

# **Needs and Resources Assessment Report**

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## Executive Summary

The purpose of this Needs and Resources Assessment conducted by Texas State University for the Texas Department of State Health Services (DSHS), on behalf of the Texas Traumatic Brain Injury Advisory Council, was to make recommendations to DSHS and other stakeholders about the feasibility of establishing a separate TBI Registry in Texas and the improvement of transition services for school-aged children with TBI. Specifically, the study addressed the following four questions:

1. What is the current status of TBI data collected using the EMS/Trauma Registry through DSHS in terms of: reporting requirements, reporting compliance, and problems and obstacles?
2. Should a separate TBI Registry be established in Texas and what is the feasibility, efficiency, and estimated cost of such a registry?
3. How well are children and adolescents with TBI who are identified in the medical community transitioned to the public school system?
4. How can school-based identification of children with TBI be improved?

Major findings related to question one were divided into three areas: (a) general database management, (b) database structure and end-user accessibility, and (c) ease of reporting and guidelines provided to users. There were grave concerns with the current EMS/Trauma Registry. These included the lack of rigorous ongoing monitoring of the data acquisition (i.e., quality and

accuracy), the inability to provide useful summary information for key stakeholders in DSHS and external units, and the relatively small numbers of EMS providers and hospitals submitting timely or for that matter, any reports into the current registry.

Major findings related to question two were focused on the feasibility of developing a separate TBI Registry including the associated costs. Texas stakeholders provided a clear message that the current registry was inadequate with lack of funding and insufficient number of staff viewed as the underlying problems. Seven states with CNS or TBI Registries provided the following information related to cost and efficiency: (a) development costs ranged from \$100,000 to \$150,000 and maintenance costs ranged from \$50,000 to \$180,000 annually, (b) in many states the funding mechanism is reinstatement fees from traffic violations, (c) successful registries are governed by mandates that require compliance, and (d) successful registries are able to link services to individuals with TBI.

Question three findings were divided into three areas: (a) transition for students with TBI, (b) procedures school districts uses to facilitate transition, and (c) discrepancies in databases reporting numbers of students with TBI. Our findings indicated that transition of students with TBI is often not occurring, although for those school districts that do have procedures related to transition, several positive findings were noted. Specifically, a very high percent (86%) of

hospitals that responded to our web-based survey indicated that they did not request medical releases to contact a child's (with TBI) school. Furthermore, several special education directors in school districts stated they had never been notified by a hospital or rehabilitation center of a student's pending transition. On a positive note, school districts that did facilitate transition of students with TBI indicated that they had the following procedures in place: convene a prereferral planning meeting, provide relevant school records to medical or rehabilitation center, request medical information, and contact the family. A comparison of the number of students with TBI reported by the Texas Education Agency (TEA) to the EMS/Trauma Registry database showed that the TEA number was much lower. Possible explanations include: many students with TBI who require special education are served under a different disability category, lack of educational need demonstrated by the student, or treatment and services are provided in alternative settings.

Major findings related to question four focused on transition services in rehabilitation centers and key elements of five states' model transition programs. Rehabilitation centers reported that more education on the part of school districts was needed and that most schools were not equipped to handle children with TBI. Common elements of model transition programs in other states included: (a) education was provided to teachers, parents, and students; (b) a plan was in place for hospital to school linkage, and (c) a method was

developed to track progress of students with TBI who are transitioned to schools.

Based on these findings, we made the following recommendations:

**Recommendation One:** Establish a separate TBI Registry.

**Recommendation Two:** Fund two full-time database/warehouse managers whose job duties are to monitor the ongoing acquisition and integrity of data.

**Recommendation Three:** Contract with an outside consultant to advise during the conceptualization of the database structure.

**Recommendation Four:** Contract with an outside firm to create a graphical user interface.

**Recommendation Five:** Increase awareness of medical, early childhood intervention, and school service professionals, including Child Find.

**Recommendation Six:** Consider a broader educational definition of TBI.

**Recommendation Seven:** Develop a process to link the TBI Registry data to transition services for school-aged individuals with TBI.

**Recommendation Eight:** Develop a Texas model for promoting improved transition and tracking of students with TBI.

Recommendations 1 through 4 are concerned with the establishment of a Texas TBI Registry. If Texas does decide to establish a separate TBI Registry, they will want to ensure that they have adequate support staff. In addition, the organizational structure of the database and the usability to the end user must

be carefully considered. In particular, the type and level of measurement, design and construction of the survey instrument, and data acquisition process must be well conceptualized so that the end-user can easily access and use information contained in the database.

Recommendations five through eight relate to transition of school-aged patients with TBI from rehabilitation centers or hospitals to schools. Important first steps to improving the transition process is to increase awareness of professionals responsible for transition and to provide a link from the proposed TBI Registry to services for all patients, including school-aged patients. One of the findings reported in this study is that many schools have stated that they have no students with TBI enrolled in their districts. This may be partly due to the narrow educational definition of TBI or that these students are being identified as needing special education services under a different diagnostic category. Therefore, Texas should consider broadening their educational definition of TBI, which in turn may heighten awareness of the educational needs of this population and may result in the establishment of a Texas model for tracking and serving these students.

## Introduction

The potential long-term and life-changing effects of traumatic brain injury (TBI) are extensive and well documented (Langlois, Rutland-Brown, & Wald, 2006). However, TBI is sometimes referred to as the “silent epidemic” because resulting problems are not always visible according to the Centers for Disease Control (CDC) (2008). Even a mild TBI can result in prolonged emotional symptoms such as impulsiveness and mood swings. Consequences can include limitations in basic activities of daily living, and in major activities such as school and work, as well as in social integration (CDC). Of great concern are the instances where children and adolescents experience a TBI with cognitive, behavioral, and/or emotional consequences, but, for various reasons, the sequelae are not linked to the injury. In such cases, these individuals may be misdiagnosed or not recognized as in need of intervention for the brain injury, resulting in educational and social frustration or even failure.

Although estimates of incidence vary, TBI is considered a leading cause of death and disability among school-age children (Yeates & Taylor, 2006). According to the CDC, with estimates based on data gathered from surveillance programs across the nation, the annual incidence of TBI in the United States is about 1.4 million each year. This number is considered an underestimate for several reasons; it does not include persons treated for TBI in settings other than emergency rooms or hospitals, nor does it include persons for whom the TBI is

not diagnosed when medical treatment is received or those for whom no medical treatment is sought. While not immediately relevant to consideration of TBI among children and adolescents, the CDC estimate also does not include TBIs treated in military facilities. When emergency room visits, hospitalizations, and deaths are combined, TBIs are more likely to be sustained among children from 0-4 years and adolescents from 15-19 years than among other age groups. Langlois et al. further estimate that 1 in 10, or about 5.3 million, of the 54 million Americans with disabilities have a disability related to TBI. A related concern is the propensity of individuals who sustain TBIs to be at risk for other health conditions, including substance abuse, epilepsy, emotional disorders, and Alzheimer's (Langlois et al.).

In a study of academic and intellectual outcomes of TBI among children and adolescents, Arroyos-Jurado, Paulsen, Ehly, and Max (2006), interpret the incidence data to suggest that annually at least 1 of every 550 school-age children will sustain a TBI that can lead to long-term disability. While severe TBIs are easier to identify, data suggests that 75% of all TBI injuries are considered "mild" and only 50% are even reported to medical professionals (CDC, 2008).

The recognition, identification and remediation of TBI is problematic in school-aged populations, even though services for TBI are legally mandated through the Individuals with Disabilities Education Act (IDEA, <http://www.ed.gov/policy/speced/leg/idea/idea.pdf>) and opportunities for

intervention are present. For example, 1,424 students ages 0-22 in Texas were served in special education under the eligibility category of TBI during 2007-2008 school year (Texas Education Agency [TEA], 2008), while at least 6,432 Texas children between ages 1 and 21 years sustained a TBI in 2004 (the latest year for which data is available, according to a report by the Texas Department of State Health Services in 2007 (Johnson, 2007). Far more children are likely suffering from less obvious impairment since this estimate includes only those individuals admitted to an acute care hospital for treatment of an acute incident in which a TBI was sustained and documented. Some of these children may receive services under a different special education classification or in a non-public school facility, which makes them harder to track within the special education system. Of the 474,681 children served through special education in Texas in 2007-08, students identified as TBI constituted only 0.3% of the total. This percentage appears strikingly small given that TBI is considered a leading cause of death and disability among school-age children.

Another possible contributor to the low number of students with TBI served through special education is that not all children and adolescents who sustain a TBI require special education services. Nevertheless, the weight of the research supports ongoing monitoring of progress and change over time, since in some cases cognitive, behavioral, or emotional problems may emerge at a later point in development. The cumulative number of school-age children with TBI

clearly exceeds the number receiving special education services under this classification. This discrepancy substantiates the impression that children with TBI are under identified for special education intervention (Hibbard, Gordon, Martin, Raskin, & Brown, 2001).

In Texas, as in numerous other states, it is mandated by law that all EMS providers and hospitals designated to provide trauma care report case of injury to the EMS/Trauma Registry maintained by the Texas Department of State Health Services (<http://www.dshs.state.tx.us>). However, even this reporting requirement yields limited data, since hospitals must only report cause of injury for hospitalizations for at least 48 hours, leaving emergency room or overnight hospitalizations unreported. Further, the reporting guidelines for diagnosis may result in the omission of causes in which TBI is not the primary diagnosis or cause of injury (<http://www.dshs.state.tx.us>). Across the nation, TBI surveillance and reporting practices vary considerably, making the determination of incidence among children and adolescents quite difficult, especially with regard to mild or moderate injuries that might not result in extended hospitalization.

This report is a Needs and Resources Assessment that was funded as part of the three-year implementation grant, Texas TBI Partnership Initiative in 2006. Its purposes were to assess the feasibility of developing a separate Texas TBI Registry and to address the gaps in identification, reporting, and provision of

school-based services for children and adolescents in Texas who sustain traumatic brain injury.

### **Methods**

This report addressed the following questions:

1. What is the current status of TBI data collected using the EMS/Trauma Registry through DSHS in terms of: reporting requirements, reporting compliance, and problems and obstacles?
2. Should a separate TBI Registry be established in Texas and what is the feasibility, efficiency, and estimated cost of such a registry?
3. How well are children and adolescents with TBI who are identified in the medical community transitioned to the public school system?
4. How can school-based identification of children with TBI be improved?

Question one was answered by examining the most current (2004) databases for both hospitals and EMS providers who reported to the EMS/Trauma Registry to address how Texas might improve its data collection process and the usability of its data. Second, we conducted a web-based survey of a stratified random sample of EMS providers and hospitals that reported to the EMS/Trauma Registry about the ease of reporting, guidelines, and use of data.

