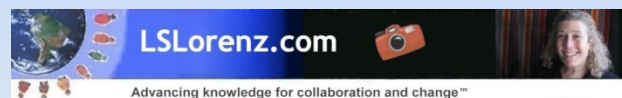


Family and Patient Support: New Approaches to Fostering Dialogue and Hope

National Capacity Building Project
Center for Victims of Torture

Laura S. Lorenz, PhD, MEd, CBIS
Institute for Behavioral Health
The Heller School for Social Policy & Management
Brandeis University

November 17, 2010



Outline for Today

- 1. Background**
- 2. Identify when THI/TBI-affected torture survivors need referral to rehabilitation**
- 3. Learn what THI/TBI patient and family support can be administered in a torture treatment center**
- 4. Learn about patient and family lived experience with THI/TBI**
- 5. Connect with patient and family THI/TBI supports in the community**

Prior Seminars in Series

- Frequency of undiagnosed THI/TBI in torture survivors
- Value of determining possible cognitive and other THI/TBI-related deficits
- Impact of THI/TBI – especially mild TBI
- Diagnostic tool
- Rehabilitation approaches

Meeting Needs of TBI Patients & Families

- Pair education and awareness about TBI with the needs of family members
- Combining education and support can mean finding a delicate balance

Russell, 2009

After a Diagnosis of THI/TBI

When a family member is diagnosed with brain injury, families may:

- Experience isolation and loss of emotional support
- Feel bewilderment, frustration, guilt, fear, and depression
- Have little knowledge about TBI, rehabilitation, disabilities or deficits

THI/TBI creates complex, long-term demands on families and communities

Russell, 2009

Primary Resources for Today

- Brain Injury Association of Massachusetts (BIA-MA). Caregiver resource guide. Westborough, MA: BIA-MA. www.biama.org
- Cavallo, M. M. and T. Kay. (2005). The family system. In J. M. Silver, T. W. McAllister & S. D. Yudofsky (Eds.), *Textbook of traumatic brain injury* (pp. 533-88). Washington, DC and London, England: American Psychiatric Publishing, Inc.
- Lorenz, L. S. (2010). *Brain injury survivors: Narratives of rehabilitation and healing*. Boulder, CO: Lynne Rienner Publishers Inc.
- Lorenz, L. S. (2010b). Visual metaphors of living with brain injury: Exploring and communicating lived experience with an invisible injury. *Visual Studies*, 25(3), 210-223 (December)
- Prigatano, G. P. (1989). Work, love, and play after brain injury. *Bulletin of the Menninger Clinic*, 53, 414-431.
- Prigatano, G. P. (1999). *Principles of neuropsychological rehabilitation*. New York: Oxford University Press.
- Russell, D. (2009). Chapter 7: Family. In the Academy of Certified Brain Injury Specialists (Eds.), *The essential brain injury guide (Edition 4.0)* (pp 123-34). Vienna, VA: Brain Injury Association of America. www.biausa.org
- Senelick, R. and K. Dougherty. (2001). *Living with brain injury: A guide for families (2nd edition)*. Birmingham, AL: HealthSouth.

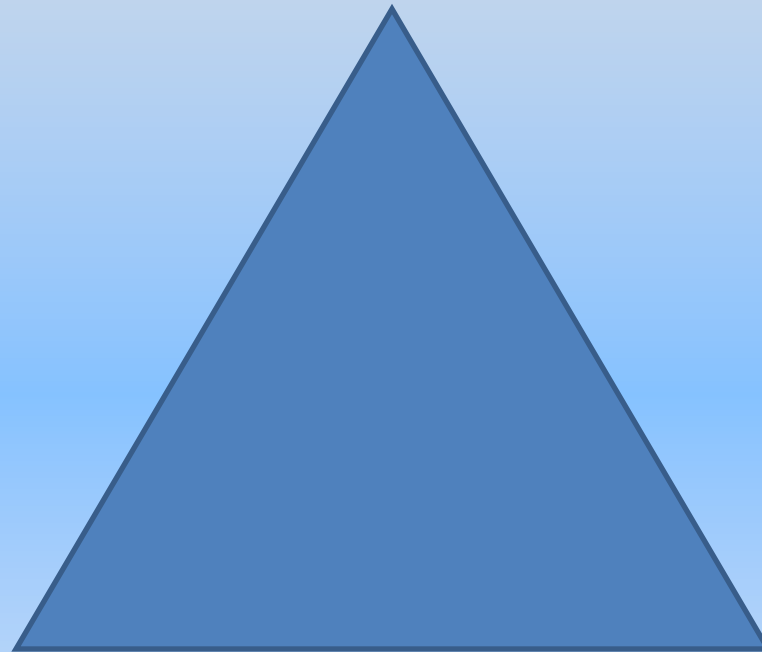
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Mild TBI - Triangle of Symptoms

Physical

Fatigue, sensitivity to light and noise, ringing in ears



Emotional

Anxiety, mood swings, sleep disturbances, irritability, loss of libido

Cognitive

Memory loss, difficulty concentrating, distractibility, difficulty reading, inability to pay attention or solve problems

Senelick & Dougherty, 2001

A Hidden Injury

- The mild TBI patient may well look “normal” yet have anxiety, depression, loss of self-esteem, and increasing dysfunction over time
- Family confusion about the discrepancy between appearance and symptoms can exacerbate symptoms and loss of function
- Often the mild TBI patient cannot be helped back to production functioning without addressing what is often a deteriorated family situation

When refer?

