Resource Facilitation:

A Consensus of Principles and Best Practices to Guide Program Development and Operation in Brain Injury
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Resource Facilitation: A Consensus of Principles and Best Practices to Guide Program Development and Operation in Brain Injury

Executive Summary

Resource facilitation is a partnership that helps individuals and communities choose, get and keep information, services and supports to make informed choices and meet their goals. The collaborative process involves participants (individuals with brain injury and their personal support systems) working in partnership with facilitators (individuals who provide assistance in navigating systems) to achieve agreed upon goals.

An estimated 6,250 individuals in the United States participate in one of 16 resource facilitation programs for people with brain injury. Depending on the program, resources are acquired through referral, purchase or direct provision of services and supports. Based on program descriptions collected by the Brain Injury Association (BIA), the estimated annual cost of resource facilitation was $1,200 per person in 1999. State government agencies, nonprofit organizations and for-profit entities offer the program, often at no charge or on a sliding scale fee basis, to the participants. Facilitation may begin at the onset of the injury, following acute rehabilitation or during community re-entry. Programs may last for weeks, months or years. Where available, resource facilitation programs are usually community-based. However, information and emotional support is increasingly offered through the telephone and electronic mail.

The principles and best practices contained in this guide were developed at a two-day Resource Facilitation Summit hosted by BIA in September 2000 in Kansas City, Missouri. Forty people, including individuals with brain injury, family members, resource facilitators, agency administrators, advocates and others, participated.

According to Summit participants, developing a resource facilitation program is a four-step process involving (1) establishing the need; (2) identifying possible funding sources; (3) building community-based partnerships; and (4) taking action. Once a program is established, the facilitation process generally includes assessment, planning, identification, negotiation, monitoring, reassessment, outreach, education and training, emotional support and advocacy. Basic principles for the development and operation of resource facilitation programs include:

- Facilitation is individualized
- Facilitation is accessible
- Facilitation is holistic
- Facilitation is effective and valued
- Facilitation is participant driven
- Facilitation is creative and flexible
- Facilitation builds community partnerships
Program participants and resource facilitators attending the Summit reported that surveys indicated individuals with brain injury and their personal support providers feel they have information not available elsewhere and can therefore make more informed choices as a result of access to resource facilitation. Summit participants also reported that communities demonstrate increased capacity to serve and support persons affected by brain injury through natural supports. Most important, participants attribute, in part, their increased personal or life satisfaction to the resource facilitation program.

The U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), sponsored the Summit and publication of this guide as part of its Partnership for Information and Communication (PIC) Cooperative Agreement with the BIA (Project No. CFDA 93.110G). Financial support from the HRSA is not necessarily an endorsement of the concepts presented.
Resource Facilitation in Brain Injury:
A Consensus of Principles and Best Practices to Guide Program Development and Operation

Introduction

In September 2000, the Brain Injury Association (BIA), Inc., the national organization creating a better future through brain injury prevention, research, education and advocacy, hosted a two-day Summit on Resource Facilitation. Resource facilitation is a partnership that helps individuals and communities choose, get and keep information, services and supports to make informed choices and meet their goals.

The purpose of the Summit was to establish consensus on principles and best practices among existing resource facilitation programs and to assemble instructions and tools for establishing new programs. This was a first-of-its-kind effort sponsored by the Federal government and involved both State agencies and state BIAs. Individuals with brain injury, family members, personal support providers, resource facilitators, program administrators and others who work both within and outside of the brain injury field attended the Summit.

Because Summit participants represented both public and private agencies working with funds from varied sources and operating in both urban and rural settings, achieving consensus was not always possible. Where there is no one right answer for all programs, this guide provides alternatives suggested by Summit participants and BIA staff.

BIA anticipates that the Summit and this guide will enhance existing operations and foster the development of resource facilitation in states where it does not exist. BIA believes the creation of new facilitation programs will help overcome inadequate access to information and lack of coordination of services so often encountered by persons with brain injury and their families. The U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) sponsored the Summit and publication of this guide as part of its Partnership for Information and Communication (PIC) Cooperative agreement with BIA (project no. CFDA 93.110G). Financial support from HRSA is not necessarily an endorsement of the concepts presented.

BIA gratefully acknowledges the Summit’s planning team members: Cheryl Amoruso (TX), Tracy Byrd (FL), Paul DeBoer (IA), Robert Demichelis (VA), Rene Hurley (NJ), Sandra Koplon (AL), Sandra Knutson (TBI Technical Assistance Center), Denise Stelpflug (WI), Cathy Ficker Terrill (BIA) and our advisors Augusta Cash (National Association of State Head Injury Administrators) and Betty Hastings (Health Resources and Services Administration). BIA also sincerely thanks the speakers and Summit participants who lent their expertise in developing these practice guidelines.
Overview of Traumatic Brain Injury

On February 22, 1986, the BIA, Inc. (then National Head Injury Foundation, Inc.) adopted the following definition of traumatic brain injury (TBI):

_Traumatic brain injury is an insult to the brain, not of degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment._

BIA’s definition is not intended as an exclusive statement of the persons served by the national association but rather as a means to differentiate traumatic brain injury from acquired brain injury. Acquired brain injuries are caused by internal events and external physical forces. Examples of internal events include heart attacks, strokes, infectious diseases, metabolic disorders, toxic exposure and other means.

The Centers for Disease Control and Prevention (CDC) estimate that there are 5.3 million children and adults living in the United States with a permanent disability as a result of a TBI. Further, according to the CDC, one million people are treated and released from hospital emergency departments, 50,000 TBI-related deaths occur, 250,000 people are hospitalized with TBI and survive and 80,000 people experience the onset of long-term disability as a result of TBI each year (1999).

TBI does not discriminate. People of every age, gender, race, religion and socioeconomic status sustain brain injuries. Transportation, primarily motor vehicle crashes, account for nearly 50 percent of all TBIs. Falls are the second leading cause overall and the leading cause of TBI in older Americans. Firearms and other violent behavior are also major causes of TBI (CDC, 1999).

Brain injury often results in long-term disabilities. Physical impairments may include seizures, muscle spasticity, fatigue, balance problems and impaired hearing, vision and speech. Cognitive impairments may include memory loss, concentration or processing difficulty, organizational problems, spatial disorientation, impaired judgment and inability to multi-task.

Persons who sustain TBI may also experience psychosocial, behavioral or emotional impairments such as failure to recognize deficits, lowered self esteem, increased anxiety, depression and mood swings, sexual dysfunction, impulsive behavior and an inability to initiate or complete tasks without reminders. These physical, cognitive and psychosocial impairments are often the cause of significant stress in peer and family relationships as well as poor functioning in school and work.
As cited in the 1999 Report of the NIH Consensus Development Conference on the Rehabilitation of Persons with Traumatic Brain Injury, the economic consequences of TBI are enormous. The average lifetime cost of care for a person with severe TBI ranges from $600,000 to $1,875,000 (p. 10). This figure does not include lost earnings of the person who is injured or his/her family caregiver or the cost incurred by social service systems.

Life-altering physical, cognitive and psychosocial changes coupled with huge financial burdens and significant stressors create an immediate and ongoing need for access to information, training, services, supports and resources for both the person with TBI and his/her personal support system.

Definitions and Terms

Language can be a deterrent in consensus building. A review of the literature revealed the following commonly used definitions:

In Section 4302(A) of the Medicaid Manual, the U.S. Department of Health and Human Services, Health Care Financing Administration defines case management as “an activity which assists individuals eligible for Medicaid in gaining and coordinating access to necessary care and services appropriate to the needs of an individual.”

The U.S. Department of Health and Human Services, National Institutes of Health, National Institute of Neurological Disorders and Stroke, in its 1989 Interagency Head Injury Task Force Report, defines care management as “…ensuring that the resources of the facility, community and region are made available to the TBI patient in a coordinated, efficient and effective manner” (p. 16).

In some ways these descriptions echo the system-controlled medical model that disability rights leaders fought against during the last quarter of the 20th century. Therefore, the Summit’s participants discarded familiar definitions and terms in favor of:

- Resource facilitation is a partnership that helps individuals and communities choose, get and keep information, services and supports to make informed choices and meet their goals.

Summit participants describe resource facilitation as a collaborative process that respects and encourages the involvement and choices of individuals with brain injury and their personal support providers in setting goals and in identifying and accessing information, services and supports that are desired. The process may involve medical and allied health professionals; service providers; State, county or city agencies; employers; educators; and others. Each program varies as to the terms used to describe those involved in the process. For consistency, this guide refers to individuals with brain injury and their personal support providers as participants; individuals who provide assistance in navigating service systems as facilitators; and individuals who operate and supervise programs as administrators.
Resource facilitation combines individualized coordination of services, information and resources and community capacity building. Facilitation activities often include assessment, planning, identification, negotiation, monitoring, reassessment, outreach, education and training, resource development, emotional support and advocacy.

