

Brain and Spinal Cord Injury Advisory Council

Minutes

Date: October 22, 2009

Time: 8:30 a.m. to 4:15 p.m. EST

CHAIR		Marilyn (Mimi) Sutherland, BSN, MS, CNRN
ATTENDEES		
NAME	PRESENT	Staff Present
(Council Members)		
Marilyn Sutherland, RN, BSN, MS, CNRN, Chair	<input checked="" type="checkbox"/>	Thom DeLilla, Bureau Chief
Thomas R. Kerkhoff, PhD. Vice Chair	<input checked="" type="checkbox"/>	Janette Barbe
Patricia Byers, MD, FACS	<input checked="" type="checkbox"/>	Mary Brown
James F. Carrell	<input type="checkbox"/>	Teresa Hall
Erick H. Collazo	<input type="checkbox"/>	Scott Homb
James Edwards, BSN, RN, CRRN	<input checked="" type="checkbox"/>	Suzanne Kelly
R. Patrick Jacob, MD	<input checked="" type="checkbox"/>	Marilyn Larrieu
Paul Kornberg, MD	<input checked="" type="checkbox"/>	Susan Redmon
David Kushner, M.D.	<input checked="" type="checkbox"/>	William Reineking
Robert G. Melia, Jr.	<input checked="" type="checkbox"/>	Becky Robinson
Julia Paul, R.N.	<input type="checkbox"/>	Kris Russell
Grace Peay	<input checked="" type="checkbox"/>	Rick Schwarz
Lester Rice	<input checked="" type="checkbox"/>	Kris Shields
Dale S. Santella	<input checked="" type="checkbox"/>	Andrea Slapion
Karly Schweitzer	<input checked="" type="checkbox"/>	
Kenneth Weas	<input checked="" type="checkbox"/>	

Agenda topic: Welcome and Introduction

Discussion	The meeting was called to order by Mimi Sutherland at 8:30 a.m. Council members introduced themselves to meeting attendees. The audience members introduced themselves.		
Action Items	Person(s) Responsible	Deadline	
None.			

Agenda topic: Review and Approval of Minutes

Discussion	Tom Kerkhoff made the motion to approve the minutes. Paul Kornberg seconded the motion. The motion passed unanimously.		
Action Items	Person(s) Responsible	Deadline	
None.			

Agenda topic: Review and Approval of Bylaws

Discussion	Jim Edwards made the motion to approve the amended bylaws. Dale Santella seconded the motion. The motion passed unanimously.		
Action Items	Person(s) Responsible	Deadline	
None.			

Agenda topic: Legislative Issues

<p>Discussion</p>	<p>Thom DeLilla and Victor Johnson discussed legislative issues the Brain and Spinal Cord Injury Program and the Office of Trauma have been involved in during this legislative season. The programs submitted two Budget Issue Proposals for consideration this year. The first proposal was a joint request with the Agency for Health Care Administration (AHCA) to develop specialized skilled nursing facilities for individuals on ventilators. These facilities would be required to meet specific standards and criteria to serve individuals on ventilators. The proposal also included an enhanced Medicaid payment to those facilities. The Office of Trauma agreed to transfer a million dollars out of their trust fund to AHCA to be used as match. This proposal was cut by the department after it was contacted by the Governor’s office requesting they cut any issues that had General Revenue tied to it. As a result of this directive, AHCA also pulled their joint proposal. Mr. DeLilla stated that the Brain and Spinal Cord Injury Program needs a champion outside of the department who could move these bills through the House and Senate.</p> <p>The second Budget Issue Proposal the program put forth this year is to expand the Medicaid Waiver Program by 25 slots and to request funding for one position to aid the program administrator in the administration of the program. At this time, the proposal has been accepted, but has been modified to remove the requested position. Again this was due to the request for General Revenue to fund the position.</p> <p>Mr. Johnson briefly discussed the Adult Cystic Fibrosis Program and its placement within the Brain and Spinal Cord Injury Program. The program is currently managed by Kris Shields through a contract with Abilities of Florida. The program receives its own General Revenue appropriation and does not utilize any trust fund dollars. It is anticipated that the program will eventually become a waiver program.</p> <p>Mr. DeLilla introduced Susan McPhee, a representative of AHCA. Ms. McPhee will be attending council meetings on behalf of AHCA and will bring back any issues relating to Medicaid that the agency can assist with.</p>		
<p>Action Items</p> <p>None.</p>	<p>Person(s) Responsible</p>	<p>Deadline</p>	

Agenda topic: Brain and Spinal Cord Injury Program Budget

<p>Discussion</p>	<p>Victor Johnson reported on the status of the Brain and Spinal Cord Injury Program’s budget. For this fiscal year, the budget is \$27,075,990. The program has been working diligently to reduce expenditures throughout all areas of the program in response to cuts in the program’s general revenue appropriations and reduced revenues from fees coming in. It is expected that additional cuts will be made in general revenue this fiscal year and that revenues from fees will continue to decline. Mr. Johnson discussed that the program is adjusting the budget quarterly in response to revenue projections. The program is reviewing and evaluating all purchases, and monitoring and reconciling all expenditures to ensure accuracy and to avoid duplications.</p> <p>The discussion then began to center around ideas for increasing revenue. Ms. Sutherland suggested the following: seek a portion of the primary seatbelt fines; seek a portion of the fees for inspections for facilities being accessible; and partner with Contemporary Forums on an educational program. Mr. DeLilla discussed that there is a task force reviewing other states personal injury protection programs. Barbara Martelli suggested reevaluating the contracts with Brain Injury Association of Florida and the Florida Alliance for Assistive Services and Technology. Mary Brown suggested reducing the administrative costs associated with the Medicaid Waiver by implementing direct provider billing and Mr. DeLilla discussed working with Medicaid to increase the number of inpatient hospital days to more than 45 for individuals with severe, catastrophic injuries. Grace Peay recommended reducing the costs associated with lodging and meeting space for Advisory Council meetings. Steve Howells discussed actively promoting “money follows a person” demonstration grants where the money from Medicaid beds goes into the community for individuals with disabilities; working to collect internet sales tax and receiving a</p>		
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	<p>portion of those funds; focusing on subrogation agreements; and working on a cooperative agreement with vocational rehabilitation to receive a portion of the Social Security reimbursements they receive after an individual returns to work. Mr. DeLilla noted that the program has done very well over the past several years increasing the funds received from subrogation agreements, but that they seem to be lower this year during the first quarter. He will contact the department’s legal office to determine what is happening.</p> <p>Mr. Howells also recommended that the program make inquiries into the collections reported by the clerks of court. There has been a dispute between the courts and clerks of court on how fines are collected, where the money goes and how it is divided. Dr. Kushner asked about the possibility of creating a fee that the insurance industry would pay towards the program. Andrea Slapion discussed that when she sustained her injury she discovered that her state of Florida health insurance did not cover inpatient rehabilitation or transitional living services. She also discussed that there is no cost-sharing or financial eligibility for the program and suggested that this be considered. Mr. DeLilla suggested that a representative or group from the Advisory Council attend a meeting of the Governor’s Commission for People with Disabilities meeting to request they support a recommendation that the state health insurance include rehabilitation when these contracts are negotiated each year. He also discussed that he addressed the issue of the waiting period for Medicare following an injury (24 months) with the commission, but recommends that individuals send letters to their local representatives/senators about the need for individuals to be approved for Medicare immediately following their injuries so that acute care and inpatient rehabilitation could be funded.</p> <p>Mr. DeLilla discussed that great ideas come from unexpected places and that he strongly recommends that individuals (council members and attendees) have frank discussions with their local representatives about the program, the services it provides and the need for funds. He stated that it is often better that an individual ask their local representative, rather than the program work through its bureaucracy.</p>
Action Items	Person(s) Responsible Deadline
Follow-up with General Counsel’s office on reduced funds from subrogation agreements.	Thom DeLilla

