



**National Collaborative on  
Children's Brain Injury  
Minutes**

**National Collaborative on Children's Brain Injury  
Minutes  
Quarterly Meeting  
Monday November 5, 2018**

**In attendance:**

Judy, Roberta, Janet, Keri, Julie, Sharon, Susan Davies, Leslie, Heather, Karen, Kristen, Drew, Gerry, Brenda, Liane, Susan Vaughn, Melissa, and Ann

**Announcements and Updates**

- **Belfast IPBIS Highlights** - Pre-conference Ann & Audrey presented and Roberta moderated a panel, Melissa and Gerry each did presentations. Julie and Sharon were both there as well.
- **Concussion Guidelines Conference in Ontario** – Gerry reported this was an update to the 2014 Ontario Neurotrauma pediatric concussion guidelines ([ONF guidelines](#)); about 40 people including Gerry, Ann, and Roberta contributed. Facilitated by Nick Reed and Roger Zemek, the group looked at updated evidence and voted on the strength of recommendations. Will be re-issued in Spring of 2019, now electronically, in a manner that will allow various groups to use very practical recommendations – interested in dissemination, NCCBI will likely play a role.
- **International Pediatric Brain Injury Society** – Sharon reported that Ron confirmed 2020 NYC (New Yorker Hotel) either late August or early September – 2022 will be in New Zealand. NCCBI is invited to participate and co-chair a program like we did at NABIS – focus perhaps on educational strategies that could be used world-wide. Could get 450-500 people attending. Need someone representing NCCBI on IPBIS Program Committee – Sharon volunteered to form a NCCBI Conference Committee.
- **International Brain Injury Association Conference** is in Toronto March 13-16, 2019. The call for papers is still open until December, and there is a pediatric track ([abstract portal here](#)). Sharon, Brenda, Janet, Roberta, Julie, (and possibly Melissa) are going. Ann will follow up with IBIA re; NCCBI facilitating a 2-hour symposium to continue the work started at NABIS.
- Sharon suggested that NCCBI establish a conference/education committee. The group agreed this would be a good idea. *Anyone interested in being part of this group should email Judy and Sharon.*

**New Members** – Will introduce Thom Campbell at next meeting as he could not be with us today

**Current Initiatives:**

- A. Community of Practice Update** – Melissa reported that Laura continues to add new research and new information – a collection of new information and new resources. May need to look for new sources to support in the future. *See information at end of minutes re; how to access the CoP.*
- B. Policy Work Group** – Drew/Judy reported that after initial discussions about making recommendations about IDEA re-authorization, this group is restructuring to write a white paper around existing requirements of IDEA. We are considering reaching out through NASDE and talking with Special Education Directors to see what they think about approaching Department of Ed about

trying to enforce what's already there in the law, and maybe get a statement of need from them, and then use that for advocacy. Also, we could take each piece of the IDEA that relates to brain injury, and lay out each of those points, and use the literature to support what needs to happen. Take Child Find, and our Under-identification Paper, and maybe create 5 or 6 points in the existing law about what's not working, and from that make a white paper to drive recommendations in the field. Focus on:

- Child Find – Under-identification
- RTI vs. other forms of assessment - Colorado Matrix-Building Blocks of Brain Development/NC NeuroCognitive Model - training element for teachers and other school personnel
- Evidence-based Interventions - new EBR Cog Rehab Systematic Review
- Susan Vaughn's chart about how each state is meeting/not meeting the requirements for IDEA.

Lianne also suggested including cost of lack of intervention and the costs to the states as a result, i.e., juvenile justice system, graduation rates, etc. Susan mentioned that Mt. Sinai's research grant with CDC on Juvenile Justice is putting a guide together for states doing work in Juvenile Justice. 2<sup>nd</sup> part of project is doing something with National Conference of State Legislators for bringing attention to state law makers on the correlation between brain injury and juvenile justice. Leslie suggested another topic NIDILRR has - project on comprehensive knowledge translation plan, which has a part on inmates with TBI – Judy and Drew to explore further.

- C. Family Initiative** – Liane reported their group appreciates what Laura has done for their area with Community of Practice. Would like to open things up a bit more on Conferences to get families to participate. It is empowering for families to be there to learn and to get support and validation from professionals, and also pre-conference panel may be a good place to allow them to participate and give back some of their experience. New ACBIS Fundamentals Certificate is now available and can be offered as a Pre-Conference Training – might appeal to family members.
- D. RTL WorkGroup** – Karen/Brenda reported that the consensus paper went through 2 rounds of edits with the original journal. In the 2<sup>nd</sup> round, too many changes were requested, so it was felt that might void the consensus process and endorsements, so now are in the process of looking for a different journal – looking at educational journals. Clarification of authorship – the workgroup is primary, and the whole NCCBI membership was given a chance for input on the initial draft and will be given recognition on paper.
- E. Common Data Elements** – Susan D. reported they got together a couple weeks ago on the process of identifying CDE in educational settings. They are going to identify preliminary CDEs and will meet again in December. This was requested at NABIS because a lot of folks said we have to get CDEs together in order to look at outcomes across states. Cate participated and challenged the Workgroup to decide whether these are important for research/practice or both.

***Next NCCBI Quarterly Meeting: March 4, 2019 @ 11 AM PT, 12 PM MT, 1 PM CT, 2 PM ET***

### Community of Practice

- The Brain Injury in Youth - Supports for School Success is a Community of Practice (CoP). This CoP is a nationwide interactive online resource community designed for those currently working in the field of education and brain injuries. The purpose of the site is to share ideas, discuss issues, and generate strategies for those who educate, advocate for, and support children and adolescents with brain injury in schools.
- This site has useful information for all types of brain injuries: traumatic brain injury (TBI), including concussion, and non-traumatic brain injury. Although those injuries have different mechanisms, their effects and interventions are generally similar.
- You will find descriptions of the types of brain injury and links to our [Resource Collections](#), topic-specific collections of research, best practices, and resources.
- This is a FREE resource. Check back often. Interact, ask questions, and collaborate with colleagues from across the United States who are also working to support students with brain injury.
- This Community of Practice was created by the [National Collaborative on Children's Brain Injury \(NCCBI\)](#), which is composed of representatives from state departments of education, state lead agencies on brain injury, national brain injury organizations, federal brain injury partners, rehabilitation clinicians, and brain injury researchers.

Link to Brain Injury in Youth: Community of Practice- <https://youthbraininjury.obaverse.net/welcome/>

If you don't already have an account, you will need to create a username and password. Just click on "create an account" and follow the directions.

## **National Collaborative on Children's Brain Injury**

**Minutes Friday June 29, 2018**

**11 AM PT, 12 PM MT, 1 PM CT, 2 PM ET**

- I. Introductions and Welcome** – Drew Nagele, Judy Dettmer, Julie Haarbauer-Krupa, Gavin Atwood, Keri Bennett, Sharon Grandinette, Susan Vaughn, Susan Davies, Heather Hotchkiss, Paula Denslow, Melissa McCart, Amy Colberg, Janet Tyler, Kristen Hildebrand, Brenda Eagan-Brown
- II. Announcements and Updates** - good representation at the InterAgency Conference.
- Sharon has submitted proposal to CEC for January in Indianapolis and is waiting to hear.
  - ACL grants have been awarded, see NASHIA Newsletter.
    - i. Mentor States – transition to employment, working in schools, juvenile justice CO, PA, IN, IA, MA, NB, OR, TN, VA, WV
    - ii. Partner States - AL, AR, CA, KS, MD, MI *add others*
    - iii. Working with National Technical Assistance and Dissemination – Grant Thornton – will work closer with that.
- III. New Members** – Judy introduced Susan Davies, who coordinates School Psychology at University of Dayton, and how school psychologists can help students with all levels of severity of brain injury, and how to get medical rehab involved. Sharon Grandinette, who has a background in special ed, started and ran two public school programs for children with brain injury – helped start BIACA, worked with ACBIS, on Exec Board of NABIS, does legal and expert work for children with brain injury. A representative of ACL has also been invited.
- IV. Current Initiatives:**
- A. Community of Practice Update** – Melissa reported that Laura Beck has been updating with research and new groups. It's kind of slow with people interacting with it. Concussion in Youth – being updated with support from University of Oregon (Ann). <https://youthbraininjury.obaverse.net/>
- B. Policy Committee** – Drew/Judy – Under-Identification paper is being revised and will be submitted to the journal Education Policy Analysis Archives <https://epaa.asu.edu/ojs/> Have been working on a position statement for Re-Authorization of IDEA. NCCBI Members stated the need uniform system for identifying TBI in children for all – medical documentation not a requirement, this is the state's purview and contributes to the variability. Susan Davies, Heather Hotchkiss, Brenda Eagan Brown, Paula Denslow wants to be involved in this. Julie reported that CDC about to release guidelines, which will address what healthcare community should be doing that will help schools. Also a paper about children injured before the age of 5, and then effect on later school years, these children are not in the clinical range and probably won't get picked up for services in the school – may get translated into behavioral differences. This is especially true for the mild-complex brain injury.