**Program and Policy Origins**

Helping people access services while controlling quality and cost was a fundamental construct of this country’s anti-poverty programs of the 1960s. In the 1970s, case management was introduced in the medical and rehabilitation fields as a means for achieving “client wellness and functional capability” (Commission for Case Manager Certification, 2000, p. ii). Initially, case management was viewed as a method for maximizing medical services and improving health outcomes. Later, case management, what Summit participants redefined as resource facilitation, proves to be valuable in meeting the wide range of needs and preferences necessary to assure quality of life in the community.

**Developmental Disabilities**

By the late 1970s, case management was embraced by the developmental disabilities field. Section 102(8)(3) of the Developmental Disabilities Assistance and Bill of Rights Act of 1978 provided the rationale for applying the tenets of case management to an array of medical, social and educational supports by including the need for coordinated services as part of the definition of developmental disabilities:

- Reflects the person’s need for a combination and sequence of special interdisciplinary or generic services, supports or other assistance that is lifelong or of extended duration and is individually planned and coordinated

The disability rights movement of the 1970s and beyond and its accompanying “nothing about me without me” motto laid the groundwork for a new paradigm. The conceptual shift brought with it a new vocabulary. References to social work and case management slowly ebbed in favor of service coordination, support broker and other person-centered terms. The paradigm shift brought systems change as well.

In 1981, the public recognized that the Medicaid program had a bias toward institutional care. Amendments in section 1915(c)(4)(B) of the Social Security Act paved the way for the creation of optional Home and Community-Based Services (HCBS) waivers to help overcome this bias. Using a waiver, States can make home and community-based services available to individuals who otherwise would qualify for long-term supports funded by Medicaid only if they were in an institutional setting. The word “waiver” comes from the fact that States may request that the Federal government waive certain rules that impede the development of Medicaid-funded community-based long-term care supports and services. Case management was included among a short list of services and supports available under a Medicaid waiver program.
In 1987 the Consolidated Omnibus Budget Reconciliation Act (P.L. 99-272, COBRA) added targeted case management to the list of optional services that may be provided in a State’s plan under Medicaid. Although care coordination services had been part of the Medicaid program since its inception, it was not until enactment of this law that States could provide case management as a distinct service under Medicaid without the use of waiver authority (HFCA Manual, Section 4302).

Developmental disabilities leaders were largely responsible for advocating for these Federal policy changes and maximized their opportunities for expanded services and self-determination at the State and local levels. In 1991, Nebraska’s Developmental Disabilities Services Act revamped the former Office of Mental Retardation to become more accessible and accountable to consumers. By 1996, the Kansas Division of Health Care Policy introduced a Self-Determination Option in programs serving persons with developmental disabilities. Similar innovations in Medicaid HCBS waivers engineered consumer choice and control for people with developmental disabilities in Michigan, Minnesota, Indiana and other States (Gaylord et al., 1999/2000). According to Cooper and Smith (1998), about 480,000 people with developmental disabilities received case management-like services in 1996 at a cost of just over $537 million.

**Brain Injury**

Resource facilitation got its start in brain injury in 1984 when the Missouri Department of Health dedicated two service coordinators to its Head Injury Program (MO Department of Health, p. ii). The positions were originally funded by a CDC grant as part of a demonstration project to reduce secondary health conditions among persons with brain injuries. The following year, the Massachusetts Rehabilitation Commission introduced its service coordination program as part of its Statewide Head Injury Program (SHIP). SHIP was created to “increase survivors’ ability to be more independent in their homes, communities and at work” (Commonwealth of MA, 1998, p. 2). Today, more than 350 people participate in SHIP’s service coordination program each year.

In 1988, the Secretary of the U.S. Department of Health and Human Services appointed an Interagency Head Injury Task Force to identify gaps in research, training and service delivery and recommend solutions to meet the needs of persons with brain injury. In its 1989 Report, the Task Force encourages the development of working groups at the state and local level to provide leadership and coordination. The report states that, “lead agencies … must ensure that surveillance and service coordination occurs” (p. 12). To accomplish this, the report “encourages the use of ‘care manager’ systems that operate throughout all stages of care from acute care through community reentry” (p. 16).

The Community Support Network (CSN), which is the first known resource facilitation program operated by a state BIA, was introduced in 1989 as a collaborative project of the Minnesota Head Injury Association (now the BIA of Minnesota) and the Minnesota Division of Rehabilitation Services. With funding from the U.S. Department of Education, Rehabilitation Services Administration (RSA), this three-year experiment was launched to enhance access to information and stimulate the development of community support services for persons with brain injury and their families in non-metropolitan areas of Minnesota.
Although the Federal grant ended in 1992, many aspects of the CSN model are used today. Some of the most frequently replicated program components include: (1) individualized goal setting; (2) flexibility to allow for changing goals and needs over time; (3) non-traditional, solution-focused approaches to meeting needs in systems where specialized services do not exist; and (4) ongoing outreach and training for family members, professionals and the general public.

In July 2000, the HRSA, through its contractor, the TBI Technical Assistance Center, engaged John Corrigan, Ph.D., Director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation in the Department of Physical Medicine and Rehabilitation at The Ohio State University, to conduct a comparative analysis of needs assessment data collected by 11 States that were participating in the HRSA State Demonstration Grant Program in 1998. The analyses conducted were qualitative and included comparisons of constituencies surveyed, methods used and conclusions reached regarding the needs of individuals with TBI and the resources required to address those needs. Corrigan found that service coordination was a challenge identified in some form by every State:

- Coordination was identified as lacking both within and between health care and social service providers. It was further noted in some States that neither health care nor social service systems coordinated with the education or criminal justice systems, both of which may play a critical role in the lives of persons with TBI. In response to this lack of coordination, numerous action plans stated that there was a need for service coordinators who would be knowledgeable in brain injury and work without conflict of interest for the needs of the individual and family… In States that used case managers within individual service delivery systems, it was suggested that a service coordinator with expertise in brain injury be superordinate to these service system-specific case managers (p. 10).

Just like people with developmental disabilities, people with brain injuries need an individually planned and coordinated approach to services and supports in which easing access, maximizing dollars and teaching independence is valued because it leads to an enhanced quality of life.

Given the longevity of service coordination in Missouri, the proven success of the Community Support Network in Minnesota and the clear need documented by the Health Resources and Services Administration TBI State planning grants, advocates fought for the inclusion of resource facilitation-like initiatives in federal policy. On October 17, 2000, President William Jefferson Clinton signed the Children’s Health Act of 2000. Title XIII of this law amended and reauthorized the Traumatic Brain Injury Act of 1996 to allow the Health Resources and Services Administration to continue grants to State governments to build capacity. The reauthorization emphasizes community integration activities including the development of case management or service coordination programs as well as service system linkage.

Summit participants believe that people who have adequate, accurate and pertinent information will make decisions that lead to more productive and satisfying lives. For these reasons, resource facilitation should be available nationwide regardless of age, culture or income. The Health Resources and Services Administration grant program has been and should continue to be used to develop statewide systems of resource facilitation in brain injury.
Current Status In Brain Injury

Today, brain injury resource facilitation exists in 16 States with an estimated 6,250 individuals served nationwide each year. Program descriptions are available from BIA’s State Affairs Department and are posted to the web site of the National Association of State Head Injury Administrators at www.nashia.org. The programs vary in terms of how services, supports and resources are acquired by participants. Common methods include:

- Refer – proactive linkage to purchasers and providers, help completing application forms, assistance in finding natural supports and leveraging of donated services
- Purchase – payment for services and supports through direct billing or voucher systems
- Provide – services are provided directly

In general, state BIAs and other nonprofit advocacy organizations tend to use referral as a method for facilitating service access. In general, State health and human service departments and Medicaid agencies tend to serve as the payor for services. In some cases, facilitation is provided in conjunction with direct service. For example, the resource facilitator and occupational therapist both work for the same organization.

Regardless of the facilitation method used, it is important to keep in mind that the anticipated results of resource facilitation are not the same as the anticipated outcomes of the service delivered.

Patricia K. Patterson and others (1999) published the results of a study evaluating the evidence for effectiveness of case management during recovery from TBI. Eighty-three articles published between 1976 and 1997 and identified through Medline, HealthSTAR, CINAHL, PsychINFO and the Cochrane Library databases were evaluated. Studies that included anecdotal evidence, such as testimony of patients and caregivers, were not evaluated. Instead, only studies that met Class II or Class III research protocols, which typically involve experimental design using random samples and blind controls, were included. In critically appraising the three studies that met the rigorous criteria, the evaluators found no clear evidence of the effectiveness or ineffectiveness of case management. This does not mean that case management is of no value; rather, it means that the brain injury field lacks the scientific evidence necessary to prove or disprove case management’s consistent effectiveness on functional ability, vocational status, living status, family impact and other measures.

