

November 2003



Report of the

**Post-critical
trauma care
commission**



TABLE OF CONTENTS

Executive summary	5
Introduction and background	9
A Model Patient Bill of Rights and Responsibilities for Trauma Patients Receiving Post-critical Trauma Care in Ohio	19
Rehabilitation Service Locator	29
A statewide system of resource facilitation	33
Meeting the educational needs of children who have had traumatic injuries	41
Substance abuse and traumatic injury	49
The Ohio Trauma Follow-up Registry	55
Appendices	60

“Trauma care is a continuum that stretches from injury prevention to work force – school re-entry.”

Joseph W. Luria, M.D.,
*Chair, State Trauma Committee
 Cincinnati Children’s
 Department of Pediatrics*



EXECUTIVE SUMMARY

The Centers for Disease Control and Prevention (CDC) reported that, in 1999, 150,000 Americans died from injuries, and one in 10 survived an injury serious enough to require at least an emergency room visit (CDC Injury Research Agenda, 2002). Injuries are the leading cause of death for people ages 1 to 44. Of all hospital stays, 8 percent are due to injuries. Traumatic brain injury, spinal cord injury and burns tend to result in more serious and long-term consequences. It is estimated 5.3 million Americans have long-term disabilities from traumatic brain injury, with 80,000 new cases added each year. Another 200,000 Americans have disabilities due to traumatic spinal cord injury, with 11,000 new cases annually. Beyond limitations on movement and thinking, persons who survive traumatic injuries often experience post-traumatic stress disorder, depression, substance abuse, and problems at school, work or family.

According to data reported to the Ohio Trauma Registry, in the four-year period between Jan. 1, 1999, and Dec. 31, 2002, 78,200 Ohio citizens survived traumatic injuries severe enough to require at least two days of hospitalization or transfer to a trauma center. Falls and motor vehicle crashes accounted for two-thirds of these injuries. Traumatic brain injury and spinal cord injury resulted in the most severe injuries. Of these two types of injuries, 78 percent were due to falls and vehicular crashes.

Legislative authority and commission membership

Recognizing the importance of addressing this public health concern for the well-being of Ohio citizens, the Ohio General Assembly enacted House Bill (H.B.) 138 November 2000, creating the Post-critical Trauma Care Commission. H.B. 138 required the director of health organize and coordinate a temporary commission “to determine how to improve the accessibility, affordability, quality, and cost effectiveness of post-critical adult and pediatric trauma care.” The commission was required to complete its work by Nov. 3, 2003.

H.B. 138 also delineated a variety of participants for the commission and required the director of health appoint representation from those organizations and entities identified in the legislation. The enabling legislation established that “[C]ommission members shall have expertise in rehabilitation and retraining of injury victims, broadly represent relevant disciplines, and represent all regions of the state.” H.B. 138 required mandatory members, including representatives from the majority and minority parties of both houses of the Ohio General Assembly and certain specified state agencies as follows:

Ohio Bureau of Workers’ Compensation



Ohio Department of Aging



Ohio Department of Health



Ohio Department of Job and Family Services



Ohio Rehabilitation Services Commission



All five of these agencies have indicated their support for this final report. In fulfilling the charge for broad representation among many potential stakeholders, 28 organizations and associations were invited to nominate a primary and alternate representative to the commission. Agencies and organizations subsequently represented and supporting this report were:

Ohio Association of Health Plans	Ohio Farm Bureau Federation
Ohio Business Coalition on Health	Ohio Public Health Association
Ohio Department of Public Safety	Ohio Rehabilitation Association
Ohio Department of Alcohol and Drug Addiction Services	The Salvation Army
Ohio Department of Education	Ohio Legal Rights Service
Ohio Fire Chiefs' Association	American Physical Therapy Association
Ohio Hospital Association	Association of Ohio Philanthropic Homes, Housing and Services for the Aging
Ohio Nurses Association	Ohio State Chiropractic Association
Ohio Psychological Association	Ohio Association of Professional Fire Fighters
Ohio State Medical Association	Ohio Society of Trauma Nurse Coordinators
Brain Injury Association of Ohio	Ohio Osteopathic Association
Ohio Association of Rehabilitation Facilities	State Trauma Committee
Ohio Children's Hospitals Association	Central Ohio Trauma System

Findings

The state's system of delivering trauma services, and its enabling legislation, adequately address first response, transport to a trauma center, and reporting to the Ohio Trauma Registry. The system does not address post-critical trauma care adequately, with little or no attention given to reverse transport, follow-up services, and the roles of non-trauma center hospitals and other post-acute care providers in an overall state system of trauma services. The lack of systematic resources for persons with traumatic injuries increases the occurrence of unmet needs resulting in additional medical complications, loss of productivity, recurring injury, and reduced life satisfaction.

Post-critical trauma care of individuals coping with the consequences of an injury for which they have no preparation presents its own unique and complex set of challenges to patients, caregivers, health-care professionals, educators, and society at large. While the aftermath of a traumatic injury is challenging for many reasons, difficulties this patient population has accessing appropriate services via the existing health and human service systems are paramount.

Transitioning from the hospital or other acute-care setting into work, home, school, and community should be as seamless as possible to meet adequately the individual needs of persons requiring post-critical trauma care. Patient, family and provider access to up-to-date and comprehensive information concerning the array of resources that may be available in a community is key to successful community reintegration. However, in the end, the foundation for successful reintegration of the post-critical trauma care patient consists of access to services of the patient's choice, mutual respect for the strengths that patients and professionals bring to the reintegration process, early and ongoing consumer and family involvement, and promotion of self-direction and decision making.

Through deliberation, a series of recommendations evolved intended to address selected aspects of identified shortcomings in the current service delivery systems. The following recommendations are detailed in subsequent chapters of this report. Crucial to identifying topics and developing recommendation was the overarching goal of improving the accessibility, affordability, quality, and cost effectiveness of post-critical trauma care.

Recommendation 1: Providers and health-care facilities delivering post-critical care to trauma patients should adopt and comply with a patient bill of rights and responsibilities that recognizes the unique needs of those undergoing rehabilitation and recovery, and contributes to an effective and responsive patient-care program.

Recommendation 2: A rehabilitation service locator should be created and maintained to allow patients, their families, and acute-care providers to identify sources of needed follow-up rehabilitation services and compare salient characteristics of available providers.

Recommendation 3: To address the lifetime needs of Ohio citizens with disability due to injury, a system of resource facilitation should be established that provides access to information and services, increases the capacity for community support, and, as needed, coordinates services for individuals and their families.

Recommendation 4: To ensure the most appropriate educational experience for children who have had traumatic injuries, hospital and school personnel need additional training on issues for educational re-entry; classroom teachers need access to resources about reintegrating these students; and mechanisms are needed to ensure providers, internal and external to the school system, take a coordinated approach. More research is needed on educating students who have incurred traumatic injuries.

Recommendation 5: Organizations and agencies with an interest in minimizing the effects of substance use disorders on injury outcomes should be convened to identify opportunities for improving secondary substance abuse prevention and treatment for persons during and following trauma care.

Recommendation 6: A follow-up registry should be established to provide information about the long-term complications and outcomes for trauma-care patients. Data collection methodology should be an extension of the existing Ohio Trauma Registry and should provide information for local, regional and statewide prevention programming and health-care service planning.

Recommendation 7: Within the broader framework of responsibility for injury and trauma, leadership concerning longer-term issues and needs following traumatic injury should have a single, identifiable, and permanent location within Ohio's state government.



“The findings and recommendations presented in the Commission’s comprehensive and thoroughly researched report are sobering, yet hopeful.”

Tom Hayes
*Director,
Ohio Department of Job
& Family Services*

INTRODUCTION AND BACKGROUND

The Centers for Disease Control and Prevention (CDC) reported that, in 1999, 150,000 Americans died from injuries, and one in 10 survived an injury serious enough to require at least an emergency room visit (CDC Injury Research Agenda, 2002. See Injury Fact Sheet in appendix A). Injuries are the leading cause of death from in people ages 1 to 44. Of all hospital stays, 8 percent are due to injuries. It is estimated that 5.3 million Americans have long-term disabilities from traumatic brain injury, with 80,000 new cases added each year. Another 200,000 Americans have disabilities due to traumatic spinal cord injury, with 11,000 new cases annually. Injuries to limbs, the back, and eyes, as well as burn injuries, also are causes of disability. Beyond limitations on movement and thinking, persons who survive traumatic injuries often experience post-traumatic stress disorder, depression, substance abuse, and problems in school, work or family.

Trauma or traumatic injury means severe damage to or destruction of tissue that creates a significant risk of loss of life; loss of a limb; significant, permanent disfigurement; significant, permanent disability; and is caused by blunt or penetrating injury; exposure to electromagnetic, chemical, or radioactive energy; drowning, suffocation, or strangulation; a deficit or excess of heat. (O.R.C. 4765.01(N))

Trauma care means the assessment, diagnosis, transportation, treatment, or rehabilitation of a trauma patient by emergency medical personnel or by appropriately credentialed health-care professionals within the prescribed scope of practice.

Trauma center is any hospital verified by the American College of Surgeons.

Pediatric patient is a patient younger than 16 years of age.

Adult or geriatric patient is a patient who is not a pediatric patient.

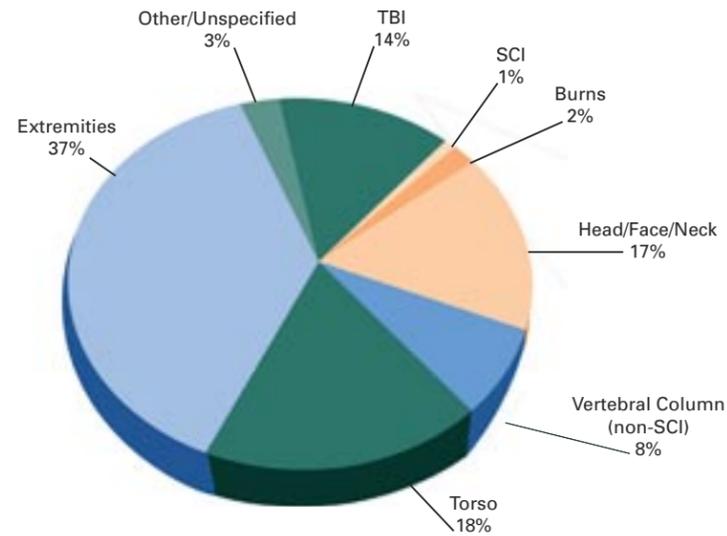
Post-critical trauma care refers to recognizing the needs of trauma patients requiring or undergoing rehabilitation and recovery care or services following release or transfer from a trauma center.

Over the past four years Ohio hospitals participating in the Ohio Trauma Registry reported that 78,205 patients survived traumatic injuries and were discharged from the hospital (see Figure 1). One in five patients had traumatic brain injury, spinal cord injury, or burns as their primary injury.

Injury patterns

N=78,205 (survivors)
January 1999 – December 2002

Injury Patterns based upon ICD-9-CM Diagnosis Code groups utilized in the Barell Matrix. Inj Prev 2002;8:91-6



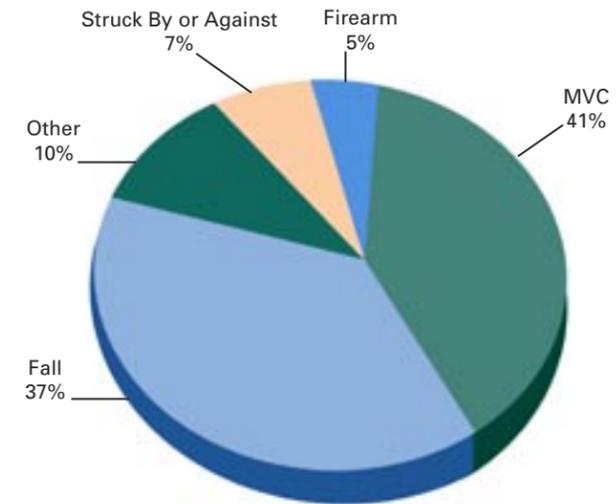
This graph depicts trauma patients whose length of stay in the intensive care unit was three or more days. Although there are many factors that affect a patient's length of stay in the intensive care unit, a higher severity of injury is one main reason. Thirty percent of these patients suffered traumatic brain injury, spinal cord injury or burns.

This graph shows the top five causes or mechanisms of injury that produced a primary injury to the spinal cord, severe enough to be reported to the Ohio Trauma Registry. Motor vehicle crashes, (including pedestrians and pedal cyclists) and falls account for more than 75 percent of all spinal cord injuries.

Top five causes of Spinal Cord Injury (SCI)

N=1,250 (survivors)
01/01/99 - 12/31/02

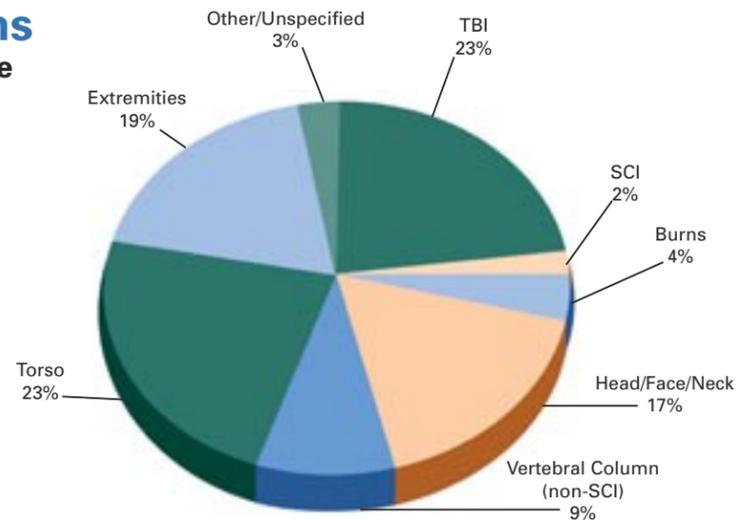
Cause of injury based upon ICD-9-CM External Cause of Injury Codes
MMWR 1997;46(RR-14)



This graph describes the top five causes or mechanisms of injury that produced a primary traumatic brain injury, severe enough to be reported to the Ohio Trauma Registry. Motor vehicle crashes, (including pedestrians and pedal cyclists) are the leading cause, followed closely by falls. Together they account for 78% of all traumatic brain injuries.

Injury patterns Length of stay in the ICU ≥ 3 days

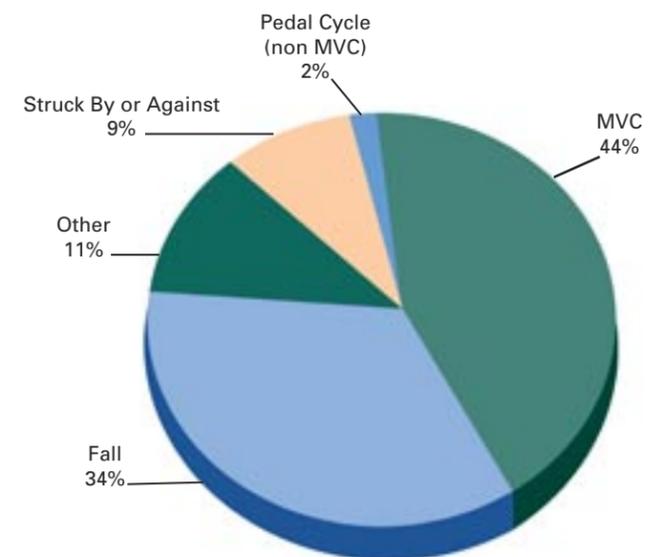
Injury patterns based upon ICD-9-CM Diagnosis Code groups utilized in the Barell Matrix. Inj Prev 2002;8:91-6



Top five causes of Traumatic Brain Injury (TBI)

N=18,731 (survivors)
01/01/99 - 12/31/02

Cause of injury based upon ICD-9-CM External Cause of Injury Codes
MMWR 1997;46(RR-14)



Commission authority

Recognizing the importance of addressing this public health concern for the well-being of Ohio citizens, in November 2000 the Ohio General Assembly enacted H.B. 138, creating the Post-critical Trauma Care Commission. (The full text of section 6 of Amended Substitute H.B. 138 as enacted by the 123rd General Assembly is included in appendix B.) H.B. 138 required the director of health organize and coordinate a temporary commission “to determine how to improve the accessibility, affordability, quality, and cost effectiveness of post-critical adult and pediatric trauma care.” The commission was required to complete its work by Nov. 3, 2003.

