



# Brain Injury Information Network of Maine

2010-2011 Annual Report

## BIIN Partners

211 Maine

Acquired Brain Injury Advisory Council of Maine

Aging and Disability Resource Centers

Alpha One

Aroostook Medical Center

Brewer Rehabilitation and Living

Charlotte White Center

Creative Works Systems

Disability Rights Center

Goodwill Industries of Northern New England

Lakeview NeuroRehabilitation Center

Long-term Care Ombudsman

Iris Network

Maine Cite

Maine Center for Integrated Rehabilitation

Maine Concussion Management Initiative

Maine Medical Center Neuroscience Institute

Maine Military & Community Network

Maine Parent Federation

NAMI Maine

New England Rehabilitation Hospital

OACPDS/Maine DHHS

RiverRidge Center

Southern Maine Area Agency on Aging

Seniors Plus

Spectrum Generations

The mission of the Brain Injury information Network of Maine (BIIN) is to assist people living with brain injuries and those who support them. BIIN is Maine's clearinghouse and a provider of education, information, networking, advocacy and support. BIIN offers understanding and hope with knowledge, experience, expertise and advocacy.

Quotes throughout this report are from individuals, family members, BIIN Partners and other providers of social and brain injury services.

The focus of this report is on activities that have taken place during BIIN's first full year of operations April 1, 2010 –March 31, 2011

## Data

BIIN partners have been exploring different methods to collect useful data that will begin to quantify and capture the use of the Network.

This data is being used to evaluate the best way to distribute and assess the value of various programs and services of BIIN.

We also appreciate the need to respect current data collections systems that our partners are using and their staff capacity to take on other work. We developed and evaluated a variety of tools and each partner is choosing to adapt and modify their systems individually (one example is the Southern Maine Agency on Aging updated their I&R database to include a check off for brain injury at the same time they updated their entire system).

*"It's nice not be alone, I didn't know there were others."  
Jen*

## Data

There are limitations to this system and we are not collecting personal or detailed demographic information. At this time we are not able to keep clean data on the types of issues or the number of discreet contacts versus duplicated ones.

Not all Partners are collecting this information but this is providing an overall picture of the demand for BIIN.

The data summarized in the box to the right was collected from April 2010- March 31, 2011.

***“The workshop opened my eyes to the fact that brain injury maybe why my client is always coming back.” Ray***

<p>INFORMATION RESOURCES AND REFERRALS: 2,700+</p> <p>WEBSITE HITS: 22,304</p> <p>WORKSHOPS: 49 WORKSHOPS 822+ PARTICIPANTS</p> <p>OUTREACH: 53 EVENTS 2800+ PEOPLE</p> <p>MEDIA MARCH 2011: 13 TV SPOTS AND ARTICLES</p>
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## Resource Guide

The Brain Injury Information Network's Resource Guide is an ongoing activity.

The purpose is to provide free comprehensive and accurate listings of resources specific to brain injury in addition to other needed services or supports.

We have added many features over the past year: basic definitions and descriptions can be found in the front portion of *the Guide*, explanations and definitions are also located throughout to clarify either a service or what a particular expert provides.

### Formats

Online: MS word version with a searchable table of contents, it is accessible for persons who are blind, visually impaired or prefer voice access and use a screen reader.

Online: PDF version is also available. It is preferred when making a print copy.

Print: a magazine style layout is available in black and white- please contact us to request it. Toll free 888 893 -0123

The guides have been updated and new resources added 5 times throughout this year.

## Website [www.biin.org](http://www.biin.org)

The Website was created using an available template from “Go Daddy” web hosting. We have revised it many times throughout the year. It is a technical challenge and difficult to keep updated as often as we had hoped for. We do not have adequate expertise in this area, but we are hoping to find some volunteer expertise.

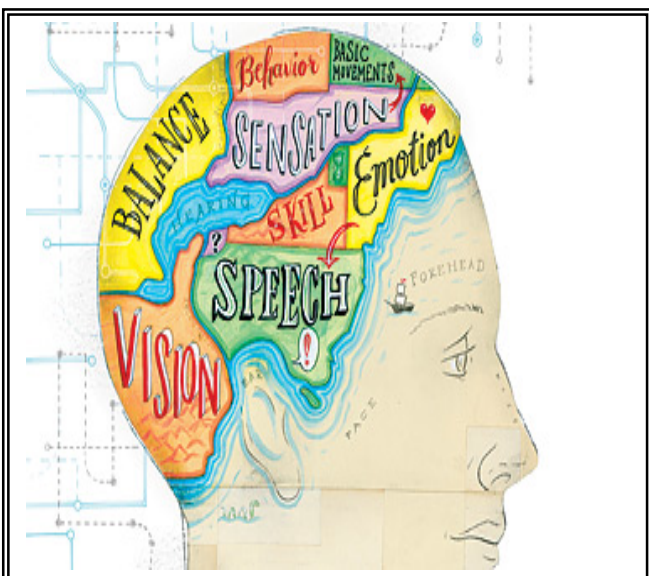
We must be doing something right with an average of 100 hits per day since October 2010.

