

The Pennsylvania State Summit on Brain Injury
November 29, 2005

Executive Summary

On November 29, 2005, the Pennsylvania Department of Health hosted a day-long meeting, the Pennsylvania State Summit on Brain Injury. This was a working meeting, attended by multiple stakeholders in the Summit's theme of *Seamless Services and Supports for People Living with Brain Injury*. In this Executive Summary we describe the impetus of the Summit, the planning and design process, the Summit itself, and its short-term outcomes.

Impetus for the Summit

The idea for the Summit grew from discussions within the state's Traumatic Brain Injury (TBI) Advisory Board, concerning how best to further the Pennsylvania State Traumatic Brain Injury Action Plan, and the goals of Pennsylvania's HRSA-funded TBI Implementation Grant. The broad objectives of this grant are to improve awareness of brain injury and to enhance services, training and education for the benefit of Pennsylvanians with brain injury and their families.

A committee consisting of both Advisory Board members and non-members was formed to discuss the idea of a state-wide conference. Committee members were Tessa Hart (chair), Mike Miller, Becky Kishbaugh, Drew Nagele, Symme Trachtenberg, Mary Pat Murphy, Ginny Rogers, Jill Garland, and Bonnie Bardell. Carolyn Cass also provided assistance on behalf of the Department of Health.

Planning and Designing the Summit

The Summit Committee planned the meeting over an approximately 6 month period starting in late April, 2005. The planning was done in several steps:

1. The committee first brainstormed about the desired objectives and overall structure for a first state-wide conference. What did we want to accomplish? Who should attend, and what activities should be included? We proposed as our main objective to develop action plans to improve services for brain injury, not to disseminate information. This led to the decision to adopt a *working group* model with a relatively small attendance, rather than holding a large educational conference at this time.
2. The committee next turned to the attendance list and the structure for the Summit. We wanted to have broad stakeholder representation that included people with brain injury and their families, health care providers, and members of the TBI Advisory Board. Most critically, we wanted to include decision-makers from all state Departments that are, or need to be, involved in brain injury services and supports. Committee members divided into small working groups or pairs charged with contacting leaders in key Departments to solicit advice about the Summit, and to learn more about the organization and delivery of state services. We developed a template for an "interview" to be carried out with each contact person so that standard information could be brought back to the Committee.
3. An invitation letter was composed by the Committee and sent in mid-October, 2005, to prospective attendees from diverse stakeholder groups, including policy and program leaders from the following Departments:

- Aging
- Corrections
- Education
- Health
- Insurance
- Labor & Industry
- Public Welfare
- Transportation
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Representatives of the following stakeholder groups were also invited:

- People with brain injury and family members
 - Healthcare providers from around the state, and from Pennsylvania Association of Rehabilitation Facilities
 - Pennsylvania Protection and Advocacy
 - Governor’s Office of Healthcare Reform
 - Pennsylvania Brain Injury Association and National Association of State Head Injury Associations
 - Department of Public Welfare’s Home and Community Based Services Stakeholder Planning Team (the mission of this group is to address barriers and gaps in services across the lifespan for children and adults with brain injury).
4. The Committee decided to engage a professional facilitator who could help to design and implement the meeting. Chrissa Merron, MA began meeting with the Committee in early fall, 2005. Ms. Merron suggested and adapted the Future Search format for the Summit (see below), and was largely responsible for running the day.

The Day of the Summit

The Summit was attended by 68 people, including 37 employees of the State from multiple departments, 19 providers, and 12 people representing the consumer community. The day began with brief presentations by Committee members (Drs. Hart and Nagele and Mr. Miller) to illuminate brain injury issues from the national, state and consumer perspectives, respectively. This introduction was also used to present the 3 over-arching objectives of the Summit:

1. *To understand what’s being done now for people living with brain injury, and what we’d like to do better.*
2. *To create a vision for the ideal future of seamless services and supports for people with brain injury.*
3. *To develop collaborative action plans toward that future, plans that are both do-able and worth doing.*

