

TBI Trust Funds: Issues in Startup and Management

May 19, 2005

ANNE KING: Hello, everyone and welcome to our webcast on TBI Trust Funds: Issues in Startup and Management. I'm Anne King from the National Association of State Head Injury Administrators and I will be moderating this webcast, which is an effort of the TBI Technical Assistance Center at NASHIA. We would like to thank Jane Martin Heppel, Director of the TBI Federal Program and the Maternal and Child Health Bureau for their support of this effort. We would also like to thank our wonderful technical support people here at the Center for Advancement in Distance Education at the University of Illinois-Chicago for broadcasting this presentation.

Over the past few months I've spoken with Trust Fund program administrators across the United States and have learned that there is quite a variety in the way trust fund programs are structured and the way that revenue is used. We intend to compile the information that I have gathered from these conversations and will publish the results and make them available to you sometime this summer.

For our webcast today we've invited representatives from three states whose trust fund programs all provide support to individual consumers but whose program structure and management issues may be very different. Joining me today are Bill Ditto, Director of the Division of Disability Services in New Jersey, Kristen Vincent, Executive Director of the

Brain and Spinal Injury Trust Fund Commission in Georgia, and Robert Walker, Assistant Professor in the Department of Psychiatry and Center on Drug and Alcohol Research at the University of Kentucky. Robert is also a member of the Trust Fund Board of Directors in Kentucky.

Those of you in our viewing audience are free to send us a question at any time during this broadcast. However, we will probably wait until the end of the broadcast to address these questions. Simply type your question in the white message window on the right of the interface, select "questions for speaker" from the dropdown menu and hit "send". Please include your state or organization in your message so that we know where you are participating from. The questions will be relayed onto the speakers. We will be compiling the questions that we don't have an opportunity to address at the end of this webcast and they will be attached to the archived version of this webcast today.

On the left of the interface is the video window. You can adjust the volume of the audio using the volume control slider which you can access by clicking on the loudspeaker icon. Those of you who selected accessibility features when you registered will see text captioning underneath the video window. At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation. Please take a couple of minutes to do so. Your responses will help us plan future broadcasts in this series and improve our technical support.

For purposes of discussion today we'll define a trust fund as a non-reverting, interest-bearing account set up through legislation for a specific purpose and funded by fees, fines, assessment or surcharges.

In order to give our audience a frame of reference I believe we'll begin today by asking each one of our panelists who administers your program, what your revenue source is, and also how long your program has been in operation. And then we'll launch into a discussion about the legislative process. Would you like to begin, Bill?

WILLIAM DITTO: Sure, thanks very much. Anne. New Jersey has had trust fund legislation in place since 2001 and we actually implemented the program fully in July of 2004. Our fund comes from a surcharge on motor vehicle registrations in the State of New Jersey and it generates approximately \$3.4 million dollars a year which goes into a non-lapsing interest bearing revolving fund account administered by the state. My agency, the Division of Disability Services, is the administering agency for the fund, and we are responsible for all aspects of administration of the fund in New Jersey.

ANNE KING: Thank you. And Kristen?

KRISTEN VINCENT: Thanks, Anne. The Brain and Spinal Injury Trust Fund in the State of Georgia is administered by the Brain and Spinal Injury Trust Fund Commission which is an attached agency to the Department of Human Resources but is its own authority and answers directly to the Governor of Georgia. Our revenue source is a 10% surcharge on

D.U.I. fines and our average revenue has been about \$2.2 million dollars a year. Our legislation was passed in 1998. We actually began operation in 2002.

ANNE KING: And Robert?

ROBERT WALKER: In Kentucky we started about that same time frame in 2000 starting (earlier) with legislation that was introduced by advocates, structured very similarly in the sense that our revenue base comes from court costs levied on DUI and some other traffic offenses. That goes into a fund which is administered by a division or a unit within our Department for Mental Health, Substance Abuse, and Mental Retardation. Within that department a special unit was created called the brain injury services unit. That entity is responsible for overseeing the disbursement of funds. We, however - somewhat differently from the other two states – actually contract with another entity to administer the fund to eligible persons so the state is not directly administering the fund to the community or to resources. I've been on board since the beginning of it and look forward to having discussion with everyone today about how we progressed.

ANNE KING: Thank you. Okay, we going to back up a bit and talk about legislation. And let's start with Bill. Describe the advocacy efforts leading to legislation - whether legislation was passed the first time and some of those kinds of things.

WILLIAM DITTO: Actually, in New Jersey we have a very strong Brain Injury Association affiliate chapter and they were really the primary spearhead behind the development of

the legislation. We worked inside state government to prepare the Governor and the executive branch of government to understand the importance of having a fund of this sort available; and so working really together as a team with external advocacy and internal advocacy the legislation passed the first time it was introduced and was quickly signed into law by the Governor. So, I have to say in New Jersey we were fortunate to have a strong advocacy effort on the outside, a lot of agreement on the inside of government about the importance of the fund, and it led to a very successful conclusion.

ANNE KING: Great. And Kristen, do you have something you would like to share about your legislation?

KRISTEN VINCENT: I do. I just wanted to be able to sort of emphasize the importance of grass roots efforts in getting any kind of trust fund legislation passed. As Bill talked about, the people at the local level either through the Brain Injury Association or just throughout the state were really key in getting the Brain and Spinal Injury Trust Fund started in the State of Georgia. And just to sort of illustrate how that worked, the legislation was first introduced in 1997. It was not passed that year - not because of problems or concerns about the trust fund itself - but more because of politics between different legislators. And so that sort of gave -- sent some additional need to get the legislation passed in 1998. And at the point at which it was about to be sort of hung up again in 1998, the Speaker of our House, Tom Murphy at the time, said that he received the most phone calls, the most faxes, the most letters on this piece of legislation that he had ever received on any piece of legislation in his history. Many of you may know that the Speaker of our House in

Georgia served for many, many years, actually many decades. And later on, our legislation was taken to the voters of Georgia to be passed as a referendum and the referendum passed with the highest amount of "yea" votes of any referendum in Georgia history. And so what that told us was that the people at the local level are really the ones who will make sure the legislation gets passed and any way you can involve them - that will be your key to success.

ANNE KING: Georgia is unique in having a statewide referendum. Do you know why it was put to the public vote?

KRISTEN VINCENT: It's a particular thing with Georgia law that anything -- any new law that is going to have to deal with money, specifically additional fines or fees -- has to be put towards the voters in a referendum. And so, again, the legislation was passed in the legislative session in 1998 but then taken to the voters during the general election in November of 1998 and, again, that then gave the state the authority to set aside these special fines and fees for this particular trust fund and allowed that money then to not have to go through the traditional state process of appropriating funds because it's not funds that are coming out of the state budget.

ANNE KING: OK. Robert, was there anything in legislation in Kentucky you would like to share?

ROBERT WALKER: I think so, Anne. One of the things that happened in Kentucky is that our legislation grew out of the wake of another major state effort. The state was launching a plan for a Community-Based Waiver in the Medicaid program to serve some individuals with brain injuries. That kind of elevated the expectations for services among a wide variety of consumers and family members and created maybe a heightened awareness of the service need. Now, into that, I would very much agree with what Kristen said. We have a very strong Brain Injury Association in Kentucky and we have some advocates there who are very persistent and very dogged in addressing legislators. We identified some legislators who had family members who also had been affected by brain injury. So their advocacy within the General Assembly was both personal as well as looking at state policy as a whole. We had a pretty smooth sail if you look at the economic circumstances at that time for getting our legislation passed and we have continued to work closely with the legislature in Kentucky.

ANNE KING: For each of you, does your legislation prescribe how funds will be used? Does it safeguard funds in any way for legislation to be prescriptive or does it limit you too much and how detailed should the legislative definitions of brain injury and services be? Like to start (referring to Bill)?

WILLIAM DITTO: Sure. I think that it's important to have a legislative framework or statutory framework in order to assure that the money gets used in the way in which the legislature and the Governor and, in fact, the people have wanted it to work. So I think there is some benefit to having some parameters within the legislation. But by the same

token, in any statute you want to have the flexibility to be able to change things over time. If you find something is not working, if you find something is problematic, you want to be able to go back in and make a change. Sometimes when a statute is very prescriptive you end up with a situation where it is going to take a lot of political will and a lot of effort and a lot of time to actually make those changes. So generally I would say, on balance, you want broad legislation and then you're going to define in regulation, in policy and subsequent sort of bureaucratic activities how that actually works out. But I will say that, in the case of New Jersey, the fact that the legislature set a lifetime maximum in terms of expenditure and also an annual cap for expenditures per individual under the program has been helpful to us in administering the fund.

ANNE KING: OK. Kristen?

KRISTEN VINCENT: I would agree with what Bill says. I do think it's most important that you not get too specific and too detailed in your legislation; because, again, if for some reason on down the line you feel the need to change a specific policy, if it's set in your legislation, then you are going to have to go through legislative changes which can be quite time consuming. To give you sort of a specific example, the legislation for Georgia is fairly broad. What it says is that the trust fund is to be used to provide for the costs of care and rehabilitative services for people with brain and spinal cord injuries. So that is clearly very broad language and it is left up to the Commission to sort of define what care and rehabilitative services are and how those funds will be distributed. And that, too, is provided for by our legislation, which says that the responsibilities of the Commission are

first to adopt rules and regulations as to how the trust fund is administered and second, to accept applications for disbursement. And so that again leaves the authority and decision making process to the Commission which allows them to then continue to be responsive and flexible depending upon the needs of the people in your state.

