Report of the Task Force on Services and Supports for Individuals with Acquired Brain Injuries
(House Concurrent Resolution 67)

Research Memorandum No. 496

Legislative Research Commission
Frankfort, Kentucky
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COMMONWEALTH OF KENTUCKY

LEGISLATIVE RESEARCH COMMISSION

State Capitol **700 Capital Avenue** **Frankfort KY 40601**

502/564-8100

Capitol FAX 502-223-5094
Annex FAX 502-564-6543
www.lrc.state.ky.us/home.htm

Robert Sherman
Director

TO: Senator David Williams
Representative Jody Richards
Members of the Legislative Research Commission

FROM: Senator Julie Denton, Co-Chair
Representative Mary Lou Marzian, Co-Chair

SUBJECT: **Final Report of the Task Force on Services and Supports for Individuals with Acquired Brain Injuries**

DATE: October 30, 2002

House Concurrent Resolution 67 of the 2001 General Assembly established the Task Force on Services and Supports for Individuals with Acquired Brain Injuries and directed the Task Force to make recommendations concerning services for brain-injured individuals. This report contains the recommendations and is presented for your review. The work of the Task Force was completed by September 30, 2002.

We were pleased to have the opportunity to learn more about the needs of people with brain injuries and understand the value of injury prevention efforts. Please contact either of us if additional issues or question arise.

Staff of the Legislative Research Commission prepared the report, and their assistance to the Task Force is gratefully acknowledged.

Task Force on Services and Supports for Individuals with Acquired Brain Injuries

2001 HCR 67

Legislative Members

Senator Julie Denton, Co-Chair

Representative Mary Lou Marzian, Co-Chair

Citizen Members

Mary Hass, Chair
Traumatic Brain Injury Trust Fund Board

Scott Furkin, Executive Director
Brain Injury Association of Kentucky

Barth Weinberg, Chief Executive Officer
Frazier Rehabilitation Center

Bruce Crump
Department of Vocational Rehabilitation

Richard T. Purvis, Psy.D.
Division of Mental Health
Department of Corrections

James Woodrum, Executive Director
Kentucky Jailers' Association

Marilyn Duke, Deputy Commissioner
Department for Medicaid Services
Cabinet for Health Services

Margaret Pennington, Commissioner
Department for Mental Health and Mental Retardation Services

Elizabeth Runyon
Seven Counties Services

Janell Hill
Bowling Green, KY

Michael Townsend, Director
Division of Substance Abuse
Department for Mental Health and Mental Retardation Services

Kevin Lightle, Ed.D., Director
Division of Mental Retardation and Developmental Disabilities
Department for Mental Health and Mental Retardation Services

Lisa Rice, R.N.
Nurse Consultant Inspector
Division of Mental Health
Department for Mental Health and Mental Retardation Services

Colleen Ryall, Ed.D.
Director, Brain Injuries Services Unit
Division of Mental Health
Department for Mental Health and Mental Retardation Services

Chad Jackson
Cumberland River Comprehensive Care

Linda Dierking
Catastrophic Consultants

Legislative Research Commission Task Force Staff

Murray Wood, Betty M. Davis
Rhonda Carter, Dawn Groves, Gina Rigsby

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EXECUTIVE SUMMARY

It is estimated that over 5,000 people in Kentucky sustain a brain injury each year, with almost 3,400 surviving. The major causes of aquired brain injuries (ABI) are motor vehicle accidents, falls, and violent crimes. Improvements in medical care and technology have increased the likelihood and rates of survival for individuals with a severe brain injury. Individuals with brain injury have cognitive, physical, and emotional difficulties that include difficulty driving, working, maintaining relationships, remembering recent events, managing a household, recognizing safety hazards, controlling their behavior, and living and performing daily activities without support. The specific impact of a brain injury on an individual depends on the area of the brain affected. Unlike many other physical conditions, there is often no improvement in the physical condition of the brain, and individuals who sustain brain injuries often have these difficulties for the rest of their lives.

Kentucky has two recent sources of funding for services specifically designed for individuals with ABI - the Medicaid ABI waiver program and the Traumatic Brain Injury Trust Fund. Long-term services may be available through the programs that provide assistance to other disabled persons, such as Medicaid, Medicare, Social Security Disability, and the Supports for Community Living program and other programs that serve persons with developmental disabilities. Professionals who work with persons with ABI indicate that the needs of the persons with ABI are not met through existing service systems because of the unique disabilities that occur with brain injuries and the lack of awareness and expertise regarding ABI among existing service providers.

The 2001 General Assembly enacted House Concurrent Resolution 67 establishing a sixteen-member Task Force on Services and Supports for Individuals with Acquired Brain Injuries (Attachment A). The Task Force was required to develop recommendations regarding:

- Mechanisms for a more accurate assessment of the number of adults and children with ABI who receive publicly-funded services;
- Changes to existing administrative regulations governing publicly funded programs that would increase access to existing services and supports for individuals with ABI;
- The elimination of barriers to the access to and the provision of services;
- Strategies to develop intensive inpatient services that provide crisis stabilization, specialized evaluation, and treatment for individuals with ABI;
- Strategies for the decriminalization of individuals with ABI; and
- Strategies to increase the employment of, vocational training and educational services to, and case management services for individuals with ABI.

Task Force Activity

The "ABI Task Force" met seven times between December 12, 2001, and September 30, 2002, to address the directives of 2001 House Concurrent Resolution 67. The Task Force established workgroups to address improving data collection, refining and developing services for people with acquired brain injuries, increasing capacity for crisis intervention and stabilization services, and diverting individuals with brain injuries from the criminal justice system to appropriate treatment programs.

RECOMMENDATIONS

The Task Force adopted the following recommendations:

1. Re-establish the task force to further study:
    a. Barriers to services;
    b. The fiscal impact of increasing services available to individuals with brain injuries;
    c. The fiscal impact of increasing the number of individuals served;
    d. The availability of long-term services and supports; and
    e. Other system improvements, including but not limited to the creation of mobile assertive community treatment teams and inpatient neurobehavioral units.

2. Encourage the development of regional, multidisciplinary clinical teams to provide consultation and promote effective case planning and treatment.

3. Encourage cross-training for public and private professionals who work in the areas of brain injuries, substance abuse, mental health, mental retardation and developmental disabilities, criminal justice, employment services, and vocational rehabilitation services and provide cost analysis for training.

4. Advocate for prevention strategies that include legislation requiring helmet use in open vehicles and a "primary offense" seat belt law.

5. Recommend removal of the trust fund's revenue cap to provide more resources for services.

6. Improve data collection to better inform policymakers by:
    a. Conducting a prevalence survey to obtain a baseline estimate of prevalence by region by October, 2004;
    b. Examining the methods for developing a statewide injury reporting system, in conjunction with existing data and reporting systems, that includes requirements for reporting from key sources and capture data and cost of services related to brain injury from all providers;
    c. Collecting data annually on the number of users of crisis stabilization units and inpatient neurobehavioral units;
    d. Adding questions to existing risk behavior surveys related to brain injuries; and

    e. Adding screening questions relating to brain injury to the Patient Pre-Admission and Screening Review instrument that is required for patients entering nursing homes.

7. Maximize the ability of people with acquired brain injuries, their families, and their loved ones to plan for and support themselves in their own homes and communities by:

    a. Improving patient education about the effects of acquired brain injuries and the services available to help cope with those effects at hospitals, acute care facilities, and rehabilitation centers;
    b. Providing a centralized information and referral source for people seeking information about brain injury or related services, such as a "single point of information" similar to the KY CARES network but inclusive of eligibility criteria for existing programs;
    c. Facilitating workshops for families about legal and financial issues, including guardianship, advance directives, involvement with the legal system, and advocacy;
    d. Developing family support groups, modeled from the "Concerned Persons" support group in substance abuse treatment programs; and
    e. Defining the roles and responsibilities of primary and secondary case managers when multiple case managers are involved with families.

8. Maximize the use of existing programs and resources available to persons with brain injuries by:

    a. Increasing the number of case managers statewide who are aware of brain injury issues and providing information and cost-effective training to all case managers and support staff;
    b. Updating the resource guide for case managers, advocates, and referral sources and making it available electronically; and
    c. Conducting a detailed review of program rules to identify and amend policies and procedures that prevent or inhibit access to services.

9. Partner with existing programs and providers to increase their capacity and expertise to meet the needs of individuals with brain injuries by:

    a. Developing a cadre of consultants or program specialists to provide easily accessible consultation to providers working with individuals with brain injuries;
    b. Enhancing case managers involvement with substance abuse treatment programs where appropriate and educating case managers on service and funding resources and on resources in addition to the Traumatic Brain Injury Trust Fund;
    c. Promoting participation of people with brain injuries in the advocacy efforts of groups supporting persons with disabilities, such as coalitions for mental health, substance abuse, and mental retardation, and other developmental disabilities;

   d. Developing education and "best practices" training that includes early intervention efforts for all service and government agencies and organizations involved with individuals with brain injuries to improve service delivery and promote collaboration among service agencies; and
   e. Developing a brain injury screening tool for non-mental health professionals in the criminal justice system and other service systems to help identify when specific expertise or intervention is necessary.

10. Create the necessary "safety net" of specialized services for individuals with brain injuries by:

    a. Maximizing the use of existing crisis stabilization units and providing training and clinical support for staff of crisis units;
    b. Developing mobile assertive community treatment teams that provide intensive oversight and case management; and
    c. Developing neurobehavioral inpatient units in facilities that could receive Medicaid reimbursement for services.

11. Prevent crises by:

    a. Providing appropriate information about the nature of brain injury and about available services and supports to families as soon after the injury as possible; and
    b. Insuring that case management services are available to assist the family to obtain specialized services such as neuropsychological evaluations, counseling, substance abuse treatment, medication management, and accommodations for impaired memory and communication.

12. Provide crisis intervention and stabilization by:

    a. Having temporary placements (one month or less) that provide safety in the community rather than in institutions; and
    b. Staffing crisis placements with specially trained individuals for evaluation, service planning, and follow up services.

13. Provide access to neurobehavioral treatment by:

    a. Having available neuropsychological evaluation, medication evaluation, health evaluation, speech and occupational therapy, counseling, and substance abuse treatment in a structured health care facility for one to six months that includes facility-based case management services, discharge planning, and family follow up; and
    b. Working with the courts and the legal system, including training for criminal justice system personnel, to divert individuals from jails to treatment.

14. Increase vocational and educational opportunities for individuals with acquired brain injuries by:

    a. Working with the Business Leadership Network and the Interdisciplinary Human Development Institute at the University of Kentucky to develop employment networks;
    b. Increasing the number of supported employment providers;
    c. Providing training and education for employers on issues relating to individuals with brain injuries, including how employment income affects disability and health care benefits;
    d. Developing employment networks to implement the Ticket to Work program;
    e. Supporting efforts to establish a Medicaid Buy-In program for Kentucky; and
    f. Offering education and training on brain injuries to the Kentucky Association on Higher Education and Disability.

INTRODUCTION

Information on the nature and scope of brain injuries was presented to the Task Force by state and national experts. The following sections summarize the information provided and include definitions of brain injury; discussion on prevalence data and the difficulty in identifying persons with brain injuries; description of the effects of brain injury on the lives of Kentuckians; consideration of prevention issues; description of current publicly-funded services available, and identification of service needs.

DEFINITIONS

A brain injury is an injury with structural, non-degenerative brain damage that occurs after birth and that is not inherited nor congenital. The term does not include mental retardation, autism, or a degenerative condition like brain cancer. A brain injury may be caused by injury from physical trauma, typically a blow to the head, and is called "traumatic brain injury" (TBI), or it may be caused by damage from anoxia or hypoxia (low or no oxygen to the brain) or damage from an allergic condition, toxic substance, or other acute medical incident. These types of injuries are called "acquired brain injury" (ABI).