Question two was answered by first conducting an online interview of stakeholders who were members of the Traumatic Brain Injury Advisory council to attain information regarding the need for a TBI registry beyond the existing

EMS/Trauma Registry. Next, we developed a registry status report for the U.S. using the CDC website and selected states' websites information. Third, states with TBI registries were asked to participate in a web-based survey regarding the time frame for development, cost, and perceived effectiveness and problems encountered in gathering or using data from a TBI Registry. We asked all respondents to participate in a follow up telephone interview.

Several methods were used to answer question three. First, several questions concerning transition from hospitals to schools were added to the web-based survey we sent to EMS providers and hospitals (see question 1). These questions were asked only of respondents from hospitals. Second, we chose a stratified random sample of directors of special education of Texas school districts or cooperatives and sent them a web-based survey regarding procedures for transition and training provided to teachers in their districts. We followed this with telephone interviews with three special education directors. Lastly, a comparison of the EMS/Trauma Registry data for school-aged individuals and the Texas Education Agency incidence data for students receiving special education for having a traumatic brain injury was made.

Question four was answered by contacting six Texas rehabilitation providers and asking a series of questions about their transition services for school-aged patients. Lastly, we examined four states' model transition programs to determine components that might provide guidance to Texas.

## **Findings**

Section one discusses the findings of our needs and resources assessment related to the development of a Texas TBI Registry. Section two discusses the findings related to transition of the school-aged population of individuals with TBIs from hospitals or rehabilitation centers to schools.

### *TBI Registry*

#### *Texas EMS/Trauma Registry Data*

Based on a comprehensive review of the hospital-based and EMS data files provided by DSHS, our findings are divided into two respective programmatic areas: (a) general database management and (b) database structure and end-user accessibility. The following paragraphs provide specific details regarding the findings within each of these two strategic areas. The most current registry data available was from 2004; DSHS is currently cleaning 2005 and 2006 data. DSHS has one fulltime person designated as the data manager overseeing the EMS/Trauma Registry.

Our review of the hospital and EMS databases revealed several areas of concern. These areas include rigorous ongoing monitoring of the data acquisition (i.e., quality and accuracy), and providing useful summary information for key stakeholders in DSHS and external units such as hospitals and the legislature. Quality control needs to be ensured, which includes the inspection and cleaning of the data immediately upon acquisition and on an ongoing basis (i.e., at least

on a weekly basis and possibly more often) for out-of-range values, missing information, incorrect/incongruent data values as operationally measured by the respective data collection instrumentation. Aggressive, ongoing monitoring of the database is essential in order to ensure the accuracy of the information that may ultimately be used in state-level decision-making and policy implementation. Keep in mind that the data examined for this report were from 2004 and some of these issues were rectified the next year. Many built-in error warnings were turned on in 2005, which resulted in more accuracy although there are still many problems with data input (Ryan Beal, personal communication, October 2, 2008).

Next, in order for policy decisions to be well-informed, key stakeholders in the Texas Department of Health require current, accurate, and reliable information to advance their positions and ideas to state legislators who in turn are able to affect legislation. Of particular importance is the issue of identification and referral of K-12 students who exhibit TBI-related impairment. This step is critical to meeting the educational needs of these students. Therefore, the organizational structure of the database and the end-user interface is perhaps the most important aspect regarding the ability of stakeholders to effectively use the acquired information. The current system allows end-users to access data in tab delimited, database, SPSS, or SAS file

formats. In addition, the data are out-of-date, typically three or four years old.

These two issues result in data that have limited usability.

*Texas EMS Provider and Hospital Web-Based Survey*

A web-based survey for Texas EMS providers and hospitals that reported to the EMS/Trauma Registry was designed to address questions regarding the purpose and usability of the Registry (see Appendix A for the survey items). The survey was sent via email to representatives at hospitals and EMS providers.

*Survey Respondents.* The original intent was to sample 317 participants stratified on agency type (EMS provider or hospital) and geographic location (north, south, east, west) within the state. The sample size was determined by several factors including the size of the population of interest. DSHS provided two excel files containing EMS providers (N=1,011) and hospitals (N=1,618) that reported to the EMS/Trauma Registry. These two lists served as the sample frames. We randomly selected 197 EMS providers and 120 hospitals based on the two strata and requested contact information from DSHS. DSHS could only provide contact information for those agencies with established accounts in the registry system, which in this case consisted of about two-thirds of the selected sample. We selected a second random sample in an attempt to obtain our target sample of 317, but again received only partial contact information. Therefore, the final sample consisted of 262 EMS providers and hospitals.

An email explaining the project and the purpose of the survey was sent to the 262 possible respondents. Thirty-three emails came back with invalid email addresses resulting in a final sample size of 229. Eighty-one EMS providers and hospitals responded for a response rate of 35%.

*Discussion of EMS Provider and Hospital Responses.* Tables 1 through 7 show the results of the web-based survey pertinent to the existing EMS/Trauma Registry (in section 2 of this report, several tables show the responses of hospital representatives to questions about transition services for school-aged patients). Table 1 illustrates that of the 81 participants who responded to the survey, 40 were EMS providers and 41 were hospitals. Thirty-eight of the EMS providers and 36 of the hospitals indicated that they submitted data related to TBIs to the EMS/Trauma Registry.

**Table 1**  
***Number and Percent of Responses to: Are you submitting data related to TBIs to the EMS/Trauma Registry online system?***

	EMS Provider		Hospitals		Total	
	N	%	N	%	N	%
Yes	38	88.4	36	87.8	74	88.0
No	2	4.7	5	12.2	7	8.3
<b>Total</b>	<b>40</b>	<b>93.0</b>	<b>41</b>	<b>100</b>	<b>81</b>	<b>96.4</b>

The next two questions asked participants how often they submit data and if they contract with a business associate to submit data to the registry (See Tables 2 and 3). Most respondents submitted data monthly and about one-third contracted with an associate for submission of data.

**Table 2**  
**Number and Percent of Responses to: How often do you submit data?**

	EMS Provider		Hospitals		Total	
	N	%	N	%	N	%
Weekly	7	16.3			7	16.3
Monthly	17	39.5	12	29.3	29	34.5
Quarterly	11	25.6	16	39.0	27	32.1
Bi-annually	1	2.3	1	2.4	2	2.3
Annually			1	2.4	1	2.4
Other	2	4.7	6	14.6	8	9.5
<b>Total</b>	<b>38</b>	<b>88.4</b>	<b>36</b>	<b>87.8</b>	<b>74</b>	<b>88.0</b>

*Note. Only EMS Providers and Hospitals that submitted data to the EMS/Trauma Registry asked to respond to this question.*

**Table 3**  
**Number and Percent of Responses to: Is your electronic data submitted through a business associate?**

	EMS Provider		Hospitals		Total	
	N	%	N	%	N	%
Yes	16	37.2	5	12.2	21	25.0
No	22	51.2	31	75.6	53	63.0
<b>Total</b>	<b>38</b>	<b>88.4</b>	<b>36</b>	<b>87.8</b>	<b>74</b>	<b>88.0</b>

*Note. Only EMS Providers and Hospitals that submitted data to the EMS/Trauma Registry asked to respond to this question.*

We next asked respondents if they received training to use the EMS/Trauma registry and if they answered yes, how they received that training. Less than half the EMS providers received training, while three-fourths of hospitals received training. Of those who received training about 15 percent received it on the DSHS website.

**Table 4**  
**Number and Percent of Responses to: Have you received training to use the EMS/Trauma registry?**

	EMS Provider		Hospitals		Total	
	N	%	N	%	N	%
Yes	18	41.9	32	78.0	50	59.5
No	21	48.8	9	22.0	30	35.7
<b>Total</b>	<b>39</b>	<b>90.7</b>	<b>41</b>	<b>100.0</b>	<b>80</b>	<b>95.2</b>

*Note. Totals vary due to missing data.*

**Table 5**  
**Number and Percent of Responses to: How do you receive training?**

	EMS Provider		Hospitals		Total	
	N	%	N	%	N	%
DSHS website training	7	16.3	6	14.6	13	15.4
Site based training	8	18.6	12	29.3	20	23.8
Other	3	7.0	14	34.1	17	20.2
<b>Total</b>	<b>18</b>	<b>41.9</b>	<b>32</b>	<b>78.0</b>	<b>50</b>	<b>59.5</b>

*Note. Only EMS Providers and Hospitals that received training to use the EMS/Trauma registry were asked to respond to this question.*

The next three questions asked about how easy the EMS/Trauma Registry was to use in terms of the coding guidelines, online data entry system and web-based training. Of those who responded, most found all three components to be very or somewhat easy to understand and/or use (see Table 6).

**Table 6**  
***Number and Percent of Responses to: How easy it is to understand and/or use each of the following?***

	EMS Provider		Hospitals		Total	
	N	%	N	%	N	%
Coding Guidelines						
Very	11	25.6	7	17.1	18	21.4
Somewhat	14	32.6	27	65.9	41	48.8
Not at all	5	11.6	4	9.8	9	10.7
NA	5	11.6	1	2.4	6	7.1
<b>Total</b>	<b>35</b>	<b>81.4</b>	<b>39</b>	<b>95.1</b>	<b>74</b>	<b>88.0</b>
Online system for entering data						
Very	12	27.9	15	36.6	27	32.1
Somewhat	9	20.9	19	46.3	28	33.3
Not at all	9	20.9	5	12.2	14	16.6
NA	5	11.6			5	11.6
<b>Total</b>	<b>35</b>	<b>81.4</b>	<b>39</b>	<b>95.1</b>	<b>74</b>	<b>88.0</b>
Web-based training						
Very	10	23.3	4	9.8	14	16.6
Somewhat	10	23.3	19	46.3	29	34.5
Not at all	6	14.0	4	9.8	10	11.9
NA	9	20.9	12	29.3	21	25.0
<b>Total</b>	<b>35</b>	<b>81.4</b>	<b>39</b>	<b>95.1</b>	<b>74</b>	<b>88.0</b>

*Note. Only EMS Providers and Hospitals that submitted data to the EMS/Trauma Registry asked to respond to this question.*

We next asked the hospital representatives *only* about referrals they made for discharged patients. Most representatives indicated that they made some sort of referral for further services; only 20 percent indicated that they made no additional referrals (see Table 7).

**Table 7**  
**Number and Percent of Responses to: Do you provide referrals for discharged patients?**

	N	%
No	8	19.5
Long term facility	15	36.6
Acute Care facility	22	53.7
Neuropsychological assessment	10	24.4
Occupational therapy services	14	34.1
Physical therapy services	16	39.0
Speech therapy services	13	31.7
Other	9	22.0

*Texas Stakeholders*

A survey for stakeholders was designed to address questions regarding the purpose, feasibility, efficiency, and estimated cost of a TBI registry (distinct from the existing EMS/Trauma Registry) for the state of Texas (see Appendix B for the survey items). The survey was sent via email to representatives from DSHS Environmental Epidemiology and Injury Surveillance Group and the Texas Brain Injury Association Advisory Council(?? There is the Brain Injury Association of Texas - that may/may not have an advisory council - and the Texas Traumatic Brain Injury Advisory Council. I am not sure which one you mean here. Is the name correct? I have the same comment on the next page where the same term is used.). Representatives of these entities then forwarded the survey to other stakeholders from whom they felt input were valuable. It is unclear how many surveys were forwarded to other individuals; however, eight replies to the

survey, some completed by multiple informants, were returned by email. A description of survey respondents and a discussion of the findings are provided below.