## Workshops

The BIIN office presented 49 workshops over the past year. Each workshop was customized for the audience’s expertise and interests. The workshops were also modified to fit a wide range of timeframes from 20 minutes to 4 hours. Most workshops are tailored versions of Brain Injury 101 with research to address additional issues for each group .

Examples of workshops presented:

- ◆ Homeless service providers
- ◆ Staff training for residential programs
- ◆ Parent to parent programs
- ◆ Frontline staff at domestic violence programs
- ◆ Prevention
- ◆ Mental health providers
- ◆ Long term care
- ◆ **Brain Injury Information Network Partners Cross Trainings**



*“I didn’t like that the information about domestic violence really challenged my thinking. It was clear that the goal was to provide the information and than work together to solve the problem. This is hard.”*

*Bill*

*Outreach and creating new opportunities*



- Recruiting new BIIN Partners
- o Iris Network
  - o Long-term care Ombudsman
  - o Maine Concussion Management Initiative

- From Facebook- Conferences- Community Events BIIN was there.
- This is a brief list
- ◆ Managing Arrangements for Conferences
  - ◆ Convening new stakeholders
  - ◆ Maine Neuropsychologists meetings
  - ◆ Bangor area support group startup
  - ◆ Community Events, fairs and sporting events
  - ◆ Concussion workshops and events
  - ◆ Support Group meetings
  - ◆ Exhibiting at conferences
  - ◆ Maine Military and Community Events
  - ◆ Award presented to Lewis and Clara Lamont for their *Inspiring Advocacy*
  - ◆ Workshops

We established a Face book page in April 2010 with the goal of establishing an active option for the exchange of information and support yet we still seem to be on learning curve. We recognize the importance of social networks the use of technology and hope to improve participation on Facebook and other social networks.

BIIN has been able to post the Maine Faces Brain Injury Video (created by the Aroostook advocacy group) on You Tube with links on our website. We also made and distributed copies of the DVD.

Video from last year's forum on the "Implications of Brain Injury and Homelessness " were also posted to You Tube.

March 2011 Brain Injury Awareness Month Activities resulted in at least 13 television interviews throughout Maine on multiple Networks. Interviewees included members of BIIN, the Acquired Brain Injury Advisory Council, support group members and individuals with brain injuries, family members and providers.



You Tube



[www.facebook.com/BIINME](http://www.facebook.com/BIINME)

## Advocacy

BIIN believes it is important to provide public policy information to Partners and other interested persons. We are non-partisan and provide education, we do not lobby.

On our website we had provided information regarding the Affordable Care Act with highlights on the portions that may impact brain injury.

The Acquired Brain Injury Advisory Council of Maine (ABIAC) priorities have a special page on the website and BIIN works with Council to support their work.



We encourage activities from community members to voice their support or opposition to legislation, in writing or in person. There are diverse issues related to brain injury such as concussion, domestic violence, veterans etc. and a need to increase understanding that unidentified brain injuries also create a significant societal impact.

BIIN is able to receive input from a variety of stakeholders regarding access to short term and long term medically necessary services and supports that are needed for recovery. BIIN participates with other stakeholders in the public policy process to ensure issues related to brain injury are addressed.

Awareness and advocacy efforts to address domestic violence, children, military, sports and law enforcement help to make the connections to improve services and gain allies.

Brain Injury has an impact on families, schools, employers and the health and well-being of Maine citizens and Maine Communities.

## Financial Status

Our first years' funding was provided from a one time only HRSA grant through DHHS and from the DRC. April 1, 2010 - March 31, 2011.

The ground work had been laid throughout 2009 by bringing stakeholders together to discuss the need and a model resulting in the creation of Brain injury Information Network with Partners signing an MOU (memorandum of understanding). Partners agreed to establish basic competencies in order to improve the provision of accurate information and positive interactions for persons making inquiries to member organizations.

The partners also agreed to cross training to ensure better understanding of resources and expertise throughout the Network and Maine.

