



Brain Injury in Iowa

February 23, 2011



2011

Brain Injury in Iowa

- More than 95,000 Iowans live with long-term disability from brain injury.
- More than 600 Iowans with brain injury sit on a waiting list for Medicaid Home and Community Based services.
 - Being forced onto a waiting list for services often dramatically reduces the quality of long-term outcomes for Iowans with brain injury.
 - The Iowa Department of Public Health's Brain Injury Services Program improves outcomes for Iowans with brain injury through neuro-resource facilitation and training services.
- The Neuro-Resource Facilitation Program of the Brain Injury Association of Iowa serves over 1600 Iowan's with brain injury and family members connecting them with services and supports.
- Falls and motor vehicle crashes are the leading cause of brain injury in Iowa.
- More than 2500 Iowans per year sustain a traumatic brain injury severe enough to require hospitalization. These numbers do not include the thousands of Iowans who experience brain injury but are not hospitalized.
- The impact of concussion in our youth athletes is now known to be a very serious issue.
 - Concussion **is** a mild traumatic brain injury.
 - As many as 3.8 million sports and recreation related concussions occur in the United States each year.



2011 Advocacy Day

Service Issue #1 – Eliminate the Brain Injury Waiver Waiting List

Appropriations needed to eliminate wait for critical services.

Problem / Background:

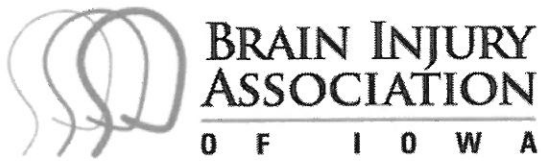
- The incidence and prevalence of brain injury in Iowa is astonishing, with an estimated 95,000 Iowans living with long-term disability from brain injury and an additional 400 to 600 experiencing long-term disability each year.
- Currently more than 640 Iowans (January, 2011) are on the HCBS BI Waiver waiting list.
- Iowans with brain injury must wait over 18 months for vital services that prevent costly institutionalization.
- Not only is this delay a cost to taxpayers, but also it is devastating to the continuum of care so necessary for steady progress in rehabilitation following a brain injury.
- Delays in service access often cause or worsen secondary conditions related to the injury, like mental health issues, substance use and financial devastation, not to mention unnecessary and costly institutionalization.

Remedy:

- The Brain Injury Association of Iowa requests the Iowa Legislature appropriate funds to the Iowa Department of Human Services to specifically eliminate the waiting list for Medicaid Brain Injury Waiver Program.
- The cost of this has been estimated to be approximately \$1.5 million.

Rationale:

- An 18 month or more wait for needed community based services is both unreasonable and medically damaging to a healing brain.
- An 18 month or more wait is in violation of the U.S. Supreme Court "Olmstead" decision which ruled that states may have a reasonable waiting period for services.
- An 18 month or more wait puts the state at risk of litigation to require it to comply with this Supreme Court ruling.



2011 Advocacy Day

Service Issue #2 – Funding for the Brain Injury Services Program

Appropriations needed to support Iowa's ONLY safety net for persons with brain injury and their families

Problem / Background:

- The incidence and prevalence of brain injury in Iowa is astonishing, with an estimated 95,000 Iowans living with long-term disability from brain injury.
- Brain Injury is "mentioned" in only 4 of 99 County MH/DD plans .
- There is an increasing pace of research and practice on how to live with brain injury. There is a concurrent need for certified training for brain injury service providers.
- Lack of information about brain injury and local service options often results in severe secondary conditions related to the injury, such as mental health issues, substance use and financial devastation, not to mention unnecessary and costly institutionalization.
- Funding for the evidence-based service of Neuro-Resource Facilitation **was recently cut** by \$32,770 for **current fiscal year**.

Remedies:

- BIA-Iowa recommends that the Chronic Conditions appropriation to the Iowa Department of Public Health for the Brain Injury Services Program be restored in **current fiscal year** by \$32,770
- BIA-Iowa recommends that the Chronic Conditions appropriation to the Iowa Department of Public Health for the Brain Injury Services Program be increased in **coming fiscal year** to \$1 million to provide the a minimum level of Neuro-Resource Facilitation and training.