*Survey Respondents.* One survey response, with input from multiple members, was returned by the Texas Brain Injury Association Advisory Council(Please see comment on previous page) . A second survey response was received from the Group Manager of the DSHS Environmental Epidemiology and Injury Surveillance Group. A third survey, with input from two program specialists, was received from the Children with Special Health Care Needs Services Program in the Department of State Health Services. A fourth survey was completed by the TBI Grant Project Coordinator for the Traumatic Brain Injury Advisory Council. An Injury Prevention Coordinator from a Disaster Management and Trauma Services Unit provided a fifth survey response. One parent of a child who sustained a TBI responded to the survey. One individual did not identify his or her role or position, but responded from the perspective of an advocate for a family with a TBI survivor.

*Discussion of Stakeholder Survey Responses.* Question 1: **What are the specific reasons for requesting evaluation of the need for and feasibility, efficiency and cost of a TBI Registry in Texas?** Specific reasons clustered around several major themes: (1) generating useful data; (2) connecting individuals affected by TBI to appropriate services; (3) seeking and obtaining funding; and

(4) injury prevention. Each of these themes will be discussed with respect to the responses of stakeholders.

The need to collect useful data permeated the survey responses of most stakeholders. Data regarding the incidence, patterns, and outcomes of TBI are needed to develop injury prevention and intervention programs. Accurate and reliable data are needed to track and monitor TBI occurrences and outcomes, including costs. Incidence data are needed for school-age groups in order to determine whether and how these children are identified and served by public school systems.

Provision of services to individuals who have sustained TBIs is a major focus of the stakeholders. Respondents noted that with the current EMS/Trauma Registry, there are no means to identify need for services, match survivors and their families with services, or track outcome of interventions. Stakeholders requested that exploration of TBI registries in other states would be relevant, particularly with regard to the tracking of children and adolescents and how they are referred to needed services in their schools. Particular interest was expressed in the “disconnect” between children who sustain a TBI and the provision of school-based interventions; within this framework, clarification of patterns across rural, urban, and frontier areas of the state, and among individuals sustaining mild, moderate, and severe TBIs is needed, with respect to incidence, intervention, and outcome.

A repeated theme in stakeholders' responses was the importance of seeking and obtaining funding for TBI identification, prevention, monitoring, and intervention. Identification of costs associated with setting up a TBI Registry in Texas was central to this theme, with one stakeholder noting that a registry would provide data that would help with requests for funding from the legislature for prevention, treatment, and residential care. Such funding could ultimately ameliorate costs associated with TBI by reducing number of injuries and by increasing coordinated and appropriate supports to improve outcomes.

Finally, injury prevention emerged as a primary reason for requesting this needs and resources assessment. The treatment of injuries, including TBI, costs the state millions of dollars plus years of potential life lost. An injury prevention program must be premised upon adequate surveillance to determine how, when, where, and for whom TBIs occur, so that risk factors can be identified and prevention/intervention programs efficiently designed and disseminated.

**Questions 2 and 3: Why did your group decide to pursue the TBI needs and resources assessment at this particular time (completion of the project by November, 2008)? Who (individual, entity) initiated the effort to complete the TBI needs and resources assessment within this time frame?**

Funding for this project was made available through a three-year Implementation Grant ("Texas TBI Partnership Initiative") from the HRSA Maternal and Child Health Bureau, TBI State Grants Program issued to the Texas

TBI Advisory Council (TBIAC)/Department of State Health Services (DSHS) in 2006. This Needs and Resources Assessment is consistent with the goals for the third year of the grant cycle. Some respondents stated that the updated assessment is required by the grant. The TBIAC determined that, given the state's population growth and inflation, an updated comprehensive assessment is needed, from which a Revised Statewide Action Plan will be formulated.

**Question 4: What prior efforts have been made to improve the collection of TBI data and the identification and provision of appropriate follow-up?** The current EMS/Trauma Registry represents the response to legislation in the 1990s to collection information regarding TBI. TBI data is extracted from this registry, but has limitations including irregular reporting and lack of data for individuals hospitalized less than 48 hours. No identifying information is available that could allow for contacting patients to gain more information, refer for supports/services, or track outcomes due to concerns about confidentiality and HIPAA requirements. Survey respondents noted that general efforts have been made to improve the quality of the data submitted to the registry, but no details were provided. However, one respondent stated that a member of the TBIAC is also a member of the Governor's EMS and Trauma Advisory Council (GETAC). The TBIAC will in the future work with the data informatics group of GETAC to evaluate the possibility of using the EMS/Trauma Registry to track outcomes for individuals with brain injury.

Question 5: **What problems, if any, have been associated with the current EMS/Trauma Registry with respect to TBI identification and follow-up?**

Many problems with the data generated by the current registry were reported, with lack of funding and insufficient number of staff viewed as underlying the problems with the database. The lack of identifying information discussed above with regard to connection to services and follow-up regarding outcomes is a primary concern, with HIPAA requirements an issue that has not been satisfactorily addressed. The following list includes general categories of concern gleaned from multiple respondents:

- “essentially voluntary” nature of the registry, so that reporting is irregular and incomplete;
- the age of the data (most current available data is from 2004);
- missing and duplicate data; errors in data entry;
- lack of ease and efficiency for user access;
- inconsistency with the national database (Centers for Disease Control), with respect to data collection elements (e.g., mild and moderate injuries may not be reported at all—reporting of severity is inconsistent);
- available data is not “scalable” with respect to studying injury characteristics and outcomes (the structure of the data is not amenable to use for answering research questions);

- stakeholders have had no input into what data is collected and in what form, which is necessary for data to be used to generate useful findings for prevention, intervention, and follow-up;
- data ends with patient discharge, so that links to prior or subsequent admissions, diagnoses, treatments, and outcomes is missing;
- public health involvement was missing from the outset of registry development; it does not operate as a tool for public health in its current form.

Question 6: **What other information would you like to share that is relevant to this needs and resources assessment?** One respondent noted that this assessment should take into account what stakeholders would want to see in a TBI Registry. Several respondents noted that an effective registry would benefit patients and their caregivers by connecting them with resources and services without their having to individually navigate a complex system. Concern was reiterated regarding the lack of sufficient staff to focus on TBI and to provide statewide case management. The need for longitudinal information to increase understanding of outcome in relation to injury characteristics and context was emphasized. One respondent noted the issues associated with under-diagnosis (and its association with inability to pay for long-term rehabilitation) and lack of coordination with school systems, both of which operate to reduce degree of recovery from TBI among children.

*State by State Analysis*

As a starting point in researching other states that may have TBI registries, we first explored the National Center for Injury Prevention and Control (NCIPC) website (link from CDC website at [www.cdc.gov/ncipc/profiles/tbi/about.htm](http://www.cdc.gov/ncipc/profiles/tbi/about.htm)). This site provides state-by-state profiles with respect to TBI data collection. During the time we accessed this site (June through September, 2008), it was reported that 17 states had TBI-specific registries that were established by statute. A TBI Registry, according to the above website, is a method of systematic and ongoing data collection that is population-based, includes personal identifying and contact information for each case, and may be used for follow-up of cases over time and/or for linking individuals to services. States may also use surveillance systems, trauma registries, or other data sets to determine incidence and other TBI information (See Appendix C for a table illustrating state-by-state TBI data collection status, according to the above website and our follow-up research).

When we attempted to establish email or telephone contacts for individuals from states that were identified as having TBI registries, we encountered some problems, including disconnected telephones, statements that registries had closed, and uncertainty as to registry status or contact persons. For these reasons, we contacted Dr. Jean Langlois, epidemiologist with CDC's NCICP, Division of Injury Response, regarding the status of registry

information at CDC. From this telephone conversation, we learned that the CDC website is not up-to-date regarding each state's data collection methods.

Dr. Langlois also informed us that in 2002, the establishment of state TBI registries was a special project of CDC; however, since that time there has been debate about whether CDC should support registries or surveillance systems. Surveillance systems, which involve systematic and ongoing data collection using methods that are practical, uniform, and focus on rapid data collection rather than complete accuracy, are viewed as more cost-efficient and consistent with the CDC's mission of establishing a national data collection program. Dr. Langlois noted that a surveillance system is not a substitute for a registry, which can have the advantages of providing links to services for individuals and allowing for follow-up on case outcomes. However, such state registries are too expensive for CDC to fund throughout the United States. Dr. Langlois reported that some states have legislative authority to use the electronic hospital discharge and vital statistics data sets (surveillance systems) within their states as registries (Judith Langlois, personal communication, July 22, 2008).

#### *Web-based Survey to States with TBI Registries*

Every state on the CDC website that indicated it had a TBI Registry, or was named by Dr. Langlois as a state with a registry, was contacted by telephone to ascertain registry status. When possible, an individual representing the TBI Registry to receive a web-based survey via email was identified. The survey was

designed to address questions regarding the legislative mandate, purpose, usefulness, and estimated initial and maintenance costs of their states' TBI/CNS registry (see Appendix D for the survey items).

*Survey Respondents.* The survey was sent to representatives from 10 states with eight responding to the survey, one emailing the principal investigators indicating that he was the wrong contact (but did not supply correct contact information), and one not responding. The final response rate was 80%. Representatives from the following states responded: Arkansas, Alabama, Florida, Minnesota, Nebraska, South Carolina, Tennessee, and West Virginia. The representative from Arkansas indicated that they did not have a TBI or CNS Registry and was routed out of the survey. The results below are reported for seven states.

*Discussion of States with TBI Registries Representatives' Responses.* Four states had TBI Registries and three states had CNS Registries. Six of the seven states indicated that they had a law that mandated the development of their TBI Registry. Six states established their TBI Registries in 1996 and one established it in 1999. Table 11 illustrates the funding sources for the TBI Registry; some states indicated that they have more than one funding source. Three states indicated that they have a trust fund, which in many cases is funded by reinstatement fees for traffic violations.

**Table 11**  
***Number and Percent of Responses to: What was the Funding Source for your TBI Registry?***

Response	N	%
CDC	1	14.3
State Government	1	14.3
State Agency(ies)	2	28.6
Trust Fund	3	42.9
Reinstatement fees for traffic violations	2	28.6
No funds	1	14.3

Respondents were asked to provide an estimated cost for the development and maintenance of their state’s TBI Registry. Estimated costs of development ranged from \$100,000 to \$200,000, while estimated maintenance ranged from \$50,000 to \$180,000 annually.

