due to more than 150 disorders that affect our brain, there are at least 17 million Americans living with the consequences of brain injury and illness. This number is greater than the combined population of Chicago, New York City, Miami, Houston, and Los Angeles. Unfortunately, as our Baby-Boomers age and our veterans return the number of people with brain related disorders will not plateau at 17 million but will increase.

Through the enactment of The Children's Health Act of 2000 (Public Law 106-310) the United States Congress charged the Center for Disease Control and Prevention (CDC) with "determining

the prevalence of traumatic brain injury in the all age groups in the general population of the United States." In its study conducted from 1995 - 2001 and report of October, 2004 the CDC reported that at least 1.4 million traumatic brain injuries (TBI) occur in the United States each year. These traumatic brain injuries resulted in 50,000 deaths, 235,000 hospitalizations and 1.1 million emergency department visits. Per the CDC it was determined that falls by children and the elderly accounted for the majority of TBI's overall, while motor vehicle accidents accounted for the majority of TBI in the young adult population only. Other causes of TBI include sports, recreation, assaults and firearms. More telling is the number of TBI's that went un-reported.

Agreeing with the IDPH Expert Panel Report *(IDPH p. 5-6)* dated 2013:

"Veterans' advocates estimate that 10 - 20 % of service members have experienced a TBI, and 30% of patients admitted to Walter Reed Army Hospital are diagnosed as having a TBI.

Symptoms from TBI can appear immediately, or they may appear weeks, months or even years after the time of injury.

Other types of brain disorders also contribute an oversized share of the disease and disability burden in the United States:

- *Each year, nearly 800,000 Americans suffer a stroke, and of these, about 140,000 will die. Stroke is the leading cause of long-term disability in the United States.*
- *Each year, about 30,000 Americans experience a ruptured brain aneurysm. Of these, approximately 40% will die. Among the survivors, approximately, 66% will experience some kind of disability.*
- *Alzheimer's disease is the most common form of dementia. One in eight older Americans has Alzheimer's disease, and Alzheimer's is the sixth leading cause of death. As the U.S. population ages, rates of Alzheimer's are expected to increase.*
- *More than 500,000 Americans have Parkinson's disease. The risk for Parkinson's increases as a person ages, so as with Alzheimer's disease, population prevalence is expected to increase as U.S. demographics skew older.*
- *An estimated 1 in 88 children in the United States is diagnosed with a disorder along the Autism Spectrum. Of these, 38% are estimated to have an intellectual disability."*

Per the American Heart Association there are currently 3,000,000 Americans living with the sequale of stroke. Per the CDC Division of Heart and Stroke (July, 2013) every year about 715,000 Americans have a heart attack about 85% survive. Because of lack of oxygen to the brain during the heart attack these survivors will have some form of anoxic brain injury.

These numbers are staggering and although specialty centers of excellence have repeatedly proven their worth in terms of treatments, prevention and cost in the fields of cardiology, orthopedics, pediatrics and cancer treatment, at this time, there is no comprehensive center of excellence dedicated to research, treatment and prevention of acute or chronic brain injuries and illnesses.

We would like to thank the voting members of the Review Committee and citizen attendees for their time, insights and opinions. As demonstrated by the non - scientific survey to provide an environmental scan of the resources and gaps in the treatment of people with brain illnesses and diseases and during the three meetings at IDPH (January, July & September, 2013) there was a consensus that further research, educational programs, clinical work and services are needed to address the needs of our aging baby boomers, returning veterans and growing number of our population with acute, chronic and neuropsychological conditions.