Rationale:

- *Neuro-Resource Facilitation* is a data driven, evidence based, best practice program that has shown increased access to services and supports and a positive economic impact on recipients. It is a service that was deployed by the legislature in response to a statewide needs assessment and the subsequent Iowa State Plan for Brain Injury (developed in the IDPH).
- *Neuro-Resource Facilitation* is the only service of its kind available to all Iowans with brain injury. It works to prevent individuals from secondary effects of brain injury and to prevent families from becoming impoverished as a result of inadequate understanding of the consequence of brain injury.
- *Neuro-Resource Facilitation* most critically links Iowans with brain injury to local health care services and local supports. It is a vital component of the trauma system, which is used to connect to and support Iowans who often have significant health access challenges after brain injury.

Testimony on Need for Brain Injury Program Funding
Joint Health and Human Services Sub-Committee on Appropriations

Kay E. Graber

February 23, 2011

Good morning. My name is Kay Graber. I'm Vice President of the Brain Injury Association of Iowa Board, a former chair of the Advisory Council on Brain Injuries, and on the board of the local chapter in the Cedar Rapids-Iowa City area. I'm also a 30-year advocate for brain injury services and funding. I was trying to think last night who was in front of me the first time I spoke at a legislative hearing, and the only person I could remember was Del Stromer. The only reason I bring this up is the irony that I'm here again and I'm still asking for funding.

I came into this life as a family member, and even though I have held a number of decision-making offices, I try to keep as grounded as I can through personal relationships and support group activities for those persons that hearings such as this are all about...the survivors themselves. In the Cedar Rapids area, we have nearly 75 survivors that are in our contact base. In the Iowa City area, there are nearly 70 survivors within our touch.

One of the things that is so evident in interacting with survivors is the dramatic difference in outcomes between those injured 20-30 years ago and those injured within the last 5-10 years. Most of that difference has come from tremendous research and successes in terms of what we call "acute care" and rehabilitation. You all have been riveted as I was during Bob Woodward's journey back to health from his IUD injuries in Iraq or Congresswoman Gifford's rehabilitation journey that is just beginning. When you hear such things as freezing bodies in intensive care, inducing comas so the brain can heal gently, and removing skulls so brains have room to swell, you may not even realize such treatments weren't thought of 20 years ago. People have learned to sit, crawl, stand and walk again...to swallow and chew and speak. As you heard from Dr. Anderson, the whole field of cognitive rehabilitation, or what educators call "higher order thinking skills", has exploded. We can now retrain minds to make good choices, to laugh appropriately, to learn to be tactful and not blurt out first thoughts, and to use coping strategies and assistive devices to aid memory.

What a shame, then...what a terrible shame that persons who have benefitted from such remarkable treatment and near-miraculous recoveries come home, ready for community-based services to help them get their lives back together, and they are put on a waiting list for 12-18 months.

And what a great waste to the community to lose that potential employee or skilled worker. What a challenge to the family to be faced with a son or daughter, husband or wife, who has become a new person that they don't know, a person who is depressed and sometimes angry and belligerent or even suicidal. And there are those survivors who have no family close to them, who are moving from apartment to apartment because they can't pay their rent, they have few friends, and they don't know how to access the poverty system, let alone the human services system.

(over)

May I leave you with these thoughts.

1. Brain injury is an event-based disability. By that I mean that most injuries are the result of some specific exterior force that has intruded on the brain....through motor vehicle accidents, sports or diving accidents, assaults, falls, or even loss of oxygen or use of drugs
2. Because of that, we have many more adults than children who are newly injured. For example, we have only two persons in our support groups who sustained their injuries as children. The rest were all injured as adults.
3. Those newly injured adults have had a previous life. They no longer have that same life, and many of them have to relearn things they learned as children; yet, they don't have the benefit of 21 years of special education in which to do that. They're plunged right back into adulthood, and they still need a continuum of therapies and supportive training to return to any kind of normalcy in their lives. The only community-based services available to them come through the Home and Community based BI Waiver. That waiver has as of this month 672 people on the waiting list. At the rate they are going, the next person to get on the waiver will have applied in August of 2009. This is March of 2011.
4. Survivors and their families are also plunged suddenly into negotiating first a medical system and then a human services system with very little transition inbetween. To even know what all the terms and acronyms mean is a challenge. That's why the one brain injury program we do have for everyone, the NeuroResource Facilitator Program, is so vital and needed. And that too is facing funding problems. Geoff is going to talk a bit more about that.