**Table 12**  
***Estimated Cost for the Development and Maintenance of the State’s TBI Registry***

State	Development	Maintenance
Alabama	DK	DK
Florida	DK	DK
Minnesota	\$150,000	\$180,000
Nebraska	\$100,000	\$150,000
South Carolina	\$200,000	\$125,000
Tennessee	\$116,000	\$86,000
West Virginia	DK	\$50,000

We asked states how they used the data that was reported to the TBI/CNS Registries. Table 13 shows that six of the seven states that responded reported using the data to prepare reports to the public and to their state’s

legislature. In addition, five of the seven states reported using the data to improve services for individuals with TBI and four of the seven reported using it to track individuals with TBI. Other responses were recorded and are reported in Table 13.

**Table 13**  
***Number and Percent of Responses to: How do you use the data collected in your registry?***

Response	N	%
Reports to the public	6	85.7
Reports to the legislature	6	85.7
Improve services for individuals with TBI	5	71.4
Track individuals with TBI	4	57.1
Epidemiologic public health surveillance	1	14.3
Quantify the prevalence of TBI/SCI	1	14.3
Manuscripts	1	14.3
Offer available services and funding	1	14.3

States were next asked why they would recommend developing a TBI/CNS Registry to other states. Six of seven states responded that linking services, increasing public awareness, and increasing the ability to track individuals with TBI were the most important reasons for developing a TBI Registry (see Table 14).

**Table 14**  
***Number and Percent of Responses to: Why would you recommend to other states that they develop a TBI Registry?***

Response	N	%
Data are more comprehensive	4	57.1
Data are more accurate	4	57.1
Improvement in ability to link individuals to services	6	85.7
Increase in public awareness of TBI	6	85.7
Increase in ability to track individuals with TBI	6	85.7
Seek waiver programs (e.g., Medicaid)	1	14.3

Lastly, we asked the states’ representatives if they would participate in a telephone interview. Six of the seven responded that they would participate. Of those, we used a standard set of questions (Appendix E) to conduct telephone interviews with representatives from Florida, Minnesota, South Carolina, Tennessee, and West Virginia.

*Telephone Interviews with State Representatives*

The specific telephone interview questions and synopses of respondents’ answers are presented below. Nebraska responded to the survey and has a registry, but did not respond to efforts to make telephone contact. Alabama responded to the electronic survey, but did not consent to a telephone interview. Responses from each state to each question are reported separately since there were specific and significant differences among the states that would be obscured by general summaries for each question.

Questions 1 and 2: **What agencies developed the registry? What agencies are responsible for the maintenance and reporting of the data?**

- Florida: The brain and spinal cord injury program was established through the Vocational Rehabilitation Office in 1973, at which time they developed a Spinal Cord Registry in conjunction with CDC grant funding. This initial registry helped establish the need for a central registry. The Florida Department of Health is now responsible to ensure that referrals are entered into the database and to follow up if referrals are incomplete.
- Minnesota: The MN Department of Health, in partnership with the Brain Injury Association of MN and Department of Human Services (to a lesser degree). The Department of Health is responsible for maintenance and reporting of results. Minnesota has a Central Nervous System Registry (CNS Registry, includes brain and spinal cord injuries).
- South Carolina: Department of Disabilities and Special Needs. By law, the registry (which is actually a surveillance system) is housed with this agency under the Head and Spinal Cord Injury Division and serves both head and spinal cord injuries. The Department of Disabilities and Special Needs is also responsible for maintenance and reporting of data.
- Tennessee: Department of Health Office of Information, which is staffed by two statistical analysts. This same office and staff are responsible for maintenance and reporting of data.

- West Virginia: The registry was initially developed by the WVA Department of Rehabilitation Services in partnership with the WVA Bureau of Public Health. Currently, the Bureau of Public Health (Division of Trauma) contracts with the WV University Center for Excellence in Disabilities to maintain the registry, ensure that patients receive the information and resources needed for optimal recovery, and generate reports.

**Question 3: What entities report to the Registry?**

- Florida: Florida law requires that all hospitals, attending physicians, public, private, or social agencies refer all new traumatic moderate-to-severe brain or spinal cord injuries to the Central Registry. Every hospital is mandated to report to the central registry within five days of admission, with both civil and criminal penalties in place for non-reporters. The law, which states that any person or agency that knows about an injury must report, has three parts: prevention, coordinated system of care, and payment for patients who have exhausted all other means of payment. Compliance with reporting is 95-98%. Trust fund benefits are provided to help transport patients and pay for some health care expenses if all other benefits are exhausted.
- Minnesota: Data come from all acute care hospitals in Minnesota. All hospitals that discharge patients diagnosed with TBI (who have been admitted) must report that case to the CNS Registry within 60 days. Cases

that are seen only in the Emergency Department (ED) are not directly reported to the registry.

- South Carolina: All hospitals must report to the CNS Registry, although military hospitals are exempt since they are federally funded and this is a state mandate.
- Tennessee: All hospitals report information on individuals admitted for more than 24 hours. Most hospitals reliably report and submit data on a quarterly basis.
- West Virginia: All hospitals are supposed to report, but in reality mostly Level 1 and Level 2 Trauma Units report since TBI cases are transferred to them. There is a separate Trauma Registry to which all hospitals report, and WVA is trying to get EMS worked into this system. It is much stricter regarding compliance requirements than is the TBI Registry.

Question 4: **What data do you collect in the registry?**

- Florida: Epidemiological information with a focus on prevention is included in the referral form, including identifying information, site of the injury, Glasgow and Rancho scores, whether wearing protective gear, etc. The data collection process includes a checks and balances system to alert the agency about discrepancies and allow for the input of additional information about these discrepancies.

- Minnesota: In addition to the reports from acute hospitals to the CNS Registry, the Dept. of Health looks at all hospital data provided by the Minnesota Hospital Association, which includes data on all cases treated in the ED, to try to capture patients seen in the Emergency Dept. (ED) but not admitted into the hospital. The number of TBIs treated only in the ED is their estimate of the number of mild TBIs. The two databases (CNS Registry and Hospital Association) are regularly compared to look for discordant cases (both include some identifying information so that data sets can be compared), with follow-up letters sent to the hospitals when needed (see Appendix F). The Dept. of Health sends out a letter (see Appendix G) to every patient who is discharged with TBI or spinal cord injury to provide support, rehabilitation, and reintegration information. The CNS Registry (which contains patient names) is a protected data set, so no information can be released to any other agency or group by law. The Hospital Association data set (which contains no patient names but does contain epidemiological data including medical case #) is accessible to other groups and subpoenaable.
- South Carolina: Hospital discharge information is collected every three months for every case of CNS injury. Of this group, a random sample of 20% is reviewed for additional information. Last year, a CDC-funded project involved randomly selecting 35% of those with severe TBI, 15% with

- moderate TBI, and 5% with mild TBI and conducting a follow-up study of outcomes.
- Tennessee: Name, address, ICD-10 codes, country of residence, date of birth, gender, ethnicity, date of injury, and date of admission are included in the registry. This information is used to send a letter to identified individuals, asking them to contact the agency regarding their injury and follow-up. If the individual responds, then follow-up is provided. About 20% of those contacted respond. It generally takes five to six months from the time of injury for the agency to send the letter.
  - West Virginia: The only reporting fields allowed by WVA law are name, address, and age. Any other information is collected via a follow-up survey (see Appendix H). Of the follow-up surveys mailed to reported TBI victims, about 20% respond; of these, about 10% are requests to remove the name from the Registry or reports of death. Approximately 10% of individuals complete and return the survey, providing information about the nature of the injury and need for services. This survey data is then used to connect individuals to resources and for further research.

Question 5: **How have your data improved as a result of implementation of the TBI Registry?**

- Florida: Immense improvement is reported. The Dept. of Health works with a company for instructional technology (IT) support; this company dedicates

three staff to work with the Dept. of Health IT staff. All data is immediately accessible through a real-time database system. Compared to 1995 data, there is a significant drop in injuries because of prevention programs associated with registry data.

- Minnesota: Data improvement is a continual and intentional effort. Respondent and colleagues meet with hospital information management staff around the state, attend regional meetings of the management association, and provide feedback to local hospital groups about how the data is used. The Dept. of Health group publishes articles in the state medical association journal on how data is used to drive policy. They have seen a decrease in reporting errors and greater specificity in reporting causes of TBI.
- South Carolina: The legislative mandate and use of a surveillance system have been great.
- Tennessee: The TBI Registry has been a great improvement over the Trauma Registry, which was described as “useless.” The data is used for reports to the public and to the legislature. This data has been used proactively, e.g., to prevent the revoking of the helmet law for motorcycles by showing the legislature the link between TBI and riding without a helmet.
- West Virginia: Improvements began to be noted only recently, when the WVA University Center for Excellence in Disabilities began to conduct follow-up surveys with reported victims. They now collect more information

regarding how the TBI occurred, along with unmet needs and barriers to service. The survey was implemented with funds made available by the state for statewide resources coordination.

Questions 6 and 7: **What obstacles were encountered in developing the registry? What problems or obstacles remain?**

- Florida: There was agreement by the legislature in 1988 to implement the registry; some high profile child death cases had put CNS injuries in the spotlight. Initial political obstacles included hospitals fearing penalties based upon reporting large numbers of CNS injuries, but this issue has been largely resolved. Ongoing issues include a decrease in the trust fund related to downturns in tourism and the housing market. The estimate is that about \$18 million is generated and spent each year through the trust fund (dedicated to CNS, not part of the general revenue fund). There had been \$10 million invested, but that investment is now depleted and the program operates off real dollars earned.
- Minnesota: The registry has been legally mandated to serve both prevention/epidemiology purposes and intervention (link to services) purposes. This mission is complex, and it would be easier to serve only one of these purposes. The timeliness of reporting, while improved, still needs to get better (law says 60 days from date of discharge, median is 85-90 days). Staff are committed to not being a burden to hospitals, and not requiring

- that they duplicate reporting to the state. Data quality varies with staffing and personnel change in hospitals. As more hospitals are established, there is increased need for training, particularly in the accuracy of data coding. From a surveillance perspective, they have good data (e.g., 90% sensitivity).
- South Carolina: The respondent described the importance of preliminary work to establishing an effective registry. This work began in 1992 with a CDC-funded capacity building grant that required the Department of Health to conduct a surveillance program; after two years, SC formed an advisory council in which the SC Paralyzed Veterans and two state legislators with family members with TBI were involved. The advisory council formed a relationship with the SC Hospital Association and tied the registry to cost benefits associated with proactive prevention. The Hospital Association provided funds for an economic cost-benefit analysis, and key points from this study were used to make a successful case to the legislature. No obstacles to the operation of the registry remain.
  - Tennessee: When the registry was first established, reporting by hospitals was not mandated and they were resistant to reporting. In 1995, the law was changed to make reporting mandatory. The Department of Health worked with attorneys of several hospitals and with Vanderbilt University to increase hospital staff comfort level about reporting. No obstacles to the operation of the registry remain.