ROBERT WALKER: General agreement with a couple of slight variations here. I think one of the things that we faced in Kentucky, that the statute gave us some important help with, is that we found through the statute a way of, perhaps, curtailing people's expectation that this was an entitlement program. Really, it's not an entitlement program and we've had to rely upon some statutory authority to set some boundaries on exactly what the scope of services and available goods would be under this program. Two elements that we have found particularly useful: one, the statute mandated the trust fund board to assess services and availability within the state. That gave us a planning function that was important to roll in here and we also - as Kristen was saying here - we had the authority - and I think Bill was saying the same - to generate regulations so we could change some of the core structure and build more legal support for our actions. Those two ingredients were really important.

ANNE KING: Thank you. Let's move on into talking about how the program actually gets started. What are the mechanics of getting the fund set up and the money coming in? And does the money have to be appropriated in order for the program to have spending authority? You want to start with that, Bill?

WILLIAM DITTO: Kristen, why don't we let you start with that.

KRISTEN VINCENT: I was not actually around at the time that they were getting the trust fund started. That happened before my time. But my understanding is that the trust fund money goes directly into a treasury account that is set up for us that is obviously managed by the State of Georgia. So clearly they needed to get that set up and then do some education and training for the local clerks - the court clerks - who were collecting the money from the 10% surcharges and sending that in so that they understood that there was a new beneficiary out there, a new surcharge to collect and get them to begin to start sending that money in. That did take some time. We have definitely seen an increase in our revenue collections generally over the first three or four years. Beyond that, the main part that we sort of focused our attention on was getting the Commission going and, again, this Commission is an authority that is set up by the Governor of Georgia, there are 15 people on that. He appoints ten of them and state agencies appoint the other five. So they had to get the Commission together and then their main job was really in deciding how the trust fund was going to work. You know, what the definitions were going to be, what the policies were going to be, what the application process was going to be like. And so they spent quite a bit of time getting that part done and then hiring the staff and getting the office opened.

WILLIAM DITTO: We were, I think, fairly lucky in New Jersey in that, because our funding comes from a surcharge on motor vehicle registrations, it's kind of an automatic and not very complicated way of obtaining money. The Motor Vehicle Commission in New Jersey

simply upped the registration fee by 50 cents after the effective date of the legislation in July of 2001; and when they collect that money they automatically transfer it to the State Treasurer and the Treasurer places it in the non-lapsing, interest bearing account and then the Department of Human Services, where I'm located, actually draws from that account the money it needs to operate the fund. We try to be very conservative in terms of what we draw out of that account because we want to leave as much money as possible in there in order to gain interest. So we draw money out periodically throughout the year as we have expenditures but we do try to leave as much as we can in the fund account itself. I would say it has been a relatively easy process for us. I don't think most citizens in New Jersey really even noticed the 50 cent increase in the motor vehicle registration fee. It was really helpful to us because in New Jersey people are required to register and reregister their cars every year so it's a continuing source of revenue.

ANNE KING: I believe when you and I have talked previously you also said that you may include some kind of flyer with the D.M.V. registration to alert people?

WILLIAM DITTO: Yes. One of the things we're planning to do in the future is to include an insert with the motor vehicle registration renewal forms when they go out advising people about the fund and what the fund does, because we think at this point having some time under our belt in terms of operating the program, that we're in a position to, you know, make the public aware that this relatively small contribution in terms of their registration has made a very significant difference in the lives of people in New Jersey with brain injury.

ROBERT WALKER: Robert, in Kentucky I believe you have more than one source of income.

ROBERT WALKER: Well, we have more than one charge. We are still relying upon court fees, a percentage of court fees to generate our revenue base. Politically that's been a very difficult issue in Kentucky because the court clerks have been hit up by a number of entities looking for some little sliver of that fee to fund some new service or intervention. So, we're right now really doing a little head scratching around some of this and thinking that maybe it's time to grow our program and to look at some more direct line item budgeting for brain injury services – but that is sometime in the future. We earned our money through the court fees. We had to wait for it to accumulate before we had a sufficient fund to begin administering it. What we did is, during that period between the legislation passing and the procedures being set up for the fees to be collected and generated into the account, we used that time to generate our core procedures and navigate the course through state government as to how we would be administering the funds along with the contract entity.

ANNE KING: Okay, thank you. Some -- part of this question has already been answered. But how long did it take you to get your program up and running? And what are some of the other activities that actually had to occur before you could start serving individuals?

WILLIAM DITTO: Well, in New Jersey, the way the statute was written that created the fund, one of the responsibilities for the Governor's Advisory Council on Traumatic Brain Injury was to be responsible for the oversight of the program in conjunction with the state agency, and we took this very seriously. And so we asked the Advisory Council to establish a subcommittee to look purely at how to set this fund up. What should we cover? What should the eligibility criteria be? How should we structure it? They spent close to a year in meetings developing what they saw as sort of a template or a plan for implementing the trust fund. During those deliberations (which included brain injury survivors, family members, advocates, providers, government folks - it was a very good representational group), but what we found during that process was that there were a lot of areas where the group could not reach consensus. So they came back to the Advisory Council and to the Division basically with an idea of what they thought the fund should look like and how it should operate; but they also came to us with a list of sort of unanswered questions or dilemmas. So at that point, that's when we sort of moved the bureaucracy into the picture and began the process of developing the actual rules and regulations. It is a fairly time consuming process. It's a time consuming process because, first of all, you want to develop a program that's equitable, you want to develop a program that's comprehensible to the public. Yet at the same time, because you are dealing with public funds, you feel a pressure to make sure what you're doing is something that would be understandable and acceptable to the general public. You want to support people but not hold out a false expectation. I would like to say we started in July of 2001 collecting the actual money, but it wasn't really until July of 2004 that we had promulgated the regulations necessary to actually make the fund begin operation. So I think it may take

people longer than they think it will. And my advice to folks out there who are contemplating the establishment of a fund is that you do have to allow yourself some real lead time to put things in place. It is not something that you can do overnight. It is a very big undertaking especially if it's a program like ours where we're providing direct financial assistance to individuals. There are a lot of things that you have to think about in that process. So I would say that, you know, it is a process. I would also say that the involvement of our advisory board and the work group that came from that advisory board were very critical in terms of developing the program the way it is today.

ANNE KING: Now is that consistent with your thinking both in Georgia and Kentucky?

ROBERT WALKER: Sort of. [LAUGHTER]

ROBERT WALKER: Kentucky always has to be a little bit different. It's an issue. I think we had one -- this thing I was referring to earlier about the Medicaid waiver -- we had an advantage in that our legislation really kind of grew up along with a lot of other thinking around brain injury services in the state. We had the advantage of a lot of planning functions and enlisted the aid of hundreds of family members and consumers along with some of the Medicaid work - that kind of provided a roadmap for what services were needed in Kentucky and we were able to short circuit some of that (lengthy planning between legislation and operation). I do agree that planning input is absolutely essential. You need consensus from the provider community, you need consensus from consumers

and family members that your roadmap is one that people can live with and that can meet needs.

KRISTEN VINCENT: I would say two things about that. We had a very similar experience to the other states. It does take quite a bit of time to develop the policies, to figure out how your trust fund is going to be distributed. Our Commission really spent a great deal of time. They really understood their responsibility to the people with brain injury and spinal cord injuries in Georgia and understood the need to develop a trust fund that would really be responsive to their needs. And so they took a lot of time in thinking about how the trust fund could best be distributed. At the same time they also, I think, were really reluctant to finalize the policies and get it started because they wanted to be sure that their policies were perfect, that the application process was going to work perfectly, and there was just no way to know how it was going to work until you actually did it. So they finally, I think, came to the conclusion that they just needed to start somewhere and they sort of illustrated that by calling their first set of policies their interim distribution policies to sort of underscore the fact that these are the policies that will get us started, that will at least get the application process going and get the money out there; and we recognize that once we do that, we'll learn what is working and what's not working and be able to revise policies as necessary. We're actually at the point of our second major revision of those distribution policies because of the experience that we have at this point. So I think it's OK one to take a lot of time to do that but also to start somewhere and understand that later you'll be able to revise. The other benefit that I would say in taking the time to get your trust fund up and running is that the money is coming in steadily as you're taking the time

to develop those policies. And certainly New Jersey knows as well as Georgia does that in that time, you know, you're building up quite a good cash reserve. We now have a fairly large cash reserve because there were a few years in which the money was being collected but not distributed. So that is going to allow us to be able to serve more people and do more significant things.

ROBERT WALKER: You both have raised that point. I think it's an interesting one and has some political considerations that some states might want to look at as well. In both of these instances you're talking about building up a pretty good cash reserve to work from. In Kentucky we felt we couldn't really do that because we have legislators already breathing down our neck saying "What's out there? We're hearing from our constituents who need services. We have a waiting list." And so we felt it was going to be pretty imperative to draw down the funds rather rapidly. We have created enough of a cushion to hold us if there is some loss of revenue stream for a short period of time, but we've not allowed ourselves the luxury (which is what I think all of us in our hearts would have liked to have done) of building a nice reserve for a rainy day. Politically it was not tenable in Kentucky.

WILLIAM DITTO: I would like to also address that. I think you're right, Bob, New Jersey has been concerned about this as well. It was fine to be collecting the funds for a period of time. But particularly in these tough economic times for the state, we have to be cognizant of the fact that if you have money sitting out there that looks like it isn't immediately needed, it becomes attractive to legislators as well as to the Governor's

Office of Management and Budget to take a long, hard look at that. I think it's a balancing act in a way, if you will, between understanding that it's good to have built up some money to start the program off, but then you really have to make sure you're expending money so that you're demonstrating that there is really a need out there. That, I think, should be a concern for any state in this budget climate. If these things had started 20 years ago we would be in a much different place than we are now.

ROBERT WALKER: Particularly if you were to look at going and asking for more funds and you aren't drawing down everything you've got - that's where the political rub gets really sensitive. We just have to be careful with that.

