

Colorado Traumatic Brain Injury Program

Report to the General Assembly

February 1, 2006

Program Overview

The Colorado Traumatic Brain Injury (TBI) Program was created by Title 26, Article 1, Part 3 of the Colorado Revised Statutes to improve the lives of Colorado residents who have survived traumatic brain injuries. This statute created the Colorado Traumatic Brain Injury Trust Fund (Trust Fund) to finance program activities, and the Colorado Traumatic Brain Injury Board to oversee the operations of the Trust Fund.

The TBI Trust Fund receives revenue from surcharges assessed for convictions of certain traffic offenses. The Trust Fund receives \$15 for each conviction of driving under the influence of alcohol (DUI) or driving while ability is impaired (DWAI), and \$10 for each conviction of speeding. Moneys in the Trust Fund pay for all program services and program administration.

By statute, approximately 65 percent of the moneys collected for the Trust Fund are used to provide services to persons with traumatic brain injuries; 30 percent are used to support research related to the treatment and understanding of traumatic brain injuries; and 5 percent are used to provide education for individuals with traumatic brain injuries and to assist educators, parents, and non-medical professionals in the identification of traumatic brain injuries so as to assist such persons in seeking proper medical intervention or treatment.

The TBI Board is located within the Colorado Department of Human Services (CDHS). Three members are designated in statute and ten members are appointed by the Governor with the consent of the Senate. Attachment A is a list of current Board members. The Board has established three ongoing committees: Services, Research, and Education.

The Board is required to submit a report on February 1st of each year to the Joint Budget Committee and to the Health and Human Services Committees of the House of Representatives and the Senate. This report must address the operations of the Trust Fund, the moneys expended, the number of individuals with traumatic brain injuries offered services, the research grants awarded and the progress on such grants, and the educational information provided pursuant to the statute.

Revenue and Expenditures

During calendar year 2005, the Trust Fund received \$1,864,404, and expended \$1,029,944.

2004 was the initial year of the TBI Program. Revenues began in January of that year, while program services began in stages throughout 2004 and progressed towards full implementation in 2005. During the first two years of the program, revenues have exceeded expenditures, however, the monthly differential between revenues and expenditures has steadily decreased as the program has progressed towards full implementation. The TBI Board plans to expend most of the current funding reserve over the next several years, and then maintain a modest fund balance in order to responsibly manage the monthly fluctuation that occurs in both revenue and expenditures.

Services

Client services began in 2004 and accelerated in 2005.

All individuals receiving assistance from the Trust Fund receive care coordination services. In addition, the Trust Fund may be used to provide a variety of other services including but not limited to:

- community residential services;
- structured day program services;
- psychological and mental health services for the individual with the traumatic brain injury and the individual's family;
- prevocational services;
- supported employment;
- companion services;
- respite care;
- occupational therapy;
- speech and language therapy;
- cognitive rehabilitation;
- physical rehabilitation; and
- one-time home modifications.

These additional services (beyond care coordination) are referred to as "purchased services."

The Trust Fund may not be used to pay for institutionalization, hospitalization, or medications.

Intake, Eligibility and Referral Services

The Department of Human Services contracts with the Brain Injury Association of Colorado (BIAC) for client intake, eligibility and referral services. BIAC is a statewide non-profit organization that provides information and referral services to the brain injury community, and is known to many brain injury survivors, family members, and professionals throughout the state. Individuals seeking services through the Trust Fund apply to the Brain Injury Association for program services. BIAC assists individuals with the application process, determines program eligibility, and refers eligible individuals to the appropriate care coordination agency for services.

In 2005, BIAC reviewed 74 applications for children's services and 301 applications for adult services. Ninety-one percent of applicants under age 21 were determined eligible for Trust Fund services, and 93 percent of adults were determined eligible for Trust Fund services.

During 2005, the Application for program services was revised based on client feedback during the first year of the program. The new Application is significantly shorter and easier to complete.

Children's Services

The Department of Human Services has an Interagency Agreement with the Colorado Department of Public Health and Environment (CDPHE) to provide care coordination services to children under age 21. The Health Care Program for Children with Special Needs within CDPHE contracts with 14 regional health departments to provide care coordination services to children with special needs throughout the state. This program is well known to schools, parents of children with special needs, and other community resources, and was a logical choice for providing care coordination services for children with traumatic brain injuries.

Children's care coordination services began July 1, 2004. In 2005, CDPHE provided care coordination services to 85 children and their families.