The difference between "acquired" and "traumatic" brain injury is important because some states provide services for traumatic brain injury only, and nationwide statistics from the Centers for Disease Control and Prevention (CDC) include only TBI, resulting in an underestimation of the population of individuals with acquired brain injury. Kentucky's publicly funded services include both TBI and ABI.

INCIDENCE AND DATA COLLECTION

It is estimated that two million people nationwide suffer TBI each year, and 80,000 of those have a long-term disability. Approximately 5.3 million Americans live with a TBI disability. In comparison, it is estimated that 5.4 million people have a persistent mental illness and 7.2 million people have mental retardation.

The President and CEO of the Brain Injury Association of America told the task force that there is a false perception that brain injury is a low incidence problem, yet TBI occurs more frequently than Alzheimer's Disease and spinal cord injury, and more people suffer from a brain injury than multiple sclerosis, HIV, and breast cancer combined. He indicated that individuals with brain injuries are the most unserved, underserved, misdiagnosed, and undiagnosed constituency of the disabilities community, and as part of that community, they are also a protected class under the Americans With Disabilities Act and the *Olmstead* decision.

In Kentucky, it is estimated that over 5,000 individuals sustain a brain injury each year, with almost 3,400 surviving. The major causes of acquired brain injury are motor vehicle accidents, falls, and violent crime. The CDC estimates that 50% of persons who receive a TBI are intoxicated at the time of injury.

The Task Force acknowledged the need for accurate data collection on the incidence and prevalence of brain injury to assist with program planning, service planning, and related policy decisions. With improved medical technology and higher survival rates, the number of people living with a disabling brain injury will continue to grow. Data is also needed to promote prevention strategies and to promote more appropriate treatment within existing service systems to address issues specific to working with individuals with brain injuries.

The legislation establishing the TBI Trust Fund requires a medical registry and includes permissive legislation for reporting brain and spinal cord injuries; however, there have been no administrative regulations promulgated on this specific issue, and there are currently no requirements for mandatory reporting by health care or behavioral health care entities.

Representatives of the TBI Trust Fund Board of Directors report that these requirements have been implemented as surveillance rather than as a true registry because of the legislative limitations on funding for this purpose. The TBI Trust Fund Board receives data on hospitalizations due to brain and spinal cord injuries.

Nationwide uniform health care data is collected from standardized billing forms, and that information is collected by the Kentucky Hospital Association for Kentucky. The information from billing forms and discharge data often include diagnosis codes and relate to what treatments and procedures are billed, but may not reflect services that are specific to brain injuries.

Specific data is lacking from emergency rooms, emergency medical responders, the Kentucky Injury Prevention Research Center, nursing homes, mental health services, substance abuse services, Medicaid, children's services systems, and the educational system. Some data may be available through workers' compensation programs. Nursing home data is important because of implications for meeting the community-based service provisions of the *Olmstead* decision. With policy changes, obtaining data from publicly-funded systems and services is possible, but significant data from private service providers would be missing.

Recommendations regarding data collection include:

- Conduct prevalence survey; estimate prevalence by region;
- Develop a mandatory statewide injury reporting system;
- Require risk behavior surveys to include questions on brain injuries;
- Add questions to federally-required nursing home screening instrument;
- Require state agencies to conduct research and data collection; and
- Develop methods to capture data and cost of services from all providers.

THE IMPACT OF ACQUIRED BRAIN INJURIES

Individuals with brain injury have cognitive, physical, and emotional difficulties that include difficulty driving, working, maintaining relationships, remembering recent events, managing a household, recognizing safety hazards, controlling their behavior, and living and performing daily activities without support. The specific impact of a brain injury on an individual depends on the area of the brain affected. Unlike many other physical conditions, there is often no improvement in the physical condition of the brain, and individuals who sustain brain injuries often have these difficulties for the rest of their lives.

Family members who testified before the task force described the difficulty of being a full-time caretaker of an injured individual and provided examples of the behaviors that lead brain-injured individuals to involvement with the criminal justice system. Family members described the following issues related to caring for brain injured individuals:

- Changes in behavior (e.g., poor judgment, alcoholism, paranoid thinking, behavior leading to incarceration);
- Changes in academic performance;
- Need for long-term assistance (e.g., income, physical rehabilitation, psychiatric care, employment);
- Susceptibility to subsequent brain injuries;
- Misdiagnosis leading to inappropriate and ineffective treatment;
- Gaps in services (e.g., age limits for certain services, regional availability of services);
- Susceptibility to becoming targets for predators;
- Lack of help in identifying, accessing, and coordinating services;
- Lack of long-term supports and case management;
- Limitations of health care insurance;
- Lack of providers and inadequate services if they exist (e.g., adult day programs, vocational rehabilitation);
- Lack of training for professionals coming into contact with brain-injured individuals;
- Effects of injury on remaining family members;
- Workplace issues (e.g., cognitive changes affecting ability to continue previous employment or training for different employment, changes in behavior that affect ability to gain or retain employment); and
- Lack of information about the effects of the brain injury and expectations.

Recommendations regarding services for families and caretakers include:

- Improve patient education about the effects of acquired brain injuries and the services available to help cope with those effects at hospitals, acute care facilities, and rehabilitation centers;

- Provide a centralized information and referral source for people seeking information about brain injury or related services, such as a "single point of information" similar to the KY CARES network but inclusive of eligibility criteria for existing programs;
- Facilitate workshops for families about legal and financial issues, including guardianship, advance directives, involvement with the legal system, and advocacy;
- Develop mentors to work with families at the time of injury, while the patient is still hospitalized;
- Define the roles and responsibilities of primary and secondary case managers when multiple case managers are involved with families;
- Develop family support groups, modeled from the "Concerned Persons" support group in substance abuse treatment programs; and
- Promote participation of people with brain injuries in the advocacy efforts of groups supporting persons with disabilities, such as coalitions for mental health, substance abuse, and mental retardation and other developmental disabilities.

In September 2002, Kentucky's Protection and Advocacy Division of the Public Protection and Regulation Cabinet was awarded one of the twenty-eight state grants by the U.S. Health Resources and Services Administration to provide advocacy services specifically for persons with TBI. The grant is $50,000 per year for three years.

PREVENTION

The task force noted the importance of injury prevention as the only "cure" for brain injuries and the resulting life-long impact on the injured individual and their family members.

Recommendations regarding prevention of brain injuries include:

- Advocate for legislation requiring helmet use in open vehicles; and
- Advocate for legislation for a "primary offense" seat belt law.

SERVICES AVAILABLE

Two programs are specific to individuals with brain injuries: Medicaid's Acquired Brain Injury Waiver Program, managed by the Brain Injury Services Unit of the Department for Mental Health and Mental Retardation Services; and the Traumatic Brain Injury Trust Fund program, managed by an executive board.

Medicaid ABI Waiver Program

The Acquired Brain Injury Medicaid Waiver program was implemented in 1999 and provides Medicaid-funded services for 110 individuals who meet eligibility requirements each year. The Department for Medicaid Services reported expenditures were $639,755 in FY ‘01 and $1,442,779 in FY ‘02. Forecasted amounts are $1,029,672 for FY ‘03 and $1,109,910 for FY ‘04.

The ratio of the brain-injured population to the mentally retarded/developmentally disabled population is 5:7; and there are 2,000 “slots” for individuals with mental retardation/developmental disabilities in the Supports for Community Living Waiver program and only 110 “slots” for individuals with brain injuries in the ABI Waiver program. Medicaid representatives explained that once a person receives funding, he or she retains the “slot” for the entire year, whether or not the recipient uses the allotted funds and remains in the program until services are no longer needed. The Co-Chairs contacted the Kentucky Congressional delegation to ask for their support in working with the Centers for Medicaid and Medicare Services to seek options for providing ABI waiver services to more people.

The Department for Medicaid Services provided information about the number of persons with a brain injury that were served by Medicaid, excluding those served under the ABI Waiver program. A query was made using the most common diagnoses found within the ABI Waiver program, and a total number served and paid claims was produced. The data is aggregate, and it does not distinguish between services provided as a result of the brain injury versus services provided for other health care needs. The data report indicates that over 31,300 unduplicated recipients were served and expenditures exceeded $30.7 million in FY 2001. Department staff cautioned that this data was incomplete and care should be taken about conclusions based solely on the report submitted.

Traumatic Brain Injury Trust Fund (TBI Trust Fund)

The TBI Trust Fund was created in 1998 by HB 299,[1] and the provisions governing the Trust Fund and its nine-member board are codified as KRS 211.470 to 211.478 (Attachment B). The definition of “traumatic brain injury” in the statutes includes acquired brain injuries.

The trust fund is required to maintain a registry of brain and spinal cord injuries and to provide funding for services and supports for injured individuals. Funds are received from fines collected statewide for moving vehicle violations and DUI convictions. This revenue averages approximately $250,000 per month. Benefits are limited to $15,000 per individual per year and up to $60,000 for lifetime benefits per individual. Revenue for FY 2001 was $2,249,536; expenditures in FY 2001 were $1,370,076. Revenue for FY 2002 was $2,134,777; expenditures in FY 2002 were $3,111,909. Over five hundred adults and children receive services through the trust fund during this time.

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[1] 98 Senate Bill 145 also established a Traumatic Brain Injury Trust Fund, was passed by the General Assembly, and vetoed by the Governor. The veto message indicated that the provisions of HB 299 were preferred.

As a result of House Bill 452 passed by the 2002 General Assembly, changes were made to the system for collection and disbursement of court-imposed fines and fees for all entities that receive this revenue. Instead of each entity (such as the General Fund, correctional facilities, Spinal Cord and Head Injury Research, Traumatic Brain Injury Trust, public advocates, etc.) receiving a specific amount per fine, all fines and fees will be deposited into a state account, and each entity will receive a percentage of the total. The Traumatic Brain Injury Trust Fund will receive 5.5 percent of the total amount of fines and fees deposited in the statewide account. The fiscal note prepared for this legislation estimated that "the disbursements made to the Traumatic Brain Injury Trust Fund would increase by approximately $500,000 as a result of this Act." The law became effective July 15, 2002.

The current trust fund benefits manager reported that due to increased demand, it became necessary to implement a waiting list in December 2001. As of August, 2002, over two hundred individuals were waiting for consideration for approval for trust fund benefits.

Individuals with ABI may receive services from other programs serving persons with disabilities, although eligibility for these programs is contingent upon the individual's having another diagnosis that would qualify the person for services. Persons with brain injuries may demonstrate problems similar to persons with mental retardation or other developmental disabilities, or similar to substance abuse or emotional disturbances, but the cause of their problems differs and clinical interventions may need to be adapted to be effective with brain injured individuals.

Recommendations regarding existing services include:

- Increase the number of case managers statewide who are aware of brain injury issues and provide information and cost-effective training to all case managers and support staff;
- Enhance case managers involvement with substance abuse treatment programs where appropriate and educate case managers on services and resources in addition to the Traumatic Brain Injury Trust Fund;
- Update the resource guide for case managers, advocates, and referral sources and make it available electronically;
- Conduct a detailed review of program rules to identify and amend policies and procedures that prevent or inhibit access to services;
- Develop a cadre of consultants or program specialists to provide easily accessible consultation to providers working with individuals with brain injuries;
- Develop education and "best practices" training that includes early intervention efforts for all service and government agencies and organizations involved with individuals with brain injuries to improve service delivery and promote collaboration among service agencies;
- Maximize the use of existing crisis stabilization units and provide training and clinical support for staff of crisis units;

- Provide training and education for employers on issues relating to individuals with brain injuries, including how employment income affects disability and health care benefits;
- Provide education and training on brain injuries to the Kentucky Association on Higher Education and Disability.

SERVICE NEEDS

The cognitive, physical, and emotional consequences of a brain injury can present considerable challenges to injured individuals and their families, including behaviors that present significant risks of injury or harm to the individual or others. If family members are unable to manage the risks or behaviors, the individual may be arrested, inappropriately jailed or hospitalized, or suffer further injury. A task force member who is a brain injury survivor explained that memory loss complicates treatment and rehabilitation.