KRISTEN VINCENT: There have been a couple of states that had cash reserves and they were actually raided. I know that Florida's was. Tennessee's was under threat. I don't remember if they were actually raided or not, but it's a very real thing to be concerned about and we've certainly had questions from our legislators about our cash reserve. The main thing that we did to try to address their questions and show that we were planning to use it and that there was great need for that cash reserve, we actually enlisted the help of the University of Georgia (they have a think-tank on disability called the Institute on Human Development and Disability, and there is one of those in each state) to look at the cash reserve, look at the needs of people with brain and spinal cord injuries in Georgia and actually make recommendations on how that cash reserve could be used. And so we actually have academic research, as well as a plan from the Commission, that says here

is what we're going to need to do with that cash reserve. So I think that will help us when we have those conversations with legislators.

WILLIAM DITTO: That's an excellent way of approaching it. One of the things that we have talked about is developing actually a projection into the future that looks at the uptake of applications over the period of time since we started and what that means projected into the future in terms of the revenue that is coming in. Because I am quite sure that we're going to eclipse our revenue at some point in the future, that we'll be paying out as much as we're taking in. At that point we may have to impose some limits, which we haven't had to impose up until this point. So I think a lot of that is very important ground work, and I would urge people to do that very early on and not wait until someone starts eyeing that unexpended money.

KRISTEN VINCENT: Absolutely. Right.

ANNE KING: Okay, let's talk about the actual operation of the fund. And this is a biggie question. Describe how your program works, what you offer, any program restrictions, who determines the eligibility, and how you ultimately get services or supports to consumers. And then, if you care to share it, what is your average expenditure and most frequently requested support? And I'll be happy to break that down into smaller components.

KRISTEN VINCENT: Sure, that would be good.

WILLIAM DITTO: I would like to start with the end of your question which I think is the easiest part, actually. We have - in terms of the most frequently requested supports in New Jersey - I actually have a small list here based on our application experience so far. The most requested service in New Jersey has actually been cognitive therapy. Second most requested service has been home modification. We've done a fair amount of that, widening doorways, putting in ramps, lowering cabinets, modifying bathrooms. In fact we had several nice success stories in terms of bringing people out of nursing facilities and other institutions back home as a result of having that funding available. Third is physical, occupational and speech/language therapy. Fourth is service coordination, which you can also translate as case management, and the fifth most requested service is assistive technology. That's kind of how ours has broken out. Maybe in terms of addressing this question, maybe we can all talk about that a little. That's a good way of starting.

KRISTEN VINCENT: Absolutely. Our number one request by far has been transportation. That has been consistent over the three years that we have now been distributing the trust fund in Georgia. An average of 23% of our total trust fund dollars is going to transportation each year. Second is home modifications. That is averaging about 16 to 18% per year. And third is personal assistance -attendant care, which is roughly averaging about 13% of our total overall award per year.

ROBERT WALKER: Our service array is structured a little bit more open-endedly, perhaps. We have in our legislation among the services that were outlined by the statute

this clever little term called case management and we took your term - service coordination - and began looking at literature on case management and looking at other practices within other program areas within the state and decided to bring into that a concept called wraparound service. That has been extremely important - really a vital part of how our service benefit works. Wraparound is this. It's anything will help that person stay successfully in a community environment as opposed to any other environment. So we have done home modifications, we have done purchase of vehicles, we have purchased computers, we have purchased any number of things that would assist someone in keeping a job, getting to a job, transportation, obviously through the vans. Respite, though, has been the big ticket. Respite has been probably the thing that has eaten the largest chunk of our budget, 40% overall. It's by far the largest one. The wraparound concept is an intriguing one and maybe one we'll come back to in a couple of points later on. As the board wrestles with that - when you're buying everything from dental care, eyeglasses, etc., where there is no other funding source - it is fragmenting or feels kind of fragmenting to a Board, and we wonder if we are doing the right thing with our services. But if you collect data on it, you can find some important things there that help. We do buy behavior programming and do buy rehab and other treatment-type services, but respite has been the standout among these wraparound services.

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WILLIAM DITTO: It occurs to me, too, I think it will depend on what the current picture of services is in a given state that will very much determine that. When I heard you talking about respite I'm saying New Jersey has had a statewide respite care program for a long time and we have respite as one of our services under the fund. I don't think it's requested as much because people have been able to access that. We have no payment source for

cognitive therapy other than the Medicaid waiver which only serves about 300 people. So I can see where in New Jersey cognitive therapy would be a top-ranked service. So I guess for each state it will really depend to some extent on what your present constellation of services is in terms of how your fund fits into that picture.

KRISTEN VINCENT: Absolutely. Also the way that you set your policies and define how it is that your trust fund is going to work in the midst of and in coordination with all of these other services that are in your state. The language that we have in our policies for the trust fund in Georgia is that we are a payer of last resort. Certainly we have had, you know, arguments and conversations with other services in Georgia who feel like they're the payer of last resort. The difference is they are an entitlement and we're not; and so they, by law, must provide specific services and that sort of thing. What we have really made sure that the trust fund can do is to support people being independent and being included in their community. We feel like by far that is the single greatest thing that we can do for people with brain and spinal cord injuries in Georgia. So our policies state that we will provide funding for anything that is not covered by those entitlement services that would support independence and inclusion and I think that's probably what you're getting at with the wrap around services.

ROBERT WALKER: We have struggled really hard to have a high degree of accountability but at the same time not create yet another bureaucracy for people to have to struggle with. So there's been this tension between a funding pattern that is flexible enough to meet needs and at the same time making sure we cover ourselves with the legislature and

with the policymakers to make sure we aren't spending money irresponsibly. It's Tricky. Understanding that full service mix is essential, and what ours has done in Kentucky by virtue of some of its breadth, is that we have a lot of holes to fill with brain injury cases in Kentucky.

WILLIAM DITTO: Going back, Anne, to your original rather lengthy question to us, you know, we have some very basic criteria, eligibility criteria for the fund. You have to be a New Jersey resident for at least 90 days prior to the point of application. We require medical documentation of an acquired brain injury, and you have to have self-declared liquid assets of less than \$100,000, which means that those are things that you could easily convert into cash - savings accounts, stocks, bonds, that sort of thing - and then we say in terms of the services that the services requested must be directly related to the brain injury. We have to see a demonstrated link between what you're requesting and brain injury. If there are clinical services, we are requiring there be a prescriber in the picture - someone who is saying "yes, this is necessary". And that comes out of lessons learned where we had providers who wanted to get paid and said "Mr. X definitely needs 65 sessions of cognitive therapy", and we came to realize we needed an independent authority to say "yes, that's what he needs and he'll benefit from it". And like Kristen mentioned, we consider ourselves the payer of last resort. We could do an entire conference on what does it mean to be the payer of last resort? I'm not sure anyone knows. It's a popular term in government. If you look in everybody's statute and legislation they're always the payer of last resort. I haven't figured out who really is the payer of last resort.

ROBERT WALKER: I'll comment on that for a second, if that would be all right. What we did in Kentucky rather than for the state to administer this fund, we contracted with a case management entity to do it. What they do through the case management model is they make that assessment about payer of last resort in a variety of ways. One, they look for documentation and they look for effort the individual has made to contact some other agency or if they've even examined insurance policies and looked at what is available. Secondly, we've looked at the community to see what can be volunteered and we've kept records on what the case manager has gotten for the person that did not come from the trust fund. To date we're looking at about \$2 million dollars worth of services that this case management entity has found on behalf of recipients that didn't cost us a nickel. We're pretty confident that we're pushing the envelope and getting to payer of last resort as best we can. One other footnote here. Each person who applies for a service or a benefit through our program has a case management assessment and then that case manager goes to a service planning committee made up of a group of people from all disciplines who share an interest and expertise in TBI and that entity makes a decision about whether or not the service should be provided and at what level. So we have that as another kind of screening level in the decision process before allocating the funds.

WILLIAM DITTO: That's interesting that you mentioned that, because the way we have set up our program, I think, has some of the same features that yours does, Bob. We have a situation where people request an application, we send them an application. That in itself was a big part of our development process – developing an application form that would be

easy for people with cognitive disabilities to complete that got just the essential information we need but didn't ask the extraneous questions. And, understanding that people aren't always able to articulate exactly what they need, we set up a system where: you send in the application; we review it to make sure we have the data we need and then assign a case manager contracted through the Division who actually goes out and visits face-to-face and goes over it with the individual, fills in any missing blanks; and the applicant and the case manager jointly develop the support plan - that's what we call them. The support plan then details everything the person is going to be getting. Just like you have mentioned, Bob, the case managers have done a great job in getting people to other sources of help in the community that they were completely unaware of. We had a lot of people applying for pharmaceutical assistance. And we have a state pharmaceutical assistance program for people with disabilities and sometimes people were completely unaware of that. That case management visit in and of itself solved a lot of problems and diverted them from coming near the fund at least for that particular service. When the support plan comes back in from the case manager, then we have a review panel, or review committee made up of seven individuals that actually go over the applications and make a determination of what will be approved and what will be acceptable. And for the most part up until this point, we have approved almost all the applications that we have received. Sometimes we've modified them a little. We haven't necessarily agreed with everything that was requested in the application but we've at least been able to approve a goodly amount of what people were asking for.