CDPHE has not been able to provide purchased services because it is not a covered entity under the Health Insurance Portability and Accountability Act (HIPAA). The TBI Board, Department of Human Services, and Department of Public Health and Environment worked throughout 2005 to find a way to provide purchased services while maintaining the role of the State and local health departments in providing care coordination for program clients. In November 2005, the Department of Human Services signed a contract with Denver Options, Inc. to operate the children's services program for the Trust Fund, effective January 1, 2006. Denver Options, Inc. is the Community Centered Board providing services to CDHS clients with developmental disabilities in Denver, and

provides both care coordination and purchased services to this population. For the TBI Program, Denver Options, Inc. will provide purchased services, and will subcontract with the Department of Public Health and Environment to provide care coordination services to children and their families. Now that purchased services are available to children and families, we expect the number of families seeking services through the TBI Program to increase.

Adult Services

The Department of Human Services contracts with Goodwill Industries of Colorado Springs to provide services to adults. Goodwill Industries of Colorado Springs utilizes care coordinators from all three Goodwill Industries in Colorado (Denver, Pueblo and Colorado Springs) and contracts with other organizations and individuals to provide care coordination and purchased services throughout the state.

Adult care coordination services began October 1, 2004, and purchased services began in February 2005. In 2005, Goodwill Industries provided services to 267 adults with traumatic brain injuries.

At the end of 2005, there were 104 adults on a wait list for services. Newly eligible clients are placed on a wait list when the demand for program services exceeds the funds available for services. Since each client receives services for one year, some cases are closed each month and clients at the top of the wait list begin their year of services. The average amount of time that clients are expected to be on the wait list before beginning services is currently 4-6 months.

By statute, 65% of trust funds are designated for client services, 30% for research, and 5% for education. Therefore, it is possible to have a wait list for services, even through total program expenditures may be less than the appropriation for the fiscal year.

Chart Review and Client Survey

The TBI Board arranged for a review of client records and a survey of clients, to help assess the quality and outcomes of services provided. The chart review and survey were conducted in November and December of 2005.

Chart Review – Random samples were selected from all the adults and children who received program services. Charts of 25 adults and 15 children were selected for review. Professionals with appropriate expertise reviewed the client charts to assess the quality of the care coordination plans, and the implementation of services identified in the plans.

The results of the review of children's charts were very positive. The review found that care plans are appropriate, care coordinators are creative in finding services to meet needs, there is good coordination with schools and other systems, and services are timely. The report included a few recommendations, mostly pertaining to documentation.

The results of the review of adult charts were mixed. The review found that the care plans are timely, reflect client input, include appropriate goals, and are properly signed and approved. The review also found lengthy delays in providing services after care plans were in place, with services being more timely since May of 2005 than prior to that time. Also, the review identified a number of deficiencies with documentation. The Department has been working with Goodwill Industries since the spring of 2005 to address the delays in services. These delays were first identified by clients contacting Goodwill Industries and the Department. Goodwill has taken appropriate steps to address this issue, including staffing changes, reducing its use of subcontractors to provide care coordination services, and increasing its management oversight of the program. These improvements are reflected in the audit finding that services have been more timely since May of 2005.

Client Survey – All adults who received program services, and the parents/guardians of all children who received services, were asked if they would be willing to participate in an in-depth interview about their experiences with the TBI Program. Approximately 40 percent of the adults and 40 percent of the parents/guardians agreed to participate in the survey. From these individuals, random samples of 23 adults and 13 parents/guardians were interviewed. The independent evaluators who conducted the survey noted in their report that this methodology may result in samples that have a negative bias towards the program. As a result, the findings of the survey can be generalized to the population of people who agreed to participate in the survey, but cannot be generalized to the entire population of program clients.

Adult clients and parents of children generally expressed strong support for the TBI Trust Fund Program, and are thankful that this resource is now available to help meet their needs. At the same time, however, many interviewees reported difficulties accessing services and expressed frustration with some aspects of the program.

Adult clients reported significant difficulties with the application process, however, parents of children did not share these difficulties. The report noted that this is likely due to the fact that adult clients have cognitive difficulties that parents of children with brain injuries do not have. The report recommended increased efforts to simplify the application process and to assist adults to complete the process.

Adult clients also reported lengthy delays in getting services, which corroborates the same finding from the chart review. These clients noted that the responsiveness of the care coordinators and the timeliness of services had improved in recent months, providing further evidence that Goodwill Industries has made significant progress in addressing this issue.

Both adults and parents of children reported difficulty obtaining clear written information on the types of services provided through the Trust Fund. In addition, care coordinators often told them what to do and who to contact, when these clients really needed their care coordinators to make the phone calls, accompany them to appointments, or otherwise provide more hands-on assistance.

Parents of children were especially frustrated that purchased services were not available during the first year and a half of the program.

