

**The National Pediatric Acquired Brain Injury Plan – FIRST DRAFT***Drafted by the Working Group of the**National Advisory Board of**The Sarah Jane Brain Foundation***TABLE OF CONTENTS**

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## FOREWORD

*by Sarah Jane Donohue*

When I was only five days old, the baby nurse my parents hired to help them in my first two months of life shook me so hard, she broke three ribs, both collarbones and caused a severe brain injury. While I lay helpless for over a week, the monster told no one. I was unable to cry, became very lethargic and was finally brought back to the hospital where I was born healthy just two weeks earlier. The monster quickly confessed to her crime and my family was left dealing with the fact I would never be the same child again.

While being discharged from the hospital several weeks later, the pediatric neurologist told my parents the injury was an eight on a scale of one to 10. When they asked, he said I would never be a normal child and I would probably never walk or talk. The correct answer by this doctor should have been, "I don't know." Fortunately for me, my Daddy doesn't listen to bad doctors!

I was immediately enrolled in Early Intervention and began a rigorous therapy regimen that built up to physical, occupational, vision, feeding/speech therapies and special instruction - up to three hours of each therapy per week! When I was one year old my Daddy created a special crawler which allowed me to move independently. Then, for Christmas that year, he built me my very own walker and he even adapted it so I could walk on the treadmill!

My Daddy read as many books about neuroplasticity and neurology as he could handle (although I think some of the books he just skimmed because they were very complex). The more he read, the more he realized how little was known about the brain at all, let alone an infant's brain. He also realized there was no single repository of information about neurological breakthroughs or discoveries – it is an extremely fractured field. It reminded him of the computer science industry in the 1950s and 1960s, where brilliant people were working all over the world in the same areas, but no one knew specifically what anyone else was doing.

He took that idea and then asked himself, "Where are all the breakthroughs occurring today?" The answer was in Open Source Principles, which is basically the concept of shared knowledge. Since no one was using those principles in the field of neuroscience, Daddy decided to do it himself. He launched The Sarah Jane Brain Project in October 2007, and Phase One entailed putting all of my medical records and videos of my therapy sessions online in an Open Source format – the first time in medical history this had ever been done.

Phase Two of the Sarah Jane Brain Project involved recruiting other families of children like me who have brain injuries to participate, since the more of us who gather together, the stronger we are. During this phase, he also began to recruit the best in the field of pediatric acquired brain injury to help him develop the first-ever National Pediatric Acquired Brain Injury Plan (PABI Plan). Every family affected by brain injury my Daddy has ever connected with talked about having to reinvent the wheel in learning how to perform basic care and receive basic services for their child instead of being able to focus on the uniqueness of their child's specific issues.

Phase Three consisted of having the National Advisory Board of the Sarah Jane Brain Foundation develop the first draft of the National PABI Plan. This document is designed to outline a comprehensive continuum of care, from prevention of pediatric brain injuries to acute medical care to reintegration and rehabilitation in the community and transition into adult systems.

Phase Four will involve fully funding and implementing the National PABI Plan across the country. My Daddy has promised to have this done before my fourth birthday on June 5, 2009.

While I still cannot talk or walk on my own yet, my Daddy has taught me his philosophy in life, "Things work out best for those who make the best out of the way things work out!" I cannot begin to thank the National Advisory Board enough for being my voice and the voice of the millions of children and young adults around the country who suffer from pediatric acquired brain injury. Someday I will thank each and every one of you myself with my own voice! Until then, please keep talking for me.

## PREFACE

Brain injury is the #1 leading cause of death and disability in the United States for children, adolescents and young adults. Particularly because their brains are still developing, it can result in wide-spread impairments and dysfunction not only in cognition and motor function but also in behavior and social function. The injury can also affect the developmental trajectory which in itself can increase dysfunction or exacerbate impairment. A developing child/youth's recovery, rehabilitation and habilitation from a brain injury is a complex process influenced by premorbid child and social environmental characteristics, acute monitoring and treatment, and the responses of family, school, and community during this process. As such, it requires a coordinated interdisciplinary response to facilitate long-term rehabilitation.

The Sarah Jane Brain Project (SJBP) recognizes many of the practices described in this document are currently being implemented. It is the purpose of this document to build on the many individualized practices that exist. However, the consistent availability, coordination and integration of the numerous well-established interventions, programs, and supports do not exist at the present time on a national level. A seamless, standardized, evidence-based system of care universally accessible for all individuals and their families regardless of where they live needs to be developed. This system of care is called the National Pediatric Acquired Brain Injury Plan (PABI Plan). The Sarah Jane Brain Project will facilitate this integration along with ongoing development of effective interventions and supports, and their validation through research guided by theory, existing data across disability populations, and participant needs.

There are many definitions of pediatric acquired brain injury (PABI) and pediatric traumatic brain injury (PTBI). For the purpose of this document, the term PA/TBI will be used. This includes traumatic causes such as those sustained as a result of motor vehicle accidents, sports-related injuries, blast injuries from war, assaults/child abuse, gun shot wounds and falls along with non-traumatic causes including but not limited to anoxia, infection, brain tumor, stroke, seizure, inflammation, toxins, meningitis, substance abuse and metabolic disorders. The focus of the SJBP is on children, adolescents and young adults, ranging in age from birth to 25 who have sustained a traumatic or non-traumatic acquired brain injury. Young adults are included due to the fact that their brains are still developing, as indicated by biological measures (brain metabolism, myelination), neurocognitive measures (executive functions, inhibitions) and social measures (beginnings of independence, transition to adult privileges and responsibilities).

In order to carry out this integrated seamless system of care, the Sarah Jane Brain Family (SJBF) Centers of Excellence will be created. With advances in technology, neuroinformatics and

assessment including functional brain imaging and genomics, the establishment of a SJBF Center of Excellence in every state will dramatically improve the lives of children by increasing our understanding of the determinants of rehabilitation from PA/TBI and to inform the development of innovative, empirically-based interventions. Such a system will offer significant cost efficiencies, funding efficiencies and independent revenue models.

The terms recovery, rehabilitation, and habilitation are used throughout these documents and represent overlapping processes. Definitions of these terms are needed, as well as clarification of how they relate to intervention and key reintegration periods (transition from hospital to rehabilitation, reintegration from hospital to home, reintegration into the school system, and transitions into each stage of life).

Recovery is defined here as an ongoing process that begins as soon as the patient is medically stable and continues until the patient no longer shows improvement in any impaired functions. The process continues across acute, sub-acute, and chronic phases. In the acute phase, recovery represents stabilization of neurologic, metabolic, and/or medical status, usually through interventions targeted to brain and body health (i.e., stabilization of intracranial pressure, inflammation, etc.). The use of the term recovery in the sub-acute and chronic phases is used to reflect continuing biological changes in brain function and plasticity. These almost certainly interact with processes of normal brain development.

Neuroimaging research in humans suggests these recovery processes may continue for years after injury. The end of the acute recovery process is determined when the effects of injury on cognition, mood, and behavior can begin to be most accurately assessed. However, recovery may not occur spontaneously and should be actively promoted through rehabilitation and habilitation.

Rehabilitation in this document is intended to represent periods of active intervention that might include but are not limited to: pharmacological, physical, occupational, vision, speech-language, psychological, behavioral, and/or educational therapies. Rehabilitation should continue as long as it results in improvements in function. When interventions no longer yield improvements in function, the child transitions into a period of habilitation.

We must acknowledge these periods are not clearly definable stages nor do they necessarily occur along a continuum. The entire process of recovery from injury will include multiple

periods of active rehabilitation interspersed with periods of habilitation as new concerns are identified such as when children transition from one stage of life to another. The key is initial identification of brain injury, control of the cascade of injury processes during the acute phase, and active surveillance to identify any developmental stalls or new concerns.

*Please note: this document is titled “First Draft” since we are asking our colleagues and interested parties (including survivors, families, public policy, healthcare and educational professionals) from around the world to offer any changes, edits or suggestions and to submit them no later than February 6, 2009. We will be issuing the Final Version after reviewing all of the proposed changes, edits and suggestions.*

### *Principles for SJBFCenters of Excellence*

Once the SJBFCenters are in operation, they will be guided by four over-arching goals:

- 1) To prevent PA/TBI through changes in social practices and policy.
- 2) To facilitate the provision of care and services to maximize the child/youth's recovery and development after PA/TBI and to support the family through all stages of recovery.
- 3) To improve the capacity of schools and community agencies to deliver rehabilitative and educational services and support to the child/youth and family.
- 4) To use research to better understand the effects of neurological insults on the developing brain, to research the individual, medical and social environmental determinants of recovery and function, as well as the most effective interventions for improving child/youth and family outcomes.

These centers will serve not only as primary, secondary and tertiary care facilities but also as resources for individual physicians, caregivers, families and other hospitals (see Figure 1). Data will be incorporated into a centralized Registry (see Chapter 8), allowing for the efficient evaluation of best practices. Findings from research will be disseminated using methods developed by the SJBFCenters to share knowledge gained with the entire brain injury community. The specific principles underlying these goals are outlined below.

**Principle 1:** Prevention is the best possible treatment for any brain injury and includes preventing the initial insult as well as preventing secondary medical, social, and behavioral consequences, including preventing a second injury.

**Principle 2:** The developmental stage of the child/youth at the time of injury and recovery across the lifespan must always be considered, and all treatments and interventions should be implemented by individuals with pediatric training and special expertise in PA/TBI.

**Principle 3:** Providers and all professionals should adhere to the principles of family- and person-centered care, engaging the family and child/youth themselves in a collaborative process for setting and achieving treatment goals.

**Principle 4:** Early identification of PA/TBI is critical to improving long-term outcomes.

**Principle 5:** Best clinical practices need to be determined based upon evidence from research and then standardized to be effective and efficient.

**Principle 6:** Children's recoveries are strongly influenced by their environmental contexts (home, school, community). Beyond early hospitalization, interventions to improve outcomes for children and youth with PA/TBI must occur in the settings in which children and youth with PA/TBI live and function (school, home, and community), and must involve the "everyday people" in these settings such as parents/caregivers, teachers, and peers.

**Principle 7:** Interventions for children and youth with PA/TBI must acknowledge the overlap among different disability populations in terms of treatment needs and useful interventions.

**Principle 8:** Research should use a variety of methodologies to examine hypotheses regarding recovery and intervention (prospective, naturalistic follow-up studies, randomized controlled trials, single subject experiments, qualitative studies, and animal models).

**Principle 9:** Interventions for children with PA/TBI occur at multiple levels (e.g., physical, medical, psychological, family, school, community) and across a continuum of care (e.g., acute care, rehabilitation, re-entry, and ongoing educational, social, and vocational life). Research on the effectiveness and efficacy of intervention should link both vertically (i.e., across levels) and horizontally (i.e., across the continuum of care), must follow children and families long-term, recognize that needs are likely to change over time, use functional outcome measures, and measure generalization to a variety of functional contexts of application.

**Principle 10:** Interventions for children with PA/TBI occur across a developmental spectrum that varies according to age at injury, time since injury, and age at intervention. The effectiveness and efficacy of any intervention may vary as a function of these developmental parameters because of critical variations both in neural developmental and environmental contexts.

**Principle 11:** Proper PA/TBI training and education for future medical and educational professionals should be integrated into current graduate and medical school programs in order to ensure continuity of care is taught to those just entering the medical or educational profession.