- C. Family Initiative** – Liane/Paula – reported that this initiative is now part of the Community of Practice – Supporting Students with Brain Injury. New family portal is there to learn and share with other families to get them engaged and involved. Laura Beck has helped get this section up and running and they thank her, and thanks to Melissa McCart for all her help.
- D. RTL** – Karen/Brenda reported that JHTR has send article back requesting minor edits, and has been resubmitted. This paper describes consensus from 18 national organizations, 13 of which participated. 13 RTL statements were derived, and this was sent back out for endorsement by the national organizations. Waiting for feedback.
- E. Quality Indicators** – Judy/Janet – Judy reported this initiative has not really gotten off the ground, but was to develop benchmarks for Dept of Ed so they could know if they are doing a good job with students with brain injury. We think we can combine it with the new initiative below.

**V. New Initiative:**

- A. Common Data Elements** Judy reported that we have talked about this since the Summit in Penn State in 2012. Look at what outcomes are currently being collected, and what needs to be added to that. Shari Wade has developed some CDE, but these are more medical, and we want to focus on some school based outcome measures. Gerry and Susan have indicated they would like to be involved. Julie has a grant in the CDC portfolio that uses CDE, and it's important to capture what we actually want them to capture. Nurse visits, office referrals, suspensions, time on-task, time-off task, grades, achievement scores, drop-out rates, transition to adult. Julie, Ann, Gerry, Heather, Melissa, Judy, Paula, Susan Vaughn. Ann will get first meeting scheduled.

**Conference Call**  
**Phone: 1-877-820-7831**  
**Passcode: 495085#**

*Next Meeting: Monday, September 24 at NASHIA State of the States Conference 5pm CT. Phone option will be made available.*

## Agenda: National Collaborative on Children's Brain Injury

**Wednesday March 14, 2018**

3 PM PT, 4 PM MT, 5 PM CT, 6 PM ET

### I. Present: Roberta, Judy, Ann, Liane, Melissa, Cate, Paula, Drew, Keri, Leslie, Heather, Brenda, Janet, Susan, Julie

- **Introductions and Welcome – Drew and Judy NABIS Pre-Conference & Pediatric Track - Houston March 14-17** – <http://abi2018.org/> - Drew reported that Janet, Ann, Judy, and Roberta will be presenting along with Barry Willer, Chris Giza, and Lori Cook at a Pediatric Pre-Conference co-sponsored by NCCBI. A portion of proceeds from the Pre-Conference will be donated to children/families in need from the Houston flooding. Julie will be presenting during the main Conference on the Report to Congress, and several other NCCBI members have abstracts that will be presented as well. soon. Chris Giza, Barry Willer, Lori Cook did a terrific job!

### II. Announcements and Updates

- **IPBIS** – Ann - Belfast September 26-28 will be fabulous, Ron gave preview, targeting on kids, international presenters from all continents - meet new friends, high caliber presentations. Gala dinner at Taipan Museum - over the top
  - **IPBIS** conference in Belfast: <http://www.internationalbrain.org/third-international-conference-on-paediatric-acquired-brain-injury/>
- **CDC updates** – Julie
  - **Report to Congress is released!**
  - Creating a spreadsheet on how people are disseminating, so we can see how it is used, and how it might be having an impact
  - Editor of Archives of PMR wants to do an editorial on it.
  - Cannot customize the Fact Sheets, but are encouraged to distribute them, as is
  - Could NCCBI do a Survey on how the Report is being used? Has it changed policy? Has it helped children get services? Perhaps mining those states that do have registries could answer these questions.
  - Guidelines for diagnosis of MTBI and Research Gaps for Children with MTBI will be released sometime in 2018
  - Trying to get more funding for Return to School and studying Student Outcomes. School record data abstraction form; ABCD Study? Youth Risk Behavioral Survey YRBS is self report of grades; Health Survey by parents asks questions about brain injury. What are the Common Data Elements CDEs we want to collect related to Academics, and what criteria are States using to measure benchmarks and how we can utilize that data - what outcomes are relevant and have credibility in the school domain. Cate mentioned that NINDS and NIDILIR were working on pediatric CDEs, Shari Wade submitted a project proposal for developing CDEs. The larger CDE effort at NIH has included many different illness groups, and TBI was one of them. Could we ask Mona Hicks (now retired from NIH) or her successor Pat Belgowan, about whether they would provide support for Version 2 or an Addendum to the pediatric CDEs, that would include an academic module. However there is no more money at NIH for new CDEs, but they have housed at the National Library a series of documents that could give you what you want for CDEs. Possibly OSERS might have a small amount of money to support this, as this is within their scope. How much money would it take? Expert Contributors were not paid, done pro bono, so it would probably just take a Principal Investigator, and the expense to bring people together for a day or two meeting to kick off the initiative, develop a structure, and then the rest of it is by phone calls.

Tennessee Disability Coalition offers small grants \$10K to build capacity. CDC might also be able to host a meeting.

- **ACL**
- **Funding Announcement is out**, and encouraged to develop Registry about people with identifiers for the purpose of follow-up, and then linkage of those people to services. Interested in the follow-up
- **NIDILRR - Cate and Leslie reported on Federal InterAgency June 11-13 at Hilton** - on-line program is available, still accepting papers and proposals. Shari Wade is a plenary speaker, Judy and Drew presenting. No pediatric track but there is pediatric content sprinkled throughout. There is an application out for Disability and Rehabilitation Research Project - 5 year \$425K per year, on coordinated post secondary and employment services, due April 9. TBI Model Systems Collaborative - \$600K per year just closed. NIDILIR's Model Systems are now looking for opportunities to work across TBI, SCR, and Burn Model Systems. About to embark on working with the surgeon's community on coordinating data on all surgeries, and they are looking at these Model Systems as a model.
- **TBI Stake Holders Day - Susan reported is next Monday 9-5 at HHS Room 8000**
- **NASHISA (Hill Day) – Susan V. next Tuesday Congressional Brain Injury Awareness Day**, starting in Rayburn Foyer, exhibits plus a Brown Bag Meeting in Longworth 1500, Congressional Briefing 2:30 in Longworth Lance Robertson, Drew Nagele, Dan Keating, Gerry Donovan, Douglas Brewer + Reception 5-7 PM. With regard to TBI Act - Reauthorization good through 2019 but because Senator Hatch is retiring, could he do it a year early?

**Membership** - Judy - wanted to nominate a couple new people - recruit some new members, suggested;

- **Tom Campbell or Dana Fink - representing ACL**
- **Sharon Grandinette - representing NABIS**
- **Susan Davies from Ohio - post secondary University of Dayton, trains school psych**

**Consensus was we should go ahead and invite these people. Also suggested to consider for future was**

- **Jenny Lundine - from Nationwide Children's**
- **Angela Ciccia**
- **Lori Cook**
- **Adam Politis - medical perspective**
- **Steven Barr**
- **someone from Depart of Education/OSERS**
- **someone from National Association of School Nurses**
- **someone from National Family Voices/PTO**

● **Current Initiatives:**

- A. Community of Practice Update** - Melissa
- B. Policy Committee** – Drew/Judy (no-report)
- C. Family Initiative** – Liane/Paula - EMSC Family Emergency Medical Network - co chair of Society Emergency Medicine Consensus Conference - looking for patient advocates to tell your story - Paula, and her son are going to share their experiences with emergency medicine. Setting agenda for next 10 years, such as consistent documentation/identification of concussion in kids! Will be published by end of year Society for Emergency Medicine
- D. RTL** – Karen/Brenda - 12 endorsements so far - not everyone endorsed, like PT, AAP, AAN might still come through. Paper is being finalized for submission to JHTR. 13 statements -
- E. Quality Indicators** – Judy/Janet (no-report)



**F. New Initiatives? Heather reported she and Karen are presenting at the National Association for Educating Children with Medical Needs AECMM**