- When TBI/THI behavioral, emotional, and cognitive problems are hard to manage
- When hidden financial, physical, and emotional costs associated with caring for TBI/THI survivor are wearing on family members
- When patient and family are open to seeking rehabilitation supports

Russell, 2009

Caring for the Care-Taker

- Recognize when family needs are neglected
- Provide emotional and other support when demands have become overwhelming
- Support families in sharing responsibilities, care-taking, and help-seeking
- Act as a gatekeeper in providing needed information and facilitating access to needed services and supports
- Be open to providing information and support about sexual concerns

Russell, 2009

R.E.C.H.A.R.G.E.

Family members may not realize their levels of stress and exhaustion. They may need to:

R – REST

E – EAT RIGHT

C – COMMUNICATE NEEDS TO OTHERS

H – HYDRATE

A – ACCEPT SELF

R – RESPITE

G – GET ENOUGH SLEEP

E – EXERCISE

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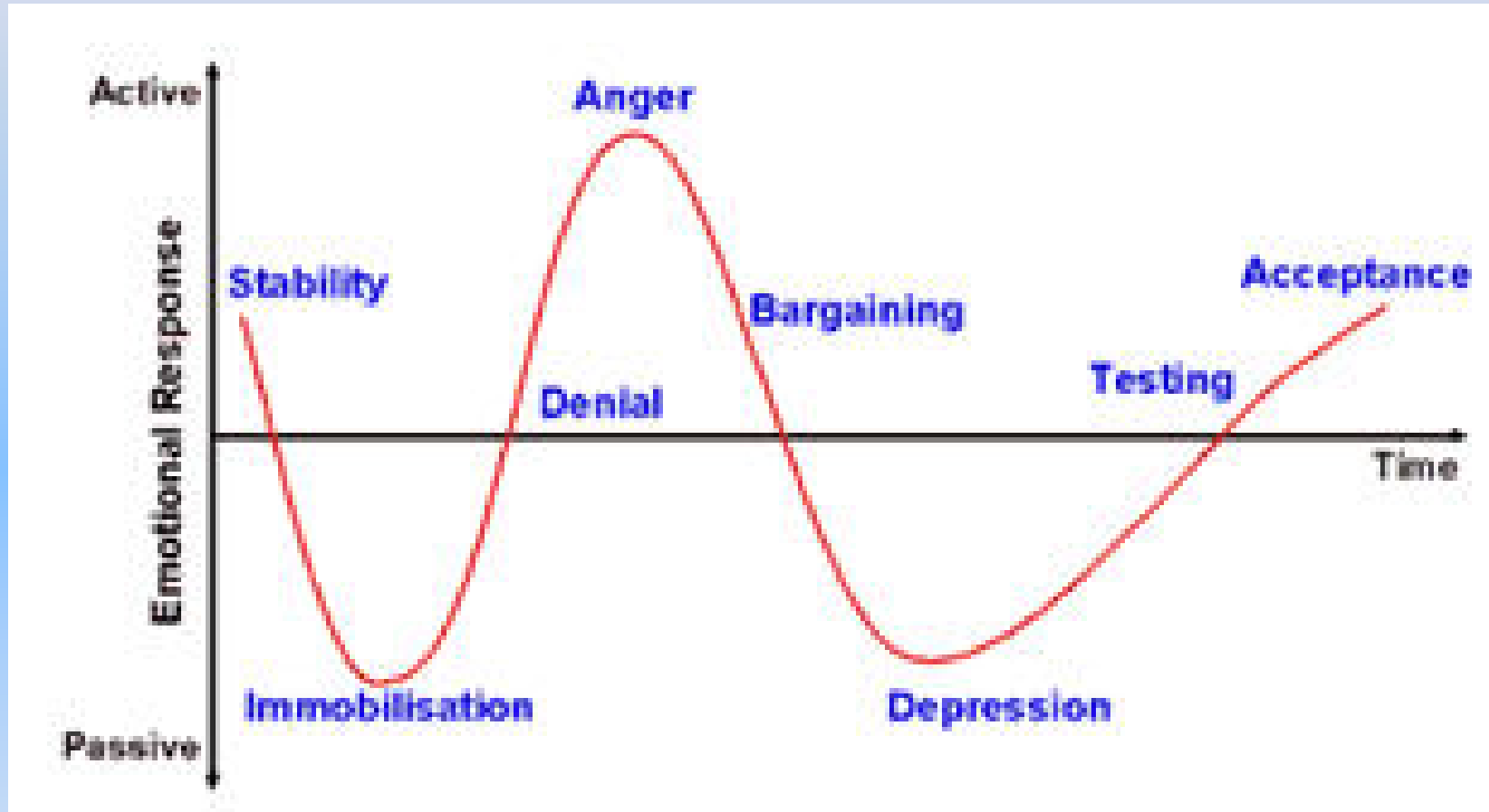
A Good Start

- Helping a family adjust to the impact of a THI/TBI and move toward greater functioning by all family members requires attentive listening to their needs

Stages of Recovery for Families

- Relate to stages of recovery for the individual
- Many people have been injured many years prior
- As awareness of TBI is new, they may be facing these stages for the first time
- For some, the diagnosis will be a great relief
- For others, it will be a time of fear and despair
- **You can help** by listening, educating, and connecting families to rehabilitation, resources, and supports

Stages of Grief



Kubler-Ross & Kessler, 2005

Cautions

- The family's process of adjusting to TBI evolves over time (Cavallo & Kay, 2005)
- These stages of adjustment are similar to Kubler-Ross stages of grief (Lorenz, 2010)
- Individuals and families may experience all of these stages in any given day, even many years after brain injury (Russell, 2009; Lorenz, 2010)