Appointments to the commission began March 2001, and the inaugural meeting was held July 2001, at the Ohio Department of Health. John D. Corrigan, Ph.D., from the department of physical medicine and rehabilitation at The Ohio State University, was appointed as commission chair and Cynthia Iske, M.S. O.T.R./L., from Children’s Hospital of Columbus was appointed as commission vice chair.

Guiding principles

Although in some contexts, post-critical trauma care is considered one component of the broader concept of trauma care, this report distinguishes it as a discipline with standards of care, treatment, and follow-up tailored to specific medical, social, psychological, and educational needs resulting from a traumatic incident that occurs post-injury and has potential lifetime consequences.

Post-critical trauma care of individuals coping with the aftermath of an injury for which they have no preparation presents its own unique and complex set of challenges to patients, caregivers, health-care professionals, educators, and society at large.

Post-critical trauma care is challenging for many reasons, chief among them is that it is often difficult for this patient population with diverse needs to fit easily into existing service systems.

The foundation for successful reintegration of the post-critical trauma-care patient into the home and community consists of access to services of the patient’s choice, mutual respect for the strengths patients and professionals bring to the reintegration process, early and ongoing consumer and family involvement, and promotion of self-direction and decision making.

Patient and provider access to up-to-date and comprehensive information concerning the broad array of post-critical trauma care resources available in a community is key to successful rehabilitation.

Transitioning from the hospital or other acute care setting into work, home, school, and community living should be as seamless as possible to meet adequately the specialized needs of the post-critical trauma-care individual.

Commission recommendations

The state’s system of delivering trauma services, and its enabling legislation, adequately addresses traumatic injury from first response, transport to a trauma center, and reporting to the Ohio Trauma Registry. The system does not address post-critical trauma care adequately, with little or no attention given to reverse transport, follow-up services, and the roles of non-trauma center hospitals and other post-acute care providers in an overall state system of trauma services. The lack of systematic resources for persons with traumatic injuries increases the occurrence of unmet needs. This results in additional medical complications, loss of productivity, recurring injuries, and reduced life satisfaction. Addressing these recognized shortfalls guided the commission in its work.

Through deliberation, a series of recommendations evolved intended to address identified shortcomings. These recommendations are detailed in subsequent chapters of this report. Crucial to identifying topics and developing recommendations was the overarching goal of improving the accessibility, affordability, quality, and cost-effectiveness of post-critical trauma care. Chapters in this report describe the following recommendations:

Patient bill of rights and responsibilities

Providers and health-care facilities delivering post-critical care to trauma patients should adopt and comply with a Patient Bill of Rights and Responsibilities that recognizes the unique needs of those undergoing rehabilitation and recovery, and contributes to an effective and responsive patient care program.

Rehabilitation service locator

A rehabilitation service locator should be created and maintained to allow patients, their families, and acute care providers to identify sources of needed follow-up rehabilitation services and compare salient characteristics of available providers.

Statewide system of resource facilitation

To address the lifetime needs of Ohio citizens with disability due to injury, a system of resource facilitation should be established that provides access to information and services, increases the capacity for community support, and, as needed, coordinates services for individuals and their families.

Meeting educational needs of children who have had traumatic injuries

To ensure the most appropriate educational experience for children who have had traumatic injuries, hospital and school personnel need additional training on issues for educational re-entry; classroom teachers need access to resources about reintegrating these students; and mechanisms are needed to ensure all providers, internal and external to the school system, take a coordinated approach. More research is needed on educating students who have incurred traumatic injuries.

Substance use and traumatic injury

Organizations and agencies with an interest in minimizing the effects of substance use disorders on injury outcomes should be convened to identify opportunities for improving secondary prevention of substance abuse and treatment for persons during and following trauma care.

Ohio trauma follow-up registry

A follow-up registry should be established to provide information about the long-term complications and outcomes for trauma care patients. Data collection methodology should be an extension of the existing Ohio Trauma Registry and should provide information for local, regional and statewide prevention programming and health-care service planning.

On-going responsibility for post-critical trauma care issues

The commission made a final recommendation pertaining to the continued attention that will be required to pursue these recommendations. While many agencies and organizations should be involved in implementation of the above recommendations, there is a need for a single focus of oversight and leadership related to the issues the commission raised, as well as other challenges affecting individuals after their initial care. Specifically, the commission recommends that, in the process of identifying the locus of leadership and responsibilities in Ohio government for issues of injury and trauma, leadership for concerns about the needs and services following critical care should have a single, identifiable location within the resulting structure.

Commission process

Recommendations toward improvement of post-critical trauma care would have to first determine where post-critical care begins. It would require identification of appropriate stakeholders, the needs of the patient and the systems of care, as well as the processes by which accessibility, affordability, cost-effectiveness and quality of care and services can be ensured.

Five areas of study or concentration were set forth for the commission in the legislation:

- Transfer of trauma patients from regional trauma centers to other facilities;
- Physical, psychological, and vocational rehabilitation of trauma patients;
- Reemployment of trauma patients;
- Social support mechanisms for families of trauma patients;
- Mitigation of the effects of pediatric and geriatric trauma.

In its inaugural meeting, the commission determined that, before a comprehensive work plan could be developed, certain questions would need to be addressed and answered to the extent possible. These were initially identified as:

- Determining what quantitative data was available and accessible to the commission;
- Assessing where the current system in Ohio is in the delivery of post-critical trauma care;
- Identifying where the needs for improvement exist;
- Identifying where the current system is succeeding and in turn failing;
- Determining to the extent possible what direction the trauma system needs to take in the future to ensure improvement in the accessibility, affordability, cost-effectiveness, and quality of post-critical trauma care.

Data needs initially identified to address these questions included:

- The number of patients entering rehabilitation and other post-acute care as a result of traumatic injury. The existing state trauma registry was suggested as a source for some of this data;
- Review models from other states that have undertaken to quantify post-critical trauma care needs;
- Accounting of rehabilitation and post-acute care options currently available statewide;
- Data on traumatic injury recovery, rehabilitation, and costs to Medicaid and workers' compensation.

While considerable effort was made to identify sources of this information, one of the commission's first conclusions was objective data about the eventual consequences of trauma were not available in Ohio or nationally.

In January 2002, it was decided the most advantageous use of the level of expertise and experience on the commission, plus the means to ensure concentrated efforts would be to divide the commission into three committees:

- Medical rehabilitation – Priorities categorized into four basic issues: geographic availability; insurance and coverage; service matching; and patient tracking. By looking at these issues, this committee hoped to be able to recommend a methodology wherein referring hospitals and other initial treating facilities had a better means of matching patient acuity and service needs with service provision.
- Disability – Directed attention to the issues of re-entry into the workforce or education system; examined resources for social support; and inquiry into the impact of age and family on long-term rehabilitation.

- Data and follow-up registry – Provided objective information on which to base public and private policy decisions about post-critical trauma care. The committee recommended a system that allows research on the nature and scope of consequences of trauma, and provides an informed basis for meeting the needs of those injured.

After meeting in committees for 15 months, the commission systematically reviewed, evaluated and revised specific recommendations brought forth by the three committees. Five areas of recommendations emerged, and in the course of deliberations two additional focus areas were identified: substance abuse and on-going responsibility for post-critical trauma care issues. Committees and the commission as a whole engaged in monthly, iterative discussions of the recommendations, their rationale, and suggestions for implementation. This work concluded at the end of June 2003, when the commission reached consensus on the content of its final report.

From July 2003, through the conclusion of the commission's work, efforts focused on disseminating the report and recommendations. Special emphasis was given to gaining support for the final report from sponsoring agencies and organizations, as well as the means by which the commission's findings would be shared with the Governor and the Ohio General Assembly.

Benchmarks

November 2000	Substitute H.B. 138 effective date.
February 2001	Ohio Department of Health (ODH) staff directed to organize and provide administrative support to the Post-critical Trauma Care Commission.
March 2001	State agencies, organizations, and professional associations invited to nominate representatives to the commission.
April 2001	Letters of appointment sent to selected representatives.
July 2001	Ohio Commission on Dispute Resolution and Conflict Management Inaugural meeting held at ODH.
August 2001, to May 2002	Monthly commission meetings.
May 2002	Committees' preliminary recommendations presented to full commission.
January 2003	First draft of final report presented to full commission.
February to June 2003	Bi-monthly commission meetings to review, evaluate and revise committee recommendations, rationale and suggestions for implementation.
June 2003	Commission approved revised final report for distribution to sponsoring organization and agencies.
September 2003	Letters supporting the final report were received from numerous agencies and organizations.
November 2003	Final report was presented to the Governor and the Ohio General Assembly.

Membership and collaboration

H.B. 138 delineated a variety of participants for the commission and required the director of health appoint representation from organizations and entities identified in the legislation. H.B. 138 established that “[C]ommission members shall have expertise in rehabilitation and retraining of injury victims, broadly represent relevant disciplines, and represent all regions of the state.” Throughout its deliberations and study, the commission relied on the expertise, experience, and affiliations of its membership not only for first-hand contributions to the process, but to provide external contributory sources as well. Therefore, the commission’s final work product, which follows in subsequent parts of this report, reflects a compilation of data and information from multiple sources provided through the good offices of commission representatives and their supporting organizations.

Mandatory members required by the legislation included representatives from the majority and minority parties of both houses of the General Assembly and certain specified state agencies as follows:

Ohio Bureau of Workers’ Compensation
Ohio Department of Aging
Ohio Department of Health
Ohio Department of Job & Family Services
Ohio Rehabilitation Services Commission

In fulfilling the charge for non-state agency representation, department of health staff developed a listing of 54 possible sources for commission membership. From this original listing, 28 organizations and associations were invited to nominate a primary and alternate representative to the commission. Agencies and organizations represented by members and endorsing this report are:

Brain Injury Association of Ohio	Ohio Farm Bureau Federation
Ohio Association of Health Plans	Ohio Public Health Association
Ohio Business Coalition on Health	Ohio Rehabilitation Association
Ohio Children’s Hospitals Association	The Salvation Army
Ohio Department of Public Safety	Ohio Legal Rights Service
Ohio Department of Alcohol and Drug Addiction Services	American Physical Therapy Association
Ohio Department of Education	Association of Ohio Philanthropic Homes, Housing and Services for the Aging
Ohio Fire Chiefs Association	Ohio State Chiropractic Association
Ohio Hospital Association	Ohio Association of Professional Fire Fighters
Ohio Nurses Association	Ohio Society of Trauma Nurse Coordinators
Ohio Psychological Association	Ohio Osteopathic Association
Ohio State Medical Association	State Trauma Committee
Ohio Association of Rehabilitation Facilities	Central Ohio Trauma System

Over the course of the commission’s work the original membership altered somewhat due to personal and agency/organizational commitments. The final membership roster by name is included in appendix C of this report.

Acknowledgements

The chair, vice chair and members of the Post-critical Trauma Care Commission wish to also acknowledge the support received from the following sources over the course of its deliberations:

- Roy Croy, Ohio Department of Health, Bureau of Community Health Care Facilities and Services for his steady hand and sage advice.
- Linda Vojtush, executive secretary, Ohio Department of Health, Bureau of Community Health Care Facilities and Services for her tireless administrative support in scheduling and setting up meetings, and in recording, preparing, and distributing commission meeting minutes in an always reliable and timely manner.
- Virginia Haller, M.D., Ohio Department of Health, for her keen interest in the commission’s work and valuable insights into injury prevention and Ohio’s activities in that field.
- Margaret Lewis, Fred Bartenstein, and Ed Krauss of the Ohio Commission on Dispute Resolution and Conflict Management for their facilitation in the early stages of commission meetings. The advice, assistance, and expertise provided by these professional facilitators contributed immeasurably to start up, organization, and work planning for the commission’s later endeavors.
- Judy Roush, commission member and her parent organization, the Ohio Farm Bureau, for providing excellent accommodations for the commission’s meetings.
- The Ohio Bureau of Workers’ Compensation for their invaluable assistance in preparing this final report.



“Many of the issues of the Commission studied are relevant to workplace traumas and the injured worker population served by the Ohio Bureau of Workers’ Compensation.”

James Conrad
Administrator/CEO,
Ohio Bureau of
Workers’ Compensation

A MODEL PATIENT BILL OF RIGHTS AND RESPONSIBILITIES FOR TRAUMA PATIENTS RECEIVING POST-CRITICAL TRAUMA CARE IN OHIO

Recommendation: Providers and health-care facilities delivering post-critical care to trauma patients should adopt and comply with a patient bill of rights and responsibilities that recognizes the unique needs of those undergoing rehabilitation and recovery, and contributes to an effective and responsive patient care program.

Vision

Philosophies and guiding principles for treating trauma patients, and the treatments themselves, should reflect not only medically and technologically advanced practices, but also will reflect the highest regard for the uniqueness of the patient, the sanctity of the caregiver-patient relationship, and an awareness that the likelihood of successful rehabilitation increases when patients, families, and caregivers demonstrate respect, cooperation, dignity, and responsibility.

Description of the problem

Richard J. Mullins wrote in an article published in 1999, “Many authors have identified the publication of *Accidental Death and Disability: The Neglected Disease of Modern Society* in 1966...as the inaugural event in what was to become a sustained effort sponsored by government to control ‘accidental injury’ as a health problem...In this publication, strong government leadership was proposed as essential in the effort to solve the ‘neglected epidemic’ of death and disability from injury. The authors detailed the problem’s enormous magnitude: the tragedy of early death among the young, the burden of disability, and costs of billions of dollars. The authors emphasized that the scope of the problem was all the more alarming when contrasted with the public’s apathetic attitude toward trauma care.” (1)

Recognizing the still significant relevance of that milestone white paper, as well as the evolution of medicine and public health in this arena, this chapter puts forth recommendations meant to inform public policy and public awareness, and most importantly, empower trauma patients as they move through the process of healing and regaining their independence.

The continuum of care required by trauma patients is a broad spectrum that will, in most cases, expose these individuals to medical care and social support systems that are, to varying degrees, coordinated, provided by qualified health professionals, and responsive to each patient’s specialized needs. Across this continuum of care, from triage to rehabilitation, trauma patients encounter a host of often challenging and stressful experiences, as well as the need to make decisions for which they usually have no preparation or prior experience. As a result, the importance of the caregiver-patient relationship becomes a touchstone for trauma patients’ successful rehabilitation.



In his article, "Gift From Within," Frank M. Ochberg, M.D., refers to a principle of individuality that states, "Every individual has a unique pathway to recovery after traumatic stress." (2) Although Dr. Ochberg refers to the emotional impact of traumatic stress (emotional disorder vs. physical injury) resulting from events such as violence, abuse, crime, or other environmental stress, his principle translates in its entirety to individuals coping with the aftermath of traumatic injury. While it is difficult to experience medical diagnosis and treatment in the acute care setting, the needs of trauma patients become even more unique as they attempt to rehabilitate and integrate themselves back into a society more equipped and comfortable in accommodating its most healthy and productive members. Learning to drive, coping with disfigurement, re-entering the work force, dealing with depression, and a host of other challenges that face the trauma patient require special attention and a commitment on the part of professionals and support persons to recognize that

their patient, family member, or friend has unique needs, personal preferences, and a pathway to recovery not exactly like any other. It is within this context that concern for patients' rights needs to be considered and that caregivers assume responsibility for informing and explaining these rights to patients and their families.