KRISTEN VINCENT: We have some similarities to what both Kentucky and New Jersey are doing and certainly some differences as well. The process of accessing the trust fund in Georgia starts with an application that people fill out in which they talk about their injury, the extent of their injury and the extent of their levels of support that are available to them - family, friends, service providers, that sort of thing - and that talks about the nature of their request and how it will impact their life, how it will help them achieve independence and become more included in their community and reach their goals and that sort of thing. That application is then sent in to our office where it's reviewed by our staff. They enter the information into their database. They talk with people if their application is incomplete. But then the staff do pretty thorough reviews on that application. They actually talk to people and talk to them about what is going on in their lives, what their various issues are, what their various needs are. Quite often what we find is that people will put one need on their application but they have a whole variety of things that they need. Sometimes, you know, the thing that they're asking the trust fund for could be met by another resource in the community. That's what you all have touched on. In some cases we have actually talked with them about changing their request so that they can get the first needs met by another resource that is available to them. And then that way they have the trust fund dollars available to meet a second need. Part of what has come out of that work - there are a couple of things - one, we have a very, very low denial rate. And I'm very proud of that and I'm very proud of the work that the staff are doing because, what that means is that, people are learning upfront how the trust fund can best work for them. If there is a request that they're making that doesn't fit within our guidelines or policies, how they can look at doing something different or, again, how they can get that need met in some other way,

you know, besides just the trust funds. The other issue that I think that raises that you're sort of hearing in this discussion is whether or not you use some kind of case management model, some kind of resource coordination model or some other model entirely. The trust fund in Georgia, we have done a lot of work in just kind of reviewing the models throughout the states. We have actually chosen not to go with the case management model but are looking more at a resource coordination model. There are some differences and many similarities. It's really about having somebody at the local level that can meet face-to-face with that person, that can help reduce the bureaucracy, that can again help them to look at their whole range of needs, their whole range of resources that are available to them. And so I think the key piece in the resource coordination is helping them get better connected with their community, with their local community. It is really about teaching people to fish rather than having them -- giving them a fish from day-to-day. So that is the model that we are looking at pursuing in the State of Georgia. Again, we really see this opportunity with our trust fund to help people get better connected at the local level. If we can do that, then they will be able to be independent and be involved in their communities long after the trust fund has been involved in their lives.

ANNE KING: Do each of your programs have a cap on the amount of funds that -- what are those caps?

KRISTEN VINCENT: We have a cap of \$5,000 per person per year. And that sounds low and, in some cases, it is. What is interesting about that, it goes back to my earlier point

where the Commission, you know, struggled for so long trying to figure out what the cap should be and they finally said let's start conservatively. Let's start with \$5,000 just to get the money flowing and then we'll see if that works. And we are again at the point of looking at whether or not to raise that cap. We've had some very, very interesting discussions and very good discussions that have come out of that. There are a couple of things. Again, we have also been working on this issue with the University of Georgia - their Human Development Institute - in helping us to think about whether or not we will raise our caps. And actually what has come out of that is that we'll probably not raise our caps, at least the current recommendation on the table is not to raise the cap from \$5,000. In most cases, that amount is working. It is enough for people to get their significant needs met. There are some areas, though, in which \$5,000 does not go far enough and it goes back to the statistics that I talked about earlier. Transportation, home modifications, personal assistance. Those are clearly the three things that are most requested. They are also the three things that have very high dollar costs attached to them. And thirdly, those are the things that can really make sure that people get out into the community and become and remain independent. And so those are the three services in which we are looking to raise caps. Interestingly enough and I know when you all talk about caps you'll talk about lifetime caps, and we sort of went back and forth about whether or not to do a lifetime cap. And part of that was because people are starting to look at this as an entitlement. We're having that issue. We're hearing just sort of scuttlebutt around the state "there is this trust fund, I can get \$5,000 a year for the rest of my life. This year I'll get this thing, next year I'll get that thing" and not really thinking about the fact this is not an entitlement and it is a limited pot of money. The recommendation that has come out of the

University of Georgia is that we keep the \$5,000 per person per year and we allow people to apply for that as many times as they want, but the third time that they apply to us that we actually sit down and do some person-centered planning with them to get them to really think long term about what their needs are, what's available to them, and, you know, hopefully get them to look again at how to fish for themselves so that they don't become dependent upon the trust fund. We're really clear about not creating a dependency upon the trust fund. And that's another reason why we aren't looking at raising that cap too much beyond the \$5,000.

WILLIAM DITTO: I think what you're saying, Kristen, has brought up two issues for me that are very important. I think one of them we didn't really touch on yet. In getting the word out about the availability of trust funds, I think we have to be very careful that people do not think that this is an entitlement. We had a lot of people calling us in the early months of our program. We have a cap of \$15,000 a year and a lifetime maximum expenditure of \$100,000 although our statute does, in fact, allow us to make exceptions to that. We have some flexibility but we got calls in the beginning, "Well, I'm ready for my \$15,000. When will you send me the check?" We were taken aback by this and we shouldn't have been. We should be smart enough to know that's going to happen. There was an expectation out there if you have a brain injury you're now entitled to \$15,000 a year in the State of New Jersey. Interestingly enough, our average expenditure per case thus far has been \$4,000 a year. It bears out your \$5,000 in a way. We had -- that ranges all the way from a person who got \$150 worth of help to someone who got the full \$15,000

– it was a home modification case. But on average it's about \$4,000 a person. It's very interesting to see that your figure may be a realistic ballpark figure for assisting people.

ROBERT WALKER: We've had corollary experiences in Kentucky. Our cap is \$15,000 and our lifetime max is \$60,000. Again using, and I don't know what term will work best here. Our legislation says case management. We sometimes say service coordination or resource coordination. We aren't talking about case management in a sense that health maintenance organizations use case management. We are talking about that very hands on, face-to-face personal planning process with our recipients. One of the fascinating things - it has genuinely been an encouraging thing to experience - (is) the number of recipients who, on listening to the scope of the plan and getting their needs looked at in the context of a case manager, have themselves decided, "I don't really need this. I can either do without this - it's not that essential or maybe I can get it from some other resource", because they're very much keeping their eye on that lifetime max and they aren't wanting to waste resources. And (they) literally will say that. So we have really not had to police that terribly hard. We've had a few cases that have challenged us but by and large, the consumers themselves are doing a great job of working through and thinking through that process. Our case average is a lot lower. We're really around the \$2,000 mark in terms of allocation per recipient. We have a lot of them on the very low end and small numbers on the high end and exceptionally small number who are at the max -only one or two that have been at the max – a very small number.

ANNE KING: I understand in Kentucky that there is a proposal under consideration for children. If a child has used up their lifetime maximum to start the process over again as an adult.

ROBERT WALKER: I think all of us see that as a very critical need - that boundary. It wasn't envisioned at the time of the legislation and we all see a need to make a modification on that.

ANNE KING: What are the typical roadblocks or sentinel problems that programs can expect as they begin implementing a trust fund?

WILLIAM DITTO: Well I think, as I mentioned before, first of all the expectation that it's an entitlement is one of the things that I think you can expect to encounter. The other thing is that in order to process -- I'll defer to the other states to talk about their experiences -- but in order to process these applications in an orderly fashion, we do them by batches which means we have basically six batches a year in which we consider applications. I think a lot of times people think they'll apply to the fund on Monday and on Friday somebody will call them and say your application is approved, you know, we'll pay for these things, the payment will start flowing next week. It takes a lot longer than that. So we have needed to really do a lot in the way of public education because we get people that are very frustrated with us. I think part of that is the nature of the folks that we're serving. They have cognitive problems and so it is an issue for them. They are having trouble understanding what the process is.

We've had to spend a lot of time trying at the very beginning when they first apply to let them know how this works, to let them know their application probably isn't going to get to the review committee for a couple of months. So it is going to take a while before they hear from us. We do have a provision for emergency services, so we're able to respond to people where there is truly an emergent need and they need help right away. We don't have to wait for the committee to meet in order to deal with those. We (like to) keep them to an absolute minimum. They have to be emergent circumstances where there is documentation of emergent need for services. That has been a stumbling block for us and we have had dissatisfied folk who have gone right to their legislators and are saying they applied to the trust fund and they're not doing anything for me. It's not the case. We're trying to work with them. There is a process involved in this. The other thing is that we have found, anyway, getting the payment out to the vendors of service for the fund is also a very, very labor intensive job. We're talking about setting up a whole group of folks that the state has not necessarily paid before and actually issuing payment to them. It has involved a lot of work. That can be a daunting task.

KRISTEN VINCENT: We started out in the same place that New Jersey did with the application process. We also took batches of applications. We had an application deadline. And at the time of the deadline we took whatever applications were in our office at that point and then processed them. What we found was that it was taking quite a long time because we had, you know, a couple of hundred applications to go through all at once and so it was taking about four to five months to turn around any kind of a decision

to people and then for them to be able to begin to get their services. We recognized that number one, it wasn't working internally. It was too much of a drain on both the staff and the Commission to have to review that many applications all at once. But secondly, it was not -- it was not remaining relevant for the people that we serve. In many cases, in the four to five months from the time they had applied, their needs had changed or the amount of whatever service they had applied for had changed. The service that they really needed, they needed it immediately. It was an emergency kind of need and we didn't have a way to handle that at the time. So after doing two batches of applications, we actually changed to an ongoing application process. And so now we accept applications on an ongoing basis. As the need arises people send their application in and in doing that, we became very committed to making sure this process stayed very immediate to again recognize that people have immediate needs. And so we have committed to turning our process around, turning an application around within six to eight weeks from the time it reaches our office. That's assuming that it's a complete application and has everything we need in it, that there are no issues with it. That has really helped. It has made it sort of a routine cyclical process for our staff. They've got it down to a science. It has also made our recipients and applicants very happy because they see this is going to happen very immediately for them. We have, you know, being a state agency we certainly have issues in getting checks out but for the most part we're able to do that fairly well. Again, we have an administrative agency, the Department of Human Resources, that issues the checks for us and they are able to turn checks around generally within two to three weeks which I think is reasonable and actually pretty good for a state agency. That's the process that we have.