**Conference Call  
Phone: 1-877-820-7831  
Passcode: 495085#**

*Next Meeting: Friday, June 22 @ 1pm ET, 12pm CT, 11am MT, 10am PT*

## Minutes, Wednesday 17, 2017

**I. Present** – Brenda Eagan Brown, Amy Colberg, Paula Denslow, Judy Dettmer, Liane Gelman-Wegener, Ann Glang, Julie Haarbauer-Krupa, Kristen Hildebrant, Heather Hotchkiss, Karen McAvoy, Melissa McCart, Cate Miller, Drew Nagele, Janet Tyler, Susan Vaughn

### **II. Announcements and Updates**

- **IPBIS** – Ann reported on this meeting next September 26-28, 2018
  - **IPBIS** conference in Belfast: <http://www.internationalbrain.org/third-international-conference-on-paediatric-acquired-brain-injury/> for abstract submission link. The conference committee is looking for sponsors \$600-\$10,000 - Ann will send more info on that.
- **CDC updates - Report to Congress** - Julie thanked everyone for their interest and participation in this project. It is currently sitting with CDC's marketing contractor and hoping for release by the end of January. There will be a webpage with the Report, with 1 page fact sheet downloads. They are still looking for ideas for dissemination. Amy reported that although we would like to get a Congressional Hearing on this Report, there are a lot of competing agendas on the Hill right now, BIAA and NASHIA will continue to work on that.
- **NABIS Pre-Conference & Pediatric Track - Houston March 14-17** – <http://abi2018.org/> - Drew reported that Janet, Ann, Judy, and Roberta will be presenting along with Barry Willer, Chris Giza, and Lori Cook at a Pediatric Pre-Conference co-sponsored by NCCBI. A portion of proceeds from the Pre-Conference will be donated to children/families in need from the Houston flooding. Julie will be presenting during the main Conference on the Report to Congress, and several other NCCBI members have abstracts that will be presented as well. Please publicize this widely among your groups and colleagues - we hope to have a flyer out soon.
- **Other Federal Initiatives** - Cate reported that Model Systems funding is in place for next several years. ACL is planning on stakeholder calls within the next several weeks, in the service of a Federal Interagency coordination plan on TBI initiatives. Cate will send info on this as it becomes available.

### **III. Current Initiatives:**

- A. Community of Practice Update** - Melissa reported that Laura has been working on new collections - Transition to Adulthood, On-Line Learning, Current research (last 12 months), Working with Families. The standard collections are getting little use - most traffic occurs on Forum Post. Melissa encouraged all of us to post stuff that we are doing or involved in. Drew suggested that doing live webinars might be a way to generate more traffic (like they do on Transition CoP). Perhaps having Julie on the Report to Congress, using Facebook Live, or using something else that CDC has developed.
- B. Policy Work Group** – Drew/Judy reported on attempts to publish the "under-identification of brain injury in schools" paper. Although it was not accepted by

*Education Policy* we are planning to re-submit to *Education Policy Analysis Archives*. Once it is published, we discussed possible dissemination perhaps through Dept of Ed Directors of Special Ed - present the paper and the policy recommendations. The paper has implications for revising the definitions of brain injury and how children are counted/classified. The Policy Work Group also discussed whether the timing is now right to be working on recommendations for IDEA Re-Authorization. Amy had shared a request by the Division for Early Childhood of the Council for Exceptional Children for input on reauthorization, which is due Feb 9 <https://form.jotform.com/73446681958169> and individuals with experience in early childhood should feel free to respond to that. NCCBI would like to develop more specific recommendations for children with brain injury, and Ann will chat with Susan Kauffman about timing and guidelines for working with SPED on this. The Policy Work Group will also survey our NCCBI Membership about their ideas about what needs to be changed in the IDEA Re-authorization, beginning with an open ended survey.

- C. **Family Initiative** – Liane/Paula reported that there have been positive steps - Family Voices of Tennessee starting up again. Paula has an intern working on getting the family initiative moving through the end of April. This will be a family portal on the Community of Practice. Wants to create Informational Tip Card for families like the ones she found at CHOP years ago.
- D. **RTL** –Brenda reported the Consensus RTL paper went out and has so far been endorsed by NASP, NABIS, NASHIA, DoD, NATA, NFHS, RIO, and BIAA. The only no was from AAP because they want their existing paper to stand as the resource they refer to. Still waiting to hear from a handful of organizations, and by February, hope to submit to Journal of Head Trauma Rehabilitation.
- E. **Quality Indicators** – Judy reported that they were originally looking at benchmarks for State Departments of Ed to consider when working with students with brain injury. Do we need a different approach? We tried a pilot of this in certain states represented by NCCBI, but the task may have been too large for anything to be actualized. However, the Quality Indicators approach has worked for other groups like Autism and Serious Emotional Disabilities. These Quality Indicators may be more at the systems level, not the individual student level. Could we pull a group together to look at what was done, and try to narrow the focus, to something that could realistically be done? Are people interested in further defining the issue, and developing a work-group that could be part of that? Judy, Ann, Brenda, Heather, and Janet expressed some interest, Judy will set up the 1st meeting.
- F. **New Initiatives**
  - o **Membership** - Judy, Ann, and Drew have recognized that we have a core group of people interested in being on calls and workgroups, and then others who just want to get the minutes. Are there people/groups that we are missing, for example NABIS/IBIA/USBIA/OSERS-WIOA/ACL (Thom Campbell)? also NINDS/NCMRR/NICHD/EPSTD/Title V/AAP. This will be discussed more in our March meeting.

*Next Meeting: For those attending the NABIS in Houston TX, we will be meeting in person immediately following the pre-conference on Wednesday March 14, 2018 from 5pm-6:30pm CT. Exact location to be determined. We will also make a conference call available.*

# National Collaborative on Children's Brain Injury

## Monday, September 11, 2017

Present: Judy, Roberta, Steve, Brenda, Melissa, Paula, Karen, Drew, Keri, Julie

### I. Introductions and Welcome – Drew and Judy

### II. Announcements and Updates

- **Judy** did introduction to NCCBI at NASHIA
- **IPBIS** – Roberta
  - [IPBIS](#) conference in Rome - will be a wonderful conference starting September 20. Conference is full attendance, program is quite extensive. Next conference in 2 years in Belfast.
- **CDC updates** – Julie that the Report to Congress is still waiting to be approved. CDC got a new Director in July, and it is still with her. Once the report is released there are dissemination products like fact sheets to be cleared. Can email Dr. Houry or ask Policy folks to reach out. University of Maryland Law School is reviewing Return to Learn/Return to Play. Conducted a stakeholder meeting in 2016, but this cannot be published directly. Return to Learn Evaluability Project looked at Program Operations and want to use it to understand how kids are being missed. A webinar was given to applicants in August about results, and there will be another general webinar about what they learned in the Fall. Also working on a falls paper for children under 4 - most of the falls involve beds. Mild TBI Guidelines (based on review of 34K abstracts) are also about to be published. Julie will share the link.
- **ACRM updates** - there will be a subgroup forming from the BI-ISIG Pediatric & Adolescent Task Force that will be starting another Pediatric Cog Rehab Systematic Review to see what is new out there in the literature. Melissa and Drew reported they each have Chapters in a book on Pediatric Cog Rehab that is coming out edited by Beth Slomine and Gina Locascio.
- **NABIS Pre-Conference & Pediatric Track** – Roberta reported that the Hyatt Hotel in Houston was not harmed, so we are probably going ahead with the Conference in Houston at same date March 14-18, 2018. Ron invited NCCBI to co-sponsor a pre-conference with 3 speakers who are researchers - Dr. Chris Giza and 2 others. No cost to NCCBI, but any money that is earned. We asked that \$10 from each registrant go to children's needs in Houston. Also offered a Plenary (possibly Julie H-K) and a 2.5 hour seminar/workshop

- 3 speakers 15 minutes each and have a real facilitated discussion - possibly get written up somewhere. Others are encouraged to apply for seminars/posters. Call for papers not out yet, but probably due in January. Return to Learn, Under-Identification, Family stuff would be good topics. If there is a profit on the Pre-Conference they will share it 50/50. Hoping they will allow people who are local to come just to the Pre-Conference if they want. Paula asked about a live-broadcast of this event - Roberta will pursue, possibly through Go To Meeting and then charge for the Log-In.