In *American Independence and the Right to Emergency Care*, Robert Baker, Ph.D., observes that, "Asserting a right is a powerful statement in the American political rhetoric. In this country, medicine has recognized patients' rights for over 150 years. As early as 1886 there was a proposal to 'draw up...a Bill of Rights which shall secure patients from any injustice from the votaries of science.'" (3)

The American Hospital Association (AHA) first adopted a patient bill of rights in 1973. Subsequently, on Oct. 21, 1992, the AHA Board of Trustees approved a revised version of its original bill of rights. The AHA developed these rights with the expectations that hospitals and health-care institutions would support these rights in the interest of delivering effective patient care. A random review across an array of health-care providers and advocacy organizations reveals many such institutions and providers have developed patient bills of rights that incorporate the principles reflected in the AHA model, which is a practice the AHA promotes and supports. In its introduction, the AHA Patient's Bill of Rights states that, "The American Hospital Association encourages health care institutions to tailor this bill of rights to their patient community by translating and/or simplifying the language of this bill of rights as may be necessary to ensure that patients and their families understand their rights and responsibilities." (4)

Proposed strategies

Goal

Caregivers and the facilities within which they treat and minister to trauma patients undergoing rehabilitation and recovery will adopt, formally through written and visible public displays, as well as informally, through their personal norms and approaches to care, a code of rights and responsibilities that contributes to and creates a nurturing, respectful, and outcome-based environment.

Principles

- The Model Patient Bill of Rights and Responsibilities will augment, and not supplant, existing and similar bills of rights already in use in facilities that provide post-critical trauma care;
- The Model Patient Bill of Rights and Responsibilities incorporates rights and responsibilities specific to patients who are experiencing challenges unique to post-critical trauma care and are undergoing rehabilitation and recovery related to their trauma;
- The Model Patient Bill of Rights and Responsibilities recognizes that adults and children have unique sets of challenges and may require standards of care, treatments, and follow-up tailored not only to their specific medical and trauma-related circumstances, but also to their unique age and stage-of-life-based needs;
- The Model Patient Bill of Rights and Responsibilities is only one of many tools contributing to the creation and maintenance of a culture that reflects an ingrained and inherent respect for the uniqueness of the individual and an environment where caregivers and families feel safe interacting collegially to enhance the physical, emotional, and spiritual healing of the trauma patient.

Keeping in mind Dr. Ochberg's "unique pathway to recovery," the Post-critical Trauma Care Commission's Medical Rehabilitation Committee reviewed a number of existing patient bills of rights used by a variety of health-care institutions and facilities. The committee particularly searched for patient bills of rights drafted for post-acute patients with complex and varied needs and more specifically, for those addressing post-critical trauma patient needs. Although the review did not employ formal research methodologies, it did reveal that the use of general patient bills of rights is widespread in the health-care profession, particularly in hospitals. Patient bills of rights specific to the needs of trauma patients were not found readily.

The commission decided developing a Model Patient Bill of Rights and Responsibilities for Trauma Patients Receiving Post-critical Trauma Care in Ohio would be a valuable contribution to ensuring this vulnerable population receives the highest quality care in settings that respect the rights and roles of patients, families, and caregivers. To that end, the commission recommends that the Model Bill of Rights and Responsibilities contained herein be adopted as a model for use by institutions and facilities that provide post acute and/or rehabilitative treatment or care, as well as those that provide social services that support such care, to trauma patients in Ohio.

The following is the *Post-critical Trauma Care Commission's Model Patient Bill of Rights and Responsibilities for Trauma Patients Receiving Post-critical Trauma Care in Ohio*. The end of the chapter includes a list of patient bills of rights that were reviewed as part of the research and drafting process.



Model Patient Bill of Rights and Responsibilities for Trauma Patients Receiving Post-critical Trauma Care in Ohio

The Post-critical Trauma Care Commission, as authorized by H. B. 138 of the 123rd General Assembly, recommends providers and health-care facilities administering post-critical care to trauma patients in Ohio adopt and comply with a patient bill of rights and responsibilities that recognizes the unique needs of individuals undergoing rehabilitation and recovery, and contributes to an effective and responsive patient-care program. Further, the commission recommends facilities adopt the following model patient bill of rights and responsibilities or one that reflects its precepts and principles.

Patient rights

This facility's post-critical trauma care patients, including adults, children, and parents or guardians of children who are patients, have the following rights:

1. Patients have the right to receive appropriate, individualized care and treatment, and to:

- Up-to-date, comprehensive information about their condition, including appropriate care and treatment options, and to have that information explained in terms they are able to understand;
- Participate as an equal partner of the health team in all decisions concerning their care, including the right to accept, refuse, modify, or discontinue treatment;
- Be advised of the risks of any treatment, procedure, or therapy and the right to be informed of the possible medical consequences of accepting or refusing a course of action;
- Be informed of clinical trials, experimental treatments, or unproven research protocols that may be available for their treatment or rehabilitation, as well as the right to accept or refuse participation in such research;
- Expect the best possible care, including specialty care, from providers trained, credentialed, and experienced in managing their condition. Should a facility or provider not be able to provide appropriate care at any time during the course of treatment, patients have the right to expect timely referrals to providers able to provide such care;
- Receive appropriate care free from unlawful discrimination of any type.

Pediatric patients have the right to:

- Be treated in American College of Surgeons (ACS)-verified pediatric trauma centers. Adult centers that have not undertaken a pediatric review process parallel to the adult verification process are not interchangeable with pediatric trauma centers;
- Be treated in pediatric rehabilitation centers that focus on school re-entry, family-centered care, and community reintegration. Adult rehabilitation facilities with pediatric resources are not interchangeable with Commission for Accreditation of Rehabilitation Facilities (CARF)-accredited pediatric rehabilitation facilities.

2. Patients have the right to receive care that is coordinated and ongoing, as needed, across a broad spectrum of settings, including home, hospital, nursing home, school, workplace, therapeutic, and rehabilitative care settings. These include the right to:

- Expect continuity of care, as well as appropriate follow-up care, that focuses on helping them achieve the highest possible degree of functionality, greater independence, and a rapid return to productivity;
- Expect prompt and effective communication among the health-care professionals attending to their treatment, recovery, and rehabilitative needs, including timely sharing of information related to medical history, individualized plans of care, prognosis, treatment, and follow-up regimens when multidisciplinary provider teams are involved;
- Seek multiple opinions from professionals on their care team in any setting, or from sources of their own choosing, without fear of experiencing negative consequences as the result of seeking additional or alternate information;
- Know the names, credentials, experience, and professional status of their caregivers, as well as which caregiver has primary responsibility for coordinating and managing their care;
- Expect their family members are encouraged to participate as members of the care team so they can provide care continuity as the patient navigates the health-care system.

3. Patients have the right to be treated at all times with respect, dignity, and consideration and to expect health-care professionals to place high priority on safeguarding their privacy. These include the right to:

- Participate in decisions concerning their health care based on their religious beliefs, spiritual values, or cultural identity;
- Expect consideration of their personal privacy and comfort during physical examinations, therapeutic interventions, or rehabilitative interventions;
- Access their medical records and to expect that no other persons, other than those involved with their care or allowed by law, have access to their records without the patient's written permission;
- Expect confidentiality in communications with their caregivers and to have their health-care providers maintain their records and communications maintained confidentially, unless patients waive their confidentiality rights;
- Prepare advance directives to express end-of-life preferences.

4. Patients have the right to receive assistance and support to maintain, and whenever possible, enhance, the quality of their lives. These include the right to:

- Be informed of available resources throughout the course of their treatment (and especially as part of the discharge process), including appropriate support groups; pastoral/spiritual care; psychological counseling; employment counseling; local community social services; national referral sources, including associations and organizations; government sources for information and assistance; protective or advocacy services; translator services; patient education programs; and other services as appropriate and available;
- Expect that their health-care professionals will take the necessary measures to ensure that patients will, to the extent possible, be relieved of pain throughout the course of their treatment and as part of long-term follow-up;
- Be approached and treated at all times as a "whole" person and to expect that all aspects of treatment, follow-up, and support reflect their emotional, physical, spiritual, and psychological needs. Families of pediatric patients have the right to be viewed as extensions of the patient and provided with information and services that enable them to create an environment in which the pediatric patient can thrive.

5. Patients have the right to understand the policies and procedures of a facility or provider, including those concerning patient conduct, payment and billing, and complaint and appeal processes. These include the right to:

- Be advised of and understand any policies or rules that apply to their conduct in their role as a patient, including expectations regarding compliance with instructions from their health-care team, provision of accurate personal medical information to caregivers, notification of appointment cancellations, and other patient responsibilities, as specified by the provider;
- Obtain complete and detailed information concerning the costs of their care. Patients have the right to itemized listings, as well as total charges, for the services they have received. Patients have the right to an explanation of the charges for any and all items they do not understand;
- Understand what, if any, third-party payors have responsibility for any portion of their bills, as well as any co-payments, deductibles, or non-covered services for which the patient may be responsible;
- Obtain information on how to receive assistance in paying their bills, including referrals to programs for which the patient may be eligible;
- Be advised of any complaint, grievance, or appeal processes available to them related to their care or payment for services.

Patient responsibilities

Post-critical trauma care patients of this facility, including adults, children, and the parents or guardians of children who are patients, have the following responsibilities:

- 1. Patients have the responsibility to provide, to the best of their ability, full and complete information concerning matters related to their health, including the responsibility to:**
 - Inform providers and/or caregivers of their past medical history, current diagnoses and/or symptoms, treatment plans developed by other providers, current and past medications, past hospitalizations, and other information related to their care and treatment;
 - Tell their providers of any changes to their medical condition, adverse reactions to treatment or medications, and changes to contact information, including phone numbers and addresses.
- 2. Patients have the responsibility to follow through with agreed upon plans of treatment, including scheduled appointments and self-care, including the responsibility to:**
 - Follow the instructions and read or have read and explained to them educational materials, special instructions, or self-care plans provided by the health-care team to ensure the best possible treatment outcomes;
 - Inform their providers, and ask questions if they are uncertain or not clear, regarding any aspect of their health care, including planned treatment and/or follow-up regimens, medication dosages and schedules, or instructions from physicians, nurses, or other caregivers;
 - Attend follow-up medical appointments, inform provider offices in a timely manner if there is a need to cancel an appointment, and reschedule appointments promptly;
 - Understand that, if they refuse treatment or do not follow the agreed upon treatment plan, they assume responsibility for outcomes resulting from their choices;
 - Inform their caregivers or health-care team of non-medical concerns related to their diagnosis and treatment, including those of an emotional, psychological, spiritual, or family-related nature, so appropriate referrals can be made to address concerns promptly.
- 3. Patients have the responsibility to meet the financial obligations of their health-care treatment, including the responsibility to:**
 - Understand and/or ask questions concerning the costs of their care and to ask specific and detailed questions regarding their provider bills and any third party coverage;
 - Pay their providers promptly and to provide information to the provider or insurer/third party as required or requested to facilitate coordination and payment of benefits;
 - Advise providers and insurers/third parties of changes to employment, addresses, phone numbers, and other information used to identify or contact patients.
- 4. Patients have the responsibility to demonstrate respect and dignity to other patients and health-care staff in the environment where care is provided, including the responsibility to:**
 - Be considerate of others in the health-care setting, including being polite and respectful, ensuring appropriate behavior by their guests, assisting to control unnecessary noise, distractions, and prohibited activities, such as smoking, and honoring the rights of others in the health care setting;
 - Be respectful of the facility's property and the property of other patients.
- 5. Patients have the responsibility to follow the rules, regulations, and policies of their health-care setting, as well as for knowing their rights in the setting, including the responsibility to:**
 - Follow facility rules concerning patient conduct and to ask questions regarding policies that they do not understand. Additionally, patients have the responsibility to limit the number of their visitors, per the facility's policy, and, to the best of their ability, ensure their visitors adhere to facility rules and regulations;
 - Know and understand their rights concerning care and conduct in the facility and to follow the facility's administrative process for addressing concerns about their rights.

Implementation

Implementation of a strategy to adopt, endorse, and promote a Patient Bill of Rights and Responsibilities for Trauma Patients Receiving Post-critical Trauma Care in Ohio should take the following steps:

- 1. The Model Patient Bill of Rights and Responsibilities for Trauma Patients Receiving Post-critical Trauma Care in Ohio** should be endorsed and promoted through legislative action (e.g., joint House and Senate resolution).
- The Ohio Association of Rehabilitation Facilities (OARF), the Ohio Hospital Association, the Ohio Department of Health, the Ohio Department of Public Safety, Emergency Medical Services, the Ohio Department of Job & Family Services, the Ohio Department of Aging, the Ohio Bureau of Workers' Compensation, the Ohio Chapter Committee on Trauma of the American College of Surgeons, and others as appropriate, should collaborate to promote and implement the following initiatives:
 - Encourage facilities that provide post-critical trauma care to review their existing patient bills of rights with an eye toward including rights that specifically reflect trauma care principles as expressed in the commission's report. The commission recommends its bill of rights be promoted as a model rather than a mandate, with a preference that existing structures be used to ensure patient-focused environments that foster quality outcomes. Further, the commission recommends the stakeholders identified above communicate to regulatory bodies, such as the Commission for Accreditation of Rehabilitation Facilities (CARF), that inclusion of trauma-related rights in a facility's patient bill of rights become part of the accreditation review process.
 - Develop and lead an awareness campaign that publicizes and promotes the *Model Patient Bill of Rights and Responsibilities* to educate facilities and their caregivers on the expectations, standards, and benefits associated with establishing an environment that encourages openness, teamwork, and mutual respect.
 - Develop and implement a best practices program to publicly recognize and reward facilities and caregivers who demonstrate exemplary effort in providing post-critical trauma care to trauma patients in Ohio, with particular emphasis on innovative initiatives that reflect productive and successful caregiver-family partnerships.

Legislative support

Representatives of the Post-critical Trauma Care Commission, including the chief executives of the state agencies named in H.B. 138, will impress upon the Ohio General Assembly members the importance of formalizing a *Model Patient Bill of Rights and Responsibilities for Trauma Patients Receiving Post-critical Trauma Care in Ohio*. The commission will stress its proposed model be promoted and supported through a joint resolution of the House and Senate or some other legislative vehicle that underscores the importance of the principles contained within the model. Should the leadership of the General Assembly be so inclined, they may also sponsor legislation that would require any facility providing care specific to this population include as part of their operating procedures the proposed model bill of rights and responsibilities or a similar credo that incorporates the same principles. Although the commission does not at this time recommend this specific model be mandated for use by facilities, an eventual developmental step may be introducing legislation that would require facilities providing care to this population to

adopt and incorporate into their operating procedures and existing bills of rights language that clearly delineates and specifically protects the rights of post-critical trauma care patients. The commission does not anticipate that this would require a significant amount of funding. However, establishing a specific source of funds for this purpose in the Ohio Department of Health would elevate its profile and signal to the public and their elected representatives the importance attached to it.

Accrediting body support

The commission recommends discussions ensue with representatives of the major accrediting bodies for facilities that serve trauma patients receiving post-critical trauma care regarding patient rights-related accreditation requirements. Information sharing with CARF, the Ohio chapter of the American College of Surgeons, the Ohio Hospital Association, the Ohio Health Care Association, and others as appropriate, could focus on incorporating these principles in the oversight and accrediting activities and standards maintained and enforced by these organizations. Additionally, specific strategies for regular review and feedback for facility practices related to patient and family involvement could be an ongoing topic of discussion. The commission believes open and visible discussion of these issues, as well as their elevation to a place of importance at least equal to those of a clinical or operational nature, would contribute to the potential for improved patient outcomes, as well as an enhanced quality of life for patients and providers.