- West Virginia: The respondent was not involved with the initial development of the registry, but reported that getting legislative approval for the reporting to the registry of name, address, and age was a big issue due to questions about confidentiality and system security with respect to HIPAA. Continued obstacles include getting enough hospitals to report and expanding the reporting to include mild head injuries (no reporting of TBI with less than 24-hour admission). They are beginning to explore extraction of data from the primary Trauma Registry but this has not yet been done. They did not have success with an online reporting system (no one used it) and switched to a hard copy form returned by mail. One data entry person then enters the name, address, and age manually.

Question 8: **What have you learned as a result of developing and implementing your registry?**

- Florida: There are big benefits for states in terms of prevention and operating as a community. Community partners will step up to take care of patients even if there is no money from the trust fund.
- Minnesota: Do not underestimate the importance of partnerships to accomplish establishment of a registry. Perspectives should include those from the Texas Brain Injury Association, rehabilitation facilities representatives, neurosurgeons and trauma professionals, and community-level service providers as well as those with TBI. A registry is too big a task for

just one group to operate, even though at the end one agency will be responsible. Department of Health has access to information technology and epidemiology experts along with statutes that let them collect and use data. Data must be used to drive effective policy and program development.

- South Carolina: The registry is very useful. Issues regarding confidentiality were addressed by legal mandate specifying exceptions to nondisclosure of identifying information. Money for the registry is generated through \$10 dedicated from every traffic violation and \$100 for every DUI. This money (about \$1 million annually) goes to the Medical University of South Carolina, with much of it devoted to research and funding of an endowed chair.
- Tennessee: The registry is very useful. There is a dedicated trust fund stream based on four traffic violations. The Department of Public Safety collects monies and sends part of it to the trust fund: reckless driving \$30; revoked license \$15; DUI \$15; speeding \$5.
- West Virginia: Incidence numbers are not a reliable representation of TBI occurrence and should not be used to justify funding. Relationships must be maintained with hospitals and trauma centers to encourage reporting. Bureau of Health staff attend regular meetings and reminder letters are sent to entities that are not reporting. The state provided the initial funding for developing the Registry via the federal Health and Human Services, HRSA, Maternal and Child Health Bureau 3 year partnership grant; they have

continued to get renewal grants (competitive) through the same federal source, which means that so far the state has not had to pay for the registry, although it seems that the state came up with funds for the statewide resources coordination. They employ only one person to mail surveys and enter data—this is where the \$50,000 maintenance estimate comes from.

### *Transition of the School-Aged Population to School*

#### *Texas EMS Provider and Hospital Web-Based Survey*

Earlier in the report, we discussed the selection process of respondents to this web-based survey (see page 14). Of particular interest to this study was the transition from hospitals to schools for the school-age population. Therefore, hospitals were asked if they requested medical releases to contact the child's (with TBI) school. Only 15 percent of hospitals in the sample responded affirmatively (see Table 15). Of those, two-thirds indicated that they reported limitations on activity and medical status, while one-half provided recommended interventions (see Table 16). This was based on a sample size of 6 and should be interpreted with caution. Most hospitals that responded to this survey did not ask parents for medical release to contact the child's school; these hospitals were asked if they advised families to provide information about their child's TBI to the schools. Thirteen or 37 percent of these hospitals responded that even though they did not ask for medical release, they advised parents to provide information about their child's TBI to the school (see Table 17).

**Table 15**

***Number and Percent of Responses to: For your school-age patients with TBIs, do you ask parents for medical release to contact the child’s school?***

Hospitals	N	%
Yes	6	14.6
No	35	85.4
Total	41	100.0

**Table 16**

***Number and Percent of Responses to: What types of information do you provide to the child’s school?***

Hospitals	N	%
Limitations on activity	4	66.7
Medical Status	4	66.7
Recommended interventions	3	50.0
Other	1	16.7

*Note. Only hospitals that asked parents for medical release to contact the child’s school were asked to respond to this question.*

**Table 17**

***Number and Percent of Responses to: Do you advise families to provide information about their child’s TBI to the school?***

Hospitals	N	%
Yes	13	37.1
No	22	62.9
Total	35	100.0

*Note. Only hospitals that did not ask parents for medical release to contact the child’s school were asked to respond to this question.*

*Texas Special Education Directors’ Web-Based Survey*

A web-based survey for special education directors at Texas school districts was designed to address questions regarding procedures schools have in place for transition of students with TBI from hospitals or rehabilitation centers

to schools (see Appendix I for the survey items). The survey was sent via email to special education directors of all 20 regional education service centers.

*Survey Respondents.* The sample frame for this survey consisted of an excel file of 629 special education directors that was obtained from the Texas Education Agency website. We selected a stratified random sample with regional education service centers as the stratum. Two hundred nineteen special education directors were randomly selected and sent an email in which the project was explained and a link to the survey provided. Twenty-eight emails came back as invalid resulting in a final sample size of 191. Seventy one special education directors responded for a response rate of 37%.

*Discussion of Special Education Director Responses.* We asked special education directors to state which regional education service center served their district and to indicate their size. All regions and sizes were fairly well represented. Table 18 shows that 59 percent of respondents stated that their districts had a person or team responsible for facilitating the transition process for students with TBIs. They further reported that the most likely person to facilitate this process was an educational diagnostician (see Table 19).

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**Table 18**  
**Number and Percent of Responses to: Do you have a person or team who is responsible for facilitating students who are transitioning from medical or rehabilitation agencies to school?**

	N	%
Yes	42	59.2
No	29	40.8
Total	71	100

**Table 19**  
**Number and Percent of Responses to: What personnel serve in this role?**

Personnel	Yes		No	
	N	%	N	%
Special education teacher	22	52.4	20	47.6
Licensed specialist in school psychology (LSSP)	23	54.8	19	45.2
Educational Diagnostician	33	78.6	9	21.4
Physical, Occupational or Speech Therapist	22	52.4	20	47.6
School Administrators	25	59.5	17	40.5
Other	10	23.8	32	76.2

*Note. Only districts that had a person or team responsible for transition services were asked to respond to this question.*

Participants were asked what procedures they follow upon learning that a student with TBI was being transitioned to their school. Almost every school district responding stated that they requested current medical information and that they contacted the family to share information.

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**Table 20**  
**Number and Percent of Responses to: Which of the procedures do you follow upon learning that a student who has sustained a TBI is being transitioned to a school in your district from a medical or rehabilitation facility?**

Procedures	Yes		No	
	N	%	N	%
Convene a prereferral team meeting	60	88.2	8	11.8
Begin a referral for an ARD meeting	49	72.1	19	27.9
Provide relevant school records to medical facility	57	83.8	11	16.2
Request current medical information	67	98.5	1	1.5
Identify school personnel to attend discharge planning meeting	44	64.7	24	35.3
Contact the family to share information	65	95.6	3	4.4
Other	15	22.1	53	77.9

Participants were asked if they offered in-service training to their district personnel for providing services to students with TBI. As Table 21 shows, only 31 percent (n=21) of districts offer this type of training. The participants who responded “yes” were asked how personnel in their district are offered training and who provides the training. Eighty six percent of school districts indicated that they provide training every two to five years (Table 22). This training was provided by sending district personnel to conferences, attending training sessions offered by outside experts, or by district personnel (Table 23).

**Table 21**  
**Number and Percent of Responses to: Has your district received in service training for providing services to students with TBI?**

	N	%
Yes	21	30.9
No	36	52.9
Don't Know	11	16.2
Total	68	100.0

**Table 22**  
**Number and Percent of Responses to: How often do they receive this training?**

	N	%
Every 6 years or longer	1	4.8
Every 2 to 5 years	18	85.7
Annually	1	4.8
More often than annually	1	4.8
Total	21	100.0

*Note. Only special education directors that provided training were asked to respond to this question.*

**Table 23**  
**Number and Percent of Responses to: Who provides the training?**

	Yes		No	
	N	%	N	%
District Personnel	12	57.1	9	42.9
Outside Experts	13	61.9	8	38.1
Attends conferences or trainings	16	76.2	5	23.8
Education Service Center	2	2.4	82	97.6

*Note. Only special education directors that provided training were asked to respond to this question.*

*Special Education Director Telephone Interviews*

Requests to participate in a telephone interview regarding TBI transition practices were sent by email to six directors of special education across the state. Four directors responded to this request. One director of a central Texas

school district indicated that there had been no students with TBI in that district for years (2004 Trauma Registry data indicated 66 documented TBIs in the 0 through 21 age group in the county in which the school district resides). Thus she declined to participate in the telephone interview.

Telephone interview questions are provided in Appendix J. This summary reflects insights provided by the three special education directors who participated in the telephone interview. One respondent is the director of a cooperative of five school districts in East Texas, one heads an urban school district in West Texas, and one heads a suburban Houston area school district.

When asked a general question about transition services, all three respondents noted that they have very few children in their districts with TBI (fewer than 10 in the past five years were reported in any of the three districts), which limited any generalizations or routine practices they could describe about transition services. One respondent discussed the low numbers of children identified with TBI with respect to two factors: the restrictive definition in federal and state laws, and the likelihood that children who have educational need receive services under other disability categories because of the lack of appropriate documentation of an injury that may have occurred years before. One director stated that they evaluate each child before admitting to special education to determine educational need. Another noted that children with TBI can be better tracked when they already lived and attended school in the district

before the TBI. These responses underscore the infrequency with which children with TBI come to the attention of even well-trained school personnel unless they are already in the district and have a high profile (e.g., all three respondents described local cases in which a child who was already enrolled in the district sustained a severe TBI then later returned to school).

With regard to specific teams or individuals assigned to transition for children with TBI, responses varied from special education teachers to the nurse supervisor, to the assessment specialists and homebound teachers. Transition services, which included obtaining medical records, visiting the child's home, and sharing medical records with school personnel, were described as individualized depending upon the specific case. No specialized assessments were described as routinely employed for returning students with TBI; frequent breaks, sensitivity to fatigue, and assessment in the areas that medical providers have indicated are problematic were mentioned as possible considerations. One respondent noted that what testing is completed depends on the information that is received from the rehabilitation facility. Similarly, services that are provided by the school are individualized based on need and recommendations from medical and rehabilitation providers, rather than on the TBI diagnosis, according to respondents.

Directors were asked about information they receive from the treatment facilities when children with TBI are transitioned back to school. One respondent

indicated that she has experienced no difficulty in telephone communication or transmission of records from rehabilitation facilities. One noted that the district gains consent to work with the medical doctor, but the neuropsychological evaluations are often not helpful. Another noted that they receive no academic assessment or intervention information.

Specific training for school personnel regarding TBI was not viewed as a priority since so few cases were reported in these districts. They indicated consultants would be brought in if needed to work with teachers of children with TBI. In summary, preparation of school staff was described as completed on a case-by-case basis.