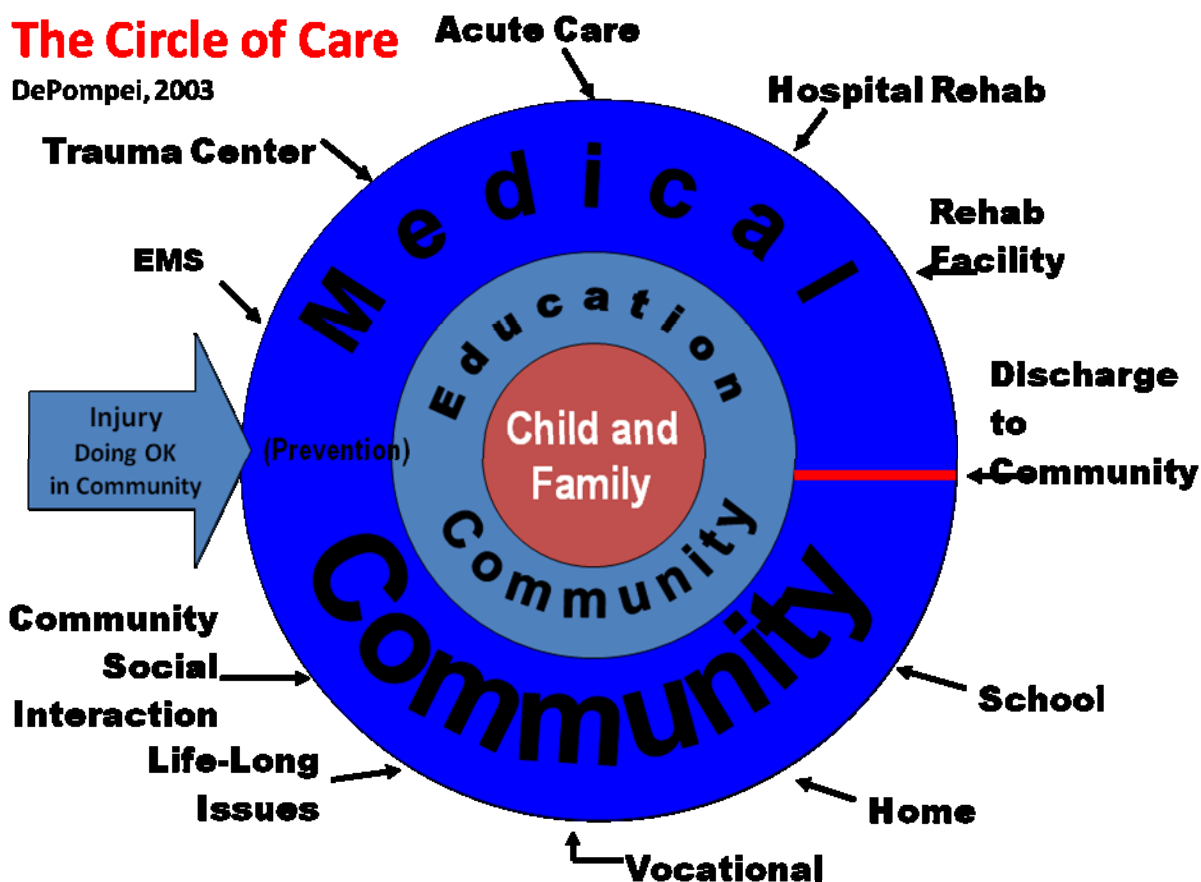
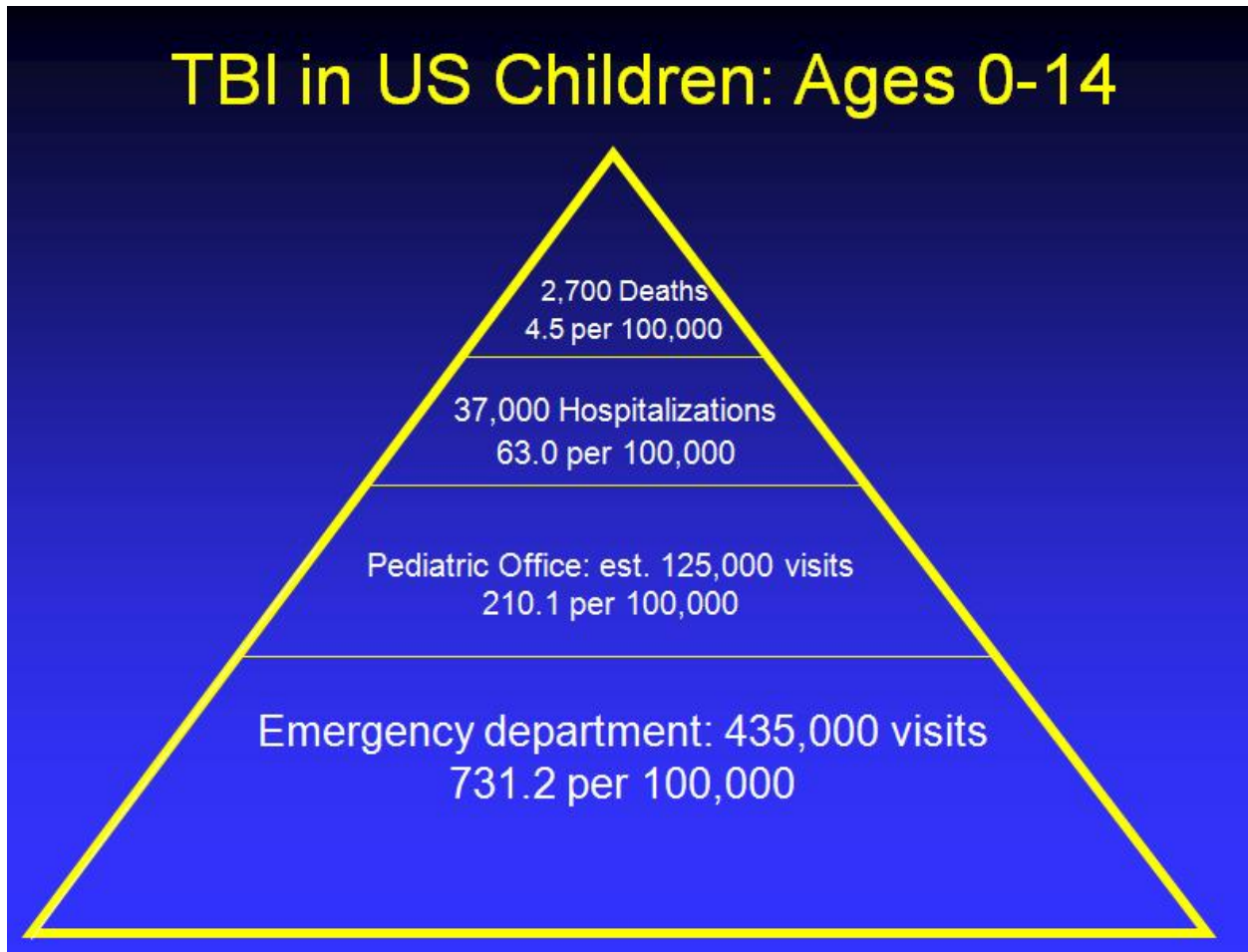


Figure 1: The Circle of Care Model

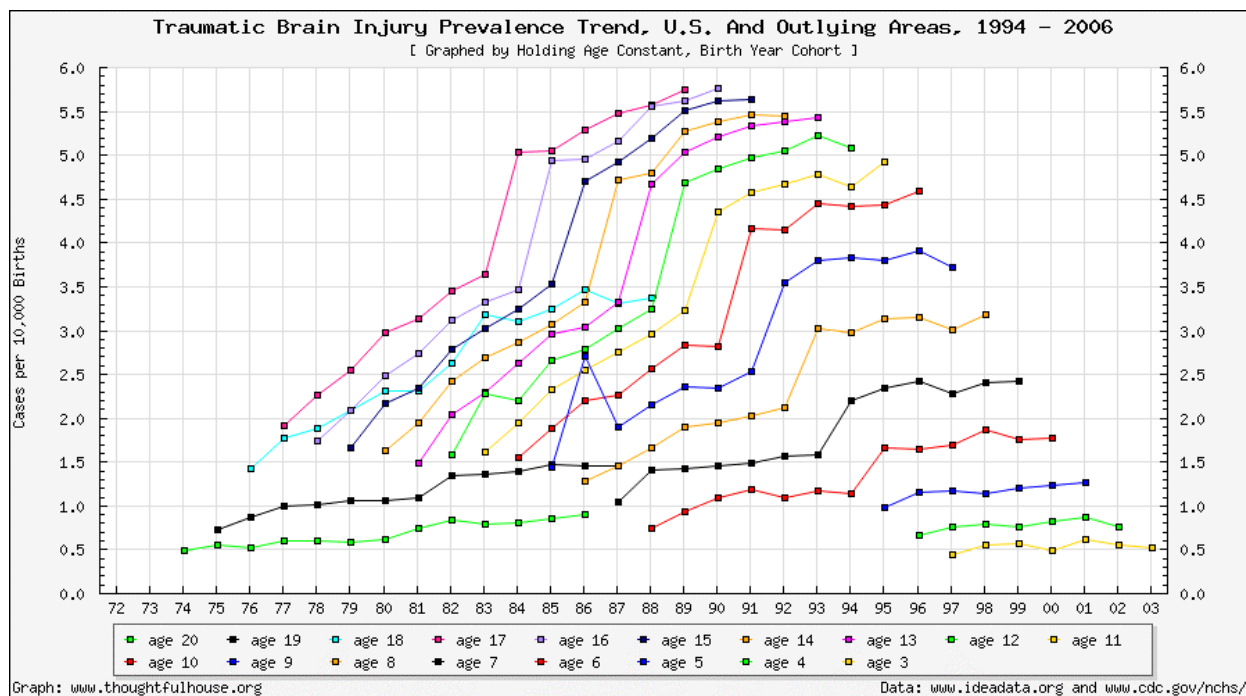
## **EXECUTIVE SUMMARY**

Pediatric Acquired/Traumatic Brain Injury (PA/TBI) is a national disaster. Because a brain injury is typically “invisible,” it remains unrecognized or under-recognized, thereby markedly increasing the burden of care in all aspects of society. The effects of a PA/TBI are complex and require the integration of medical, educational, judicial and social service systems.

PA/TBIs are truly an epidemic. The Centers for Disease Control and Prevention (CDC) reports that for children aged 14 and under there are 2,685 deaths, 37,000 hospitalizations, and 435,000 emergency room visits attributable to TBI annually (see Figure 2). As the incidence of PA/TBI is at its maximum for those aged 16 to 24 years, and due to the fact that not all individuals with TBI present to an acute care hospital, these staggering numbers can only be underestimates of the true rates of PA/TBI.



**Figure 2: CDC figures for death and disability due to PTBI annually**



**Figure 3: CDC figures for TBI prevalence by age**

The World Health Organization (WHO) has noted that PTBI is the NUMBER ONE cause of morbidity and mortality for children and youth. Children are 20 times more likely to die from PTBI than from asthma and 38 times more likely to die than from cystic fibrosis. Additionally, the WHO reported in 2008 that there were twice as many children who suffered a brain injury than those who received stitches.

The financial burden of PTBI is estimated to cost well over \$12 billion a year (2000 CDC data). This figure does not include the significant financial impact of those children and youth, who because of their PTBI will never be able to contribute financially or otherwise to society as adults, nor does it include lost productivity of the child/youth's parents and family. These numbers also do not include those children who acquire their injuries from non-traumatic causes such as stroke, brain tumors, infections of the brain and anoxic/hypoxic injuries.

While the economic cost of PA/TBI is clearly underestimated and growing every year, the positive impact of enacting the National PABI Plan is clear. Since there is a huge decrease in lifetime earnings and other outcomes such as educational achievement of children/youth with PA/TBI, any positive improvement in functioning and contributions to society has an enormous compounding impact. In addition, since the SJBFC Centers are focused on supporting families as well as the child/youth, the exponential increase in productivity of the parents/caregivers over time as a result of that support is staggering. Since most parents become the primary caregivers/case coordinators for their children, this becomes another distinguishing difference between the adult ABI and PA/TBI population.

Since these SJBFC Centers will be gathering considerable quality information through a specially designed registry, it will be possible to examine the economic benefit from a particular treatment or care management plan, whereby changes in said earnings could be measured compared to their counterparts that do not receive such treatment. It will be possible to combine the estimates of the change in the cost of care based on such treatment. Some potential outcomes to consider include the additional savings per life saved, the additional savings per life year gained, the additional net economic savings per life year gained, the additional savings per quality adjusted life year (QALY), the additional net economic benefit per QALY gained and the net economic benefit of any particular intervention. These types of economic analyses are currently unrealistic because of the dearth and quality of data.

For the families who have experienced a child/youth with a PA/TBI, it is a terrifying and challenging experience. Their children are often not diagnosed and many are misdiagnosed. Access to comprehensive and integrative care is extremely rare. Most troubling, ongoing and coordinated support for the lifetime needs of someone with a PA/TBI is virtually nonexistent. Families have to be constantly searching and reinventing services because there is no coordinated, seamless circle of care for those with PA/TBI or their families.

Historically, PA/TBI has been studied and addressed primarily as a medical issue. Program development has taken place largely at the level of medical rehabilitative treatment. Most of the research has focused on this level of treatment as well as on children's outcome from the perspective of their neurological impairments. However, a number of important considerations mandate a sharpened focus on long-term issues from psycho-social, educational and environmental perspectives, as well as increased support for ongoing rehabilitative, educational, and support services provided by the school systems and other community providers.

The school systems are now acknowledged to be the major provider of rehabilitative as well as educational services for children and adolescents with PA/TBI. Following a severe brain injury at age 10, for example, a child/youth may receive services for three months in acute and rehabilitative medical care, followed by eight years of services in the school system, a ratio of 1:32. Investigators agree that rehabilitative needs evolve and often grow in number and intensity over the years after PA/TBI, resulting in seriously compromised adult outcomes.

Furthermore, because school professionals have less training than medical and rehabilitation professionals in understanding and managing PA/TBI-related issues, their need for training and support is greater than that of medical and rehabilitation professionals. Fortunately, the few studies that exist suggest that well-conceived interventions and supports delivered after discharge from medical rehabilitation can be effective, significantly benefitting the child/youth, family members and education staff.

For all of these reasons, the SJBF Centers of Excellence will provide leadership in designing, studying, and disseminating long-term interventions and supports for children with PA/TBI and their families, delivered by effectively trained and supported community professionals.

### ***Sarah Jane Brain Project (SJBP):***

In an effort to address this major gap in care, the SJBP organized and consulted with the Working Group of its National Advisory Board. These experts in the field of PA/TBI have over 1,000 years of collective experience and their task was to analyze the continuum of care for PA/TBI, identify the problems along this continuum and then propose solutions. As a result of this effort, the following National PABI Plan has been drafted. What follows is a suggested comprehensive, integrative, accessible, culturally sensitive, long-term and child/family centered circle of care for PA/TBI. These experts include families and family advocacy organizations, physicians, allied health care professionals, educators and researchers.

Wherever possible, these recommendations are based on evidence derived from "good" science. However, there is little research being done in the broad field of PA/TBI in comparison to the magnitude of the problem. We have identified key research questions that must be addressed immediately to improve the management and long-term treatment of PA/TBI. There were two key research components examined by the Working Group along the continuum: 1) translational research – “What are the questions needed to be asked and what data need to be gathered to ensure the PABI Plan is tested, evidence-based, and replicable?” and 2) basic science research –

“What are the questions needed to be asked and what data need to be gathered to advance the field of PA/TBI?”

The long-term research agenda of the SJBF Centers will be formed by emerging clinical and research evidence and reflect an interdisciplinary integration of research questions and methodology. It should be noted this research agenda is by no means complete, but does represent the areas of research that can provide the maximum help in the management of PA/TBI as quickly as possible with future research needs to be delineated over time. Indeed, the entire circle of care will need to be modified as more evidence of best treatments is documented.

For the purposes of this position paper and overall initiative, the expert working group recognizes that Traumatic Brain Injury (TBI) is a subset of Acquired Brain Injury (ABI). As such, to ensure that there is no gap in the discussion, issues, and services between these areas of Pediatric Acquired Brain Injury (PABI), the terms are being combined and will be herewith referred to as Pediatric Acquired/Traumatic Brain Injury (PA/TBI). This group of experts was divided and asked to address (1) prevention, (2) acute care needs, (3) transition to the community and ongoing rehabilitation, (4) long-term needs, (5) research which will span all phases and (6) child/youth, parents/caregivers, siblings and other family considerations at each stage. Where necessary, the severity and cause of the PA/TBI was also addressed.