- **R-24 BrainSTEPS Initiative** – Drew reported that BIAPA is working with Wayne Gordon at Mt. Sinai and the folks at Craig Hospital and the Colorado Brain Injury Project to apply for this grant that will use BrainSTEPS as a vehicle for research data collection, to study the long term outcomes of children with brain injury through this program. Need a few more states to implement the BrainSTEPS model in order for this to be a multi-state effort. Tennessee has someone in the Department of Education who knows their Project Brain, and may champion this effort. Other possibilities may be Indiana, Nebraska, North Carolina. Brenda and Janet to reach out to Keri and Steve.
- **Logo** - what do you think about the new logo at the top of the page, Chad Haynes from NABIS designed this for us for free!

### III. **Current Initiatives:**

- A. Community of Practice Update** - Melissa reported that Laura has added new pages and content. We need people to get on there and post stuff, or posting some questions. When we post stuff, we get activity. Brenda, Janet, and Heather can you please sign people on the CoP when you do your trainings.
- B. NCCBI website updated** - we have a brand new website that Laura put up. Check it out at <https://cbirt.org/nccbi>
- C. Quality Indicators** – Janet - discussion about continuing
- D. Policy Committee** – Drew/Judy
  - "Under-Identification of Students with Traumatic Brain Injury (TBI) for Special Education: Analysis of Causes and Potential Remedies"
  - Re-authorization of the IDEA
- E. Return to Learn Consensus paper** – Brenda/Karen - that article was reviewed by specialists in consensus/Delphi and a statistician. Ready soon to send out to the NCCBI Return to Learn Workgroup, then can share with the NCCBI group (but do not expect feedback), and then submit to JHTR.
- F. Family Initiative** – Liane/Paula - reported that Family Voices in her organization has been going through a lot of changes. Will continue to pursue.
- G. Other New Initiatives** - Paula described how Project Brain has been nominated as one of 4 finalists in a competition to receive 100 hours working with a data architect that will work with them to develop a data dashboard that will represent all of their work. We need to vote for them by going <http://www.thinkdatainsights.com/data-analytics-dashboard-giveaway/>. There is a video that highlights Paula's granddaughter and Ceil Franklin. 1 email per person per day. See info below:

Dear Friends of Project BRAIN,

Thank you in advance for a couple minutes of your time! I want to ask for your help with an exciting opportunity presented to Project BRAIN!

A well-respected Tennessee firm, [Think Data Insights](#), has been creating data analytics and business intelligence solutions for large and small organizations for the last 20 years. They are offering an opportunity for us to engage them on a project that would propel our mission forward. This project will be FREE.

Over the past several years, Think Data Insights principals have served many nonprofit organizations and spoken to many more who have needs around maximizing efficiencies, economies, or gaining more insight and impact by using the data that is generated and captured in our everyday operations and community service. We would like to be the next group they provide these business intelligence capabilities to.

Project BRAIN is one (1) of the four (4) nonprofit organizations/ programs that have been nominated and are eligible to receive this free service worth \$35,000 in man hours. **The FREE offer will be awarded to the one (1) who receives the most votes.** We need you to vote for us!

**Voting is happening now and will run through September 28th.**

**Check out our spotlight video.**

For more information and to vote, go to the [Data Analytics Dashboard Giveaway](#): <http://www.thinkdatainsights.com/data-analytics-dashboard-giveaway/> **The winner will be announced on September 29th!**

Because of your steadfast commitment of our efforts, together we continue to make a difference in the lives of children!

Please [Vote](#) for Us!

**Next Meeting: TBD in January 2018**

## Agenda: National Collaborative on Children's Brain Injury

**Friday 5/12/17**

2:00-3:00 ET, 1:00-2:00 CT, 12:00-1:00 MT, 11:00-12:00 PT

Minutes

### I. Introductions and Welcome – Drew and Judy

In Attendance: Keri Bennett, Amy Colberg, Leslie Caplan, Paula Denslow, Roberta DePompei, Judy Dettmer, Rose Dymacek, Brenda Eagan-Brown, Liane Gelman-Wegener, Ann Glang, Julie Haarbauer Kruppa, Kristen Hildebrant, Steve Hooper, Heather Hotchkiss, Karen McAvoy, Drew Nagele, Janet Tyler, Susan Vaughn, and Shari Wade.

### II. Announcements and Updates

- **IBIA** – Ann, Steve, Karen, Brenda, Julie, Shari, Janet, Roberta  
NCCBI was well represented at IBIA. Julie stated she presented at the post-congress session on sex and gender differences and discussed male vs. female brain injury rates.
- **Hill Day & ACL Mtg.**  
Administrators for Community Living had a meeting the day before Hill Day. Several panels there - discussed measuring outcomes on getting people back in the community. Hill Day – fair was largely attended, continues to grow each year. NASHIA and BIAA pushed having meetings with their representatives to get bi-partisan support for funding federal projects such as Model Systems. Everyone is encouraged to write their representatives to ask for continued support of TBI project funding.

Amy forwarded the following information regarding contacting congress:  
*“Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies Outside Witness Testimony Instructions Fiscal Year 2018.* Appropriations as in past years, the Senate Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies will accept written testimony from outside witnesses in accordance with the guidelines below. GUIDELINES Format: · Testimony (including any supporting material) should be a maximum of four (4) pages, on 8 ½” x 11” paper, single sided, single spaced, and have a 1” margin. · Do not include a cover page. At the top of the first page, list the name of the person or organization submitting testimony; that it is prepared for the Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies; and which Department and/or Agency the testimony is addressing. Delivery: · Delivery is by electronic submission only, as described below. Other forms of delivery, including fax and delivery through the mail, will not be accepted. · Please e-mail testimony to [lhhs@appro.senate.gov](mailto:lhhs@appro.senate.gov) with the subject line “FY2018 LHHS OWT.” · To facilitate printing, we can only accept testimony in Microsoft Word or Word Perfect formats. **DO NOT SEND PDF FILES.** · In the email, please include contact information (name, email, physical address and telephone). Deadline: All material must be received no

later than close of business, Friday, June 2, 2017. This deadline will be strictly enforced. Thank you. Subcommittee on Labor, Health and Human Services, and Education, and Related Agencies Committee on Appropriations United States Senate Washington, DC 20510 [202-224-7230](tel:202-224-7230)”

- **IPBIS – Roberta**

- Roberta encouraged the group to attend the [IPBIS](#) conference in Rome.
- The UK is developing an international toolbox for brain injury resources. Roberta emailed everyone the form. Please return by June 30 (return information is on form).
- IBIA distributed a Disorders of Consciousness survey. Please fill out if you can (see survey information Roberta forwarded to the group.)

- **CDC updates – Julie**

Report to congress is still in clearance (hoping to get it out soon.) Working with contractors on messaging – will need 6-7 (8 max) people to review. If interested please email Julie. Mild TBI guidelines are in progress. Probably won't be released until 2018. Return to Learn project – looking at laws that may be barriers, evaluating programs, etc. Hope to do a webinar based on what they learned from programs.

Judy announced the NASHIA [State of States in Head Injury Conference](#) is September 11-14, 2017 in Arizona. There is a pre-conference focus on pediatric transition.

### **III. Discussion of definition of brain injury**

Judy asked the group how states define brain injury in general (for state programs and education). The question generated much discussion. People had opinions on broadening or narrowing the definition based on perspectives regarding obtaining services, securing funding, conducting research, history, etc. Due to time, the discussion was tabled. Judy suggested that a smaller group be formed to discuss this issue.

### **IV. Current Initiatives:**

#### **A. Community of Practice Update**

1. Laura Beck from CBIRT has direction from the CoP subcommittee on next steps for the CoP. Once her contract with the Colorado Brain Injury Program at the CO Dept. of Human Services is finalized, she'll begin with that work. She'll check in with the subcommittee with any questions that arise.

2. NCCBI website: The CBIRT website has been under construction. Once it is back online, Ann will work on updating the NCCBI website. Please email Ann if you have ideas for the site.

#### **B. Quality Indicators – Janet Summer project!**



**C. Policy Committee – Drew**

1. Our manuscript entitled "Under-Identification of Students with Traumatic Brain Injury (TBI) for Special Education: Analysis of Causes and Potential Remedies" has been successfully submitted online and is presently being given full consideration for publication in Educational Policy. Their turn-around-time is 4-5 months, which means we should hear by the end of July or August.

2. Some recent "rumors" have been circulating about the possibility of re-authorization of the IDEA, and several people are working on tracking those rumors down. In the meantime, Susan Vaughn has observed that NCCBI should be ready (whenever the opportunity arises) to weigh in on the IDEA, and so the Policy Task Force is going to work on recommendations taken from our various NCCBI papers to develop action BRIEFS in a similar fashion to what the CEC has done (attached). Drew will be floating a doodle poll for the middle-end of June for this purpose.