Awareness campaign

Patients receive post-critical trauma care in a variety of settings throughout Ohio. Once a patient has received initial treatment at a designated trauma center, there are numerous options for the next phases of care. Patients may receive acute rehabilitation services through an inpatient facility (hospital, nursing or long-term care facility, stand-alone rehabilitation facility, etc.) or may be referred to an outpatient rehabilitation setting (vocational rehabilitation, sports medicine, etc.). It is the commission's contention the concepts and principles of the Model Patient Bill of Rights and Responsibilities are equally applicable to any facility that provides care for this vulnerable population. Therefore, the commission recommends the previously identified stakeholders collaborate to undertake a public awareness campaign targeted toward the promotion of the model bill of rights and best practices related to the demonstration of patient and family-centered principles. Promotional activities could include direct mailings to providers that would include the commission's vision and goals, as well as a copy of the model bill of rights; references to established Web sites, including the resource locator, the long-term care consumer guide, and others; and examples of best practices of facilities in Ohio that emphasize collaborative, team-oriented, and respectful treatment of individuals coping with the ongoing challenges of trauma rehabilitation.

Best practices

The commission recommends the previously identified stakeholders, in collaboration with interested organizations, agencies, and individuals, establish a formal mechanism to recognize and publicize best practices demonstrated by post-critical trauma care providers throughout Ohio. Incentives and possibilities for reward are as broad as the imagination. Public acknowledgment and praise for creative use of the model bill of rights, for example, is just one jumping-off point for a variety of strategies and initiatives that could be advertised and promoted throughout the industry and to the public. The commission believes bringing to the forefront of the public agenda positive and ongoing attention concerning challenges and opportunities facing trauma patients will contribute to meaningful forces of change and empowerment.

Footnotes

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4. **AHA Board of Trustees**, *A Patient's Bill of Rights*, American Hospital Association, Oct. 21, 1992.

Patient bills of rights reviewed

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Centura Health Patient Bill of Rights, **Littleton Adventist Hospital**, Littleton, CO.

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Code of Ethics, **International Chiropractors Association of California**, Board of Directors, as amended Sept. 21, 1996.

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Patient's Bill of Rights, **American Academy of Pain Management**, Sonora, CA, July 16, 2001.

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Resident Bill of Rights Summary and Residents' Responsibilities/Rules, **St. Augustine Health Campus**, Cleveland, OH.

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"...the recommendation to develop a service locator fits well with our No Wrong Door project..."

Joan W. Lawrence
Director, Ohio Department of Aging

REHABILITATION SERVICE LOCATOR

Recommendation: A rehabilitation service locator should be created and maintained to allow patients, their families, and acute-care providers to identify sources of needed follow-up rehabilitation services and compare salient characteristics of available providers.

Vision

The intent of the locator service is to assist trauma patients and their families to identify and select prescribed discharge services that meet their needs.

Description of the problem

Trauma patients, family members, and health-care professionals lack comprehensive information about health-care services (medical and therapeutic) available in Ohio to treat trauma patients after discharge from the critical/acute care hospital setting. Trauma patients' medical and therapy needs post discharge can be varied and complex depending on the severity of the injury. Often hospital discharge planning falls short of appropriately matching the trauma patient's needs with the most appropriate and best quality health-care provider. Health-care services frequently change, which poses a challenge to health-care professionals to know all the service options available (based on quality and location). There is no comprehensive listing of resources for professionals or consumers regarding service availability. A rehabilitation service locator provides a comprehensive service listing. The locator allows the user to conduct a self-directed search of the most appropriate service based on their post-acute needs. Services identified in the locator are intended to assist patients throughout the continuum from pediatrics through adulthood to geriatrics.

The service locator concept was developed to address the Post-critical Trauma Care Commission's mission. The service locator will help families and professionals identify services in a specific geographic location and match this to their service needs. Each facility listed in the service locator will identify the funding they accept. There is also the possibility to link to sites/contacts similar to MedAssist Inc., which is a free service for patients to qualify for various funding sources. Companies such as this will assist patients in obtaining Medicaid, Bureau of Children with Medical Handicaps (BCMh), charitable services or other types of services. They have a mission to assist uninsured patients through the often difficult and confusing process of applying for public assistance to satisfy their obligation to the medical provider. The locator database will gather various data points that address quality, such as accreditation, outcomes, and patient satisfaction. If each patient is matched appropriately with the right facility, we would anticipate the cost effectiveness and quality aspects of the mission are met.

The overriding principle of the service locator is to provide information regarding quality health-care service availability and enhancing consumer choice. The service locator will enhance and, in some cases, facilitate the transfer decision-making process from acute care to the next appropriate level of care. The locator can be Web-based and have a user-friendly look-up function or search capability. The user could input specific information about the patient together with the patient's needs and, through the

search function, could find compatible service providers that meet the patient's specifications. Although the specific services categories maintained on the locator may change as the system matures, it is recommended the following services be included initially: location, demographics, years of operation, types of services offered, types of professionals available, funding accepted, patient characteristics, accreditations, admission/discharge criteria, outcomes, linkages to consumer guides (e.g., a guide to finding the right rehabilitation facility).

The purpose of the rehabilitation service locator is to provide a comprehensive tool of service availability. To bridge the gap between the trauma patient, family and caregivers with health-care professionals it is proposed that a Web-based rehabilitation service locator be created. Trauma patients and their families, as well as health-care providers, can use this locator service (e.g., discharge planners, social workers, physicians, case managers and insurers). Similar in principle to the Ohio Long-Term Care Consumer Guide at www.ltcoho.org, which assists consumers and professionals in identifying long-term nursing services, the rehabilitation service locator would be designed to meet the trauma patient's specific needs.

Benefits of the rehabilitation service locator are:

- Trauma patients and their families will be able to access up-to-date information regarding the availability of post-acute health-care services that might otherwise be unknown;
- Health-care providers (discharge planners, social workers, physicians, case managers and insurers) will be able to access up-to-date information regarding the availability of post-critical/acute health-care services that might otherwise be unknown;
- The Web-based locator can be populated and updated easily as facility information changes.
- The Web-based locator can be accessed easily from the home or office;
- Standardization of facility services and detail will provide comparison opportunity;
- Trauma patients will be more likely to receive quality post-critical/acute services in their communities;
- Smaller facilities will be able to market their services appropriately to a larger audience;
- Funding for development and maintenance will be absorbed by contributing facilities;
- Facilities will be more likely to update their individual information;
- The opportunity for consumer and insurer funding comparisons will be improved.

Proposed strategies

Goal

The goal of the Rehabilitation Service Locator is to promote patient and caregiver choice for post-acute discharge services.

Principles

1. The Rehabilitation Service Locator Web site should be developed to house comprehensive information about Ohio's inpatient and outpatient rehabilitation services.
2. The Rehabilitation Service Locator Web site should be designed to provide users with information regarding facilities and the services they offer (e.g., location, demographics, services offered, professionals available, funding accepted, patient characteristics, accreditation, admission criteria and outcomes).

3. The locator's target population should be Ohio trauma patients and their families; however it should be available for use by other consumers and health-care professionals in their search for inpatient and outpatient rehabilitation services.
4. Locator information should be updated routinely to maintain its accuracy, and links should be provided to related Web sites (e.g., the Brain Injury Association of Ohio).

Implementation

1. Create Rehabilitation Service Locator Web site: It would be ideal to piggyback with the long-term care Web site locator; however, may need to consider the trauma system's Web site location, if the cost of conformity to the existing long-term care locator is too significant.
 - a. Develop specific data points for the service locator.
 - b. Develop plan for submission: The locator information is supplied by facilities and providers voluntarily, using standardized definitions and data formats, and funded by a nominal fee paid by submitting facilities.
 - c. Initial mailing of a letter introducing the service locator to various inpatient and outpatient rehabilitation providers in Ohio. Enclosed will be the data collection form with the needed information.
 - d. Developing the plan for ongoing maintenance — possibly through annual subscription fees paid by health-care providers to be listed on the Web site.
 - e. Once created, a major initiative will involve marketing the locator to the potential users. A full-scale awareness campaign will be needed to reach health-care providers, agencies that serve this population, the trauma patients and their families.
2. Create a satisfaction measure: A final step of implementation is to create a measure of the locator's effectiveness that can be used to justify its existence and secure ongoing funding but mostly to tweak its functionality for the user. A defined set of criteria should be developed that includes utilization (e.g., number of hits) and user satisfaction. Contract with an outside service/company to evaluate customer satisfaction results uniformly. The goal is to display results that can be compared evenly across facilities, similar to the insurance companies and LTC Web site.
3. Create a multidisciplinary group: Although the Rehabilitation Service Locator recommendations list a multitude of service types for inclusion on the locator, it is felt that a multidisciplinary group is needed to further analyze and develop standard definitions for service types using published national references (e.g., the *Brain Injury Association of America Provider Directory*). It will be important that facilities included in the locator abide by the standard definitions when describing their services so the user can make valid comparisons and decisions.





“The report does offer a sound roadmap for Ohio to follow as it constructs a comprehensive system of post-critical care for Ohioans who suffered traumatic injuries.”

John M. Connelly
*Executive director, State of Ohio
 Rehabilitation Services Commission*

A STATEWIDE SYSTEM OF RESOURCE FACILITATION

Recommendation: To address the lifetime needs of Ohio citizens with disability due to injury, a resource facilitation system should be established to provide access to information and services, increase the capacity for community support and, as needed, coordinate services for individuals and their families. The resource facilitation system should model the one the Brain Injury Association of Ohio is developing, but be expanded to include all causes of disability due to injury and extended to all regions of the state.

Vision

Ohio citizens with long-term needs due to traumatic injury, as well as professionals who work with them, should have easy access to the best available knowledge and resources about injury and its effects. A statewide system of resource facilitation (1) should be in place to provide a comprehensive yet economic approach to promoting informed choices. Knowledge of the resource facilitation system and its use should be widespread, allowing timely use of its services.

Description of the problem

Children and adults with long-term needs due to trauma require assistance from knowledgeable and trained individuals to help them identify, obtain and maintain the services and supports they require to maximize recovery and reintegration into home and community life. Assistance is particularly critical for those individuals who do not fit within eligibility criteria established for the major human service agencies. In fact, most of the state agencies that comprise today’s human service system were established before large numbers of individuals began surviving significant and debilitating traumatic injuries.

Though the make-up of the disability population has changed over the last quarter of a century — with the proportion of individuals with long-term needs due to trauma on the rise — the service system has not responded to these population shifts. A conclusion from the 1995 report by the National Conference of State Legislators titled, *What Legislators Need to Know About Traumatic Brain Injury*, (2) applies to others with long-term needs due to traumatic injury:

These people have diverse needs that make it difficult for them to fit easily into existing service systems. State delivery systems tend to be based on diagnosis (developmental disabilities, mental illness, special health-care needs) or on financial need, such as Medicaid. These services are not always available or appropriate for people with brain injuries. Federal funding streams have shaped state services, making it difficult to restructure or expand existing services . . .” (2)

Unquestionably the fragmented, bureaucratic nature of the current human service system presents a significant obstacle to accessing needed assistance and supports for individuals with long-term needs due to trauma. For those with cognitive deficits following trauma, the very nature of their disability

compounds their difficulty in working through the bureaucratic maze to acquire assistance that may be available to them. Additionally, their need for information, resource coordination and problem-solving assistance may persist for years following their injury. For example, of those using the Brain Injury Association of Ohio's Helpline and Community Support Network programs during 2002, 16 percent were three months or less post injury, 20 percent were between four and 12 months post injury, 21 percent were between 13 and 36 months post injury, 27 percent were between 37 months and 10 years post injury and 16 percent were more than 11 years post injury. (6)

Without assistance, individuals with long-term needs associated with trauma experience significant barriers and delays in finding and accessing services available to them through the current service system. Failure to obtain needed services and supports in a timely and coordinated fashion, in turn, puts them at greater risks for common secondary complications, such as depression, substance abuse, and long-term unemployment, as well as other negative outcomes.

In the 1989 Interagency Head Injury Task Force Report (3) issued by the U.S. Department of Health and Human Services, "Encouraging the use of 'care manager' systems that operate throughout all stages of care, from acute care through community reentry" was listed as an implementation strategy to achieve a national agenda with six key recommendations. In 1990, Ohio enacted legislation (Amended Substitute H.B. 594) (4) to create the Head Injury Program and its Advisory Council in the Ohio Department of Health. (The program has since been transferred to the Ohio Rehabilitation Services Commission and is known as the Brain Injury Program and Advisory Committee.) Three of the program's eight legislated purposes pertain to facilitating access to information and services:

- Identify existing services in this state to assist survivors of head injury and their families;
- Promote service coordination for survivors of head injury and their families;
- Explore options for delivering case management services to residents of this state who are survivors of head injury.

The on-going need for assistance accessing resources was validated through the National Institutes of Health's Rehabilitation of Persons with Traumatic Brain Injury Consensus Statement (5) synthesized from testimony provided at an Oct. 26 through 28, 1998, Consensus Development Conference. It states, "Community-based, non-medical services should be components of the extended care and rehabilitation available to persons with traumatic brain injury. These include but are not necessarily limited to "...case manager programs to support practical life skill redevelopment and to help navigate through the public assistance and medical-rehabilitative care systems..." (5)

The need to assist individuals with spinal cord injuries is also apparent from statements and recommendations stemming from several meetings sponsored by the Centers for Disease Control and Prevention. The first, convened in November 1999, was titled, "Future Directions for Community-Based Spinal Cord Injury Program Research and Development." Held in Atlanta, approximately 20 spinal cord injury researchers and public health officials reviewed community-based methods for preventing secondary conditions of spinal cord injury. At a March 2001 follow-up meeting to further develop the national research agenda, interagency representatives *"discussed the progression of health needs following spinal cord injury and identified gaps in current service delivery for persons with spinal cord injury, developed an inventory of activities being conducted across federal agencies and explored a coordinated response to better serve this population."* (6) (Italics added.)



A system of resource facilitation

A resource facilitation system should be a comprehensive, coordinated program with three basic functions: 1) provide timely and up-to-date information to individuals, families, providers, and the public; 2) assist individuals who have been injured in obtaining available services and supports to maximize their health, independence, and integration into family, work, and community; and 3) build the local community's capacity to address their needs. Three program components offer graduated levels of assistance matching the degree of help required at a given point in time:

- A toll-free, statewide information and resource (I&R) telephone service;
- Regional offices addressing local needs and resources in all 88 Ohio counties;
- Individual service coordination, as needed, for more complex needs.

The I&R telephone service is designed to be the primary point of entry into the system, and represents the least intensive level of assistance in the program continuum. Those with greater resource facilitation needs are linked to regional offices, or if their needs are intensive and on-going, to programs offering the assistance of individualized service coordination. As the intensity of individuals' needs for resource facilitation services increase or decrease, they move up or down the program continuum to obtain the appropriate level of assistance. Individuals may drop out of the system entirely if their resource facilitation needs are met, and on-going assistance is no longer required, with the assurance they can return for help at a later time, should it become necessary. Core administrative, information management and communication services underpin these three programmatic components, promoting the development of an integrated, efficient and effective system.

The Brain Injury Association of Ohio (BIA-Ohio) has developed and operates two of the three program components of a resource facilitation system. BIA-Ohio operates the toll-free Helpline, and six of 15 proposed Community Support Network offices. BIA-Ohio also provides Infrastructure Support Functions. (See the schematic at the end of this chapter).