Agenda topic: The Role of the Advisory Council and BSCIP’s Expectations

Discussion	<p>Mr. DeLilla discussed the role of the Advisory Council and the program expectations of what council members’ duties should be. Florida Statutes state that the council will provide the department with advice and expertise in the operation and development of the program and will be comprised of individuals with specific skills and abilities. It is expected that council members will attend the council meetings (two each year), be prepared and will actively participate in the meetings. Council members should notify the program if they will be unable to attend meetings. Mr. DeLilla also discussed that the Council develops task forces and members agree to participate. He would like to see members put in the time and effort into helping the task forces accomplish their goals and objectives.</p> <p>Discussion then centered around council members becoming advocates for the program. Mr. DeLilla discussed that he would like to see council members actively work individually and as a group to reach out to and educate our state representatives about the program, the individuals it serves and the services it provides. He spoke about new council member Ms. Rice’s skills and experience working as a legislative advocate for her organization and as a former legislative aide and how she can share this expertise with council members to assist them in becoming advocates.</p> <p>Ms. Shields discussed that the council meetings need to be “less show and tell” and more “rolling up your sleeves and helping us develop a program”.</p> <p>Mr. DeLilla continued with ideas for ways the council could provide assistance. Council members, particularly the physicians could request meetings with the Agency for Health Care Administration’s Medicaid director about issues and concerns; the Governor’s Commission on Disabilities; the State Surgeon General; or the Governor. Dr. Kushner asked if the Council could</p>
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plan a specific date when perhaps they could go to Tallahassee and have a schedule of meetings with different people. Mr. DeLilla indicated that the Council would need to work independently on making these arrangements perhaps with Ms. Rice's oversight. If the Brain and Spinal Cord Injury Program were involved in the process, it would have to receive approval from multiple levels of command and would have to provide a script of what would be discussed.

Dr. Kerkhoff discussed that the program would need to educate the council on the benefits that the program provides to the consumers, so they would have the information available at their fingertips. He mentioned that Ms. Slapion has reams of data that would be useful to pass along in a concise form. The council would need hard data to be effective.

Ms. Rice discussed that as a former legislative aide to Senators McKay and Bennett she has been in Tallahassee and knows and understands how the process works. She believes the council should form a legislative advocacy program that is comprehensive, cohesive and well-planned. The program should have the facts and figures to be able to argue its case effectively. She would like to have a "talking point sheet" put together before the Legislative session that could be used by council members when meeting with local representatives. She believes this also needs to go to the federal level and indicated that council members need to start developing relationships with their state and federal legislators.

Mr. DeLilla indicated that council members and meeting attendees who are interested would benefit from some type of training on how to be effective, what the protocols are to reach out and meet with legislators.

Ms. Rice discussed that it is much more effective to meet with legislators "on their home turf when they're in their district because then you are their constituent than when you meet with them in Tallahassee and they have the power of the body behind them. Then they're thinking more on political party lines as opposed to when they're at home and, quite honestly, they see you as a vote." In addition, Ms. Rice stated that legislators want to hear not only what the problem is, but what your solution is. She recommended that the council and program office start developing the case statement in brief - a one page document that states the issue, suggested solution, and talking points. It must include positive stories about the effectiveness of the program to get their attention.

Ms. Peay and Ms. Schweitzer both expressed frustration about wanting to volunteer assistance, but not having opportunities to serve for different reasons. At this point, the chair recognized Ms. Breen. Ms. Breen discussed that the Brain Injury Association of Florida (BIAF) in partnership with BSCIP holds quarterly teleconferences with 35 support group leaders around the state. Although these support groups are not official chapters of BIAF, they have a cooperative partnership with them to provide materials and education. BIAF recently held advocacy training at their Jamboree and 12 individuals attended. In addition, they provided two statewide teleconferences on advocacy training to the support groups. Ms. Breen invited Ms. Peay to contact Tina Dillahunt about the training. Ms. Peay requested that BIAF send information about these types of opportunities to the council members in the future.

Dr. Kornberg discussed that the Council needs to pool its resources and to dedicate more time at the meetings to focus on rolling up its sleeves and developing an action plan to translate to each task force's mission. As a clinician he requested direction on how "we" get together, who we talk to and in what format. We then would need to use that time in an efficient way because unfortunately, time is something that we all need to think about and how we can commit it. He restated, that the Advisory Council meetings should dedicate more time into an action plan and not just to discuss issues at hand.

Ms. Sutherland asked that audience members, as well as the council complete a one page form that asked what expertise, resources and time commitments they would be able to provide to the work of the Advisory Council and on behalf of the program. These were collected after the lunch break.

	<p>Mr. DeLilla indicated that he was very pleased to hear the excitement from some of the council members and their eagerness to participate. He understands that we all have our own individual stories we could share with legislators and the problems we face daily, but that this is not really the direction he would like to see the efforts go to. He is looking for the council to come together as a team or group that would support the program by distributing and working with community partners to address the individual needs that people have. It should be structured, in that if we asked a council member to advocate on our behalf, they would know that the issue that is critical now is the preservation of the program and our concerns about the budget and the need for additional revenue sources. He worried that if individual council members went out that the message would be spread thin and that they wouldn't know what we want.</p> <p>Mr. Howells discussed that one thing that has been very effective on all of the public policy committees he has served on over the years is to have legislative awareness day with issue briefs. They made appointments with key players. He volunteered that FFAST would be happy to use their infrastructure to assist the council and program draft legislative briefs specific to our needs. He referenced an example brief that was prepared by FFAST located under tab 9 in the notebook provided by FFAST to the council members. These briefs could be used to prepare the individuals meeting the legislative staff and then given to the legislative staff. Again he stated "We can do all of that work and have a BSCIP awareness day at the capitol."</p> <p>Ms. Rice asked Ms. Breen if they had a brain injury association awareness day. Ms. Breen responded that they had and would like to do another one. Ms. Rice discussed that rather than reinvent the wheel, maybe the council and program could "piggyback" on their process. Ms. Breen responded that the event last year was held in partnership with DOH. Ms. Rice praised the advocacy packet that has been developed by BIAF. She said it spells out what to do, how to say it, how to present yourself, what the protocols are, and what the do's and don'ts are. She would like to be able to borrow it for council and asked if we could have copies.</p>
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Action Items	Person(s) Responsible	Deadline
Obtain copies of the Legislative Advocacy Packet from BIAF.	Kris Shields	

Agenda topic: Brain and Spinal Cord Injury Program Priority Issues

Discussion	<p>Ms. Sutherland asked Mr. DeLilla to share what the program's priority issues are. Mr. DeLilla stated that his major concern is the budget. He needs the council during its round table type discussions to focus on budget issues and to help him deal with the realities of the revenues that are coming in to the program. He needs the council's input on what they believe would be the best utilization of the limited resources available. He needs the group to help him brainstorm other revenue sources. He shared he has discussed with his staff that the amount of money we really have available is not sufficient to address the needs of the population that is out there. We need to acknowledge that we have been under-serving people. He continued by discussing options of how the program might utilize its available budget, for example, you might decide that you would allocate a percentage of your budget to contractual obligations and the remainder would be distributed to the regions, or do we just contract out and whatever change is left distribute to the regions. Do we decide that we'll pay for inpatient therapy or a ramp? Which is more critical? It's hard, because it's all necessary.</p> <p>He discussed that another priority is educating our local representatives. He knows there are some initiatives, but we can get more focused. He understands Brain Injury Awareness Day and Spinal Cord Injury Awareness Day, but would prefer Brain and Spinal Cord Injury Awareness Week.</p> <p>He concluded that his priorities are: budget, new revenue sources, and some type of formula that could guide us in education of our elected officials.</p>
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Action Items	Person(s) Responsible	Deadline

Agenda topic: Research Awards Task Force

Discussion	<p>Dr. Kerkhoff updated the council about where the research awards task force is. There are two graduate student researchers who are finishing their projects. The projects could not be presented during this council meeting, due to the fullness of the agenda. We have requested PowerPoint presentations from them for the next Advisory Council meeting. Dr. Kerkhoff's concern is that there has not been a good response to the requests for research proposals. He is interested in obtaining consumer satisfaction results from both the student researcher and their major professors regarding the program and whether it was valued from their point of view. This may help the task force make a decision at the next meeting about whether to continue the task force.</p>		
Action Items	Person(s) Responsible	Deadline	