Stage 1: One to Three Months

- The shock of the injury dominates
- There are hopes for quick recovery
- Denial is common
- Feelings are repressed



Denial

Stage 2: Three to Nine Months

- The long-term nature of the injury is recognized
- Feelings of helplessness, hopelessness, and frustration often escalate
- Denial shifts to anxiety, anger, fear, depression, and loss

Anger

Stage 3: Six to Twenty-Four Months

- Annoyance with the THI/TBI survivor may grow
- Start to recognize the reality of impairments
- Feelings of depression, guilt, and discouragement may grow
- Family members may re-read brain injury materials and seek additional information

Depression

Stage 4: Ten to Twenty-Four Months

- Realism sets in
- Family members may feel exhausted and need breaks
- Some family members may disengage a little
- Grief may dominate



Grief

Russell, 2009

Stage 5: Twelve to 24 months

- Profound sadness
- Families begin to grieve again
- Mourn the loss of loved one's personality
- Hopes for recovery may fade
- With time and support, most families pass this stage and progress toward understanding

Russell, 2009

**Testin
g**

Stage 6: Two to Three Years Later

- Greater understanding of the situation
- Beginning of acceptance
- May be ready to address needs of the entire family unit

Acceptance

Russell, 2009

Your Job

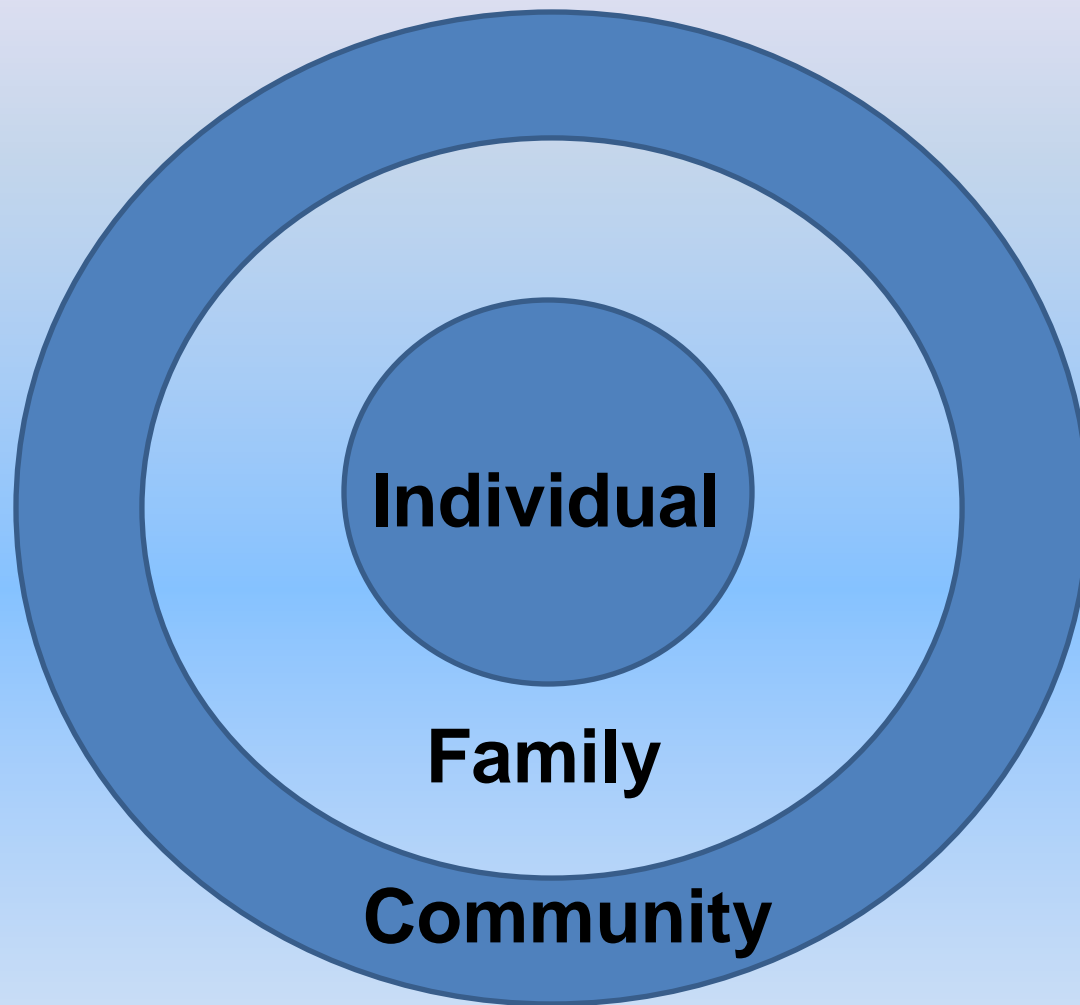
- Recognize that not all family members go through these stages equally or in this order – there is no objectively and universally true sequence (Cavallo & Kay, 2005)
- Listen to family needs – Listening the most important support you can provide (Lorenz, 2010)
- Connect the family with resources – while understanding that THI/TBI cannot be erased (Russell, 2009)
- Support families in transforming the experience (Russell, 2009)

Provide Family-Centered Care

- Family support should be proactive, flexible, health- and prevention-oriented, and responsive to the needs of families within the context of a progressive reestablishment of family equilibrium after a diagnosis of THI/TBI