The environmental scan showed that:

- *"Illinois does not have the adequate continuum of care for persons with brain injuries" (IDPH p.16 #2)*

- *"Community-based resources are inadequate, in part due to third-party reimbursement issues, and in part due to lack of awareness and expertise related to brain injury issues" (IDPH p.17 #6)*

- *"There exist a lack of recognition within the medical community and among the broader public about the causality of brain injuries as well as the short term and long term consequences which in some cases may not appear for months or years after the initial trauma" (IDPH p.17 #7)*

- *"Outpatient and community based supports for brain injury patients should be expanded and improved"(IDPH p.18 #2)*

- *"Additional research should be conducted to develop evidence based standardized protocols for dealing with acute brain injury, and these protocols should be widely disseminated."* Moreover, *"The committee notes that the current standard of care for cardiac events provides an instructive example of the types of standardized protocols needed in this area" (IDPH p.19#7)*

Maintaining that existing facilities are currently providing sufficient care for brain injury patients, members that voted (8-4) against moving forward with the feasibility study did so along corporate preservation lines. They also felt that any gaps in services could be attributed to poor infrastructure, inadequate funding, third party reimbursements and increasingly restrictive regulations.

Although the vote was 8-4, the statements made are more telling of the true needs

- *"I am concerned that there are inappropriate strategies used at the beginning (acute), which causes long term problems with recovery"(IDPH p.36 adults#1)*

- *"Children often suffer multiple undetected brain injuries that have long term cumulative effects" (IDPH p.36 children #1)*

- *"There is a need to ensure that first responders are adequately trained in recognizing brain injury" (IDPH p.36 children #2)*

- *"Major rehab centers (RIC, Schwab, Marionjoy, etc) are sufficiently staffed with highly skilled practitioners but could likely not absorb a higher admissions rate and are financially inaccessible to some at a time when we face a local influx of returning veterans and increasing awareness of brain injuries. These factors, as well as increasing at risk population for stroke and dementia, suggest a need for additional neurological rehabilitation services. Limitations in availability and variability in quality may lead to poorer prognosis" (IDPH p.37 rehab hospital #2)*

- *"PCP (primary care physicians) are usually not aware of BI (brain injury) issues and complications" (IDPH p.38 physician office #1)*

- *"Excluding neurologist, physiatrist, and some psychiatrist most general practitioners have less than optimal knowledge of brain injuries. Their attempt to treat brain injury patients may lead to critical delays in assessment/diagnosis/ interventions for brain injury patient" (IDPH p.38 physician office #2)*

- *"Treatment is often too brief and not consistent. The average physician spends less than 15 minutes with their head injury patients" (IDPH p.38 physician office #3)*

- *I can't begin to describe the horror stories that my patients have shared with me regard their difficulties in locating appropriate services following their discharge from acute care and subacute rehabilitation facilities. They and their families face daunting challenges in addressing their long term needs and emerging disabilities in a decentralized environment with high disparity in access to care" (IDPH p.44 other #2)*

- *"Acute care facilities operate under an assumption that follow up will be made by down the line providers. There are many patients who simply fall through the cracks after acute care and miss critical therapeutic junctures for interventions" (IDPH p.47 discharge planning #1)*

- *"Patients and their families are justifiably confused by the decentralized services provided locally. A brain center of excellence should offer a centralized approach for patients/family education and continued assistance in navigating the system over longer periods of time than are feasible for acute and rehabilitation centers" (IDPH p.47 navigate the system #1)*

- *"The Illinois Brain and Spinal Cord Injury Advisory Council has long since dropped the ball. The needs of neurological patients are too great to place in the hands of the advisory council. A brain center of excellence, whether located within or outside of metropolitan Chicago, would formally address the needs of this population. Clearly, the mission of such a center would include continued advocacy dedicated to this vulnerable patient population. Although I believe that having the center within metropolitan Chicago, I would strongly advocate for a feasibility study to determine the most appropriate location based upon the service needs of patients in Illinois"(IDPH p.50 comments/observations #2)*

The statements that best summarize the issues are the following:

- *"I am in support of further exploring the development of a brain center of excellence in the Chicago area, as proposed by Dr. Senno. We should further determine the level of need through a feasibility study to objectify our impression beyond the expert opinions of the task force team members, some of whom may be motivated by a desire to minimize competition with existing programs"(IDPH p.42 other #1)*