In addition, the definition of PA/TBI takes into consideration and includes the age range from birth to age 25 years because of the recognized physiological developmental changes that the brain is still undergoing in the third decade of life. As such, it encompasses the care of over 73.3 million children and youth within the United States of America based on the 2000 census.

The entire program is based on the following premise: the most important way to treat PA/TBI is to prevent it in the first place. Prevention has been conceptualized broadly to include programs that are available to prevent PA/TBI caused by everything from motor vehicle collisions to programs addressing other forms of acquired brain insult such as those to encourage sound immunization regimens and improved nutrition.

Prevention occurs at a number of different levels including primary prevention which entails forestalling PA/TBI in the first place, secondary prevention which involves limiting the impact of PA/TBI, and tertiary prevention, or preventing repeat brain injury. Prevention programs must be evaluated to prove they make a difference and actually decrease the incidence of PA/TBI.

Existing programs that have been or are being shown to be effective should be expanded and instituted nationwide, when replicable. New programs should be developed, based on evidence, to increase the dissemination of prevention information and this information should be widely distributed.

Education is also a key part of the circle of care. Education should address important aspects of PA/TBI, including: definition, prevention, diagnosis and treatment, facilitation of recovery, provision of needed assistance in schools and participation in the community. Education must target children and young adults, parents and extended family, educators, health care providers across the continuum, and mental health specialists to optimize appropriate identification and treatment over time. Those providing direct services to children/young adults with PA/TBI and their families must be well informed. Although there are many with expertise throughout the nation, the current accessibility to these experts and their overall numbers are insufficient to address the full scope of the problem.

The SJB Centers will seek to standardize acute care for PA/TBI during field-side assessment, Emergency Department triage and stabilization, critical and acute care management in hospital and rehabilitation based on state-of-the-art evidence. This standardized approach must encapsulate all areas of healthcare delivery and healthcare personnel education/training. In addition, the Centers will emphasize the importance of timing rehabilitative interventions appropriately in the care of the child/youth with a brain injury. Ongoing research is essential and will be conducted in the best way to care for children with PA/TBI, and as new information emerges it will be disseminated to other sites as rapidly as possible. Each Center will have exceptionally-trained SJB Family Specialists who will operate as “super-caseworkers” for each family.

Rehabilitation begins during the acute recovery phase and can continue throughout the child or young adult’s life. The SJB Centers will seek to expand our understanding of how much, what kind and when rehabilitation is necessary for various kinds of PA/TBI. Communication with the family and the initiation of the transition the family will undergo is imperative. Initiating rehabilitation programs early is paramount, but so is the recognition that the rehabilitative process continues in the child/youth’s community and this rehabilitation needs to be ongoing as the child/youth develops and grows and the brain undergoes the physiologic preplanned growth and refinement necessary for brain maturation. Indeed, one of the reasons why PA/TBI is so different from adult A/TBI, is the fact the brain is maturing and new skills are emerging. Infants, children and young adults often manifest their PA/TBI when they fail to meet expected developmental milestones at the appropriate times.

***Sarah Jane Brain Legal Center:***

An additional component of the National PABI Plan is the Sarah Jane Brain Legal (SJBL) Center. The purpose of the SJBL Center is to provide children and adolescents with the best means of accessing the supports and services necessary for individuals with PA/TBI. The legal center will incorporate education about and the most effective means for obtaining these services from the medical, educational and social services communities or organizations, as well as other legal entities, in the most efficient manner. Always taking into consideration the needs of the child/youth and family, the legal center will ensure a continuum of service delivery into, through and beyond the legal age for those services. The legal center will serve as a legal hub for any legal issues the child/youth and family needs and also facilitate appropriate transition and access of services into the adult world and support continuity of those services.

## ***Chapter 1: The TBI Model System and the PA/TBI Model System***

### **The Current Status of The TBI Model System**

The TBI Model Systems came into existence in 1984 when the National Institute of Disability and Rehabilitation Research (NIDRR), United States Department of Education funded four centers as five-year grants. The four centers were located at Medical College of Virginia, Mount Sinai Medical Center, Rehabilitation Institute of Michigan and Santa Clara Valley Medical Center. A data center at SUNY Buffalo was funded as well.

The initial funding for the centers was about \$250,000 per year (direct and indirect costs). Every five years the Model Systems are re-competed and some centers are re-funded, some centers are de-funded and new centers are funded. Therefore, the “cadre” of TBI Model Systems has not been stable over the 25 years of the program. The current cohort of the TBI Model Systems was funded in October 2007, and consists of 16 centers, a data center that is located at Craig Hospital in Denver, Colorado and a Knowledge Translation Center that is located at the University of Washington. Current funding is about \$420-450,000 per year (direct and indirect costs).

These 16 programs are located at: Baylor College of Medicine, Craig Hospital, Dallas Rehabilitation Center, JFK-Johnson Rehabilitation Institute, Kessler Institute for Rehabilitation, Medical College of Virginia, Mass Rehabilitation Hospital, the Mayo Clinic, Mount Sinai Medical Center, Ohio State University, Rehabilitation Institute of Chicago, Rehabilitation Institute of Michigan, Santa Clara Valley Medical Center, Shepherd Center, University of Alabama, and University of Washington.

Although there is no standardization of the rehabilitation programs provided by the TBI Model Systems, the programs are CARF and JCAHO accredited. Each program is supported for its “local” research as well as its contribution to multi-site knowledge development projects and clinical trials. Currently, there are more than 50 research projects ongoing within the TBI Model Systems. Thus, the TBI Model Systems are research centers.

In addition, each center contributes between 35-40 new cases each year of individuals with moderate-severe TBI who receive their acute care and rehabilitation within the model system. These individuals are followed at intervals of 1, 2, 5, 10, 15 and 20 years post-injury. Currently, there are about 8,000 individuals with TBI included in the TBI Model System database that are

being followed. Thus the TBI Model System represents the only longitudinal database on the long-term outcome and challenges of individuals with TBI.

The TBI Model System includes only those individuals who are older than 16 years of age. The age was originally set based on the JCAHO parameters and not based on any specific neurological evidence. Most of the TBI research over the years has been targeted towards the adult TBI population. It is worth noting children are not “little adults.”

### **Challenges For Developing A PA/TBI Model System**

There are several challenges that are barriers to developing and implementing a PA/TBI Model System. They include the following:

1. There is little if any basic laboratory research on the acute stage of PA/TBI regarding pharmacological or surgical treatment, nor are there any studies on interim or long-term neurological outcomes resulting from early stage interventions.
2. The epidemiology of pediatric moderate-severe TBI is not well studied, therefore the number and characteristics of children who would meet the inclusion criteria in a national database (however defined) is not known.
2. The pediatric “model system” has not been defined because the pathways of care are not well defined. In other words, what proportion of those with moderate-severe PA/TBI receives inpatient rehabilitation as opposed to being discharged to their homes directly from acute care? Once home they receive community-based or home-based services. Appropriate models of care or transition remain ill-defined. Standardized methods for tracking and identifying children with “mild” TBI are lacking. The nature of the problem remains ill-defined: is a model system for those with moderate and severe injuries or for those with mild injuries as well?
3. The model of care for children and adults is very different. More specifically for adults there are diverse programs of post-acute inpatient and outpatient services available. There is no such care network available for children. Indeed the panoply of outpatient programs available to adults is replaced by “educational” systems that are not prepared to provide adequate services to children with PA/TBI. There are few “model” programs of either outpatient or school-based programs of care that could be used as models for system development.

4. School systems are ill-equipped to deal with children with PA/TBI and are more comfortable classifying them with disabilities that are more consistent with ongoing service delivery schemes.
5. There is no standardized method for identifying children with PA/TBI when they enter school or in the years that follow. Thus, the true number with children with PA/TBI is not known and is a deduction; therefore, the extent of the problem remains unknown.
6. While there is some longitudinal data on “recovery” from moderate-severe PA/TBI, follow-up periods are limited and the long-term follow-up data on those with all ranges of PA/TBI severity remains unknown. Thus, we do not know the social consequences of PA/TBI in terms of unemployment, substance abuse, psychiatric disability, delinquency, violence, etc.
7. There are few Departments of Rehabilitation Medicine currently admitting a sufficient number of children with PA/TBI so they are unable to create specialized PA/TBI rehabilitation programs.

### **Solutions For Developing A PA/TBI Model System**

1. Epidemiological studies need to be funded examining the epidemiology and longitudinal course of PA/TBI. Better information is needed in terms of the number of children with mild, moderate, and severe injuries who are injured each year, what services they receive and what happens to them over time.
2. Data from epidemiological studies need to be applied to the development of an interdisciplinary basic research program to develop early-stage interventional treatments using PA/TBI laboratory models.
2. States need to “buy” into identification of PA/TBI. Children must be identified when they enter school and each subsequent year thereafter.
3. Best practices need to be established for statewide programs of identification, teacher training and classroom interventions.
4. Evidence-based practices for classroom intervention need to be established
5. Evidence-based programs of cognitive rehabilitation for children with PA/TBI need to be developed consistent with the child’s development age.
6. Evidence practices for family-based intervention need to be established.

7. Models of care need to be developed consistent with the child's cognitive, behavioral, physical, sensory and emotional challenges.
8. Model programs for points 2-7 need to be identified and replicated.

## ***Chapter 2: Prevention***

THE BEST POSSIBLE TREATMENT FOR ANY BRAIN INJURY IS *PREVENTION*

### **Current Status & Problems:**

Brain injuries can be prevented and controlled. Various prevention models have been proposed, but for the purpose of this report the classic model will be used. Primary prevention entails preventing new injuries, secondary prevention involves reducing the severity of injuries and tertiary prevention is decreasing the frequency and severity of disability after an injury. (WHO)

Prevention needs to include all aspects of PA/TBI including but not limited to: prevention of meningitis/encephalitis, near-drownings, strokes, playground safety, gun safety, trauma, recreational safety, automobile and bicycle safety, prevention of domestic violence and child abuse, fall prevention and sports/concussion prevention.

There are a variety of primary prevention programs currently in existence. Many have not been evaluated as to their usefulness and often overlap in their activities. Examples of some effective primary prevention programs for preventing injury include: Think First, SafeKids, ImPACT, Period of PURPLE Crying, WalkSafe, etc.

Primary prevention programs should be based on the WHO Model, whereby multiple agencies partner together to implement a five-“E” program: Education, Engineering, Enforcement, Evaluation, and Encouragement. This 5-E model developed by WalkSafe in 2003, which has been adopted by the National Safe Routes To School Program (SRTS) is an example of a primary prevention program. The purpose of Safe Routes to School is to enable and encourage more children to safely walk and bicycle to school whereby multiple agencies partnered together to implement the 5-“E” program.

A public health perspective also allows for an integrative approach to address childhood injury. Such an approach brings together as partners national and local agencies and organizations involved in injury prevention. The Public Health Model paradigm includes: surveillance of a

problem (what is the problem), identifying risk factors (what are the causes), implementation of a program (how is it done) and then development and evaluation of the interventions (what works).

There are few nationally-implemented primary prevention programs. There are even fewer secondary and tertiary prevention programs. The need to prevent a second brain injury following an initial insult cannot be overemphasized. There is a serious need to reduce the morbidity of PA/TBI by preventing/limiting/minimizing subsequent developmental stall and identify and assess chronic behavioral and psychiatric issues associated with it.

### **Family Perspective:**

The importance of preventing a brain injury is not well-appreciated by families and their communities until an injury actually occurs. Many simple but effective preventive measures (helmets, seat belts, car seats) are still underutilized or improperly utilized. Particular issues include the impact of a concussion on cognitive, psychosocial and emotional competencies; the implications of shaking a baby; and the impact any PA/TBI has, not only on the child/youth, but on the family and community long-term. Continued reflection and consideration is needed based upon all families' experiences for the development of the types of prevention and communication strategies effective in preventing PA/TBI. Furthermore, there are many successful prevention advocacy organizations needing additional funding and support to expand upon their successes.

### **Solutions:**

1. Application of WHO methods for primary and secondary prevention and employing educational initiatives for injury prevention.
2. Collection of targeted injury data for identifying priority issues and high risk parameters, using a standardized dictionary of terms for uniformity across all stakeholders in A/TBI.
3. Refinement, development and testing of evidence-based prevention programs which are sustainable and able to be generalized for any given community.
4. Increased availability of prevention education/re-education programs with active research.
5. Utilization of a "train the trainer" model of education and support.

### **Secondary/ tertiary prevention:**

1. Advocacy training of families.

2. Training of medical personnel, community, school, sports/recreational agencies regarding risks of re-injury and/or current injury exacerbation.
3. Risk reduction for homelessness, addictions, abuse and psychiatric sequelae.
4. Target education and screening within the correctional/prison system and special programs within schools, as well as direct education of pediatric and adolescent psychiatrists and psychologists to better identify children with a history of trauma.

**Research Priorities (not in particular order):**

1. Identification of risk factors for various types of injuries (e.g. MVA/falls/sports/child abuse/military).
2. Investigation of the effective prevention strategies for each main mechanism, type and severity of injury.
3. Improved identification of secondary injuries by means of biomarkers.
4. Establishment of effective measures for the prevention of repeated injuries.
5. Recognition of risk factors for psychiatric co-morbidities.

### ***Chapter 3: Acute Assessment and Identification***

#### **Current Status:**

Mild TBI represents the overwhelming majority of brain injuries (approximately 75-90%), likely 2+ million per year in the United States alone. Knowledge and understanding of mild TBI within medical, educational, recreational and family systems is variable at best, and early identification of mild TBI is poor. However, the impact of moderate and severe TBI on the patient, family unit, and society cannot be underestimated and prevention of progression of mild to more severe forms of TBI is critical.