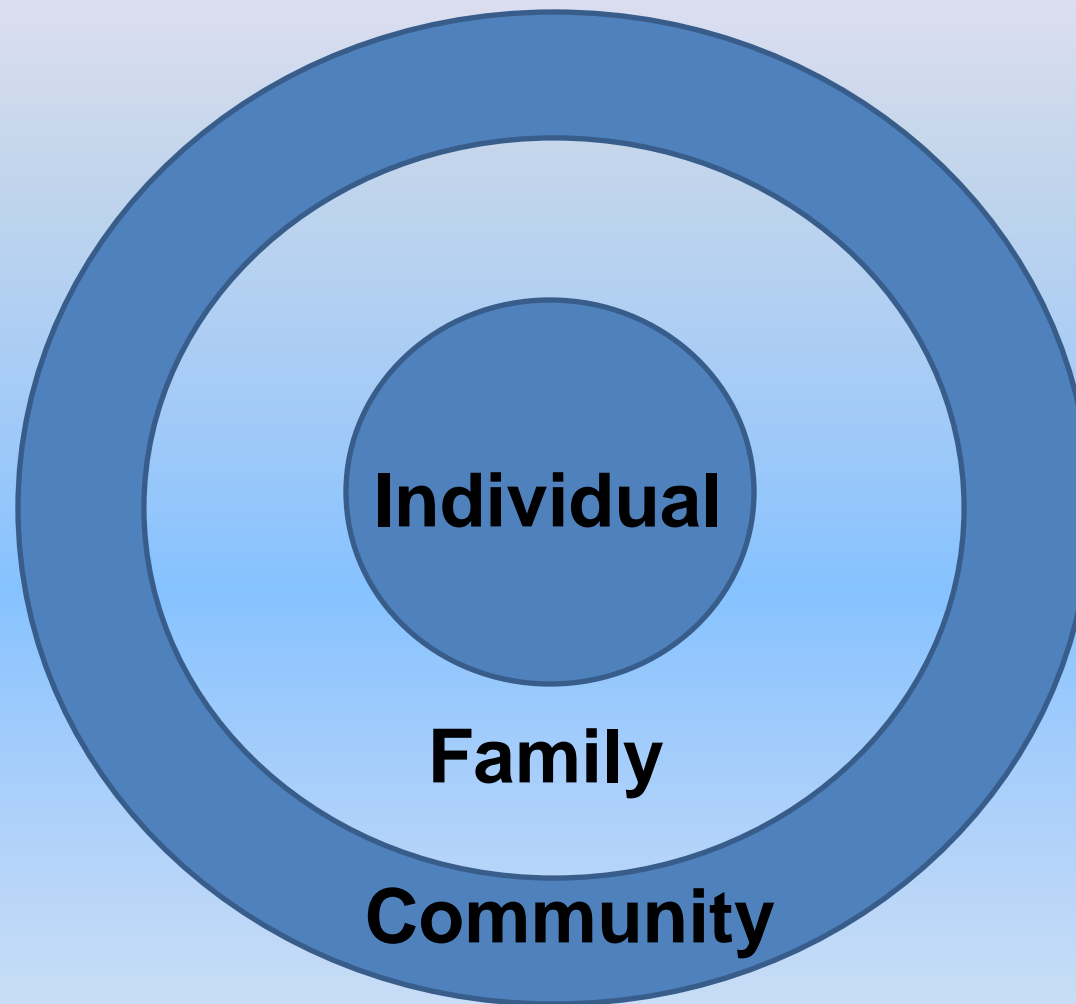
Cavallo & Kay, 2005

Model of Assessment & Intervention



Cavallo & Kay, 2005

Model of Assessment & Intervention

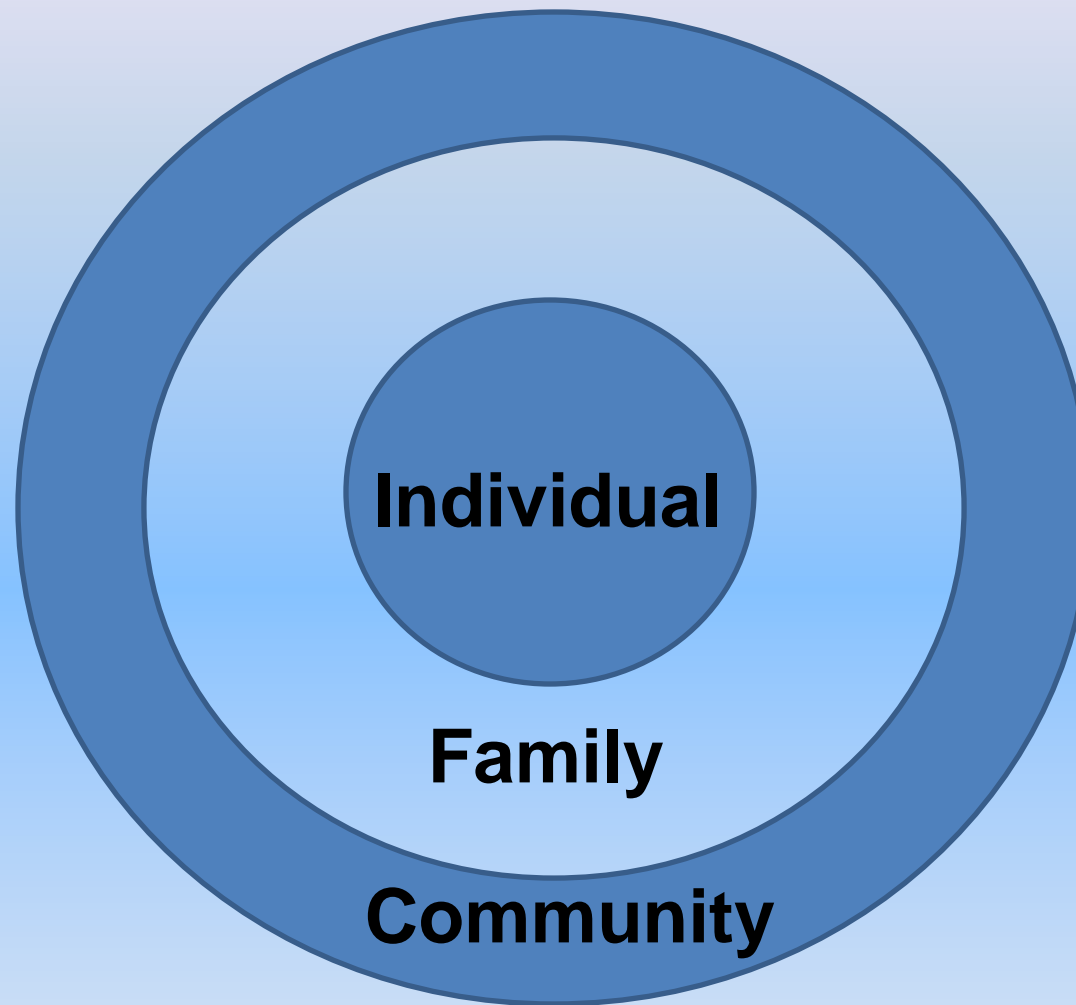


Each level can be assessed independently

Have different possibilities of support

Each family member may have attitudes, limitations, and strengths (e.g., ability to