BIA-Ohio's system has been developed incrementally over a period of almost 15 years as advocates have been able to acquire funding. Financial support has come primarily from grants awarded by the Brain Injury Advisory Committee at the Ohio Rehabilitation Services Commission, drawing upon state appropriations and federal match through the U.S. departments of Education, and Health and Human Services. BIA-Ohio has acquired supplemental support to help sustain and/or further develop the system through private foundation awards, as well as contributions from individuals and corporations. Donated office space and miscellaneous support services offered by the agencies that house the Community Support Network programs also contribute to their sustainability and promote cross-agency communication and collaboration. However, funding fluctuations associated with time-limited grant awards have made further development and stabilization of the system difficult.

The third programmatic component of resource facilitation — individual resource coordination — offers the most intensive assistance, but is also the least developed in Ohio. Only a few programs provide specialized individual service coordination for persons with brain injury. Though there is a demand for this type of specialized assistance, funding to sustain programs is lacking and, where it can be cobbled together, is unstable for any significant duration. Compounding the problem is the fact that, though some individuals with long-term needs due to trauma are eligible for case-management services provided through other systems, the personnel within those systems typically are unprepared to recognize or cope with their special needs. While training and certain accommodations could remedy this situation, no systematic approach has been developed to do so.

Proposed strategy

Goal

Extend the resource facilitation system developed for individuals with brain injury so information, services and supports are available to all Ohio citizens who experience disability as a result of traumatic injury.

Principles

The envisioned resource facilitation system should:

- Be integrated and comprehensive, not duplicative;
- Respect individual choice and promote self-direction;
- Encourage consumer and family involvement;
- Value home and community-based supports so individuals may take their places in the most integrated settings;
- Promote inclusiveness and cultural sensitivity in terms of outreach, program design and implementation.

Implementation

This proposal for development of a resource facilitation system for persons with a traumatic injury responds to the director of health's charge and the Post-critical Trauma Care Commission's purposes as identified in H.B. 138 by:

- Promoting accessibility to existing services and supports related to individuals' physical, psychological, vocational rehabilitation, re-employment and social support needs;
- Capitalizing on an established, well-developed and nationally recognized conceptual framework for the system's design and quality assurance mechanisms;
- Saving costs by building on a partially developed system that has been phased in over a 15-year period;
- Promoting efficiency and program cohesiveness through cross-system communication, collaboration and training;
- Encouraging self-direction and cost-efficiency through a three-tiered system that promotes choice and matches individuals' level of need to the appropriate level of assistance.

The following steps are suggested for implementation of a resource facilitation system for Ohio citizens who incurred traumatic injury.

- 1) Convene a stakeholder's workgroup to expand the BIA-Ohio system's design to accommodate the needs of all populations with long-term needs due to injury, and to promote cross-agency buy-in and consumer involvement.
- 2) Draw on expertise and leadership from the Ohio departments of Health, Aging, Jobs and Family Services, and Public Safety, along with the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and The Ohio State University's Traumatic Brain Injury Model System, (7) to guide the workgroup's efforts and synchronize them with national trends and initiatives.
- 3) Establish incremental achievement benchmarks, along with corresponding outcome, quality assurance measures, and reporting protocols, to ensure forward progression leading to the system's full implementation.
- 4) Develop memorandums of agreement outlining state-agency roles and actions to contribute to the system's efficiency and effectiveness. Issues addressed in the memorandums may include, but not necessarily be limited to, activating the current system to better serve individuals with long-term needs due to trauma through personnel training, program modifications, outreach, joint initiatives, and resource identification and development.
- 5) Build on and fortify those components and infrastructure of the proposed resource facilitation system thus far developed, so they may serve as a starting point for the system's full implementation.

- 6) Monitor and take necessary action to integrate the long-term needs of individuals with disability due to trauma into contemporaneous system change initiatives. Such opportunities may include: the New Freedom Initiative/Ohio Access and related systems change grants, Ticket to Work and Work Incentives Improvement Act of 1999, and Ohio's newly adopted rules for implementation of Individuals with Disabilities Education Act.
- 7) Develop awareness campaigns, targeting the general public and personnel within service providing agencies to promote knowledge and use of the resource facilitation system. Campaigns should address the growing number of individuals who experience disability due to traumatic injury and provide contact information to access the resource facilitation system.
- 8) Ensure individuals who staff Ohio's resource facilitation system are knowledgeable about challenges associated with disabilities due to trauma and assistance offered through the complex service delivery system.
- 9) Adhere to values promoting development of a culturally sensitive resource facilitation system that is holistic, person and family centered, and encourages choice, self direction, and availability of community-based supports.

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- 4 **Amended Substitute H.B. 594** creating the Office on Head Injury and Advisory Council at the Ohio Department of Health, signed into law in 1990.
- 5 **National Institutes of Health, National Institutes of Child Health and Development.** (1999). *Report of the NIH Consensus Development Conference on the Rehabilitation of Persons With Traumatic Brain Injury*. Bethesda, MD.
- 6 **National Center for Injury Prevention and Control.** *Injury Fact Book 2001-2002*. Atlanta, GA: Centers for Disease Control and Prevention; 2001.
- 7 **Ohio Regional Traumatic Brain Injury Model System** (Ohio Valley Center (OVC) for Brain Injury Prevention and Rehabilitation), one of 17 research and demonstration grants funded through the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) to establish the Traumatic Brain Injury Model Systems of Care. The OVC Model Systems grant is administered through the Department of Physical Medicine at The Ohio State University; its principal investigator is John Corrigan, Ph.D. Model systems grants primarily focus on: 1) developing and demonstrating a model system of care for persons with traumatic brain injury, stressing continuity and comprehensiveness of care; and 2) maintaining a standardized national database for innovative analyses of traumatic brain injury treatment and outcomes.

Brain Injury Association of Ohio Resource Facilitation System		
One	Two	Three
<p>Toll-free Statewide Helpline</p>  <p>Operated by BIAOH</p>	<p>Community Support Networks</p>  <p>Operated by BIAOH; dotted areas on map show the 6 CSN locations currently funded</p>	<p>Individual Service Coordination</p>  <p>Only a few programs exist in Ohio offering Individual Resource Facilitation Services (case management); access to programs serving other disability populations is limited due to eligibility criteria that often excludes people w/BI.</p>
Infrastructure Support Functions (ISF)		
<p>Administrative: Administrative support for the system's first two program components (Helpline and Community Support Networks), provided by the Brain Injury Association of Ohio, includes financial and personnel management, and maintenance of the Information Management System.</p>		
<p>Information Management System: At the system's center are relational databases maintained on a server and accessible to Helpline and Community Support Network staff via the Internet. Information stored in the databases includes a statewide inventory of 72 types of programs and services, locations and meeting times for support groups around the state, contact information for distributing educational materials and event notices, and records on individuals seeking assistance through the program – the nature of their needs, how they learned about the service, how helpful they found it to be, etc. The IMS supports management, evaluation, reporting and development aspects of the program.</p>		
<p>Communication & Outreach: The system's primary "point of entry" is through the toll-free Helpline. Its number is included in various resource directories, and is publicized through public service announcements, at trainings and events and through literature distribution.</p>		
<p>Education & Training: Is required for: 1) resource facilitation personnel at each of the system's three levels; 2) professionals and service providers within established systems; and 3) individuals with long-term needs due to trauma, their families and advocates. Content should include: causes, consequences of injuries due to trauma, risks and prevention strategies for secondary complications, person-centered planning, understanding the current service system and how to navigate it, natural supports, basic advocacy skills, and assistance available through the Resource Facilitation System.</p>		
<p>Interagency Collaboration: The system relies heavily on cross-system, interdisciplinary collaboration in its design, development and maintenance. Informal networking as well as formalized agreements to collaborate in areas of training, planning, problem solving, resource sharing and development and coordination of services at an individual level are essential to the System's success.</p>		
<p>Development: Identification and acquisition of federal, state and local (formula and fee-for-service) funding, supplemented with private sector support from diverse sources Resource.</p>		



"...Ohio must exercise leadership in addressing over time the continuing challenges facing post-critical trauma care patients. This is especially true for children, since they face obstacles in achieving educational success and in recovering from devastating injuries so early in life."

Andrew Carter
President,
Ohio Children's Hospitals Association

MEETING THE EDUCATIONAL NEEDS OF CHILDREN WHO HAVE HAD TRAUMATIC INJURIES

Recommendation: To ensure the most appropriate educational experience for children who have had traumatic injuries, hospital and school personnel need additional training on issues for educational re-entry. Classroom teachers need access to resources about reintegrating these students; and mechanisms are needed to ensure providers, internal and external to the school system, take a coordinated approach in providing care. More research is needed on educating students who have incurred traumatic injuries.

Vision

Educational services should be affordable and accessible, and should ensure high educational expectations and achievement for children, including those who have experienced traumatic injuries.

Description of the problem

Educating children with traumatic injury can be a complex task for the educational system when the child is discharged from the hospital or rehabilitation setting. The child brings a medical label of traumatic injury with them to the school system, and the local educational agency (LEA) is responsible for providing appropriate reentry and educational services for the child.

At this point, confusion and/or frustration may occur for the patient, the family, and the educational agency on how to provide appropriate educational services since post-critical trauma or traumatic injury is not a disability category listed under the *Individuals with Disabilities Education Act* (IDEA). Traumatic injury, as defined by H.B. 138, can include such injuries as nerve or spinal cord injury, burns, vascular injury, limb amputation, internal organ injury, bone fractures, or brain injury.

Ensuring a seamless system for children with traumatic injury transitioning from the hospital to home, school, work, and community living is one area of concern. Transition and educational intervention requires a multidimensional approach and the use of a variety of strategies and resource materials. Although educators are providing services to meet the needs of children with traumatic injury, programs have not been developed adequately to meet the educational needs of these children. The solution is to provide training and support for teachers, therapists, and staff in the schools.

Another area of concern is the lack of knowledge and understanding of what is available in the LEAs under IDEA to meet the needs of the child with traumatic injury. IDEA provides the avenue for the educational agencies to evaluate the children to determine the educational and related service needs. In addition, IDEA requires documentation of services to meet the child's needs with a free appropriate public



education (FAPE) in the least restrictive environment (LRE). Under IDEA, there is not a disability category of traumatic injury. However, LEAs can provide services to children with traumatic injury(ies) identified as:

- Other health impaired;
- Orthopedically impaired;
- Multiple disabled;
- Traumatic brain injury;
- Emotional disturbance;
- Cognitive disabled.

The solution for this concern is not only training but ensuring a variety of methods for disseminating information pertaining to FAPE.

Another area of concern is the lack of controlled empirical studies regarding educational reintegration. There are discrepancies between hospital numbers of children treated with post-critical trauma and the lower incidence and prevalence of children receiving FAPE, as identified under IDEA in the educational system.

In addition, few empirical studies have been conducted to validate specific special education intervention to ensure children with traumatic injury are successful in school. The solution would be to conduct the research with controlled studies over a period of time.

The fourth area of concern is to ensure children with traumatic injury who are receiving services from a number of different agencies (i.e., medical, educational, mental health, mental retardation, drug, alcohol, and social) do not slip through the cracks of the system. Many times, it is not clear who will accept management responsibility for the child. The solution will require a system change on the part of a variety of agencies.

Definition of terms

Cognitive disability (mental retardation) - [3301-51-01(F)(3)(b)] Means significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child's educational performance. (i) Significantly subaverage general intellectual functioning refers to an intelligence quotient of 70 or below as determined through a measure of cognitive functioning administered by a school psychologist or a qualified psychologist using a test designed for individual administration. Based on a standard error of measurement and clinical judgment, a child may be determined to have significant subaverage general intellectual functioning with an intelligence quotient not to exceed 75. (ii) Deficits in adaptive behavior means deficits in two or more applicable skill areas occurring within the context of the child's environments

and typical of the child's chronological age peers. (iii) A child who was identified by an Ohio school district as having a developmental handicap as of the effective date of this rule shall be considered a child with a disability if the child continues to meet the definition for developmental handicap set forth under *Rules for the Education of Handicapped Children*, effective 1982, and shall be eligible to receive special education and related services in accordance with *Operating Standards for Ohio's Schools Serving Children with Disabilities*, effective July 1, 2002.

Emotional disturbance - [3301-51-03(F)(3)(e)] Means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance: (i) An inability to learn that cannot be explained by intellectual, sensory, or health factors; (ii) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers; (iii) Inappropriate types of behavior or feelings under normal circumstances; (iv) A general pervasive mood of unhappiness or depression; (v) A tendency to develop physical symptoms or fears associated with personal or school problems. The term includes schizophrenia. The term does not apply to children who are socially maladjusted, unless it is determined they have an emotional disturbance.

Individuals with Disabilities Education Act (IDEA) - This is the federal law that supports special education and related service programming for children and youth with disabilities. Formerly know as the Education for the Handicapped Act (EHA), IDEA has its roots in Public Law 94-142 (the Education of All Handicapped Children Act), which originally was enacted in 1975 to establish grants to states for educating children with disabilities.

Amendments structure IDEA into four parts: part A addresses general provisions; part B covers the Assistance for Education of All Children with Disabilities; part C covers Infants and Toddlers with Disabilities; and part D addresses National Activities to Improve the Education of Children with Disabilities.

IDEA requires FAPE, which includes special education and related services, be available to children and youth with disabilities in mandated age ranges.

Orthopedic impairment - [3301-51-01(f)(3)(h)] Means a severe orthopedic impairment that adversely affects a child's educational performance. The term includes impairments caused by congenital anomaly (e.g., clubfoot, absence of some member, etc.), impairments caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).

Other health impairment - [3301-51-01(F)(3)(i)] Means having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness to the educational environment. This condition is due to chronic or acute health problems, such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia, and adversely affects a child's educational performance.

Paraprofessional services - [3301-51-01(CC)] According to *Operating Standards for Ohio's Schools Serving Children with Disabilities*, paraprofessional services include services provided by school, county board of mental retardation and developmental disabilities, and other educational agency employees who are trained adequately to assist in the provision of special education and related services to children with disabilities. Paraprofessionals work under the supervision of teachers, intervention specialists, and/or related service providers. Other titles used to identify these service providers include teacher assistants, educational aides, and job coaches.

Traumatic brain injury - [3301-51-01(F)(3)(I)] According to *Operating Standards for Ohio's Schools Serving Children with Disabilities*, traumatic brain injury means an acquired injury to the brain caused by an external physical force or by other medical conditions, including but not limited to stroke, anoxia, infectious disease, aneurysm, brain tumors and neurological insults resulting from medical or surgical treatments. The injury results in total or partial functional disability or psychosocial impairment or both, which adversely affects a child's educational performance. The term applies to open or closed head injuries, as well as to other medical conditions that result in acquired brain injuries. Injuries result in impairments in one or more areas such as cognition, language, memory, attention, reasoning, abstract thinking, judgment, problem-solving, sensory, perceptual and motor abilities, psychosocial behavior, physical functions, information process and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.

Proposed strategies and implementation

Strategy 1: Training and support is needed for teachers, therapists, and staff in the LEAs

Hospital and school personnel should receive training to plan for school reintegration and transitions. Presently, there are not enough personnel who have an understanding of the unique behaviors and educational challenges of these children or who know what teaching strategies can be applied to assist learning.

Implementation:

- Mandate professional development
 - Pre-service: When working with universities, include information about post-critical trauma education (special education and regular education) courses and in allied health careers.
 - In-service: Require educational agency staff to receive quality training in the special needs of this population.
- Provide technical assistance programs for ongoing instructional assistance.
- Develop teacher-based competencies at the national and state levels.
- Ensure teachers have access to personnel with a specialization in post-critical trauma; investigate through cost-benefit analysis the potential benefit of such teacher support.
- Investigate the effectiveness of having trained teams available to consult in a particular area versus traditional teacher trainings.
- Ensure paraprofessionals are included in school-based training. Investigate the effectiveness of para-educator training on child outcomes.