There was no financial commitment to join since many key groups are struggling with their own funding issues.

The first 6 months were used to implement and test our concepts to provide relevant services to collect data and to engage stakeholders. The response has been dramatic. The demand continues and grows. Brain Injury is in the news almost every day. But the other everyday news item is about our struggling economy.

The organizational support from hospitals, providers and other key stakeholder is limited or not available at all. As a new organization it will take time to build relationships that will yield the level of support needed to secure operations on an ongoing basis.

## Current Status

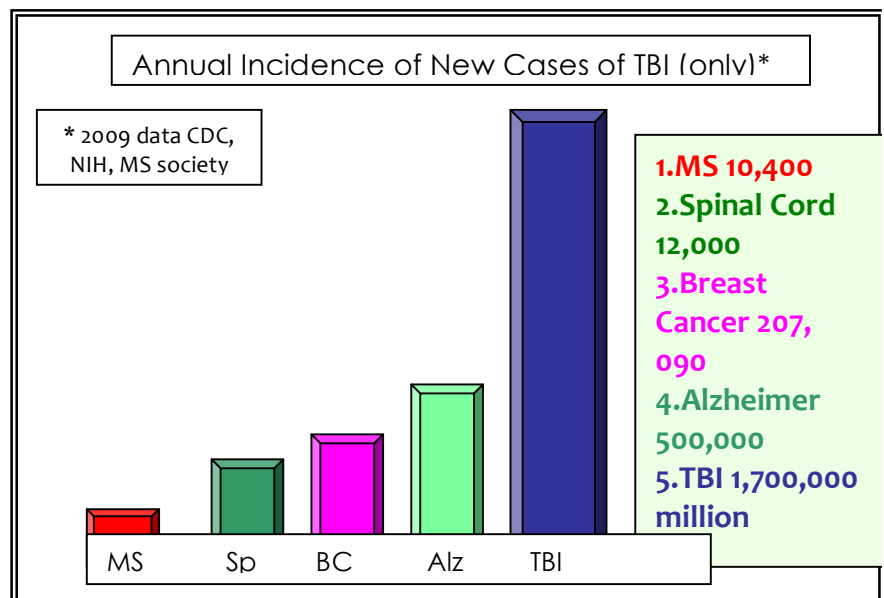
As of spring 2011 we have enough funding through August this year.

The Disability Rights Center is acting as our fiscal sponsor under their 501 (c) 3. They are also generously providing office space, phone, website other associated supports and financial management. This has been an essential and substantial support that has enabled BIIN to get off the ground. They are willing to continue to provide this support as we transition to an independent non-profit.

We are working with an attorney from SCORE and have begun the initial phases of the 501 (c) 3 process to apply for IRS approval and set up assurances for management controls. The current BIIN Partners are acting as our Advisory Committee as we work on a strategic plan and select a Board of Directors. This transition planning has taken into account the expertise, and available energy, resources and opportunities to ensure we are engaging our current Network and encouraging new Partners.

Financing the organization will require recruiting key organizations and individuals with the resources and connections to bring the necessary funding to not just sustain operations but continue to build capacity for the future. Fundraising approaches have changed radically in the past few years. Starting a new organization is always challenging. The topic of brain injury seems to have an added stigma to work through in order market our message. This environment necessitates a great deal of creativity and energy to bring key people and adequate funding to organization in a timeframe that will allow us to meet demands and fulfill our purpose.

The past year we have taken a multi-pronged approach in order to raise funds in a new and rapidly changing environment. Utilizing research and volunteer experts a variety of proposals were created to aid with soliciting support and contributions from organizations, corporations, foundations and individual donors.



## Sustainability Plan

The Disability Rights Center (DRC) in the past year and will continue to provide as an in-kind donation overhead expenses + financial management + administrative support totaling \$19,000.

We would like to acknowledge Contributions from many of our partner organizations: Lakeview NeuroRehab, Goodwill, Creative Work Systems, Maine Medical Center Neuroscience Institute and RiverRidge Center.

BIIN also has a grant of \$12,000 from HRSA through the Maine OACPDS DHHS, Brain injury services through June 2011.

To view a complete list of donors please check our website.

Many corporations and organizations have been approached and relationships are being cultivated with hope that with new budgets being developed for summer fiscal cycles allocations will be committed and delivered in July and August.

Revised website sponsorship programs have been created and branded with new logo. We are hoping that lowering our website and other sponsorship fees will encourage more participation.