drive, to remain calm under stress, to be flexible, to be creative)

Family as a System



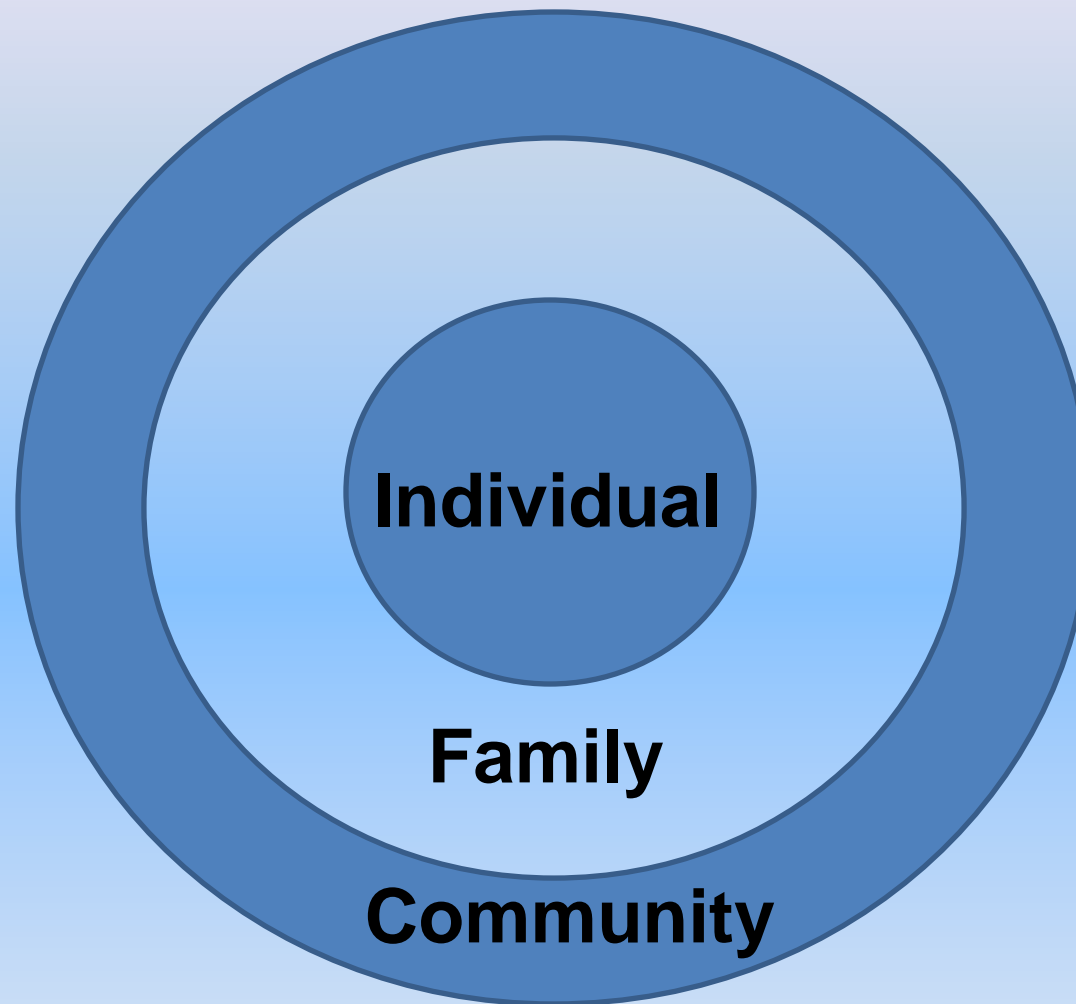
Relates to roles and structure of family unit

How cohesive is the unit?

What are the patterns of relationships, communication, and problem-solving?

What family cultural norms will mesh well or conflict with the rehabilitation team?