Agenda topic: Utilization of Assistive Technology Task Force

Discussion	<p>Andrea Slapion reported that the assistive technology task force no longer has a council representative or any other members as a result of the members moving on. The task force was moving along well prior to the departure of its membership. An infrastructure was developed by Michael Daniels and FFAST. There are now cognitive, assistive devices in the FFAST loan program and trainings on how to evaluate individuals for the best device were conducted. As a result of the budget shortfalls, things stalled, but the needs remain. Ms. Slapion requested that a council member volunteer to take on the Chair role and move the task force towards completion. She believes the task force should evaluate if the infrastructure will work.</p> <p>Dr. Kerkhoff suggested the task force incorporate the Florida OT Association and the Florida Speech Association to help get the word out to individuals who may be interested in working on the topic.</p>		
Action Items	Person(s) Responsible	Deadline	

Agenda topic: Roundtable Discussion of the Top BSCIP Priority Issue - Budget

Discussion	<p>Prior to Mr. DeLilla's discussion of this agenda item, Ms. Sutherland recognized Bud Bell. Ms. Bell recently died at the age of 94. Ms. Bell was recognized as one of the most effective advocates in terms of lobbying the Legislature. She was a special individual who mentored many in the legislative process.</p> <p>Mr. DeLilla began his discussion by quickly reviewing the earlier budget discussion for council members who arrived late. He asked that council members brainstorm for areas where the program could generate additional revenue and how to best utilize the purchase client service dollars the program currently has whether it be provided for direct client services, such as inpatient services, outpatient services, transitional type services, home or vehicle modifications, through contractual services to include resource information, peer mentoring programs, satisfaction and follow-along surveys. He discussed that the primary responsibility of the program is to work with individuals and their families to utilize all third party resources including personal resources, insurance, Medicaid, community-based services, other state agencies, vocational rehabilitation, food stamps, housing assistance, loans, etc. The trust fund should be used to fill gaps. He also discussed that currently it takes 24 months to get onto Medicare. By then, people have exhausted their insurance, have no insurance or are under-insured. They end up on Medicaid which requires you to lose all of your resources except \$1500, your home and car.</p> <p>Dan Newman addressed decisions made by Medicaid relating to the provision of durable medical equipment. The approval process is not working for the purchase of equipment that will meet the needs of brain and spinal cord injured individuals. For example, fully electric beds to assist with chair to bed transfers, pressure relief mattresses (only approved after development of a stage three pressure sore), ramps, lift transfer systems, bath aids, etc.</p> <p>Mr. DeLilla discussed that he has had the opportunity to meet briefly with Susan McPhee, AHCA</p>		
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to discuss how the program can begin to work more effectively with the Medicaid program. He stated that a lot of the work will have to be done locally.

Mr. Melia discussed briefly his experience when he was first injured. He spent almost 10 months in inpatient rehab and then a year in outpatient. Today, Medicaid pays for 13 PT visits, no OT. As a result, he believes clients are not gaining their independences, are in and out of the hospital, and are developing more pressure sores and UTIs. He feels if Medicaid looked at the big picture, they would see that putting dollars upfront would save money in the long run.

Ms. Sutherland stated that to expect a newly injured individual to be ready psychologically to begin rehab in three weeks is also unrealistic.

Mr. DeLilla stated that something from the Advisory Council should go to the Governor's office and to our national delegations regarding the 24-month wait period for people on Social Security Disability. He reiterated that BSCIP regional managers must meet with local area Medicaid offices to develop relationships and dialogue. He stated we need to work with Social Security on the issue of individuals with brain injury being denied. He will arrange for someone with the Department of Health, Division of Disability Determinations to be available to assist the program and we assist them in terms of getting individuals approved.

Ms. Sutherland asked how the process works and what benefits are provided for veterans that are returning with brain and spinal cord injuries.

Mr. Weas responded that he would have to get back with the council on the specifics, but that he could say that rehab is more than a few weeks, it's months. Poly trauma, depending on the severity and their multiple disciplines, could be even a year. Veteran's rehab planning and discharge is based on their condition, not on a time requirement.

Mr. Edwards added that in the sense of time parameters, the VA is similar to what occurred within the private civilian sector 20 years ago. They are not encumbered by the three-hour rule per day or other requirements that the private sector is locked into with a traditional rehab hospital today. However, they do face unique challenges. There are cracks between moving from the military healthcare system into the VA healthcare system. It is better today, than it was three years ago, but there are still problems. He indicated the "checks don't always start from the VA as quickly as you might like either. So the VA faces its challenges as well. They are making phenomenal strides to improve them but there are still issues."

Mr. Weas stated that a veteran is not eligible for any VA system or the Social Security VA combined until they are fully discharged from the Department of Defense. There are currently several veterans who are still active duty a year after being injured. They have to be discharged from DOD into the VA system. That's a bigger challenge than their rehab, because they continue with rehab regardless of which branch of service they're in or what government is providing their care. He indicated he would do research to see what the average time is on SCI/TBI and will report back to the Council.

Ms. Schweitzer stated that a head injury, if it is not visible to others, it's not an injury, so we need to educate the Legislature and whoever is making the laws about the severity of it.

Ms. Breen discussed that about eight years ago, the BSCIP drew down federal dollars through HRSA and partnered with BIAF to conduct a one year study and a training program with the Office of Disability Determinations and Social Security. A review of the red flag process was conducted because it was not working for TBIs because they kept showing progress in the hospitals. As long as an individual showed progress they couldn't determine disability. A system was worked out with them where there were impairment pieces within disability requirements and red flag where you could do presumptive disability on TBI, but it required a combination of neuropsychology and communication between the offices. The grant ended and the momentum was lost, so red flag continues to work more for spinal cord injury than brain. She indicated that BIAF's family support program continues to deal with this issue.

Mr. DeLilla reiterated that is about developing relationships at the local level, that it's important for the administrator of the rehab hospital, as well as the people in social work, the primary treating physician to contact the local Social Security Disability office, Social Security Administration and Disability Determination. They should be invited to the facilities, introduced to people with TBI and SCI, educated about these disabilities and then express the problems and issues of them being denied. He stated that a lot of the decisions are based on how it reads in the case notes. For example, a case note may say that a TBI client can't blink their eye, and then the next day they can. The case note will say, making progress. When the report is reviewed, a disability determinations worker will say "Geez, they're making progress so we'll have to just watch this for a period of time to see whether this continues to improve." We need to ensure that case notes are phrased appropriately so that the disability determinations worker knows this person has a significant and severe disability that is going to last more than 12 months and that they will not be going back to work. Mr. DeLilla stated he would tell Jim McHargue, Director of Disability Determinations, "Well look, Jim. We're in this together. If these people are cured, I'm going to call you and then you can stop the benefits. We're not into harboring cured people to get their Social Security check. That's ludicrous. Please work with us."

Ms. Sutherland stated there is a dichotomy to that and being in the clinical world they also document to "cater or please the insurance companies" because if they don't document progress they're out. "It's a catch 22 and a very fine line in both the clinical acute care and rehab."

Ms. Slapion commented that many times the budget is misunderstood. People tend to divide it up and think about the funds spent on services vs. other program activities. Many of the individuals the program serves do not actually use services dollars (70%). BSCIP case managers spend a majority of their time and efforts notifying, evaluating and assessing community referral information resources. She wanted to emphasize that when people do the "math equations in their head to remember that our charge is to notify, identify, evaluate and screen for program eligibility. That is a whole caseload unto itself."

Ms. Sutherland stated that as the budget figures are presented, we should discuss direct client services, but should also discuss the indirect client services. When we look at contracts and salaries we look at these things as indirect client services.