The Brain Injury Services Unit of the Department for Mental Health and Mental Retardation Services received a grant from the U.S. Department of Health and Human Services to conduct a one-year planning project to determine which services and supports people with ABI need to remain in their homes and in their communities. Findings of focus groups conducted by the planning project indicated that the most frequently mentioned service needs were:

- Case management;
- Psychological and mental health services;
- Cognitive rehabilitation;
- Residential services; and
- Employment services.

The President and CEO of the Brain Injury Association of America remarked that an entire new service delivery system does not need to be created specifically for people with acquired brain injuries, but capacity needs to be built within the existing systems. He said that professional training, education, and information is needed because this constituency is different, and their needs should be addressed differently from mental retardation and mental illness. Many children with acquired brain injury are not being appropriately served under federal special education laws and early intervention programs because professional staff are unaware and unskilled in working with brain-injured individuals.

Provider Issues

Task force members heard presentations from several service providers who work with brain- injured individuals. They addressed the unique needs of brain injured clients, the lack of resources dedicated to specialty services in comparison to the population of individuals with mental retardation and other developmental disabilities, and the need for long-term services. Another representative of providers spoke about concerns regarding the lack of existing resources and the administration of the ABI Waiver program. Other providers discussed employment difficulties, including disincentives to work, and other program management issues.

A representative of the agency that in past years contracted with the Brain Injury Services Unit as the benefits manager for the trust fund, reported that many providers who work with brain-injured individuals will not accept persons with alcohol or substance abuse problems, and that residential programs are needed in the state's more populated areas. Early access to neuropsychological evaluations to develop appropriate plans of care is needed for efficiency and effectiveness.

Neuropsychological Evaluations

The task force heard concerns regarding a lack of access to neuropspychological evaluations. The evaluations are performed by a physician or a psychologist practicing with a physician and involve a battery of clinical assessments. They are used to design individual treatment plans. The Cabinet for Health Services surveyed the community mental health centers and concluded that only four of the fourteen centers had appropriately trained and credentialed professionals on staff. The cabinet reported that collaborative efforts are underway to increase the availability of providers of neuropsychological evaluations through the community mental health centers.

Substance Abuse

A presentation on brain injury and substance abuse included a discussion on several studies that revealed increased use of controlled substances and increased mental health issues among the population of brain-injured individuals. It was indicated for treatment to be effective, interventions should specifically target brain-injured individuals. Substance abuse, brain injury, and mental health problems are likely to have compounding effects on the individual. It was suggested that extensive cross-training is needed for rehabilitation, mental health, and substance abuse treatment professionals; funding streams should be designed to recognize co-occurring disorders and complex treatment approaches; innovative case management-type services are needed for individuals with brain injuries who have substance abuse disorders; long-term, episodic, "refresher" treatment and rehabilitation could be effective; with skill enhancement, many day programs and residential facilities could meet the needs of individuals with co-occurring disorders; and family-based inventions and active engagement of families to address substance abuse can be particularly constructive.

Criminal Justice System

Information was provided on coordination between the mental health and criminal justice systems. The Kentucky Commission on Services and Supports for Individuals with Mental Illness, Alcohol and Other Drug Abuse Disorders, and Dual Diagnoses, known as the "843 Commission," established a Criminal Justice/Mental Health Interface Workgroup. This workgroup continues to address issues in conjunction with the

Kentucky Criminal Justice Council regarding persons who end up in the criminal justice system because of behavior that may be beyond their control. This workgroup has drafted recommendations for jailer training that would include screening and identification of individuals with ABI. Funds are included in the Governor's spending plan for jailer training and mental health consultation in the jails.

In addition to the Criminal Justice/Mental Health Interface Workgroup, the following mental health initiatives are underway:

- A mental health counselor is positioned at Kentucky State Reformatory to link inmates to community resources;
- Interagency review teams are conducting pre-release planning for inmates who will be released within three months;
- There is cross systems training coordination with the National Alliance for the Mentally Ill that has helped form police mental health crisis response teams; and
- Specialized intensive case management is being provided by staff of some of the community mental health centers for persons with severe mental illness who have a history of violence or involvement with the criminal justice system.

Because of the movement and effort from the 843 Commission regarding the criminal justice system issues, the task force acknowledged it would be most productive to seek assurance from the 843 Commission that the specific issues relating to individuals with brain injuries would be included in their efforts. This assurance has been received, and the draft documents produced by the Criminal Justice/Mental Health Interface Workgroup of the 843 Commission include specific training regarding the effects of brain injuries.

Recommendations regarding service needs include:

- Create the necessary "safety net" of specialized services and provide training and clinical support for staff working with for individuals with brain injuries;
- Develop mobile assertive community treatment teams that provide intensive oversight and case management;
- Develop inpatient units in facilities that could receive Medicaid reimbursement for neuropsychological evaluation, medication evaluation, health evaluation, speech and occupational therapy, counseling, and substance abuse treatment in a structured health care facility (for one to six months) that includes facility-based case management services, discharge planning, and family follow up;
- Provide temporary placements (one month or less) that provide safety in the community rather than in institutions with specially trained staff for evaluation, service planning, and follow up services;
- Develop a brain injury screening tool for non-mental health professionals in the criminal justice system and other service systems to help identify when specific expertise or intervention is necessary;
- Assure that individuals with brain injuries are included in the Criminal Justice/Mental Health Interface Workgroup of the 843 Commission;

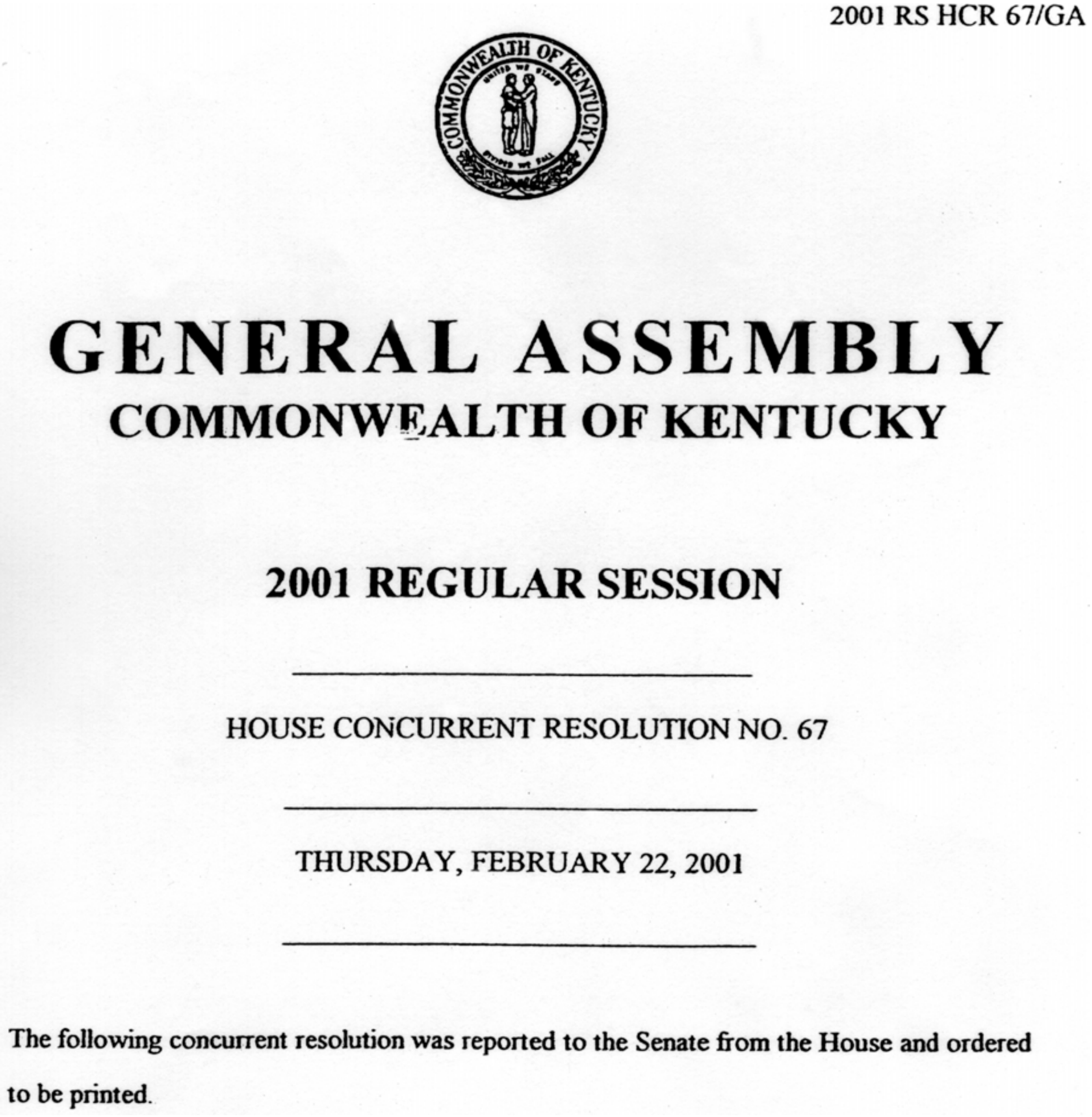
- Increase vocational and educational opportunities for individuals with acquired brain injuries by increasing the number of supported employment providers;
- Develop employment networks to implement the Ticket to Work program; and
- Support efforts to establish a Medicaid Buy-In program for Kentucky.

CONCLUSION

The task force found that the needs of individuals with brain injuries and their families were great and that there is no mechanism for long-term support unless the individual has another primary diagnosis that permits eligibility for services for individuals with other disabilities. Even if other services are accessed (which is difficult because of waiting lists), the providers may not be knowledgeable or experienced in working with the unique needs of individuals with brain injuries. Critical review of program guidelines and eligibility requirements was not completed. There was consensus that the work of the task force should be continued.

ATTACHMENT A

2001 HOUSE CONCURRENT RESOLUTION 67



2001 RS HCR 67/GA

GENERAL ASSEMBLY
COMMONWEALTH OF KENTUCKY

2001 REGULAR SESSION

HOUSE CONCURRENT RESOLUTION NO. 67

THURSDAY, FEBRUARY 22, 2001

The following concurrent resolution was reported to the Senate from the House and ordered to be printed.

A CONCURRENT RESOLUTION establishing a task force on services and supports for individuals with acquired brain injuries.

WHEREAS, it is estimated that each year thousands of Kentuckians suffer from acquired brain injuries; and the physical, emotional, vocational, and rehabilitative needs of individuals with acquired brain injuries are complex and may involve a combination of issues and services, such as health care, employment, substance abuse, mental health, physical and sexual abuse, criminal behavior, emotional disabilities, developmental and learning disabilities, and behavior disorders; and

WHEREAS, there is a lack of public and professional recognition of acquired brain injury as a mental health condition; and

WHEREAS, individuals with acquired brain injuries and their families can plan fulfilling lives but may need life-long supports and services; and

WHEREAS, existing services are limited and unavailable in many areas of the state and do not provide life-long supports and services; and

WHEREAS, in this Commonwealth there are no intensive, inpatient services for adults with acquired brain injuries who are in need of specialized crisis stabilization, evaluation, and treatment; and

WHEREAS, the lack of services and supports, including treatment for behavior disorders may result in the arrest and incarceration of individuals with acquired brain injuries; and

WHEREAS, the provision of the appropriate level of care, treatment, and services is in the best interests of the individuals with acquired brain injuries, their families, their employers, their communities and the Commonwealth at large;

NOW, THEREFORE,

Be it resolved by the House of Representatives of the General Assembly of the Commonwealth of Kentucky, the Senate concurring therein:

Section 1. There shall be created a Task Force on Services and Supports for Individuals with

Acquired Brain Injuries. The task force shall be charged to make recommendations regarding:

(1) Mechanisms to make a more accurate assessment of the number of adults and children with acquired brain injuries that receive publicly funded services;

(2) Changes to existing administrative regulations governing existing publicly funded programs that would increase access to existing services and supports for individuals with acquired brain injuries;

(3) The elimination of barriers to the access to and provision of services;

(4) Strategies to develop intensive inpatient services that provide crisis stabilization, specialized evaluation, and treatment for adults with acquired brain injuries;

(5) Strategies for the decriminalization of individuals with acquired brain injuries; and

(6) Strategies to increase the employment of, vocational training and educational services to, and case management services for individuals with acquired brain injuries.