ROBERT WALKER: Your opening question, I want to go to that, too. What are the biggest threats or stop gaps or problems that you run into? I may be speaking just for myself but I think our board has wrestled with this from day one. That is to not become a bureaucracy. That has been one of the primary things that we've sought to do. We wanted to create a structure that was accountable but flexible. We are struggling with that. That comes up in every single meeting we've had to deal with as a potential barrier to making it work the way we want it to work. The processing - and in Kentucky we're extraordinarily fortunate in having a case management entity that can process emergency requests and now well over half of our requests are emergency requests - swiftly, effectively. The longer term less emerging cases are the ones that are really a sticky wicket for us. We have a waiting list that is very large. We simply, we do not have the resources to meet the level of need as it is standing at our front door right now, and we don't have a good solution frankly. We're trying to find a solution - a way to chip away at those people that are standing in the queue. That's a major problem and I think anyone wanting to start a trust fund needs to give some serious thought to that from day one. We were joking in a meeting earlier. When we were first getting started this case management entity suggested to us that they would be delighted to do public relations on behalf of the trust fund by announcing it to the state and getting people interested in it. We never spent a nickel on it. The minute the door was open people were lined up immediately. We had no need for that. That demand for service is very great and I think it represents one of the major problems for us to handle administratively.

KRISTEN VINCENT: Actually, we don't have a waiting list in Georgia. We, you know, again, we are young and so up until this time we have had enough money to meet the needs of the people who have sent in applications. We're actually in our first year in which we're going to expend every dollar that we have budgeted and in some cases will not be able to meet all of the need. But we are not collecting names-- we are not putting people on a waiting list because we don't want to have to deal with a waiting list or we don't want people to feel like they are waiting in line for the trust fund. In the cases where we can't meet the need we want to work more on the service coordination, the resource coordination to be able to help people find ways to get their needs met.

ROBERT WALKER: And I need to clarify (that). We do go ahead and offer that. They may be waiting for the home modification or transportation assistance, but we begin the case management service because it's critical and may lead to other solutions for people. But that end product is still sometimes months away.

KRISTEN VINCENT: In terms of addressing your question about major roadblocks or problems that we have encountered, I know that for those states that are interested in developing a trust fund generally one of the things that you would do is collect copies of sample legislation from other states to see what that legislation looks like. Just so that you know, if you happen to get a copy of the legislation for the trust fund in Georgia you'll see a line in there that says that distributions for the trust fund are approved by the Commission but then must be approved by the Governor before they can go out. That was set in place as sort of a checks and balances measure just to make sure in the beginning

the trust fund was working well and that the money was going out the way it should and that sort of thing. It's become a real problem for us. Again, we had really committed to turning applications around in six to eight weeks but then we don't have any control once those recommendations hit the governor's office, we have no control over how long it takes his staff to return those recommendations to us. So we are now actually in talks with the Governor's office about either addressing that or hopefully removing that piece from our legislation. So again, just fair warning. If you see Georgia's legislation, you know, it's good to model any other pieces of that legislation except that one line.

WILLIAM DITTO: I was very interested when you were talking, Kristen. So if I understand you properly, when you get an application in, you process that application through using your staff. You don't use a review committee of some sort? Who makes the final decision about what is acceptable in an application?

KRISTEN VINCENT: We do actually have a review committee. It does begin with the staff. We have staff who, again, review the application, they talk with people, they try to make sure that the application is within our guidelines and that sort of thing. They make the initial recommendations for whether or not to award a distribution. The staff then meet with the distribution committee which is a subcommittee of our Commission. It's made up of Commission members, and people with brain and spinal cord injuries. Members of service providers as well as a case manager serve on the committee. The staff meet with them. They review the recommendations, and then they make final recommendations to the full Commission. Our Commission meets on a monthly basis. So every month they're

meeting and reviewing the list of award recommendations and voting to approve those recommendations.

ROBERT WALKER: We in Kentucky, Bill, what we do, the case management entity brings the roster of all the cases that they have decided on and we kind of lay hands on post facto. Our legislation also calls for our Board to approve these. But the legislation also had a little caveat in there that you can only spend 3% of the funds on administration so we quickly figured out we needed to do something rather differently about that. But we really sped up the approval process by essentially taking our authority to approve those and handing it over to the case management entity and we approve them in large batches after the fact.

KRISTEN VINCENT: I'm curious to know, how do you address the issue of 3% administrative cost in your legislation? Were you actually able to change it?

ROBERT WALKER: No, we did not. Our contract with the entity is with the case management process and all they need to do with the case management - that isn't counted in the 3%. That's exclusively the state government expense which is in the brain injury unit staff. Our director is there. That's the purely administrative function. That was a challenge.

KRISTEN VINCENT: It is an issue that your state is going to have to address. I think it's a very, very real issue and certainly one we're having to address right now in the State of

Georgia. We have actually made a recommendation to hire additional staff to work at the local level again to provide that resource coordination for people applying to the trust fund, and the Governor's office and the state legislature have asked or actually questioned the amount of our total overall trust fund budget going towards operating costs. And our recommendation for that staff was based on our review of what other states are doing all across the country. We looked at Kentucky, we looked at New Mexico, we looked at Tennessee, Florida, many of the other states with trust funds and they are all putting a significant portion of their budget into administrative costs. Certainly I hear how you all are doing that through the case management company. But so the question is, do you want all your money to go into straight trust fund distributions, which would be ideal, or do you need to make the investment in staff. What we've found in our review of other states across the country is there is that need for investing in staff. Those states that have actually put money into case management or into staff for coordination are been able to help more people and use fewer trust fund dollars per person. What that says is more people are getting their needs met using fewer trust fund dollars so in the end you're still actually able to help as many people, but actually more. And so that's the conversation that we're having with our Governor's office right now and again it is probably a question that you'll have to address with your state.

ROBERT WALKER: As you relate to legislators on this - when they think of administrative costs they aren't thinking about some of the indirect costs that a provider agency might have. It's a subtlety that's not generally a part of that discussion. When they think about administrative costs, they are thinking about state government employees who've become

permanent cost burdens to the state. What we have done in Kentucky - we've made it a tiny piece of the pie. Really minuscule. I don't think we quite spend 3%, as a matter of fact. We're really showing ourselves to be exemplary stewards in that sense. But it is a very sensitive political issue and I think every state will face questions about how much is going into administration. They don't understand it takes administration to make things work.

WILLIAM DITTO: I hope I'm not becoming a cost burden to New Jersey. Probably am already. What I -- I wanted to say that about that, too, I think it very much depends upon your presentation of the information. We look at the case management function actually as a direct service to fund applicants. We say every time a case manager visits someone at home, even if it's to steer them away from the fund, they have received a very valuable human service and those case managers are all nurses or social workers and they all have a background in brain injury. We require it as part of our contractual arrangement. We look at administrative costs from the standpoint of the staff in the Division, the manager and manager's assistant that operates the program. I would say we're a very low-cost operation in terms of administration and a lot of it is direct services. Sometimes it's hard to get people to understand that's what you're really doing. I think it's a challenge in terms of presenting this information because obviously if you're going to provide direct assistance to people, it is going to be a costly undertaking. I mean, when you look at analogous human service programs that provide direct benefits to people, a major cost to the programs is the administrative side of it. There is no question about it. Plus everybody wants reports from you, everybody wants statistics and data. Those things don't come out of no where. They come out of staff time that is put into maintaining --

designing and maintaining databases and generating reports and that sort of thing. There needs to be some credit given for some of the activities that need to take place in that context. The other thing I realize in this most recent discussion that I forgot to mention was our fund really has two purposes under statute. One of them is to provide direct assistance to individuals. The other part was to provide for public education, outreach, information and prevention activities in the community. We annually contract with the Brain Injury Association of New Jersey to provide those services and we do use part of the fund for that purpose, because we think it's very important to get the message out there about brain injury. The general public, as most of our viewers I'm sure really already know, are completely unaware of brain injury and its consequences. In something like a trust fund where we don't have any severity criteria, if you have a documented brain injury you can come to the fund. It doesn't matter if it's a mild brain injury, a moderate brain injury, or a severe brain injury. We're talking about an expanded population - folks that have not normally been served in a lot of the state's Human Services system. People with severe brain injury we know about, we serve them, we pay for them. We're involved with them. People with moderate and mild brain injuries have, by and large, been ignored by public agencies so that public outreach and education and information piece has been very, very critical for us. We think that's also a very wise use of trust fund money.

ROBERT WALKER: I would like to share one brief point about Kentucky and check it out with your two states. What we did in order to get services again widely distributed in that cap of the \$15,000 and \$60,000, we aren't really putting case management costs into that. The person is going to get case management services, period. The \$15,000 or \$60,000

are a part of the other services we have to purchase for the person or with the person.

Does that work the same in ya'll's program?

WILLIAM DITTO: Exactly the same. We didn't feel it was fair to charge up against the potentially available money for the individual for their needs. So we consider that to be a cost of the program that is not borne by the individual. I have a problem with mandating case management on people and then making them pay for it. It doesn't seem very equitable to me somehow.

ANNE KING: You mentioned data so I'll go ahead and ask this question. What data should be collected and how can data be used to support your efforts?

WILLIAM DITTO: Well, what can I tell you? Data drives policy. There is no other way to put it simply and so if you're not collecting good information on the folks you're serving, on the degree of unmet need, on the types of things that people are requiring and really on the outcomes, I mean, really, I think one of the areas in brain injury services in general that needs focus and attention is on outcome measures and so I think we really need to be looking at what was the impact of providing this particular service, this particular type of help, this home modification? What does it mean both in economic terms. I can certainly make a good case for the folks that we got out of nursing facilities back into their own communities and homes in terms of the cost change and the cost shift from paying for them in a nursing facility to having them live back in the community. I think we have that kind of thing and we also have sort of the personal level of achievement measure which is

kind of how far have people gone as a result of what we've been able to provide them with? I would say that data collection and data analysis are two very important administrative functions of funds. And I think they also go a long way to justifying your existence into the future.