Additionally, early recognition of neurologic deterioration for all types of PA/TBI is a significant problem and if not recognized, the patient's condition will likely worsen and increase the burden of the injury. This is particularly important for the problem of inflicted TBI (abusive head trauma). In these cases, the presenting symptoms may be non-specific and the infant may arrive at a medical facility without a complete history of the injury. It is known that many cases of mortality and morbidity due to inflicted TBI occur after an initial presentation where the diagnosis of TBI was not recognized.

#### **Problems:**

With poor identification and no active management, there is an increased risk of delayed recovery, re-injury, and catastrophic outcome.

Many health and educational professionals are undereducated about the delayed sequelae of remote PA/TBI and their manifestations and as such under-identify these children.

#### **Family Perspective:**

Without early identification of PA/TBI, the family bears the sustained burden from the injury, including financial, social, familial, psychological, and educational. Severe PA/TBI will most likely present with obvious signs and symptoms; mild to moderate PA/TBI may not. Identification and assessment of mild to moderate PA/TBI therefore requires collaboration with medical, psychological, educational, familial and social communities. Parents/caregivers need to alert medical professionals when they notice unexplained changes in their child/youth, even if

they are not aware of a possible cause. They may then still be dismissed by the health care or educational professional as being “overprotective,” their parenting skills might be questioned or the changes in the child/youth might be misattributed to a psychiatric or related misdiagnosis. When this occurs, parents/caregivers must learn to continue advocacy efforts for their child. Parents need to understand that the psychological, emotional, behavioral and cognitive challenges can persist long after the injury has occurred, and that there can be a period of latency before symptoms reappear. This will be another role for the SJBFC Centers to assist parents who suspect their child suffers from PA/TBI but cannot get an adequate diagnosis.

### **Solutions:**

1. Crucial EARLY identification and assessment, leading to best possible outcomes and maintaining quality of life.
2. Facilitation of more effective individualized treatment, thereby improving recovery and reducing adverse outcomes.
3. Multiple sites of identification and evaluation of PA/TBI– family, family MD/pediatrician, ER, psychologists, sports, schools, recreational organizations, etc.
4. Use of toolkits such as the CDC Physician’s and Coach’s toolkit (and others) for mild and non-hospital or field-side assessment.
5. EDUCATION for everyone involved in the care of a child/youth is needed to improve recognition and management of the immediate and long-term manifestations of PA/TBI.
6. Evidence of effectiveness for educational programs.
7. Improved training of acute medical staff for anticipating and intervening in physiological deterioration.
8. Improved communication among health care professionals, school personnel, coaches and parents and family is crucial to improve understanding and identification of actual/potential problems.

### **Research Priorities (not in particular order):**

1. Improve identification and classification of mild PA/TBI (including validation of existing scales across the age range and across injury mechanisms)
2. Improve specific identification of mild TBI in the very young child (e.g., panel of clinical biomarkers, utility of baseline cognitive testing, etc.)
3. Develop an effective educational program for identification/classification of children with mild PA/TBI
4. Validate a better clinical scale for classification of all types of PA/TBI based on underlying pathophysiology
5. Investigate genetic risk factors and/or imaging or other physiologic biomarkers for outcomes from pediatric PA/TBI
6. Develop age-specific neuroprotective strategies for children after PA/TBI

7. Develop age-appropriate experimental laboratory models relevant to children after PA/TBI

## ***Chapter 4: Critical Care***

### **Current Status:**

Severe PA/TBI acute clinical management guidelines exist (2003, with update in progress) but the evidence base remains sparse. There remains a lack of precision and frequent delay of appropriate therapy for pediatric victims of traumatic brain injury. These unnecessary delays in care represent missed therapeutic opportunity and undermine quality and extent of recovery. There is a need for improved infant/young child injury scales.

A new approach to classification of injury based upon underlying pathophysiology and neurobiological mechanism is needed to allow appropriate categorization and target treatment. Age-specific pediatric physiological variables, in combination with genetic markers and anatomical and metabolic imaging, may serve as a means to achieve this goal.

Most neurocritical monitoring is not routinely performed in pediatric ICUs, and when it is, use is generally simply extrapolated from the adult experience rather than driven by specific pediatric clinical evidence. It is increasingly becoming clear that many medications routinely used in infants and young children may have strikingly different efficacy and side effects from their use in adults. Outcomes are currently measured as survival or short term global outcomes that fail to fully describe the level of developmental recovery across developmental domains and over time.

### **Problems:**

Although there have been advanced care courses developed by national organizations, and while there are evidence-based guidelines for the acute care management of infants, children and adolescents, the process of resuscitation and initial evaluation is still variable among centers and even providers and the impact of these guidelines on care processes and outcomes is not known. As a result, the process and effect of resuscitation remains poorly defined and unnecessarily imprecise. This lack of precision and timely initiation of appropriate therapy causes avoidable delays in care which results in poor outcome. Improper fluid volume or content, or inadequate blood pressure resuscitation may add to neuronal injury and result in missed therapeutic opportunities.

The process of acute care and resuscitation is intended to optimize recovery from injury and minimize injury related damage. Current critical care processes are not yet sophisticated enough

to link cell signaling or organ system cross talk to specific clinical problems related to multiple organ dysfunctions.

The main problems with advancing acute PA/TBI clinical care are:

1. There is substantial variability in injury type, severity and developmental stage not addressed by current grading scales.
2. There is substantial variability in processes and procedures for initial assessment and physiological stabilization of children with severe poly system trauma with and without TBI.
3. Management of PA/TBI is extrapolated from adult A/TBI protocols, many of which are inappropriate for children or do not consider the special developmental concerns of children.
4. There is inadequate linkage of multimodal acute physiological variables (vitals, intracranial pressures, EEG, neurologic exams, neuroimaging) with long-term developmental and functional outcomes and rehabilitation interventions (developmental assessments, neuropsychological testing, and developmental/behavioral diagnoses).
5. There is a lack of good age-specific animal models for preclinical testing of hypotheses and interventions in the acute care/ICU setting. Secondary problems are identifying appropriate ages between humans and different animal species, inconsistent implementation of current pediatric A/TBI protocols, understanding age-specific toxicities/side effects of medications and monitoring effects of environmental stimulation during the acute phase.
6. In the setting of polytrauma, whereby there are significant orthopedic or internal organ injuries, mild PA/TBI is often overlooked. Standardized screening for PA/TBI should be mandatory for all ER visits by children with orthopedic trauma.
7. Administration of PA/TBI care is variable across practitioners, institutions and geographic regions making it difficult to draw meaningful conclusions from existing data.
8. Accurate and relevant premorbid and early post-morbid data are rarely available.
9. Obtaining informed consent for interventional and translational studies.
10. Non-medical factors influence the delivery of appropriate medical care.
11. Little data is available on efficacy of, and guidelines for use of, treatments such as hypothermia, craniotomy, and others in the PA/TBI population.

### **Family Perspective:**

This is a critical point in time along the continuum of care when parents and family of children with severe injuries are traumatized themselves, and they must slowly acknowledge the child/youth has been seriously injured and may no longer be the same child as before. Careful, sensitive, and comprehensive family education about the injury and its effects on the child/youth and the family as a whole is crucial at this stage. In addition, support for the family is needed to

deal with the impact of the injury by starting a transitional process that is sensitive to the family's emotional state at that time and helping them to adapt to live with the effect(s) of the PA/TBI. Diagnosis of mild to moderate PA/TBI may be delayed in event of polytrauma; hospital and medical personnel follow-up is imperative.

### **Solutions:**

1. Develop and maintain a multicenter network of collaborating centers in order to generate meaningful data and conclusions.
2. Identify natural age ranges and then develop a normative database of physiological parameters for children.
3. Implement a data management system that provides long-term surveillance and includes standardized elements that can be extrapolated to analyze effects of variability in care on outcome.
4. Develop pathophysiology-based injury scales to properly categorize patients and direct treatment. PA/TBI should not be viewed as a single disease entity but a constellation of multiple distinct but overlapping diagnoses.
5. Delineate the utility and circumstances for advanced neuromonitoring in pediatric ICUs and examine the role these tools play in hemodynamic management.
6. Standardize acute trauma/critical care based on clinical pathways, uniform clinical reporting mechanisms and informatics designed to enhance clinical decision support.
7. Facilitate development of more sophisticated PA/TBI models, with particular focus on proper age-range translation between animal and humans and on modeling common secondary injuries seen in pediatrics.
8. Design translational studies to incorporate both acute physiological measurements and long-term outcomes in the same individuals (for both animal studies and prospective human observational studies).
9. Increase awareness and integrate knowledge about age-specific complications of drug treatments into translational pediatric studies.
10. Monitor for effects of environmental stimulation (both intentional and incidental) during the acute injury phase after PA/TBI.
11. Acquire data to determine the effects of non-medical factors on delivery of appropriate PA/TBI care such as socio-cultural, family, pre-injury factors.
12. Increased utilization of technology to facilitate monitoring, data review, team communication and access to specialists.
13. Improve communication among ICU physicians, consulting physicians, other care providers and family members in addition to initiating contact with a SJB Family Specialist.
14. Develop joint education programs for health care providers to promote interdisciplinary approaches and communication.
15. Monitor efficacy and potential side effects of therapies in children.
16. Develop strategies to study the effects of smooth transition out of the ICU and initiation of early rehabilitative interventions.

17. Review and augment current neuroimaging paradigms using evidence-based studies and foster the development of new neuroimaging research related to the PA/TBI patient at all levels of their injury from immediate/acute management to long-term care and rehabilitation.
18. Identification of biomarkers reflecting cellular changes and deployment of an integrated informatics system enabling the clinician to recognize them will support development of preemptive approaches to critical care management. Moreover, these biomarkers will enable objective assessment of therapeutic efficacy and define immediate results of intervention.
19. Carry out controlled multivariate studies of the efficacy of specific therapeutic interventions (medications, hypothermia surgery) on short-term and long-term outcomes across the phases of care, rehabilitation and reintegration.
20. Standardize process of acute critical care based on clinical pathways, uniform clinical reporting mechanisms and informatics designed to enhance clinical decision support. Specific components of management can be reviewed at <https://www.I-trauma.com/ITwiki>
21. Standardize care paradigms across units that care for children with PA/TBI (ED, OR, ICU, etc).
22. Create value streams for best practice (quality improvement loops).

**Research Priorities (not in particular order):**

1. Timing, volume, type, and technique of fluid resuscitation of the child with polytrauma and TBI have not been evidence-based or directly linked with long-term neurocognitive performance.
2. Timing, type and techniques of systemic and neuromonitoring, and hemodynamic goals has not been adequately investigated or linked to long term outcomes
3. Effect of systemic therapy on cerebral physiology and long term outcomes.
4. Timing and type of secondary insults on secondary TBI are not well defined and linked to long term outcome.
5. The effect of delay throughout, especially when the continuum of care involves inter-facility transfer has not been accurately described nor linked to long-term outcome.
6. Identify candidate biomarkers (inflammatory, physiologic, etc) and translate these from animal models, and validate in humans.
7. Develop and test safe and effective early-stage neuroprotective interventions that can be tested in subsequent clinical trials specifically designed for a pediatric population.
8. Age and development related effects of various biomarker functions must be determined and applied to critical care of infants and children.
9. Informatics systems that link laboratory data, imaging, and bedside biometric monitoring must be evaluated and integrated with artificial intelligence systems to facilitate clinical management, provide timely identification of organ system dysfunction, and provide objective evidence of response to therapeutic intervention.
10. Examine barriers to adoption of interventions and implementation of evidence based guidelines.

11. Delineate the timeline and therapeutic window of treatment/interventions
12. Examine combination therapies/interventions to improve outcomes

## ***Chapter 5: Intermediate Care***

### **Current Status:**

The definition of intermediate care varies widely across institutions, but for the purposes of this document it is defined as when the child/youth no longer requires monitoring in an intensive care setting but still requires hospitalization. Children may also enter this phase of hospital care for observation following their PA/TBI who do not need ICU-level care, but still require acute medical management. The important decision at this level is whether the child/youth will require inpatient rehabilitation, or long-term care or can they be discharged into the community and receive rehabilitation within the community. While in this phase of hospital care it is clear that all should continue receiving early rehabilitation services using a multi or interdisciplinary model.

This intermediate period was developed in 1992 at the University of Miami/Jackson Memorial Medical Center as the Intermediate Head Injury Service (IHI) for adults. In 2001, a similar service was developed for children and adolescents (Hotz & Kuluz, 2005). This program was found to:

- decrease the child/youth's length of stay in the PICU, thereby decreasing costs,
- improve and centralize specialized neurological management for these children to one unit on an acute care floor,
- begin appropriate early rehabilitation,
- begin discharge planning with case management support, and
- begin education for child and family about brain injury in the acute phase of recovery

The purpose of an IHI is to provide an acute multidisciplinary team approach for establishing a comprehensive early medical/rehab intervention and identification system for the assessment and treatment of children recovering from brain injury. There are very few centers that manage children with brain injury in an intermediate care unit specializing in neurological management and early therapy. This specialized unit may prove to be beneficial to optimize recovery and functional outcomes.

### **Problems:**

The use of this level of care is variable with some patients going straight from intensive care to inpatient rehabilitation (as in The Children's Hospital, Denver model) and others staying in the intermediate care ward for further medical stabilization before either discharge home and community rehabilitation or into an inpatient rehabilitation program or a long term care facility for a minimally conscious level or seemingly minimally conscious level child/youth. There is a lack of consensus in all areas of medical and allied health care based literature upon the insufficient understanding and research of the various rehabilitation models and protocols. For example, questions regarding the rehabilitation potential of coma and the minimally conscious

patient are even less well understood.

