

ADVOCACY



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6th Annual Northern Kentucky TBI Conference
March 23, 2012
www.bridgenky.org

Definition of Advocacy

- ▶ “Advocacy means speaking or acting on behalf of oneself or others, or on behalf of a particular issue, with self-sacrificing vigor and vehemence.” *William & Shoultz*
- ▶ The act of pleading or arguing in favor of something, such as a cause, idea, or policy; active support. *The American Heritage® Dictionary of the English Language*
- ▶ Active support, especially of a cause. *Collins English Dictionary*

Types of Advocacy

- ▶ Self
- ▶ Citizen/group
- ▶ Family/significant other

Basis of Advocacy

The basis of advocacy is to support people in addressing their concerns, asserting their rights and helping them gain access to health, legal and social care services.

Self Advocacy

- ▶ Self advocacy is when an individual speaks for his or herself
- ▶ The individual tells others their needs and interests
- ▶ The individual speaks to us, or to the group
- ▶ A person with a disability self advocates by voicing his or her opinions
- ▶ A person with severe disabilities self advocates by his or her presence in the meeting or group
- ▶ The individual's inherent right to be in and a part of society (or the group, or treatment team, etc) must be seen and upheld by us

Self Advocacy (continued)

- ▶ Self-advocacy is based on the belief that people are their own best advocates.
- ▶ Self advocacy is about having choices

Citizen/Group Advocacy

- ▶ As a group, you can speak with “one” voice
- ▶ Group representation provides for a “louder” voice
- ▶ Group advocacy supports “larger” causes, that benefit more than one person and a population as a whole
- ▶ Examples:
 - ▶ Improved access to public buildings
 - ▶ Improved access to local transportation
 - ▶ Improved funding for educational needs
 - ▶ Integration in the community education system
 - ▶ Improved medical and psychiatric care



Family/Significant Other Advocacy

- ▶ Speak for and on behalf of the individual
- ▶ Assists the individual to voice their needs, interests and wishes
- ▶ Always requests that the individual be present for meetings, discussions and planning
- ▶ Politely insists the individual be heard when speaking about his or her needs and interests
- ▶ Focuses on the wishes of the individual as they advocate for them



Effective Advocacy by Family/Significant Other

- ▶ Prepare questions in advance
- ▶ Keep a written record
- ▶ Remain calm
- ▶ Communicate clearly
- ▶ Be persistent
- ▶ Find the right person
- ▶ Find the right time
- ▶ Find a support group!



Goals of Advocacy

- ▶ **Potential:**
 - ▶ To enable brain injury survivors to develop to their maximum potential
- ▶ **Educational:**
 - ▶ To instill in society the human value and dignity of brain injury survivors
- ▶ **Integration:**
 - ▶ To integrate and involve brain injury survivors in the community.
- ▶ **Rights:**
 - ▶ To support and ensure the rights of the brain injury survivor are clearly understood and enforced.



Basic Rights

- ▶ Each person has a right to be treated respectfully
- ▶ Each person has the right to say no without explanation and without guilt
- ▶ Each person has the right to slow down and take time to think
- ▶ Each person has the right to change his or her mind
- ▶ Each person has the right to ask for what he/she wants
- ▶ Each person has the right to ask for information
- ▶ Each person has the right to make mistakes
- ▶ Each person has the right to make choices and accept consequences of those choices
- ▶ Each person has the right to own and express his/her own feelings
- ▶ Each person has the right to ask for help
- ▶ Each person has the right to maintain a separate self that is independent of the expectations, the approval or the influence of others



Challenges of Advocacy

- ▶ **Control:**
 - ▶ Non-disabled people tend to take control of brain injury survivors.
- ▶ **Respect:**
 - ▶ The views and feeling of the brain injury survivor may not be respected.
- ▶ **Shy/Verbal Aggression, other behaviors:**
 - ▶ Brain injury survivor may be too shy to speak, or speak inappropriately.
- ▶ **Support:**
 - ▶ Lack of consistent support from other people.
- ▶ **Environment:**
 - ▶ Negative social environment.
- ▶ **Process:**
 - ▶ A slow process before results are seen causing success to be doubted.



Resources in Kentucky

- ▶ Acquired Brain Injury Waiver Programs
- ▶ Traumatic Brain Injury Trust Fund
- ▶ Brain Injury Alliance of Kentucky
- ▶ Local support groups
- ▶ Natural supports
- ▶ Medical treatment team, therapists
- ▶ Internet, research



Questions and Answers