Mr. Edwards discussed looking at the budget in the traditional model where you are able to look at your assets and your liabilities. We are challenged in this respect because we can say "Yes, we spent X number of dollars on client services", but how do we demonstrate what our output is, what our outcome measures are. To say we touched X number of lives. We have a trauma registry, we know about injury statistics, but need to be able to have aggregate numbers between the dollars we have used through contracted services with BIAF, the CILs, those indirect services.

Ms. Sutherland stated the next biggest issue is cost savings. That's what people are going to want to hear. "What does the program do to save money from whatever pocket you want to talk about?"

Mr. Edwards discussed that the healthcare market today has the latest and greatest drugs, test, and procedures, but the bottom line is "So what? What difference did it make?" We have to be able to demonstrate positive outcome measures.

Ms. Redmon discussed that what is happening with BSCIP is happening across disability groups. Fifteen to 25 years ago, children served under the CMS program weren't living into their teens and adult years. No one was thinking about the healthcare transition from pediatric to adult services because there were so few that it was an issue for. As a result of advances in pharmaceuticals, surgical procedures and treatments children are living. The medical community is in the current century and maybe a little beyond, but legislation and services and

programs have not kept pace for whatever reason. She stated "while we're looking specifically at brain and spinal cord injury not to forget that there is strength in numbers." and that "there are many individuals throughout the state, throughout the country who are just as challenged to find a way to participate in a quality of life in their community because of their chronic health problem or disability." She stated we "need to remember there are opportunities to get legislation pushed through when we're part of a larger group."

Dr. Kerkhoff asked "Given that the military systems and the VA systems are essentially mini versions of the universal health system for their eligible participants, how do they make a decision about allocation of resources, time and therapeutic effort within those systems since they are accountable to the government, to a public entity for justifying quality outcome?"

Mr. Weas gave a layman's version of the system. The VA is divided into division networks (23). Florida is division 8. The VA allocates \$57,400 per SCI/TBI per veteran annually. The allocation is based on your disability. This allocation is funneled out to the different facilities that the individual veteran uses. For example, Mr. Weas uses Orlando for primary care and they get a percentage of the dollars, and he uses Tampa for an annual evaluation so they receive a percentage of the allocation. He doesn't understand the formula, but he knows this is the dollar amount because they use it when advocating for veterans.

An unidentified speaker discussed that he has worked with various systems (private, worker's compensation, the VA) and that he currently has a client who was served at the VA at James Haley for 18 months with a bedsore wound. Their motto and philosophy is no one goes home until their wound is healed. He has had clients in this program who he can't even get wound care for, so there is an enormous disparity.

Mr. Howells stated the VA model should be the model we advocate for with Medicaid, Medicare, and the state of Florida and beyond.

Ms. Byers discussed that the private sector has stopped funding long-term care and it happened with little notice and public comment. Individuals are having to drop their insurance they've had for their entire lives and go on Medicaid because the insurance companies refuse to cover their long term problem at any level. She stated it might be a good time to lobby for some liability in terms of the insurance companies and insurance reform. It should be very clear on policies, that the policy does not include "any catastrophic long-term problem", and have a reasonable price to pick up a long-term trailer type of thing. She's been listening to the healthcare debates and hasn't heard this issue once.

Mr. Howells discussed that he served as an adjudicator for Social Security Administration and had run a program that sued Disability Determinations in federal court for not making timely decisions. Neither is required to make decisions within 90 days. He stated their record is getting better due to the use of technology. He stated Social Security denies 90% of all disability claims on the first application and on reconsideration. You have a 50-50 chance if you appear before an administrative judge. It is a system designed for denial, not allowance. He discussed it is vital to know what to include on the 3368 form. Doctors need to declare that a person is likely to not return to work for a period over one year. They need to clearly document the severity of the disability, and this should be done by the doctor, not the client. He stated most congressional offices have aides that do primarily Social Security inquiries and if they get involved a flag will go on the case and will move more quickly and with more attention. He stated you need to claim multiple disabilities, because Social Security has to take multiple disabilities into account. For example, brain injury and depression may need to be claimed, spinal cord injury and depression, or learning disability. You must claim it because then it has to be assessed as a part of a full case. He offered to put together some talking points that may help the case managers and would be glad to work with BIAF on the subject.

David Jones discussed briefly his experience following his traumatic brain injury 20 years ago. His rehab experience led him professionally to provide recreation and active leisure to people with all disability types. He received three months of rehab in a rehab hospital that included a

very active recreational therapy program. Individuals today are not receiving recreational therapy. He stated with the shortened stays in hospitals now, it is "just survival and out. So either you're not ready for any type of community reintegration or you're not ready for any type of preparing for the rest of your life." He stated it's important that "the council know that providing active leisure and the tools for such, assistive technology and resources and services to enable people to stay active in their leisure time is so important." He stated being active will help prevent pressure sores. It's what you do with the rest of your life, the quality of your life, contributing to society. It will contribute to the role you play on the burden of society, back in the hospital, etc. He stated that he has been very active in the recreation world. He is serving on the National Parks Recreation Association Board, and has begun serving the second three year term on the TR section. He's learned a lot about healthcare and recreation and stated that the country is beginning to "get it that dollars spent up front will prevent dollars, many, many more dollars spent on the tail end." He believes the healthcare crisis in the country is causing experts and research people to document and show outcomes through studies and surveys that prove that interaction and involvement with active leisure and recreational opportunities are saving money. He believes the recreational world is rapidly becoming a key player in the healthcare world. He believes Florida has the opportunity to step up and take advantage of the trend because the healthcare crisis is not going away. We will need to step up and provide resources and community opportunities to do what's best for the country and that means bottom-line dollars, too.

Mr. DeLilla stated that a lot of ideas and things to consider had been presented. He sees the value in everything discussed and that we will need to take actions on them. He then proceeded to bring the topic back to the program's budget. He asked the council to provide input into how the program should utilize the purchased client services budget. He asked them to entertain discussion about how to distribute this budget. For example, should the program set aside a percentage to use for contracted services and the rest distributed to the regions for direct client services (inpatient rehab, outpatient rehab, transition programs, and home/vehicle modifications)? He asked for other ideas.

Ms. Breen stated that "it's not an issue of terminology of contract, direct client services, etc. The issue is critical and essential services for people with TBI and SCI at about a 6 to 1 ratio in terms of numbers." She also stated that the issue is "how much of these contracts are direct client services? She believes it's not about coming up with percentages, as much as understanding what all is being delivered. She discussed that the program, itself, could not deliver services to individuals with mild brain injury because it couldn't hire staff, it had eligibility criteria that was limited, and so used its providers and community partners to get these services out.

A short break was taken, and when the meeting resumed, Ms. Sutherland wrapped up this session. She indicated that after some thought, she would call for another meeting to focus entirely on this topic. The meeting would be for advisory council members only and asked that information from the VA system be provided. A representative from each of the contractual agencies will be invited to present and will be asked to provide a priority list of services and their dollar amounts. The contractual partners should also indicate what other funding sources they may have. The council will need more information on the budget allocations both contractually and the infrastructure. Once the contractual partners have presented they will leave so that the council can sit and discuss what they need to do for an action plan. Ms. Sutherland asked that Ms. Schweitzer, Ms. Peay, Mr. Melia, Mr. Santella and Mr. Weas put together a three-quarter-page sheet of what you would like to say to a Legislature if you went to visit him. She asked that the bottom section be left blank and that the council would decide what "we're going to ask for" at the next council meeting. These should be sent to Suzanne Kelly.

Ms. Peay indicated that she felt uncomfortable in having "a say in how much is cut" in the contracts.