KRISTEN VINCENT: Absolutely. Similarly, we keep quite good data - particularly on where the money is going, what the most requested services are, how many applicants are coming in on an annual basis, how many of them are being -- their applications are being approved or denied or they're ineligible, what the average expenditure is. We also keep a pretty tight eye in terms of budgetary issues. What we have done to ensure that the trust fund dollars are spread evenly across the state is we've divided the state into ten regions and then looked at the population of each of those ten regions and divided the total trust fund budget according to the population in that region so that we can make sure that it is fairly equitable. So we keep a pretty close eye on the data to be able to make sure that our trust fund awards are really staying pretty much in line with the population of that given region. But as Bill said, outcome measures is really an issue, a very, very hot button issue for our Commission at this point. We just came out of a three-day strategic planning retreat three weeks ago in which this was a major focus of our discussion. We brought in a researcher to talk with us about how to develop a measurement tool we could use to really measure whether the award has -- that the distribution award has done the thing that the person hoped it would do for them. You know, how does it make them, you know, be more independent? Did it actually get them more out into the community or really help them get a job or that sort of thing? We're really looking now at developing

some kind of a tool. You know, I think that would be an important role that NASHIA could fill in helping states share models of outcome measurements so no one has to reinvent the wheel because it's a key issue.

ROBERT WALKER: I want to break that into a couple of segments. One, as you're structuring a trust fund board if you were to do it to build in more components, part of your mandate is to find out what service needs exist, what is the lay of the land. That requires a considerable amount of data collection. We've addressed it in a couple of ways. One, we contract with the University of Kentucky with an injury service – an injury research center to collect data on hospital discharges with brain injury. So we're able to get a measure of the new incidents each year that are coming into the state. – individuals with brain injuries. We've also assessed the prevalence of households that have a person with brain injury in the state and we're collecting data constantly on available services. In addition to that, the data that you just heard talked about in terms of the actual service entity you provide, I can't say enough about it.

When we go to the legislature we're able to say exactly what we've spent on every single condition that we've worked with, what we spend per recipient, what we spend per county and per region. We just -- we find that legislators ask those questions and if we don't have the answer we are dead in the water. You have to -- if you contract for the service, you certainly want to contract with an entity that has data sophistication and can give you both financial information pieces as well as clinical information and that the two are reconciled with each other. The issue with outcomes is the third piece. We've struggled with this. The

range of disorders. We serve people with aneurisms, anoxic events, assault related injuries, brain tumors, CVAs, infectious disease, motor vehicle accidents, etc. The scope of damage from the injuries is humongous. It's very, very great. And looking at exactly what it is that we do that really changes whatever it is that the person wants changed is very tricky. What we've been wrestling with is, because of so much diversity at that level we don't have a common element that we're comfortable with other than a subjective life satisfaction or consumer satisfaction model which we may have to go with. We do some consumer satisfaction now. I personally as a researcher have very little confidence in what it says but the legislators like to see it. It's pretty soft stuff. I wouldn't do much with that kind of data. It is tricky and I think coordinating among all the brain injury trust fund boards would be a smart thing to do in looking at outcomes. It's a tricky thing. There are a lot of outcomes reports being generated that when you look closely at the methodology and what the measures are, it's kind of junk. Hate to say that in a public forum like this, but it's junk, a lot of it is really not very good.

WILLIAM DITTO: I think that -- I think you're absolutely right about that and I think we have to be very careful in designing any kind of outcome measures that we use. And I think we also might need to use different outcome measures for different groups of folks depending upon what their circumstances are. If we're serving a child at five years old with a concussive injury the whole outcome thing is a lot different than an 18-year-old who just is getting out of high school as opposed to a 55-year-old who had to stop working as a result of a brain injury. I think we have to think about that as well. I mean, it is not going to be a one-size fits all. One of the things as you were going over your list there, I was saying

boy, that's just like New Jersey. Although we call it the traumatic brain injury fund we are really using an acquired brain injury definition for the people we serve. I feel that it's common with both Georgia and Kentucky. That's another thing states that are thinking about establishing trust funds are going to have to grapple with. We felt strongly that because our Medicaid waiver covers people with acquired brain injury that our TBI fund should also cover people with an acquired brain injury. And yet I will tell you that in the State of New Jersey there were a number of people that felt very strongly that we should confine this to traumatically brain injured people using a more traditional traumatic brain injury definition. I don't know if you've had any of that discussion in your state.

ROBERT WALKER: We have it still continually. Our legislation maps out what we're to cover. But we still can struggle with that. There are very good arguments on both sides of it. It's tricky.

KRISTEN VINCENT: In Georgia we don't serve ABI. Our eligibility criteria specifies it must be a traumatic brain injury and a traumatic spinal cord injury. We aren't including aneurysms, anoxic events, and that sort of thing. We certainly have questions about it. Of course people who fit the definitions of ABI wonder why the trust fund is not open to them. Part of our concern is that our revenue is very limited. It really is a limited pot of money. People have a tendency to think this is a lot of money. You know, they hear the word million, after the number so they just think it is an unlimited source of funds. Again, our average revenue in Georgia is \$2.2 million dollars. It has actually gone down a little bit because of some other issues. And so, you know, if we stay at that cap of \$5,000 per

person per year that's only 400 people or just over that per year. When the CDC estimates there are over 50,000 new traumatic brain injuries just in our state - in the State of Georgia - every year, again, we aren't even coming close to meeting the need of people with traumatic brain injury much less acquired brain injury.

WILLIAM DITTO: That issue is one... we decided to adopt the definition from the federal act and that definition covers acquired brain injury. But when you look at the revenues and you look at the financial circumstances that we may be up against, that's when the argument begins, you know, about, well, the -- we were lucky because our statute said traumatic brain injury but it left the definition part up to us. So when we published our regulations in the New Jersey Register - which is how we do things in the state- it gets published in this thing called the register which is rules and regulations from all state agencies - we used the definition which we lifted directly from the federal TBI Act. Nobody commented on it. You know we have a public comment period before we made a final adoption. I forgot to mention earlier also that's another way of getting input into the process of developing the fund. When those regulations came out, they went out for public comment and there was a 60-day public comment period in which people had the opportunity to respond. We did make adjustments and changes in the initial rule proposal as a result of comments we got from the public. It was very helpful, actually. People pointed out things they thought didn't make sense or were inconsistent and they made some nice catches for us and we were able to go back in and say "you're right, we didn't define that very well or we didn't explain that very well. There is a better way to do it." That can be an important part of the process. We're getting ready to republish our regulations

again - I guess like Georgia is saying - we really do need to shape the program again. We now have almost a year's experience under our belt in terms of administering the program. There are some things we need to handle differently. And the regulations need to reflect that.

ANNE KING: Right. We've been talking a little bit about revenue and each of you has a different revenue source. Have you had problems with revenue collection and if so, what are you doing or what have you already done to try to remedy this problem?

KRISTEN VINCENT: We have that issue and we actually had to focus quite a bit of time and energy in our first couple of years getting started on making sure that courts were aware that they were supposed to be imposing and then collecting this surcharge. We were the new kid on the block, so to speak, in terms of additional fines and fees and so many of the court clerks hadn't gotten the message they needed to do this. There was a lot of initial education and training for the court clerks. There has been the problem that's been mentioned earlier about, you know, the courts not always collecting that fine. Judges are not always imposing it. And then the additional problem that defendants, the people who are convicted of D.U.I., are not always able to pay their full fine and fee. The issue that we're having now, we're actually seeing a decrease in our collections because in Georgia, we have what is called a partial payment priority list. There are actually 13 beneficiaries, which means 13 special fines and fees in Georgia, and what's happening is if the defendant is not able to pay their full fine or fee, then there is a priority list in terms of who gets those first few dollars that come trickling in and we're dead last on that list. And

so unfortunately, if the person never pays their full fine, then we will not get any money.

That has been kind of a -- there has been some new developments. We were actually going up and up and up each year in our revenues and the past year they've started to go down as a result of this issue. This is a problem we are having to deal with specifically in Georgia.

ROBERT WALKER: I think it's interesting to think about these allocations. I think we're about \$2.3 or 2.4 million per year but our population is only four million. I don't know what the population of New Jersey and Georgia is. If you calculate it as a dollar amount per resident citizen of the state you might see some very interesting differences.

KRISTEN VINCENT: I can actually give you those numbers. The University of Georgia report looked at all of the different trust funds including Kentucky and New Jersey and they calculated how much of the trust fund actually goes, if you broke it up, to every single citizen in the state. And, you know, I forget the specific numbers. I think Kentucky was 60 cents per person and Georgia is 28 cents.

ROBERT WALKER: And if we compare what we're looking at as a footnote in terms of other funding issues, we're looking at now putting together a report that shows what those allocations are for brain injury compared to mental illness, compared to substance abuse and some other disabilities. And, let me tell you, 60 cents per head ain't even in the ballpark. If you're looking at brain injury getting funded at such an extraordinarily low level, compared to these other service areas it's a pretty compelling figure.

KRISTEN VINCENT: That was one thing I meant to say earlier when we were talking about the whole question about administrative costs and how much of your overall trust fund budget goes toward operating costs. Again, there is the issue that the people, the case managers or coordinators really are providing a direct service but in addition to that, you know, the thing that we're trying to educate our Governor and legislators about is that the incidence of traumatic brain injury is so incredibly high and yet there is no state agency in our state that is dedicated to serving the needs of people with brain injury as there is mental illness, as there is developmental disabilities, people with substance abuse issues. So again if you're only going to take, you know, a 10% surcharge of D.U.I. fines which only equals about \$2 million a year and that's all you'll give to an issue, you know, that has an incredible incidence rate that's not adequate. A trust fund is one way to get started but I think it's just the beginning of the conversation about how your state needs to really put some money in to addressing this very, very significant issue.