Participants spent most of the day in a variety of small working groups, composed of both “like” and diverse stakeholders. The format chosen for the Summit was adapted from the Future Search conference model developed by M. Weisbord. The Future Search is considered an optimal planning strategy for large, ambiguous problems that cross traditional policy and practice boundaries. In Future Search, diverse stakeholders focus on their past experiences related to the topic at hand. They then work together to map out a comprehensive picture of the present issues and trends bearing on the conference theme-- in this case, *seamless services and supports for brain injury*. At the Summit, this process resulted in a “Mind Map” literally

covering one wall, depicting the scores of issues bearing on brain injury services and supports. Participants then placed dots on the map to “vote” for the issues most important to them. The process was not only useful for beginning to prioritize among a large number of complex problems, but also for highlighting differences in priority among stakeholder groups. For example, funding issues were more important to providers than to consumers. Conversely, employment and socialization opportunities were of high priority for consumers, less so for providers and state workers. Public awareness and service access/ service coordination issues were important across stakeholder groups.

The last part of the Summit day was spent in exercises visualizing the ideal future of seamless services and supports, and identifying the most important issues to work on to achieve that future. After considerable discussion to establish consensus, the following 6 issues were identified as being of highest priority across stakeholder groups:

1. Transportation, especially access in rural areas and across county lines
2. Lifelong service coordination
3. Single point of access to services
4. Funding
5. Person-centered services
6. Public education and awareness

At the end of the day, participants were asked to sort themselves into 6 groups who would select a chair and a liaison to the TBI Advisory Board, exchange contact information, and develop an initial plan to continue working on their theme. No participants selected the Transportation group, but each of the others had enough members to establish them as working groups. (All 6 groups were later consolidated by the Board into 4—see below).

Summit Outcomes

Several weeks after the Summit, participants were sent a 1-page evaluation form and asked to return it by e-mail or fax. Evaluations were returned by 49 attendees (72%), many of whom wrote lengthy and thoughtful comments. The overall ratings of the Summit were overwhelmingly positive: 94% thought it was “excellent” (29 respondents) or “good” (17). All but 6 respondents said they “definitely” would want to attend the next Summit. Most of the positive comments fell into four categories:

- There were many comments about the unusual diversity of the attendee group, with special appreciation expressed for the number of state departments represented and for the viewpoints of people with TBI and family members.
- It was stated that the Summit was well organized and that its leaders were very well prepared.
- There was much appreciation for the energy and positive attitude generated by the day.
- The opportunity to gain new knowledge and perspectives was appreciated by many.

Respondents also offered many thoughtful suggestions for how future meetings could be improved, with the following themes predominant:

- Many participants did not like the facilitated exercise format, finding it tedious, repetitive or rigid.
- There was disappointment expressed that some departments had delegated Summit attendance to trainees, employees without decision making power, or participants who left early.
- There were many comments that there was too much “crammed” into one day, with not enough time to complete action plans.
- On a related note, concern was expressed that the Summit ended with lack of clarity about what its true outcomes would be or how the work would be carried forward.

At the January, 2006 TBI Advisory Board meeting, a summary of the evaluations of the Summit was distributed and discussed. At the same meeting, each of the five work groups created at the Summit gave a brief report on its activities to date; most had been able to meet once or twice by conference call to begin forming plans of action. In discussion by the Board, it was decided that some of the work groups should merge to avoid fragmentation of effort and that a Transportation group should be formulated. The resulting work groups are:

- Funding
- Public Awareness and Prevention
- Person-Centered Services (a consolidation of the groups focusing on person-centered services, single point of contact for services, and lifelong service coordination)
- Transportation

Conclusions

Did the Pennsylvania Summit on Brain Injury meet its objectives? The Summit was effective in bringing diverse stakeholders together, many of whom were in the same room, let alone “at the same table,” for the first time. People who are affected by brain injury services and supports in very different ways had the opportunity to learn from each other’s points of view about what works, and what doesn’t. At least for the participants that day, the Summit seems to have been effective in meeting the objective of *understanding what’s being done now for people living with brain injury, and what we’d like to do better*. The future search format did begin to *create a vision for the ideal future of seamless services and supports for people with brain injury*. However, there were mixed reviews on whether the format and the time allotted to it were necessary to create this vision, or sufficient to establish priorities of equivalent importance to the multiple stakeholder groups.

Whether the Summit succeeded at *developing collaborative action plans toward that future, plans that are both do-able and worth doing*, remains an open question. If the work groups draw in new collaborators who were energized by the Summit, if their action plans are informed by the ideas generated that day, and if their results bring us closer to the ideal of seamless services and supports for brain injury, the resources committed to the Summit will have been well spent.