**D. Return to Learn Consensus paper – Brenda/Karen**

Karen reported that the RTL paper is being written in such a manner to explain the Delphi research process. It is being reviewed by someone who knows the Delphi process for input.

**E. Family Initiative – Liane/Paula**

Paula reported as of today, there is a new TN's Family Voices (FV) director, Kara Adams. Kara has been with their organization for years, this change just took place and Paula has not yet set a time to discuss where they are with connecting to the national folks. Previously Paula reported that she and Liane had had discussions with their former director who was well connected with [Family Voices National](#), which looks like a great avenue to have the CoP listed and shared.

**Next Meeting: TBD**

**Minutes: National Collaborative on Children's Brain Injury**

**4/25/16**

**V. Introductions and Welcome – Drew and Judy**

In attendance:, Brenda Eagan Brown, Leslie Caplan, Keri Bennett, Judy Dettmer, Liane Gelman-Wegener, Gerry Gioia, Ann Glang, Julie Haarbauer Kruppa, Kristen Hildebrant, Heather Hotchkiss, Drew Nagele, Janet Tyler, Keri Bennett, Kristen Hildebrandt, Leslie Caplan, Melissa McCart, Paula Denslow, Steve Hooper, Susan Kauffman, and Shari Wade

## **VI.** Announcements and Updates

- ED conversation: NASHIA (Judy, Susan and Becky) met with Susan Kauffman and Cate Miller to discuss strategies for partnering with US Dept. of Education. NASHIA will be writing a brief paper outlining the issues/concerns/needs, current initiatives, and recommendations for next steps.
- TN put together compilation of all videos, Paula will send link and post to CoP site.
- Lollipop kids: Susan Kauffman shared an initiative called Lollipop kids which is focused on teaching children how to react to other children with disabilities.

## **VII.** Neurorehabilitation Journal submissions – Roberta/Ann

Roberta and Ann are co-editing a special issue on academic reentry for the journal NeuroRehabilitation. The issue will be published in July of 2018. The issue will include contributions from international researchers in childhood TBI. The issue will include topics such as what medical providers need to know about supporting kids back at school (Karen and Brenda), results from a qualitative study on return to school in the Pacific Northwest (Melissa and Bonnie Todis) and a systematic review of community support/interventions/re-integration programs for children, adolescents and young adults following traumatic brain injury (Betony Clasby, Cathy Catroppa and others).

## **VIII.** IPBIS Recommendations – Roberta

Roberta was not able to be on the call however, she previously shared a document that was produced by the International Pediatric Brain Injury Society (IPBIS). IPBIS has drafted international recommendations for pediatric brain injury. This is the first attempt at an international document.

### Action:

NCCBI members will review and provide feedback about any recommendations that we as a collaborative have any concerns/questions about for further consideration. Feedback due to Judy and Roberta by May 15<sup>th</sup> (see the follow up email Roberta sent for more details).

## **IX.** Current Initiatives:

### **F.** Community of Practice Update – Heather/Drew

Heather updated on the CoP. There are 401 users of the CoP. Questions have occasionally come in. Heather will be sending out an email to the work group regarding process for approval of items that get posted on the site. Drew asked about using CoP to ask information for states to weigh in on WIOA. Leslie Caplan suggested that CSAVR might also be a good route to obtain information on what states are doing for this group related to transition. Keri Bennett indicated that her boss is the chair for CSAVR. That might be one avenue. Leslie recommended the following contact: Kimberly Osmani, Transition Coordinator for OK VR. [kosmani@okdrs.gov](mailto:kosmani@okdrs.gov).

Drew suggested we send out an update email to our groups and let them know that we have a new initiative. Melissa suggested that we post information and then people will get an email notice that something was posted.

**Action Steps:**

1. Remind our groups of the CoP
2. All NCCBI members should sign up for CoP
3. Group members should initiate and respond to posting
4. NCCBI members should visit site regularly
5. Specifics of WIOA, see below under policy

**G. Quality Indicators – Melissa**

Melissa has taken this over from Brenda/Bonnie. She will schedule a sub-committee call to ensure she is on the same page with what has been accomplished so far and what the next steps are.

**Action Steps:**

1. Judy will send Melissa names/contacts for NCCBI group members on this work group.
2. Melissa will send out Doodle Poll to schedule a meeting.

**H. Policy Committee – Drew/Judy**

- ESSA, Recommendations Paper: Susan V. shared that the Department of ED is seeking recommendations as it relates to supporting students with disabilities. There has been a paper by another disability group that we could model after.
- Under Identification Paper: Waiting for updated numbers from CDC. Suggestion made to do two papers, one that is with the current data and one that is updated for the journal of neurorehab. The committee will take this under consideration.
- WIOA: CSAVR survey potential as well as a question posted to CoP. Leslie recommended that we reach out to Kimberly Osmani, coordinator of the CSAVR transition committee (see above).

**Action Steps:**

1. Drew will email Kimberly
2. Possible initiate a survey related to WIOA
3. Ann, Drew and Judy will explore the ESSA paper
4. All committee members will get draft sections of the under-identification paper to Judy and Drew prior to the next meeting.
5. Drew will schedule the next meeting

**I. Return to Learn paper – Brenda/Karen**

Brenda and Karen are working on final draft of paper to send to participants. They are a week behind due to Brenda's broken wrist. Notification went to group. Each draft will take one month. There will be 3 drafts. 45 pages now but they will bring that down as go through revisions.

**X. Wrap up and Next Meeting – Drew and Judy**

*Next Meeting: Thursday 7/22/16 2pm ET.*

**Agenda: National Collaborative on Children's Brain Injury**

**1/21/16**

**2:00-3:00 ET, 1:00-2:00 CT, 12:00-1:00 MT, 11:00-12:00 PT**

**CALL IN INFORMATION**

**Phone: 1.877.820.7831**

**Access Code: 495085#**

**XI. Introductions and Welcome – Drew and Judy**

*In Attendance: Gavin Attwood, Brenda Eagan Brown, Leslie Caplan, Amy Colberg, Paula Denslow, Judy Dettmer, Liane Gelman-Wegener, Gerry Gioia, Julie Haarbauer-Krupa, Heather Hotchkiss, Melissa McCart, Drew Nagele, Bonnie Nelson, Janet Tyler*

**XII. Announcements and Updates**

- *Paula–Tennessee is looking into return to learn protocol*
- *Ann & Roberta- Guest editors for an upcoming Journal in 2017. Looking for articles to be submitted. Roberta and Ann will report on this at our April meeting.*

**XIII. Current Initiatives:**

**A. Community of Practice (CoP) Update – Heather/Drew**

- *CoP materials (hard copy and electronic) are almost ready to roll out – scheduled for end of January – beginning of February 2016.*
- Figuring out what type of data we can collect to help assist in this CoP development*
- *All NCCBI members will receive information so you can forward it on to your colleagues – to send to your listservs – we want it disbursed far and wide*
- *Idea is to get as many people to sign onto the CoP as possible. There is a “Forum” that allows people to put in topics of interest to them.*
- CoP Committee will look at member search data on a regular basis to adjust the site content over time*
- Heather and Drew will send out an email template.*
- All NCCBI members will send out to their listservs in state or nationally*
- *Social media campaign will also follow – please post links we send to you for the CoP on your personal or public social media pages*

**B. Mild Brain Injury White Paper Update – Gerry**

- Is there anything that we want to do now that we have published 2 papers?*

- Julie – We might want to think about using both papers for a Knowledge Translation Product– falls under Policy Committee - for a broad range of consumers
- Drew will bring this up to the Policy Committee

### C. Quality Indicators – Brenda

- In November - 6 states were emailed the T-SAT Tool to pilot, had responses from 5, 4 filled out completely
- In December Created a survey ABOUT the Piloted Tool – sent to states, 1 returned and PA’s Director of Special Ed for the state had written a long email about her concerns with the tool wording. It was due back to Brenda by January 8.
- T-SAT Responses and Survey responses were all compiled in a spreadsheet and sent out to the workgroup.