### **Family Perspective:**

Families need to participate in the plan of care for their children/youth both in the short term and long term. Families require either initiation or ongoing support in the transitioning process of having a child/youth with PA/TBI. It is important that the family's concerns be heard and addressed, as their home-based actualities of having a child/youth with PA/TBI might not match the understanding of the medical/educational/psychological communities.

### **Solutions:**

1. Using evidence-based research, standardize the definition and the process of transition from ICU to rehabilitative care in an appropriate timeframe.
2. Improve availability through increased access to inpatient and community-based rehabilitation that is child/youth and family-centered and evidence-based as much as possible.
3. Provide continuity of care in terms of providers when available (i.e., same inpatient and outpatient providers).
4. Long term care facilities need to be aware of the need for slower paced rehabilitation including the medical and therapeutic services.
5. Improve understanding of patterns of recovery and pathophysiology.
6. Develop treatment specific to these patients.
7. Baseline and continuous assessment to measure treatment effectiveness and monitor recovery that is pediatric specific and that can lead to standardization of care.
8. In addition, ongoing education and training are needed to continuously upgrade therapeutics and skills based on new research, evidence and technology.
9. Improve communication among physicians, other care providers and family members in addition to maintaining continuing contact with a SJB Family Specialist.

## ***Chapter 6: Inpatient Rehabilitation***

### **Definition:**

This level of rehabilitation refers to inpatient services for the individual with PA/TBI provided by collaborative treatment teams addressing the individual medical, physical, psychological and social needs of patients. The goal is to maximize independent function and educate families regarding home care in a fashion that facilitates ongoing clinical improvement and follow-up after discharge.

### **Current Status:**

Multiple program types meeting various criteria:

1. There are currently only 7 pediatric inpatient rehabilitation programs which have CARF (Commission on Accreditation of Rehabilitation Facilities) accreditation with specialization in Pediatric Brain Injury. There are other programs in the country with qualified medical, therapeutic, psychological, and family services which also provide a high quality of care for this population.
2. There are 28 CARF accredited Pediatric Family Centered/Pediatric Specialty programs within Children's Hospitals as of 2008.
3. According to UDSMR (Uniform Data Systems for Medical Rehabilitation), 24 Pediatric Inpatient Rehabilitation Programs within Children's Hospitals use WeeFIM as a standard outcome measure. Many facilities use other standardized outcome measures (PEDI, etc.).
4. There are few centers providing a comprehensive approach to PA/TBI treatment throughout the continuum of care, including services in the acute, intermediate, acute rehabilitation, and long term post-discharge stages including transitioning into adulthood.
5. There is variation regarding timing of initiation of inpatient rehabilitation and criteria to qualify (frequently dictated by insurance coverage, local system structures).

### **Problems:**

1. Barriers to seamless transition from acute care to rehabilitation persist.
  - a. Lack of funding frequently eliminates or delays critically needed acute rehabilitation
  - b. Parental confusion often results in loss of eligibility for certain government sponsored programs
2. Minimal evidence exists for the mode of delivery and types of medical rehabilitation:

- a. There is a lack of evidence for rehabilitation therapies, that is, lack of research and/or evidence-based practice regarding admission criteria, pharmacologic management, therapy type, timing, length or intensity of therapy.
  - b. There has been little progress in this area since the 1999 Agency for Health Care Policy and Research report *Rehabilitation for Traumatic Brain Injury in Children and Youth*
3. Minimal evidence exists for system issues:
- a. Lack of common data collection in uniform fashion
  - b. Lack of awareness/education among healthcare practitioners and administrators
  - c. Lack of qualified personnel
  - d. Lack of financial support
  - e. Lack of minimum requirements to provide service (i.e. pediatric specialty), especially regarding third party payers in-network providers
  - f. Lack of ability to extend treatment plan to local community
  - g. Limited ability to serve individuals who are slow to recover or who are considered to have plateaued.
4. There exists a significant and deleterious discontinuity of care and knowledge about PA/TBI between the inpatient hospital setting and personnel and normal everyday community-based school, medical, and therapeutic personnel.

### **Family Perspective:**

The initiation of inpatient rehabilitation services, when and where available, often offers for families the first chance to begin to appreciate and understand the multitude of challenges related to habilitation from brain injury. Families frequently arrive with minimal understanding of the severity and long-term nature of the many challenges faced by survivors and families dealing with acquired brain injuries.

While there are often significant improvements in mobility and self-care during this time, the cognitive, behavioral, emotional, and learning challenges often persist and worsen, and can become lifelong struggles. Families need to receive a great deal of information and training during this time, but they are in various stages of grieving and acceptance and so require persistent education regarding the ongoing needs of the patient after discharge. Supportive services for families are essential during this time for coping with the alteration in the family unit and are critical to begin to link families to the resources available in their local community.

Additionally, during an inpatient rehabilitation admission, families are trying to balance maintaining employment, caring for other siblings, and maintaining marriages and relationships. Often the stressors brought on by the profound shift in family dynamic that occurs after acquired brain injury results in divorce, depression, and substance abuse, among others, further disrupting family units.

As well, children/youth who have been discharged home and are later able to participate in more aggressive rehabilitation would often benefit from an inpatient rehabilitation admission for further treatment, but access to these services is almost always severely restricted or denied. Currently, once a child/youth is discharged from inpatient rehabilitation, families often have difficulty obtaining appropriate outpatient therapy or school-based services in their local communities due to the limited number of pediatric-trained specialists and lack of funding. The physical needs and therapies of a child/youth in the first six months after discharge are often met, but the psychosocial, emotional, educational, and behavioral needs start to become apparent at about six to nine months after the injury, at a time when parents and teachers think the child/youth is recovered, because s/he looks fine physically.

Thus, the immense attention to education of the family and intensity of therapy services received by the patient immediately after the brain injury during inpatient rehabilitation is met with a resounding lack of education and resources in the local community after discharge, resulting in significant and ongoing frustration for patients and families, and significant worsening of the child/youth's functional status.

### **Solutions:**

1. Establish a Model PA/TBI Network to include inpatient rehabilitation to form a base for patient care, research, education, and development of evidence-based practice for specific pharmacologic agents, stem cell trials, nutrition, occupational, vision, physical, speech, and behavioral therapies, and/or combinations thereof. Specifically, current experimental models should be translated into clinical trials. Information regarding optimal timing, intensity, and length of inpatient rehabilitation must be elucidated.
2. Establish a protocol for discharge including a case manager who works with the rehabilitation team to assist patients/families in navigating networks of care, identifying local resources, reintegrating into community/school, etc. Specifically regarding school there should be an identified individual to facilitate re-entry.
3. Establish within each model group a process for advocating, educating, and implementing PA/TBI recommendations for governmental agencies, third party payers, health care systems, and communities.

4. Ensure practices (assessment, intervention, service delivery) are sensitive to developmental, socio-cultural, and linguistic factors that consider the post-discharge needs and realities of the child/youth and family.

**Research Priorities (not in any particular order):**

1. Assess interventions including specific pharmacologic agents, stem cell trials, nutrition, occupational, vision, physical, speech, and behavioral therapies, and/or combinations thereof with experimental study designs.
2. Translate current experimental models into clinical trials.
3. Elucidate information regarding optimal timing, intensity, and length of inpatient rehabilitation. This will be informed to some extent by further research into the natural history of acquired brain injury.
4. Evaluate transition and follow-up programs that have been shown effective in adult TBI Model Systems research programs (e.g., University of Seattle Medical Center) for utility in the PA/TBI system.

## ***Chapter 7: Reintegration, Transition, & Long-term Care***

### **Problems:**

The availability and provision of transitional services following pediatric A/TBI varies tremendously, depending on the nature and severity of the injury (e.g., concussion versus brain tumor).

However in general, when a child/youth is ready to be discharged from the ED or hospital following PA/TBI, or is identified in the community as having a PA/TBI, there is no systematic plan for connecting children and families with the necessary services within the school and community.

Several factors likely account for the failure to link children and families to community services:

1. Hospital staff may perceive the child/youth as doing well, and thus not foresee a need for community involvement/support after discharge, especially following mild/moderate injuries.
2. Parents may fail to recognize the possibility of life-altering challenges for their child/youth, or they may feel stigmatized by the label of brain injury, and as a consequence do not want community agencies notified.
3. The standardized assessments commonly used in hospitals and rehabilitation facilities are of questionable validity in predicting the child/youth's needs in returning to school and home.
4. The schools and other community agencies themselves, when notified, may be poorly educated regarding the effects of PA/TBI and not recognize the need to advocate for and work with the child/youth who has an PA/TBI, especially if the injury/insult is less severe and resulting challenges are not obvious.

Because early predictors of long-term outcome are poorly understood and available services are limited, children who are at risk for long-term functional deficits may fall through the cracks.

Furthermore, some difficulties such as academic, vocational or social, may not become apparent until later developing skills fail to emerge. When such developmental stall occurs, it may not be connected to the original insult and thus misdiagnosed.

Additionally, transitions from hospital to school, school to school, and school to community and adult systems are fragmented, uncoordinated, and not universally accessible. Thus, access to services is inconsistent across our country and many parents try to navigate our many agency systems without guidance.

In addition, there is a paucity of research that has examined interventions to assist with reintegration of children and youth with PA/TBI into home, school, and community life along with the transition into adult life. Also, there is a dearth of measures that have been developed to examine these important outcomes.

In order to ensure a seamless transition into adult based A/TBI resources and effective rehabilitation, there is a vital need to make certain if a 24-year-old person will still require essential youth-oriented services precisely because cognitive impairments, emotional issues or psychological immaturity stemming from the brain insult will preclude him/her from functioning effectively in an environment where complex demands are made upon him/her.

The current approach to service delivery (inadequate services and supports in school, home and community) results in poor long-term youth outcomes that are costly to society (e.g., unemployment, public-assisted housing, incarceration). Figures 3 & 4 depict the current and proposed approach to intervention supports and concomitant costs of each.

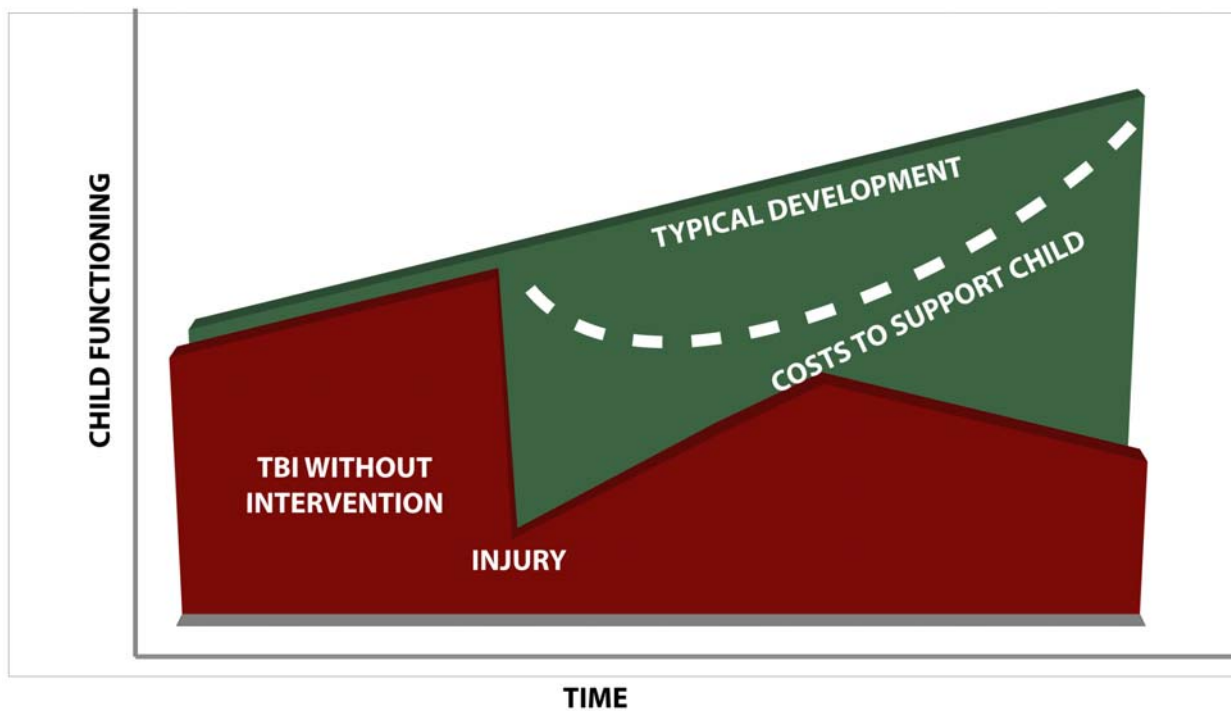


Figure 3. Effects on child/youth functioning and related costs of inadequate treatment supports.