WILLIAM DITTO: Of course, that is generally true across the board in terms of adult onset disabilities in particular. There is -- there are no dedicated sources of funding. It's true in spinal cord injury, it's true in brain injury, it's true with multiple sclerosis. It's a major problem. If you're injured in the developmental period you often can get help from the state's developmental disability agency or if you have a mental health problem. When it comes to this other group of people there are no direct appropriations. These funds are among the first things that anyone has been able to do to really get some revenue stream in there that is really useful.

ANNE KING: I'm just going to ask again that people go ahead and send in their questions. We'll continue our dialogue here but we are running a little bit short on time so I would encourage if you have questions to go ahead and start sending those in.

KRISTEN VINCENT: Can I just say one thing? This is a diversion from where we just left off in the conversation, but I meant to bring it up before. There are differences in the way that our agencies are set up in general. As I have mentioned before, the Brain and Spinal Injury Trust Fund Commission in the State of Georgia is a Commission that answers directly to the Governor. What that means is we're essentially our own agency. We are a separate agency. In many cases, including New Jersey, the trust fund is within a larger state department. And in Georgia we are a separate agency that is only focused on the task of distributing this trust fund. It is a little bit of a different setup. There are not many states that are doing it. I'm not sure exactly how Kentucky is set up.

ROBERT WALKER: Our trust fund board -- all of us are appointed by the governor and we in essence report only to the governor. However, the administrative side is done through the Department for Mental Health. So we have a pretty free hand. We're not -- we are constrained by some realities but not by any authorities within the executive branch other than the Governor.

KRISTEN VINCENT: That's interesting because we've all talked about the need to reduce bureaucracy again recognizing that there are people with really significant needs out there

who are very vulnerable who need these services immediately. You know, typically state government doesn't have the capacity to address immediate needs and so, you know, like my colleagues here, we have really tried to make sure that the trust fund is immediate and accessible to people. And I think being an independent agency that is solely focused on the job of distributing the trust fund really allows us to do some things that are not always - other agencies are not always able to do. We answer directly to the Commission which answers directly to the Governor so we have a lot of flexibility. We aren't bound by a lot of the overall administrative policies, recommendations and bureaucracy that comes from being in a larger agency. And yet, I know that those trust funds that are within state agencies have been able to make that work and still be accessible.

WILLIAM DITTO: I'm trying to say "don't despair" to those of you out there where a separate commission is not a potential reality. In fact, traditionally our Governors in New Jersey have been very loathe to create new commissions that report directly to the Governor because then the Governor's office becomes overwhelmed with responsibility with boards and commissions. I think there are a couple of very practical suggestions that I can make in this regard. One of them is that what we have done is to basically contract with our Brain Injury Association in New Jersey to handle our emergency payments. So when we make a determination in the Division that someone is -- if they're losing their house because they're behind in their mortgage payment and if we can just get them stabilized, pay the back mortgage they'll be fine after that, they have enough money to meet their monthly mortgage obligation, they got behind as a result of the breadwinner having a brain injury or whatever -- I can approve those things as a Division Director and I

don't have to go to the review committee. We go right to the Brain Injury Association which means the check is issued within the same day or within the next day. So simply by setting up this contractual arrangement with them for emergency services we sort of bypass the normal bureaucracy. Then the Brain Injury Association submits an invoice to the state and we provide the money that they actually put out. But their bookkeeper can issue a check on the same day. You always have that as a possibility for making a quick response where it's appropriate. The other thing I might say. It might not be true everywhere. I enjoy a tremendous amount of support from other parts of the department in administering the funds. All of our checks that go out go out through a completely separate budget and accounting office that I don't have responsibility for, that do not drain my payroll, that don't take money out of the fund at all. That entire payment process and accounting process takes place at no cost to the fund. I have a full public information unit within the department that supports me if I want to send out press releases, if I want to do public media campaigns. Those kinds of ancillary supports that exist in a bureaucracy can actually be very helpful in the long run. You can get a lot of mileage out of those.

ROBERT WALKER: You can, Counterargument. I was introduced as an Assistant Professor at the University of Kentucky. That's a fairly recent change for me. I spent almost 30 years as an agency director in Mental Health. I'm a bureaucrat in recovery and can comment to some extent about this.. The advantage of contracting most of the services with a contract entity - a private agency out there - is that unlike government at times, you can tell this contract agency what to do, when to do it and when to change doing it from one way to another. Now, that sounds crass and crude but it really is an

important factor and we've had to work with our agency a number of times to say, "gosh, maybe we need to do it this way or that" and they've been really good at coming back to us and saying "we detected a problem you guys haven't been thinking about and we need some guidance on it. Give us a policy decision on this." It's been really a wonderful relationship. I can't say enough about the advantages of having a really good partnering agency, that does a strong locally-based case management or service coordination or resource coordination, whatever you want to call it. It does give you control and authority over the direction of how things are done.

KRISTEN VINCENT: I do want to respond really quickly to Bill's comment. Every board and commission in the State of Georgia - and this may be true in other states - they have to be administratively attached to a particular state department and as I said before we're administratively attached to the Department of Human Resources. That means they write our checks, issue our payroll, handle technical support, bring in the computer guys for us, that sort of thing. So we're still able to save our budget expenses for other direct costs for the trust fund and still get some of that benefit.

ROBERT WALKER: We're sort of the same with the Department for Mental Health. I don't think the Commissioner of the Department for Mental Health can tell us what to do - they don't have that sort of control - but there is that administrative tie-in budgetarily.

ANNE KING: I was going to ask Robert for any of our viewing audience that might be interested in contracting with an outside agency such as Kentucky has done, what would be the criteria for what you would look for in a good contract agency?

ROBERT WALKER: What we did is put out an R.F.P. We sent out a blanket request for proposals across the state. We had, if memory serves me right, nine serious applicants who came in with notebooks full of what they were able to offer and do in response. We sent out an R.F.P. or R.F.A. that was very complete and thorough saying exactly what it was we wanted. When we interviewed and looked at their responses we were looking at "can they do this and do this?" We were looking at the specific skills and expertise that they could have that matched what we wanted. The other thing that I think you have to be very cautious about this. It's very easy to select a partner that is not going to work really well with you. I personally am heavily invested in looking at providers who are good with data. If they're good with data that tells me something about their level of accountability and responsibility. What is their track record for doing case management? You can get references on these corporations, on these agencies. And that's very much what you need to do. Find out how they've been viewed by other community providers. Just a footnote, ask a few questions about where their staff have worked before and how long the staff have worked with them now. If you have a firm that's coming to you and all of their staff were recruited within the last six months, I'm not interested. I want some longevity and history here of some performance before launching something of this scale with that organization.

WILLIAM DITTO: It made me think about the fact that maybe I wasn't completely clear. The case management services that we use under the fund are actually contracted services. They're not provided by state employees. And what we did is just slightly different -- rather than going for a request for proposals and selecting a single vendor, we actually set up a series of standards and said anyone may come and provide this case management service if they meet this criteria. We laid out the educational criteria, the experiential criteria, the agency criteria and said if you can meet this standard and document that you meet this standard, we will let you come in and actually provide the service. And then because we had some very good case management agencies that didn't have brain injury specific background. They had -- their case managers were superb, we know them from other programs, great reputations - (but) they weren't knowledgeable about brain injury. We worked with the Brain Injury Association to develop a course for these people and (were) saying you can't use these people to serve our clients until they've completed the program.

ROBERT WALKER: We insisted on some nucleus of that skill area and set up a training program.

WILLIAM DITTO: It worked out nicely for us. It's done two things. It's increased the number of professionals with a solid knowledge of brain injury available throughout the state. So they might be working with clients in a completely different program that have brain injuries. They now have some skills and knowledge there. Plus it also brought the message of brain injury home to a larger group of human service professionals in the

State of New Jersey. To me it was a win/win situation. I was very happy with that. I frankly think that in most states - I can't speak for all of them - you're much better off contracting for case management services than trying to use state staff to do this. The expenditures in terms of hiring somebody and maintaining them in the state system are high; and second of all, every time you have turnover you're fraught with this terrible problem of trying to get somebody into the chair; and depending on what your state budget looks like, it might take you months and months and months to get somebody else sitting in the chair that person vacated. By using contract agencies they can hire people every other day if they want to. We found they are more able to be responsive plus we can then be rather critical of their performance and say "you know, we really think you need to be doing more of this on the case plan." We had a problem with one of our agencies. The support plans that were coming in were not very well done. My staff came to me and said, "look at the support plan" and I said, "we won't pay these folks unless they straighten up and fly right." We went to the agency director and basically said, "this is an unacceptable level of performance and we'll terminate our contract with you unless something changes". And, you know, they wanted the business so they were more than happy to begin a corrective action plan to bring themselves up to snuff.

KRISTEN VINCENT: Again, I do want to say, there is a lot of good in having a case management model and contracting with a case management company. There are trust funds that have been able to work in hiring the staff, contracting to hire the staff to do the resource coordination. We have looked a lot at the example of Alabama and their head injury fund. They don't contract with any kind of case management company. They are

working with their Brain Injury Association to actually hire the staff who are called resource coordinators who work at the local level who, again, are really kind of connecting with people to get them connected to their local community and to, again, help them understand what all they have at their disposal. One of the criticisms that we hear quite a lot in Georgia from the disability community is "I just don't need one more case manager." People with disabilities are used to having a lot of case managers and so I think that's one of the things that we have to be kind of aware of and just be sensitive to. Some people haven't had any case management services whatsoever and they have absolutely no one to do anything for them. But we are certainly looking at the model in Alabama in terms of trying to have some kind of local staff that are doing more resource coordination.