*Quality Indicators – focused more on DOE, National Association of Directors of Special Education, BSE isn’t interested in concussion overall. In PA, BSE considers concussion return to earn work as a screening tool for more intensive services via BrainSTEPS to justify funding/time.*

#### **T-SAT Pilot Responses from:**

1. CO
2. OR
3. OH
4. NE

#### **T-SAT Survey Responses about the T-SAT TOOL from:**

1. PA
  2. CO
- **Gerry** – If special education is not looking at concussion as something they own (which they shouldn’t) then who does own it within state DOEs? School nurses? Dept of Health? Student Personnel Pupil?
    - Melissa - Oregon – a constant struggle with DOE to let her do anything with concussed students at all. Melissa said it is like a spectrum disorder, and therefore she needs to keep track of all severities.
  - **Expand the Quality Indicators** – from NASDSE to Regular Ed. Currently, State Special Ed Directors in pilot states were asked to fill out the T-SAT.
    - **Add concussion quality indicators for state DOEs-**
      - Ask specifically Who in your state is responsible for concussion/school day management (not return to sports) in YOUR STATE?
  - States in need of more direction after filling out QI – T-SAT will be directed to the NCCBI CoP.
    - Doodle poll will be sent out to work group to determine a day to conference call and discuss next steps for revising the tool based on feedback received.

- Committee will discuss possibility of expanding tool or developing a new tool for concussion.*

#### **D. Policy Committee – Drew**

- Creating a Policy Nook on NCCBI & CoP websites*
- Looking for appropriate journals to submit to*
- Possible Juvenile Justice Summit*
- *Taken most conservative approach – looking at kids who were hospitalized (moderate/severe) and taking a further cut of them using the reduction of 19% (Selassi) of moderate/severe TBI would require special ed services*
- Policy committee will draft paper and share with larger NCCBI*

#### **E. Return to Learn paper – Brenda/Karen**

- Rather than a white paper, it has been decided after careful investigation through literature searches, that a Return to Learn Consensus paper was needed to help guide schools.*
- Brenda, Karen, and Judy had a conference call with John Corrigan, the editor of Journal Head Trauma Rehab. He said that this would be a great fit not only for a consensus paper, but for his journal*
- We researched various processes and the Delphi Process was chosen for this specific consensus process. It will be conducted through a series of comprehensive online questionnaires with specific deadlines that must be followed.*
- All organizations will be asked to submit the names of 1 representative to Karen and Brenda by the deadline of February 16, 2016. And upon doing so, their organization also agrees that their representative will come to a consensus by the end of the process and their organization will publically endorse the consensus paper.*
- *Gerry Gioia - he did the modified Delphi process to come to a consensus for the ACE with hospitals a few years ago and is willing to help with the Delphi Process– details like structure of questions, anonymous, periodic re-questioning until we get everyone to agree.*
- Karen and Brenda created an email invitation that Judy will send out to show each of you the email that we will be sending out to key organizations across the United State.*
- *Karen and Brenda will send out a list of all organizations that we plan to invite. If you know of a key leader in an APPROPRIATE organization that is not listed, please email Karen and Brenda that person's name, email address and organization by next THURSDAY, FEBRUARY 4th, 2016 and we will add them to the list.*
- Brenda will send out a workgroup poll via doodle.*

#### **XIV. Wrap up and Next Meeting – Drew and Judy**

- Looking at alternate days for this NCCBI quarterly call*
- Judy will send out an email to see which days are best.*

***Next Meeting: Thursday 4/21/16 2pm ET.***

**National Collaborative on Children's Brain Injury  
Agenda and Minutes**

**10/26/15**

**7:00pm-8:00pm ET, 6:00pm-7:00pm CT, 5:00pm-6:00pm MT, 4:00pm-5:00pm PT**

<b>CALL IN INFORMATION</b> <b>Phone: 1.877.820.7831</b> <b>Access Code: 495085#</b>
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**Attendees:** Keri Bennett, Brenda Eagan Brown, Paula Denslow, Roberta DePompei, Judy Dettmer, Rose Dymacek, Liane Gelman-Wegener, Julie Haarbauer-Krupa, Heather Hotchkiss, Karen McAvoy, Melissa McCart, Drew Nagele, Janet Tyler, Susan Vaughn, and Shari Wade

- XV.** Introductions and Welcome: Drew and Judy (5 minutes)
- XVI.** Announcements and Updates: (15 minutes)
- A. Tribute, Jeanne Dise-Lewis (Roberta)  
*Roberta reported that the tribute has been published in JHTR. She emailed the group the tribute. Hal, Jeanne's husband was very involved in the writing of the tribute. Group thanked Roberta for her work getting this completed and published.*
- B. International Congress on Pediatric Acquired Brain Injury (Roberta)  
*Roberta provided an update to the group about the International Congress on Pediatric Acquired Brain Injury (ICPABI). ICPABI was held in Liverpool. The meeting focused on current research. It was a great opportunity for networking. The organizers anticipated approximately 250 individuals and there were 420 in attendance. Roberta will let us know where this will be hosted next, likely in 2017. She and Shari indicated this is a good conference for this group to be present.*
- C. CDC Report to Congress (Julie)  
*Julie reported on the current report to congress that CDC is writing with the involvement of many stakeholders. The report will have a focus on pediatrics. The first meeting was held to gather input on what the report should contain. Julie anticipates the report to be completed and released in November 2016.*
- D. ACRM Pediatric Task Force (Julie)
- *Julie provided an update on the ACRM Pediatric Task Force. This task force has grown from 3 members to 27. The group is focused on developing a paper that will provide an overview on the care needs of peds primarily from a medical perspective but will include the intersect between medical and schools. Specifically the paper will focus on best practices for transitioning from acute care to home and school settings, the importance of ED information being shared with schools and how to navigate the systems to ensure the correct people have the right information.*
  - *Paula Denslow is the family representative for TN.*
  - *ACRM is interested in tracking pediatric transition into adulthood.*
- XVII.** Protocol for NCCBI Work/Products: Drew and Judy (15 minutes)
- A. Identify the initiative and leaders for the initiative
- B. Leaders identify work group members
- C. Work group develops the product/paper etc.

- D. Larger NCCBI reviews and suggests edits
- E. Work group discusses edits and comes to consensus and incorporates edits
- F. Final review by the work group

*Judy reviewed the NCCBI protocol for the development and dissemination of NCCBI work/products. See above. The group was in agreement that this was the best protocol to follow.*

**XVIII. Current Initiatives: (20 minutes)**

J. Community of Practice Update – Heather

- 1. Update on status
- 2. Feedback from larger NCCBI
- 3. Roll out/dissemination plan
- 4. Maintenance/sustainability

*Heather and Drew reported on the progress of the CoP. CoP is housed on the ObaVerse at the University of Oregon. It is in good shape at this point. In terms of the protocol outlined above, this project is on step E. Heather and Drew will be pulling together the work group to do some final editing before the new year. A concern at this point is maintenance and sustainability. Heather shared with the group an estimate on cost if we were able to fund an individual to simply maintain the site.*

*Maintenance of current CoP site: estimate up to 3 hrs per week @ \$20-25 per hr = \$ 3750 yr (50 weeks)*

*Includes:*

- *respond to any questions*
- *ensure content questions are addressed by identified NCCBI individuals in timely manner and users get a response*
- *check for/fix broken links*
- *making adjustments/additions to content*
- *adding new collection(s) (if content is developed and vetted by NCCBI/Workgroup point person) – once developed and vetted, post content to CoP and work with Oba staff (if necessary)*

*She also discussed an estimate on cost if we would like this site to be dynamic with updates, chats, blogs, etc. happening.*

*Expansion of CoP site: estimate up to 10 hrs per week @ \$40-50 per hr = \$ 6000 (3 months/12 weeks)*

*Includes:*

- *adding new collections (if content is developed outside of NCCBI/Workgroup), develop content, creating or collecting appropriate resources, links, video, etc. for collection, manage vetting process with NCCBI/Workgroup (via google docs, survey monkey, etc.), post content to CoP and work with Oba staff (if necessary)*
- *gathering and/or development of resources*
- *interactive content management/development – forums, blogs, guest writers/speakers, conference calls, hot topic threaded conversations, identifying and collaborating with NCCBI members, etc.*

*The group feels it is best to have it be more dynamic as was the intention in the first place. The group provided suggestions regarding how this may happen, e.g. setting up a Go Fund Me account etc.*

*Action Item: Heather and Drew will get the work group together before the end of the year to discuss strategies for on-going support of this site as well as to make a decision when and*



*how to roll out the site.*

K. Mild Brain Injury White Paper Update – Ann and Gerry

*Brenda reported that the paper is in the queue for publication at JHTR. The committee decided to wait for the paper to both be published in the journal as well as on-line vs. just on-line.*