The TBI Board and staff will be working in partnership with the Brain Injury Association of Colorado, Goodwill Industries, the Department of Public Health and Environment, and Denver Options throughout 2006 to use the results of the chart review and the client survey to improve the delivery of program services.

Research

The TBI Board has established the following three research priorities for the research program:

1. Basic Science: Mechanisms of neuroplasticity following TBI; mechanisms of cell death and rescue following TBI; and neurogenetics of TBI.
2. Clinical Science: Pharmacologic and/or non-pharmacologic interventions for the purpose of neuroprotection or the treatment of cognitive, emotional, behavioral, or neurological problems following TBI. These projects may involve either novel or existing therapeutic approaches.
3. Health Services and Outcome Research: The effects of TBI on developmental transitions across the lifespan; identification of gaps in the types and availability of healthcare services for persons with TBI; and the effects of cognitive rehabilitation on long-term outcome following TBI.

The Board awarded the first 5 research grants in the spring of 2005. Each award was for \$50,000. Grant work began in July 2005, and will continue through the summer of 2006. Research grants were awarded for the following projects:

Title: Clinical Outcome and Brain Extracellular CSF, Serum Biochemical Markers Concentrations Correlation Following Traumatic Brain Injury

Principal Investigator: Alan T. Villavicencio, M.D.

Institution: Boulder Community Hospital, Boulder, CO

Title: Reliability and Validity of a Preliminary Screening Tool for Identification of Acquired Brain Injury

Principal Investigator: Pat L. Sample, Ph.D.

Institution: Colorado State University, Fort Collins, CO

Title: Comparison of Three Early Educational Interventions Following Pediatric Concussion

Principal Investigator: Michael W. Kirkwood, Ph.D.

Institution: The Children's Hospital, Denver, CO

Title: Traumatic Brain Injury and Post Traumatic Stress Disorder: The Exploration of a Combination Syndrome

Principal Investigator: Lisa Brenner, Ph.D.

Institution: Department of Veterans Affairs Eastern Colorado Health Care System, Denver, CO

Title: The Impact of Traumatic Brain Injury on Female Endocrine Functioning

Principal Investigator: David L. Ripley, M.D.

Institution: Craig Hospital, Englewood, CO

The TBI Board issued its second Program Announcement and Solicitation of Letters of Intent on September 1, 2005. This announcement and solicitation notified the TBI research community that the Board intends to fund research grants in 2006, with funding of up to \$100,000 for each grant (\$50,000 per year for up to two years). The Board received 8 letters of intent from prospective researchers. After review, the Board invited all 8 researchers to submit full research proposals. Those proposals are due February 1, 2006. Experts from across the country will evaluate the research proposals that are submitted and recommend proposals for grant awards. Notification of research grant awards will be completed by May 1, 2006, and projects will begin in July 2006.

Education

Education efforts that began in 2004 were expanded in 2005. The Department of Human Services contracted with CTAT Training (a division of Denver Options, Inc.) to provide education and to assist the Education Committee of the Board to develop the education program. Educational efforts in 2005 include the following:

Grants for Community Education Projects – The Board established an Education Grants program in 2005. The goal of this program is to educate people throughout Colorado about traumatic brain injury by funding a variety of grassroots community education projects. The Board solicited applications in the fall of 2005 and awarded 9 grants in December. The total amount of funds awarded was \$22,155, with individual awards ranging from \$455 to \$5,000. Education grants were awarded for the following projects:

Organization: Tri-County Health Department
Amount: \$455
Geographic Area: Adams, Arapahoe and Douglas Counties
Description: Provide BrainSTARS manuals to 7 families of children with TBI

Organization: Cherry Creek School District
Amount: \$1,250
Geographic Area: Douglas County
Description: Provide mentoring, training and collaboration to the new Douglas County School District TBI Team

Organization: Colorado Division of Vocational Rehabilitation
Amount: \$1,250
Geographic Area: Statewide
Description: Provide a workshop for Vocational Rehabilitation Counselors

Organization: Craig Hospital
Amount: \$1,700
Geographic Area: Denver Metro
Description: Educate parks and recreational program directors, coaches and parents participating in the parks and recreation district programs

Organization: The Brain Trust
Amount: \$2,500
Geographic Area: Boulder County
Description: Provide presentations and written information on mild TBI to police departments throughout the county

Organization: Brain Injury Association of Colorado
Amount: \$2,500
Geographic Area: Fort Morgan/Brush, La Junta, Durango, and Fort Collins
Description: Provide Brain Injury 101 education to survivors, family members and professionals