Ms. Dreker stated that she supports the opportunity to review what the contractual partners

	<p>provide and the costs associated, but wants to ensure that the budget across the board is looked at closely for other possible cuts.</p> <p>Ms. Sutherland agreed. Mr. Johnson asked for clarification on what the council would like to review. Ms. Sutherland requested that the current revenue information be provided, as well as projections. She asked the council members to think about and send in feedback on what they would like to know at least two weeks before the meeting.</p> <p>Mr. DeLilla wanted to reiterate that of the \$27 million dollars the program has in its budget that \$1 million is legislatively mandated to the universities, close to a million goes to the Broward Children’s Center and nearly a million is for the Adult Cystic Fibrosis Program. These costs are unrelated to the program, but appear in the program’s budget authority.</p> <p>There was discussion relating to the university funding and their accountability for how it is used. Mr. DeLilla stated that he would ask representatives to attend the meeting to talk about where this funding was being utilized. He also talked briefly about the Medicaid Waiver allocations and their cost savings over the long-term.</p> <p>The format of the next meeting was reviewed again.</p>
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Action Items	Person(s) Responsible	Deadline
Work with the DOH, DDD to identify an individual to work with BSCIP in an effort to facilitate the approval process for brain and spinal cord injured individuals.	Thom DeLilla	
Research the average length of rehab for SCI/TBI veterans and report back to the Council.	Ken Weas	
Develop a three-quarter-page sheet of what you would like to say to a Legislature if you went to visit him and forward to Suzanne Kelly.	Karly Schweitzer, Grace Peay, Bob Melia, Dale Santella, and Ken Weas	
Send in feedback on what you would like to know about the budget.	Advisory Council	

Agenda topic: Advisory Council Elections

Discussion	<p>Suzanne Kelly reviewed the timeline for Advisory Council chair and vice-chair elections. Nominations forms were provided to the council during the meeting. She asked that council members talk to each other before nominating an individual to ensure their nominee would be interested in serving. Nominations must be received no later than November 30th. Ms. Kelly will then send a ballot out electronically. These must be completed and returned no later than January 1st. Ms. Sutherland asked that council members review the remaining terms of council members and keep in mind succession and leadership when making their nominees.</p>
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Action Items	Person(s) Responsible	Deadline

Agenda topic: Day One Wrap-Up and Instructions for Day Two Location

Discussion	<p>Dr. Byers asked that council members go to trauma.com and provide input into a SWAT analysis that they are using to develop a five-year plan. Ms. Sutherland wrapped the meeting up by reminding attendees to be on time and be prepared to meet as a group to go out and see the FAAST Assistive Technology Van demonstration. The meeting adjourned at 4:15 p.m.</p>
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Action Items	Person(s) Responsible	Deadline

CHAIR		Marilyn (Mimi) Sutherland, BSN, MS, CNRN
ATTENDEES		
NAME	PRESENT	Staff Present
(Council Members)		
Marilyn Sutherland, RN, BSN, MS, CNRN, Chair	<input checked="" type="checkbox"/>	Thom DeLilla, Bureau Chief
Thomas R. Kerkhoff, PhD. Vice Chair	<input checked="" type="checkbox"/>	Janette Barbe
Patricia Byers, MD, FACS	<input checked="" type="checkbox"/>	Mary Brown
James F. Carrell	<input type="checkbox"/>	Teresa Hall
Erick H. Collazo	<input checked="" type="checkbox"/>	Scott Homb
James Edwards, BSN, RN, CRRN	<input checked="" type="checkbox"/>	Suzanne Kelly
R. Patrick Jacob, MD	<input checked="" type="checkbox"/>	Marilyn Larrieu
Paul Kornberg, MD	<input checked="" type="checkbox"/>	Susan Redmon
David Kushner, M.D.	<input checked="" type="checkbox"/>	William Reineking
Robert G. Melia, Jr.	<input checked="" type="checkbox"/>	Becky Robinson
Julia Paul, R.N.	<input type="checkbox"/>	Kris Russell
Grace Peay	<input checked="" type="checkbox"/>	Rick Schwarz
Lester Rice	<input checked="" type="checkbox"/>	Kris Shields
Dale S. Santella	<input checked="" type="checkbox"/>	Andrea Slapion
Karly Schweitzer	<input checked="" type="checkbox"/>	
Kenneth Weas	<input checked="" type="checkbox"/>	

Agenda topic: Welcome and Introduction

Discussion	The meeting was called to order by Mimi Sutherland.		
Action Items	Person(s) Responsible	Deadline	
None.			

Agenda topic: Demonstration of FFAST Assistive Technology Van

Discussion	Mr. Howells began the presentation discussing the contents of the notebooks he provided the council. He stated that he wanted to make it clear that the van that they would be demonstrating was not paid for using BSCIP funds. The van is taking technology to the people. Currently FFAST has six regional demonstration centers around the state to teach people how to use technology. He discussed there are slots available for an ethics training (mastery system) that they will be conducting. They also do a number of resource guides including <u>Your Rights in Nursing Homes</u> , <u>Your Rights for Older Americans</u> , and <u>Housing Resource Guide</u> . He reviewed their provider web guide, talked about other publications they offer, and discussed their technology loan program. Andre' Howard began a demonstration of assistive technology that can be loaned out to consumers for trial periods. The group moved outside for a demonstration of the Assistive Technology van.		
Action Items	Person(s) Responsible	Deadline	

Agenda topic: Videoconferencing Demonstration

Discussion	Susan Redmon discussed that the program recently received funding from a DOH Centers for Disease Control grant to purchase video conferencing equipment. The grant's focus was to provide opportunities for access and networking for vulnerable populations. The video conferencing equipment will be used for a variety of purposes. Frank Gholston with Children's Medical Services (CMS) provided assistance to the program in selecting the equipment, getting it installed and providing training to staff in its use. Ms. Redmon discussed ways the CMS program is using video conferencing to provide telemedicine services for children who may be 2-3 hours away from the specialist who needs to see them and to the child protection teams. They use the equipment to hold meetings and trainings between the 22 CMS area offices.		
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She discussed that BSCIP has been using the equipment to conduct statewide meetings of its staff which reduces travel expense. There is no charge to use the equipment because it is on the DOH computer network. It promotes a positive working relationship. People do not multitask when they use the video conferencing equipment, and are more engaged in what's going on. The program is considering the use of small handheld cameras to use in the field to assist in doing assessments. The department is expanding their technology and network to connect to the Florida trauma centers and the Florida burn centers. Mr. Gholston provided a presentation on the technology of teleconferencing.

Action Items	Person(s) Responsible	Deadline

Agenda topic: Kids and Canines Program Presentation

Discussion
 Jennifer Wise, students of the Kids and Canines Program, and dogs in training conducted a demonstration of training techniques. The program places dogs with varied disability type individuals (brain injured, spinal cord injured, children with autism, etc.) The program uses at-risk kids from 6th to 12th grade as trainers. The children learn patience, self-control, responsibility, problem-solving, and positive reinforcement and then carry that through to the animal they are training. She stated their motto is "what works for a dog works for a person". The dogs are trained for an average of three years before being placed with an individual. There is an application process for receiving a dog.

She discussed that they are a "kind of double program". They are a school district program. The children receive grades and she is a school district employee. They are also a non-profit service dog program. They are accredited with Assistive Dog International, a worldwide accrediting organization. They use volunteers and depend on a large amount of fundraising to provide the dogs, facility, food, vet services, training and equipment. They generally use breed dogs (Goldens, Labradors, and Doodles) and start working with them at eight weeks old. They do not use rescue dogs because they require a higher skill level for training and are a liability issue due to unknown temperaments.

Action Items	Person(s) Responsible	Deadline

Agenda topic: Medicaid Home and Community-Based Waiver and Nursing Home Transition Updates

Discussion
 Kristen Russell discussed changes that have occurred within the Medicaid Waiver Program. BSCIP has signed an agreement with Vitaver and Associates to contract for eight Medicaid Waiver Specialists statewide. These specialists work independently from home offices. The program provides them a cell phone, copier/fax machine and laptops. They are paid mileage for client-related travel. Their role is to help ensure the health and safety of our clients and to ensure fiscal accountability. They continuously evaluate the need for services and provide our clients choices and alternatives for providers. They oversee the community support coordinators.