Family's Relationship to the Community



Another area for improvement & supports

Has two parts: professional rehab community & psychosocial community

Problem-solve family issues with rehabilitation team

Identify clinical translators

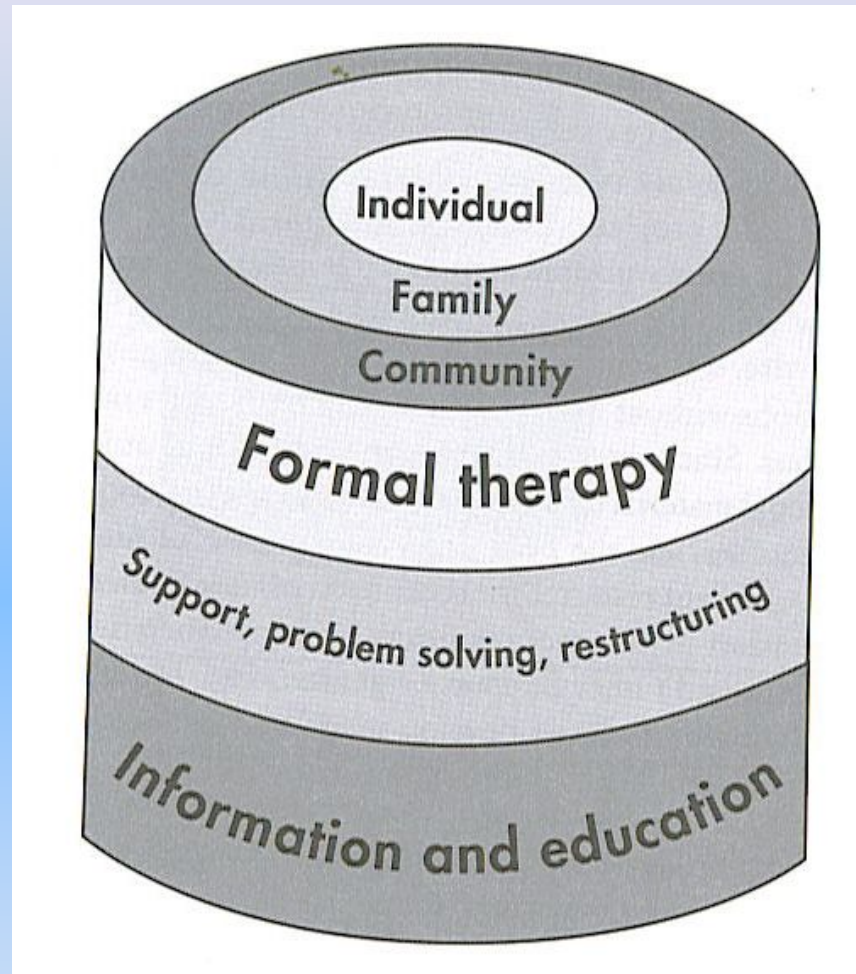
Support integration into community life

Relationship of Family to Community

- Help families learn to draw comfortably on existing resources of extended family, friends, employers, churches and others
- Help them resist the tendency to become isolated, ashamed, and self-conscious, or to shield the community from the injured person
- Family intervention may include a circle of support that is wider than may be comfortable for the family: family-to-family programs, self-help groups, family outreach and advocacy, and community networking are all valuable supports

Cavallo & Kay, 2005

Levels of Intervention



Cavallo & Kay, 2005, p 545

Information and Education

- Information and education are the most crucial intervention early on after a diagnosis of THI/TBI.
- Families need to know what a diagnosis of THI/TBI can mean, and what types of treatments and services may be available and helpful.
- They need to know what their insurance and legal options are.

Support, Problem Solving, & Restructuring

- Can be effective or needed at all levels
- Requires an active therapist who knows TBI and can build on strengths of family and its members
- Can be simple: Helping a family negotiate transportation, figuring out needed supports, or finding a good social outlet

Cavallo & Kay, 2005

Build on Family Strengths

- Ability to listen
- Shared perceptions
- Spirituality
- Ability to realize redemptive power of a tragic event
- Ability to accept and assist in disability-related problems
- Willingness to take care of themselves
- Ability to focus on the present
- Ability to reinforce each other
- Ability to discuss concerns
- Ability to provide atmosphere of belonging
- Use of trans-generational coping strategies

Russell, 2009

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Elaborate and Collaborate

- Providing THI/TBI support can mean helping individuals and families identify and work toward their goals
- Identify the spirit of the goal (e.g., increased independence, increased participation in community life, helping others)
- Break down the goal into steps and tackle them one at a time
- Engage in a collaborative process of discovery of steps, resources, and decisions
- Substitute reasonable alternatives based on the spirit of the goal (e.g., “helping others” could mean becoming a doctor—or perhaps more realistically, volunteering in the community)

Cavallo & Kay, 2005

Encourage Reflection

- Developing individual and family goals and understanding the steps involved in reaching them, means encouraging people to reflect on their lives and needs and communicate—with each other and with you
- Support groups and individual work can be important elements in recognizing challenges and strengths, getting people on the same page, and developing goals

Brain Injury Association Support Groups

- BIA affiliation can provide access to information, resources, and expertise
- Can bring awareness of TBI in torture survivors to policymakers and the wider TBI community
- Can open new doors to services and service providers – rehabilitation, legal, case management

Contact your BIA affiliate to find out about joining an existing group or starting a new support group in your center

Welcome to the Brain Injury Association of America - Windows Internet Explorer

http://www.biausa.org/index.htm

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BRAIN INJURY ASSOCIATION OF AMERICA

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THE VOICE OF AWARENESS AND ADVOCACY.

Welcome to the Brain Injury Association of America

Brain injury is not an event or an outcome. It is the start of a misdiagnosed, misunderstood, under-funded neurological disease. Individuals who sustain brain injuries must have timely access to expert trauma care, specialized rehabilitation, lifelong disease management and individualized services and supports in order to live healthy, independent and satisfying lives.