- *"This project should be given full consideration and a feasibility study should be undertaken. We face increasing need for brain injury services given an aging population of less-than-healthy individuals, increasing awareness of the impact of brain injuries, longevity of brain injury survivors (including those who would not have survived without recent advances in the neurosciences), and the return of veterans who may present with atypical neurological injuries (i.e., chronic traumatic encephalopathy). I felt that there were great attempts by some members of the task force to protect their turf. I would be far more interested in protecting this vulnerable patient populations, reducing the utilization of long-term care services, encouraging and maximizing opportunities to re-engage in the work force, and improving the quality of life for patients/families affected by brain injury. The status quo is unacceptable and too frequently lamented (among our peers and patients) for us to miss this valuable opportunity. We are locally blessed to have many of the best training institutions in the country within our service region. Our ability to identify and acquire the most talented doctors, allied clinicians, and supporting staff should be very high. By centralizing services, advocacy, education, and rehabilitation, the center of excellence should reduce the burden on patients, their families, and even their clinicians in providing for their needs for the duration necessary"(IDPH p.51 comments/observations #1)*

NOTE: The above comments were made in reference to questions and panel discussion regarding the spectrum of issues being faced at different points of brain injury or illness diagnosis, treatment and recovery as well as for different settings. (For specifics please see IDPH report)

All of the issues mentioned in clinical treatment, research, education and advocacy would certainly be addressed by a centralized center of excellence. However, lets not put the cart before the horse - the first step is a scientific needs assessment and feasibility/framework study that will analyze the current and future demographics of brain related disorders, the needs of patients and their families, the shortcomings of the current structure, the reimbursement environment, research potential as well as look at self sustaining revenue streams. It was stated that the Governor's Advisory Council on Brain and Spinal Cord Injury should be assigned to conduct the needs assessment. However, by its own admission this council has been dormant and not met since 2009, has great difficulty filling their long standing vacancies and has been silent in the area of brain injury medicine. As of the date this report, we have not seen evidence that the advisory council is reconstituting and historically the positions are difficult to fill and maintain. In addition the Advisory Council lacks the expertise in performing such a in- depth study.

At certain times a vote does not reflect the majority of opinions but rather those of the minority; therefore we are including letters in support of a needs assessment and feasibility/framework study.

Encouraged by the support of citizens and highly trained professionals present at the IDPH meetings, we should proceed with funding a feasibility study for the Brain Medicine Institute & Education - Research Center of Excellence. A feasibility study and needs assessment could be finished in 12 to 18 months. This study should be commissioned to a university or private company.

The existing facilities, as good as they are, are not centers of excellence for brain disorders but rather general rehabilitation centers and hospitals. The Brain Medicine Institute & Research - Education Center of Excellence will be at the forefront of research, education and technologies supporting future prevention, treatments, and cure therapies. Therefore, it will act as a catalyst and model for future centers. It will promote proactive problem solving, root cause and evidence based care, utilize integrative translational research, cooperate with existing centers, incorporate current federal health care plans, be cost effective, self sustainable and through dynamic employment stimulate the economy. Moreover, Illinois can be the leader in the field of Brain Medicine

As always, we deeply appreciate the time, effort and consideration put forth by the Governor's Office, The Office of the Speaker the House of Representatives, the Illinois Department of Public Health, the Review Committee (especially the recommendation made by Dr. Thornton) as well as acknowledge previous meetings with Senator Durbin and Illinois Secretary of State White, the recommendations and feedback has been invaluable. The information that was the result of these meetings will no doubt have a great impact on the services available to brain injured patients and families now and into the future.

ILLINOIS HOUSE OF REPRESENTATIVES

For the benefit of our State, our people and our veterans - we are in full support of proceeding with a needs assessment and feasibility/framework study. Please feel free to contact us for further details.

Sincerely,

Cynthia Soto
Representative, Illinois General Assembly

Ricardo G. Senno, MD, MS, FAAPMR

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NOTE: References have been incorporated into the body of this report
When a quote was taken from the IDPH report it has been placed within quotations marks, italicized and referenced
The preparation of this report has met all of the regulations and rules as set forth in the bylaws and the Open Meeting Act.

CC:

President Barack Obama
Governor Pat Quinn
Speaker Michael Madigan
Senator Dick Durbin
Dr. LaMar Hasbrouck, MD, MPH