Resource facilitation’s cost-effectiveness has been documented. In a May 16, 1999, communication to The Honorable Jeb Bush, Governor of the State of Florida, Margaret Cashwell Bowden, a researcher at Florida State University’s Center for Policy Studies writes of BIA of Florida’s resource facilitation program:

- As a mechanism to reduce the incidence of inappropriate institutionalization (nursing home, hospital mental illness facility, or correctional institute), it appears to be the most cost effective. A review of three years of records reveals that the total average cost per client is less than $100 per month. Compare this, for example, with an average nursing home cost of $4000 per month.
In Fiscal Year 2000, with funding from the Alabama Impaired Drivers Trust Fund, the Alabama Head Injury Foundation (AHIF) served 1,269 persons in its Resource Coordination Program at a cost of $520,380. Incredibly, AHIF’s resource coordinators secured $593,619 from the community through in-kind donations of medical and dental services, assistive technology, equipment repair, home maintenance and improvement and other supports. Had the AHIF program not been in place, the program participants would have gone without essential services or the State of Alabama would have incurred expenses for them. Instead, the program paid for itself and dramatically improved the lives of Alabamians with brain injuries.

The Alabama Impaired Drivers Trust Fund Advisory Board Annual Report, October 1, 1996 – September 30, 1997, profiles the lives of five individuals, one of whom is Barbara:

* Barbara, now 24, sustained a traumatic brain injury in 1991 when she was shot in the head. The injury resulted in blindness, seizures and mobility impairments… Initially, emotional support and community resource referral were the greatest needs…Barbara then pursued her goal of living independently… “My coordinator brought me out of my shell,” says Barbara, who was then spending her time isolated in her bedroom. “Now I have a life.” (p. 8)

There are hundreds of resource facilitation-like initiatives based in hospitals and rehabilitation facilities and offered through community reentry programs, law firms and by private case managers. Often friends, family members and others comprising the individual’s support network are called upon to act as facilitators.

Although the principles and practices described in this publication may be applicable to these providers and support networks, the consensus statements and alternative suggestions that follow are targeted primarily to programs that are administered by State government agencies or by state BIAs, which often operate under contract to State-based authorities.

**Principles**

Tracy Byrd, Director of Family Support for the BIA of Florida and one of the Summit’s planning team leaders said, “Regardless of the agency you work for, the program you participate in, or the system you’re trying to navigate, there are fundamental principles that apply to all of us.” The guiding principles for resource facilitation as defined by Summit participants include:

**Principle No. 1 – Facilitation is individualized**

Persons involved and materials used in the process are culturally sensitive to age, gender, race, orientation, religion and persons with multiple disabilities. It also means facilitation is cognitively and life stage-appropriate to the individual, and facilitation activities incorporate decision-making practices that embrace each individual’s dignity of risk.
**Principle No. 2 – Facilitation is accessible**

Facilitation activities are conducted in a simple and clear manner. Communication is offered in alternative formats. Facilitation participants are fully informed of the services and supports available to them so that their choice and control is maximized.

**Principle No. 3 – Facilitation is holistic**

Facilitation is available to participants throughout their lives as needed. It encompasses the whole person, including physical, environmental, emotional, social, spiritual and lifestyle values. Facilitators are knowledgeable of the broad range of information, services and supports that will help individuals maximize their efforts to achieve balance and well being.

**Principle No. 4 – Facilitation is effective and valued**

Facilitation is available in a timely and competent manner. The facilitation process is practical and goal-directed and not burdened by unnecessary and/or duplicative paperwork and approval procedures. Participants are satisfied and desired outcomes as defined by the individual are measured and achieved.

**Principle No. 5 – Facilitation is participant directed**

Facilitation plans are person-centered and based on the individual’s strengths rather than system-directed and based on the individual’s impairments. It means persons with brain injuries and their personal support systems are involved to the fullest extent possible in all aspects of the planning and decision making process. Facilitation participants are empowered to advocate for themselves.

**Principle No. 6 – Facilitation is creative and flexible**

Facilitation practices adapt to the individual’s changing needs and environments and are resilient to external economic and political forces. Program participants, facilitators and administrators embrace innovation and new ideas as needs change.

**Principle No. 7 – Facilitation builds community partnerships**

Facilitation programs actively seek input and feedback on program development and operation from participants, professionals and other people in the community. A solution-focused, team approach is used in developing and using information, services and supports.
Program Development

The development and sustainability of resource facilitation is an ongoing process. It requires the involvement of and communication with stakeholders and partners in each phase. As Sandra Knutson, Outreach Coordinator for the TBI Technical Assistance Center and a Summit planning team member said, “It is hard to get people going with you if they don’t know where they’re going.” Success depends upon inside advocates and outside advocates working in tandem. Inside advocates are generally influential State agency employees who are willing to vocalize support for the initiative. Outside advocates are individuals and groups who are known to public officials, respected for their knowledge and experience and have a proven track record in public policy issues.

Step No. 1 – Establish the Need

Determine the incidence and prevalence of TBI. In the absence of a State-based trauma registry or surveillance system, advocates may use the Estimated Annual Rates of TBI by State, 1996, updated in April, 2001 to include year 2000 U.S. population data, by the National Center for Injury Prevention and Control (NCIPC), an arm of the Centers for Disease Control and Prevention (CDC). These CDC-backed, state-by-state figures are available from the BIA’s State Affairs Department. As part of this process and for comparison purposes, advocates may also wish to establish the statewide incidence and prevalence of more commonly understood conditions such as spinal cord injuries, cerebral palsy, epilepsy, Alzheimer’s disease, persistent mental illness and mental retardation. Nationally comparative prevalence rates are available from the BIA’s Communications Department.

Identify what services, including resource facilitation, currently exist. This work may have been completed as part of a Health Resources and Services Administration TBI State Grant Program planning grant. If not, or if the information is outdated, advocates can encourage a State agency to conduct a needs and resources assessment and assist in data collection. Alternatively, state BIAs can conduct the assessment independently or with a university partner. An assessment instrument is available from the Health Resources and Service Administration’s TBI Technical Assistance Center (TBI TAC) web site at www.tbitac.org.

Evaluate the success of current services in meeting the needs of persons with brain injuries and their families. Determine how many people are on waiting lists and the length of time before they are served. Host statewide town meetings or forums to determine what services do not exist and the level of interest and need for resource facilitation. The information gathered at town meetings can help create a vision for how resource facilitation can be implemented as well as expand the cadre of advocates willing to fight for it.

Analyze services included in the State Medicaid Plan and in existing Medicaid Waivers. According to the Health Care Financing Administration’s Medicaid Services By State, a chart published in October 1996 by the Division of Intergovernmental Affairs based on data supplied by individual regional offices, 46 of the 56 States and US Territories have included case management in their menu of State Plan optional services. Advocates can check to see what the State Medicaid Plan and/or Home and Community-Based Service waivers services are available to persons with brain injuries, how many people are actually being served through these
mechanisms and what barriers may exist. Advocates will also want to interview providers who serve persons with disabilities other than TBI to determine if, with training, the providers can offer services and supports to individuals with TBI. It may not be necessary to create a whole new resource facilitation program but rather broaden the eligibility scope or educate those administering existing services on the unique aspects of brain injury.

Examine what other States have already done. Advocates can use program descriptions available from BIA to learn more about facilitation activities in other States. Advocates will also want to review the National Directory of State Government Brain Injury Contacts, published by National Association of State Head Injury Administrators (NASHIA), to learn about case management and service coordination programs.

Throughout the process, identify champions inside and outside State government and the brain injury field who will support the next steps.

Step No. 2 – Identify Possible Funding Sources

The BIA estimates the annual cost of resource facilitation is approximately $1200 per program participant (see calculation methods explained on pages 23 and 24). On average, each program involves 450 participants. Fortunately, resource facilitation is ideally suited to small beginnings and incremental growth.

The Alabama Head Injury Foundation Resource Coordination program began with approximately $90,000 in funding from the Alabama Developmental Disabilities Planning Council for pilot sites in Mobile and Huntsville. BIA of Florida’s first Family Support Specialist was hired on contract for $20 per hour to identify the needs of ten families and explore ways to help them improve their situations. In both Alabama and Florida, identifying seed funds and then other multiple funding sources was a key task in program development. For new facilitation programs, possible funding prospects include:

General Funds. According to BIA’s 1999 Benchmark Study of State BIAs, an annual appropriation from general funds for TBI-specific services is made by the legislature in 12 States. The appropriation may be allocated to a health department, a disability-specific division or department, injury prevention unit or split among several agencies. Depending on the economy, State agencies may find unspent dollars toward the close of the current fiscal year or may be able to add pilot projects or service development initiatives in the next budget cycle. The budgeting process varies in each State. For example, the State of Florida appropriates funds in a special category known as “Member’s Projects.”

Trust Funds. Trust funds are established through State legislation to receive funding from fines and surcharges to provide designated services to people with brain injuries. In some States the trust fund pays for services for people with brain injury as well as people with spinal cord injury. The Florida Brain and Spinal Cord Injury Rehabilitation Trust Fund receives funding from surcharges on temporary auto license tags and fines for speeding, driving while under the influence and other civil penalties. The Commonwealth of Massachusetts assesses a $125 “head injury fee” for convictions of driving under the influence and driving to endanger. Using surcharges and fines to fund services is sometimes more agreeable to policymakers because it ties the payment to the people who are part of the problem. That’s why speeding and
blood alcohol content level fines tend to be more appealing to legislators. Nevertheless, advocates also can explore fines on safety belt and helmet violations as well as violations on handicap-parking restrictions. Other options may include surcharges on all drivers’ licenses, a surcharge on insurance policies that cover drivers under age 25, a surcharge on firearm registrations or a tax on firearm sales.