- Parents should be informed of present and future consequences for learning and life-long living of such an injury.
- If a medical-care facility is involved, a correct diagnosis of a post-critical trauma must be noted. This information should be provided to educational agencies prior to discharging the child. One suggestion would be for hospitals to note this diagnosis in their discharge instructions.
- Agencies providing services must have a coordinated professional development effort.

Strategy 2: An organized and easily accessible system of disseminating information must be developed.

A variety of books, manuals, educational brochures, and magazine and journal articles contain information about reintegrating children with post-critical trauma into the community or students with post-critical trauma into schools, and what teaching strategies work. While these materials exist, they do not seem to be in the hands of educators who can best use them.

Implementation:

- Web sites that will assist individuals in accessing a variety of information and materials must be organized.
- Place credit-bearing courses from universities on the Internet for a broader access to training and information.
- Contact existing sources for materials/resources before placing additional research or development funds into creating training materials that presently exist and can be adapted.

Strategy 3: Conduct scientifically based research

While there are many anecdotal and well-devised application articles regarding educating this population, there are very few well-controlled empirical studies over time.

Implementation:

There are many areas of pediatric research that are pressing equally for funding. Regarding educational reintegration, two areas were determined to be critical for research:



- Incidence and prevalence: Discrepancies between hospital numbers of youth treated with post-critical trauma and special education numbers need to be clarified. Recommendations include:
 - Fund a comprehensive longitudinal study in which children with all degrees of traumatic injury are followed for many years using valid formal and informal assessment procedures to determine progress for educational need and qualitative methods to document post-injury educational experiences and quality of life.
 - Identify early predictors of long-term educational need through studies of outcome, especially in the case of children with mild to moderate injuries.
 - Include a question about head injuries and brain diseases in special education and kindergarten screenings with positive responses triggering attention to issues common in this population. In addition, follow-up research on how early identification impacts the students educational success.
- Teacher techniques: While a number of recommendations exist for strategies employed to educate children with post-critical trauma, few empirical investigations have been undertaken to validate specific special educational interventions or management practices. Research recommendations include:
 - Investigate effectiveness of educational interventions that draw from the existing body of relevant educational research.
 - Emphasize in teacher trainings and educational materials development the existing research-based teaching methodologies while highlighting the flexibility and experimental orientation often required when applying existing strategies to meet these children's needs.
 - Educational research must meet the scientific research requirements of the no child left behind philosophy.

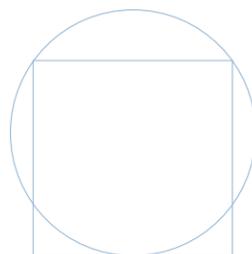
Strategy 4: To effectively meet the needs of children with traumatic injury, a systems change in health-care facilities and educational agencies need to occur



Transitions for children or students may require a number of agencies' involvement (medical, educational, mental health, mental retardation, drug, alcohol, and social). Many slip through the cracks of these systems, and often it is not clear who will accept management responsibility for the case.

Implementation:

- Fund projects that will reward collaborative efforts for children or students with post-critical trauma or traumatic injury.
- Convene task force meetings of individuals who represent agencies who can make a change in policy and procedures.
- Educate policy makers about the special needs of this population and encourage them to require collaboration in agencies when providing funding for ongoing operation and special projects.



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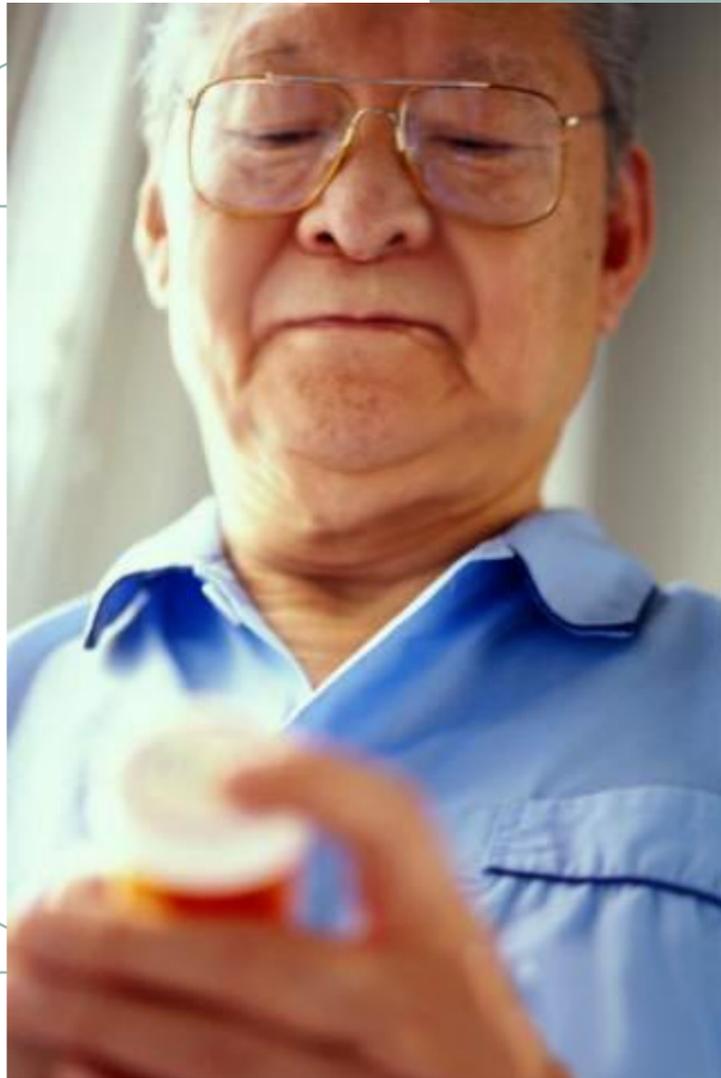
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“Please be assured that the Ohio Psychological Association strongly supports the recommendations of the Commission.”

Michael O. Ranney, MPA
Executive director,
Ohio Psychological Association

SUBSTANCE ABUSE AND TRAUMATIC INJURY

Recommendation: Organizations and agencies with an interest in minimizing the effects of substance use disorders on injury outcomes should convene to identify opportunities for improving secondary prevention of substance abuse and treatment for persons during and following trauma care.

Vision

Ohioans who have substance use disorders and incur a traumatic injury should be provided with accurate and timely information about how to reduce their dependence on alcohol and other drugs. Information on ways that have been proven effective for both reducing substance use and the risk of subsequent injury should be provided. For patients requiring formal substance abuse treatment to accomplish these ends, there should be ready access to service providers who are able to work with people with disability due to injury.

Description of the problem

Alcohol use frequently is a factor in all types of injury. Substance use has long been recognized as a major, independent risk factor in unintentional injuries, as well as intentional injuries such as assaults, homicides, and suicides. In 40 percent to 50 percent of fatal motor vehicle crashes and 25 percent to 35 percent of non-fatal crashes, at least one participant is legally intoxicated. Alcohol has been found to play a role in more than half of homicides, more than half of burns, almost half of hypothermia and frost bite cases, and 40 percent of falls. Intoxication is present in between one-quarter and one-third of individuals incurring traumatic brain or spinal cord injuries. Although the role of drugs other than alcohol in traumatic injuries has not been investigated as thoroughly, studies have shown cocaine, amphetamines, and marijuana, especially in combination with alcohol, play a significant role in traumatic injuries of all kinds.

Whether or not an individual is intoxicated at the time of injury, a significant proportion of individuals who incur injuries have histories of chronic substance use disorders. Waller (1988) conservatively estimated 20 percent to 25 percent of all patients hospitalized for injury are alcoholics or have a drinking problem. Studies of patients receiving rehabilitation for either traumatic spinal cord or brain injury have found more than half of adolescents and adults have diagnosable histories of substance use disorders (Heinemann, et al, 1988; Corrigan, 1995). Rivera, et al (1993a) found evidence of chronic alcoholism in up to three-fourths of adult trauma patients.

There are multiple ways in which alcohol and other drug use increases the risk for injury. Intoxication:

- Decreases the level of alertness;
- Impairs motor function, diminishing coordination and balance, and increasing reaction time;
- Impairs judgment, resulting in poor decision making;
- Diminishes perception and cognitive abilities;



- Increases risk taking behavior and especially including feelings of invulnerability (especially among adolescents and young adults);
- Reduces inhibitions and intensifies feelings of anger and depression;
- Is associated with increased violent behavior;

Additionally, chronic use may render a person more medically fragile, resulting in more severe injuries. Obtaining illicit drugs may place an individual in an unsafe environment. Beyond substance use being a risk factor for injury, injury is a risk factor for substance abuse. Contributing factors include:

- Self-medication for pain;
- Seeking relief of frustration resulting from changes in lifestyle due to disability;
- Feelings of entitlement due to lost abilities;
- Filling time to reduce boredom resulting from changed social roles and reduced daily structure;
- Seeking relief from loneliness or isolation frequently caused by disability.

Persons who experience one traumatic injury are at greatly increased risk for re-injury. For example, after one traumatic brain injury, a person is three times more likely to have a subsequent injury than someone in the general population. After a second injury, the relative risk for a third increases to eight times the norm (Annegers et al, 1980). Untreated alcohol and other drug use disorders play a significant role in re-injury. Rivera and colleagues (1993b) found the re-admission rate for more than 2,500 adult patients treated at a level I trauma center was 2.5 times more likely for patients who were intoxicated at their initial admission. Patients who showed physiological signs of chronic alcohol abuse were 3.5 times more likely to be re-admitted.

While alcohol and other drug use are associated highly with injury, it also has been found that an injury may provide an opportunity for intervention to change contributing behaviors. There is extensive evidence that traumatic injury creates a teachable moment that is a unique opportunity in the course of the addiction process (Gentilello et al, 1988; Reyna et al, 1985; Soderstrom and Cowley, 1987). When a patient makes a connection that the injury is a direct result of alcohol and other drug use, they become more open to accepting education or treatment, which can in turn reduce the alcohol or other drug consumption and improve the course of subsequent recovery. The impact of even brief interventions that take advantage of this opportunity can be quite dramatic (Gentilello et al, 1999). Thus, systematic screening and education have been recommended for acute treatment settings working with injured patients (Hungerford and Pollock, 2002).

Despite the potential benefits of screening and education, these activities are not carried out routinely in trauma centers. Limited resources during hospitalization, the singular focus on treating the immediate injury, and the perceived futility of making referrals for follow-up treatment all provided barriers to addressing substance abuse routinely. While there may be a greater opportunity during the course of rehabilitation to identify histories of substance use disorders, dramatically shorter lengths of stay and greater medical acuity of rehabilitation patients has reduced the attention given to issues viewed as psychosocial in nature.

Proposed strategies

Goal

Develop a structure in which the multiple agencies and organizations that serve persons with substance use disorders and traumatic injuries can meet, educate each other, identify specific opportunities and barriers, and develop a plan to address systematically the needs of this population. Given the scope of the problem, as well as the multiple issues and stakeholders involved, the structure developed should have sufficient resources to sustain a longer-term, systematic effort.

Principles

While there are many potential approaches to bringing together the stakeholders needed to achieve this goal, the chosen method should incorporate the following:

- Provide an opportunity for all involved to benefit from existing information about the scope of the problem of injury and substance use disorders, evidence-based methods for acute intervention, and the special needs and problems of accessing treatment for persons with disabilities arising from injury;
- Take advantage of the unique expertise and resources in each of the service-delivery systems working with these individuals;
- Find solutions that promote collaboration among stakeholders, including formal agreements for communication, consultation, and cooperative ventures;
- Allow adequate time and resources for evaluating impact and planning subsequent iterations to benefit from successes and failures.

Implementation

The Post-critical Care Trauma Commission believes the effects of alcohol and other drug use on injury outcomes, both human and economic, have been underestimated greatly. Substance abuse — current, previous, or resultant — complicates and often confounds trauma care and rehabilitation. Yet, it is equally evident to the commission that adequately addressing substance abuse will require an infusion of knowledge and funding resources not currently within the grasp of trauma care programs, rehabilitation providers, or the publicly funded substance abuse treatment system.

Therefore, the commission recommends further study of the barriers and opportunities for developing resources to address the following questions:

- **What is required to allow screening and intervention in acute medical settings to be implemented routinely?** Emergency departments, trauma programs, and rehabilitation units should be assisted in their capability for taking advantage of the “teachable moment” that can occur as the result of an injury.
- **What resources need to be made available to substance abuse treatment providers to improve the availability of services for individuals who have incurred disability as a result of injury?** The existing substance abuse treatment system should become an accessible and effective source of treatment for persons with disability due to injury.
- **How can projects be supported to identify and promote effective methods of integrated treatment for injured individuals who have co-occurring substance use disorders?** There appear to be significant gains, both human and economic, that could be achieved with greater attention to clinical programs to serve this population.

The commission also recommends consideration of potential stakeholders include, at a minimum, the following agencies and organizations: the state departments of Alcohol and Drug Addiction Services, Health, Public Safety; the Ohio Bureau of Workers’ Compensation; the Ohio Rehabilitation Services Commission; the American College of Surgeons Trauma Committee – Ohio Chapter; the Ohio Society of Trauma Nurse Coordinators; the Ohio Hospital Association; the Ohio Association of Emergency Medical Physicians; the Ohio Association of Rehabilitation Facilities; the Association of Ohio Childrens Hospitals; the Ohio Public Health Association; the Brain Injury Association of Ohio; the Ohio Association of County Behavioral Healthcare Authorities; and the Ohio Council of Behavioral Healthcare Providers.

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“The data presented by the commission point out a number of areas in which this aspect of the trauma system is in need of additional attention.”

Gary F. Joseph, *Interim director,
Ohio Public Safety*

THE OHIO TRAUMA FOLLOW-UP REGISTRY

Recommendation: A follow-up registry should be established to provide information about the long-term complications and outcomes for trauma-care patients. Data collection methodology should be an extension of the existing Ohio Trauma Registry and should provide information for local, regional and statewide prevention programming and health-care service planning.

Vision

Future examinations of issues and problems following critical trauma care should have the benefit of valid and reliable data from Ohio.

Description of the problem

In H.B. 138, the General Assembly created the Post-critical Trauma Care Commission and charged it “...to determine how to improve the accessibility, affordability, quality, and cost-effectiveness of post-critical adult and pediatric trauma care.” While there is considerable clinical experience and personal testimony to indicate needs persist and more systematic services are necessary, the commission determined there is little or no objective data to address questions such as:

- How many injury survivors experience long-term limitations in their day-to-day functioning?
- What kinds of injuries are more likely to result in long-term consequences?
- Do children have unique consequences of traumatic injuries? Do older adults?
- Are there services available to assist these individuals, and are they using them?
- How much do services cost, and are they effective?

Emergency medical services legislation enacted in 1992 established the authority for the Ohio Department of Public Safety to create the Ohio Trauma Registry. The registry, which became operational in 1999, is a database that contains information about all persons who have suffered an injury and are admitted to a hospital for at least 48 hours. The trauma registry provides information about the number of people in Ohio requiring trauma services, the cause and treatment of their injuries, and status at time of leaving the hospital. However, the registry does not provide information about longer-term consequences of injuries. Medical complications that persist after going home, problems that develop after hospital discharge, effects on independence in one’s home or community, difficulties in educational or vocational roles, or the impact on the individual’s family, all may be significant consequences of injury. These effects of trauma may also carry significant human and economic costs that should be considered when prioritizing prevention activities and planning service delivery systems.

BWC’s analysis of injuries that occurred in 1996 and resulted in workers’ compensation claims is included in Appendix D. The analysis allowed description of the types of services and costs, over the subsequent six years. Most remarkable was that 14 percent of the costs, and 21 percent of the services billed occurred after one year following the injury. These data support the presumption that important health-care issues occur over an extended period following injury.