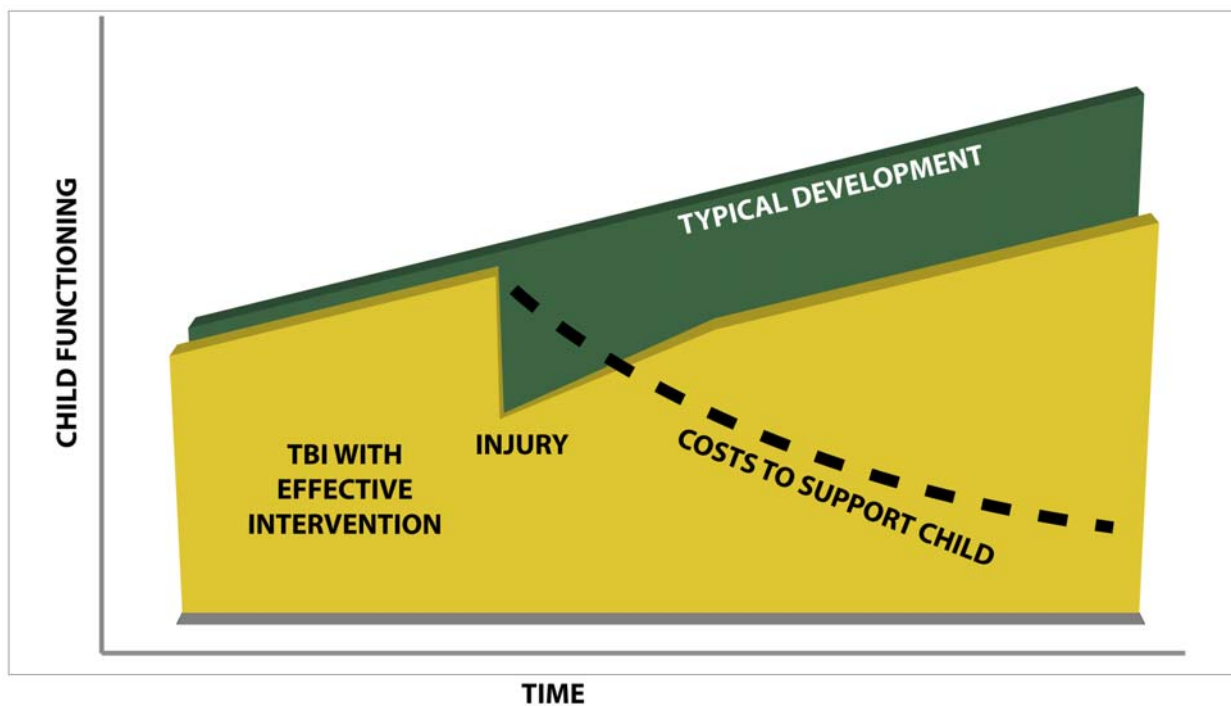


Figure 4. Effects on child/youth functioning and related costs associated with intervention and supports.

**Family Perspective:**

Once the child/youth returns home, families must come to terms with the changes in their child's functioning and, very likely, the need to provide increased levels of care due to physical and cognitive disabilities. The stress on parents created by caring for the injured child/youth often leads to increased marital conflicts and high levels of psychological symptoms and distress in family members. The picture for families usually does not improve with time; familial distress is both progressive and enduring. Further, across society, the number of family members available to help with caregiving has decreased, placing more demands on the primary caregiver. As the social network of the person with PA/TBI shrinks, family members must assume a greater support role and therefore may become somewhat socially isolated.

**Educator Perspective:**

Although PA/TBI is a high-incidence medical event and tens of thousands of children sustain long-term disabilities resulting from PA/TBI every year, from the point of view of the United States Department of Education and most State Departments of Education, PA/TBI is a low-incidence disability. Many children with PA/TBI are not identified and served appropriately in schools because of the perceived low incidence as well as a number of other factors (e.g. lack of awareness of educators, poor communication about PA/TBI between medical and educational systems, emergence of learning and behavior problems misattributed to other disabilities).

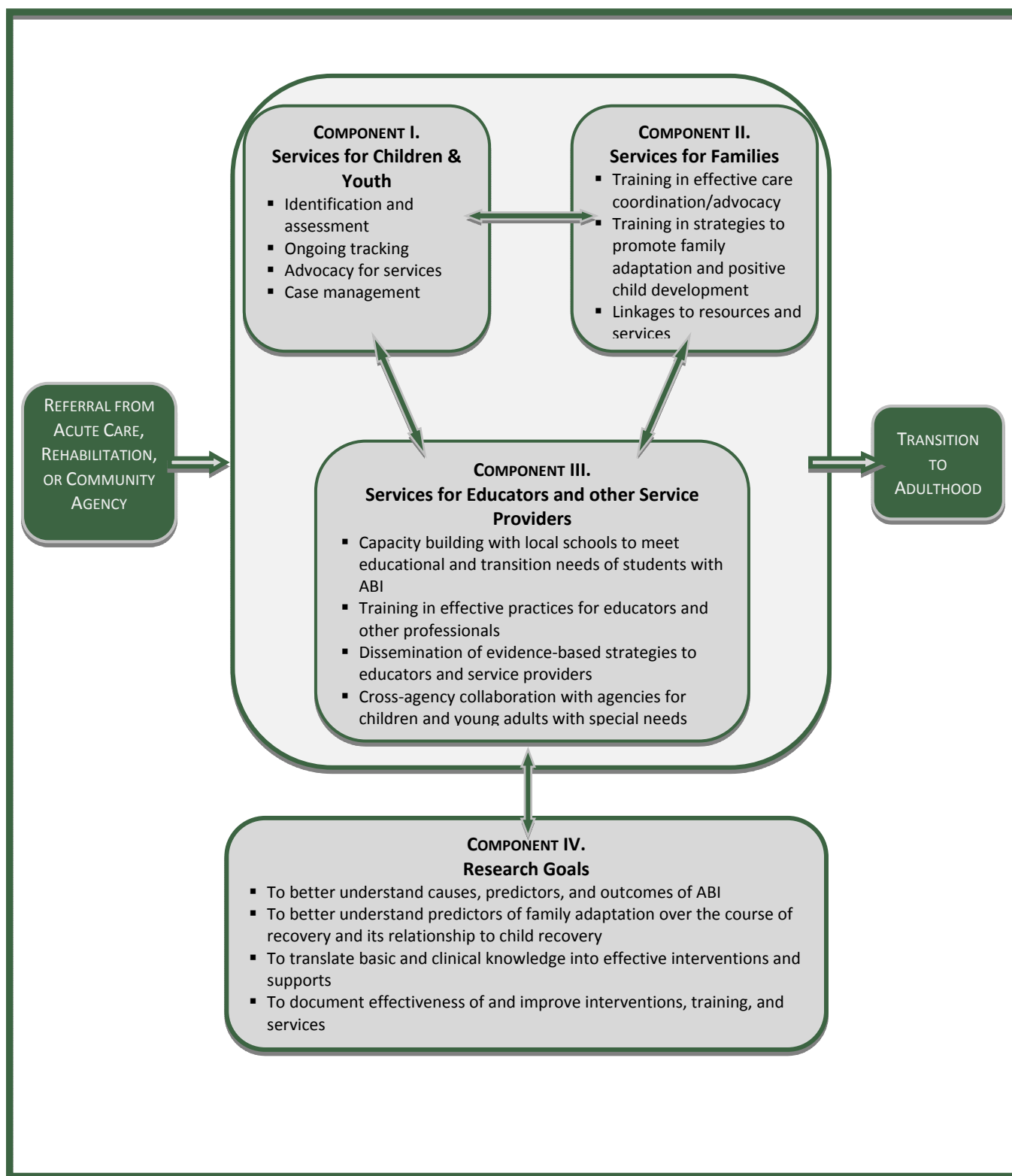
**Service Provider Perspective:**

Personnel from agencies that serve children and young adults with disabilities are, like educators, unfamiliar with the needs of children and youth with PA/TBI and their families and so are ill-prepared to meet those needs. Although PA/TBI is considered a developmental disability (DD) when it occurs before age 18 (in most states), providers of DD services see few clients with PA/TBI. Families are often unaware that they are eligible for such services. Thus, service providers experience lack of training and experience specific to PA/TBI similar to that of educators.

**Solutions:**

The solution to this complex problem requires a comprehensive and coordinated system of

identification and service provision, involving child/family services, policy development and education for hospital personnel, “standard of care” programs that explicitly link hospital experts with community-based school and medical personnel before the child/youth is discharged from the hospital, capacity building for schools and other community agencies, and an integration of research and practice. This system is reflected in the Sara Jane Brain Foundation Model for integration of research, services and supports for children with PA/TBI and their families. The four components of the model, depicted in Figure 5, are outlined below.



**Figure 5. Sarah Jane Brain Foundation Model for integration of research, services and supports for children with PA/TBI and their families**

## **Components I and II. Services for Children and Families**

### **Identification:**

The SJBFCenters will identify children/youth with PA/TBI and maintain a national Registry as described in Chapter 8. Identification of children with PA/TBI is critical to understanding long-term outcomes and to effectively providing services. There are a number of existing models that may be appropriate for the design of this database.

### **Assessment:**

The SJBFCenters will have a critical role in assessment. The assessment serves four central functions:

- 1) To identify the need for services and therapies in a variety of domains;
- 2) To evaluate the efficacy of treatment practices and interventions; and
- 3) To understand the long-term functional outcomes of PA/TBI (such as reintegration into home, school and community life, and participation in meaningful activities, optimum physical, cognitive, behavioral, social and family functioning) and the medical, biological, and social-environmental factors that influence outcomes;
- 4) To guide schools in the implementation of effective assessment for planning educational interventions and supports.

The SJBFCenters will facilitate appropriate assessment of children/youth and their families. Limited data regarding child, parent, and family functioning will be collected on all children with PA/TBI as part of the National Registry and Database.

However, more detailed assessments will also be administered to guide the provision of clinical care and better characterize outcomes in specific domains. Part of the mission of the SJBFCenters will be to identify the best standardized and functional assessment processes and procedures to assess the child/youth, family, school and social environment (assessing development over time) and to ensure that these assessment procedures are used appropriately.

Because child/youth functioning following PA/TBI varies considerably based on the context, measurement approaches will emphasize functioning in everyday contexts such as school and community, and the child, parents, and teachers will participate in ongoing developmentally appropriate assessment of real-world functioning. For educational purposes, the school conducts assessment.

The SJBFCenters will collaborate with schools (through training, consultation, and dissemination activities) to ensure schools use evidence-based assessment approaches. The Centers will also work with teachers to facilitate effective use of diagnostic teaching and experimental/dynamic assessment in the classroom.

### **TRACKING:**

The SJBFCenters will track children and family from the point of entry into the continuum, and continues to follow them over time with particular emphasis on following up at key developmental transitions (e.g., school entry, school transitions). Given the importance of understanding determinants of long-term functioning and of identifying later emerging problems, it is essential the Centers track children over the course of development into adulthood.

Initially, children and families will be followed up at short intervals to track acute recovery, and then over longer time periods throughout the continuum into adulthood. The Centers will also track the services received by the child/youth and family over time. Data on school systems and integrated services will be collected to address the following questions:

- Do the Centers' interventions and training make a difference?
- Do the child/youth get different services based on that intervention and training?
- What services made a difference?

### **Provide Advocacy & Support**

The Centers' roles in the domains of advocacy and support services to individuals with PA/TBI and their families will be a key component of the mission of the Centers. The vision is to provide and evaluate a broad range of support and advocacy services including:

1. Advocating for services for the child/young adult and family,
2. Providing training in self-advocacy and self-determination to the children/young adults,
3. Providing training in effective care coordination and advocacy to family members or other caregivers (e.g., family mentors),

4. Providing training in strategies to promote family adaptation and positive child development to parents/guardians and families.

The initial approach for delivering these services will be based upon the current empirical evidence base and best practices. However, the intent would be to conduct ongoing formative and summative evaluations of these services as part of the Centers' mission, including input from consumers/constituents (parents, children, and community agencies) to further refine and inform best practices.

Programs developed by Glang and colleagues provide an evidence-based approach for training families in effective advocacy and communication skills for interfacing with schools. Researchers in special education transition have identified evidence-based practices that are effective in teaching students with disabilities the skills needed for self-determination and self-advocacy.

Currently, however, students with PA/TBI lack access to instruction in these skills, since students with PA/TBI are under-identified in terms of eligibility for transition services, and educators and transition specialists are not skilled in working with these students when they are referred. Wade and colleagues' family problem-solving model may provide an empirically-supported approach for providing support and skills training to families. The SJBF Centers will inform existing community agencies so they recognize and qualify this population for their services. Toward this end, Glang and colleagues have developed and are currently testing a model for increasing identification and appropriate treatment of PA/TBI in the school system.

When students are properly identified for special education and transition services, linkages to community agencies will also be addressed through the students' transition plans. Finally, the SJBF Centers interface with the Sarah Jane Brain Legal Center to address legal issues. An important element of the support and advocacy mission of the SJBF Centers will be to disseminate best practices across the country and to provide technical assistance and training to ensure that best practices can be appropriately implemented across the country. Related research questions are outlined below.

### **Component III. Interface with Service Systems**

The primary provider of services for children and most youths is the educational system. Schools and community agencies are often poorly equipped to address the needs of children with PA/TBI. The SJBF Centers' role is thus to support and build the capacity of this system to meet students' needs and to facilitate cross-agency collaboration between the educational system and other agencies in an effort to bridge gaps and ensure that all children receive quality long-term supports as needed. Another crucial aspect of the SJBF Centers' mission is to increase the dissemination of evidence-based strategies to community agencies and local schools to meet the cognitive, physical, mental health, social/emotional, participation and educational needs of children with PA/TBI.

### **Increase capacity of local schools to meet educational and transitional needs of students with PA/TBI**

The SJBF Centers' role in improving the capacity of schools includes:

1. conducting systematic research on school- and community-based interventions for improving student outcomes, and
2. providing training and technical assistance in evidence-based practices for educators, including evidence derived from hypothesis-driven educational experiments with individual students.

### **Dissemination of evidence-based strategies to educators, clinicians and other service providers**

The SJBF Centers will provide dissemination to local agencies and service systems, and will interface with dissemination efforts of national and state TBI clearinghouses and lending libraries (e.g., Brain Injury Association Resource Center; Technical Assistance Center of the TBI Project at the Health Resources and Services Administration, US Department of Health and Human Services, U.S. Education Department – National Center for Dissemination of Disability Research). Research in this domain will include a range of studies focusing on child and family outcome; findings from this research will be disseminated through the Center's and other dissemination channels.

### **Cross-Agency Collaboration**

The Centers work with school districts and related community agencies to develop collaborative interactions and smooth transitions that support the family and child/youth to create seamless networking. The STEP Program, The Summit County Accessing Services for Individuals (Ohio), and the TBI Collaborative Model are examples of existing programs that are used at the initiation of SJBF Center services.