The Brain Injury Association of America (BIAA) is the voice of brain injury. We are dedicated to increasing access to quality health care and raising awareness and understanding of brain injury through advocacy, education and research. With a nationwide network of more than 40 chartered state affiliates and hundreds of local chapters and support groups, we provide help, hope and healing for individuals who live with brain injury, their families and the professionals who serve them.

News & Announcements

[2011 Brain Injury Business Practice College](#) 22-Feb-2011

Be sure to register for the 2011 Brain Injury Business Practice College. This year's conference will take place February 22-24, 2011 in San Antonio, TX. More information can be found (<http://biausa.org>). [Read More...](#)

[Upcoming Webinars](#) 28-Oct-2010

Be sure to register for BIAA's upcoming webinars in our Marketplace (<https://secure.biausa.org/SearchResults.aspx?>

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BRAIN INJURY WARNING SIGNS

Seek medical attention if you are experiencing:

- Numbness
- Excessive drowsiness
- Severe Headache
- Weakness in your arms or legs
- Dizziness or loss of vision
- Slurred speech
- Loss of consciousness or confusion
- Vomiting or nausea

[Click for more information about the signs and symptoms of brain injury](#)

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www.biaa.org or www.biausa.org

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[BIAA HOME](#) : AFFILIATES

Find Your State Brain Injury Association

The Brain Injury Association of America's nationwide network of chartered state affiliates provide direct support, information, resources, education and advocacy for individuals living with brain injury, their friends and family, professionals who provide research, treatment and services and the general public.

To find an affiliate near you, click on a state in the map below.



<http://www.biausa.org/state-affiliates.htm>

Brain Injury Association of Minnesota | Support Groups - Windows Internet Explorer

http://www.braininjurymn.org/support/supportGroups.php

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Brain Injury Association of Minnesota

Enhance the quality of life and bring the promise of a better tomorrow for all people affected by brain injury.

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About Brain Injury

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- Resource Facilitation
- Case Management
- Peer/Mentor Support Connection
- Volunteering
- Support Groups

Education

Advocacy

Military Personnel and Veterans

Resources

Volunteering and Internships

Senior Fall Prevention

Get Involved

Events

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Consumer Guide

Contact Us

The Brain Injury Association of Minnesota can help link persons with brain injury and their loved ones to self-directed, voluntary support groups. Support groups can provide a number of benefits:

- Emotional healing comes when people interact with other people.
- Sharing of similar experiences helps individuals feel less alone and more ready to deal with day-to-day issues.
- Encouragement comes from learning about how others have conquered situations similar to theirs.
- Contribution helps support group members feel meaningful.
- Education results from the exposure to information and personal experiences in a group.
- Socialization occurs when connections with people are made and confidence in social skills develops when appropriate interaction occurs in support groups.
- Self-expression, as emotions are experienced and released, creates a greater understanding of oneself.
- Confidence building results as members take responsibility for the work of the group, and see progress with the plans they made.
- Safety, in the environment of a confidential, supportive, non-judgmental group, allows for honest disclosure and sharing of common difficulties.
- A sense of growth occurs as long-term members see new participants and reminisce about where they began and how far they have come in their personal journey.

Finding a Support Group:

The Brain Injury Association of Minnesota makes referrals to support groups throughout the state, including groups for persons with brain injury, their families and friends, and caregivers.

Because support group locations and times change, please call the Association for current information at 800-669-6442. Groups are self-help, self-supporting, and independent from the Association.

Done

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Enhance the quality of life and bring the promise of a better tomorrow for all people affected by brain injury.

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Support Groups: An Example



Members of the Framingham 'Amazing' Brain Injury Survivor Support Group and friends display their artwork at "Stroke-a-Palooza 2009" at Braintree Rehabilitation Hospital, Braintree, MA

Not Just Talk

- Support groups can be useful for doing rehabilitation-related activities in a low-cost, culturally appropriate setting
- The Framingham group has led individual and series of sessions on: arts-based therapy, meditation, photovoice, poetry, brain games, and humor
- Community-based experts may volunteer or reduce their fees to work with your group
- Creativity is not lost after TBI (Prigatano, 1999) – finding creative activities to do individually or as a group can be healing for the person living with TBI and helpful for family and others

Symbols – Useful Tools for Healing

- Creative activities can lead to creation of symbols of experience
- TBI patients need symbols that will speak to their experience of what it is like to be brain damaged and that will give them some guidance in coping with the major issues of their life (Prigatano, 1989)
- The challenge is to provide concepts, symbols, and analogies that will address the patient's experience of being brain damaged (Prigatano, 1989)
- With activities like photovoice, patients produce their own symbols, through metaphor (Lorenz, 2010b)

Activity Example: Photovoice

- A group process of community and personal reflection using photographs and written narratives (Wang & Burris, 1997)
- Consciousness-raising education (Freire, 2000)
- Dialogue with policymakers, peers, and self (reflection) (Lorenz, 2010)
- Representing experience and producing knowledge through images and text (Wang & Burris, 1997)