The criteria to be on the Waiver are identical to being placed into a nursing home. You must need a certain level of care and must meet financial eligibility criteria determined by the Department of Children and Families. The waiver is administered through the Agency for Health Care Administration. BSCIP operates the waiver. The program utilizes providers who are expected to provide quality service, treat recipients with respect, and adhere to the terms of service authorizations. The recipients have responsibilities as well, including being cooperative and notifying their providers that they will not be home or need to reschedule their scheduled visits. Clients have the right to a fair hearing if they feel they have been treated adversely. An adverse action can be reduction of services, suspension of services, or termination of services. As a result of the work of the Waiver Specialists, BSCIP has prevailed in 95% of hearings so far.

Clients primarily work with a community support coordinator. They are responsible for resolving services issues or problems, and must visit the client face-to-face at least once a month. This requirement is being evaluated at this time, as it appears some clients do not need a monthly visit. Clients are expected to develop a back-up plan in the event their home health aide or companion doesn't show up. Emergencies occur and the client must be prepared, so the

support coordinators work very carefully with them to plan. The support coordinator is the first line of contact for our clients. The support coordinators are required to meet regularly with the Waiver Specialists. The Waiver Specialists supervise groups of support coordinators and will schedule monthly meetings or conference calls to discuss resources and to schedule speakers/trainers. The support coordinator is required to monitor the quality of service because they are in the home on a monthly basis. Ms. Russell stated, "They have eyes to see, ears to hear, and noses to smell. They can see what's going on in the home and can address any funky smells, any funky activity that may be happening, and we have had some pretty funky activity going on in our clients' homes. I mean, our clients, if they were bad boys before they were injured, they usually continue to be bad boys. We have found meth labs in their back yards. We have had a client ask his companion to light his crack pipe, and we can't do that."

The waiver specialists also recruit and help to enroll new providers. They are responsible for doing the initial enrollment of a new recipient. They do the initial eligibility determination and development of a care plan. They then assign the client to a support coordinator.

Currently the Waiver program serves 326 people. When the Waiver Specialists came on board, the program was serving about 250, and that was all that could be served because there were no funds available. The Waiver Specialists began evaluating each service on client care plans to determine if they were medically necessary. The primary responsibility of a service is to be medically necessary. As a result, the program has been able to increase the number of clients served because of very responsible, very careful service deductions. It was a very difficult exercise and they are still in the process of completing it. Satisfaction with waiver services is at an all-time high.

She reported that under the approved waiver from the federal Center for Medicaid and Medicare Services, we have just entered into the third year of a five-year agreement. The waiver is authorized to serve up to 375 people. There is a waiting list of 575 plus. We have not filled the remaining waiver slots due to lack of funding. Last fiscal year the waiver served 315 people with an average care plan cost of \$35,000 a year. The average cost of care in Florida for nursing home is \$85,000 per year.

A problem that has risen is a lawsuit that was filed against the Medicaid office and the Agency for Elder Affairs. BSCIP was not sued. This lawsuit states that there are people in nursing homes who want to come home and they could come home if there were waiver services available. So, as part of the settlement agreement, the Agency for Health Care Administration is allowing partnering agencies (DOH, DCF, DOEA) who have waivers to access dollars from the nursing home line item of the state Medicaid budget to bring people out of the nursing homes. The purpose is transition these individuals from nursing homes to the community, because before they were placed in the nursing home, there were no services available.

BSCIP agreed to participate since there are people on our waiting list who are in nursing homes. The benefits are we can serve more people from our waiting list, there's no BSCIP trust fund involved because the funding will come from the nursing home line item, we'll be able to utilize all of our remaining slots which will eliminate our legal jeopardy. However, there is no guarantee that the money will be there next year, so we are being very cautious. As a result, she has promised to transition 10 people. She cannot risk having no continued funding available next year. This would require that all 375 individuals be covered under the BSCIP funding and would require elimination of services across the board to stay within the limited budget.

Ms. Russell reported that to be eligible for the nursing home transitional program, individuals have to be enrolled in the program, have been in the nursing home a minimum of 60 days and must have a place to go. She has already transitioned three individuals, two with brain injuries, and one with a spinal cord injury. Two more are expected to be transitioned soon and they are both brain injured.

Ms. Sutherland made a motion that the Advisory Council communicate in writing with the state

	<p>Medicaid office urging funding with recurrent funds to fill the current waiver slots in order to reduce Medicaid expenditures for maintaining waiver eligible individuals in nursing homes and to eliminate legal jeopardy from unfilled slots. She would also like to send a copy to the legislators. The motion carried unanimously.</p> <p>Ms. Sutherland suggested that we need to invite a local legislator to each Advisory Council meeting and ask them to do a mini introduction. This would be an opportunity to education them on the program they sponsor, they fund. We would need to be very critical and strategic in what we want them to hear, concise, something that would not take a lot of their time. She also recommended BIAF invite one to speak at the Jamboree. We need to be more proactive in involving them in the process. All they hear, is we need money. We need to bring them to the table to hear what is going on.</p>
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Action Items	Person(s) Responsible	Deadline
Communicate in writing with the state Medicaid office urging funding with recurrent funds to fill the current waiver slots in order to reduce Medicaid expenditures for maintaining waiver eligible individuals in nursing homes and to eliminate legal jeopardy from unfilled slots. Copy the legislators.	Advisory Council	

Agenda topic: BSCIP Rules Update

Discussion	<p>Michael Grief provided an update on the rules currently being developed by the BSCIP. Rule 64I-1.005 governs the services delivered by transitional living facilities. AHCA has the duty to under law to govern “their bricks and mortar requirement for licensure.” We are working in combination with AHCA on the development of this rule. These rules are the product of four or five workshops that have been held over the past year.</p> <p>Mr. Grief reviewed the remaining rules. A suggestion was made that a layman’s document be prepared that explained the rules, particularly the Order of Selection rule in the event this information needed to be shared with clients. Ms. Sutherland indicated that a there was a typo in one word and that the name of the neurosurgeon referenced was spelled incorrectly. Questions were raised about adding in financial eligibility or cost sharing. Mr. Grief indicated that the statutes governing the program do not allow us to add this in. Ms. Sutherland asked that this issue be revisited as the meeting was running behind schedule. Ms. Kelly announced that the rules as written would soon be advertised in the Florida Administrative Weekly and if requested a hearing may be held.</p>
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Action Items	Person(s) Responsible	Deadline

Agenda topic: Task Force Report – Skin Care

Discussion	<p>Patricia Byers reported on the skin care task force. Dr. Byers discussed that skin care as a trauma standard had been put forward for rule development. A teleconference was held with the hospital rules planning committee and it was very well received, so they are not expecting any problems with it. It will be part of the trauma center criteria. Ms. Sutherland asked if the task force should be closed and Dr. Byers indicated that maybe it should stay active until the rule passes. Ms. Sutherland agreed. The task force will be closed at the next council meeting if the rule passes.</p>
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Action Items	Person(s) Responsible	Deadline

Agenda topic: Ventilator Dependent Task Force Update

Discussion	<p>Patricia Byers reported on the Ventilator Dependent Task Force. Dr. Byers reported the vent dependent was turned down. (legislative issue) In terms of the pacer program, she reported that it is taking on a life of its own because it is such good technology. They (Trauma Planning Committee) are starting to develop patient eligibility criteria and have forwarded it to Susan McDevitt’s office. Ms. Sutherland asked for a motion to rename the Ventilator Dependent Task Force to the Diaphragm Pacer Task Force. After discussion on the two issues, vent dependent and diaphragm pacing, the council decided to rename the task force the Diaphragm Pacer Vent Dependent Task Force. Mr. Melia made the motion; it was</p>
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	seconded by Dr. Kushner. The motion passed unanimously.	
Action Items	Person(s) Responsible	Deadline