Thank you for giving me the opportunity to speak to you. I do appreciate the challenges you are facing and the pressures that are on you to reduce spending and to examine every program. I can only say that even though I sympathize with you, I cannot be silent because even if the money isn't there, the survivors and families I represent will not be going away.

2011

MONTHLY SLOT & WAITING LIST DATA**

	1-11	2-11	3-11	4-11	5-11	6-11	7-11	8-11	9-11	10-11	11-11	12-11
ILL & HANDICAPPED												
I&H Cap that has been approved by CMS	3309	3309	3309	3309	3309	3309	3309	3309	3309	3309	3309	3309
IH waiver funding cap	3163	3163	3163	3163	3163	3163	3163	3163	3163	3163	3163	3163
I&H Consumers Currently Approved on ISIS	2405	2390										
Slots Pending Approval	464	435										
Slots Temporarily Closed	134	145										
I&H Waiting List	1707	1684										
Application date of next Consumer to receive a slot	9/21/09	10/23/09										
PHYSICAL DISABILITY												
PD Cap that has been approved by CMS	1644	1444	1444	1444	1444	1444	1444	1444	1644	1644	1644	1644
PD waiver funding cap	1292	1292	1292	1292	1292	1292	1292	1292	1292	1292	1292	1292
Consumers currently Approved on ISIS	839	838										
Slots Pending Approval Date	123	110										
Slots Temporarily Closed	55	63										
PD Waiting List	1559	1588										
Application date of next Consumer to receive a slot	8/6/09	8/26/09										
TOTAL Waiver Consumers Approved through ISIS	25309	25182										
TOTAL Consumers on all waiver waiting lists	4722	4829										

	1-11	2-11	3-11	4-11	5-11	6-11	7-11	8-11	9-11	10-11	11-11	12-11
Habilitation Services												
Consumers currently Approved on ISIS	3592	3651										
Remedial Services												
Consumers currently Approved on ISIS	11511	11486										

**2011
MONTHLY SLOT & WAITING LIST DATA****

	1-11	2-11	3-11	4-11	5-11	6-11	7-11	8-11	9-11	10-11	11-11	12-11
INTELLECTUAL DISABILITY												
ID Children Slots Cap that has been approved by CMS	2848	2848	2848	2848	2848	2848	2848	2848	2848	2848	2848	2848
ID Child waiver funding cap	2851	2851	2851	2851	2851	2851	2851	2851	2851	2851	2851	2851
ID Children Currently Approved	2497	2482										
ID Children Slots Pending Approval	343	353										
ID Children Temporarily Closed	22	26										
ID Children Waiting List	23	16										
Application date of next Consumer to receive a slot	11/22/10	1/19/11										
Res-Based SCL Slots Cap that has been approved by CMS	72	72	72	72	72	72	72	72	72	72	72	72
Res-Based SCL Consumers Served	30	31										
Currently												
Res-Based SCL Consumers Pending Approval	5	7										
Res-Based SCL Consumers Temporarily Closed	3	3										
Res-Based SCL Slots waiting list	0	0										
ID Adult State Case Slots Cap that has been approved by CMS	343	343	343	343	343	343	343	343	343	343	343	343
ID Adult State Case waiver funding cap	472	472	472	472	472	572	572	572	572	572	572	572
ID Adult State Cases Served Currently	534	529										
ID Adult State Case Slots Pending Approval	28	28										
ID Adult State Case Slots Temporarily Closed	4	8										
ID Adult State Case Waiting List	103	120										
Application date of next Consumer to receive a slot	6/24/09	6/24/09										
ID M/P/ICF/MR Slots Cap	100	100	100	100	100	100	100	100	100	100	100	100
MR ICF/MR Waiting List	0	0	0	0	0	0	0	0	0	0	0	0
Total-Children & Adults Approved on ISIS	10992	11006										