When asked about problems related to TBI have emerged, responses included:

- lack of awareness by parents of the importance of head injury and of early intervention
- difficulty identifying children with TBI who come from out of district
- access to medical intervention for some children
- confusion within schools about the differences between TBI and OHI (Other Health Impaired) as eligibility categories
- obtaining appropriate assistive technology for children with TBI

Recommendations for improving the transition process were as follows:

- getting better information from medical facilities, including tracking down which medical doctor can provide documentation
- better communication between school personnel and medical doctors
- medical doctors working more closely with parents and schools so that the parents trust the school to provide appropriate support

In summary, these three special education directors observed that they have had limited experience with transition because there have been so few student with TBI identified in their districts. Few generalizations could be made, but responses suggest that districts are more aware that a child has a TBI if they resided in the district before the accident, sustained a severe TBI, and then returned to the same district. For children with different patterns of residence and injury, identification and provision of services is much more problematic since they may not come to the awareness of the school. If they do, obtaining medical documentation is an issue, as is parent awareness of the potential significance of the TBI. All three respondents expressed a desire that there be better communication and sharing of information between medical service providers and school service providers.

#### *TEA Database/Trauma Registry Data & Discrepancies*

The most recent data available from the Texas EMS/Trauma Registry was from 2004. The report generated from this data indicated that in 2003-04, there were 6,021 reported cases of TBI in Texas among children and adolescents from

0-19 years of age who survived the injury. This number represents TBI cases that were admitted to an acute care hospitals, not including Emergency Rooms, so the number of mild TBI's is likely much higher. The Texas Education Agency publishes data reports online, with data prior to 2005-06 no longer available. According to the 2007-08 TEA report, 1,426 students statewide were served through special education under the disability category of TBI. Numbers served in the two prior years were 1,426 in 2005-06 and 1,464 in 2006-07. This number represents approximately 0.3% of the total number of children served through special education in Texas in 2007-08. It is also a cumulative total, reflecting total number of children served that year, not the number of new cases identified. It is clear that many more school-age children sustain TBIs than are identified and served through special education in the Texas public school system. For contrast purposes, a statement from the Georgia Brain & Spinal Injury Trust Fund Commission (2007) reported that in 2005, more than 25,000 children and youth ages 0 through 21 were treated in Georgia hospitals for a TBI. This number includes emergency room treatments, which accounted for a vast majority of the number of TBI cases treated in hospitals.

Consistent with national surveillance data published online by the CDC (2008) indicating that adolescents are at particularly high risk for TBI, Texas students in the age range from 12-17 account for more than half of children with TBI served through special education in 2007-08. It is worth noting that students

with the handicapping conditions of Learning Disabled (LD), Other Health Impaired (OHI), Emotionally Disturbed (ED), and Speech Impaired (SI) are identified as needing special education services at a much higher rate; when combined, these groups account for 71% of all students served through special education. The research literature, while limited, supports the interpretation of the data that many students with TBI who require special education are served under a different handicapping condition. This misclassification may be the result of several factors, including (1) lack of appropriate documentation of a TBI, particularly if it occurred years prior to referral; (2) lack of awareness on the part of parents, guardians, or school staff that the TBI is relevant to current educational needs; (3) the prominence of related features, such as emotional or behavioral lability, orthopedic, speech or health problems, or severe learning difficulties resulting in a diagnostic process that fails to consider the broader symptomatology characteristic of moderate to severe TBI; (4) a delayed manifestation of deficits stemming from the TBI, which research has shown may occur when environmental demands (such as higher level language comprehension or social skills) trigger expression of previously unrevealed cognitive or behavioral deficits; or (5) the exclusionary definition of TBI under federal law that requires that the injury be due to an external physical force and is not congenital, degenerative, or induced by birth trauma. This definition does not map neatly onto the medical diagnoses that would be made in hospital

settings, where the broader term acquired brain injury (ABI) may be employed.

In fact, Ohio has changed the definition of TBI to broaden the eligibility criteria.

Their definition reads:

“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, that adversely affects a child’ educational performance. The term applies to open or closed head injuries, as well as to other medical conditions that result in acquired brain injuries. The injuries result in impairment 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 processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.”

Other possible explanations for the discrepancy between numbers of children and adolescents who sustain TBI and numbers identified for special education include the following. (1) Lack of educational need demonstrated by the student. Not all individuals who sustain TBI demonstrate cognitive or academic skills deficits. In fact, these very skills may be the best preserved, and the student may not be referred for special education if learning problems are absent or mild. Some of these children may be served through Section 504 of the Rehabilitation Act. (2) Treatment and services provided by alternative settings, such as private schools, home schools, and residential treatment centers. In the absence of reliable incidence and tracking data from the event of the TBI to the referral and provision of services, it is not possible to determine how many

children with TBI are being served outside of public school education systems, or, within public school, under special education, Section 504, or regular education programs.

#### *Rehabilitation Provider Telephone Interviews*

A list of 11 post-acute brain injury rehabilitation facilities within the state of Texas was provided by Dr. Joanne McGee. All of these facilities were contacted by telephone, and their websites, if available, reviewed online. Representatives from six programs responded to the telephone interview. The interview questions are listed in Appendix K. Themes from interviewee responses are discussed below.

Five facilities that serve children and adolescents responded to the telephone interview. Of this group, two facilities serve clients age 8 and older, one serves clients age 5 and older, one serves ages 8 and older, and one serves primarily age 16 and older, although younger clients are sometimes considered. The percentage of clients age 21 or younger served by these facilities ranged from 10%-30%, with 30% the modal number. Of the clients in the rehabilitation facilities, the percentage who had sustained a TBI ranged from 20%-100%; one facility served only individuals with TBI while the others served other populations as well. The most frequent source of referrals to the rehabilitation facilities is acute care hospitals. Patients tend to transfer directly from acute care hospitals. Other referral mechanisms include the DARS program (if waiting for funding may

take from several months to a year), insurance company representatives, word of mouth or websites, and individual physicians. The average length of stay ranges from about two to six months.

Services provided in these post-acute rehabilitation facilities reliably include occupational therapy (OT), physical therapy (PT), and speech therapy. Most provide neuropsychology services, counseling or other psychotherapy, and some type of transition program, such as vocational training, community re-entry, or transitional living.

Of the respondents, four provided percentages of their school-age clients who transition back to public schools: the range was 50% to 90% (average of 85%), indicating that most children served by these facilities return to public school. School-age clients who do not transition directly to public school may receive homebound instruction (a public school service), a combination of day treatment in an outpatient program with part-time school attendance; intensive outpatient treatment, or residential care. The determination of where these clients transition depends upon numerous factors, including continued funds for treatment and progress toward goals.

When asked what procedures are in place for transitioning school-age children back into public schools, respondents named a variety of approaches. One facility has a school system liaison that consults with the child's primary school system to provide lessons and assignments to the child while in

rehabilitation. Another facility described an Education Department that meets with school personnel, attends Admission, Review, and Dismissal (ARD) meetings, helps to identify appropriate modifications, advocates on behalf of the students, and works cooperatively with medical doctors. One facility has an onsite charter school that provides assessments and coordinates with receiving school districts. Another facility follows a procedure whereby clients are assigned to a case manager upon admission; the case manager provides medical records to the school and maintains communication about expectations upon the student's return. All facilities that responded to the telephone interview described some sort of transition procedure; however, these were not uniform across settings.

A final question elicited information about improvements that could be made in the transition process. The recurrent themes were (1) earlier involvement with the schools and increased follow-up with schools and (2) making sure that schools have adequate resources and education to address the educational needs of children and adolescents with TBI.

The number of children and adolescents with TBI represented by the responding rehabilitation facilities is clearly relatively small given the annual incidence of TBI. Very few children with mild or even moderate TBI are likely to be represented in this sample. However, the insights documented by these informants include: (1) most children who are in rehabilitation go there directly

from acute care hospitals and return to school eventually after a fairly brief stay, (2) awareness exists that transition must be planned and facilitated, (3) transition practices vary across settings, and (4) at least some rehabilitation providers perceive that schools are underprepared for educating children with TBI and earlier involvement and longer duration of follow-up with schools is needed. Since most children who receive post-acute rehabilitation go there directly from acute care hospitals and most children who leave rehabilitation appear to return to public schools, there is a clear path for improved transition for this group. Ensuring medical documentation of TBI, including severity, in the acute care hospital, followed by documentation of educational needs and response to interventions in rehabilitation facilities, transition to public school attendant with medical and rehabilitation records, and continued collaboration between treatment providers and school staff, is desirable and achievable among the subgroup of individuals with TBI who are served in acute care hospitals and rehabilitation facilities before return to public school.

#### *Model School Transition Programs*

Five state models were examined and overviews of these models are provided. Common elements include various forms of education provided to school staff, parents, and students, and a plan for hospital-school linkage. Several include regional TBI teams (Kansas) and/or liaisons (Oregon and Pennsylvania). Other states, whose programs are not reviewed here, have

adopted the TBI Resource Team model, including Arizona, Hawaii, Iowa, Nebraska, and Tennessee.

*Kansas.* The TBI Project is funded and operated through the Kansas State Department of Education (DOE) Student Support Services and is housed in the Developmental Disabilities Center at the University of Kansas Medical Center. This project was initiated in 1987 through the Kansas DOE to provide inservice training, preservice graduate and undergraduate student training, technical assistance, and consultation in the area of traumatic brain injury. In 1991, a four-year grant from the U.S. Office of Special Education allowed for the training of 19 regional mini-teams across the state. There are now more than 250 trained mini-team members representing special education cooperatives and school districts. These teams continue to undergo training as needed and are usually comprised of school psychologists, occupational therapists, speech language pathologists, and special education directors. The TBI Project is now a part of the Neurologic Disabilities Support Project (NDSP) and helps students with a wide range of neurologic disabilities. Educators can request services and resources in the areas listed below free of charge:

- Coordination of services: Inservice training, technical assistance, and consultation to educators, related service personnel, medical personnel, and families of students with ABI/TBI

- Educational materials: Videos and written materials on intervention, program transition planning, and injury prevention
- Professional presentations: Topics such as school re-entry, memory impairment, behavioral strategies, and agency resources
- Prevention: The TBI Project partners with the Brain Injury Association of Kansas and greater Kansas City on the Schoolsite Injury Prevention Program to educate students regarding safety belts and use of helmets
- Resources and referrals: Through AccessKansas on the state website, facts sheets and resource guidebooks are provided

In summary the Kansas model emphasizes training of local school personnel most likely to be involved with transitioning children with TBI back into schools. These mini-teams then act as consultants and trainers for school district personnel as needed. A centralized source of information, resources, referrals, inservice training and presentations is located in the DOE.

*Ohio.* Information about Ohio's school program was obtained from a guidebook for parents and schools created by the Ohio Legal Rights Service produced through a grant from the U.S. Department of Health Resources and Services Administration, Maternal and Child Health Bureau (Ohio Legal Rights Service, 2007). An expanded Ohio definition of TBI, which includes internal injuries, provides the basis for delineating eligibility for special education services for children who have sustained brain injury.