Organization: The Children's Hospital
Amount: \$2,500
Geographic Area: Statewide
Description: Provide empirically supported information about pediatric mild TBI through The Children's Hospital website

Organization: Department of Veteran's Affairs, Eastern Colorado Health Care System
Amount: \$5,000
Geographic Area: Statewide
Description: Develop an information and teaching program and materials for brain-injured veterans

Organization: Western Slope CIRCLE Network
Amount: \$5,000
Geographic Area: Montrose, Grand Junction, Craig/Steamboat Springs
Description: Present 3 one-day workshops for survivors, family members and professionals

Training for the Colorado Division of Youth Corrections – The TBI Program sponsored training for the Division of Youth Corrections (DYC) on identification of youth who have traumatic brain injuries, and strategies for addressing their needs. The Center for Community Partnerships, within the Department of Occupational Therapy at Colorado State University, conducted a four-hour training session in each of the four DYC geographic regions (Greeley, Colorado Springs, Denver and Grand Junction). A total of 81 DYC staff attended the four training sessions, including client managers, psychologists, diagnosticians, licensed clinical social workers, and other direct care staff.

Training for the Aurora Community Mental Health Center – The Traumatic Brain Injury Advisory Board has identified access to appropriate mental health services as one of the greatest unmet needs for people with traumatic brain injury in Colorado. In response to this need, the TBI Program sponsored training and ongoing system consultation for the Aurora Community Mental Health Center. This project was envisioned as a pilot that could potentially be replicated at other Community Mental Health Centers. The project was designed to enhance the ability of the Mental Health Center to identify and to treat individuals with traumatic brain injury who need community mental health services. Under the direction of Dr. Lisa Brenner, a team of expert clinicians provided a series of training sessions to the Mental Health Center's staff. Following the training sessions, Dr. Brenner and Dr. Kristen Powell provided ongoing consultation to an adult services team, and to a children's services team, respectively. The purpose of the ongoing consultation is to assist these teams to identify and better

serve their clients who have traumatic brain injuries. Consultation with these teams will continue through the summer of 2006.

Television News Event – Channel 9 News in Denver featured the TBI Program during two hours of news broadcasts on the afternoon of March 17, 2005. The station reported on the incidence and causes of traumatic brain injury, featured an individual who had received services from the TBI Program, and invited viewers to call *Health Line 9* with questions about traumatic brain injury. A team of Board members and staff answered over 200 calls from viewers. The following day, the Brain Injury Association mailed information and applications to over 100 people who had called in during the news broadcast.

Participation at Professional Conferences and Community Events – Program staff and Board members staffed exhibit booths and spoke at a number of professional conferences and community events during 2005. The program's exhibit booth featured a display board on the TBI Program, flyers with information on the children's services, adult services, research opportunities and education efforts of the program, and a traumatic brain injury "fact sheet" from the Center for Disease Control. Information on traumatic brain injury and the TBI Program was disseminated at the following events:

- Pikes Peak Challenge (an annual fundraiser for the Brain Injury Association of Colorado) in Colorado Springs;
- Brain Injury Association of Colorado annual conference in Vail;
- TBI – Mental Health conference, sponsored by the Brain Injury Association, in Vail;
- Brain Injury Symposium, sponsored by Pueblo Community College, in Pueblo;
- Colorado Community Symposium, sponsored by CTAT Training, in Denver;
- TBI Educator's Conference, sponsored by the Colorado Department of Education, in Denver; and
- Division of Vocational Rehabilitation statewide conference in Pueblo.

Program Website – The TBI Program website at www.tbicolorado.org was expanded and enhanced in 2005. The website includes the program vision and mission, information on client services and how to access services, information on the research and education programs, Board meeting minutes, State rules, the State statute creating the Trust Fund and Board, and more.

Expectations for 2006

The Colorado Traumatic Brain Injury Program was implemented in 2004 and grew dramatically during 2005. During the past year, the Trust Fund provided services to 352 children and adults, awarded 5 research grants totaling \$250,000, awarded 9 community education grants totaling \$22,155, and enhanced the system for serving Colorado citizens with traumatic brain injuries in a variety of ways. As the program nears the end of its second year of operations, it will continue to grow and evolve to meet the needs of people with TBI and their families.

Children's Services – Beginning in January 2006, the Trust Fund will provide a wide variety of purchased services to children and families. These services will be managed by Denver Options, Inc. and provided by a variety of service providers throughout the state. With the addition of purchased services for children, the client services component of the TBI Program will be fully implemented. We expect the number of children and families receiving services to increase to its capacity by mid-2006.