**Research - Increase capacity of local schools to meet educational needs of students with PA/TBI**

1. Research on school-based interventions:
  - a. Determine the impact of the range of school-services on child/youth outcomes
  - b. Evaluate the efficacy of different hospital-school transition plans
  - c. Conduct studies to evaluate the impact on student performance of instructional and behavioral support strategies that have been validated with other disability groups
  - d. Validate which assessment tools and processes guide effective educational programming and effective transitioning
  - e. Evaluate the economic impact on the reintegration of students
  - f. Carry out an epidemiological study of service delivery
  - g. Determine an effective educational program for hospitals, schools, and coaches, for proper and immediate identification/classification of children with mild TBI
  - h. Evaluate the efficacy of interventions that involve agencies, colleges/universities, employers and other community members in transition planning and activities to promote success of young adults with PA/TBI in higher education, employment, and independent living
  - i. Promote self-management strategies throughout childhood and adolescence in order to reduce long-term disability risk factors
  - j. Investigate educational techniques and methods to promote ongoing recovery and development
  - k. Evaluate how cognitive and behavior strategies work for children of different ages
  - l. Determine the most effective procedures for preventing secondary behavioral and emotional problems
  - m. Determine the most effective procedures for treating secondary behavioral and emotional problems
2. Training and technical assistance for educators:
  - a. Use technology including distance learning and web sites to improve capacity building and training
  - b. Determine the costs/benefits of providing consultation and support to teachers
  - c. Determine relative effectiveness of consultation and ongoing support for educators using trained peer consultants versus full-time A/TBI consultants
  - d. from either within or outside the school system), with attention to the impact on students, families, and educators
  - e. Determine relative effectiveness of the range of training approaches (pre-service, in-service) and training delivery mechanisms (internet-delivered, traditional classroom)

**Research - Dissemination of evidence-based strategies to educators, clinicians and other service providers**

1. Evaluate the efficacy of maintenance therapy
2. Design and evaluate an IRODP (individualized recovery and ongoing development plan)

3. Determine what technology best promotes the child/youth and family function
4. Evaluate risk factors for psychiatric co-morbidities
5. Determine the timing, intensity, venue for, and type of effective rehab interventions
6. Develop a strategy for chronically injured patient to re-enter therapies and/or training protocols
7. Determine biomarkers (imaging, laboratory studies, functional assessment) of physiological recovery/neuroplasticity at each stage of development
8. Determine the optimal times/modalities for intervention in a range of domains (social, educational, emotional)
9. Evaluate what interventions promote social capital (work, social relationships, etc.)
10. Identify predictors of good long-term outcome after PA/TBI
11. Determine how to decrease the risk for psychiatric problems, substance abuse, delinquency
12. Develop substance abuse programs that take into account special populations
13. Determine the best designs and delivery features of effective dissemination activities

#### **Research - Cross-agency Collaboration**

1. Determine optimal communication strategies among different agencies and care providers
2. Determine best methods to best build community collaborations to move the child/youth into adult functioning

#### **COMPONENT IV. RESEARCH**

A primary component of the SJBFC Centers will be to conduct research:

1. To better understand the causes, predictors, and outcomes of PA/TBI;
2. To better understand predictors of family adaptation and the relationship between family adaptation and child/youth functioning over time;
3. To translate basic and clinical knowledge into effective interventions;
4. To document the efficacy and improve interventions, training, and service.
5. To document the relationship of interventions on patient outcomes.

Research will be used to inform all aspects of the SJBFC Centers' services for children, families, and community agencies. Consumers (children with PA/TBI, families, educators, and service

providers) will be actively involved in guiding the research agenda and determining the research questions.

Broad-based, interdisciplinary research agendas that cut across basic and applied domains will be used to develop a more integrated understanding of the role of age at injury, genetic, acute injury, intrapersonal, social environmental, and treatment characteristics in influencing both short and long-term outcomes as well as intervention efficacy.

Innovative treatment studies, building upon existing best practices and emerging research findings, will be implemented to inform our understanding of the optimal timing, intensity, and modalities of treatments across the care spectrum. Research will also be used to inform best practices for capacity building in schools and community agencies as well as approaches for training educators in effective approaches in the classroom. Specific research questions, grouped by domain, are listed below.

### **Research - Identification**

1. What are effective referral mechanisms across the full continuum of care and services?
2. How do we identify and classify PA/TBI? (mild, moderate, severe)
  - a. Need for validating scales (across the age range and mechanisms of injury)
3. How do we specifically identify concussion/mild TBI in the very young child?
4. How do we develop an effective educational program for schools in the proper identification and classification of children with mTBI?

### **Research – Assessment**

Reliable and valid assessment procedures will be critical to addressing virtually all of the research questions of the Center. However, as outlined below, there are a number of specific questions regarding the optimal assessment practices for specific functional domains across development. These practices must be sensitive to developmental, socio-cultural and linguistic factors.

1. What are effective assessment procedures and processes (standardized and functional) validated on A/TBI populations for specific functional domains (cognitive, behavioral, social, academic, motor, speech) and child/youth's participation in home, school and community life?
2. What are effective assessment tools to measure family stress, adaptation, and coping across systems of care and services over time?

3. What are effective assessment procedures for evaluating classroom-based instructional and management procedures and community-based programs, particularly as these relate to transition to adulthood, independent living, and vocational/higher education?
4. What is the optimal timing of assessments across development following ABI?
  - o Validation of assessment batteries to guide effective transition

### **Research - Tracking**

As with assessment, tracking children over time and at key developmental transitions will be essential for informing our understanding of predictors of long-term outcomes and functioning. Tracking will also be used to examine the relationship of provision of different types of services to short and long-term outcomes in various domains. However, it is anticipated the SJBF Centers will also conduct research studies to investigate the effectiveness of new and promising treatments in addition to examining current treatments via consistent follow-up and tracking. Specific questions regarding tracking are outlined below as well as research questions that can be answered through the SJBP Registry.

1. Determine the optimum follow-up time
2. Determine important components that need follow-up
3. Determine what measures (child/youth, family, service utilization, etc.) are most relevant
4. Evaluate the efficacy of different comprehensive transition plans
5. Evaluate the economic impact on the child/youth's reintegration into home, school and community life.
6. Carry out an epidemiological study of service delivery
7. Evaluate the effectiveness of maintenance therapy
8. Design and evaluate an IRODP (individualized recovery and ongoing development plan)
9. Determine risk factors for psychiatric co-morbidities
10. Determine the timing, intensity, venue for, and type of effective rehab interventions
11. Determine the role of the family in facilitating the outcomes of rehabilitation, school, and transition to adulthood.
12. Determine how to individualize rehabilitation treatment strategies
13. Investigate the use of combination therapies
14. Determine most effective ways of evaluating treatment outcomes
15. Develop a strategy for chronically injured patient child/youth to re-enter therapies and/or training protocols
16. Determine biomarkers (imaging, laboratory studies, functional assessment) of physiological recovery/neuroplasticity at each stage of development
17. Evaluate the optimal times/modalities for intervention in a range of domains (social, educational, emotional) and independent living and vocational training
18. Evaluate how to promote success in higher education, employment and independent living
19. Identify predictors of good long-term outcome after PA/TBI

20. Determine how to decrease the risk for psychiatric problems, substance abuse, delinquency
21. Determine how to develop substance abuse programs that take into account special populations
22. Determine how one promotes self-management strategies in order to reduce long term disability risk factors

### **Research - Advocacy & Support**

1. Identify the optimal case management strategy (e.g., directed by parents or professionals)
2. Determine how the family dynamics affect child/youth outcomes
3. Document how intervention and support for families affect longer term child/youth and family outcomes
4. Identify the best models/timing for the child/youth's self-determination skill development throughout childhood and adolescence
5. Identify the best model/timing for family training and education in a variety of skills
6. Identify who best delivers case management and child/youth self-determination skill development training consistent with validated principles of context sensitivity
7. Determine how we can use technology to best promote child/youth and family function

### **Research – New Therapies**

1. Characterize and validate new experimental models for different types of developmental brain injuries
2. Develop mechanism-based age-appropriate therapies and demonstrate effectiveness in translational models. In this setting, therapies should be thought of in a broad sense and not be limited to simply medications or physical rehabilitation, but also nutritional, educational, neural activation strategies, bio-behavioral, family-based and certainly, combination therapies
3. Rapidly disseminate experimental results to practicing clinician networks and engage in interdisciplinary design of appropriate clinical trials
4. Demonstrate efficacy of novel and innovative therapeutic interventions in real-life situations prior to establishing guidelines/protocols. However, research does not end at this point – ongoing investigations must be conducted to monitor implementation, demonstrate ability to be generalized or specific indications for therapy, and follow long-term functional outcomes.

## ***Chapter 8: SJBP Registry - An Ecosystem for PA/TBI Community***

Scientific methods and data analyses are the cornerstones of medical research and care. In the traditional model, there is a hypothesis, a question: “If I do this, will the patient benefit?” However, most projects are often done in isolation and typically centered on a particular researcher’s practice. At times, researchers collaborate in hopes of increasing the number of patients to find answers sooner.

In many ways, research reflects clinical medical practice. Although the public believes there is a free exchange of ideas and best practice technique, typically individual practices are relatively isolated. Treatment choices may be based on geography and what the caregiver is most familiar with, rather than best practice standards, or outcome-based choices.

The advent of the Internet offers a new model, one allowing active patient and caregiver collaboration. While protecting patient rights, the SJBP will provide an open registry for all those afflicted with PA/TBI and their families. This methodology (Communities for a Cure) has been extensively used for the last 8 years for other disease states and will now be made available to the PA/TBI community. The SJBP Registry will apply the best informatics management approach, used successfully with Multiple Sclerosis and Parkinson’s disease for more than a decade at the Barrow Neurological Institute (BNI) in Phoenix. Outcomes assessment, education and other technologies will be available through the registry.

The model has three simple steps: enrollment, engagement, and repeated communication.

1. **Enrollment:** Patients are enrolled in the SJBP registry - this can occur either at the time of the acute event or afterwards. The patient or a caregiver can enroll the patient by providing information about the event, age of the patient, clinical evaluation at the time, etc. In most cases, the patient’s name is recorded, but this is not necessary. A form of communication is included (email, US mail, text messaging, phone number). In the case of the SJBP, information will also be gathered from the family members whenever possible.
2. **Engagement:** Personalized content can then be provided to the patient and their family, helping them better understand their affliction and how to get help. This differs from typical, unfiltered Internet content. Over time, the SJBP will continue to add research and services partners to the registry, similar to the Apple applications store for the iPhone.
3. **Communication:** There will be repeated communication with the participants, a relationship rather than a limited engagement. Participants will be sent questionnaires at regular intervals to find out how they are doing, and what their needs are. Communication will be personalized to particular groups within the registry to facilitate research efforts over time.

At all times, the registry will follow strict federal guidelines to maintain the patients’ rights to confidentiality and engagement. The patient ultimately controls his or her own information. As noted on the SJBP web site (<http://www.TheBrainProject.org>), the intent of this effort is to foster open collaboration for better care and research.

This will be possible through SJPB's policy of an open data and communication layer. This does not mean all information will be "open" for anyone to see, but rather methods of data entry and transfer will be clearly defined for all potential partners (an open data dictionary and messaging layer). With appropriate permissions, information will be available for research and care of the participants.

The SJPB believes practice standards should constantly evolve from best practice to outcome-based methodologies. The SJPB will begin with the best practice belief, but after further interventions and their outcomes can be studied, the results of these interventions need to be measured and evaluated. Data acquired from the community will be rigorously evaluated in near-real time to look for better methods of treatment and care.

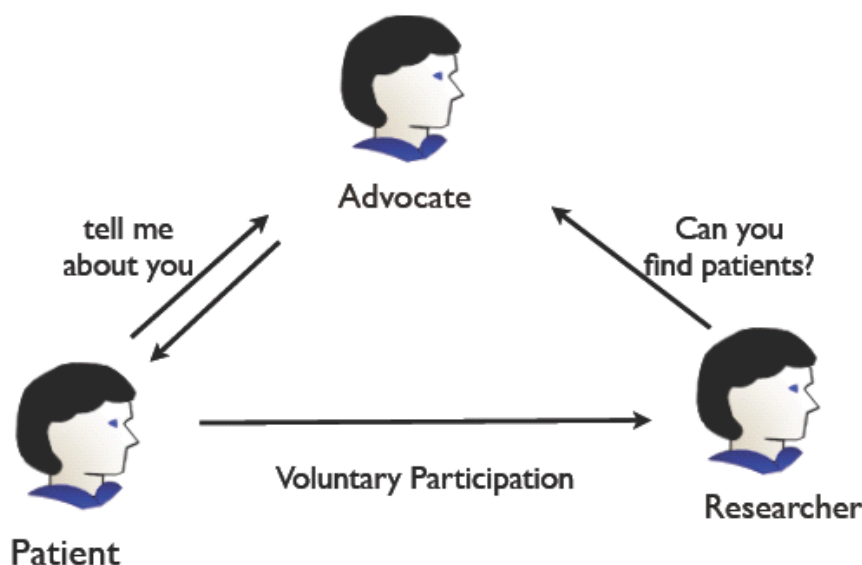
Additionally, this open standard will facilitate an information exchange throughout the continuum of care, independent of an individual hospital or care givers office practice.

The SJPB recognizes that many factors outside of the medical record are important to the well-being of the patient. Social issues, financial issues, educational barriers and access to resources are but a few of the factors that will be incorporated into the information pool. Patients care less about healthcare records, and more about well-being. The SJPB will provide the PA/TBI community an ecosystem encompassing all factors important to their well-being.

There will be three components to the SJPB Registry: 1) the core PA/TBI Ecosystem, 2) a portal to store and make the child/youth's medical records portable, and 3) the Open Source Initiative which allows participants to opt into a first-ever open source database of neuroinformatics.