Section 2. The members of the task force shall include:

(1) One (1) member of the House of Representatives who shall serve as co-chair, appointed by the Speaker of the House;

(2) One (1) member of the Senate who shall serve as co-chair, appointed by the President of the Senate;

(3) One (1) individual with acquired brain injury and one (1) family member of an individual with acquired brain injury appointed by the Legislative Research Commission from two separate lists of three (3) names submitted by the Brain Injury Association of Kentucky;

(4) The chair of the Traumatic Brain Injury Trust Fund Board or the chair’s designee;

(5) The executive director of the Brain Injury Association of Kentucky or the executive director’s designee;

(6) The executive director of the Kentucky Hospital Association or the executive director’s designee;

(7) The commissioner of the Department of Vocational Rehabilitation or designee;

(8) The secretary of the Justice Cabinet or the secretary’s designee;

(9) The president of the Kentucky Jailers Association or the president's designee;

(10) The commissioner of the Department for Medicaid Services or designee;

(11) The commissioner of the Department for Mental Health and Mental Retardation Services who shall also recommend one (1) representative from the Division of Substance Abuse, one (1) representative from the Division of Mental Retardation and Developmental Disabilities, and two (2) representatives from the Division of Mental Health, one of whom shall be a representative from the Brain Injury Services Unit of the Division of Mental Health for appointment by the Legislative Research Commission; and

(12) One (1) representative from the Kentucky Association of Regional Programs and one (1) case manager with experience in the provision of community-based services to individuals with acquired brain injuries recommended by the secretary of the Cabinet for Health Services for appointment by the Legislative Research Commission.

Section 3. The task force shall make a final report of its findings and specific legislative recommendations to the Legislative Research Commission and the Governor no later than July 1, 2002.

Section 4. Provisions of this resolution to the contrary notwithstanding, the Legislative Research Commission shall have the authority to alternately assign the issues identified herein to an interim joint committee or subcommittee thereof, and to designate a study completion date.

ATTACHMENT B

STATUTES GOVERNING THE TRAUMATIC BRAIN INJURY TRUST FUND AND BOARD

KRS 211.470 TO 211.478

211.470 Definitions for KRS 211.470 to 211.478.

As used in KRS 211.470 to 211.478:

(1) "Board" means the Traumatic Brain Injury Trust Fund Board created pursuant to KRS 211.472;

(2) "Cabinet" means the Cabinet for Health Services;

(3) "Traumatic brain injury" means a partial or total disability caused by injury to the central nervous system from physical trauma, damage to the central nervous system from anoxia, hypoxic episodes, allergic conditions, toxic substances, or other acute medical clinical incidents resulting in impaired cognitive abilities or impaired physical functioning. "Traumatic brain injury" does not include:

  (a) Strokes that can be treated in nursing facilities providing routine rehabilitation services;

  (b) Spinal cord injuries for which there are no known or obvious injuries to the intracranial central nervous system;

  (c) Progressive dementias and other mentally impairing conditions;

  (d) Depression and psychiatric disorders in which there is no known or obvious central nervous system damage;

  (e) Mental retardation and birth defect related disorders of long standing nature; or

  (f) Neurological degenerative, metabolic, and other medical conditions of a chronic, degenerative nature.

(4) "Trust fund" means the traumatic brain injury trust fund created pursuant to KRS 211.476.

Effective: July 14, 2000

History: Amended 2000 Ky. Acts ch. 124, sec. 1, effective July 14, 2000. -- Created 1998 Ky. Acts ch. 124, sec. 1, effective July 15, 1998.

211.472 Kentucky Traumatic Brain Injury Trust Fund Board.

(1) The Kentucky Traumatic Brain Injury Trust Fund Board is hereby created for the purpose of administering the trust fund. The board shall be composed of nine (9) members including the secretary of the Cabinet for Health Services or the secretary's designee, the executive director of the Brain Injury Association of Kentucky or the executive director's designee, the state medical epidemiologist, and the following members, to be appointed by the Governor:

  (a) One (1) member shall be a neurosurgeon;

  (b) One (1) member shall be a neuropsychologist or psychiatrist;

  (c) One (1) member shall be a rehabilitation specialist;

  (d) One (1) member shall be a social worker experienced in working with brain-injured individuals; and

  (e) Two (2) members shall be family members of or individuals with a brain injury.

(2) Board members shall not be compensated for serving, but shall be reimbursed for ordinary travel expenses, including meals and lodging incurred in the performance of their duties.

(3) The terms of appointed board members shall be four (4) years, except that the terms of initial members shall be staggered to end as follows:

   (a) Two (2) on June 30, 2000;
   (b) Two (2) on June 30, 2001; and
   (c) Two (2) on June 30, 2002.

(4) At the end of a term, a member shall continue to serve until a successor is appointed and qualifies. A member who is appointed after a term has begun shall serve the rest of the term and until a successor is appointed and qualifies. A member who serves two (2) consecutive four (4) year terms shall not be reappointed for four (4) years after completion of those terms.

(5) A majority of the full authorized membership shall constitute a quorum.

(6) The board shall elect, by a majority vote, a director who shall be the presiding officer of the board, preside at all meetings, and coordinate the functions and activities of the board. The director shall be elected or reelected for each calendar year.

(7) The board may establish any organizational structure it determines is necessary to accomplish its functions and duties, including the hiring of any necessary support personnel. The administrative costs of the board shall be limited to three percent (3%) of the proceeds from the trust fund.

(8) Meetings of the board shall be held at least twice a year but may be held more frequently, as deemed necessary, subject to call by the director or by the request of a majority of the board members.

(9) The board shall be attached to the cabinet for administrative purposes.

Effective: July 14, 2000

History: Amended 2000 Ky. Acts ch. 124, sec. 2, effective July 14, 2000. -- Created

211.474 Operating parameters -- Duties.

The board shall:

(1) Promulgate administrative regulations necessary to carry out the provisions of KRS 211.470 to 211.478;

(2) Formulate policies and procedures for determining individual eligibility for assistance from the trust fund in accordance with the following guidelines:

   (a) The trust fund shall serve as a funding source of last resort for residents of the Commonwealth of Kentucky. To be eligible for assistance from the trust fund, an individual must have exhausted all other funding sources that cover the type of services sought through the trust fund. Individuals who have continuing health insurance benefits, including Medicaid, may access the trust fund for services that are needed but not covered by insurance or any other funding source. Individuals who qualify for institutional care through Medicaid shall not qualify for services through the trust fund;

   (b) All individuals receiving assistance from the fund shall receive case management services;

   (c) Expenditures on behalf of any one (1) brain-injured individual may not exceed fifteen thousand dollars ($15,000) for any twelve (12) month period, and may not exceed a lifetime maximum of sixty thousand dollars ($60,000). At its discretion and subject to fund availability, the board may waive the expenditure or time limitations or both in special circumstances;

(d) Services covered by the trust fund shall include:

1. Case management;
2. Community residential services;
3. Structured day program services;
4. Psychological and mental health services;
5. Prevocational services;
6. Supported employment;
7. Companion services;
8. Respite care;
9. Occupational therapy; and
10. Speech and language therapy;

(e) Covered services shall not include institutionalization, hospitalization, or medications;

(3) Establish a confidential medical registry for traumatic brain and spinal cord injuries occurring in the Commonwealth of Kentucky, or to residents of the Commonwealth of Kentucky.

(a) The board may promulgate administrative regulations requiring licensed or certified professionals or health services providers to report the occurrence of brain and spinal cord injuries, relevant medical and epidemiological information about the injuries, and other information describing the circumstances of the injury to the board or its designated agent. The reporting of data by licensed hospitals under this section shall be limited to that which is reported to the cabinet pursuant to KRS 216.2920 to 216.2929 and the board shall obtain this data from the cabinet. Each licensed hospital shall grant the board, upon presentation of proper identification, access to the medical records of patients with reportable brain and spinal cord injuries for the sole purpose of collecting additional information that is not available in the data obtained from the cabinet. All costs associated with copying medical records shall be borne by the board. No liability of any kind shall arise or be enforced against any licensed hospital or hospital employee for providing the board access to a patient's medical record.

(b) The board and its designated agent, if one is appointed, shall observe the same confidentiality requirements established for the Kentucky birth surveillance registry in KRS 211.670;

(4) Investigate the needs of brain-injured individuals and identify gaps in current services;

(5) Assist the cabinet in developing programs for brain-injured individuals;

(6) Monitor and evaluate services provided by the trust fund; and

(7) Provide the Governor, the General Assembly, and the Legislative Research Commission an annual report by January 1 of each year summarizing the activities of the board and the trust fund.

Effective: July 14, 2000

History: Amended 2000 Ky. Acts ch. 124, sec. 3, effective July 14, 2000. -- Created 1998 Ky. Acts ch. 124, sec. 3, effective July 15, 1998.

211.476 Traumatic brain injury trust fund.

(1) The traumatic brain injury trust fund is created as a separate revolving fund.

(2) The trust fund may receive the proceeds from grants, contributions, appropriations, and any other moneys that may be made available for the purposes of the trust fund.

(3) Expenditures from the trust fund on behalf of the medical registry created under KRS 211.474 shall not exceed one hundred twenty-five thousand dollars ($125,000) for any fiscal year.

(4) Funds unexpended at the close of a fiscal year shall not lapse but shall be carried forward to the next fiscal year.

(5) Any interest earnings of the trust fund shall become a part of the trust fund and shall not lapse to the general fund.

Effective: August 1, 2002

History: Amended 2002 Ky. Acts ch. 183, sec. 20, effective August 1, 2002. -- Created 1998 Ky. Acts ch. 124, sec. 4, effective July 15, 1998.

211.478 Distribution of trust fund moneys.

Trust fund moneys shall be distributed for the following purposes:

(1) To provide services to individuals suffering from conditions that qualify for assistance from the fund, in accordance with criteria established by the board in KRS 211.474;

(2) To establish and maintain a state medical registry for traumatic brain and spinal cord injuries; and

(3) To meet the obligations incurred by the board in meeting its duties in accordance with the provisions of KRS 211.472 and 211.474.

Effective: July 15, 1998

History: Created 1998 Ky. Acts ch. 124, sec. 5, effective July 15, 1998.

ATTACHMENT C

WORKGROUP REPORTS

Workgroup Reports

Four workgroups were formed and their reports are attached. The following Task Force members and citizens participated:

Workgroup I - Incidence and Data Collection;

Colleen Ryall, Chair, Mary Hass, Margaret Pennington, Robert Walker, Steve Englender, and Dana Hawkins

Workgroup II - Increasing Access and Eliminating Barriers to Services;

Kevin Lightle, Chair, Scott Furkin, Mary Hass, Marilyn Duke, Julia Neal, Ann Smits, Darla Bailey, Joy Feist, Alice Blackwell, Karen Edens, Amy Newkirk, and Alberta Cohorn.

Workgroup III - Inpatient and Other Services, Specialized Evaluation, Crisis Stabilization and Criminal Justice Diversion Services;

Colleen Ryall, Chair, Margaret Pennington, Barth Weinburg, Linda Dierking, Mary Hass, Liz Runyon, Pam Pearson, and Kate Johnson.

Workgroup IV - Increasing Employment, Vocational and Education Services, Case Management Services, and Strategies for Decriminalization.

Mary Hass, Chair, Bruce Crump, Robert Klinglesmith, Marian Spencer, Elena Bailey, Jim Kimbrough, Leslie Blankenship, Gayle DiCesare, Wayne Dees, Artus Fox, Mary Phillips, and Kimberly Sheth.

