

TBI TRUST FUND WEBCAST QUESTIONS

Responses are from Bill Ditto from New Jersey, Kristen Vincent from Georgia, Robert Walker from Kentucky, and Anne King, NASHIA moderator.

(1) In Georgia are the 5 agency representatives ex-officio members and can they vote the same way as the members appointed by the Governor?

KRISTEN: The 5 agency representatives are full members of the Commission with all voting privileges. They are from: Dept. of Community Health (Medicaid), Dept. of Labor (DRS), Dept. of Human Resources (Public Health), Dept. of Public Safety, and Dept. of Education.

(2) Bill - how did you convince legislators that the fee should be with motor vehicle registrations since 44% of brain injuries are related to motor vehicle accidents?

BILL: That's an interesting question. I'm not sure I can answer this. I would have to go back to the Brain Injury Association to get the lowdown on this. They were actually the group that came up with the idea of the motor vehicle surcharge as a mechanism for paying for this. As I said a few minutes ago, originally the arrangement for this wasn't going to be a surcharge - it was going to be an affirmative checkoff on the registration and that probably ties more to the motor vehicle injury arising from motor vehicle accidents. To tell you the truth, the legislature didn't really, during the very brief hearings they conducted, seem to have an issue with the fact that that's where the money

was coming from. We could check with Barbara Geiger Parker, our Executive Director of the Brain Injury Association of New Jersey and find out if there was more history to that for you. I'm not sure our motor vehicle accident level was higher than any other state. I'm sure we have just as many from other sources. That's a good question, actually.

ROBERT: At least in Kentucky we're making that argument that D.U.I. causes brain injury and it makes sense to go with that source for that revenue.

KRISTEN: We did that in Georgia as well.

(3) What are the pro's/con's to using infractions or penalties to pay for this fund vs. a less punitive approach, i.e., a registration fee that is annual?

ROBERT: One other policy aspect to that. We've had some discussion on our board about this and I'm one of the sole voices, some others also share this. When we try to get our funds from sources like D.U.I. and traffic offenses, we are in many instances taking money again from some individuals who are recipients as well since persons with brain injuries may be at added risk for committing many of the violations that result in court fees. So, you know, it poses a little bit of an ethical quandary in regard to going through the people who have brain injury and whether that's a good source to be hitting up for money. I don't know. I have some mixed feelings about it. There is great resistance among court clerks to tagging additional fees onto court fees for violations. In KY, the door is largely shut to any increases of this mechanism, so it poses a limit on

funding growth. This source of revenue might be viewed as a good starting point for funding, but not as an ideal or complete source. The NJ fund derived from auto registration fees seems inherently more benign to me than fees attached to court costs. No one of these is sufficient, however, and a mix of sources seems wiser in the long run.

KRISTEN: I think a registration fee is preferable to a penalty or similar fee/fine. In Georgia we collect a 10% surcharge on DUI fines. We have problems with judges not imposing the fee, court clerks forgetting to remit the fee, and defendants who are unable to pay the fee. As a result, we do not get all of the money we should be getting. A flat fee on a vehicle registration, or similar setup, would avoid these problems and provide a reliable revenue source.

(4) Kristin - Please talk about how you created your Commission and that it was not self serving for those on the commission - thank you.

KRISTEN: Our legislation specifies the makeup of the Commission: 10 members appointed by the Governor, and 5 members appointed by 5 state agencies (see list of agencies above). The legislation requires that 7 of the 10 people appointed by the Governor be people with brain or spinal injuries, or their family members. This ensures that at least half of the Commission is made up of people who have sustained the injuries and know the issues and need for services. It also ensures that there are only a few slots remaining for other people, i.e. services providers, etc.

We have had two issues that relate to possible conflict of interest. The first involved a Commission member who has a spinal cord injury, and who wanted to apply for a Trust Fund distribution. We spent a great deal of time researching and discussing whether and how to provide distributions to Commission members with injuries, to avoid the appearance of a conflict of interest. We finally develop policies that allow for distributions to members with injuries, but that ensure proper checks and balances, and provide full disclosure to the public. So far, we have had only one Commission member apply for a distribution.

The second issue involved a Commission member who is a service provider, whose hospital submitted a large number of applications to the Trust Fund. It created a great deal of controversy and resulted in policy revisions to better regulate applications coming in from service providers.

We would be happy to provide a copy of our Distribution Policies upon request.

BILL: If I might just add to that, it's one of the reasons why in New Jersey we did not use the full advisory council for the administration and decision making functions for the fund. We set up in the regulations a separate review panel. One of our requirements for the review panel is that you cannot be a provider of service or potentially benefit from the fund and sit on it. And we actually selected very carefully the seven seats we would have on this. We have a

neuropsychologist who is sitting on that review committee with us and basically the agreement we have with her is that, if any cases come to the attention of staff that she would be deriving financial benefit from, then she is asked to excuse herself from the room during the discussion of that application.

