




Self-Advocacy: Being Your Own Best Advocate

Annie Randolph
Neuro Resource Facilitator


+ Objectives

- Review and recognize the prevalence of brain injury, along with changes and challenges after brain injury
- Neuro Resource Facilitation – what is it and how do you connect?
- How to be your own best advocate, tips and tricks to be successful



+ Prevalence

	United States	Iowa
Experience Brain Injury	1.4 million	2,500
Live With Long Term Disabilities	5.3 million	95,000



+ Definitions of Brain Injury




Acquired Brain Injury
Traumatic Brain Injury

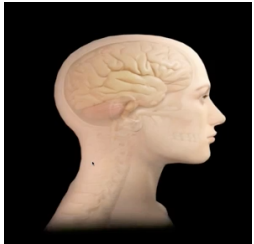


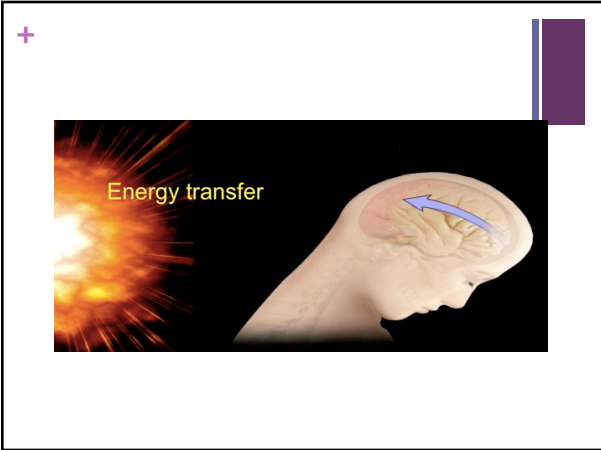
+ Definitions of Brain Injury

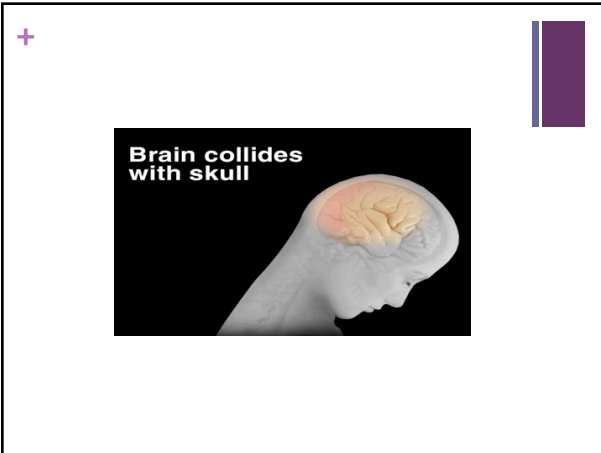
- **Brain Injury: any injury that results in the disruption or change in function of the brain**
- **Acquired Brain Injury (ABI):** An injury to the brain that occurred *after* birth. An ABI may be caused by TBI, stroke, near suffocation, infections in the brain, etc. (*Brain Injury Alliance of America, 1997*) The term does not apply to the brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma
- **Traumatic Brain Injury (TBI):** An injury to the brain caused by an external trauma to the head or violent movement of the head, such as from a fall, car crash or being shaken. TBI may or may not be combined with the loss of consciousness, an open wound or skull fracture (*Thurman et al., 1994*)

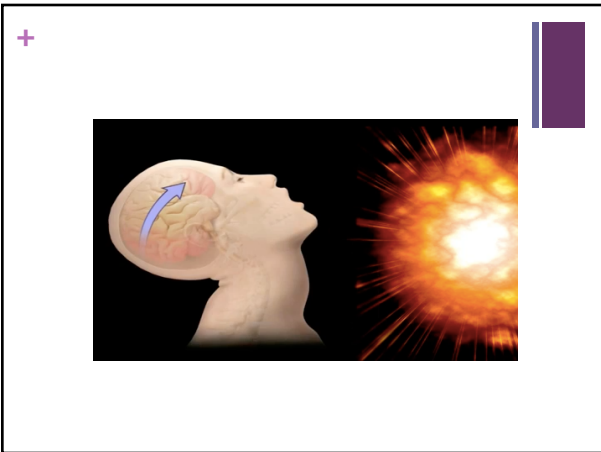


+ What happens during a concussion or traumatic brain injury?