Agenda topic: Skin Care Task Force Update

Discussion	<p>Thom DeLilla reported that the Skin Care Task Force has been successful in its efforts. He reported that he has been attending site surveys with Bill Reineking and always asks the facilities if they are using the pressure mapping systems that were purchased by BSCIP. The responses he receives are always positive, that they are being fully utilized and one facility reported wearing theirs out. He will get with Andrea Slapion to do a follow-up survey to the facilities to substantiate the utilization of the systems.</p> <p>He also discussed that the program has seen real improvements throughout the state since the pressure sore issue was identified. The PUP program was developed. Case managers began reporting cases to Mr. Reineking if they saw a patient with a decubiti. The case would be reported to Susan McDevitt who would then contact the facility. As a result, we are doing better in this area. Standards were developed also.</p>	
Action Items	Person(s) Responsible	Deadline
Develop a follow-up survey to substantiate use of pressure mapping systems.	Thom DeLilla/Andrea Slapion	

Agenda topic: BSCIP/VA Community Partnership Task Force

Discussion	<p>James Edwards reported on the BSCIP/VA Community Partnership Task Force. After numerous conference calls, the task force membership was recently finalized and is very diverse. It includes representatives from the James Haley VA, Paralyzed Veterans Association, BSCIP, BIAF, FFAST, the CIL, AHCA, VR, Florida Disabled Outdoors Association, the Office of Trauma, the Florida Department of Veteran Affairs and the University of Miami Ryder Trauma Center. Ken Weas has worked with BSCIP and conducted training for all BSCIP staff, except for Region 1 which is scheduled for December. The task force has held two meetings. The first formal meeting was a conference call on October 13, then a face-to-face meeting and teleconference yesterday. They have identified six areas of concern that they are in the process of addressing. They would like to develop a resource or pamphlet that can be available in every VA treatment facility (medical center or local clinic) and can be provided to any veteran or family member of a veteran with a brain or spinal cord injury. It would be simple and would basically say contact us so we can help you get to other community services to compliment the services provided by the VA. The task force wants to address the needs of veterans with mild TBI who are not currently reported through the Central Registry. The want to establish mutual referral between the VA, BSCIP and other community partners. Regional meetings will be held between the VA, BSCIP and local community partners so that all the interested parties know each other and understand how to contact each other and facilitate services. The task force will develop relationships with all the VA hospitals and clinics in Florida. They also want to address the issue of family support.</p> <p>To date, they have spent a significant amount of time discussing the development of the pamphlet. Ms. Breen has graciously agreed to take the lead on developing it. David Ramga with the Florida Department of Veterans' Affairs has agreed to help distribute the information. Mr. Ramga notified the task force that there will be a State/County Veterans Service Officer annual conference. This may be an opportunity to "show up, be at the table, and again represent what our program and other community partners can do for a veteran statewide." Mr. Edwards stated that they are not intending to reinvent the wheel. The VA has fantastic resources that are getting better and better. The task force wants to make sure everyone is aware of what the other community partners in the true sense can do to help each other and provide mutual support. They are just trying to connect the dots. He believes the task force will be able to wrap up sometime next year.</p>	
Action Items	Person(s) Responsible	Deadline

Agenda topic: Standards Revisions Task Force

Discussion	<p>William Reineking reported on the Standards Revisions Task Force. Mr. Reineking has a task force of about six people who have volunteered to serve. He acknowledged Tampa General for supplying a large volume of people who are interested in the project. He asked for more individuals to apply to serve on the task force. Ms. Sutherland suggested he email the designated facilities, inform them that he is doing revisions and that he is looking for a finite number of volunteers. He would then be able to fill any gaps for representatives geographically, institutionally, and by discipline. Mr. Reineking agreed. He reported that site surveys of HealthSouth Sunrise, Tampa General and Bay Front Medical Center have been completed. All three facilities received renewal certifications. The next facilities to be reviewed are Shands Rehab in Gainesville, Lee Memorial Rehab Hospital and Brooks Rehabilitation. These will wrap up in December.</p>		
Action Items	Person(s) Responsible	Deadline	

Agenda topic: School Reintegration Task Force

Discussion	<p>Karly Schweitzer reported on the School Reintegration Task Force. Ms. Schweitzer reported that the task force had a conference call on September 22nd and has come up with models developed by the task force members. Smaller groups of task force members are reviewing models presented and will consider them in the development of a new reintegration model. They are also considering the use of section 540 to provide accommodations to the core TBI, lacking or limited ability for teachers or school staff to change student’s pre-injury curriculum and the need for further education of counselors, school staff and teachers. They have been working on this algorithm. The next task that Ms. Schweitzer has identified is integrating support systems in the school system for families of the survivors. When she was injured and reintegrated back into the school system, her “parents had no where to turn. They didn’t know what to do.” She stated if there are people that have been through the process, not just professionals, that are willing to help and can advise them on what they should and shouldn’t do; she believes this will be very beneficial.</p> <p>Ms. Sutherland asked the task force to include school resource officers (school police) in education and training of the behavior issues of mild to moderate TBI. These individuals often escalate situations out of control because they don’t know how to manage these students.</p> <p>Mr. Santella stated that it’s important for the task force understand their ability to use the BIAF family support program for individuals with brain injury. They can go in and work with the families and the teachers and work with the ESE teachers to help develop the IEFs and help develop strategies for the individual students.</p> <p>Ms. Redmon discussed that she had spoken with Sheryl Sandvoss from the Department of Education. Ms. Sandvoss works out of Tallahassee and she ran the draft algorithm by 45 of the 67 counselors. These individuals thought it looked good, so she does not anticipate there will be any problem integrating it into the schools.</p> <p>Dr. Kerkhoff requested that once the algorithm is set and defined, that it be shared with the council for their input.</p> <p>Ms. Breen reported that BIAF is developing an online training specific for teachers called Disability in Disguise – About Traumatic Brain Injury. It has already been used in regional workshops for administrators in school systems.</p>		
Action Items	Person(s) Responsible	Deadline	

Agenda topic: Neuro Behavior Programs Task Force

Discussion	<p>Valerie Breen reported on the Neuro Behavior Programs Task Force. Ms. Breen discussed that the Celeste Putnam had been hired to conduct a study on model programs on neuro behavioral services throughout the country and study what Florida is doing. A summary report was included in the council member’s binders. The findings were presented at the last</p>		
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council meeting. The task force concludes that the Neuro Behavior Task Force come to a close and it be turned into a long-term care task force. They have recommended that Florida concentrate on implementing the TBI strategic plan, which incorporates the needs of persons with neuro behavior disorders as part of that work. The task force suggests that rather than having funding strictly for neuro behavior, that there are long-term care issues for all survivors of TBI, and that neuro behavior should be part of that continuum of funding. One funding option would be a home and community-based waiver designed to serve this population. She stated "since most of the individuals who need long-term care receive or are eligible for social security disability, it is more cost effective for Florida to finance their services through a traumatic brain injury waiver and maximize Medicare. Based on this reasoning, it is recommended that the state not pursue a waiver that specifically addresses persons with neurobehavior disorders, but instead design a comprehensive waiver that will provide appropriate supports and services to persons with TBI or the range of long-term care needs." She requested the council study page 5 and 15 of the TBI Five-Year Strategic Plan that provides a rationale for a lifelong, long-term system of care and offers a variety of strategies to address these long-term care issues.

Dr. Kerkhoff made a suggestion regarding the name of the proposed new task force. He felt the long-term care makes you think of institutionalization and warehousing. His recommendation was lifelong support/care. Ms. Sutherland indicated that a motion had not been made to change the name and agreed with the suggestion to find a more appropriate name for the task force. She stated that when you read lifelong care it's almost like a big red flag in what the commitment is. She liked the idea of life planning or something similar, not just care. She stated "It sounds like someone can be near vegetative and this is what we are doing. It's just got a connotation about it." She asked the task force to go back and make a decision on what to call the new task force and that they ask the people with TBI what they think it should be called. Ms. Breen agreed to the suggestion.

Ms. Slapion stated she had a concern with turning a neurobehavior topic into long-term care because there may be long-term care possibilities out there for people without neurobehavior issues, but there is nothing out there for the neurobehavior population. She does not want that to get lost in long-term care because they are a special case where there's no place for them.