(5) From WI: Where do Kentucky's funds come from? I missed that.

ROBERT: It is the court costs on D.U.I. fines and some other traffic violations. I think there are five different charges that generate a court charge. We're bundled in with several other entities that get some portion of the court costs on processing the fines. And we're one segment of it. We have not had difficulty collecting it since the early days when there was a bit of a rub with that but the administrative office of the courts took care of that and it's been pretty smooth since then.

(6) Can your Governors take the funds from these dedicated trust funds?

BILL: Our Attorney General's office has issued an opinion that says that any money collected through a state program is fair game for both the legislature and the Governor. We were advised that no funds, no matter how it is constructed or written up in statute, is protected from raiding at the discretion of the Governor and the legislature. So that's the bottom line in New Jersey.

ROBERT: Yes. Any governor or legislator can "raid" any fund source that they have created.

KRISTEN: In Georgia, the public voted on a referendum to create the Trust Fund, resulting in a constitutional amendment that specifies that the money in the Trust Fund must be used to help people with TBI and SCI pay for the costs of their care and rehab. This prevents the Governor or legislature from raiding the Trust Fund and using the funds for other purposes. Conceivably, the Governor or legislature could take the money from the Trust Fund, but they would have to use it for services for people with TBI and SCI. So far, we have not had any serious threats to the Trust Fund.

(7) Some feel that dedicated funding streams only perpetuate divided service systems and that it is better to develop more comprehensive systems that INCLUDE folks with TBI. What does a dedicated Trust Fund provide that might not be provided under a more general program such as Cash and Counseling?

ROBERT: Interesting point. I disagree, however. We have all known that there are individuals who have brain injuries who have been involved in numerous disability programs and mental health programs and substance abuse programs, but they have been a hidden entity and their invisibility as a distinct group needing focused interventions and services has been a major problem. By creating designated funding and designated programs we put brain injury on the policy radar screen, we begin to raise the consciousness of the Human Services provider community at large, policymakers, governors, legislators, etc., and we create a fund that can be

identified and targeted for growth. There are a whole group of people out here with specialized service needs that otherwise would probably never be addressed. That's what the history suggests to me. I appreciate the notion when you create a special entity like that you create a target for people, but I think the history of most other services is that until you get them on the radar map and start looking at some focused services and focused budgets around that, you come out a loser.

KRISTEN: In Georgia, we have developed extensive state systems for people with other disabilities, but have few services for people with TBI and SCI. As a result, the Georgia Trust Fund is filling a sizable gap in funding for services. Our Advisory Board also recognizes the particular needs of people with TBI and the need for specialized services and training for service providers. That being said, we do collaborate with other disability organizations to advocate for services and systems that provide for all people with disabilities, when appropriate.

BILL: I would just respond very briefly to say that, you know, the question is a provocative one and a good one. I said earlier we have really never done anything in terms of funding folks with adult onset disabilities in this country. There are very specific funding streams for folks with developmental disabilities and mental health and substance abuse. We've never enjoyed that. Part of this question speaks to the whole reason for my Division of Disability Services in New Jersey. I have to agree with my fellow panelists that we have to start somewhere. This is a major public health problem.

Things like cash and counseling address a generic population of people but they too have restrictions. You have to be at a certain income level, at a certain asset level. They're not inclusive. That is not an inclusive program. And so once again, and the other thing is, it is politically in some respects easier to sell something like brain injury given its enormous public health impact in terms of getting support behind it. I say every bit of money we add to the bucket, no matter how it gets into that bucket, is helping us in the long run.

(8) Bill - who paid for the initial case management evaluation before trust fund dollars were used?

BILL: The case management evaluation is part of the overall case management function paid for by the trust fund.

(9) Can we get copies of each of these states legislation and accompanying materials that explain their states trust fund?

ROBERT: Kentucky - See <http://lrc.ky.gov/KRS/211-00/CHAPTER.HTM> and examine KRS 211.470 – 211.478 for the statute.

BILL: New Jersey - PL 2001, Chapter 332, Section 5 can be viewed at www.njleg.state.nj.us/2000/bills/AL01/332

KRISTEN: Georgia – Official Code of Georgia, Annotated: Title 15, Chapter 21, Section 140 -152; Georgia State Constitution: Article III, Section IX, Paragraph VI (k) Information on the 1998 constitutional amendment can be found on the Carl Vincent Institute of Government webpage dedicated to the Constitution at www.cviog.uga.edu/Projects/gainfo/gacon.htm.

ANNE: NASHIA will be publishing results of conversations with all states that have Trust Fund programs and have provided information. There will be a

listserv announcement when this information becomes available. If there is any information you need which you can't find at these websites, or if the NASHIA document does not address to your satisfaction, you can contact the states directly for this information. They will be happy to help.