While there are multiple elements of this model and transition is discussed at several levels (hospital to rehabilitation, rehabilitation to school, between schools, school to community), the procedures related to transition services from post-acute treatment to school include the following:

- Parents notify the school special education coordinator in writing as soon as possible that their child has sustained a TBI and may require special services. A model letter is provided in the guidebook.
- The school monitors the child for any negative impact on learning and makes arrangements for evaluations. Parents may request evaluation at any time using a model letters for requesting an evaluation provided in the guidebook.
- School psychologists contact parents to release medical records for review.
- A comprehensive evaluation, neuropsychological evaluation, or independent educational evaluation is provided if needed.

In this model, education of the parents regarding rights and responsibilities appears to be the focus. School personnel are obligated to provide evaluation and services when needed.

*Oklahoma.* A TBI Registry Training Program for teachers, associated with Maternal Child Health, jointly developed by the Center for Learning and Leadership at the Oklahoma University Health Science Center, the Special

Education Services Division of the Oklahoma State Department of Education, and the Maternal and Child Health Division of the Oklahoma State Department of Health, has been in place in Oklahoma for 15 years. Twice yearly, 50 general and special education teachers are selected to participate in a four-day training program regarding TBI over the course of several weeks. This training includes clinical and medical aspects of TBI, assessment following TBI, and integration of findings to develop an IEP. This training program is approved and funded by the Oklahoma DOE. A summary provided in a report titled *Children and Youth Services* (March, 2008) suggests that collaborative education, service availability and access, and coordination of related programs are goals of the Oklahoma model. Head injury pamphlets and a Resource Directory Table of Contents were expected to be supplied to all schools by May, 2008.

*Oregon.* Oregon has advocated for several practices to improve school services for children with TBI (Glang & Weber, 2008). The three general areas are: (1) better screening and identification through identification of kindergartners with TBI at entry to school, an item regarding head injury on the school health form, and monitoring need as the identified child progresses through school; (2) improving hospital-school linkage through the Student Transition and ReEntry (STEP) model. In this model, the State DOE provides a single point of contact for all hospitals to call, DOE informs a trained regional liaison, and the regional liaison informs the school and offers resources to the

family and school. Further, school staff have access to training and support as needed and progress of students is tracked by the DOE annually; (3) training for educators using the TBI Resource Team Model. This model provides training for interdisciplinary teams, whose members provide consultation to schools serving students with TBI. Activities may include attending IEP meetings, telephone consultations, provision of materials, and observation in classrooms; and (4) advocacy training for parents using a comprehensive web-based tool called “Navigating the School System.”

This model is implemented through the Oregon DOE, with two major tracks through Regional Programs for Low Incidence Disabilities and the Teaching Research Institute (TRI). TRI provides, for example, statewide leadership, library services, educational opportunities, centralized data collection, referrals for parents, and a point of contact for regional medical centers. The Regional programs provide TBI coaches and regional TBI liaisons, both of whom service the school team, including parents, through special education, general education, or Section 504.

*Pennsylvania.* A Child and Adolescent Brain Injury School Re-Entry Program, titled Brain STEPS (Strategies Teaching Educators, Parents, and Students) has been implemented in Pennsylvania (Brown, 2008, April). Short-term funding was obtained through the Pennsylvania Maternal and Child Health (MCH) program, with long term funding through the Pennsylvania DOE. In this

model, regional teams (about 100 members identified) are trained by local brain injury experts. Teams are expected to (1) re-enter students back into school following brain injury; and (2) complete annual check-ups for students already identified as TBI through special education. Team members were provided with STEPS manuals and each member is expected to present twice yearly to groups within their regions, including school nurses, ER staff, coaches, parent-teacher organizations, families, teachers, etc.). The Brain STEPS program also offers each team free direct consultation with medical rehabilitation professionals on a case-by-case basis.

### **Recommendations and Discussion**

Based on the findings, we provide the following recommendations related to the establishment of a TBI Registry and transition to school services for the school-aged population of persons with TBI. We follow each recommendation with a discussion.

#### **Recommendation One: Establish a separate TBI Registry**

We recommend that Texas establish a separate TBI Registry. The funding mechanism may include reinstatement fees collected from traffic violations. If Texas decides to use this funding method, then these fees should flow into a Trust Fund, which would be earmarked to fund the registry. Further, states with successful TBI Registries have mandates for reporting compliance. For example, the state of Florida has both civil and criminal sanctions in place for non-

reporters; Texas has a mandate but should consider instituting a method for ensuring that it is followed. We also recommend that Texas develop a system to link individuals to services. Follow-up services could be provided by assignment of case managers or by sending a letter to every patient who is registered as having a TBI.

**Recommendation Two: Fund two full-time database/warehouse managers whose job duties are to monitor the ongoing acquisition and integrity of data.**

This recommendation needs to be implemented even if DSHS decides to continue using the current registry rather than establishing a separate TBI Registry. The acquisition process may include building online survey instruments and delivery systems, screening and cleaning the raw data as they are acquired, conducting periodic assessment of score reliability and validity evidence from data acquired using the survey instruments, and providing descriptive statistical (and graphical) summaries in a timely manner to key stakeholders as needed.

**Recommendation Three: Contract with an outside consultant to advise during the conceptualization of the database structure.**

The organizational structure of the database (i.e., survey item type and format) should be carefully planned in unison with the goals and content-based objectives established by DSHS personnel and external constituents with a stake in the formative and summative use of the data. That is, if the information gleaned from the field-based survey instrument is “off target” in either the

content captured or by the item format, then the information will be uninformative to stakeholders. We recommend that DSHS contract an outside consultant (e.g., a Ph.D. level psychometrician) to advise during the process of conceptualizing the type/level of measurement, design and construction of the survey instrument, and data acquisition process.

**Recommendation Four: Contract with an outside firm to create a graphical user interface.**

Another important consideration is the ability of the end-user to have easy access and a high degree of functionality when accessing and using information contained in the database. To address this issue, we recommend that a windows-based graphical user interface (GUI) dashboard be created. An interface such will require a one-time investment on the part of the State of Texas but would be able to be subsequently maintained by DSHS employees (e.g., information technologists with specific skills). The recommended “dashboard” interface is user friendly and allows end-users such as managers and stakeholders to access information within a database in “real time”; that is, as the data are acquired, cleaned and made available, end-users are able to produce descriptive summaries, tables, and graphs to be used in a variety of ways. To our knowledge, SAS Institute based in Cary, North Carolina, offers the most comprehensive package related to the complete process of data

warehouse solutions integrated with end-user accessibility. They employ consultants specific to the recommendations in this document.

**Recommendation Five: Increase awareness of medical, early childhood intervention, and school service professionals, including Child Find.**

Child Find is a continuous process of public awareness activities, required by the [Individuals with Disabilities Education Act \(IDEA\)](#). IDEA requires all states to have a "comprehensive Child Find system" to assure that all children who are in need of early intervention or special education services are located, identified, and referred as early as possible (U.S. Office of Special Education Programs 2008). In Texas, State guidelines reflect IDEA mandates. All children with disabilities residing in the State, regardless of the severity of their disabilities, and who are in need of special education and related services, must be identified, located, and evaluated: The duty includes children with TBI and extends to children who are homeless, children or are wards of the State, and children who are attending private schools (Region 18 Education Service Center). The Department of Assistive and Rehabilitative Services (DARS) coordinates the Early Childhood Education Program (ECI), of which Child Find is a component. State and federally funded through IDEA, ECI provides evaluations and assessments, at no cost to families, to determine eligibility and need for services (Texas DARS).

An occurrence of TBI will typically first be documented in the medical community; once documented, a chain of events should begin the generation of appropriate documentation and communication so that families with children who are attending or will attend public schools have adequate documentation of a brain injury to access educational resources (special education, Section 504, or regular education accommodations). Establishment of a TBI Registry would be an appropriate first step and would allow for documentation of injury date and severity. It would also be a mechanism for tracking of interventions and outcomes including special services in schools or other settings. Other mechanisms coordinated between TEA and DSHS that would support the transition process include:

- Dissemination of specific brochures regarding recognition of TBI as a potential risk for learning and behavior, generated by TEA for Child Find purposes. Such literature could be available to Emergency Departments, pediatricians, professionals in private practice such as occupational, physical, and speech therapists, and providers of Early Childhood Intervention Services.
- Education of medical professionals about the services available to children with TBI in public schools and education for school professionals about the possible outcomes for children with various levels of TBI. This education could best be accomplished by (1) direct inservice training

involving medical and special education disciplines; and (2) provision of literature, including consent for release of information forms, to hospitals and other medical doctors about the processes of referral, assessment, and provision of services to children with specific handicapping conditions in Texas schools. When a child experiences a TBI, even if it does not result in hospitalization, parents should be provided with information about possible complications and school-based resources for assessment and intervention.

- Designation of individuals within medical settings as liaisons to public schools to facilitate the transition to public schools, including transfer of medical records, recommendations for support and resources, consultation with school professionals, and guidance for families navigating this transition. Most post-acute rehabilitation facilities contacted for this project have a similar model. Discussions with special education directors suggest that when the model is operating as planned, the results for students with TBI are often positive. The system seems to break down when brain injuries are not severe enough to result in medical documentation that can be used by schools to use the TBI classification or to justify placement in post-acute rehabilitation and there are no transition services in place from hospitals or homes back into schools.

**Recommendation Six: Consider a broader educational definition of TBI.**

This broader definition as illustrated in the Ohio definition should include damage to the brain from medical conditions that are not external, such as strokes, tumors, and injuries caused by surgery. As part of this broader definition, Texas should promote recognition that a child with TBI may need formal evaluation to determine educational need. This evaluation should take into account need for frequent updating and progress monitoring, especially in the first year since the possibility that TBI-related learning and behavioral problems may emerge months or even years after the initial injury. School appraisal staff need to be aware that TBI does not conform to the same trajectory as developmental learning and behavioral disorders. Therefore, misclassification can result not only in faulty tracking and monitoring, but also in inefficient or ineffective interventions. School appraisal staff should also recognize that parents and/or other providers may not be fully aware of the relationship between TBI and educational progress, and thus may not document or report TBI when seeking school assistance for children with educational need. Appraisal staff should routinely and thoroughly review medical and developmental history, with specific questions addressing head injury provided in background questionnaires and in parent interviews.

**Recommendation Seven: Develop a process to link the TBI Registry data to transition services for school-aged individuals with TBI.**

A TBI Registry with family contact information would provide a means for notification by DSHS to families of the availability of school services and of the necessity for requesting transition planning. As discussed in Recommendation One, successful states have a mechanism in place to link services to individuals. This is a critical component to improve transition services for the school-aged population.

**Recommendation Eight: Develop a Texas model for promoting improved transition and tracking of students with TBI.**

This model requires that there be a reporting mandate for entities discharging a school-age child for return to public school. It also requires that there be a designated official at the state level to initiate the transition process, and a trained liaison or team at each ESC (please spell out) who would facilitate the transition within a local school district. In some states specific teams or liaisons are trained who then act as consultants to schools serving children with TBI. These school-based liaisons would interface and collaborate with pre-transition sites, whether they are hospitals, rehabilitation facilities, residential treatment centers, or children's homes. In some cases, the pre-transition site may conduct full neuropsychological evaluation; these evaluations must take into account school-related issues, such as special education eligibility criteria and should be shared with the receiving school. In other cases, school personnel

may provide full individual evaluations; in these cases, appraisal professionals conducting evaluations should have specific training in TBI.