Ad Hoc Committee on Surveillance and Data Collection (Workgroup 1)
June 27, 2002

Members: Robert Walker, Steve Englender, Dana Hawkins, Mary Hass, Margaret Pennington, Betty Davis, and Colleen Ryall

Problem Statement: With improved medical technology and higher survival rates, it is assumed that the numbers of people living with a disabling brain injury will continue to grow. Data is needed to promote prevention strategies, to promote more appropriate treatment within existing service systems, to guide policy makers in responding to the growing needs of this population, and to allow for planning.

At this time, it is difficult to establish a comprehensive and accurate estimate of the incidence and prevalence of brain injuries within the Commonwealth, and the long-term need for services to people who are disabled because of brain injuries. Hospitals and medical facilities are not required to report brain injuries and with the exception of the ABI Medicaid Waiver and the TBI Trust Fund programs, publicly funded programs do not routinely inquire about the existence of brain injuries among the people they serve.

Most states, including Kentucky, rely on estimates from the Center for Disease Prevention and Control, although that information is specific to traumatic injury only. There was discussion about the difficulty of refining the definitions of "traumatic" and "acquired" brain injuries that would be necessary to obtain accurate statewide information.

Current Data Collection Efforts:

The legislation establishing the TBI Trust Fund requires a medical registry and includes permissive legislation for reporting brain and spinal cord injuries, however, there have been no administrative regulations promulgated on this specific issue and there are currently no requirements for mandatory reporting by health care or behavioral health care entities. Representatives of the TBI Trust Funds Board of Directors report that these requirements have been implemented as surveillance rather than a true registry, because of the legislative limitations on funding for this purpose. The Board is limited by legislation to devoting $125,000 annually to this purpose. A true registry is likely to cost $500,000 annually. If the cap on this were amended, the representatives caution, Trust Fund money would be diverted from direct services and supports to individuals, which are greatly needed. Group members also indicated that with the advent of HIPAA requirements the collection of confidential information would be extremely difficult and expensive.

The TBI Trust Fund Board has an existing contract with the Kentucky Injury Research and Prevention Center (KIPRC) located within the University of Kentucky, to collect and summarize incidence data utilizing information from hospital discharge summaries. Additionally, the Board has funded KIPRC to do limited data analyses and data abstractions. The results of these efforts will be reported to the Board at its meeting in July and will be made available to the Task Force.

KIPRC collects nationwide uniform health care data from standardized billing forms. The information from billing forms and discharge data often include diagnosis codes and relate to what treatments and procedures are billed and may not reflect services that are specific to brain injuries. The available data reflect ONLY those diagnostic codes for which the entity is billing services.

Specific data is lacking from emergency rooms, emergency medical responders, nursing homes, mental health services, substance abuse services, Medicaid, children's services systems, and the educational system. Nursing home data is important because of implications for meeting the community-based service provisions of the *Olmstead* decision. It was reported that with policy changes, obtaining data from publicly funded systems and services is possible, but significant data from private service providers would be missing.

Some data may be available through Workers' Compensation programs, which collect information regarding which body parts are injured and the causes of the injuries. Similarly, the Department of Public Health has an existing contract with ADD districts to conduct assessments on the prevalence of "risk" behaviors (those that contribute to illness or injury). It might be possible to include questions about brain injuries or the contributing factors to brain injuries within this effort.

Work Group I Recommendations:

1. Improve data collection to better inform policymakers by:

    a. conducting a prevalence survey to obtain a baseline estimate of prevalence by region by January 2003 - the TBI Trust Fund Board may be able to fund this effort and this will be brought to the Board at its July 2002 meeting.

    b. developing a statewide injury reporting system in conjunction with existing data and reporting systems that includes requirements for reporting from key sources;

    c. working with existing risk behavior surveys to include questions related to brain injuries. Colleen Ryall of the Brain Injury Services Unit will explore this possibility with DPH.

2. Work cooperatively with the Cabinet and legislative task force to encourage efforts tocapture data and costs of services related to brain injury from all providers.

3. Propose that legislation be introduced to require the addition of screening questions relatingto brain injury to the Patient Admission Screening and Review instrument, required for patients entering nursing homes.

4. Explore whether DPH or other entities within the Cabinet could perform those functionscurrently being performed for the TBI Trust Fund Board by KIPRC at reduced or no cost. This would allow the available dollars from the Trust Fund to be applied to other datacollection efforts, pending the approval of the TBI Trust Fund Board. This issue will be brought to the TBI Trust Fund Board of Directors at its July 2002 meeting.

RECOMMENDATIONS FROM WORK GROUP I

Recommendation	Budget (Y/N)	Fiscal Implications
1. Improve data collection to better inform policymakers by:		See below.
a. conducting a prevalence survey to obtain a baseline estimate of prevalence by region by January 2003.	Y	Costs approximately $25 to $40 thousand; the TBI Trust Fund Board has committed to fund this activity and efforts to develop and conduct the survey are now underway
b. developing a statewide injury reporting system in conjunction with existing data and reporting systems that includes requirements for reporting from key sources.	Y	Costs indeterminable; staff time would be required to explore the feasibility-- to meet and discuss how current system requirements work or do not together ; determine changes needed for various MIS systems and associated costs; develop a plan for capturing, securing, and maintaining such data in a unified system, determine the most cost effective way to set up a unified system (e.g. use of GOT or other contractor), test run changes and pilot a new system.
c. working with existing risk behavior surveys to include questions related to brain injuries.	Y	Dir. of BISU has explored feasibility with DPH, cost of initiating state added questions to existing BRFSS is estimated at $9600 to $14000, depending upon number of questions. BISU Director will seek TBI Trust Fund Board approval to fund this endeavor at Sept. 2002 meeting
2. Work cooperatively with the Cabinet and legislative task force to encourage efforts to capture data and costs of services related to brain injury from all providers.	N	See item 1.b. above for potential costs involved.
3. Propose that legislation be introduced to require the addition of screening questions relating to brain injury to the Patient Admission Screening and Review instrument, required for patients entering nursing homes.	N	If adding questions to the PASAR questionnaire is restricted by federal regulation may need to explore the feasibility of developing a short questionnaire to be administered in conjunction with PASAR reviews.

4.	Explore whether DPH or other entities within the Cabinet could perform those functions currently being performed for the TBI Trust Fund Board by KIPRC at reduced or no cost; allowing available Trust Fund dollars to be applied to other data collection efforts, pending the approval of the TBI Trust Fund Board.	N	Costs indeterminable; initially, recommendation would costs only staff time needed to research, meet and discuss capacity of in-house entities to perform current and future research projects for the Trust Fund. BISU Director will explore with TBI Trust Fund Board of Directors.

WORK GROUP II OF THE BRAIN INJURY TASK FORCE
(Increasing Access and Eliminating Barriers to Service)
FRANKFORT, KY
JULY 25, 2002

PRESENT:

Mary Hass	Betty Davis
Ann Smits, Div. Of Mental Retardation	Scott Furkin
Darla Bailey	Amy Newkirk
Joy Feist	Susan Tatum
Alice Blackwell	

<table>
<tr><td colspan="4">1. Maximize the ability of people with Acquired Brain Injuries, their families and their loved ones to plan for and support themselves in their own homes and communities.</td></tr>
<tr><th>Priority</th><th>Budget</th><th>RECOMMENDATIONS</th><th>DISCUSSION</th></tr>
<tr><td>1</td><td>Y?</td><td>a. Provide a centralized information and referral source for people seeking information about brain injury or services</td><td><u>CURRENT STATUS:</u>
Central information and referral occurs with the Brain Injury Unit and the Brain Injury Association and with Eckman and Freeman.
<u>GAPS:</u>
Knowing all the eligibility criteria for all existing programs. It is not a formalized system. Would support Single Point of Information, such as KYCARES.</td></tr>
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1. **Maximize the ability of people with Acquired Brain Injuries, their families and their loved ones to plan for and support themselves in their own homes and communities**

Priority	Budget	RECOMMENDATIONS	DISCUSSION
2	**N***	**b. Improve patient education about the effects of acquired brain injuries and the services available to help cope with those effects**	**CURRENT STATUS:** Patient education currently being performed through Case Managers, TBI and Waiver programs. No formal evaluations however feedback indicates patient education is good. **GAPS:** Sufficient patient education is not occurring. A major problem is education is not occurring at the place where diagnosed or rehabilitation is being conducted. It is not occurring at the acute or sub-acute level.
3	**N***	**c. Facilitate workshops for families about financial planning, legal issues, specifically guardianship, advance directives, and the legal system.**	**CURRENT STATUS:** Facilitation is not currently occurring at any level. **GAPS:** Implementation grant is being pursued. Need for a mentor support group to get the process started while still in the hospital. Patient education is needed at all levels. Family needs a user-friendly system. Support the P & A grant for legal services. Need to include advocacy and self-advocates.
4	**N***	**d. Facilitate advocacy training and establish workshops to address advocacy issues.** ***Assuming Implementation Grant is received.**	

2. Maximize the use of existing programs and resources available to persons with disabilities.

Priority	Budget	RECOMMENDATIONS	DISCUSSION
1	**Y**	**a. Work to identify and amend regulations that may prevent or inhibit access to programs by people who have brain injuries**	**CURRENT STATUS:** Need more time for Task Force to address. **GAPS:**
2	**N**	**b. Increase the number of case managers statewide who have expertise in the field of acquired brain injury**	**CURRENT STATUS:** Redefined to mean "awareness", rather than expertise. **GAPS:** Cross training of all support staff and case managers statewide, should be generic without duplication. Single Point of Information is again a valuable method. Getting people together from the various agencies for training is costly.
3	**N**	**c. Increase awareness and educate case managers and human service providers about services available to people with brain injuries.**	
4	**N**	**d. Provide a resource guide to case managers, advocates, and potential referral sources**	**CURRENT STATUS:** We currently have a resource guide. **GAPS:** The Resource Guide needs to be updated and make it more accessible, link to education and KYCARES.

2. Maximize the use of existing programs and resources available to persons with disabilities.

Priority	Budget	RECOMMENDATIONS	DISCUSSION
5	**N**	**e. Promote participation of people with brain injuries in the advocacy efforts of other groups supporting persons with disabilities**	**<u>CURRENT STATUS:</u>** Advocacy efforts are going on in other arenas, such as the ARC, DD Council, 843, and 144. **<u>GAPS:</u>** Need to connect up with existing groups, more outreach, and programs to teach/help people advocate for themselves.

3. PARTNER WITH EXISTING PROGRAMS AND PROVIDERS TO INCREASE THEIR CAPACITY AND EXPERTISE TO MEET THE NEEDS OF PEOPLE WITH BRAIN INJURIES.

Priority	Budget	RECOMMENDATIONS	DISCUSSION
1	**N?**	**a. Facilitate the provision of easily accessible consultation to providers who are now serving people with brain injuries. Develop a cadre of consultants or program specialists who can assist providers in working with specific individuals**	**<u>CURRENT STATUS:</u>** Consultation is occurring in the Brain Injury Unit. No formal assessment process. Verbal feedback says it works. Consultation for problem issues are addressed by the team. **<u>GAPS:</u>** Need professional consultation for any provider.
2	**N**	**b. Identify and support the efforts of programs serving people with disabilities to become more accessible to persons with brain injury**	**<u>CURRENT STATUS:</u>** Occurs with SCL Providers, Home Health, Substance Abuse, Vocational Rehabilitation, and Comp Cares **<u>GAPS:</u>** Task Force requires additional time to research accessibility.

3. PARTNER WITH EXISTING PROGRAMS AND PROVIDERS TO INCREASE THEIR CAPACITY AND EXPERTISE TO MEET THE NEEDS OF PEOPLE WITH BRAIN INJURIES.

Priority	Budget	RECOMMENDATIONS	DISCUSSION
3	**N**	**c. Advocate for required training about brain injuries for professionals and for staff of publicly funded programs serving people with disabilities. Assist in the development and provision of such training**	**<u>CURRENT STATUS:</u>** **<u>GAPS:</u>** Comp Cares need to understand and screen for Brain Injury. Consider statutory/regulatory changes for Comp Cares, Substance Abuse Centers, There is the need to recognize and promote model programs, Best Practices, both at the Acute and Sub-Acute levels.