In most cases, the legislation that creates the trust fund also designates a State agency responsible for administration and creates an advisory committee for oversight. Advisory committee membership often consists of State agency personnel, a state BIA representative, rehabilitation professionals, people with brain injuries, family members and other disability advocates. In several States the vocational rehabilitation services agency administers the fund.

If a trust fund exists, a portion of the proceeds may be allocated directly to resource facilitation or may be used to leverage Federal funds for targeted case management through the State’s Medicaid program. If a trust fund does not exist, a strong, tenacious coalition involving multiple public and private partners can be formed to pursue the legislation. Be aware that trust fund legislation may not be a viable option depending on the State’s political climate and whether or not assessing citizens for this reason and in this manner is constitutional. More information on trust funds is available from NASHIA and from BIA’s State Affairs Department.

Medicaid State Plan & Optional Services. Medicaid is a jointly-funded, Federal/State health insurance program for certain people who are low-income and have special needs. It covers approximately 36 million individuals including children; adults who are aged, blind, and disabled as well as people who are eligible to receive Federally assisted income maintenance payments. Cathy Ficker Terrill, BIA’s former Vice President and a former State Medicaid Bureau Chief once said, “No one planned Medicaid.” Advocates need to understand Medicaid and many of its complexities so they can advocate for service expansion in the most integrated manner for long term care supports, including resource facilitation.

One of the most important concepts to understand is how the Federal government matches a State government’s expenditures for medical and other services for persons with disabilities and those who have low incomes. The matching funds are known as Federal Financial Participation (FFP). Under some circumstances, a State government may be able to claim FFP for those persons who are eligible for Medicaid and participate in a resource facilitation program. Under Medicaid rules, States have always been permitted to claim FFP for case management-like services when performed as a component of another service. For example, preparation of a treatment plan by a home health agency worker is considered part of the home health agency service. As such, the planning time is eligible for FFP at the Federal Medical Assistance Percentage (FMAP) rate. The FMAP rate ranges from 50 to 77 percent depending on the State. However, if a resource facilitator writes the treatment plan but does not work for the home health agency, separate payment for the planning time would not be eligible for FFP because it is not an inseparable part of the treatment.

Additionally, States can claim FFP to perform certain functions that are necessary to administer State plan services. Examples of this type of “administrative case management” include, but are not limited to, eligibility determination, preadmission screening for inpatient care, prior authorization and utilization review. States can also claim FFP for outreach and intake processing. For these types of administrative services, States claim FFP at the administrative rate, which is 80 percent.
Administrative case management may be performed by an entity other than the State Medicaid agency as long as there is an interagency agreement in effect. States that expect to claim FFP for administrative case management activities must submit a cost allocation plan to their HCFA regional office. A note of caution, under administrative case management, FFP can only be claimed for services that are covered by Medicaid. For example, babysitting is not a covered Medicaid service. Therefore, the resource facilitator’s time to arrange for childcare while the parent visits a doctor could not be claimed. When performing administrative case management, very detailed records must be kept of the facilitator’s time.

Under Medicaid rules promulgated as a result of the 1987 Consolidated Omnibus Budget Reconciliation Act (COBRA), States may add case management as an optional, freestanding service in their State Plans and may provide case management to “assist individuals eligible under the plan in gaining access to needed medical, social, educational and other services” (Medicaid Manual, Section 4302(4)(B)(2)). This means States may claim FFP at the State’s FMAP rate for the time resource facilitators spend helping people who are Medicaid-eligible access non-medical services such as energy assistance, emergency housing, food stamps and legal aid.

Additionally, COBRA established a mechanism for States to target case management to certain groups of individuals who share an identifiable characteristic or combination of characteristics. The characteristic can be age, type or degree of disability, illness or condition, or any combination of these. This targeting mechanism allows advocates to argue against the “woodworking effect” (that is, uncontrolled numbers of additional Medicaid-eligible persons who come out of the woodwork) sometimes invoked by policymakers.

If a State wants to offer targeted case management, it must be written into the State Plan as an amendment. Any conditions, such as waiver of comparability or statewide availability and qualifications of case managers, must also be written into the amendment. The amendment is submitted to the State’s HCFA regional office for processing.

If the State’s Medicaid agency is unwilling to add case management as an optional State Plan service, the legislature can compel the agency to do so as was the case in Minnesota in 1989 when the Services for Persons With Brain Injury Act was passed to add administrative case management (Murrey et al., 1998).

**Medicaid Waivers.** As has been done very effectively in the developmental disabilities field, Home and Community Based-Services (HCBS) waivers can be used to fund resource facilitation for people with brain injury. The waivers allow States to bypass or waive Federal rules that inhibit community-based services. The most commonly waived rules are *comparability*, which means that States must normally offer the same amount, duration and scope of service to all persons eligible for Medicaid. Instead, under a waiver, States can target specific groups of people. The other common rule waived is *statewide availability*. This means States can target specific geographic areas in which to provide community-based services.
To receive approval to implement a waiver, a State Medicaid agency must assure HCFA that, on average, it will not cost more to provide home and community-based services than providing institutional care would cost. Section 1915(c)(4)(B) of the Social Security Act specifically lists case management as a service that can be provided under a HCBS waiver. The service is eligible for FFP at the State’s FMAP rate. New waivers are good for three years, after which they may be renewed every five years.

**Tobacco Settlement Funds.** As a result of the master settlement with tobacco manufacturers, all States expect to receive large ongoing payments in exchange for relinquishing claims against the tobacco manufacturers relating to the costs of treating Medicaid beneficiaries for tobacco-induced illnesses. Nationwide payments are estimated to be $239.5 billion per year through 2025 (National Governors Association, 1999).

Interestingly, the funds are not restricted to payment of tobacco-related health care. Indeed, only a few States have applied the funds toward smoking cessation and cancer treatment programs. Instead, the majority of States are using the money for a myriad of public health issues including children’s health and welfare programs, services for elderly persons and medical care for those who are uninsured. Some States are using the funds for general education; one State bolstered its technology-based economic development programs using the windfall. Tobacco settlement funds have already been used to open additional BIA of Florida Family Support Centers. Because States cannot accurately predict how much money they will receive in any given year, many State legislatures have flexibility to apply the funds to current issues. Tobacco settlement funds may be an excellent source for funding a resource facilitation program.

**Family Support Dollars.** Federal and State governments have acknowledged the essential role families play in caregiving. In some states, available services include respite, family counseling, home modifications, sibling support and adaptive equipment. Traditionally persons with brain injuries have not been included in family support initiatives.

The Families of Children with Disabilities Support Act of 1994 authorizes the U.S. Department of Health, Administration on Developmental Disabilities to make grants to States for family support demonstration projects to address the problems that impede the self-sufficiency of children with disabilities. The legislation assists States in developing or expanding family-centered and family-directed, culturally competent, community-based, comprehensive statewide systems of support for families of children with disabilities. Parents with cognitive disabilities and families of children with behavioral or emotional issues were targeted among other underserved groups as potential project participants.

State agencies serving children and families may apply for these Federal funds and contract to another State agency or state BIA to facilitate service access by people with TBI. Because these are Federal funds, the functional definition of developmental disabilities is applied rather than the categorical definition of mental retardation commonly used by some States.

**Related Agencies.** Depending on how the State and its counties are organized, there may be a department, division or office on mental health, mental retardation, developmental disabilities, aging, long-term care, substance abuse, juvenile or criminal justice, education, employment, housing authority or other agency that serves persons with brain injuries along with other
populations. Any of these agencies may have pockets of money to allocate to a resource facilitation effort. For example, in New York, the Office of Mental Retardation/Developmental Disabilities contracts with the BIA of New York State to operate its Family Advocacy Counseling and Training Services program. Similarly, the Division of Developmental Disabilities funds BIA of New Jersey’s Family Support Program.

Private Sources. Funds may be available through United Way, Combined Health Appeal, community chests, civic organizations, corporations or private foundations. In some cases, funding applications may be submitted each year; other donors may make one-time or time-limited gifts. Contributions can also carry restrictions such as geographic location or age of population served. It may also be possible to charge a fee, on a sliding scale, to program participants. The Commonwealth of Massachusetts has investigated this option for services available through its Statewide Head Injury Program.

Every possible source should be explored in developing both short and long term financial plans for a resource facilitation program.