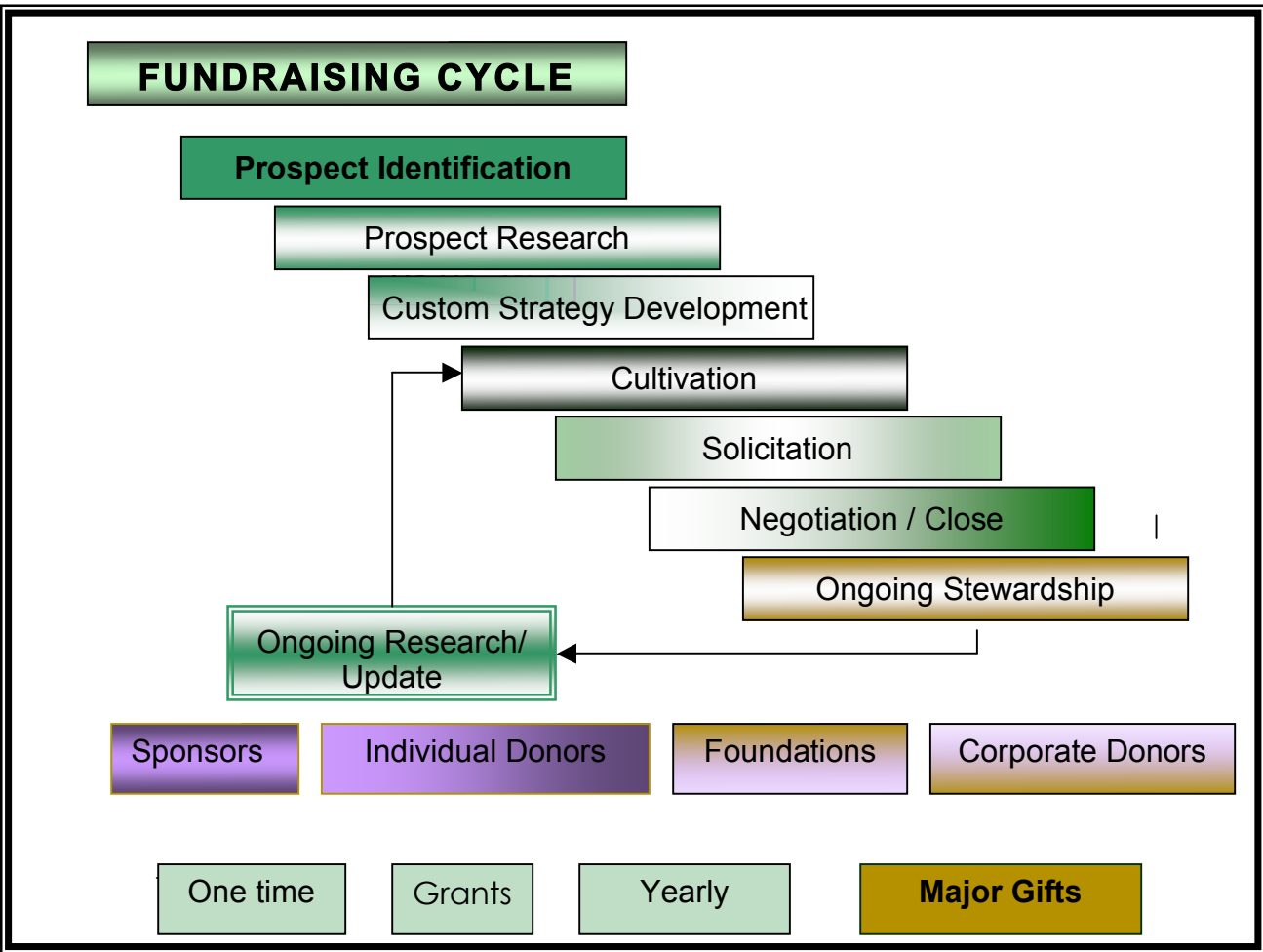
BIIN partners are searching for regional fundraising opportunities to raise awareness and dollars. The BIIN office will provide materials and support while local Partners research and schedule events.