6. PLAN FOR THE FUTURE

Priority	Budget	RECOMMENDATIONS	DISCUSSION
1	**Y**	**a. Develop long-term, in-home and community supports for people with brain injuries and their families.**	**<u>CURRENT STATUS:</u>** See gaps. **<u>GAPS:</u>** There are currently no long-term community supports.

RECOMMENDATION OF THE FULL ACQUIRED BRAIN INJURIES TASK FORCE

Propose legislation that will create a formal entity (e.g., Workgroup) with responsibility for monitoring the implementation of recommendations made by the Task Force on Services and Supports for Individuals with Acquired Brain Injuries.

Work Group III: Inpatient & Other Services, Specialized Evaluation, & Criminal Justice Diversion Services
June 20, 2002

WORK GROUP MEMBERS: Commissioner Margaret Pennington, DMHMRS; Barth Weinberg, Frazier Rehabilitation Institute; Pam Pearson, Pathways Brain Injury Program; Kate Johnson, Caritas Peace Center; Linda Dierking, Catastrophic Consultants; Mary Hass, Brain Injury Association of Kentucky; Colleen Ryall, Brain Injury Services Unit. Liz Runyon of Seven Counties Services was unable to attend.

PROBLEM STATEMENT

The cognitive, physical, and emotional consequences of a brain injury can present challenges not only to the individual who has sustained the injury, but to the family and community as well. Without effective intervention and support, an individual with a brain injury may demonstrate behavior which presents a significant risk of injury or harm to himself or herself, or others.

If the individual's caregiver is unable to effectively manage the behavior or the risk it presents, the individual may be at increased risk of arrest, incarceration, hospitalization, or further injury. There is reason to believe that insufficient supports are available in Kentucky to affected individuals. Consequently, affected individuals may be jai led or committed inappropriately to facilities for persons with mental illness or mental retardation.

This work group was charged with the responsibility to make recommendations to increase Kentucky's capacity to provide crisis intervention and stabilization services, as well as programs to divert affected individuals from the criminal justice system to treatment programs.

CHARACTERISTICS OF INDIVIDUALS IN NEED OF SERVICES:

An acquired brain injury may result in impaired judgement, reasoning, and problem solving ability. An increase in impulsivity and inappropriate social behavior may also be seen. A significant proportion of individuals who have sustained brain injuries also have co-occurring substance abuse and chemical dependency problems. The literature suggests an increased susceptibility to substance abuse following a brain injury for persons who had no such problem prior to their injuries. Individuals whose brain injuries have such effects are the focus of this work group.

These individuals are often able to independently perform personal care activities independently and are often independently mobile. Because of the nature of their brain injuries, affected persons are often unable, however, to manage their financial and legal affairs independently, maintain employment, and control their own behavior. Additionally, the nature and extent of their brain injuries may also result in their inability to perceive their own deficits, to understand the affect their behavior has on others, and to appreciate the long term consequences of their actions.

CURRENT CAPACITY:

Pathways Brain Injury Program, located at Christopher East in Louisville, is a specialized neurobehavioral unit which can serve eight (8) individuals in a secure facility. It is licensed as a skilled nursing facility and can accept both Medicaid and Medicare. The average census is six (6) or seven (7) individuals. It is often not possible to accept eight (8) persons at once, given the available space and unique needs of the people who are there. If Medicaid is the payor, services must be prior authorized.

Caritas Peace Center in Louisville is a psychiatric facility which has established a specialized neurobehavioral inpatient unit serving seventeen (17) adolescents and adults with brain injuries and co-occurring psychiatric disorders. While Medicaid can pay for services to individuals under the age of 2 1 years and over the age of 65 years in this facility, federal regulations prohibit Medicaid payment for services to adults in freestanding psychiatric hospitals. Caritas Peace Center can accept Medicare payment for adults admitted to the neurobehavioral unit.

By comparison, there is capacity to serve fifty-five (55) adults and seventy-three (73) children with mental illness in crisis stabilization units across the state. State funded psychiatric facilities have the capacity to serve 792 individuals and 170 children may be served in psychiatric facilities for children. A total of 713 individuals with mental retardation and developmental disabilities can be served in state operated ICF's/MR across the state.

CONSIDERATIONS:

The Work Group discussed and arrived at consensus regarding the services necessary to provide community based supports and jail diversion programs for the population of interest. It was concluded that a two pronged effort would be most effective. This effort is outlined below:

1. Prevention of Crises
   A. Information about the nature and consequences of brain injuries should be made available to families as soon after the injury as possible
   B. Information about available services and supports and how to access them should be provided to families as soon after the injury as possible
   C. Case management services to assist the individual and family to obtain specialized services and supports to avert crises are essential
   D. Services and supports which may be necessary to avert crises may include neuropsycho logical evaluations, counseling, substance abuse treatment, medication evaluation and management, and accommodations for impaired memory and communication.

II. Crisis Intervention and Stabilization
   A. At the time of a crisis, it may be necessary to remove the individual from the

family home and to seek temporary placement in a safe, structured environment
    1. allows respite for the family
    2. facilitates access to services and supports for the individual
  B. The structured environment should be staffed by people who are adequately trained to support individuals with brain injuries
  C. It may be necessary to provide an evaluation of the individual's deficits and need for services
  D. Follow up services should be provided which enable the individual and his or her family to access intensive services designed to prevent additional crises
  E. Average length of stay predicted to be less than one month
  F. Services provided in a community based, rather than a health care setting

III. Neurobehavioral Treatment
  A. Some individuals, because of co-occuring disorders or significant behavior problems, may need to be in a highly structured, secure facility
  B. Access to neuropsychological evaluation, medication evaluation, health evaluation, speech and occupational therapy, counseling, substance abuse treatment are essential
  C. Discharge planning and follow- up case management services are essential
  D. Average length of stay predicted to be one to six months
  E. Work with courts and legal system would be essential to divert individuals from jails to treatment
    1. education of police, jailers, courts would be a necessary part of establishing the unit
    2. Seven Counties Services has such an education program in place for persons with mental illness, as reported by Liz Runyon.
  F. Appropriate setting would be a health care facility

STRATEGIES FOR CREATING ACCESS TO NEEDED SERVICES

The Work Group considered the following strategies for creating the necessary "safety net" of specialized services for individuals with brain injuries:

I. Maximize use of existing resources
  A. Existing Crisis Stabilization Units across the state might be utilized to provide community based crisis intervention and stabilization
    1. Preliminary inquiries of Directors of Crisis Stabilization Units by Colleen Ryall, of the Brain Injury Services Unit, have been well received in some parts of the state
    2. Crisis Units are funded with state general funds and Medicaid may pay for some services in the Units. DMHMR has existing contracts for the operation of these Units.
    3. Crisis Stabilization Units would need training and clinical support to provide appropriate, adequate services to individuals with brain injuries

II. Develop mechanisms to meet the need for intensive inpatient treatment
  A. Consider use of the model of Assertive Community Treatment (ACT) teams - this involves intensive oversight and intervention by case manager and other

    clinical team members in the community, often at the home of the individual. Teams are mobile.

- B. Develop a neurobehavioral inpatient unit in a facility which allows for Medicaid reimbursement, private insurance reimbursement
    1. facilities licensed as psychiatric hospitals are not eligible for reimbursement from Medicaid, per federal regulations
    2. Massachusetts has had an inpatient neurobehavioral unit housed in a medical hospital for several years, which allows for Medicaid reimbursement and other third party payors

RECOMMENDATIONS

The Work Group recommends that the following steps be taken:

1. The Work Group should continue to meet and to complete the task which has been assigned. Members of the Work Group have expressed a willingness to continue to meet to accomplish the assigned task.
2. Colleen Ryall will contact Debra Kamen, Director of Brain Injury Services in Massachusetts, to arrange for a telephone conference regarding that state's experiences establishing and operating its inpatient neurobehavioral unit
3. Margaret Pennington and Colleen Ryall will collect information regarding ACT teams for consideration by the Work Group
4. Data regarding the number of potential users of crisis stabilization and inpatient neurobehavioral services annually should be collected
5. The costs associated with the operation of ACT teams, training of crisis stabilization unit staff, and the operation of an inpatient neurobehavioral unit should be detailed

The Work Group has identified three potential meeting dates in July, and the meeting will be scheduled contingent upon the availability of Debra Kamen on those dates. Further information about the Work Group's efforts may be obtained from Colleen Ryall at 502-564-3615.

ATTACHMENT #1

Work Group III: Inpatient & other services, specialized evaluation, & criminal justice diversion services
Conference call
July 24, 2002

Participating work group members: Barth Weinberg; Linda Dierking; Pam Pearson; Colleen Ryall

A conference call was held on July 24, 2002 for the purpose of developing final recommendations for the development of inpatient and other services for persons with brain injuries. Final recommendations are based upon earlier work and reflect the top three priorities for service development identified by the group. Due to time constraints, exhaustive exploration of the costs of service development and provision has not been completed. Estimated costs presented here should be considered with caution.

1. Establish a secure neurobehavioral inpatient to serve individuals aged 21 years or older with acquired brain injuries who are demonstrating behaviors that place themselves or others at risk. It is recommended that this unit serve 12 to 14 individuals and be housed within a facility which would render Medicaid/Medicare reimbursement possible, and which would allow for stays of 6 to 18 months. Access to the following professionals is recommended: case manager; neuropsychologist; psychiatrist; behavior analyst; pharmacologist; chemical abuse and dependency counselor; life skills trainers. Information from Massachusetts suggests that the per them rate would need to be at least $500 per day to ensure access to skilled practitioners. (See attachment #2)
2. Increase the capacity of the service delivery system to provide "step down" services for individuals released from the secure inpatient neurobehavioral unit. The existing Acquired Brain Injury Waiver program may be an appropriate mechanism for doing so. However, given the limited number of persons who can be served annually in the waiver program, it is possible that individuals receiving inpatient services could be ready for discharge and have no access to necessary community supports. The group recommends that efforts to expand the number of individuals served within the Acquired Brain Injury Waiver program be undertaken.
3. The use of existing crisis stabilization units to assist individuals with brain injuries whose behavior presents a risk to themselves or others, but who do not need intervention within a secure facility is NOT recommended. The group recommends that intensive supports be provided to individuals and their families within their own homes during periods of crises, to prevent hospitalization or institutionalization from occurring. Use the Assertive Community Treatment model, which entails daily contact, support, and services to individuals who are at risk of hospitalization or institutionalization, is recommended. Under this model, the treatment team is mobile and works with individuals in their home environments. Information from a newly formed Assertive Community Treatment team currently being operated in Kentucky has been used to gauge the approximate costs of annual operation of the team. It is estimated that 45 individuals could be provided daily intervention at a cost of

$200,000 annually, excluding the cost of services accessed through existing Medicaid funded programs. These costs include access to five full time professional staff and one case manager.

Further exploration of the feasibility of creating these services and the fiscal impact of doing so is strongly recommended. (See attachment #3)

ATTACHMENT # 2

Conference Call
Debra Kamen, Director
Massachusetts Head Injury Program
July 24, 2002

Members present: Margaret Pennington, Mary Hass, Linda Peening, Kate Johnson, Barth Weinberg, Betty Davis, Colleen Ryall

Background: Massachusetts has long had a secure inpatient neurobehavioral unit serving adults with brain injuries who exhibit behavior problems. The work group contacted Ms. Kamen for the purpose of learning how the state had designed and maintained the unit over time. All information detailed here concerns Massachusetts' inpatient neurobehavioral unit.

Admission criteria: Adults with brain injuries who exhibit behavior which presents a risk to themselves or others are eligible for admission to the Unit. Typical reasons for admission include psychiatric, sexual, behavioral, or substance abuse problems demonstrated by an individual with a brain injury. Most individuals admitted to the Unit are several years post injury.