Step No. 3 – Build Partnerships

Advocates must develop a marketing mindset. In gathering data and exploring funding sources, advocates will come in contact with a number of potential partners. Some will be enthusiastic about the resource facilitation concept and get on board immediately. Others will ask, “What’s in it for me?” Program developers must be willing to reach out to others and adapt their ideas so that the program responds to the need and is appealing to many stakeholders. Some program partners may include:

- National and State BIAs
- National Association of State Head Injury Administrators
- Family members and individuals with brain injuries not affiliated with the state’s BIA
- Medical and rehabilitation community
- Community-based providers
- State, county and city agencies employees
- State Advisory Councils
- Governor’s Councils on Disability
- Interagency Councils on Disability
- Statewide Independent Living Councils
- Developmental Disabilities Planning Councils
- Independent Living Centers or Association’s thereof
- Traffic Safety Councils
- Professional Associations
- Brain Injury research community including universities and the National Institute on Disability Rehabilitation and Research Model Systems of Care
- Faith based community
- Bar Association and/or Protection & Advocacy Services
- Insurance companies
- State Rehabilitation Councils
- Mothers Against Drunk Driving
- Bureau of Indian Affairs
- Veterans Offices

It is a good idea to keep records of contacts with all potential partners and to note what information, services, or supports they may provide. This will become the core of the resource file or resource database once the program is up and running. Advocates should also note support and resistance encountered. Program planners will use this time to confirm their understanding of the budget cycle, the executive and legislative processes and prevailing political climate.

**Step No. 4 – Take Action**

By the time program planners are ready to take action, all the homework will have been done. Planners will know if an existing program can add brain injury resource facilitation to its activities or if a new venture is necessary. Planners will have researched potential private funders and will have drawn them into the development process. Planners will have assessed the likelihood of government funding and may have drafted legislation establishing authority for resource facilitation. If legislation is to be introduced, advocates will have developed a uniform message and will be ready to launch a coalition effort. Along the way, planners will have identified any unintended consequences and developed contingency plans. Once all planning actions are taken, it will be time for implementation.

**Program Start Up & Administration**

Rene Hurley, Director of Family Services for the BIA of New Jersey and a Summit planning team member noted, “The facilitator’s job is to obtain ongoing services and helping relationships that maintain and enhance the quality of life for individuals and families over the lifespan. The administrator’s job is to do everything else.”

Some resource facilitation programs are large enough to employ a central administrator with second line supervisors to manage the facilitation staff. In other programs, the administrator is the only direct employee and resource facilitators are independent contractors or are hired and supervised by local authorities such as county agencies. Administrators are usually responsible for staffing, budgeting and program oversight and may also be assigned to a specific geographic area or may work with program participants whose situations are particularly difficult.
Staff Size

There is no one right ratio for full-time resource facilitator to active participants because the workload of each facilitator is determined on an individualized basis with consideration given to intensity of needs, availability of resources, travel distances, documentation requirements, complexity of systems and the support circle available to the participant. In general, Summit participants suggest an average of 20-40 active program participants per facilitator so that there is at least one hour of contact by the facilitator with each participant each month.

Hiring

When recruiting resource facilitators, most administrators evaluate education, experience, knowledge, skills and qualities.

Education. In general, administrators seek individuals who have a bachelor’s degree in social work or a related human service field. Some programs hire facilitators who do not have a college degree while others require case manager certification. Most programs find it helpful to have staff with varied educational backgrounds such as nursing, speech and language, occupational, physical and recreational therapy, plus liberal arts.

Experience. Most programs require a minimum of one year’s experience working with people with disabilities. If experience is accepted in lieu of education, the experience is substantially more than one year. Summit participants agree that individuals with brain injuries and family members are not more qualified or less qualified to work as resource facilitators based on their direct experience with the injury. Similarly, administrators agree that while specific knowledge of brain injury is helpful, it is not required. Nevertheless, direct experience in the disability field is required.

Knowledge & Skills. Summit participants agree that facilitators should be from the community in which they work, when possible, and have knowledge of local and State systems to be navigated. Additionally, resource facilitators must be skilled in verbal and written communication, listening, problem solving, negotiation, advocacy, planning and organization, record keeping and multi-tasking. Most administrators look for employees who can work independently, who like to teach others, who have an ability to synthesize facts from multiple sources and those who can provide emotional support in situations where there is no readily apparent solution.

In June 2000, the University of South Carolina School of Medicine, Center for Disability Resources, under contract to the South Carolina Department of Disabilities and Special Needs, developed core competencies for service coordinators. The knowledge and skill requirements were compiled from job descriptions and current literature plus interviews and focus groups conducted with program participants and staff. The chart below summarizes the Center’s findings; a copy of the complete report is available from BIA’s State Affairs Department or on NASHIA’s web site at www.nashia.org.
<table>
<thead>
<tr>
<th>Knowledge of…</th>
<th>Ability to…</th>
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<tbody>
<tr>
<td>Disabilities and special needs</td>
<td>Communicate effectively</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>Obtain pertinent information</td>
</tr>
<tr>
<td>Agency policies and procedures</td>
<td>Work collaboratively with others</td>
</tr>
<tr>
<td>Community resources</td>
<td>Prioritize tasks and manage time</td>
</tr>
<tr>
<td>Individual/family dynamics</td>
<td>Observe and analyze situations</td>
</tr>
<tr>
<td>Assessment instruments and methods</td>
<td>Analyze information</td>
</tr>
<tr>
<td>Person-centered philosophy and concepts</td>
<td>Organize and manage information</td>
</tr>
<tr>
<td>Policies regarding confidentiality and release of information</td>
<td>Be sensitive to individual/family uniqueness</td>
</tr>
<tr>
<td>Abuse and neglect indicators</td>
<td>Advocate successfully</td>
</tr>
<tr>
<td>Loss and the grieving process</td>
<td>Apply personal outcome measures</td>
</tr>
<tr>
<td>Impact of disability on individual/family functioning</td>
<td>Prepare written documents</td>
</tr>
<tr>
<td>Participant’s individual strengths and weaknesses</td>
<td>Anticipate needs and respond appropriately</td>
</tr>
<tr>
<td>Agency interface with other programs/services</td>
<td>Problem-solve creatively</td>
</tr>
<tr>
<td>Assistive technology resources</td>
<td>Work with minimal supervision</td>
</tr>
<tr>
<td>Personal outcome measures philosophy</td>
<td>Intervene effectively in crisis situations</td>
</tr>
<tr>
<td>Community services and programs</td>
<td>Facilitate and support self-determination</td>
</tr>
<tr>
<td>Time and stress management techniques</td>
<td>Adapt existing services to meet identified needs</td>
</tr>
<tr>
<td>Crisis intervention strategies</td>
<td>Conduct oneself professionally</td>
</tr>
<tr>
<td>Procedures for collecting and interpreting data</td>
<td>Establish and maintain professional networks</td>
</tr>
<tr>
<td>Advocacy strategies and techniques</td>
<td>Accurately document service delivery</td>
</tr>
<tr>
<td>Self-advocacy strategies and techniques</td>
<td>Analyze needs and create linkages</td>
</tr>
<tr>
<td>Pertinent legislation</td>
<td>Navigate the service delivery system</td>
</tr>
<tr>
<td>Funding sources</td>
<td>Negotiate and resolve conflict</td>
</tr>
<tr>
<td>Problem-solving and conflict resolution strategies</td>
<td></td>
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Qualities. In addition to education, experience, knowledge and skills, resource facilitators bring a unique combination of personal qualities to their jobs. In recruiting, administrators look for individuals who are flexible, creative, culturally diverse, diplomatic, reliable, compassionate and empathetic. Administrators seek people who are passionate about helping others, who can remain calm in stressful situations, who will work as a team player and who will maintain a sense of humor.

Orientation & Training

As with any new employee, resource facilitators must be oriented to their specific job and to the agency’s policies and procedures such as those dealing with record keeping, confidentiality and safety. Summit participants estimate that new facilitators need at least five days of orientation prior to working with their first program participants. The time can be spent reading materials, watching training videos and meeting with relevant agencies, support group leaders and key referral sources. After orientation, administrators will want to foster a continuous learning environment within their agencies or programs. This can be done through staff meetings, reading circles, discussion groups and shadowing or mentoring initiatives.
Formalized training may be obtained at BIA’s National Symposium, NASHIA’s annual State of the States meeting or conferences and workshops sponsored by state BIAs, TBI advisory councils or other professional associations. In-service training programs may be available through mental health, mental retardation/developmental disabilities and other agencies as well as other public and private organizations. The Center for Disability Resources in South Carolina frequently trains resource facilitators and can tailor its curriculum to local, regional or national audiences. At a minimum, facilitators should receive training in the following areas:

- Basics of Brain Injury
- Family Support
- Cultural Sensitivity and Competence
- Person-centered Planning
- Neurobehavioral Issues
- Entitlements (Social Security, Temporary Aid to Needy Families)
- State Systems (Education, Housing, Justice, Transportation, Vocational Rehabilitation)
- Documentation/Record Keeping
- Long-term Personal Financial Planning

**Supervision**

Supervisors will want to meet privately with each facilitator at least twice a month by telephone or in person to discuss the status of assigned program participants and gauge the facilitator’s success in finding resources and creating partnerships. In these one-on-one meetings, supervisors will want to monitor the facilitator’s overall workload ensuring there is a reasonable balance between programmatic work and administrative activities as well as coach the facilitator through perplexing situations. In just about all of the existing programs, supervisors review written reports from individual facilitators on a monthly basis. In some programs, supervisors require a weekly itinerary from each facilitator. Part of the purpose for the weekly schedule relates to safety issues.