(10) Have you used trust fund dollars to pay for legal costs - paying for neuropsych eval to prove brain injury and related deficits to help make the case?

ROBERT: In KY no funds have been allocated for legal representation.

Program restrictions prohibit the use of funds for attorney fees, court costs, or fines. Funds have been allocated to assist with SSI applications, but not as part of a defense in criminal or civil cases.

KRISTEN: In Georgia, we do not pay for legal costs. We have paid for neuropsych evals in only a few cases. We also have a medical advisory board that consists of experts in TBI who will consult and review medical documentation to determine eligibility when it is not clear.

BILL: We will pay for a neuropsych eval for purposes of establishing eligibility. We can use trust fund dollars to pay for such things as establishing guardianship to manage finances – that sort of thing. We won't assist clients in litigation.

(11) From listening it doesn't sound like any of you provide grants for neurological injury for services in your community or research on neurological injury--am I right? I think my state's trust fund (VA) is in the small percentage of those who do not provide direct consumer funds..

BILL: I think you're right. Ours does not cover those kinds of things. Probably under our public education awareness and outreach we might be able to consider doing something like that, but that was not the purpose for the fund. We do, in New Jersey now have a separate fund for traumatic brain injury research which is housed in our Department of Health and Senior Services and it is funded by some sort of percentage charge on D.W.I. and that is concentrated on research only. But it isn't the same thing as the TBI fund.

KRISTEN: I think what that says is states are acknowledging that certainly there is a need for research but there is greater need for direct services for people, and other entities are doing research in brain injury. Our legislation does allow us to provide some funding for research, however, to date we have not done so because we are focused on distributing funds to individuals.

ROBERT: No funds for research other than specific functions directly related to the mission of the TBI Trust fund. For example, the Board collects trauma data from hospital discharges and has funded a household survey of head injury in the state. The Board does not provide grants on neuro injury or for other research.

ANNE: South Dakota passed legislation in 2004 establishing a fund (not called a Trust Fund) the revenue from which will support research as well as rehabilitation services and the development of an advisory council. The Florida program uses a portion of its revenue to support research. And there are other states that use revenues to support programs or special projects as opposed to individual consumer needs. Information about these programs will be available in the NASHIA publication. There does seem to be a trend

towards using trust fund monies to support individual consumers. This may be part of the trend in the disability field in general towards person centered approaches, dollars following consumers, etc. States should look at their needs first before deciding which approach to use.

(12) Do your TBI Waiver programs connect in any way with your trust fund?

ROBERT: The staff to the TBI Board also provide staffing assistance to the Waiver program. However, there is no direct connection between the board and the waiver program per se.

KRISTEN: In Georgia, there is no formal connection between the Trust Fund and the waiver program (in Georgia, we do not have a TBI-specific waiver, but people with TBI are eligible for our Independent Care waiver program). We do ask all Trust Fund applicants if they receive the waiver, or are they on the waiting list. If they are not signed up for the waiver, and it would be appropriate for them, we encourage them to sign up while they are applying to the Trust Fund.

BILL: Our Division administers both the waiver and the trust fund. Our staff maintains a central data base; so when someone applies for services, we can steer them towards the waiver or towards the trust fund – whichever is more appropriate to meet their individual needs and is most cost efficient in the long run.

(13) Are the other Trust Funds working with volunteers who have received funds from the Trust Fund, in an effort to promote reciprocity?

KRISTEN: In Georgia, we are planning to promote reciprocity among our Trust Fund recipients. We have encountered many recipients who are so thankful for their distribution, and want to give something back or help someone else. As a result, we are planning to recruit Trust Fund recipients to serve as volunteers who will help someone fill out a Trust Fund application, give a talk about the Trust Fund in their community, or assist in some other way. We believe this will provide another opportunity for people with TBI and SCI to contribute to their community in meaningful ways and to promote a communal sense of “stewardship” for the Trust Fund.

BILL: We have become very involved in the lives of our trust fund recipients; and the personal testimonies they have shared with us tell us that they are very grateful for the trust fund. So we would also encourage some sort of reciprocity as well.

(14) Can you identify other examples of revenue sources for trust funds?

ROBERT: These are likely to be unique to your state and the economic environment there. Possible sources: Auto registration fee add-ons, add-on property tax on ATVs, add-on property tax on motorcycles.

ANNE: Discussions have not occurred with every state that has a Trust Fund yet, but here are some additional sources that I have learned about in my discussions thus far: a fee on the cost of reinstating a driver’s license following revocation, a percent of fees on felony and misdemeanor convictions, a surcharge on the cost of temporary license plates, a surcharge on motorcycle specialty tags, boating under the influence, violations of fishing and gaming

laws. Some states also have a provision that allows them to add any monies they may acquire from grants and private contributions to the trust fund.