+





Brain is violently moved and stretched within the skull

+

Causes of Acquired Brain Injury

- Loss of oxygen
- Stroke
- Electrical shock
- Trauma to head or neck
- Meningitis
- Infections
- And many others






+

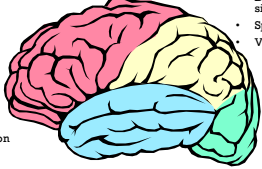
Causes of Traumatic Brain Injury

■ **The leading causes of TBI in Iowa (IDPH) 2014**

- Falls (66%)
- MVA (21%)
- Unknown/Other (8%)
 - Sports Injury
 - Military Blasts etc.
- Assaults (3%)
- Struck by/Against (2%)

Brain Behavior Relationships



Frontal Lobe

- Initiation
- Problem solving
- Judgment
- Inhibition of behavior
- Planning/anticipation
- Self-monitoring
- Motor planning
- Personality/emotions
- Awareness of abilities/limitations
- Organization
- Attention/concentration
- Mental flexibility
- Speaking (expressive language)

Parietal Lobe


- Sense of touch
- Differentiation: size, shape, color
- Spatial perception
- Visual perception

Temporal Lobe

- Memory
- Hearing
- Understanding language (receptive language)
- Organization and sequencing

Occipital Lobe


- Vision



+ Challenges and Changes After BI

Unique to each person

- Each injury and its effects are unique based on the type of the injury, severity of the injury, location of the injury, precursory factors, and rehabilitation
- Disruption to bodily functions that the brain regulates
- A brain injury survivor can be affected physically, mentally, behaviorally, emotionally and socially




+ Physical Changes

- Motor coordination
- Hearing changes
- Visual changes
- Spasticity
- Tremors
- Fatigue
- Weakness
- Taste and smell
- Balance
- Mobility
- Speech
- Seizures

Physical Example:

If a person experiences headaches and fatigue, the person's level of frustration tolerance may be lowered causing him or her to act out in anger.



+ Physical Changes


Constant headaches

Pain!

I keep dropping things

Blurred vision

The lights in their office are too bright!



My ears are ringing

I can no longer drive

I get tired so easily


Slurred speech

+ Cognitive Changes

- Memory
- Decision Making
- Planning
- Sequencing
- Judgment
- Processing Speed
- Organization
- Self-Perception
- Problem Solving
- Self-Awareness

Cognitive Example:

If a person has difficulty processing or remembering information, the person may behave in a fashion that gives the impression that he or she does not care or is unmotivated.



+ Cognitive Changes


I'm OVERWHELMED!

Why won't they slow down and let me answer?

I don't know the answer anymore

I am missing my appointments

I need things to happen in a specific order



I can't remember anything!

I don't know what to do next

I can't concentrate

I don't understand the paperwork they want me to do

+ Behavioral / Emotional Changes

- Disinhibition
- Temper Outburst
- Low Frustration Tolerance
- Inappropriate sexual language/behavior
- Lack of Interest/Motivation
- Difficulty Initiating Tasks
- Mood Swings
- Irritability
- Depression
- Social Immaturity
- Self-Centered
- Confusion
- Impulsiveness
- Restfulness/Agitation

Behavioral Example:

If a person has difficulty controlling impulses this may negatively effect their ability to re/develop "social capitol" and participate actively in their environment of choice.



+ Behavioral/Emotional Changes

I have no friends I feel all alone

Increased Impulsivity/risk taking

Loss of motivation

Depression

Anger

Anxiety

I'm an emotional rollercoaster!

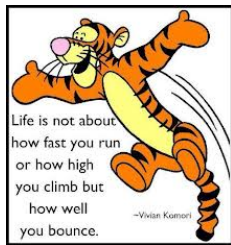
Easily agitated

Negative



+ Reach out to us!...

- The human spirit is incredibly resilient!
- Neuro Resource Facilitation is available to support the process



+ 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.

From: Resource Facilitation: A Consensus of Principles and Best Practices To Guide Program Development and Operation in Brain Injury, Brain Injury Association of America, 2001



+ How does NRF Work?



+ Recorded Webinars



Just look up our channel!
Brain Injury Alliance of Iowa



Topics Include:

- BI after DV
- Seizure Recognition
- Anger after Brain Injury
- Social and Emotional Aspects after a Concussion
- Applying for SSI and SSDI
- Employment after BI
- *And Many More!*



+ Case Consultations

Stumped? Needing ideas? What options are out there?

BIA-IA can assist with locating available brain injury resources, services and supports to help with your survivors.

Call us and we can set up a time to provide a phone consultation for your team!



+ Connect to NRF

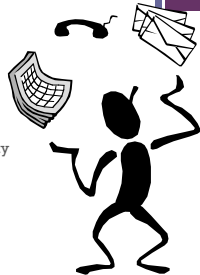
Intakes and General Information

- 855-444-6443
- info@biaia.org

Local Offices

- Urbandale, Iowa City, Waterloo and Sioux City

www.biaia.org



+ What is Advocacy?

Advocacy can mean many things, but in general, it refers to taking action. Advocacy simply involves speaking and acting on behalf of yourself or others. There are several types of action that a person can take:

- Self Advocacy
- Peer Advocacy
- Systems Advocacy
- Legal Advocacy



+ Goal of Advocacy

- To assertively ask for what you need, negotiate effectively to get services, and work collaboratively with professionals

While there's no guarantee, advocating for yourself is the most direct way to secure change.