Staff meetings should be held monthly or more often as needed to discuss program-wide issues and encourage networking among facilitators. Staff meetings can be held in person or via telephone. When facilitators work from different locations, supervisors will want to provide three to six opportunities per year for facilitators to meet with each other on a face-to-face basis. By getting together frequently, supervisors will encourage exchange of information and ideas, build teamwork and ward off some of the isolation that comes from telecommuting.

**Budgeting**

The BIA estimates the 1999 cost of resource facilitation at approximately $1,200 per participant. This amount was established by applying state-by-state program description data to the following formula:

\[
\text{Facilitator Annual Salary} \times 50 \text{ percent}\frac{1}{\text{Facilitator to Participant Ratio}}
\]

1 The 50 percent override accounts for administrative and programmatic expenses plus a portion of the supervisor’s salary and the agency’s overall costs. Where the program description provided a salary range for facilitators, the mean salary was used. In programs that noted varying facilitator/participant ratios, the mean workload was used.
The formula yielded amounts ranging from a low of $381 to a high of $2,723 per participant. From this range, the mean, or national average of $1,212 per program participant in FY 1999, was derived. The formula was tested based on actual experience. In Alabama, the formula produced an estimate of $381 per person; the actual cost was $379 per person. (The actual per person cost in Alabama for FY 2000 has increased to $410). In Florida, the formula produced an estimate of $1,041 per person; the BIA of Florida budgeted $1,200 per person in FY 1999. (In FY 2001, BIA of Florida is anticipating a cost of $1,560 per person because clerical staff will be hired for each of its Family Support Centers.)

In constructing the annual program budget, administrators may want to include the following line items:

- **Salaries** – Among existing programs, annual salaries of resource facilitators range from a low of $18,500 to a high of $46,000. The mean facilitator salary is $33,945; median is $31,000; and mode is $27,000

- **Benefits** – Among existing programs, most include health, disability and life insurance. Some provide retirement benefits and dental/vision packages. Most programs range between 15 and 21 percent of salary for benefits calculation

- **Rent** – Office space can range from $150 to $300 per month, which equals $1,800 to $3,600 per facilitator annually. This generally includes utility costs

- **Training & Education** – Estimates range from $100 to $1,000 per facilitator per year for training and continuing education

- **Dues & Subscriptions** – A new program will probably want at least $3,000 per year per facilitator to purchase periodicals and other resource materials

- **Travel** – Facilitators tend to log many hours in their personal automobiles with estimates ranging from 300 to 500 miles per week. Facilitators are usually reimbursed at the State or Federal mileage rate. A typical budget amount of $6,500 per year per facilitator may be needed

- **Meals** – Facilitators generally make day trips and are not reimbursed for meal expenses. When an overnight is required, the per diem used by State government employees is usually applied to resource facilitator programs. This varies from $25 to $40 per day nationwide

- **Telephone** – These costs will not be less than $200 per month per facilitator and could be significantly more based on the geographic area served. Factors to consider include a basic line, a second line for Internet access and/or fax machine, cell phone service, long distance charges and toll free number expenses. Realistically, at least $2,400 per year per facilitator should be budgeted
Postage – Postage can range from $35 to $50 per month per facilitator. A safe budget figure is about $500 per year

Supplies – Facilitators sometimes spend $50 per month or more on office supplies for paper, notepads, pens, pencils, printer ink, files and other consumable materials

Equipment is a depreciating asset rather than an expense. The amount and quality of the equipment acquired will impact on the facilitator’s efficiency and effectiveness. Although it certainly would not be best practice, some facilitators have started work with little more than a desk and a phone. For planning purposes, however, administrators will want to consider the following minimum requirements: a desktop computer ($2,500), all-in-one printer, fax and copier ($500) and miscellaneous furnishings including desks, chairs, bookshelves, filing cabinets and telephones ($1,000).

Other program expenses, which are not normally calculated on a per facilitator basis, include those associated with marketing and outreach, such as printed program brochures, newsletters, annual reports, as well as advertisements and liability insurance.

Marketing & Outreach

Much of the awareness of brain injury and of the resource facilitation program will happen through word-of-mouth and the facilitators’ community building efforts. In some situations, however, program administrators and staff must reach out to persons who are underserved.

Resource facilitation programs encourage communities to help themselves by offering training and by hiring staff from the communities they serve. Resource facilitation programs can become more accessible to a specific culture by involving interpreters and providing information in multiple languages and formats. Because of cultural differences, some participants may not be inclined to access certain services. Instead they may prefer to work within familiar communities, such as their places of worship. Similarly, some people may have negative feelings toward public assistance. In working with people of culturally diverse backgrounds, it is best practice to develop resources in the community in which they live.

When targeting a specific community, place marketing materials in locations where community members are most likely to spend time. For example, using Health Resources and Services Administration TBI State Grant Program funds, BIA of New York State placed cards that described common symptoms and effects of brain injury instead of just the injury diagnosis on mass transit systems. The cards, written in Spanish and English, also listed an 800 number that utilized an interpreter relay service provided by AT&T to respond to initial inquiries. Members of culturally-diverse communities served as advisors throughout the project.

Whether the program is targeting a specific culture, geographic location or some other demographic, and even when the program is serving the general public, it is best practice to gain feedback through satisfaction surveys on a regular basis from program participants, service providers and community leaders.
Data Collection

Like it or not, data drives decision making. Most resource facilitation programs were established and funded in part based on the demonstrated need. Facts and figures, along with anecdotal information, helped make the argument for start up. Data on the number of persons served and the value of services received may help keep the program funded. Most resource facilitation programs have a computer database or other mechanism to track the demographics of active and inactive program participants as well as the number and type of services purchased or donated with assigned costs/value.

The Alabama Head Injury Foundation has a Microsoft Access® database that was specifically designed for its Resource Coordination program. The database tracks the number of hours worked by each facilitator in each of the following areas:

- General
- Behavioral
- Coma
- Accessibility
- Education
- Emotional Support/Listening
- Employment
- Equipment
- Financial
- Housing
- Legal
- Recreation
- Substance Abuse
- Pediatric
- Prevention/Safety
- Transportation
- Other

Additional data may be required or useful for funding and public policy purposes as well as supervision, program planning and program development. For example, administrators may want to know how many persons received an assessment but were not eligible for the program. Similarly, it may be useful to know what services or supports are needed but are not available and why. Summit participants recommend using the categories developed for the Health Resources and Services Administration TBI State Demonstration Grant Program needs and resources assessment survey to capture and analyze unmet needs. Summit participants urge that data tracking systems not be developed in isolation. Instead, resource facilitation administrators will want to work cooperatively with Health Resources and Services Administration grantees, state BIAs, injury prevention partners and others involved in the State’s public and private health system. For example, involve a National Institute on Disability Rehabilitation and Research (NIDRR) Model Systems of Care grantee to help determine what data should be tracked.
Risk Management

It is important to have a risk management component in every resource facilitation program. Risk management involves adopting and complying with program policies and procedures that assure facilitator and participant safety. State agency programs are generally indemnified by the State, but nonprofit organizations and private providers need insurance. There are multiple types of insurance with varying coverage offered by local and national corporations and sometimes available through a consortium. This guide does not attempt to address the specifics of insurance policies but rather supplies administrators with a general overview of the field. Some of the types of insurance to consider include:

General liability. This is absolutely necessary if the organization owns or rents a physical space where unintentional injuries could be sustained by employees, volunteers or visitors. Non-owned auto coverage is also needed to protect the organization when an employee is driving a personal car for business reasons and while renting cars. Auto coverage is usually included in a general liability policy, but not always. A general liability policy may also cover wrongful termination of employees. This is usually a rider to the policy and often comes with special conditions. Program administrators will want facilitators who work from home to explore their homeowners or renters policies if agency-owned equipment and materials are used or stored there. Individuals may purchase umbrella coverage to protect themselves from general liability.

Workers compensation insurance. Though controversial because of its costs, workers comp is considered a good buy and generally offers coverage against employee lawsuits. Administrators will also want to consider professional liability insurance, for themselves as individuals as part of a personal insurance policy or as provided for all staff members by the agency. If an individual policy is obtained, the agency can be named as an additional insured.

Fidelity coverage. Organizations responsible for large amounts of money should have fidelity coverage for possible criminal acts including theft, robbery, burglary, forgery and general problems involving computers.

Directors and Officers Insurance. D&O coverage is usually carried by nongovernmental organizations to provide some protection to volunteer board members. Be aware that D&O insurance does not cover fines and penalties imposed by law, libel and slander, personal profit, dishonesty, failure to procure or maintain insurance, bodily injury and property damage claims, pollution claims or suits by one board member against another. Unless the organization’s bylaws specify otherwise, it is now presumed in many locations that the organization will indemnify volunteers for actions taken as long as no actual malfeasance is involved. Indemnification is not worth much if the organization has neither assets nor insurance. Resource facilitators, program administrators and governing boards should concentrate on acting prudently to avoid unnecessary risk rather than spend time worrying about being sued.
Program Operation

Activity No. 1 – Assessment

The purpose of assessment is to identify the current status, needs and resources of the individual and his/her family or personal support providers in all life domains. In some programs, this begins with eligibility certification.