L. Quality Indicators Tool – Brenda

1. Pilot

*Brenda and Bonnie took the lead on finalizing edits to the quality indicators tool, Traumatic Brain Injury Self-Assessment Tool (T-SAT). This tool, along with an email introduction and request, was sent to Special Education Directors and to other identified state contacts. There are 6 states in the pilot: CO, NE, OH, OR, PA, TN. At this time Nebraska is the only state to have completed the tool. PA had concerns about completing the tool as they felt it was too restrictive to Dept. of Ed and did not allow for alternative partnerships etc. that are being used to achieve the benchmarks indicated on the tool. TN has questions about the tool and would like to talk with Brenda and Judy prior to completion of the tool. The group felt it would be helpful to have a follow up survey with states to determine how they felt about the usability of the tool etc.*

*The group also asked about the NASDSE work that was done. Judy said she would send the articles that were produced by Ann, Wayne and Susan. She will also send the original work that was completed in early 2000.*

*Action Items:*

- 1. Judy will follow up with TN contact to arrange a time to meet with Brenda, Paula and Spec. Ed. Contact.*
- 2. Work group will develop a follow up survey.*
- 3. Judy will follow up with those who have not completed the tool.*
- 4. Judy will send all NASDSE related articles both current and past.*

M. Policy Committee – Drew

1. Screening Recommendation Paper; EPSDT (Susan)
2. Under Identification of TBI for IDEA paper (Stephen)
3. ACRM gap survey (Drew)

*Drew reported that the Policy Committee has not met lately. He did put out a Doodle Poll and hopes to meet soon. The goal with the committee is still to develop a paper outlining the under identification of TBI for IDEA support. Drew and Steve are spearheading this effort. Susan reported that NASHIA continues to develop a paper on screening for EPSDT. Drew has completed collecting the gap survey from NCCBI members. He will be writing up the results of this and will share with the larger group when this is completed.*

*Action Items:*

- 1. Drew will schedule Policy Work Group meeting.*
- 2. Susan will report back on progress of paper for EPSDT*
- 3. Drew will share results of gap survey when he completes the write up.*

N. Return to Learn paper – Karen/Brenda

*Brenda and Karen have developed an outline and skeleton for the paper. This has been sent out to the work group. They are hoping this paper will be comprehensive including existing state's efforts and essential elements for RTL. They are hoping to have a draft reviewed by the work group in order to have a draft for the larger NCCBI by our January meeting. Roberta suggested that the work group consider changing the term "guidelines" to "recommendations" as this more accurately reflects the work of the paper.*

*Action Item: Karen and Brenda will work with the work group to review and revise the draft and have a draft ready for the larger NCCBI by our January meeting.*

- XIX.** Membership: Judy (5 minutes)
- A. Structure
  - B. Core group vs. larger group
  - C. Recruitment
- This was not discussed as there was no time.*
- XX.** Wrap up and Next Meeting – Drew and Judy

*Next Meeting: Thursday January 21<sup>st</sup>, 2-3 ET Teleconference*

### **7/23/15 - Agenda & Minutes:**

## **National Collaborative on Children's Brain Injury**

2:00-3:00 ET, 1:00-2:00 CT, 12:00-1:00 MT, 11:00-12:00 PT

CALL IN INFORMATION Phone: 1.877.820.7831 Access Code: 495085#
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Attendees: Gavin Attwood, Keri Bennett, Brenda Eagan Brown, Amy Colberg, Roberta DePompei, Judy Dettmer, Rose Dymacek, Liane Gelman-Wegener, Ann Glang, Heather Hotchkiss, Stephen Hooper, Karen McAvoy, Cate Miller, Drew Nagele, Bonnie Nelson, Janet Tyler, Susan Vaughn, Shari Wade (18/30)

- XXI.** Introductions and Welcome – Drew and Judy
- Liane Gelman-Wegener joined as a new member of the group.  
Liane is the parent of a child who received a brain injury at age 3.  
She is now 13. Liane serves on the Connecticut Advisory for BI.
- XXII.** Announcements and Updates:
- E. Tribute, Jeanne Dise-Lewis (Roberta)  
Waiting for a response from Hal to provide more background and confirm personal information. Roberta incorporated comments that were sent in. Drew provided a photo & Judy sent Hal's phone number. Roberta will send the final draft for review by Drew, Ann, & Judy. The publication is due to come out in a couple of months, hopefully by the 1 year anniversary.
  - F. Upcoming conferences: (Many NCCBI members are presenting)
    - [The International Congress on Pediatric Acquired Brain Injury](#)  
International Brain Injury Association (IBIA)  
September 16-18, 2015, Liverpool, United Kingdom
    - [American Congress of Rehabilitation Medicine \(ACRM\)](#)  
Annual Conference, Progress in Rehabilitation Research  
October 25-30, 2015, Hilton Anatole, Dallas, TX
    - [National Association of State Head Injury Administrators \(NASHIA\)](#) October 26-29, 2015, Denver, CO (Pre-Conference: TBI within the criminal justice system)

**XXIII.** Current Initiatives:

O. Community of Practice Update – Heather

5. Update on status: Previously worked with NASDE on the Shared Work platform – there were lots of barriers and it was not user friendly. The Steering Committee investigated other free platforms and selected Obaverse to host the CoP. All of the content has been moved and reformatted. The Core Team has completed their review & the site is being tweaked to reflect recommendations for revisions. There will be capability to conduct polls, pose questions & interact & much more.
6. Feedback from larger NCCBI: \*\*A structured request/guide for feedback will be sent to the larger group. Reviewers will be asked to look at specific features and content. Laura Beck has done an outstanding job of coordinating this effort. Those who work with schools and educators may want to review using the “educator lens” to see if this will be useful for that group.

**Community of Practice (CoP) website:**

<https://youthbraininjury.obaverse.net/welcome/>

7. Roll out/dissemination plan: When ready, the plan is to disseminate as widely as possible. \*\*Need to draft a release that can be used with multiple audiences (email to members’ listservs and colleagues + possible to print postcards that could be set out at conferences?) The Go Live Target can be pending timing of feedback from the larger group and any revisions that need to be made based on the feedback.  
\*\*Discussed having a “Kickoff Event” for agencies, advisories, educators, parents, etc. It was suggested to try to time it to coincide with the 40<sup>th</sup> Anniversary of the passage of Law 94-142, November 29, 1975 by President Gerald Ford. Other anniversaries were mentioned for Medicare – 50, ADA – 25.  
\*\*Suggested making a list of topical and controversial issues plus make additions and then rank order for hot topics to interact with on the CoP.
8. Maintenance/sustainability: How? Who will work behind the scenes? The CoP needs to be led – someone to make content changes, respond to emails, etc. A technology person to revise and interact with the site. (Could be \$20-30 an hr.) Someone responding at a lesser level would receive a lesser amount per hour. \*\*Need to draft a proposal with time and budget to manage the CoP.

P. Mild Brain Injury White Paper Update – Ann and Gerry

The paper has been accepted by JHTR and will going to press. It was suggested to consider e-publishing vs. waiting 2-3 years for publication. Being published on the web, citations can still be made. (John Corrigan utilizes this process). Ann will talk with Gerry about e-publication.

Q. Benchmarks – Bonnie/Brenda

2. Status: The Core group landed on calling the tool the “TBI-Self-Assessment Tool” = T-SAT. The workgroup met July 15<sup>th</sup> & determined documents are ready to pilot
3. Pilot: Colorado, Nebraska, Ohio, Oregon, Pennsylvania, and Tennessee State Directors of Special Education will be sent an email request to participate next week + the tool. The NCCBI member from that state will serve as lead contact/mentor. They will complete and return the completed tool along with comments & questions. The Core Team will review and make adjustments as recommended. We should have the results and outcomes for the October quarterly call. It was recommended that Susan Kaufman, OSEP, should be contacted as we begin to move forward with this. Also suggested to get on the NASDE monthly call agenda when the time is right.

R. Policy Committee – Drew

4. **Screening Recommendation Paper; EPSDT RE: best practices for screening.** Susan Vaughn has drafted this as a NASHIA position paper, and is working with CDC for revisions & changes.

**We discussed dissemination of this work, as Kristen had** contacting Bright Futures who addresses early identification issues & the AAP at the national level; Maternal Child Health might be another pathway – trauma, mental health, Medicaid, Title V. Screening is a hot topic in schools, Juvenile justice system – TBI + developmental screens (on the heels of Autism screening). Stephen Hooper will check with individuals he knows regarding dissemination with AAP and possibly Title V.