+ Advocacy Myths

- I don't have time! I'm too busy!
- I don't "do" politics
- Advocacy doesn't make a difference
- I'm not an expert; what can I do?



+ Build an Advocacy Strategy

- To be an effective advocate, of any kind, you'll need a solid strategy or plan and practicing skills to help you feel comfortable and confident in reaching your goals
- In order to be effective, you should
 - Break down the problem
 - Educate yourself
 - Identify your rights
 - Develop a solution (goal) and strategy to address your problem



+ How to be an Effective Advocate

Do's and Don'ts

- **Educate yourself**
 - Be informed as much as possible on your topic, its history, and what movements are already being taken to address the problem
- **Document**
 - It can be easy to lose track of contact info, responses, conversations etc if you are not documenting
- **Self Care**
 - Take care of yourself so you have the energy to keep going!
- **Self Awareness**
 - When someone tries to change your mind or educate you on a topic, what approach works best?
- **Back up plan**
 - What will you do if your advocacy strategy fails? Even the most clear, educated, and genuine advocate can run into roadblocks



+ How to be an Effective Advocate

Do's and Don'ts

- Work **collaboratively** vs. going in "guns blazing"
- Be **solution based** vs. complaining
- **Advocacy is not:**
 - Solving all someone's problems for them
 - Telling or advising someone what YOU think they should do
 - Being argumentative/threatening. Speak calmly to avoid putting the individual you're working with on the defensive
 - Making promises you cannot deliver
 - Exaggerating
 - Expecting the impossible, or immediate action
 - Pretending to speak for everyone



+ Who, What, When, Where and How of Advocacy

There is no single method or strategy for advocacy. To be effective, an advocate must be flexible, informed, communicative, timely, and organized.

- **Who?**
 - Identify the correct person to approach
 - Ask for correct spelling of names
 - Call the office or agency before sending materials
 - Ask questions about organization
 - Understand who is responsible for the program or service that interests you



+ Who, What, When, Where and How of Advocacy

- What? – *this is extremely important*
 - Be clear on what the issue or problem is
 - Identify possible solutions for changing the situation
- Where?
 - Are you directing the issue to the correct person, department or agency?



+ Who, What, When, Where and How of Advocacy

- When?
 - Timing! It's vital to be informed on timings of meetings/appointments/phone calls and to be timely
- How?
 - Get organized
 - Keep an accurate log of all contacts
 - Put your request in writing
 - Ensure your written material and verbal are factual, don't embellish or you may lose credibility.
 - Research both sides of the issues or request and be prepared for questions

+ Who, What, When, Where and How of Advocacy

- How? *Continued...*
 - Involve people whose lives have also been affected
 - If advocating to large crowd...
 - Repeat the message at least three times to your audience
 - Provide multiple facts
 - Request an appointment to meet personally with the person who can help you
 - Be on time for all appointments or scheduled phone calls
 - Follow up with a letter of thanks



+ Does advocacy *really* make a difference?

- Advocacy can be a **difficult and time-consuming** activity, but it can also be **rewarding**. Through advocacy, people have been able to change state and federal laws so that they become more favorable toward people with brain injury and even implement new laws for the support of people with brain injury.



+ What does an advocate look like?

- A parent requesting an additional IEP meeting to ensure her questions are answered
- Appealing a decision made by your child's healthcare insurance company to deny necessary services
- Speaking with your legislators
- Attending a local community event/race/walk for your cause
- Keeping a "communication notebook" for documentation
- Liking a Parent Support/Advocacy Group on social media



+ What does an advocate look like?

- A parent helping their child become their own advocate
- Informing their child's teaching staff on what accommodations they are in need of in the classroom
- A parent at their school's PTA meeting
- Taking the time to get to know your child's teachers and build relationships
- Failing and getting back up
- Reaching out for support



+ Ways you can advocate today!

- Start talking
- Use social media
- Get on the phone
- Send a letter or email
- Meet your representatives
- Add your name



+ Hill Day

March 21, 2017
 State Capitol Building
 9:30a-3p

Join us at Iowa's State Capital as we work to educate legislators and policy makers about the needs of Iowans with brain injury and their families



+ Self-Advocacy Resources

- InfoNet
 - Using InfoNet's grassroots Advocacy Center, you can quickly email your federal and Iowa state elected officials about the issues you care about, and get tips on making your message clear and full of impact. You don't need to know who your legislators are to use the Advocacy Center, their system will find them for you. All you need is your address and you can email your legislators in less than two minutes
- Self Advocacy Online
- Find your local legislator - <https://www.legis.iowa.gov/legislators/find>
- Brainline Advocacy Toolkit



+ Connect to NRF

- Intakes and General Information
 - 855-444-6443
 - info@biaia.org
- Local Offices
 - Urbandale, Iowa City, Waterloo and Sioux City
- www.biaia.org