Service eligibility varies from state-to-state and is highly dependent on the funding source and the definition of brain injury (i.e., traumatic or acquired) used. If the services emanate from a Medicaid waiver, there may be geographic restrictions and the number of slots will be a mitigating factor. If support comes from a trust fund, eligibility criteria and/or service capitation may have been included in the authorizing legislation. The advisory council may have established eligibility rules such as enrollment in the State’s trauma registry or surveillance system and severity of injury.

It is important to understand that while some individuals may not be eligible for public services, they may still be eligible for participation in the resource facilitation program. In fact, many facilitation programs are open to all individuals who have sustained a brain injury and their family members and networks of personal support. Similarly, some programs that once operated on a “whatever it takes model” later found it was necessary to limit program participation of scope of services because of inadequate funding. In these situations, decisions were made based on current experience as well as data collected in the development stage.

Notwithstanding eligibility documentation, a resource facilitator’s first goal is to understand the individual and his/her abilities, needs, dreams and realities. Communication is essential to seeing the individual as a whole person. Accordingly, best practice is to conduct an in-person interview. The interview can be conducted in a public place, such as library or community center, or in the participant’s home. There is disagreement on the advisability of in-home interviews. Some facilitators argue that in-home meetings offer greater insight into the family dynamics and put participants at ease while others argue in-home visits compromise the individual’s privacy. In-home visits can pose a risk to employee safety. When a personal visit in the home or an alternative location isn’t possible, telephone interviews should be conducted with the individual, his/her family or support network, pertinent agencies and the professionals with whom the individual has worked.

In the interview, the resource facilitator will learn how the person has been affected by the injury, the challenges currently faced and strengths available to him/her. It is important to keep in mind that paperwork is the process, not the outcome. Some of the tools that may be helpful include:

- Functional Status Assessment
- Neuropsychological Exam
- Records (medical, educational, relevant agencies)
- Intake Form
- Resource Checklist
- Release Forms (information and/or liability)
- Proof of Residency
Samples for the forms listed above as well as other tools are available from BIA’s State Affairs Department and on NASHIA’s web site at www.nashia.org.

**Activity No. 2 – Planning**

The purpose of planning is to document the participant’s goals and information, service and support needs. The facilitator and program participant work together to construct a resource facilitation plan with input from others in the individual’s support network. The plan reflects the individual’s goals and dreams and clearly lists areas of responsibility and anticipated timelines. The plan is signed by all of the people involved in its preparation and implementation. Best practice is to identify and list within the planning tool all services needed. It is recognized that some services may not be available immediately or within the current menu of services for which the participant is eligible. Nevertheless, all needed services should be recorded so that the data may be used in future advocacy activities and to encourage facilitators to fill the need through natural supports.

**Activity No. 3 – Identification**

This activity involves locating the information, services and supports, including emotional supports, described in the plan. Best practice is to identify what is available, evaluate its effectiveness for the individual involved and then look beyond what already exists to identify new resources.

As part of the program’s development, advocates will come in contact with a number of individuals and organizations providing information or services to people with brain injuries and their families. All of these resources should be collected and catalogued to form the basis for a resource file or notebook used by facilitators. It is important for resource facilitators to keep in mind that one size rarely fits all. Sometimes facilitators will come across certain books, newsletter articles or brochures that are accurate, informative and culturally sensitive. Facilitators may find that these materials will work for many, but not all, of their program participants. Similarly, some participants will not be able to work with certain providers or organizations although those same providers have demonstrated competence in the past.

Facilitation is a very person-centered process in which program participants have maximum choice and control. When there seems to be only one alternative, or as is more often the case, when there seem to be no alternatives, facilitators must be creative in their thinking and tenacious in their pursuit of new resources. Only a limited number of resources are identified while sitting at a desk. Facilitators will want to go into the home communities of their program participants to discover specialized services as well as natural supports.

**Activity No. 4 – Negotiation**

The purpose of this activity is to facilitate access to services, supports and resources. This is where the “rubber meets the road.” The actual process varies depending on which facilitation method—refer, purchase, or provide—the program uses.

In the referral method, facilitators proactively link program participants to a variety of providers. This involves more than providing the participant with a name and phone number to call. For
example, the facilitator may call in advance on behalf of the participant or may sit with the participant as he/she initiates the call or completes an application form. Sometimes, the participant will not be eligible for a publicly funded service or the service will not exist in the participant’s community. In this situation, the facilitator may seek a donation. Examples of common donations include professional dental services, wheelchair repair and transportation. Members of the community may be willing and able to get involved if asked. Facilitators know that people with disabilities want to give back to their communities. Rather than a donation, some facilitators have developed barter arrangements where, for example, the individual with a brain injury receives a weekly ride to the grocery store in exchange for exercising the neighbor’s dog.

If the agency purchases services on behalf of program participants, specific procedures will be established for each service type. In general, the participant will have a list of providers to choose from and the facilitator may or may not offer input into the selection. Either the facilitator or program participant will contact the provider. Depending on the type of service, the provider may conduct an in-home visit to assess specific needs. The results of the assessment will be shared with both the facilitator and the participant. A purchase order, voucher, or some type of authorization form will be issued to the provider. The form will specify the amount, scope and duration of the authorized service and may also include the schedule of dates, times and location the service is to be provided. The agency will be invoiced as services are provided. A copy of the invoice may be sent to the participant to verify that services were actually received.

Throughout the process, the facilitator may negotiate with the program participant in selecting the provider, with the provider in determining scope and duration of services and within their own bureaucracy to expand the circle of providers, eligibility criteria, or service limits. Facilitators tend to think and act as advocates for the individual and yet some are actually State or county employees. Facilitators may have a short list of providers with whom they prefer to work. Conflicts of interest are almost inevitable. It is imperative that facilitators honor the preferences of program participants whenever possible.

The potential for conflict of interest is also prevalent when resource facilitators work for the same agency that provides the service. This third method for resource facilitation exists in relatively few State agency or State association facilitation programs. When it does occur, resource facilitators tend to provide more extensive documentation of the needed services. The documentation is often developed by a third party or verified by the funding source.

**Activity No. 5 – Monitoring**

The purpose of monitoring is to proactively assess the quality and appropriateness of the services, supports and resources used as well as the process, methods and relationship between the facilitator and program participants.

Best practice is to ensure ongoing communication among facilitators, individuals and families. This can be accomplished through regular meetings, telephone conversations or drop-in visits. Oversight by supervisors through review of service plans, monthly progress notes and ongoing communication between facilitators and administrators is also best practice. In one program, the supervisor makes bi-annual visits to the resource facilitator’s work location to review each participant’s file.
In addition to informal communication, it will be necessary to review records from service providers and formal evaluations from individuals, families and facilitators on the services, supports and resources used. An annual satisfaction survey of the resource facilitation program is considered best practice. On-going interviews with program participants to solicit their input on satisfaction is essential.

**Activity No. 6 – Reassessment**

Reassessment involves continual review and revision of each component of the process, including the partnership itself.

The frequency of reassessment is individualized based on the plan, the range of services required and the facilitation method used. At a minimum, quarterly reassessment is recommended for active participants; annual reassessment is sufficient for inactive participants. Although reassessment can take place by mail or telephone contact, a face-to-face meeting is recommended.

If the facilitation is inactive, it may be necessary to contact program participants in the evening or through providers. It is essential that participants not fall through the cracks. It is best practice not to close files unless the participant dies or moves or unless the facilitator is asked to do so by the participant.

**Activity No. 7 – Outreach**

The purpose of outreach is to find new services, supports, resources and program participants. Outreach is conducted on a continual basis with a balanced mix of resource finding and participant identification.

Summit participants suggest posters, circulars, community fairs, public presentations and media releases as good mechanisms for providing information about the program to the general public. Web sites, newsletters, postcards, personalized letters and individual appointments are useful vehicles for building program awareness among pediatricians, general practitioners and staff from related agencies, hospitals, rehabilitation facilities, civic and religious organizations as well as schools and day care facilities.

It is essential for resource facilitators to reach out to discharge planners, insurance workers and rehabilitation counselors so that they can inform individuals who are newly injured about the facilitation program. Facilitators are cautioned that although it may be desirable to get involved with the participant as soon as possible after the injury occurs, some facilitation programs begin once the individual returns home to allow discharge planners or hospital-based patient advocates to fulfill their responsibilities.

Support groups are also a good source for program participants. Resource facilitators often recommend speakers, work on joint projects, train new group leaders and provide logistical assistance such as notice, meeting room and snacks for support groups.