5. **Under Identification of TBI for IDEA paper (Stephen)** This paper will use hospitalization data for kids with moderate/severe brain injury, adjusted for those expected to have persistent disability, & compare numbers with those students identified in the schools under IDEA – a white paper is the goal.
6. **ACRM gap survey (Drew)** This survey will compare gaps in brain injury services/supports from the perspective of

medical rehab providers to the perspective of school personnel. The survey should come out within the next couple of weeks – NCCBI group; received 43 responses from Ped-Adol Task Force of ACRM. Need to focus on utilizing all of the information coming in to effect changes in policy and legislation.

7. Clarify who is on the committee/schedule quarterly meetings (Drew) a. Proposed phone conferences every other month for this work group (previously Drew, Susan, Judy, Ron Savage, Kristin?)

\*\*Send out a list of workgroups, tasks & update so new members can join a work group and others can select projects.

**XXIV.** Membership (Judy) **HOLD for October**

- D. Structure
- E. Core group vs. larger group
- F. Recruitment

**XXV.** New Initiatives

- A. Return to Learn paper (Ann)

Discussion around lack of policies in place in states for RtL or return to academics. 3 states have policies in place and 5 others are in the process – possible addendums to return to play laws in place. (NE, VA, NY + HW, MA, MD, VT, SC) Must have teeth in the law to be implemented.

Propose developing a consensus paper. Karen & Brenda will be the leads. Janet, Rose, Melissa & Bonnie will join the team.

**XXVI.** Wrap up and Next Meeting – Drew and Judy

***Next Meeting: Monday October 26<sup>th</sup> 4-6pm MT. NASHIA SOS conference in Denver. Call in option will be available.***

**Minutes: National Collaborative on Children's Brain Injury**

**4/23/15**

1. Announcements:

- Roberta will follow up with Hal Lewis and others for more information about Jeanne Dise-Lewis.
- Website: All upcoming conferences are on the NCCBI website: <http://cbirt.org/nccbi/>. Thanks to Susan for catching the errors on the home page. We will fix those. If you find any others, please send them to Ann (glanga@cbirt.org)

2. Community of Practice

- After considering a range of options, the CoP subcommittee selected ObaVers as the site for our CoP. With support from the Colorado TBI program, Laura Beck has been hired to build the first version of the site.
- To view, go to <https://www.obaverse.net/welcome/>. You need to create an account to participate, but it just requires an email and password. Once you are on the site, search for Brain Injury in Youth: Supports for School Success Community of Practice.
- The site will be linked with the TBI TAC site.

3. The Mild Brain Injury white paper has been submitted to Journal of Head Trauma Rehabilitation.

4. The Quality Indicators tool was circulated. Please send your feedback on the document to Bonnie Nelson ([Bonnie.Nelson@education.ohio.gov](mailto:Bonnie.Nelson@education.ohio.gov)). Next steps: We will ask several state DOE representatives to pilot the tool and will revise based on those results. We discussed the ultimate dissemination of the tool might be through State Directors of Special Ed like was done with the initial survey tool where 43 states participated.

5. Policy Subcommittee – EPSDT Screening: We talked about giving Susan feedback on this draft “guidance” from NASHIA on EPSDT. We also talked about how to actually get screening into effect, and Susan clarified that for children on Medical Assistance, they get an Annual Screen. To become part of that annual screen may require action through CMS, to be most systematic (how do we do that?). Kristen? Suggested that states take their cues on EPSDT screening from the American Association of Pediatrics, AAP Bright Futures, who puts out what it considers a priority for screening (how do we do that?)

6. Policy Subcommittee - Access barriers for IDEA: A draft manuscript is under development. We talked about adding : (1) Numbers of students classified under the TBI Classification; (2) Overall TBI prevalence data for individuals ages 3 to 24 based on either what the states have provided or based on calculations from CDC estimates; (3) Hospitalization data for TBI for ages 3 to 24 (as these are the cases that most likely will be candidates for special education supports); and (4) this annual number x 18 (to represent the approximate number of years that students can stay in school). This will be circulated to the NCCBI group.

7. NCCBI membership: Drew and Judy will contact members who have been inactive. The idea is for membership to be representative, but to be limited to people who can be very active, a CORE Group, and that the wider reach of the NCCBI would be through the CoP.

We identified 2 gaps in our CORE membership: Family members and physicians. We will invite at least one new family member to join NCCBI. We would like to include another family member and a physician.

**ACTION:** Please review the membership list on the NCCBI website and offer any suggestions you have for new members to Judy and Drew.

### **NCCBI January 22, 2015**

**Attendees:** Judy Dettmer, Ann Glang, Melissa Nowatzke (CBIRT), Elizabeth Ferguson-Greene (CBIRT), Karen McAvoy, Kristy Werther, Brenda Eagan-Brown, Bonnie Nelson, Paula Denslow, Janet Tyler, Roberta DePompei, Leslie Caplan, Rebecca Desrocher, Gavin Atwood, Shari Wade,

Jan White, Kristina, Susan Kaufmann, Susan Vaughan, Julie Haarbauer-Krupa, Steve Hooper, Keri Bennett

**Request for assistance:** Shari would like feedback from the group on the critical transitional outcomes and outcome measures for transition-age youth. *Kristy has created a Survey Monkey for this – view here:* <https://www.surveymonkey.com/s/NCCBItransitions>. Please access and provide your thoughts.

**New resource:** Judy Dettmer, on behalf of Ron Savage, let the group know about a new book, The Bend in the Road: Lenny Burke's Farm, by Yvonne Daley. The book discusses pediatric brain injury from the perspective of the mother of a child with brain injury.

### **Tribute to Jeanne Dise-Lewis**

Roberta will take responsibility for writing a letter to the editor of JHTR from NCCBI about Jeannie. "Jeanne Dise-Lewis: walking a mile in her shoes." Please send anecdotes, information, etc. From there, we could propose a full issue of JHTR with an editorial opening and both the articles based on her work (post-peer-review). Judy will send information from the memorial and get a family photo.

*Please submit materials for the letter to Roberta by February 12.*

BrainSTARS – the Children's Hospital Jeanne was part of will take over BrainSTARS and continue making it available. Not clear whether they will continue to update it, or if they're just publishing.

### **Updates from subcommittees:**

#### **1. Benchmarks**

Cate Miller made some suggestions that Ann & Judy & Bonnie will incorporate, then next steps will be dissemination/how to address budget issues so that changes can be implemented.

#### **2. Mild TBI White Paper**

Judy sent out a draft (attached to this email), Gerry and co-authors would like to incorporate NCCBI feedback prior to submission to JHTR. *Please offer feedback by February 12 – changes received after will not be incorporated. Please use track changes and send back to Judy Dettmer.*

#### **3. Policy Initiatives**

Steve: Working through the parameters of potential white paper. Looking at the differences in definitions between states and how those differences affect policy. Have another call scheduled in early February to develop outline. This has become a focus of a sub-group of the policy workgroup. There are faculty and students from both UNC and CSU assisting with this effort. Drew and Judy are also involved. The intent is to take a look at what currently is happening, what the barriers and gaps are so that we can better determine policy/legislative efforts required.

Expect paper will be finished this summer.

Strategic policy development – what are legislators currently focusing on?

Reauthorizations expected this year:

- No Child Left Behind (Elementary/Secondary Schooling Act)
- Secondary and Higher Education Act

We will, as a group and with Susan's support, monitor these activities to determine if there are logical places within these legislation to include brain injury specific agendas.

Susan Vaughn will take the lead on developing a recommendations paper on early screening for brain injury. The target audience of this paper will be Medicaid directors about screening for TBI and disabilities. Susan will develop a draft and then will look to the group for support identifying screening resources & protocols.

#### **4. Community of Practice**

Drew & Heather have been heading up the effort to build this NASDSE-facilitated website where educators interact and get resources. Recently Laura Beck was hired as support for uploading content, maintaining the site, etc.

Long-term maintenance and usability of the site is still in question; and this committee is exploring options for additional tools to reach educators working with students with TBI. Rebecca mentioned that HRSA is hoping to carve out a piece of their new domain to host a long-term community of practice site.

Stay tuned for further developments.

### **Announcements**

All pediatric TBI conferences are listed on the [NCCBI website](#)

International Brain Injury Pediatric– first international conference in Liverpool in September. Call for abstracts is now out – Here is [the link](#) to the call for abstracts-- it also appears on the NCCBI website.

NABIS is coming up in April in San Antonio.

NASHIA is in Denver at the end of October

ACRM is in Dallas at the end of October.

Next meeting will be in March – date will be released as soon as possible.