ROBERT WALKER: I do think with that, those of you who are starting these programs up, be sure to get data. I said this before. Be sure to get data on the services that your service coordinators have obtained that are of no cost to your trust fund. We're looking right now at a situation where we're getting about \$1.40 for every buck we spend and that's a good bargain.

WILLIAM DITTO: I'm surprised that we haven't had any viewer questions here. I'm sure we've done such an excellent job as a panel, I'm sure that's really the reason. But I do hope some of you out there will consider sending us a question or two because it provokes discussion and I'm sure we've touched on a lot of key points, but we must have missed something, right?

ANNE KING: It may be because I'm technology challenged. Someone may come over here and click this mouse and all of a sudden 100 messages will appear.

KRISTEN VINCENT: I know that we don't have a lot of time left and while we're waiting for any questions to come through, there is one question that you had planned for us to talk about that I think we could go ahead and start talking about which is what advice we would give to any states who want to start a trust fund. There are a couple of things that I would recommend. I'm trying to keep this list short and simple. Number one, just going back to the grass roots organization. The key to your success is to make sure that you have people at the local level that know about your effort to get a trust fund started, that understand what it is about, that understand the benefit to them and to their neighbors, their family members, that sort of thing, and get them involved. Help to empower them to be involved in the legislative process. You can go really far in getting the legislative support you need to pass any kind of legislation for a trust fund. Keep it simple.

Again we're talking about reducing bureaucracy. Whatever trust fund you set up will have to go through some kind of state agency in some form or fashion. Whatever you can do to keep the process simple, keep it immediate and keep it accessible to people so they aren't having to fight another bureaucracy, not having to wade through red tape. These are people with traumatic injuries, people who haven't had a lot of experience in accessing state systems, so they need for this to be kept simple and immediate for them. Lastly, I would just say in terms of deciding what your revenue source is going to be, I actually prefer New Jersey's model to Georgia's model in getting the fee on the motor vehicle

registrations. Because again, with drunk driving charges, you have to make sure the court is imposing that fine, you have to make sure the defendant is able to pay the fine, you are able to just get an automatic fee that everybody has to do when they're registering and you're a much smaller state and yet your revenue is over a million dollars higher than ours. So I think it's really worth looking at.

ROBERT WALKER: Nationwide the D.U.I. arrests are going down.

WILLIAM DITTO: The other thing, too, when you say much smaller state we are geographically much smaller than Georgia, but we have about eight million people in New Jersey. Our motor vehicle registration amount was based on the number of drivers and cars. We had a good estimate. Motor vehicles could tell us how many register and re-register. I think our funding source is nice because it's painless. To be perfectly candid, however, many people have said to me, "doesn't that constitute a tax in this environment of no more taxes on citizens?" People will come back at me and say that 50 cents is really a tax on people. That's unfair. Interestingly enough, when the legislation was first drafted in New Jersey, the proposal was to have an affirmative checkoff on the motor vehicle registration that said, "I wish to contribute a dollar to the brain injury fund". If you checked that off when you did your registration, a dollar of that registration would have gone into the fund. Everybody knows those checkoff things aren't necessarily very reliable, and a lot of people don't opt to do that on their income tax or whatever. We had an unlikely ally in the form of the Motor Vehicle Commission who came and testified in front of the legislature and said "that's a bureaucratic and administrative nightmare to us.

Hit everybody for 50 cents, it's a much better way to go." We were not going to argue with them at that point. We were perfectly happy. The financing of the trust fund in this budget environment is a big issue.

ROBERT WALKER: Another thing. I think we need to be looking at the longer haul with these things. All these methods for collecting a core trust fund dollar amount are great, but they are going to scratch the surface and we need to look at things as seed money and think about using our data that we get from the system to build the argument for a line item budget directly out of state government. The reality is, as we were talking about earlier, when you look at how much is going into mental health and substance abuse, public health, developmental disabilities, it is pitifully low -- very low for brain injury. We have the opportunity of learning from the trust fund board data what the level of need might be and try to turn it into some higher budget amounts.

ANNE KING: We do have some questions.

ROBERT WALKER: Great. Amazing when you push the right button.

ANNE KING: I already said I was technology challenged. This comes from Russ Spearman, and the question is: "In Georgia, are the five agency representatives ex-officio members and can they vote the same way as the members appointed by the Governor?"

KRISTEN VINCENT: And Russ, the answer to your question is the members appointed from the five state agencies are full members of the Commission with voting powers. Those five state agencies are labor, which houses our Division of Rehab Services, Public Safety, Education, Human Resources and Community Health, which houses our Medicaid office.

ANNE KING: The next question is for Bill: "How did you convince legislators that it should be with motor vehicle registration? 44% of brain injuries are related to motor vehicle accidents being a sticking point for the type of funding in Maryland?"

WILLIAM DITTO: 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.

ROBERT WALKER: 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 VINCENT: We did that in Georgia as well.

WILLIAM DITTO: 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.

ANNE KING: Our next question we've already addressed in part, but this comes from Russ again: What are the pros and cons to using infractions or penalties to pay for this fund vs. using a less punitive approach, i.e. a registration fee that is annual?

ROBERT WALKER: 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. So, you know, it's a little bit of -- 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.

ANNE KING: OK. This is from Diane Triplett for Kristen. Please talk about how you created your Commission and that it was not self-serving for those on the Commission.

KRISTEN VINCENT: I don't know if you're talking specifically about who sits on the Commission, is that the way you understand that question?

ANNE KING: I think so.

WILLIAM DITTO: Providers being on there? Conflict of interest?

KRISTEN VINCENT: It is a good question and an issue we've had to deal with. The legislation says the Governor appoints 10 of the 15, the five agencies appoint the other five. The one thing that we have in our legislation, it specifies that seven of the ten appointed by the Governor have to be people with brain and spinal cord injuries or their family members. That's an important point to make sure that we are consumer controlled. The people with the injuries and their family members are helping to guide and make decisions about the trust fund. So the remaining three seats that are on there are generally filled by service providers, experts in brain injury or spinal cord injury, in the past the Brain Injury Association. There has been an issue of conflict of interest in Georgia in which a service provider has sat on the Commission. His agency was sending in a lot of applications to the trust fund to get funding for the services that they provide and so we really had to address that and develop some policies to kind of get at that issue and try to make sure that there is, you know, as little conflict of interest in that as possible.

WILLIAM DITTO: 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.

KRISTEN VINCENT: We have followed that procedure as well. And the other policy recommendation that we are considering at this point is that a service provider would not be allowed to fill out an application on behalf of an individual if the request is for the service that that service provider provides. If you can understand that.

WILLIAM DITTO: Yeah.

KRISTEN VINCENT: So that's another way we've tried to address that issue.

ANNE KING: Robert, this is for you from Holly Fentress. She indicates that she missed what you said earlier about the revenue source for the funds in Kentucky. If you could just reiterate.

ROBERT WALKER: It is the court costs on D.U.I. fines and some other traffic violations. I think it's reckless driving. 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.

ANNE KING: This question comes from Diane. Can your Governors take the funds from these dedicated trust funds? She goes on to say, in Maryland the Governor can raid any trust fund.

WILLIAM DITTO: Well, we had a discussion about this a little earlier today when we were preparing for this webcast and 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 WALKER: Ditto.

KRISTEN VINCENT: Georgia has a little bit of a different way out in that we have that Constitutional amendment. I talked at the very beginning about the fact that our legislation had to go before the general public to vote in a referendum and it was very successful in being passed. What that did was that created a Constitutional amendment to the Georgia Constitution that provides for D.U.I. fines to be collected to go into the brain and spinal

injury trust fund to be used for the care and rehab of people with brain and spinal injuries. Because it's now in Constitutional amendment so it's not just in legislation but in our state Constitution, it means that money must go to the trust fund and must be used for the care of people with TBI and SCI. I would encourage you to look at that if that's an option in your state.

ANNE KING: The next question is: "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 WALKER: I would like to respond to part of that. I disagree with that. 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. By creating designated funding and designated programs we begin to raise the consciousness of the Human Services provider community at large, policymakers, governors, legislators, etc. 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 VINCENT: I think what I would say to that is that it's now 2005 and I think that there are only 18 states with a trust fund. There are not many other states that have any other kind of alternative dedicated funding for TBI and yet again the incidence on TBI is astounding. So the fact that we're now in the 21st century and yet states still have not dedicated any kind of funding and services to people with traumatic brain injury says we'll need to do something. So I think that, you know, states are doing what they needed to do in order to get at least something for people with brain injury. As we've said many times already it's not enough. It's just a starting point but at least it gets the conversation going.

WILLIAM DITTO: 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.

ANNE KING: OK. We are about out of time. Let's just take one more question and we'll wrap it up. And let me reiterate that, any questions that were not answered today we will get responses and we will have this as an attachment with the archived version of this broadcast today. This (question) is a biggie: " 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, which is Virginia, is in the small percentage of those who do not provide direct consumer funds. " Anyone like to tackle that?

KRISTEN VINCENT: I think they're right.

ROBERT WALKER: Yeah.

WILLIAM DITTO: 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 VINCENT: 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.

ROBERT WALKER: We have tiny pieces. As I mentioned, we're getting injury report data in the sense of doing an analysis of hospital discharge data to tell us about the new incidence of brain injury. We have one prevalence study. It is a small amount of work. Very small amount.

ANNE KING: Well, thanks to our audience today for joining us and thanks to all of you who are on our panel. Again, also to CADE for broadcasting this presentation for us. Good evening.