Part of the facilitator’s job is to actively seek new resources. Sometimes this will be done with a particular program participant in mind; other times, it will occur naturally as part of the community building efforts made by facilitators. Locating new resources is not difficult; it
merely involves asking questions. For example, individuals and family members may have relationships with neighbors, educators, medical professionals, community organizations and civic leaders that had not previously been considered. Some community-based programs designed for other populations, such as the Meals on Wheels program that is typically offered to older Americans, may also be available to support people with disabilities. Facilitators will find resources in unexpected places, but only if they are willing to look.

Activity No. 8 – Education and Training

The purpose of this activity is to teach people in the individual’s personal support system and the broader community about brain injury.

With the advent of managed care, shorter lengths of stay in hospitals and rehabilitation facilities and the increasing numbers of uninsured Americans, it is almost inevitable that individuals will be discharged to families who are not trained or equipped to deal with the aftereffects of the injury.

At the first interview, the resource facilitator should assess what the individual and family know regarding the aftereffects of brain injury. Some individuals and families will be more knowledgeable about the brain and/or the injury than the facilitator. Others may need help understanding the physical, cognitive and psychosocial changes taking place. Learning will be a continual process for the facilitator, the participant, his/her family and support network. Like all other aspects of resource facilitation, family education must be tailored to meet individual needs; an overly technical, jargon-filled presentation with too much information and too many reading materials will not be welcome. Accurate, straightforward, appropriately paced information is what’s needed.

With funding from the Health Resources and Services Administration TBI State Grant Program, the North Carolina Department of Health and Human Services established Project A.C.C.E.S.S. The project brochure describes information and education services available to participants and quotes the mother of an 11-year old pedestrian who was hit by a car, saying:

* The brain injury information that I received from Project A.C.C.E.S.S. was so helpful and described my son’s condition so well. Before I met the community transition coordinator, I had been looking at the health sciences library for information my family could understand and couldn’t find anything that wasn’t a medical textbook. (p. 6)

The BIA, HDI Publishers and L&A Publishing sell relatively inexpensive books, brochures and information materials appropriate for individuals and family members as well as professionals. Many state associations, support groups and resource facilitators maintain lending libraries. Facilitators will also want to develop some customized materials based on individual needs. Use librarians to find relevant information and conduct Internet searches through Medline and other databases. It is a good idea to track the most frequently used resources and ask web masters to place those materials on the agency’s web site.

Given the power of technology, facilitators will want to assess the participant’s computer skills and then demonstrate helpful Internet searching techniques and web sites. If the family does not have a computer, it may be possible to obtain one through the State’s vocational rehabilitation
program if the participant’s goal is employment related. Alternatively, families may receive a donated computer or may gain access through an Independent Living Center or public library. Support groups are a good venue for computer training as well as general information about brain injury. The BIA of Minnesota has developed a Brain Injury Basics curriculum for individuals and families. The curriculum is available from BIA’s State Affairs Department. For educating the broader community, BIA has developed a Brain Injury Awareness Presentation tool kit suitable for community audiences such as rotary clubs, Jaycees, parent teacher associations and others. MCHB, through a contract with NASHIA, created fact sheets for educators and other agency professionals. NASHIA, through a cooperative agreement with MCHB, created a PowerPoint® presentation for brain injury in-service training programs.

Activity No. 9 – Emotional Support

Emotional support involves proactively listening to participants’ needs. Sometimes having someone to talk to who understands what the individual and family is experiencing is more valuable than other therapeutic services or assistive devices. Supportive listening flows through and is a part of every other facilitation activity.

Facilitators often work with individuals and families who are in crisis. The facilitator’s resource file should include the contact information for social workers, counselors, psychotherapists and crisis hotlines. In situations involving abuse or neglect, it is essential that facilitators know their State’s laws pertaining to mandatory reporting to authorities and that the program has an established protocol to follow in emergency situations.

Activity No. 10 – Advocacy

The purpose of this activity is to help participants articulate to others how barriers impact their lives and to assert their rights on their own. Just like with emotional support, advocacy flows through each facilitation activity.

Throughout the partnership, resource facilitators can model advocacy techniques. Resource exploration telephone calls can be made in the presence of program participants, applications can be completed on a side-by-side basis and appeal letters can be drafted together. Rehabilitation therapists often suggest compensatory strategies for individuals who have been injured. These strategies take time to learn and must be continuously reinforced before they are incorporated into activities of daily living. Such will be the case with self-advocacy.

Several state BIAs have developed self-advocacy curricula. BIA of Colorado has SAIL – Self Advocacy for Independent Living and BIA of Washington has LIFT – Life Initiatives Family Training. Teaching Research at the University of Oregon developed an individual and family advocacy program as part of that State’s Health Resources and Services Administration TBI grant project.

Sometimes resource facilitators are called upon to participate in discharge planning meetings, individualized planning meetings for school and transportation, benefit review sessions and criminal justice inquiries. It is important to define the resource facilitator’s role in these situations and to expressly state what is and is not permitted in the program’s policies and procedures. For example, does the facilitator attend such meetings to provide support to program participants, neutral corroboration of needs and resources, or evidentiary testimony? If resource
facilitators engage in these sorts of advocacy activities, they must expressly state that they are not licensed medical practitioners, when that is the case, but rather advocates for the individual. Don Hood, a Summit participant from Oregon stated, “Facilitators must be able to advocate without being burdened by the system, without constraints, without conflict of interest.”

Results

In November 1998, the Brain & Spinal Cord Injury Program, Division of Vocational Rehabilitation, Florida Department of Labor & Employment Security contracted with Florida State University’s Center for Policy Studies in Education, Learning Ventures Cooperative to evaluate BIA of Florida’s Family Support Program. Using a systems-design approach, researcher Margaret Cashwell Boden analyzed the context, inputs, processes and results obtained during the three-year period of July 1996 to June 1999. Bowden’s report states,

- Indicators of success included participant attitudes and awareness of resources, the degree and type of integration or reintegration into the community, education (both skill development and formal education) and employment indices. Other agencies or organizations’ knowledge of TBI eligibility and needs, the quantity and quality of services they provide for persons with TBI and indicators of new practices attest to the Family Support Program’s success in the broader community. (p. 5)

Based on feedback from program participants, Summit attendees report that resource facilitation is valued because participants perceive that someone cares about them. Consequently, they have a better attitude toward themselves and their futures and a better relationship with the system of services and supports available to them. The intended results of resource facilitation include:

- Participants feel that they have help/aid to make informed choices
- Participants have information available to them that they did not have before entering the program
- Participants feel that they have options as a result of the program
- Brain injury is demystified for participants through education and information materials
- Participants have increased personal satisfaction, which is attributed in part to program participation
- The community demonstrates increased capacity to serve and support program participants
- The program operates efficiently and effectively based on the numbers of participants served, the costs and services and supports purchased or donated

Annual surveys can be used to assess participant’s satisfaction and program results. Administrators will want to keep in mind that no matter how carefully a survey is designed, some program participants will express dissatisfaction, not with the assigned facilitator, but with the services and supports to which they are referred.
Future Directions

The Resource Facilitation Summit was the first time program participants, facilitators, administrators, program developers and others across public and private agencies came together for the specific purpose of sharing knowledge and experience in brain injury\(^2\). Their work made this guide possible. It should not stop here.

A Resource Facilitation Summit should be held annually or bi-annually and facilitator training should be made available regionally or nationally. Additionally, facilitation programs should explore the promise of the Internet to develop new models that harness the power of technology in providing information and resources and for fostering self-advocacy among those who have experienced brain injury and their family members and support networks. Finally, agencies and advocates must embrace models from other fields. Although significant strides have been made in the process and methods used in brain injury resource facilitation, programs are still patterned after, and in some ways entrenched in, the case management model.

The Summit’s keynote speaker, Dennis Harkins, described a system in which resource facilitators are not agents of the system, but agents of program participants. Eligibility documentation is required of the provider, not the participant. Money is not in the system; it is in the hands of individuals who use it to purchase services and supports based on their functional abilities, not on categorical definitions or diagnostic labels. In this scenario, the individuals and the communities of people who surround them are the customers. As in other free-market enterprises, facilitators, administrators, program developers and service providers deliver that which is needed and wanted or the customer goes elsewhere.

This is not a utopian model; it is a true person-centered model that actually exists in the developmental disabilities field. Why does this model not exist in brain injury? When one strips away explanations of lack of awareness, lack of research, lack of understanding, the medical nature of the injury and the mystery surrounding the brain, it probably all boils down to advocacy. Program developers, administrators, supervisors, facilitators, participants, families, support networks and communities must be willing to fight every day for what is needed and what is right, remembering always that parity is a powerful word.

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\(^2\) In November 1997 in Birmingham, AL, 37 resource facilitators, program administrators and executive directors from ten state BIAs attended a Service Coordination Training Academy sponsored by the Comprehensive Head Injury Center-National, under a Department of Education, Rehabilitation Services Administration grant (Project No. H235L20009) with assistance of the BIA under a Department of Defense, Uniformed Services University of the Health Sciences’ Defense and Veteran’s Head Injury Program award (Grant No. MDA 905-92-Z-0001).
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