Policy makers, service providers and the general public want reliable and valid data on which to base decisions regarding the effects of medical conditions, clinical interventions, and funding priorities. Lack of data about post-hospital consequences of traumatic injuries creates a significant gap in Ohio's ability to address this major public health problem.

The target population of the proposed Ohio Trauma Follow-up Registry is defined in O.R.C. 4765 for trauma systems. The operational definition would parallel that used for the Ohio Trauma Registry. Patients in the trauma registry would be surveyed by phone at six-months post-injury, with further follow-ups at one and five years on sub-groups who have greater risk for disability. Survey respondents would be asked for information on persistent medical problems, health-care utilization since discharge, changes

in living situation, independence in daily activities, ability to engage in work or school, impact of injury on social and financial supports, and psychological functioning. Sampling would be constructed to allow conclusions about the state population and would include sufficient numbers of persons to allow detection of unique issues faced by any age group, gender, socioeconomic strata, type of insurance program, rural or urban community, and type of injury.

Data collection for the follow-up registry also should be an extension of the existing trauma registry. However, it is recommended respondent surveys be centralized and conducted under the auspices of the Trauma Committee convened by the Ohio Department of Public Safety to promote economies of scale and effectiveness of data collection methods. Legislative authority needed to establish and fund the registry should be congruent with Health Insurance Portability and Accountability Act (HIPAA) regulations, thus allowing Ohio trauma centers to provide contact information without patient consent. Beyond this contact information and data currently provided to the trauma registry, no other information or involvement would be required from participating hospitals.

The follow-up registry also would provide an opportunity to give additional information on resources for trauma patients who experience persistent problems due to their injury. All persons for whom contact information is available could be mailed informational brochures that would include statewide information and resource access points. Mailings could also be used to inform individuals about the follow-up registry and its purpose.

While the current Ohio Trauma Registry provides important information about the incidence of traumatic injuries, well-designed and selective follow-up of trauma patients will provide a complete picture of the impact of injury in Ohio. The Post-critical Trauma Care Commission is recommending creating the Ohio Trauma Follow-up Registry to provide much needed information on the consequences of traumatic injuries.

Proposed strategies

Goal

A trauma follow-up registry will provide objective information on which to base public and private policy decisions about the post-critical care and persistent needs of persons at risk of losing life or limb, or experiencing permanent disability or disfigurement. It will identify the nature and scope of the consequences of trauma, inform public policy that addresses the needs of persons who experience these injuries, provide information about access to services and supports, and guide clinical care research. The follow-up registry will allow reliable estimates of the human and economic costs of injuries — vital pieces of information for assessing the scope of this public health problem.

Principles

- The registry should serve all age, gender and socioeconomic groups, geographic regions, and types of injury.
- A public health model should be used to design and implement the registry.
- There should be public access to the data, while protecting the confidentiality of patient information.
- The registry should be flexible enough to adapt to changing needs while remaining consistent enough to be informative about low incidence conditions and outcomes.

Implementation

The Ohio Trauma Follow-up Registry is intended to provide reliable and valid information about the persistent needs of trauma patients. Prior to seeking on-going legislative support and authority for a comprehensive, statewide registry, a time-limited pilot of the methodology for data collection, database management and data analysis is considered essential to develop viable budget projections. Prior to conducting the pilot, support for pre-pilot research should be sought from the state EMS boards' EMS/trauma grant program. The pilot phase will require new resources to allow for implementing and testing the recommended methodology. Costs for ongoing operation cannot be determined without piloting, and will require new resources as well.

There are three steps to implementing the Ohio Trauma Follow-up Registry:

- Conduct pre-pilot research projects;
- Gain legislative authority and funding to conduct a pilot project;
- Gain legislative authority and support for ongoing implementation.

Pre-pilot research

Specific research projects should be conducted to identify the best approaches to sampling, data collection, and providing linkage information. The existing mechanism for the state EMS boards' EMS/trauma grant program should be sought for these projects. Projects addressing the following issues should be prioritized:

- Test methods of exchanging data with trauma centers, and using the information to contact patients;
- Test effectiveness of providing information and resource linkage to a toll-free telephone number and/or Web site;

- Analyze the trauma database to determine the sampling procedures for the levels of stratification proposed;
- Determine what issues should be addressed in the survey and the items that should be used.

The commission hopes grants addressing these issues can be funded beginning with the 2003 grant cycle. It may also be useful to allow submission of field-initiated ideas related to the conduct of a follow-up registry.

Pilot project

A large scale, pilot project is needed to determine the resources required for ongoing implementation of the follow-up registry. Based on the pre-pilot research results, a prospectus is recommended for describing the proposed methods and procedures of the follow-up registry, as well as products required to initiate a pilot. Funding will be needed from federal, state, and/or private resources for what will be a multi-year, but time-limited, project. The result of the pilot should be a thorough evaluation of the registry's effectiveness and projection of costs for its ongoing implementation. Legislative authority as described in No. 4 and No. 8 below will be required to conduct the pilot.

The following conclusions, reached by the Post-critical Trauma Care Commission, should guide the pilot phase:

1. The Ohio Trauma Follow-up Registry should be designed and conducted to provide reliable and valid information about the consequences of traumatic injury, the needs of persons who experience these injuries, and the effective use of clinical-care resources.
2. The registry also should provide information to individuals and their families about services and supports available to assist them.
3. Target population for the registry should be defined in O.R.C. 4765 for trauma systems. The operational definition should parallel that used for the Ohio Trauma Registry.
4. Legislative authority should parallel the trauma registry, with oversight by the Trauma Registry Advisory Subcommittee. A subcommittee structure may be required for start-up or ongoing review. The current structure allows public members to participate, which allows inclusion of representatives of constituencies not currently involved in the Trauma Registry Advisory Subcommittee. An administrative structure parallel to the trauma registry should be authorized, giving implementation responsibility to the Ohio Department of Public Safety.
5. Data collection should be centralized and responsibility given to the Department of Public Safety. While responsibility will be co-located with that for the trauma registry, data collection and database management could be conducted directly or via contract.
6. Sampling of respondents for the follow-up registry should be constructed to allow generalization to the entire Ohio population and should include sufficient numbers of persons to allow detection of unique issues faced by any age group, gender, socioeconomic strata, type of insurance program, rural or urban community, and type of injury.

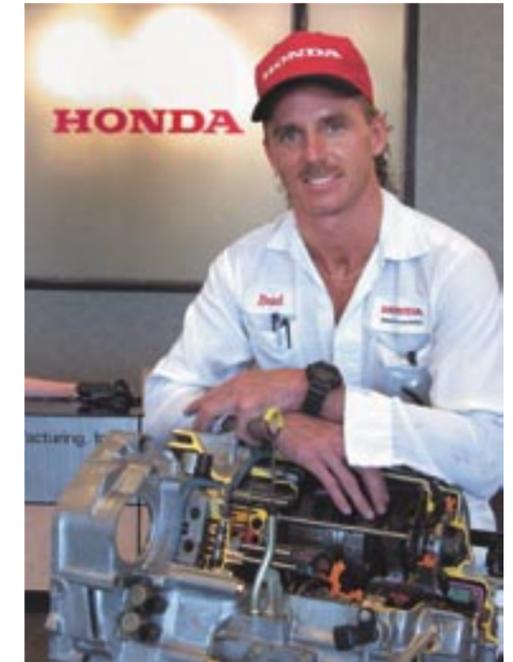
7. Telephone surveys should be conducted six months after the date of injury, with further follow-ups one and five years post-injury on trauma patients with greater risk for medical complications and disability.
8. Legislative authority should state the public health purpose of the registry so as to facilitate its congruence with the Health Insurance Portability and Accountability Act. Because patient contact information will need to be collected from trauma services, comprehensiveness will be enhanced greatly if hospitals are allowed to release personal identifying information without consent. Assent for participation would be attained at the time of follow-up contact. Legislation should explicitly protect the confidentiality of Social Security Numbers, if it is decided that this information is required.

Legislative authority for ongoing operation

Eventual implementation of the actual operative registry will require statutory changes to the Ohio Revised Code. The following issues may need to be addressed:

- Purpose for collecting the data;
- Governance structure and its powers;
- Rulemaking authority;
- Authority to specify the data elements to be collected by rule;
- Confidentiality of data;
- Authority to collect Social Security Numbers;
- Funding;
- Authority to contract for the performance of functions and hire outside consultants;
- Mandate to ensure compliance and cooperation from hospitals or other organizations;
- Realistic time frame to have the pilot project and the registry in place and operating;
- Requirements for reporting to the General Assembly, EMS Board, or other entities;
- Immunity from liability for any potentially high-risk uses of the data (e.g., risk adjusting or outcome comparisons).

To promote using the data resulting from the follow-up registry, funds should be available for research projects on an ongoing basis. Expanding existing trauma commission research funds should be considered for this purpose.



Injury fact sheet

June 25, 2002
 Contact: CDC Media Relations
 770-488-4902

Acute Care, Disability, and Rehabilitation

Public Health Issue

- Each year, Americans make between 30 and 40 million emergency department visits for injuries. While the majority of injured patients are treated and released, many are admitted to inpatient trauma units and later receive rehabilitative services.
- Trauma systems deliver coordinated care, from acute care through rehabilitation, but they are not fully operational or do not exist in many parts of the nation. Where trauma systems are lacking, as many as 30% to 40% of deaths among trauma patients are due to preventable problems in clinical care, including missed diagnoses and treatment delays. After trauma systems are introduced, follow-up studies have shown as much as a 50% reduction in preventable trauma deaths.
- Each year, an estimated 80,000 Americans sustain a traumatic brain injury (TBI) that results in long-term disability. An estimated 5.3 million Americans live with TBI-related disabilities, including cognitive problems that affect their ability to perform daily activities.
- Nearly 200,000 people in the United States are living with a disability related to a spinal cord injury (SCI). Every year, another 11,000 are hospitalized for SCI.

CDC's Role and Expertise

- CDC is the only organization in the federal government responsible for addressing all phases of injury research — from defining the problem to testing the effectiveness and public acceptance of an intervention — for the major causes of injury among all age groups. Funding state and local injury programs allows CDC to rapidly share findings from research with groups that can put the information to immediate use.
- CDC's multidisciplinary research fosters innovative approaches to clinical preventive services. For example, recognizing that alcohol is often a factor in injury, CDC convened federal agencies and experts in alcohol research, emergency medicine, and trauma care to set a research agenda to improve such services as screening for alcohol problems in emergency departments.
- CDC research and programs frequently become the underpinning for reducing the impact of traumatic brain and spinal cord injuries, or for preventing the development of secondary conditions and other adverse outcomes. CDC findings provide crucial information to help communities prevent these kinds of injuries and disabilities.

The Future of Injury Research — What's Next?

With extensive input from its academic research centers, national nonprofit organizations, and other federal agencies with a stake in injury prevention, CDC identified the top research priorities for acute care, disability, and rehabilitation — those research issues that CDC must address to fulfill its public health responsibilities. These priorities, published in the *CDC Injury Research Agenda*, will receive CDC's greatest attention and resources.

Public Health Threat	Injury Center's Research Priority
<i>Injury prevention services for at-risk patients treated in emergency departments and trauma centers are lacking.</i>	Develop and evaluate protocols that provide interventions for at-risk patients in acute care settings. Study ways to implement multiple services simultaneously.
<i>Despite evidence that trauma care systems save lives, many Americans are not served by a trauma system.</i>	Measure the benefits and costs of trauma care. Assess outcomes such as medical complications, functional status, and quality of life.
<i>People with traumatic brain or spinal cord injury face a range of secondary conditions, from medical conditions such as pressure ulcers, to behavioral changes such as depression and substance abuse.</i>	Increase understanding of risk factors for secondary conditions, especially among persons without access to state-of-the-art information and care. Develop more effective methods to treat and manage these conditions.
<i>Many people with injury-related disabilities do not get the services they need.</i>	Identify methods and strategies to link people with traumatic brain or spinal cord injury with needed services.
<i>Data from electronic, point-of-care clinical information systems are not routinely used for injury surveillance.</i>	Develop and evaluate data standards and methods of linking disparate systems to capture and report data about injuries and other acute health problems.
<i>A limited understanding of the costs and consequences of disabling injuries hinders resource allocation and policy decisions.</i>	Develop and apply methods to calculate population-based estimates of the incidence, costs, and long-term consequences of spinal cord injury and nonhospitalized, "mild" traumatic brain injury.
<i>Many populations affected by traumatic brain injury have not been well studied to date.</i>	Conduct TBI research among children, youth, working adults, institutionalized individuals, victims of intimate partner violence, and people within school systems and the criminal and justice systems.
<i>Studies to date suggest that limb injuries result in substantial disability and affect the ability to return to work.</i>	Conduct population-based studies to accurately describe the public health burden of limb injuries and suggest appropriate interventions to prevent these injuries and resulting disabilities.

Injuries are the leading cause of death for Americans under 45 and the leading cause of potential life lost before age 65. In 1999, nearly 150,000 Americans died from injuries, and one in ten was injured badly enough to seek treatment in an emergency department. The CDC Injury Research Agenda, developed by CDC's Injury Center and its many partners, will help drive the national initiative to lower the rate of both unintentional and violence-related injuries, which will result in reduced human suffering and loss of life.

Appendix B

Section 6 of amended substitute H.B. 138 as enacted by the 123rd general assembly

The Director of Health shall organize and coordinate a temporary commission to determine how to improve the accessibility, affordability, quality, and cost-effectiveness of post-critical adult and pediatric trauma care. The commission's study shall include, without limitation, consideration of appropriate transfer of adult and pediatric trauma victims from regional trauma centers to other health care facilities; physical, psychological, and vocational rehabilitation of adult and pediatric trauma victims; re-employment of trauma victims; social support mechanisms for families of adult and pediatric trauma victims; and mitigation of the effects of pediatric and geriatric trauma.

The Rehabilitation Services Commission, Department of Aging, Bureau of Workers' Compensation, and Bureau of Employment Services shall participate in and assist with the commission's study.

Within 120 days after the effective date of this act, the director shall appoint to the commission appropriate public health authorities; entities that represent injury victims; certified safety professionals; employers; employment training and placement services; agricultural organizations; highway safety and motorists' organizations; health insurers; providers of social services to injury victims; nursing and rehabilitation institutions; victims of violent crime; hospitals; and professionals active in physical, psychological, and vocational therapy. Commission members shall have expertise in rehabilitation and retraining of injury victims, broadly represent relevant disciplines, and represent all regions of the state.

Within 120 days after the effective date of this act, the Speaker of the House of Representatives shall appoint to the commission one member of the majority party and one member of the minority party in the House of Representatives and the President of the Senate shall appoint to the commission one member of the majority party and one member of the minority party in the Senate.

In conducting its study and developing its recommendations, the commission can consult with and cooperate with the Trauma Committee of the State Board of Emergency Medical Services. The commission shall conclude its study and disband not later than three years after the effective date of this section, whereupon the director shall transmit the commission's findings and recommendations to the Governor, General Assembly, chief executive of each state agency specified in this section, and other appropriate persons.

