

Evaluating State Traumatic Brain Injury Trust Fund Legislation: Some Questions to Consider

A number of States have established trust funds to finance traumatic brain injury (TBI) services and supports. Some States are actively pursuing and others are considering TBI trust fund legislation. A number of important issues should be carefully considered prior to committing to the establishment of a TBI trust fund. Particularly important is an awareness of potential negative implications that might arise from the establishment of a trust fund. For example, would a TBI-only trust fund alienate key stakeholders (e.g., cross-disability coalitions) whose support will be needed for other initiatives or would a TBI trust fund limit State appropriations to programs that serve individuals with TBI and their families?

This policy brief presents questions TBI stakeholders should address when considering whether to pursue State trust fund legislation or when developing and evaluating proposals. Questions have been organized into five categories: 1) Decision Process; 2) Financing; 3) Administration; 4) Functions; and, 5) Oversight. Decision Process includes questions related to organization, coalitions, priorities, and responsibility. The section on Financing addresses matters related to securing and sustaining financial support to meet trust fund objectives. Administration addresses issues associated with establishing and operating a program that will ensure excellent customer service and efficient use of resources. The fourth section, Functions, should help identify the kinds of services and supports a fund might finance. The final section raises the important issue of oversight—what oversight mechanisms should be established to ensure solvency and that resources are used to meet the needs of individuals with TBI and their families?

Decision Process

1. What stakeholders (e.g., government, cross-disability organizations, individuals, and community service providers) would be involved in evaluating the feasibility of pursuing a trust fund?
2. How and by whom would these stakeholders be identified?
3. How would decisions be reached (e.g., consensus agreement)?
4. To whom would the stakeholders report or provide recommendations?
5. How would the public policy objectives of a trust fund be identified and prioritized?
6. What information/data would be used to evaluate the feasibility of developing a trust fund?
7. Would a TBI trust fund alienate some stakeholders that may be helpful in pursuing other systems changes? If yes, how would this issue be addressed? If no, how could broader stakeholders help advance a trust fund proposal?

Financing

1. What would be the source of revenue (e.g., traffic fines, driving under the influence, State income tax, vehicle license charge) for the trust fund?
2. Would the trust fund be able to accept private contributions?
3. Would the funding source(s) be sufficient to meet needs?

4. How stable/predictable are the funding sources (i.e., are they tied to a sector of the economy that is subject to fluctuation)?
5. Would contributions to the trust fund be time limited?
6. Would the trust fund require periodic reauthorization by the State legislature?
7. How would trust fund solvency be reviewed/addressed to ensure services and supports are not cut and that individual and/or family needs continue to be met?
8. Would a trust fund overtly or covertly result in resources being diverted away from other TBI/disability programs?

Administration

1. If funded from fines, how would fines be assessed and collected? Would the contribution to the trust fund be a required percentage of a certain class of fines or would it be at a court's discretion? If the latter, how would court officers be trained/educated about their role in assessing/collecting penalties for the trust fund?
2. How would the trust fund allocate resources or fund services? Would the trust fund make an annual contribution to a given State agency or would individuals apply directly to the trust fund for assistance? Would the trust fund reimburse approved service providers for costs? How would the reimbursement schedule be determined and adjusted?
3. How would eligibility be determined?
4. Would the fund be restricted to a specific age or disability group?
5. Would the application process be cumbersome?
6. What appeals mechanism would be available to adjudicate disputed claims?
7. What would be the annual administrative costs of the trust fund and would these costs be paid from the trust fund?
8. Would the trust fund be administered through an existing program or a new program?
9. What training, technical assistance, education and outreach would be available to individuals, families, advocates, service providers, and other stakeholders who would seek to access the trust fund?
10. Would the trust fund operate in a person-centered or person-directed fashion?
11. Would the trust fund operate in a manner to meet the unique needs of diverse populations?
12. Could the trust fund be reprogrammed to provide/finance other State services? If yes, what authority (e.g., approval of the Governor, agency administrator, trust fund advisory board, or State legislature) is required?

Functions

1. Would the trust fund support only TBI services and supports, any services and supports needed by individuals with TBI?
2. What is the purpose of the proposed State trust fund? For example, would the trust fund cover hospital expenses for the uninsured, medical rehabilitation, durable medical equipment, cognitive rehabilitation, employment services, housing assistance, transportation assistance, assistive technology, respite care, personal attendant services, an array of services that individuals and families could choose from depending upon need, support of a State surveillance system, or prevention and public awareness?
3. Would the trust fund finance the most needed services, as identified by individuals with TBI, families, and service providers?

4. What percentage of the State's population of individuals with TBI and their families would receive assistance from the trust fund? Where would those not eligible for trust fund assistance access/finance services?

Oversight

1. Would the trust fund have an independent advisory board that includes TBI stakeholders, including individuals with TBI, families, advocacy organizations and service providers?
2. What would be the relationship between the trust fund advisory board and the trust fund? Would the trust fund's administrator be obligated to listen to/implement the recommendations of the advisory board?
3. How would members of a trust fund advisory board be selected/appointed, and for what length of service?
4. What entity will be responsible for auditing the trust fund?
5. What mechanism will be established to evaluate the effectiveness of the trust fund in meeting the needs of individuals with TBI and their families?

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You may also wish to contact the Brain Injury Association of America at (703) 236-6000 or visit www.biausa.org or the National Association of State Head Injury Administrators at (301) 320-4331 or visit www.nashia.org.