Because the Unit is not established to provide detoxification services, an individual must have completed that process prior to admission. The Unit is not used as a jail diversion program, because of the risks frequently posed by persons in such programs.

A clinical team assesses the applicant in his or her home environment prior to admission, to ascertain the seventy of the problem and to ensure that a realistic discharge plan is in place prior to admission.

Average length of stay: While it was initially thought that the average length of stay would be twelve (12) to eighteen (18) months, experience has shown that most people admitted to the Unit stay from eighteen (18) to twenty-four (24) months. Unit staff also provide follow-up services once the individual has been discharged.

Licensure: The unit was originally placed within a county medical hospital and was recently moved to a licensed private rehabilitation facility. The state made the decision not to place the unit within a psychiatric hospital because of the federal exclusion for Medicaid reimbursement for adults in institutions for mental disorders (IMD exclusion).

Reimbursement rate: The current per them rate is between $500 to $600 per day. The rate was developed based upon the professional staff compliment, including the salary of the medical director. (by comparison, the per them rate at Pathways is $380)

Funding: Initially the state funded the Unit from an appropriation by the legislature and the provider was chosen through a RFP process. Over time, third party payment was secured including private insurance and Medicaid. Services are cost reimbursed, although services delivered off site are reimbursed on a fee for service arrangement.

Capacity: The Unit originally had the capacity to serve twelve (12) people and increased it to sixteen (16) over time. Very recently, a proposal was made to increase capacity to serve twenty (20) persons.

Programming: The intention of the Unit is to provide cognitive, behavioral and psychopharmacological treatment. Activities on the Unit are highly structured and includes the use of a level system, in which restrictions are gradually lifted as the individual learns to compensate for the injury and to gain control of his or her behavior.

Staffing pattern: Staffing for the Unit includes a medical director, a neuropsychologist, a psychiatrist with expertise in brain injury, a nurse, a master's level behavior analyst, behavioral technicians, and rehabilitation technicians.

Step-down services: It has been the state's experience that approximately 25% of the individuals served on the Unit will not find placement when they are deemed ready for discharge. It has also been the state's experience that a small percentage of people will need long-term maintenance because they are unlikely to improve their functioning. Many of the people on the Unit will need long-term residential services in a structured environment upon discharge.

Recidivism rate: The recidivism rate for the Unit is comparatively low and the success rate is comparatively high.

Advice from Massachusetts:

- Develop policies and procedures in advance that will address how to respond to those individuals who are "stuck" on the Unit due to lack of a willing provider
- Maintain state control, if possible, to ensure that the mission and purpose of the Unit are preserved
- Be aware that if the Unit is used as a jail diversion program an overwhelming number of convicted persons may request admission
- Be thoughtful about the physical layout of the Unit, allowing for separation of persons by age and gender.
- Establish a per them reimbursement rate that will ensure the provision of intensive rehabilitation services and follow-up

ATTACHMENT #3

PACT (Program of Assertive Community Treatment) (NAMI)

What is PACT?

PACT is a service-delivery model that provides comprehensive, locally based treatment to people with serious and persistent mental illnesses. Unlike other community-based programs, PACT is not a linkage or brokerage case-management program that connects individuals to mental health, housing, or rehabilitation agencies or services. Rather, it provides highly individualized services directly to consumers. PACT recipients receive the multidisciplinary, round-the-clock staffing of a psychiatric unit, but within the comfort of their own home and community. To have the competencies and skills to meet a clients multiple treatment, rehabilitation, and support needs, PACT team members are trained in the areas of psychiatry, social work, nursing, substance abuse, and vocational rehabilitation. The PACT team provides these necessary services 24 hours a day, seven days a week, 365 days a year.

How did PACT begin?

Now in its 26th year, the PACT model evolved out of work led by Arnold Marx, M.D., Leonard Stein, M.D., and Mary Ann Test, Ph.D., on an inpatient research unit of Mendota State Hospital, Madison, Wisconsin in the late 1960s. Noting that the gains made by clients in the hospital were often lost when they moved back into the community, they hypothesized that the hospital's round-the-clock care helped alleviate clients' symptoms and that this ongoing support and treatment was just as important - if not more so - following discharge. In 1972, the researchers moved hospital ward treatment staff into the community to test their assumption and, thus, launched PACT.

What are the primary goals of PACT?

PACT strives to lessen or eliminate the debilitating symptoms of mental illness each individual client experiences and to minimize or prevent recurrent acute episodes of the illness. PACT strives to assist in meeting basic needs, enhancing quality of life, improving functioning in adult social and employment roles, enhancing an individual's ability to live independently in his or her own community, and in supporting the family in providing care.

What are the key features of PACT?

Treatment:

- psychopharmacologic treatment, including new atypical antispyschotic and antidepressant medications
- individual supportive therapy
- mobile crisis intervention
- hospitalization

- substance abuse treatment, including group therapy (for clients with a dual diagnosis of substance abuse and mental illness) Rehabilitation:
- behaviorally oriented skill teaching (supportive and cognitive-behavioral therapy), including structuring time and handling activities of daily living
- supported employment, both paid and volunteer work
- support for resuming education Support services:
- support, education, and skill-teaching to family members
- collaboration with families and assistance to clients with children
- direct support to help clients obtain legal and advocacy services, financial support, supported housing, money-management services, and transportation

Who benefits from the PACT model?

The PACT model is indicated for individuals in their late teens to their elderly years who have a severe and persistent mental illness causing symptoms and impairments that produce distress and major disability in adult functioning (e.g., employment self-care, and social and interpersonal relationships). PACT participants usually are people with schizophrenia or other psychotic disorders (e.g., schizoaffective disorder), and bipolar disorder (manic-depressive illness). PACT participants include those who experience significant disability from mental illnesses and are not helped by traditional outpatient models. They include persons who have difficulty getting to appointments on their own as in the traditional model of case management, persons who have had bad experiences in the traditional system and persons who have limited understanding of their need for help.

What is the difference between PACT and traditional care?

Most individuals with severe mental illnesses who are in treatment are involved in a linkage or brokerage case-management program that connects them to services provided by multiple mental health, housing, or rehabilitation agencies or programs in the community. Under this traditional system of care, a person with a mental illness is treated by a group of individual case managers who operate in the context of a case management program and have primary responsibility only for their own caseloads. In contrast, the PACT multidisciplinary staff works as a team. The PACT team works collaboratively to deliver the majority of treatment, rehabilitation, and support services required by each client to live in the community. A psychiatrist is a member of, not a consultant to, the team. The consumer is a client of the team, not of an individual staff member. Individuals with the most severe mental illnesses are typically not served well by the traditional outpatient model that directs patients to various services that they then must navigate on their own. **PACT goes to the consumer whenever and wherever needed. The consumer is not required to adapt to or follow prescriptive rules of a treatment program**.

How do PACT clients compare with those receiving hospital treatment?

PACT clients spend significantly less time in hospitals and more time in independent living situations, have less time unemployed, earn more income from competitive employment, experience more positive social relationships, express greater Satisfaction with life, and are less symptomatic. In one study, only 18 percent of PACT clients were hospitalized the first year compared to 89 percent of the non-PACT treatment group. For those PACT clients that were rehospitalized, stays were significantly shorter than stays of the non-PACT group. PACT clients also spend more time in the community. Additionally, the PACT model has shown a small economic advantage over institutional care. However, this finding does not factor in the significant societal costs of lack of access to adequate treatment (i.e., hospitalizations, suicide, unemployment, incarceration, homelessness, etc.).

How available are PACT programs?

Despite the documented treatment success of PACT, only a fraction of those with the greatest needs have access to this uniquely effective program. Only six states (DE, ID, MI, RI, TX, WI) currently have statewide PACT programs. Nineteen states have at least one or more PACT pilot programs in their state. In the United States, adults with severe and persistent mental illnesses constitute one-half to one percent of the adult population. It is estimated that the PACT model could help 20 percent to 40 percent of this group if it were available.

PACT Cost Summary (NAMI)

PACT & ISSUES OF COSTS:

1. As a guiding principal, it is most accurate to think of the implementation of a PACT demonstration program in terms of creating one PACT team to serve one specific group of client/participants. The cost formula would run: $800,000.00 to $ 1,000,000.00 = 100 clients = 10 - 12 staff for one year.

2. These costs are offset by the fact that a PACT model replaces several existing, fractured services and programs currently used by the clients. Once the individual is part of a PACT program, the team itself provides the services. PACT is designed as one-stop shopping for people with the most severe mental illnesses. PACT effectively serves people that most treatment models shy away from: those who have a co-occurring substance abuse disorder, criminal justice involvement, and people who are homeless.

3. Beyond the one-time start-up expenses (consultation on design, training of team, training of supervisory mental health authority) of $25,000 to $50,000, the program's ongoing funding mechanisms are the same as those currently being utilized: Medicaid, Medicare, mental health block grant funds, state and county mental health funds. and in some states tobacco settlement funds.

4. Some of the specific, concrete realized savings from PACT are in the tremendous reduction of time that PACT clients spend in institutional settings (psychiatric hospitals, or psychiatric wards in med/surg hospitals).' In higher fidelity (to the model) programs, hospital days are reduced by 23% points over those plans that attempt to do "PACT lite" models or traditional office-based care. (Economic Impacts of Assertive Community Treatment: A Review of the Literature by Eric Latimer, Ph.D. in The Canadian Journal of Psychiatry, Vol. 44, June 1999.)

5. In detailed studies of high fidelity PACT models vs. Intensive Case Management models of service delivery, the evidence has been that to break even, or experience savings, PACT should be the program of choice for clients who have been high users of hospital services. (Latimer, June, 1999).

6. In the early 1980s, 70% of each dollar spent on mental health services in the United States was spent in hospitals. At the same time in Dane County, Wisconsin, (birthplace of PACT), only 17% of mental health funding was spent on hospitals. 83% of MH dollars was spent on community-based treatment.(Stein & Diamond, 1985).

7. Santos et al, (1 993 study) concluded that the cost per patient per year for hospital care was $18,800 (plus) the cost of traditional outpatient care. That overall cost in hospital care DECREASED to $11,300 once PACT teams were in place in the community shows a reduction of 40% in dollars spent on hospital care.

8. In concluding his review of the published studies comparing PACT with other models of service delivery, William Hughes (Health & Social Work, May, 1999) said, **"Extensive**

studies in public and non-profit agencies have shown PACT to be the most cost-effective option for treating populations with serious illnesses and disabilities now being enrolled In Medicaid managed behavioral health plans."

9. In the published findings on the cost-effectiveness of PACT as compared with standard case management as conducted by Susan Essock, et al (American Journal of Orthopsychiatry, (4/98) there was no difference in cost to the public mental health system, the state or society between PACT and case management. In particular, the evidence showed that PACT teams increased clients days in the community as opposed to days in the hospital and those savings on hospital bed days offset the additional costs associated with P/ACT.

10. In 1999, a study of capitated PACT services was published by Daniel Chandler, et al (Psychiatric Rehabilitation Journal, spring 1999, Vol. 22 no. 4). The conclusion was that with a capitated PACT system, the per person gross costs were 25% lower and the net costs were 67% lower than the comparison group receiving traditional services through Alameda County (Calif.). Again, the largest savings came from the reduction in clients recycling through and lengths of stay in hospitals.

11. While PACT has proven to be cost-effective, especially when participants are selected for participation because of their frequent hospitalizations, we must be mindful of a statement by Laurie Flynn, the Executive Director of NAMI "PACT will never be as inexpensive as neglect". Too often, with hard-to-serve populations, neglect has become the de-facto system of care.

The National PACT Center
March 2000

ABI TASK FORCE WORKGROUP IV
INCREASING EMPLOYMENT, VOCATIONAL & EDUCATIONAL SERVICES, CASE MANAGEMENT SERVICES, AND STRATEGIES FOR DECRIMINALIZATION

JULY 23, 2002

PRESENT: Elena Bailey (Conference Call), Bruce Crump, Mary Hass, Marian Spencer, Judy Turner, Jim Woodrum (E-Mail Communication)

The above-named members of Workgroup IV met to prioritize its recommendations. Recommendations were prioritized under Non-Budgetary and Budgetary.