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Appendix A

Web-Based Survey Items: EMS Providers and Hospitals Reporting to  
EMS/Trauma Registry

1. Please indicate your status?
2. Are you submitting data related to TBIs to the EMS/Trauma Registry online system?
  - a. If yes, how often?
    - i. Is your electronic data submitted through a business associate?
    - ii. If yes, how do you ensure that the data reaches the EMS/Trauma Registry?
  - b. If no, why are you not submitting data to the EMS/Trauma Registry?
3. Have you received training to use the EMS/Trauma Registry?
  - a. If yes, how do you receive training?
4. How easy is it to understand and/or use each of the following?
  - a. Coding guidelines in the Hospital or EMS data dictionary
  - b. Online system for entering data provided by DSHS
  - c. Web based training for online reporting system
5. Upon discharge from your facility of patients with TBIs, what referrals for follow-up services do you provide patients or their families?
6. For your school-age patients with TBIs, do you ask parents for medical release to contact the child's school?
  - a. If yes, what types of information do you provide to the child's school?
  - b. If no, do you advise families to provide information about their child's TBI to the school?
7. Please provide the name of your county in which your facility is located.
8. Please add any comments or concerns about the EMS/Trauma Registry.

Appendix B

Email Survey Items: Texas Stakeholders

1. What are the specific reasons for requesting evaluation of the need for and feasibility, efficiency and cost of a TBI Registry in Texas?
2. Why did your group decide to pursue the TBI needs and resources assessment as this particular time (completion of project by November, 2008)?
3. Who (individual, entity) initiated the effort to complete the TBI needs and resources assessment within this time frame?
4. What prior efforts have been made to improve the collection of TBI data and the identification and provision of appropriate follow-up?
5. What problems, if any, have been associated with the current EMS/Trauma Registry with respect to TBI identification and follow-up?
6. What other information would you like to share that is relevant to this needs and resources assessment?

Appendix C

State-by-State Analysis of TBI Data Collection

State	CNS Registry	Central Trauma Registry	TBI Registry	Surveillance System	None	No Information
Alabama	X					
Alaska		X				
Arizona		X				
Arkansas					X	
California				X		
Colorado		X				
Connecticut						X
Delaware						X
District of Columbia						X
Florida	X					
Georgia	X					
Hawaii					X	
Idaho						X
Illinois						X
Indiana					X	
Iowa	X					
Kansas		X				
Kentucky						X
Louisiana						X
Maine						X
Maryland				X		
Massachusetts						X
Michigan						X
Minnesota	X					
Mississippi	X					
Missouri	X					
Montana						X
Nebraska			X			
Nevada		X				
New Hampshire	X					
New Jersey	X					
New Mexico						X
New York					X	
North Carolina						X
North Dakota					X	
Ohio					X	

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State	CNS Registry	Central Trauma Registry	TBI Registry	Surveillance System	None	No Information
Oklahoma				X		
Oregon						X
Pennsylvania						X
Rhode Island			X			
South Carolina			X			
South Dakota						X
Tennessee			X			
Texas		X				
Utah			X			
Vermont	X					
Virginia	X					
Washington		X				
West Virginia			X			
Wisconsin					X	
Wyoming						X

Appendix D

Web-Based Survey Items: State with TBI Registries

1. What state are you reporting about?
2. Does your state have a TBI Registry?
3. What is the law that mandates the development of your TBI Registry?
4. What year was your state's TBI Registry established?
5. How was/is your state's TBI Registry funded?
6. Please provide an estimated cost for the development of your state's TBI Registry.
7. What are the estimated annual costs for maintenance of your state's TBI Registry?
8. How do you use the data collected in your Registry?
9. Why would you recommend to other states that they develop a TBI Registry?

Appendix E

Follow-up Telephone Interview Questions: States with TBI Registries

1. What agencies developed the registry?
2. What agencies are responsible for the maintenance and reporting of the data?
3. What entities report to the registry?
4. What data do you collect in the registry?
5. How have your data improved as a result of implementation of the TBI Registry?
6. What obstacles were encountered in developing the registry?
7. What problems or obstacles remain?
8. What have you learned as a result of developing and implementing your registry?

Appendix F

Sample Letter to Hospitals, Minnesota

Dear:

Minnesota Statutes §144.661 to §144.665 require the Injury and Violence Prevention Unit of the Minnesota Department of Health to collect information related to traumatic brain and spinal cord injury (TBI/SCI, *please see Attachment 1, State Statutes and Rules*). We depend on receiving timely and accurate data from your facility. All cases are to be reported to the MDH within 60 days from the date of hospital discharge. **Please submit any final unreported 2002 cases of hospitalized traumatic brain or spinal cord injury.**

We compared the list of cases you submitted to us for 2001 (*Attachment 2, Case Line Listing*) with the UB-92 billing discharge summary data your hospital submits to the Minnesota Hospital Association (MHA). From this comparison, we identified a set of “discordant cases” (*that is, cases that were identified by one data system but not the other*) that appear, based on the codes listed at discharge in the UB data set, to be traumatic brain or spinal cord injuries but which were not included in your cases submitted to the TBI/SCI Registry. **Please review this list of cases.** Then, **complete and submit a Report of Injury form** for each of the cases that you determine to correctly be a true TBI or SCI. If you deem a case not a true TBI or SCI, please make a notation in the comment section on the line listing.

We have prepared aggregate and hospital-specific Institutional Summaries (*Attachment 3*) for you that describe our experience with your hospital’s TBI/SCI data over the past several years. Please note that we have added a new code to the definition for TBI. This is the code for Shaken infant syndrome (ICD-9-CM, 995.55; *Attachment 4, revised case definition*). **Effective January 1, 2003, please report cases of Shaken Infant Syndrome along with other TBI reported to the MDH.**

All reporting materials (statutory language, data forms, data dictionaries, electronic formats, encryption parameters, etc.) will soon be available via CD; watch your postal box! In the interim, if you are in need of a supply of Report of Injury forms or a Data Dictionary, or if you have questions or need clarification on any of the data elements, please contact Sara Westberg at (651) 281-9813 or [sara.westberg@health.state.mn.us](mailto:sara.westberg@health.state.mn.us). If any staffing changes have occurred among those responsible for reporting TBI/SCI to us from your hospital, please alert us to those changes via telephone call, e-mail or return snail mail. Thanks!

Thank you for your continued participation in the TBI/SCI Registry.

Sincerely,

**Attachments Enclosed:**

- 1) Permanent Statutes and Rules**
- 2) Case Line Listing**
- 3) Institutional Summaries**
- 4) Revised Case Definition**

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Appendix G

Sample Follow-up Letter, Minnesota

Dear Parent or Guardian:

We are sending this letter to share some resources that may be helpful following your child's recent traumatic brain and/or spinal cord injury.

In 1991, the Minnesota State Legislature directed the commissioner of the Minnesota Department of Health (MDH) to collect data about traumatic brain and spinal cord injuries from reports submitted by Minnesota hospitals. MDH analyzes this data so that we may determine the leading causes of these injuries and develop ways to prevent them in the future. All data submitted to MDH are private.

The legislature also directed MDH to send information to all people who have sustained these injuries to inform them of programs and services available to them. Enclosed are materials relating to your child's injury. You may contact any of the agencies or organizations directly or you may fill out the enclosed blue response form and return it to MDH in the postpaid envelope. You may also visit our website at: <http://www.health.state.mn.us/injury>.

You can obtain free, ongoing follow-up and support to help answer your questions and assist your child in living with a brain injury. This service is called Resource Facilitation, described on the tip card enclosed. If you wish to receive this service, contact the Brain Injury Association of Minnesota at (612) 378-2742 or 1-800-669-6442. You may receive a call from the Brain Injury Association to offer assistance in finding information, resources, and support that are appropriate to your needs. Your response is voluntary; you may indicate that you do not prefer any further contact.

We hope that this is useful to you and your family. Our staff makes every effort to ensure that this mailing is sent to a person who is living with a traumatic brain and/or spinal cord injury, or a family member. If you received this letter in error, please accept our apologies.

Thank you.



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Appendix I

Web-Based Survey Items: Texas Special Education Directors

1. Do you have a person or team who is responsible for facilitating students who are transiting from medical or rehabilitation agencies to school?
2. What personnel serve in this role (check all that apply)?
  - a. Special education teacher
  - b. Licensed Specialist in School Psychology (LSSP)
  - c. Educational Diagnostician
  - d. Physical, Occupational, or Speech Therapist
  - e. School Administrators
  - f. Other
3. Which of the following procedures do you follow upon learning that a student who has sustained a traumatic brain injury (TBI) is being transitioned to a school in your district directly from a medical or rehabilitation facility:
  - a. Convene a prereferral team meeting.
  - b. Begin a referral for an ARD meeting.
  - c. Upon appropriate release of confidential information, provide relevant school records to the medical facility from which the student is being transitioned.
  - d. Request current medical information.
  - e. Identify the school personnel who will attend the discharge planning meeting at the medical facility.
  - f. Contact the family to share information about school re-entry.
4. Has your district received inservice training to providing services to students with TBI?
5. How often do they receive this training?
6. Who provides this training (check all that apply)?
  - a. district personnel
  - b. outside experts
  - c. attends conferences or trainings
  - d. other
7. In what region is your school located?
8. What size is your school district?

## Appendix J

### Follow-up Telephone Interview Questions: Texas Special Education Directors

1. Tell us about your transition services for children who sustained TBI (i.e., students who have been in other settings, e.g., hospitals, who are coming back to school)?
  - a. Do you have team responsible for transition?
  - b. Who is on the team?
2. What special assessments do you complete on these students?
  - a. What are they and who does the testing?
  - b. How do you decide what in-school services are needed?
3. What information is provided by the treatment facility?
4. How are district staff trained to work with students with TBI?
5. What preparation is provided to teachers, parents, and/or other students before the student comes back to school?
6. What problems are you aware of in the identification and provision of services of students with TBI?
7. What recommendations would you make to improve the transition process?
8. Do you have anything you would like to add?

Appendix K

Telephone Interview Questions: Texas Rehabilitation Centers

1. What ages of clients do you serve?
2. (If facility serves children and adolescents) What percentage of your clients are age 21 or below?
3. What percentage of your clients has sustained a TBI?
4. From what sources do you get your referrals?
5. On the average, how long after hospital discharge do clients enter your rehabilitation facility?
6. What is the average length of stay?
7. What services are provided during rehabilitation?
8. What percentage of clients' transition from rehabilitation back into public schools?
9. Where else do they go after rehabilitation? (e.g., residential, home school, private school)?
10. What procedures are in place for transitioning school-age clients back into public schools?
11. What improvements could be made in the transition of children and adolescents with TBI from rehabilitation to public school?