Appendix C

MEMBERSHIP OF THE POST-CRITICAL TRAUMA CARE COMMISSION

Member Name	Represented Agency/Organization
Sen. Steve Austria	Ohio Senate, Republican Caucus
Robert Bates	Ohio State Fire Chiefs Association
Sally Betz	Ohio Nurses Association
Jerrold Blackmore	Association of Ohio Philanthropic Homes, Housing & Services for the Aging
John Corrigan, Ph.D. (Chair)	Ohio Psychological Association
John Edwards	Ohio Bureau of Workers' Compensation
Peter Feldkamp, D.C.	Ohio State Chiropractic Association
Mike Glenn	Ohio Department of Public Safety
Christopher Goff	Ohio Business Coalition on Health
June K. Gutterman, Ed.D.	Ohio Rehabilitation Services Commission
Sen. Robert Hagan	Ohio Senate, Democratic Caucus
Jill Huntley	Ohio Department of Job & Family Services
Cindy Iske (Co-chair)	Ohio Hospital Association
Tina Kielmeyer	Ohio Bureau of Workers' Compensation
Beverley Laubert	Ohio Department of Aging
Michael Link	Ohio Department of Alcohol & Drug Addiction Services
Sandra Miller, M.D.	Ohio State Medical Association
Suzanne Minnich	Brain Injury Association of Ohio
Jana Perry	Ohio Department of Education
Paul Platt	Ohio Association of Rehabilitation Facilities
Karen Nisbet Principe	Ohio Children's Hospitals Association
Judy Roush	Ohio Farm Bureau Federation
Elaine Schiwy	National Association of Social Workers
Arthur Schlesinger	Ohio Legal Rights Service
Michael Smeltzer	Ohio Public Health Association
Suman Srinivasan	Ohio Rehabilitation Association
Larry Sowers	Ohio State Building Trades
Ron Suprenant, M.D.	Ohio Association of Health Plans
Michael Williams	American Physical Therapy Association
Sheila Young, L.S.W.	The Salvation Army

A longitudinal investigation of medical cost and treatment volume for traumatic injuries: 1996-2002

Ohio Bureau of Workers’ Compensation (BWC) research projects unit for the Ohio Post-critical Trauma Care Commission

Summary

This investigation of the long-term needs of people who suffer traumatic injuries demonstrates the medical needs of these individuals persist long after the acute phase of their treatment ends. Thirty-six percent of the medical payments and 45 percent of the services for traumatic injuries occurred from two months to five years following the injury. In the first month following a traumatic injury, most of the necessary services are provided by physicians and hospitals. As time passes, services are more often provided by non-physician professionals and are likely to involve rehabilitation activities. The proposed Ohio Trauma Follow-up Registry would enable Ohio’s health-care providers to plan for the long-term needs of these individuals and provide the necessary services at the appropriate time.

Introduction

H.B. 138, enacted by the 123rd Ohio General Assembly created the Post-critical Trauma Care Commission. The commission was established to “...determine how to improve the accessibility, affordability, quality, and cost-effectiveness of post-critical adult and pediatric care.” The commission has been meeting since July 2001 to draft recommendations for the Governor, General Assembly and the sponsoring state agencies.

One proposed recommendation is that “a follow-up registry be established to provide data on the longer-term outcomes for trauma-care patients.” A follow-up registry would provide “objective information on which to base public and private policy decisions about the post-critical care and persistent needs of persons at risk of losing life or limb, or experiencing permanent disability or disfigurement. It would (a) identify the nature and scope of the consequences of trauma, (b) inform public policy addressing the needs of persons who experience these injuries, (c) provide information about access to services and supports, and (d) allow clinical research.”

The proposed follow-up registry is viewed as an extension of the Ohio Trauma Registry. The Ohio Department of Public Safety administers the Ohio Trauma Registry , which became operational in 1999, with oversight by the Trauma Registry Advisory Committee. It is a database of information on all people who suffer an injury and are admitted to a hospital for at least 48 hours. The database includes information about the number of people who require trauma services, the cause of the injuries, the treatment provided and the status at discharge from the hospital. One limitation of the Ohio Trauma Registry is that it does not provide information on the long-term consequences of injuries.

The claim records of the BWC provide a unique opportunity to conduct longitudinal investigations of injuries prior to establishing a follow-up registry. BWC claims data include injuries sustained by the worker, the type and timing of the treatment provided, and the treatment cost. By statute, the injured worker is eligible to receive medical treatment for consequences of an industrial injury for as long as necessary, allowing study of the injuries and their long-term effects.

The Ohio Trauma Registry collects information on injuries coded according to the International Classification of Diseases Revision 9 (ICD-9). The code groups are displayed in table 1.

Table 1. ICD-9 code groups included in the Ohio Trauma Registry.

Code group	Group description
800-805	Skull fracture
802-803	Facial fracture
805-807	Spinal fracture
807-808	Chest fracture (rib or sternum)
808-809	Pelvis fracture
810-812	Shoulder girdle fracture
812-820	Upper extremity fracture
820-830	Lower extremity fracture
830-840	Dislocation (includes jaw)
850-851	Concussion
851-852	Brain contusion
852-855	Intracranial hemorrhage
860-861	Hemo/pneumothorax
861.2-861.3	Lung injury
863-864	Gastrointestinal hollow organ injury
864-865	Liver injury
865-866	Spleen injury
870-874	Scalp or facial laceration
875-880	Torso laceration
880-887	Upper extremity laceration or minor amputation
887-888	Upper extremity amputation
890-896	Lower extremity laceration or minor amputation
900-905	Vascular injury
941-949	Burns
950-958	Nerve or spinal cord injury

It should be noted that BWC’s claims data differ from the Ohio Trauma Registry data in two important ways. First, BWC records include only persons who are injured in the course of their employment. Thus, the claims records don’t include data on pediatric or childhood injuries, very little data on teenagers and no data on injuries that befall persons who are not working or are retired. Second, the available records do not permit identification of injuries that require a 48-hour stay in a hospital, one of the Ohio Trauma Registry’s criteria. In light of these differences, BWC data can be expected to include a narrower demographic range of injured persons and a broader range of severity, i.e., from relatively minor to quite significant injuries within each code group. It is assumed that if it were possible to exclude the injuries that do not require admission to a hospital for at least 48 hours, the findings of this study would be amplified.

Methodology

All claims involving the 25 ICD-9 code groups listed above with dates of injury between Jan. 1, 1996, and Dec. 31, 1996, were retrieved from the BWC Data Warehouse. Treatment types and costs were identified by retrieving the first service date and the ICD-9 code for which the provider submitted the bill, bill category (hospital, non-physician, nursing service, other, physician, rehabilitation, vendor, and drug), line item units of service (UOS) provided, reimbursed amount (the amount paid to the provider). The first service date was used to create five treatment intervals that correspond to the anticipated follow-up intervals:

- Interval 1 included treatments provided within 30 days of the date of injury;
- Interval 2 included treatments provided two to six months following the date of injury;

- Interval 3 included treatments provided from six months to one year following the date of injury;
 - Interval 4 included treatments provided from one to five years following the date of injury;
 - Interval 5 included treatments provided more than five years following the date of injury.
- The reimbursed amount and units of service were summed for each ICD-9 group, each bill category and each treatment interval.

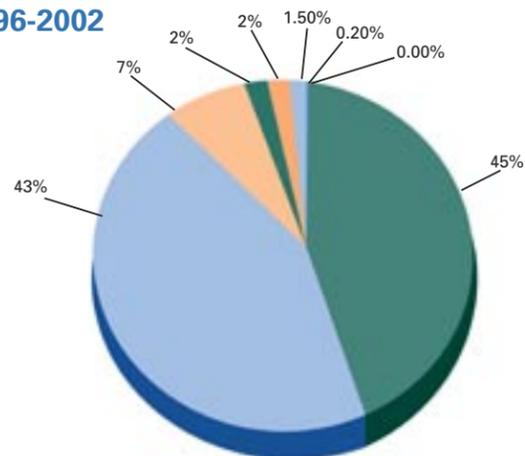
Results

The 25 ICD-9 groups included 106,590 claims. However, since any one injured worker might suffer injuries in more than one ICD-9 grouping, an additional analysis was performed to identify unique individuals. The study sample included 91,738 injured workers. Seventy-five percent were male and 25 percent were female. The mean age of the sample was 41 years and, mean age at injury was 35 years.

The totals and percentages of payments and units of service and percentages for each bill category are displayed in table 2. The table shows that \$74,275,624.38 was paid for medical services from the date of injury to 2002. Forty-five percent of these expenses were for physician services and 43 percent for hospital services. The total units of service for the same period was 2,546,672, with 31 percent (784,352) provided by physicians and 44 percent (1,116,526) in hospitals. The percentage of total medical payments for each bill category is shown in chart 1.

Bill category	Amount paid	Amount paid %	Units of service billed	Units of service billed %
Grand total	\$ 74,275,624.38		2,546,672	
Physician	\$ 33,098,017.46	45%	784,352	31%
Hospital	\$ 31,906,549.08	43%	1,116,526	44%
Non-physician	\$ 4,938,977.03	7%	219,892	9%
Nursing service	\$ 1,668,703.53	2%	42,236	2%
Rehabilitation	\$ 1,349,017.97	2%	197,087	8%
Vendor	\$ 1,128,407.72	2%	111,042	4%
Drug	\$ 184,821.59	0%	59,274	2%
Other	\$ 1,130.00	0%	16,263	1%

**Medical Payments for Traumatic Injuries
by Bill Category: 1996-2002**



The proportions of medical payments during each treatment interval are displayed in chart 2. Sixty-four percent of the payments, totaling \$47,802,315.65, were for treatment services provided during the month following the date of injury. Fifty-five percent of the units of service, totaling 1,411,935, were provided during the same period. Fifteen percent of the payments (\$11,289,466.33) and 17 percent of the units of service (437,215) were provided from one to six months following the injury. From six months to one year following the date of injury, 6 percent of payments (\$4,769,215.50) and 7 percent of units of service (\$168,573) were provided. The first year following the date of injury accounted for 85 percent of the total medical costs and for 79 percent of the units of service provided to injured workers. Table 3 presents the distribution of medical costs and units of service for each treatment interval.

Treatment Interval	Amount paid	Amount paid %	Units of service billed	Units of service billed %
Grand total	\$ 74,275,624.38		2,546,672	
1 (DOI + 30 days)	\$ 47,802,315.65	64%	1,411,935	55%
2 (DOI + 1-6 months)	\$ 11,289,466.33	15%	437,215	17%
3 (DOI + 6 months-1 year)	\$ 4,769,215.50	6%	168,573	7%
4 (DOI + 1-5 years)	\$ 9,401,275.57	13%	465,135	18%
5 (DOI + 5 years or more)	\$ 1,013,351.33	1%	63,814	3%

Tables 4 and 5 show the percentages of payments and units of service by bill category and treatment interval. It is not surprising the hospital service volume and payments to hospitals decrease over time following the injury. Physician payments and service volume also decrease over time, but at a lesser rate. Payments in the non-physician category (e.g., physical, occupational and other therapists) increase one to six months following the date of injury and continue for the duration of the period studied. It is also evident that services in the rehabilitation category become much more important later in the history of the injury. Payments in this category constitute only 2 percent of total payments and 8 percent of total units of service, but the volume of services is highest in the one to five years and five years or more treatment intervals.

Bill category	1 (DOI + 1 month)	2 (DOI + 1-6 months)	3 (DOI + 6 months to 1 year)	4 (DOI + 1-5 years)	5 (DOI + 5 years or more)	totals
All categories	64%	15%	6%	13%	1%	100%
Hospital	54%	30%	24%	16%	18%	43%
Physician	44%	46%	46%	44%	42%	45%
Non-physician	1%	19%	19%	13%	12%	7%
Nursing service	0%	2%	4%	11%	5%	2%
Rehabilitation	0%	1%	4%	10%	12%	2%
Vendor	0%	2%	3%	5%	10%	2%
Drug	0%	0%	0%	1%	1%	0%
Other	0%	0%	0%	0%	0%	0%

Letters of support for the Post-critical Trauma Care Commission’s recommendations

The following organizations presented letters of support for the research and recommendations provided by the Post-critical Trauma Care Commission. Members of the commission wish to acknowledge and thank these organizations for their support.

- American Physical Therapy Association, Ohio Component, Jonathan Cooperman, P.T., J.D., M.S., president
- Association of Ohio Philanthropic Homes, Housing and Services for the Aging, John Alfano, president/CEO
- Brain Injury Association of Ohio, Philip E. Cole, president
- Central Ohio Trauma System, Jonathan I. Groner, M.D., F.A.C.S., president
- Ohio Association of Professional Fire Fighters, Kevin Watts, president
- Ohio Association of Rehabilitation Facilities, Julie A. Keil, M.P.A., executive director
- Ohio Bureau of Workers’ Compensation, James Conrad, administrator/CEO
- Ohio Children’s Hospital Association, Andrew Carter, president
- Ohio Department of Aging, Joan W. Lawrence, director
- Ohio Department of Alcohol and Drug Addiction Services, Gary Q. Tester, director
- Ohio Department of Education, Susan Tave Zelman, superintendent of public instruction
- Ohio Department of Public Safety, Gary F. Joseph, interim director
- Ohio Farm Bureau, John C. Fisher, executive vice president
- Ohio Fire Chiefs’ Association Inc., Chief Stan Crosley, president
- Ohio Hospital Association, Bridget Gargan, vice president, State Policy & Advocacy
- Ohio Job & Family Services, Tom Hayes, director
- Ohio Legal Rights Service, Carolyn S. Knight, executive director
- Ohio Nurses Association, Gingy Harshey-Mead, M.S.N., R.N., C.N.A.A., chief executive officer
- Ohio Osteopathic Association, Paul A. Martin, D.O., president
- Ohio Psychological Association, Michael O. Ranney, M.P.A., executive director
- Ohio Public Health Association Inc., Ruth Shrock, president
- Ohio Rehabilitation Association, Robin Markey, president
- Ohio Rehabilitation Services Commission, John M. Connelly, executive director
- Ohio Society of Trauma Nurse Coordinators, Vickie Graymire, R.N., M.S., C.E.N., president
- Ohio State Medical Association, William C. Sternfeld, M.D., president
- Ohio State Chiropractic Association, Peter D. Feldkamp, D.C., president
- The Salvation Army, Major Paul Cain, area coordinator
- State of Ohio Rehabilitation Services Commission, John M. Connelly, executive director

Bill category	1 (DOI + 30 days)	2 (DOI + 31–183 days)	3 (DOI + 184–365 days)	4 (DOI + 1-5 years)	5 (DOI + 5 years or more)	Totals
All categories	55%	17%	7%	18%	3%	100%
Hospital	60%	33%	26%	15%	11%	44%
Physician	35%	28%	28%	25%	13%	31%
Non-physician	2%	26%	22%	10%	6%	9%
Nursing service	0%	1%	15%	30%	41%	8%
Rehabilitation	1%	4%	4%	13%	13%	4%
Vendor	1%	4%	3%	3%	1%	2%
Drug	1%	3%	2%	4%	15%	2%
Other	1%	1%	1%	0%	0%	1%

Discussion

This brief investigation of the long-term needs of persons who suffer traumatic injuries demonstrates the medical needs of these individuals persist long after the acute phase of their treatment ends. Claims records of injured workers, retrieved from BWC’s Data Warehouse, show that 64 percent of payments and 55 percent of units of service provided for traumatic injuries occur in the first month following an injury. The months that follow, up to five years after the injury, account for 36 percent of the payments and 45 percent of the services provided to these individuals. Clearly, individuals who suffer traumatic injuries may continue to require treatment for up to five years following the injury.

The investigation also demonstrates how these needs change over time. It is hardly surprising that, in the first month following a traumatic injury, physicians and hospitals provide most of the necessary services. Physicians continue to provide a significant proportion of services for the duration of the study period. However, as time passes, services are more often provided by non-physician professionals and are likely to involve rehabilitation activities.

While the population served by BWC does not precisely correspond to the population the Ohio Trauma Registry monitors, this study suggests individuals who sustain an injury involving “risk of losing life or limb, or experiencing permanent disability or disfigurement” have continuing needs for treatment and care long after acute treatment ends. At the present time, the State of Ohio has no means of systematically identifying and responding to these needs. The proposed Ohio Trauma Follow-up Registry would provide timely and statistically sound data on the needs of trauma patients at several points in the recovery process. It would enable Ohio’s health-care providers to plan for these individuals’ long-term needs and provide the necessary services at the appropriate time.