We have implemented several fundraising activities that are ongoing and others that are being implemented in phases:

- ◆ Partner Requests
- ◆ Medical services and associations
- ◆ Legal services
- ◆ Website Sponsors- Program Sponsors
- ◆ Maine Foundations
- ◆ Maine Corporations and businesses
- ◆ Media
- ◆ BIIN Pins small donors
- ◆ Requests from related non profits
- ◆ Resource guide services and providers

Proposed Budget 2011-2012 Current 5/11	
Total = \$105,000.00	
<u>Expenses:</u>	
Operating Expenses	\$20,000
Salary +	\$55,000
Programs & Services	\$30,000
<u>Income:</u>	
Operating Expenses In kind DRC	\$20,000
Grants	\$12,000
Sponsors	\$11,000
Contributions	\$ 7,000
Balance required	\$55,000

***“There will be fewer resources (there weren’t many to start with) yet we have a greater awareness resulting in greater demand, at least BIIN is an organization that understands and is creative with bringing resources together.”***  
***Val***



## Goals

*Short term: Secure funding*

Progress is being made in the application process for 501(c)3 status which we hope will provide assurances for donors. We are currently still fortunate to be able to raise tax-deductible donations under the DRC non-profit status.

Branding over the past year we realized there is some confusion with regards to public perception of who the Brain Injury Information Network is. People who were familiar with the Brain Injury Association of Maine either were unaware of their closing or believe that BIIN is the BIA with another name instead of a distinct organization.



There also is some confusion regarding the Acquired Brain Injury Advisory Council of Maine (ABIAC) though we work with and support their efforts, we are an independent non-profit that is able to address a broader range of issues. Their mandate is to advise Maine DHHS on brain injury issues within their jurisdiction.

A new logo and mission are being adapted to begin to differentiate BIIN as a unique and independent organization.

BIIN is packaging our Services and Programs to improve recognition as BIIN products and encourage sponsorship opportunities.

Website improvements are underway for increased ease of use and expanded content. Incorporate new logo and branding.

## Long term



- ◆ BIIN must build a sustainable donor base to ensure ongoing and adequate funding to build a stable foundation for a relevant and meaningful organization that can provide the services and supports that address our mission. With a meaningful donor base, applications for grants to support special projects can be added to the funding mix.
- ◆ BIIN will expand our outreach to engage industry and business as natural partners who will be able to recognize and support their staff and family members facing brain injury and enhance their organizations prevention efforts at work and home.
- ◆ Increase BIIN 's access and use of needed supports and people to meet demands.
- ◆ Ensure excellent governance through a Board of Directors, which will establish necessary fiduciary functions to address risks and create a stable organization.
- ◆ Build relevance and responsiveness into the organization to address the rapid increase of brain injury understanding and the fluid economic situation.
- ◆ Continue to expand Network partners and our capacity to meet demand and stay relevant.
- ◆ Access expertise to take advantage of technology to expand and continue outreach and awareness efforts.
- ◆ Provide quality educational programs to expand the number of experts in medicine, social services, prevention, mental health and with in our communities.

***I feel more balanced after reading all the information you sent. I have been using your tips, created some of my own. My kitchen table was clear for a week. FB***

*We want to thank all of you for your support and encouragement.*

*With special acknowledgements to; Judy Underwood, Gary Cooper, Stacie Linkel, Gary Wolcott, Kim Moody, Leeann Mosley, Peter Rice & Aroostook Advocacy Group.*

## Conclusions

**We face a very real critical deadline in the next few months deciding on the viability of maintaining the operations of the Brain Injury Information Network. We continue to make progress and believe that within the next 2 years the Network will have established a broad sustainable base of funding and will be a recognized as “ the brain injury” resource. We need time. We must have money now to literally buy the time.**

If BIIN fails there will be NO organization in Maine to focus on the issues of Brain Injury it would be unlikely for another organization to start up with a comprehensive mission in the current environment.

The continuum of steps necessary for building a successful new organization is to face the need to rapidly adapt, adjust and learn with the ebb and flow of information, media and the economy. It has required being circumspect yet taking determined actions to chart a course for success in a tumultuous year.

It is always difficult for a new organization or small business to become established. We have been able to collect data and feedback that validate the demand for the services and supports that BIIN provides. We have begun to successfully to bring together the medical community, social services, and mental health to recognize the brain injury within their specialties and the need for greater collaboration for better outcomes.

We are concerned that as our service members return home from the wars and they once again become full time Mainer’s there will not be access to the services and supports they need here at home for them and their families. BIIN will be an important resource and advocate.

Children and the elderly and any of us in between maybe facing the medical, financial and social problems that often are a result of brain injury. BIIN has the expertise .

There is a way to get help and support that can help rebuild a better life by avoiding unnecessary mistakes, with better diagnosis, treatment and understanding.

***“We cannot waste knowledge or lives or money. BIIN can help use what we know- to help, we maybe a small organization but we connect to a lot of information and people.” Marcia***

If you would like additional Information please call Marcia Cooper at 207 621 1410 or email [mcooper@biin.org](mailto:mcooper@biin.org)