2011

MONTHLY SLOT & WAITING LIST DATA**

Definitions	
Waiver Cap that has been approved by CMS	The amount of slots allowed by CMS
Waiver funding cap	The amount of slots allowed by how much funding we have for the slots.
Consumers currently Approved on ISIS	The number of slots Approved (being utilized) in ISIS
Slots Pending Approval Date	The number of slots that have been given to a consumer but have not yet been approved in ISIS.
Slots Temporarily Closed	The number of slots that have been given but not reassigned due to holding the slot for the consumer for a certain amount of time
Waiver Waiting List	The number of consumers that are waiting for a slot
Application date of next Consumer to receive a slot	The oldest application date on the waiting list. (the next consumer to receive a slot will have the oldest application date per each waiver)

**NUMBERS LISTED REPRESENT PRIOR MONTH'S ELIGIBILITY STATS

	1-11	2-11	3-11	4-11	5-11	6-11	7-11	8-11	9-11	10-11	11-11	12-11
AIDS/HIV												
AIDS/HIV Cap that has been approved by CMS	165	165	165	165	165	165	165	165	165	165	165	165
AIDS/HIV waiver funding cap	56	56	56	56	56	56	56	56	56	56	56	56
Consumers currently Approved on ISIS	41	41										
Slots Pending Approval Date	13	13										
Slots Temporarily Closed	2	2										
AIDS/HIV Waiting List	7	6										
Application date of next Consumer to receive a slot	10/15/10	10/29/10										
BRAIN INJURY												
BI Cap that has been approved by CMS	1261	1261	1261	1261	1261	1261	1261	1261	1261	1261	1261	1261
BI waiver funding cap	1168	1168	1168	1168	1168	1168	1168	1168	1168	1168	1168	1168
Consumers Currently Approved on ISIS	1095	1091										
Slots Pending Approval Date	160	160										
Slots Temporarily Closed	36	29										
BI Waiting List	644	672										
BI Applicants since 1996	4445	4484										
Application date of next Consumer to receive a slot	8/14/09	8/28/09										

2011
MONTHLY SLOT & WAITING LIST DATA**

	1-11	2-11	3-11	4-11	5-11	6-11	7-11	8-11	9-11	10-11	11-11	12-11
BI Slots for ICF/MR, NF, OOS												
BI Slots Cap for ICF/MR, NF, OOS	15	15	15	15	15	15	15	15	15	15	15	15
BI OOS Consumers Currently Approved	0	1										
Slots Pending Approval Date	3	4										
Slots Temporarily Closed	1	1										
Slots Closed	3	3										
BI/CF/MR, NF, OOS Waiting List	0	0										
CMH WAIVER												
CMH Funding slots cap	1117	1117	1117	1117	1117	1117	1117	1117	1117	1117	1117	1117
CMH Consumers Currently Approved on ISIS	683	699										
Slots Pending Approval	140	86										
Slots Temporarily Closed	48	39										
CMH Waiting List	679	743										
Application date of next Consumer to receive a slot	2/12/10	2/12/10										
CMH Reserved Capacity Slots												
CMH Reserved Capacity Slots Cap	10	10	10	10	10	10	10	10	10	10	10	10
CMH Reserved Capacity Slots Currently Approved on ISIS	8	8										
CMH Reserved Capacity Slots Pending Approval Date	1	0										
CMH Reserved Capacity Slots Temporarily Closed	0	0										
CMH Reserved Capacity Slots Closed	1	2										
ELDERLY												
Elderly funding Cap	12052	12052	12052	12052	12052	12052	12052	12052	12052	12052	12052	12052
Consumers currently approved on ISIS	9254	9117										