The SJPB Registry will have customized entry points for patients, their families, clinicians and researchers. All of these users can enter specifically relevant data. For example, a patient or guardian may enter information about the patient's daily routine and self-reported symptoms. A healthcare provider may enter data about clinical interventions and results. A researcher may aggregate and analyze the data for new information, or may identify a novel approach to care for further research. If they desire, any or all of these groups may participate in conversations amongst themselves or one another fostering support, new personal knowledge and new clinical knowledge.

## Basic Model



**Figure 6: The integration of the data across providers, patients and locations provides a new and unique resource for addressing PA/TBI.**

### **SJBP Technology Solutions:**

#### **Registry Technology for Research Communities**

To advance research, creation of a research-specific data registry portal can be accelerated. Using the registry platform, a typical IRB can be published for data acquisition in 8-10 weeks with real time reporting of data elements. For example, Communities for a Cure currently is focused on Multiple Sclerosis (MS) and Parkinson's disease. These communities have more than 50,000 participants enrolled nationwide. With their portals, an advocacy group (currently MAPRC and NARCOMS) communicate with and collect data from their participants. This information can be used to identify subjects for study. A researcher can identify specific groups for study (for example, women of a certain age with a two-year history of MS using fewer than two medications). These participants can be invited to participate in a trial and contact the researcher directly. The community can also be contacted with a question; a recent question asking about smoking and MS received 2000 responses within 24 hours. These registries are self-reported by patient, invested in finding a cure for their own disease. Registries have been extensively validated over the last decade.

### **Registry Technology Supporting Research Databases**

Registry technology has been used at BNI for generation of research data bases. Dr. Spetzler, the director of the Barrow Neurological Institute, is using a solution for the BRAT database, large trial evaluating different treatment options for cerebral aneurysms. Web-hosted registries enable multi-institutional trials. These solutions have also been extend to Cleveland Clinic (Wingspan Trial), Hopkins, and GWU.

### **Automated Outcomes Measures**

Particularly for PA/TBI, automated outcomes measures would likely be of value. There are several outcomes measures to be advanced and leveraged for PA/TBI. One technology, ANAM4 (Automated Neuropsychological Assessment Metrics from Vista Partners, LLC, in Denver) is based on decades of public and private research and is the DoD standard for pre-deployment assessment by the U.S. military. It is used as a baseline measure for neurocognitive change they may result from injury or exposure. ANAM4 is used extensively in ABI research and clinical care related to head trauma, chemical and pharmacological exposure, disease-specific research including LUPUS and MS, environmental exposure, aging, and more. ANAM4 is available to providers through the registry and can store outcomes data for use by caregivers and clinicians.

### **Registries and Repositories for Real-Time Data Analysis**

Real-time data analysis will be facilitated through the SJBP Registry and repository technology. For example, at the BNI, Dr. Spetzler, receives updates of his trials (crossovers, complications, etc.) weekly as an email update with graphical representations of current data. Stryker funded creation of a registry/repository at BNI for low back pain, providing a common platform for back pain specialists. This platform allows patients to register and complete a history form on line. The clinical encounter is completed. The patient then receives automated pain scales to evaluate outcomes (P4P data). The BNI's Dr. Nicholas Theodore plans to extend this platform to other providers in his referral network, effectively allowing data exchange across practices. The referral network may elect integration these data elements into their own EMR via HL7 integration, or alternatively, print the data and add to their chart. In either case, this allows for a disease or health specific record to be generated across providers. Further, these data elements could easily be added to or incorporated for study.

### **Technology Supporting Education and Documentation**

Technology can deliver education and documentation, including that related to trauma related to child abuse (NAT) and related injuries from motor vehicle accidents, falls and sports injuries. The SJBP Registry will enable practitioners to register cases on line (with or without identifiers). The web portal guides the caregiver through a suggested work up (did you consider ordering this or that, incorporating related educational pieces, etc.). Online educational methodologies (e.g. Qube.com) can be tied to real-time reporting for surveillance and follow up. The practitioner can be sent a message reporting outcomes measures and enabling analysis of what measures assisted in the evaluation. A patient-centered ecosystem incorporating all aspects of the care cycle can be used for long-term study, from initial event detection to first hospitalization and on through clinical follow up and home care.

**Summary**

Many technologies should be applied to PA/TBI. Fundamental to all of them is data interoperability. The platform will enable data exchange between these future additional solutions. Key features to success are:

1. Real-time reporting
2. Messaging, allowing the community to be tied together in a relationship
3. Web hosting
4. Personalized content delivery

To dramatically change PA/TBI for patients, providers and researchers, the full power of technology must be leveraged. Data management, communications, outcomes measures and education are among the technologies enabled by the SJBP. Millions of children will benefit from this process, and hundreds of thousands of care providers will be empowered as well.

## ***Chapter 9: Nutrition after PA/TBI***

### **Current Status:**

1. Nutrition plays a role in the recovery of injured and critically ill patients.
2. There is a dearth of data on various aspects of nutrition support or diet during any phase of the pediatric brain injury continuum. For the purposes of the development of a PA/TBI Model System, we should develop some standards of care for the acute and recovery phases based on available resources and experience. In addition, there are numerous research questions to address.

### **Problems:**

1. Existing literature is sparse. Cochrane Reviews in 2006 suggested that there is likely enough good data to conclude that early feeding may improve survival and disability in adults. A few recent studies suggest (again in adults) that malnutrition or a delay in nutrition support increases length of stay and increases mortality rates.
2. The lack of adequate data for the role of nutrition in PA/TBI necessitates extrapolation from adult brain injury literature and experience, not necessarily an optimal approach.
3. There may be data from neonatal nutrition and brain development that one could consider relevant in PA/TBI, such as the value of specific types and amounts of protein or micronutrients.
4. Research questions abound:
  - a. How does nutrition support/diet in different phases influence outcomes in PA/TBI
    - i. Mortality
    - ii. Disability/final outcome include time to recovery
    - iii. Morbidity including length of stay
  - b. Nutrient delivery
    - i. How do we overcome barriers to nutrient delivery
    - ii. How do complications of PA/TBI affect nutrient delivery and how can we avoid those proactively
    - iii. What modalities can we utilize to maximize nutrient delivery
  - c. Develop an understanding of energy expenditure during different phases and types of injury to better understand calorie needs and maximize recovery while minimizing negative effects of over-nutrition.
  - d. Are there preferred fuels (macronutrients) for different phases of recovery
    - i. Is there value in high-protein diets or specialty types of protein (e.g. branch chains)
    - ii. Do different types or amounts of lipids influence recovery (e.g. fish oils, structured lipids)
    - iii. How does glucose homeostasis affect outcome and/or cause ongoing damage

- e. What role do micronutrients play in acute and long term recovery
  - i. Antioxidants (Vitamins, phytochemicals/flavanoids)
  - ii. Zinc and other metals
  - iii. Anti-inflammatory compounds
  - iv. Herbal and other complementary products

**Solutions:**

1. Without a good basis in the literature, we will be forced to develop a nutritional care delivery model based on a combination of limited adult data, extrapolation from the general pediatric nutrition literature and practices, and experiential information gleaned from expert clinicians.
2. The questions noted above should be the basis for development of multicenter clinical studies. If possible, we should overlay a nutrition component to any longitudinal studies we develop. The SJBP will employ translational research methodology for many of the topics, in particular to study the influence of nutrient types, both macro and micronutrients. The SJBP will also collaborate with neonatology colleagues to ascertain whether certain nutrition and brain development studies might be applicable and designed to answer PA/TBI related questions as well.
3. Further development of experimental models that incorporate nutritional variables is essential to unravel the complex effects of diet/nutrition on injury response and recovery.

## ***Chapter 10: Psychiatric Aspects - Intermediate Care through Adult Transitions***

### **Current Status:**

1. The prevalence of psychiatric disorder in children who have PA/TBI is high. This is a function of high rates of psychiatric disorder already present before the injury (33% - 50%) as well as high rates of new psychiatric disorder that develop after the PA/TBI.
2. There are biological, psychological, and social factors identified consistently in research studies that increase the risk for the development of new psychiatric disorders. These factors include severity of injury, family function, family psychiatric history, socioeconomic status, pre-injury personal psychiatric disorder, and pre-injury personal adaptive function.
3. When a child/youth with PA/TBI is evaluated by a child psychiatrist this generally occurs as a consultation from another professional. University medical centers generally have a child psychiatry consultation/liaison service to provide suggestions for the management of children in intermediate care or inpatient rehabilitation when behavioral or emotional problems impede treatment. It is unusual for child psychiatrists to be actively involved in discharge planning and community reintegration even in high risk patients.
4. In the outpatient setting, emotional and/or behavioral disturbances are most often recognized at school and at home. Psychologists, therapists, speech pathologists, or other professionals may be consulted first. Psychiatrists typically become involved following referral from other professionals after problems manifest.
5. Youth with PA/TBI in the process of transitioning to jobs or independent living situations seldom have a consulting or treating psychiatrist to help navigate this passage.
6. There are no prospective longitudinal controlled psychiatric studies of children with mild TBI.
7. There are no prospective longitudinal controlled psychiatric studies of preschool children with PA/TBI.

### **Problems:**

1. While the overlap of PA/TBI and psychiatric disorders is extensive, related treatment and research does not always follow because of a shortage of child psychiatrists with relevant training and experience.
2. Systematic assessment of known risk factors for the development of psychiatric disorders after PA/TBI is not conducted on a routine basis. This problem exists because of limits with regard to the resources and related expenses that would be necessary to conduct the assessment. Furthermore, if problems are identified, there is an ethical issue of providing intervention which consumes further scarce resources.
3. The involvement of child psychiatrists as consultants in intermediate care and inpatient rehabilitation is appropriate in the context of a consultation/liaison service. The absence

of child psychiatry input into discharge planning and community reintegration is problematic because this leads to a delay in diagnosing and treating predictable disturbances.

4. There tends to be little coordination of outpatient care, including psychiatric treatment, especially for children whose PA/TBI's are not severe. Parents may minimize or tolerate the problems initially because the child/youth has survived a life-threatening PA/TBI. Schools may not always have sufficient information to link the PA/TBI with the new emotional and/or behavioral disturbance.
5. The typical absence of a psychiatrist providing input regarding appropriate work or independent living plans can lead to suboptimal choices. This may be due to a poor fit between the person with a PA/TBI and characteristics of the job such as attention demands, inherent stress, required interpersonal skills, and even flexible sleep schedules in shift jobs.
6. There are no data guiding psychiatric surveillance and management of the most common cause of PA/TBI, i.e., children with mild TBI.
7. There are no data guiding psychiatric surveillance and management of pre-school children with PA/TBI.

### **Solutions:**

1. Address the supply shortage of child psychiatrists trained to manage PA/TBI.
  - a. Support existing initiatives within the American Academy of Child and Adolescent Psychiatry to improve the supply of board eligible child and adolescent psychiatrists.
  - b. Sponsor workshops and symposia on clinical and research aspects of PA/TBI at national, regional, and county conferences attended by child and adolescent psychiatrists.
  - c. Lobby for specific inclusion of PA/TBI lectures in child and adolescent residency programs.
  - d. Encourage local "area education agencies" or school-districts to identify a child and adolescent psychiatrist with interest in PA/TBI. Fund the involvement of the identified psychiatrist to consult on systems and clinical issues relevant to local needs across the PA/TBI continuum.
2. Improve the identification of children who are at high risk for development of psychiatric disorders related to PA/TBI.
  - a. Fund studies assessing the benefits and costs of routinely assessing the risk for development of psychiatric disorders in PA/TBI. If it can be shown that early assessment of risk improves outcome, then the use of limited resources can be justified by health-care institutions and insurance providers.
  - b. Foster closer relationships between psychiatrists and child psychiatrists in inpatient rehabilitation units. Encourage psychiatric input at the inpatient rehabilitation discharge planning meeting. This will require fiscal changes within institutions and buy-in from insurance companies.
3. Improve psychiatric treatment of children with PA/TBI

- a. Fund intervention studies for psychiatric disorders that develop after PA/TBI. These will include psychopharmacological studies and psychosocial studies.
4. Improve the understanding of psychiatric outcome in children with mild TBI.
  - a. Fund prospective longitudinal controlled psychiatric studies of children with mild TBI.
5. Improve the understanding of psychiatric outcome in preschool children with TBI.
  - a. Fund prospective longitudinal controlled psychiatric studies of preschool children with TBI.

## ***Chapter 11: Acute and Post-Acute Neuropsychological Recovery***

### **Current Status:**

1. The role of neuromodulatory, neuroprotective and psychopharmacological agents in promoting neuropsychological recovery has not been well researched or explored. Limited case studies, case series are in publication. However, to date there has not been systematic class I research in this area.

### **Problems:**

1. Neuropsychological recovery following PA/TBI has been a well documented problem during both acute and post acute recovery.
2. To date little is known about the role of neuromodulatory, neuroprotective and psychopharmacological agents in promoting or inhibiting neurocognitive, neurobehavioral and neuroemotional skills. In addition, the role of neuromodulatory agents and psychopharmacologic agents across the spectrum of situations including disorders of consciousness, cognitive enhancement and psychomotor recovery.
3. While much of recovery relies on rehabilitation therapies that are sophisticated instructional interventions, little is currently known about how pharmacological agents may contribute to neurobiological recovery.

### **Solutions:**

1. A network of pediatric rehabilitation/acute and post acute centers should be organized so as to carry out systematic laboratory and clinical class I and II studies on existing agents used in treatment of children following PA/TBI.
  - a. More specifically, this network should be organized to explore both existing mental health issues of mood disorder, anxiety, and related mental status changes that compromise the child/youth's recovery.
  - b. Such a network would have a coordinated informational system, data collection capability.
  - c. Also, the network would work collaboratively, raising the possible levels of enrollment and participation so as to yield adequate sample and power the findings.
  - d. Members of this network would have sufficient research experience so as to make possible class I and class II investigational design.
  - e. This network would have not only translational research experience but adequate biostatistical staffing to guide research design and analysis of results.

- f. This network would not only exist within each site of research but also exist electronically as an entity for management, recruitment and research integration.

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