JUNE 21, 2002

PRESENT: Elena Bailey, Leslie Blankenship, Betty Davis, Gayle DiCesare, Bruce Crump, Wayne Dees, Artus Fox, Mary Hass, Jim Kimbrough, Robert Klinglesmith, Mary Phillips, Kimberly Sheth, Marian Spencer, Murray Wood

Workgroup IV met on Friday, June 21 at the Department of Vocational Rehabilitation at 209 St Clair Street in Frankfort. The Workgroup recommended strategies for decriminalization; increased employment, vocational training and educational services; and case management services.

DECRIMINALIZATION
ISSUES

- Structured Day Treatment Programs
- Mental Health to Assist with Programming & Training
- Best Practice for Mental Health System Staff to be Knowledgeable of BI
- Basic Knowledge of BI to enable screeners at jail and other law enforcement officers to identify BI at first contact with the Criminal Justice system
- Identify Appropriate Assessment Tool - Currently Form 202b is completed by Comp Care Centers to recommend treatment or programming when person being held in psychiatric unit of hospital or in jail
- Develop Screening Tool for Non-Clinical staff
- How to identify if there might be a mental health issue
    - Non-Clinical Corrections Staff
    - Qualified Mental Health Professionals
- Diversion Programs - House Bill 843
- Mental Health Counselors need BI Training
- More Integrated Approach with Case Managers, Integrated Case Management System with Comp Care Centers, Trust Fund, & Medicaid Waiver - Communication across All Agencies.
- Definition of Case Management and Qualifications of the Case Manager
- Group Therapy for Dual Diagnosis
- Crisis Intervention - Negotiation Training Inclusive of BI
- Concerned Person Program -Mentoring Program at Seven Counties JADAC could be used as a model program.
- KY Dept of Education has Manual for Acquired Brain Injury - Good Resource.
- Lack of Identification of Children with BI in Educational System
- Juvenile Detention - Dept of Justice has program to identify Dual Diagnosis
- Early Intervention: Family Support
    - First Steps, EPSDT, Impact, Impact +, Commission on Children with Special Health Care Needs

DECRIMINALIZATION RECOMMENDATIONS PRIORITIZED

NON-BUDGETARY

1 . Require that Education and Training in Best Practices for Special Needs of Individuals with Acquired Brain Injury be made available for all organizations including Department of Education, Justice Cabinet, Mental Health, Substance Abuse, Vocational Rehabilitation, Rehabilitation Units, Emergency Rooms, and EMS Units. This will allow for collaboration among all program areas.

2. Establish Early Point of Intervention with Collaborative Efforts between Departments of Justice & Education, Children's Programs, Hospitals, and EMS Units.

3. Develop Questionnaire/Assessment Tool to be used by Screeners at Jails and Law Enforcement Officers. Note: The Kentucky Minimum Standards for Local Jails is currently reviewing the standards for revision.

4. Involve Administrative Office of the Courts regarding Diversion, Court Advocates, and Guardianship issues.

5. Develop Referral List of Trained Professionals with Expertise in Brain Injury, originating out of BISU office.

BUDGETARY

1. Establish Concerned Person Program with funding source to be identified. Note: Implementation Grant might be possible source of funding for a Concerned Person Program/Mentoring Program.

EMPLOYMENT/VOCATIONAL AND EDUCATIONAL SERVICES ISSUES

- Ticket to Work - Jim Kimbrough with KY Protection and Advocacy presented an overview of Ticket to Work. Several issues were identified; namely, that individuals must not be drawing any Social Security disability benefits by end of fifth year; providers will be paid over a 5 year period; partnerships and collaboration will be a crucial component; and individuals will not be able to tap into the ABI Medicaid Waiver Program.
- Medicaid Spend Down is a disincentive to work.
- More Job Coaches are needed.
- Supported employment issues were discussed. DVR monies must be spent first for individual placement services; additional providers are needed; and additional sources for the long-term support dollars are also needed.
- Individuals fear the loss of disability benefits and medical coverage.
- Availability and Accessibility of Transportation
- Adequate Training and Education
- Employers are hesitant to hire individuals with BI, fears and stigma of BI fuel this hesitation.
- Companies need to offer a broader range of job opportunities, not just entry-level positions.
- Integration of Job Coaching Programs and Rehabilitation Programs.
- The negative perception of BI needs to be downplayed. Employment success stories should be highlighted.

EMPLOYMENT/VOCATIONAL AND EDUCATIONAL SERVICES RECOMMENDATIONS
PRIORITIZED

NON-BUDGETARY

1. Encourage the development of Individual Education Plans (IEP) for students with brain injuries that include appropriate transition from school to work.

2. Work with the Business Leadership Network, Interdisciplinary Human Development Institute at the University of Kentucky to develop more Supported Employment providers.

3. Service providers will identify and encourage more Vocational Training and Educational Opportunities for individuals with brain injuries.

4. Encourage the KY Association on Higher Education And Disability (AHEAD) to obtain training on accommodations for students with brain injuries.

5. Encourage the development of Employment Networks for implementation of Ticket to Work in State of KY.

6. Identify and encourage service providers to become knowledgeable about Social Security and Medicaid financial eligibility.

7. Work with the Center for Accessible Living and Independence Place Employment Project. This project provides advice to individuals who are receiving disability benefits as to the effect of employment income on level/loss of benefits and all issues of independent living. Other service providers need to develop this expertise.

BUDGETARY

1. Encourage the development and implementation of a Medicaid Buy-In Program in the State of KY.

CASE MANAGEMENT
ISSUES

- Multiple case managers for one individual.
- Many case managers initially referring to Trust Fund without seeking out other funding sources.

CASE MANAGEMENT RECOMMENDATIONS
PRIORITIZED

NON-BUDGETARY

1. Encourage Case Managers to make referrals of individuals with dual diagnosis to Drug and Alcohol Programs and Risk Reduction Programs.
2. Create a network of advocates who could interface with multiple case managers. Example: Family Members or Mentors.
3. Encourage communications between case managers when multiple service providers/programs involved so as to enhance service delivery for individuals with brain injuries.
4. Encourage Case Managers to seek other resources for service needs rather than always referring to the Trust Fund. Example: Literacy needs through Adult Education or Low Income Housing through HUD
5. Brain Injury Services Unit identify unmet needs that have been identified on the Medicaid Waiver Plans of Care and provide this data to the Task Force for future recommendations.

BUDGETARY

1. Recommend the removal of the monetary cap placed on the TBI Trust Fund (HB452).

GENERAL RECOMMENDATIONS

1. Continuation of Task Force to complete the task that has been assigned.
2. Advocate for passage of a Primary Seat Belt Law in Kentucky.
3. Advocate for passage of a Helmet Law for all open vehicles.

ATTACHMENT D

AGENDAS

TASK FORCE ON SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ACQUIRED BRAIN INJURIES

Meeting No. 1

TIME: **10:00 p.m.**

PLACE: **Room 131, Capitol Annex**

DATE: **December 12, 2001**

I. Call to Order and Roll Call.

II. Introduction of Members

III. **Brain Injury Services Unit**
Colleen Ryall, M.D.
Division of Mental Health
Cabinet for Health Services

IV. **Traumatic Brain Injury Trust Fund Board**
Mary Hass, Chairperson

V. **Brain Injury Association of Kentucky**
Scott Furkin, Executive Director

VI. Discussion

VII. Next Meeting Date

VIII. Adjournment

TASK FORCE ON SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ACQUIRED BRAIN INJURIES

Meeting No. 2

DRAFT AGENDA

TIME:	**12:00 Noon**
PLACE:	**Room 131, Capitol Annex**
DATE:	**January 25, 2002**

I. Call to Order and Roll Call.

II. Approval of Minutes.

III. Comments from Families Affected by Brain Injury

Sandy Michaels
Murray, KY

Dr. Judith Broadus
Lexington, KY

Bill and Jennifer Stephenson
Lexington, KY

Bob O'Daniel
Lebanon, KY

Bob and Janelle Hill
Bowling Green, KY

Shannon Heacock
Glasgow, KY

IV. Discussion

V. Next Meeting Date

VI. Adjournment

TASK FORCE ON
ACQUIRED BRAIN INJURY SERVICES & SUPPORTS

Agenda

Meeting No. 3

DATE:	**Thursday April 18, 2002**
TIME:	**11:45 AM**
PLACE:	**Cardinal Hill Hospital Lexington, KY**

1. Call to order and roll call
2. Approval of Minutes (January 25, 2002)
3. Allen Bergman, President and CEO, Brain Injury Association of America
4. Old Business
5. New Business
6. Adjournment

TASK FORCE ON SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ACQUIRED BRAIN INJURIES

Meeting No. 4

TIME:	**10:00 a.m.**
PLACE:	**Louisville, Kentucky**
DATE:	**May 21, 2002**

I. Call to Order and Roll Call

II. Approval of Minutes of April 18, 2002

III. Review of Issues List

IV. Discussion of Work Plan

V. Next Meeting Date

VI. Adjournment

TASK FORCE ON SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ACQUIRED BRAIN INJURIES

Meeting No. 5

TIME:	**1:00 p.m.**
PLACE:	**Room 131, Capitol Annex**
DATE:	**June 24, 2002**

I. **Call to Order and Roll Call**

II. **Approval of Minutes of May 21, 2002**

III. **Testimony from Service Providers**

Presenters:

Kim Arington, President
Kentuckiana Nursing Services
Louisville, Kentucky

William A. Kraft, Ph.D., Director
Brain Injury and Spinal Cord Injury Program
Psychology Department and Neuro-Psychological Services
Assistant Clinical Professor of Medicine
University of Louisville Medical School

Jeff Bradford, Owner and Director
Kentucky Independent Case Management
Lexington, Kentucky

IV. **Reports from Workgroups II, III, and IV**

V. **Findings and Recommendations**

VI. **Approval of Final Report**

VII. **Adjournment**

TASK FORCE ON SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ACQUIRED BRAIN INJURIES

Meeting No. 7

TIME:	**1:00 p.m.**
PLACE:	**Room 131, Capitol Annex**
DATE:	**August 27, 2002**

I. Call to Order and Roll Call

II. Approval of Minutes of July 30, 2002

III. Decriminalization/Diversion and Brain Injury

Rita Ruggles, Health Program Administrator
Department of Mental Health/Mental Retardation Services
Cabinet for Health Services

IV. Estimated Costs of Medicaid Services Provided for People with Brain Injuries

Tricia Salyer, Director
Division of Medicaid Services for Mental Health/Mental Retardation

V. Use of Trust Fund for Services

Cindy Whitehouse, Vice-President of Operations
Eckman/Freeman and Associates

VI. Discussion of Workgroup Recommendations

VII. Closing Comments

VIII. Adjournment

TASK FORCE ON SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ACQUIRED BRAIN INJURIES

Meeting No. 6

TIME:	**1:00 p.m.**
PLACE:	**Room 131, Capitol Annex**
DATE:	**July 30, 2002**

I. Call to Order and Roll Call

II. Approval of Minutes of June 24, 2002

III. Presentations

Susan Stokes, President
HMR Associations, Inc.
Lexington, KY

Liz Runyon
Seven Counties Services
Louisville, KY

Darla Bailey, President
Kaleidoscope, Inc.
Louisville, KY

Robert Walker,
Assistant Professor
Center for Drug and
Alcohol Studies
University of Kentucky
Lexington, KY

Elena Bailey
Implement
Neurorehabilitation
Ashland, KY

Bill Baumann, Vice
President
Terri Traughbor,
Program Director
Center for
Comprehensive Services
Paducah, KY

Amy Newkirk
Executive Director/Case
Manager
Louisville Independent
Case Management
Louisville, KY

IV. Report from Workgroup I

V. Discussion

VI. Adjournment

*******The next meeting will be Tuesday, August 27, 2002, from 1 to 4 p.m. in Room 131 of the Capitol Annex.*******