Adult Services – The TBI Board expects the strong demand for adult services to continue, and for the program to continue to provide care coordination and purchased services to the maximum number of adults possible within the program's budget. Staff will monitor the wait list and advise the Board on any programmatic and/or policy changes that may be needed if the wait list grows to a point where entry into services is not timely.

Evaluation of Client Services – The TBI Board has arranged for an evaluation to be conducted of the client services program in 2006. The evaluation will include in-depth interviews with clients, a written client survey, chart reviews, interviews with contractor staff and service providers, and review of other contractor documents.

Research Grants – Work on the 5 research grants awarded in 2005 will conclude in the summer of 2006. The results of these research projects will be reported on the program website. The TBI Board plans to award up to 8 new research grants in May 2006. Work on those grants will begin in July 2006 and will continue for up to two years. The Board will solicit proposals for the next funding cycle in the fall of 2006.

Education Grants – Work on the 9 community education grants awarded in December of 2005 will be completed in June of 2006. The results of these education projects will be reported on the program website. The TBI Board plans to expand the education grants program in 2006 to fund a larger number of projects and to consider funding some projects that are larger in size and scope.

The Board will solicit proposals for the next funding cycle in the spring of 2006, and projects will begin in the summer of 2006.

Educational Seminars – The TBI Program will sponsor a series of monthly seminars on traumatic brain injury during the first 6 months of 2006. Seminars are designed to address the unique needs of TBI survivors, family members, educators, and professionals. The program will use feedback from these initial seminars to plan future seminars.

Program Administration

The TBI program is administered by the Department of Human Services, Office of Behavioral Health and Housing. CDHS staff work closely with the TBI Board and perform the following functions for the program:

- financial management – staff monitor Trust Fund revenues, pay invoices, track expenditures, prepare and update the program budget, and report revenues and expenditures to the Board monthly.
- policy development – staff research policy options and develop draft policies for Board consideration.
- program development and implementation – staff design, implement and modify the Trust Fund program based on Board policies and decisions.
- contract management – staff write requests for proposals, conduct competitive bid processes, and develop and manage contracts with vendors.
- program monitoring – staff perform monitoring activities to determine program performance and contractor compliance with contract requirements.
- administrative support – staff provide support to the Board and its committees including scheduling meetings, preparing agendas, taking and transcribing minutes, photocopying, records maintenance, and other administrative functions.
- web site maintenance – staff develop and maintain the program web site.
- public assistance and information – staff assist clients and their families, health care professionals and service providers, State and local agencies, and other stakeholders by answering questions, providing information, resolving problems, and distributing materials about program activities.

- reporting – staff report to the Board on program activities, accomplishments, challenges and opportunities for improvement, and develop an annual report for the General Assembly.
- marketing and public relations – staff represent and increase the awareness of the TBI program at public and professional meetings, conferences, trainings, and other forums.

Additional Information

For additional information on the Traumatic Brain Injury Program, please visit the program website at www.tbicolorado.org or contact Bill Bush, TBI Program Director, at 303-866-7477, or by email at bill.bush@state.co.us.

Attachment A

Colorado Traumatic Brain Injury Board Members

David Arciniegas, MD
University of Colorado Health Sciences Center
Department of Psychiatry
4200 East 9th Avenue
Campus Box C268-68
Denver, CO 80262

Judy Dettmer, Chairperson
Colorado State University
Center for Community Partnerships
300 OT Building
Fort Collins, CO 80523

Jeanne Dise-Lewis, Ph.D
The Children's Hospital
1056 East 19th Avenue, B285
Denver, CO 80218

Melissa Francis
Colorado Neurological Institute
701 E. Hampden Avenue, Suite 330
Englewood, CO 80113

Joy Henika
341 Fox Lane
Superior, CO 80027

Christine Highnam
Colorado Department of Human Services
Supportive Housing & Homeless Programs
4020 South Newton
Denver, CO 80236

Kenny Hosack, M.A.
Craig Hospital
3425 Clarkson Street
Englewood, CO 80113

Pam Law, Ph.D.
P.O. Box 350415
Westminster, CO 80031

Stewart Levy, M.D.
Intermountain Neurosurgery
4101 West Conejos Place, Suite 225
Denver, CO 80204

Susan Parker-Singler
REM Colorado, Inc.
4815 List Drive, Suite 111
Colorado Springs, CO 80919

Kathy Rohan-Hague
3650 Utica Street, #7
Denver, CO 80212

Peggy Spaulding
Brain Injury Association of Colorado
4200 West Conejos Place, #524
Denver, CO 80204

Kathy Watters
Colorado Department of Public Health & Environment
Children & Youth with Special Health Care Needs Section
4300 Cherry Creek Drive South
Denver, CO 80246