Mr. DeLilla discussed that the program has put a lot of time and effort into working with AHCA in terms of developing standards and criteria for enhanced payments in skilled nursing home facilities for people on the diaphragm pacing system or ventilators. The agency sees merit in this and he believes that they are interested in moving in that direction when they can secure state match for the development of this kind of program. He had the opportunity to also discuss with AHCA the possibility of exploring the development of standards and criteria for enhanced payments for serving people with TBI in a wing of a facility that could be used to provide neurobehavior care. With an enhanced payment you are talking about several hundred dollars a day of additional fees on top of the state plan services. Standards and criteria for eligibility would have to be developed, but this would be a vehicle to provide a place for these individuals to go without Baker Acting them or putting them in prison.

Ms. Breen discussed that there is an administrative fee issue. Massachusetts was able to come up with a way to enhance or waiver costs in hospitals through their Medicaid. Florida does not have this in place. The task force's next step is to work with AHCA to get a printout of how many people with TBI are currently Medicaid eligible. She stated the problem is if you focus on a very small population with very severe needs and you put in a continuum of care it's cost prohibitive. She referred back to page 14 of the strategic plan and its array of services which includes neurobehavior services.

Mr. DeLilla stated "an enhanced payment to an already existing program is more palatable" and that AHCA had indicated interest. The costs will need to be brought in line, something they can absorb. It would be limited to those individuals who have no chance of being integrated into the community on a Medicaid waiver where the service limitations would not

be sufficient. He believes it would be a viable alternative and would prefer to see a task force study the issue more clearly and carefully to see if that's something that could be done. He mentioned the previous discussions on the nursing home transition initiative and said the nursing homes are going to get worried that we are going to be emptying out some of their beds and they are going to be an obstacle. But if you provide them with another vehicle to redevelop some of their beds to accommodate a needed population, they may be interested in that. Ms. Sutherland added "especially if there is an enhanced payment."

Ms. Breen encouraged the group to read the study report. They did a "huge study on the costs". She stated she will go back to the task force and they will reconsider the name and the focus. Through the contract with BSCIP, they have continued to keep Celeste's services to continue working on the issue of the array of services and funding through Medicaid. She indicated that she will have Celeste talk to Thom.

Ms. Peay related that she understands the issue of neurobehavior being lifelong. She has found that over the 13 years since her injury that she may take one step forward, but then another part goes back. For example, she has noticed she now uses more profanity than she did previously and that this is a new neurobehavioral issue for her. She stated "Things hit somebody with a brain injury at a certain time line and so to stick it in neurobehavior, it seems advantageous to me because you'll have somebody hit it at this point and then somebody else there, but because you have already included it in a neurobehavior, it just goes straight along and waits for everybody to hit it."

Action Items	Person(s) Responsible	Deadline

Agenda topic: Comprehensive Benefits for Catastrophic Injuries

Discussion	
	<p>Eric Collazo reported on the Comprehensive Benefits for Catastrophic Injuries Task Force. Mr. Collazo reported that the task force renamed itself because the original name had an insurance nomenclature and the task force did not want to raise the ire of the insurance industry. The task force has held several conference calls and has identified seven members. It still needs three members, but they want to bring in professionals outside of the medical industry and their profession to assist the task force in running a "Yes we can" campaign. He stated, "It's going to be a presidential campaign because we are going to have to change a lot of mindsets."</p> <p>The conference calls have been to develop a framework and to compare ourselves to what's happened in Michigan. Their objective is to review and recommend to the Legislature a program that would ensure brain and spinal cord survivors immediate, intermediate, and long-term care, similar to the state of Michigan. They have discussed that they need to build a construct to be able to educate legislators and decision makers on what's happening in Florida.</p> <p>He discussed what typically happens in an auto accident in Florida. Under a typical insurance policy, your policy pays about \$10,000 premium PIP coverage and then your auto insurance company turns it over to your health insurance. If not, you're going right to Medicaid. Your health insurance company then relies on your uninsured motorist if you or the other driver has uninsured motorist coverage. If you don't, you fall to Medicaid. Then BSCIP picks up anything that the insurance companies haven't picked up and then you are into your personal funds and once you have depleted these you are into Medicaid. What that leads to is basically bankruptcy. You have gone through your insurance policies, your benefits, your personal funds. The Michigan model provides for long-term care after auto and motorcycle accidents. It allows for inpatient, outpatient, acute, sub-acute, and in-home care. They will modify your home. It allows for continuous occupational, speech and neurobehavioral therapy and it provides for long-term medication so you are not relying on your insurance or the Medicaid program. Once you surpass a certain level for your costs, the fund kicks in. The fund was established in 1972 and the revenue is derived by a fee you pay on your auto insurance. The estimated fund through 2008 is \$10 billion. This is held in a trust which is managed by the insurance companies of Michigan. A board "polices" what the insurance companies are paying</p>

for. Shortcomings include: if you are injured in a vehicle or a motorcycle you are covered, however, if you are hurt in a boating accident, jet ski accident, football, etc. you are not covered. The task force would address this issue for Florida. In addition, there are complaints of potential abuse and fraud because the fund covers so much. The task force issues are: they want to set up a board of representatives that have business, legal and medical interests. They require assistance gathering data and would like to put together some actuarial models to be able to educate the Legislature on exactly how this program would work, comparing it to what's happening in Michigan and demonstrating how much money Michigan is saving in their Medicaid program by having this insurance policy. The task force would like to have a broad pool, so they are looking at various fees and/or insurance programs that would allow them to implement a fund. The next step is to identify a consultant to assist with the actuarial models. They want to identify stakeholders both pro and con and to understand what the con issues are going to be. They want to identify legislative supporters that will sponsor the program so that it is not only us coming at this particular legislative issue.

Ms. Sutherland recommended that the task force take a look at New Zealand's trauma plan. The plan includes natives and visitors and does not include insurance. If you are injured, whatever the injury, you are covered and its very comprehensive. You are taken to the nearest facility, stabilized, etc. "They have found that without the administrative insurance costs, just getting rid of all the bureaucracy, they have been able to pay for the care. It costs more to administer the insurance than it did to provide the care."

Mr. Reineking asked if Michigan found that the insurance companies were able to reduce any amount of coverage and provide cost savings to drivers since the fee was being collected. Mr. Collazo discussed that there is a surcharge on your auto policy that is approximately \$120 per year. By having the surcharge on the policy, the insurance companies are limited to an exposure of \$440,000, which is a 20-day stay at an ICU here in Florida. So once the insurance company pay the first \$440,000, the rest is paid by the trust fund. As a result, the insurance companies have been able to lower their rates. The big issue that we will have to get around is what happens to the legal side of it because attorneys will not be making the fees that they are used to because everything is capped. In Michigan, there is an allowance for how the fees are structured to the attorneys. Mr. DeLilla stated they are limited to pain and suffering which substantially reduced the amount of settlements and the amount of fees that they would be able to collect. He stated that when the list of adversaries was developed, they would be the group that would have some concerns.

Action Items	Person(s) Responsible	Deadline

Agenda topic: Other Council Business/Next Council Meeting

Discussion	<p>Ms. Sutherland began wrapping up the meeting by asking Ms. Kelly to review the process for council nominations that was discussed the day before. Ms. Kelly reviewed the process. She then suggested that council members spend a few minutes following the close of the meeting working with her or Ms. Hall to complete their travel reimbursement requests. Mr. Edwards asked about nominations for five outgoing council members within the coming year. Mr. DeLilla requested that those present identify and nominate individuals to serve on the council. The program maintains a file of potential applicants and uses it to fill slots as they become vacant. Ms. Slapion requested that the council assist her in finding an Advisory Council liaison to work on the Assistive Technology Task Force. Dr. Kornberg agreed to serve. Ms. Slapion and Dr. Kornberg will need to recruit members to serve on the task force. The council was adjourned at 3:35 p.m.</p>
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Action Items	Person(s) Responsible	Deadline

Respectfully submitted by Suzanne Kelly, Advisory Council Liaison