Used with Individuals & Groups

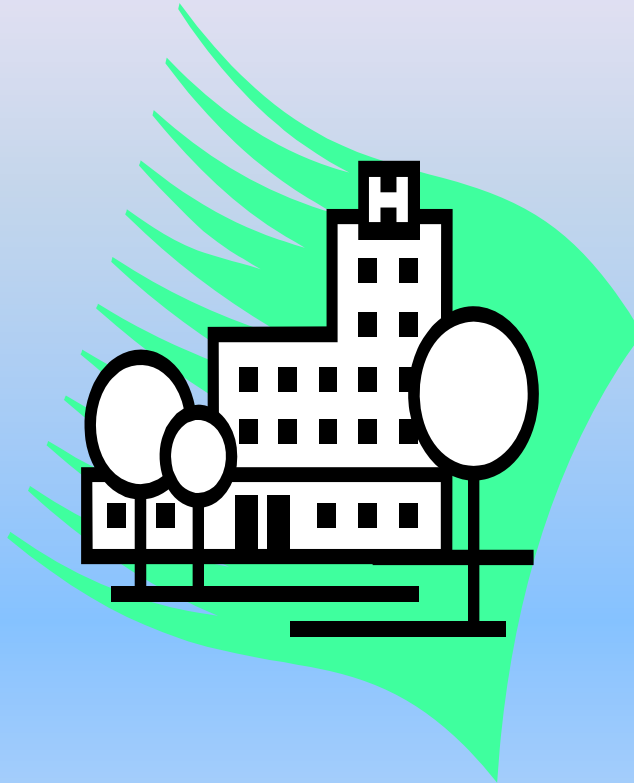


Photo-elicitation: 6 patients accessing outpatient services at a rehabilitation hospital, 2006-2008

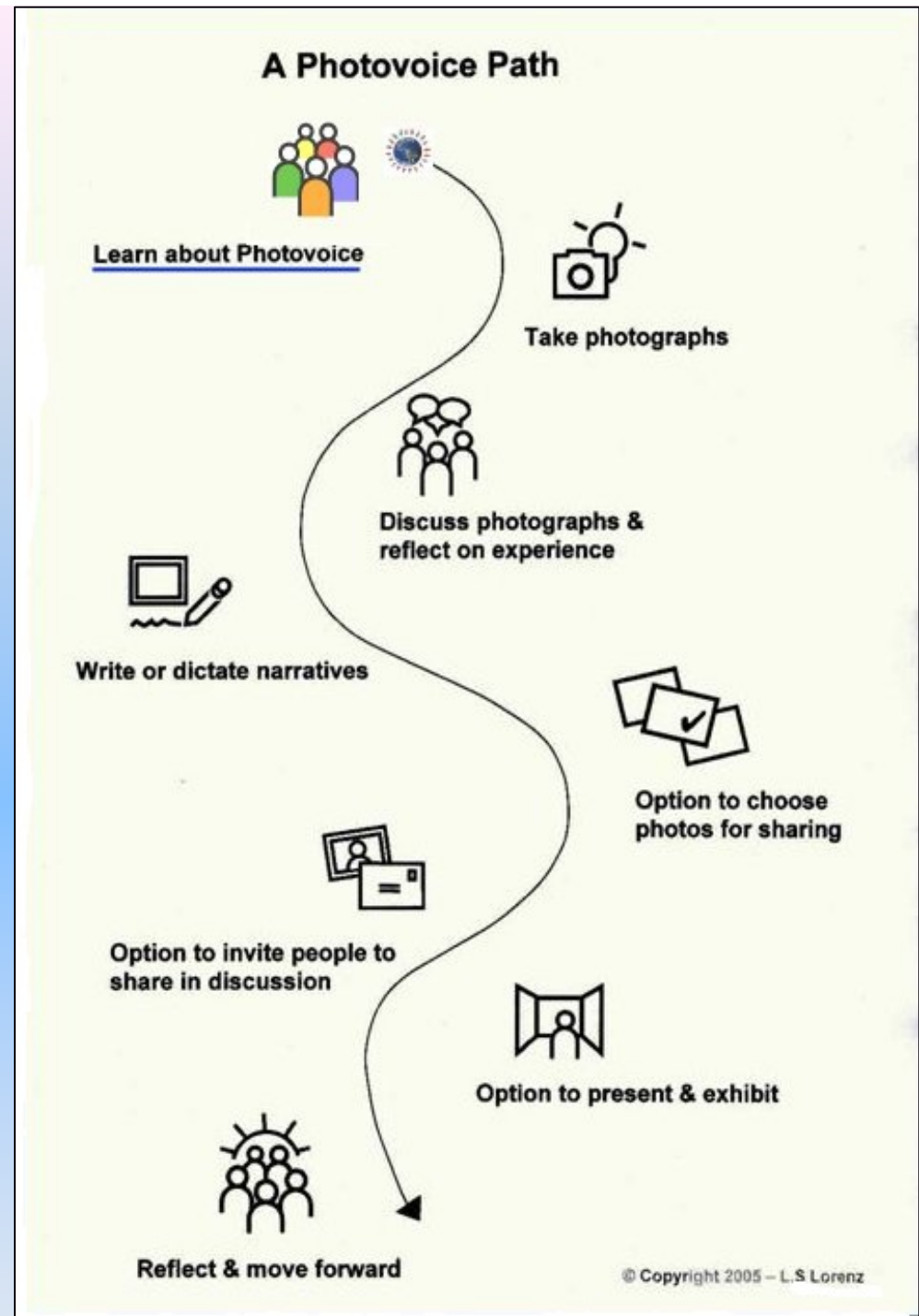


Photovoice: 8 members of a brain injury survivor support group supported by BIA-MA (2006 to present)

A Possibility: Start with photovoice—add individual interviews about photos after

A Photovoice Path

Photovoice: Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)



Sample Visual 'Research' Questions

- What is it like to live with TBI?
- What in my life or community has improved my quality of life living with TBI?
- What in my life or community has affected my quality of life in a negative way as I live with TBI?
- What do I want to tell other people about living with TBI?
- How is my life different now from how it was before I developed TBI? What is better? What is worse?
- What are my hopes for the future? And what might help me get there?

A Photovoice Path

Photovoice: Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)

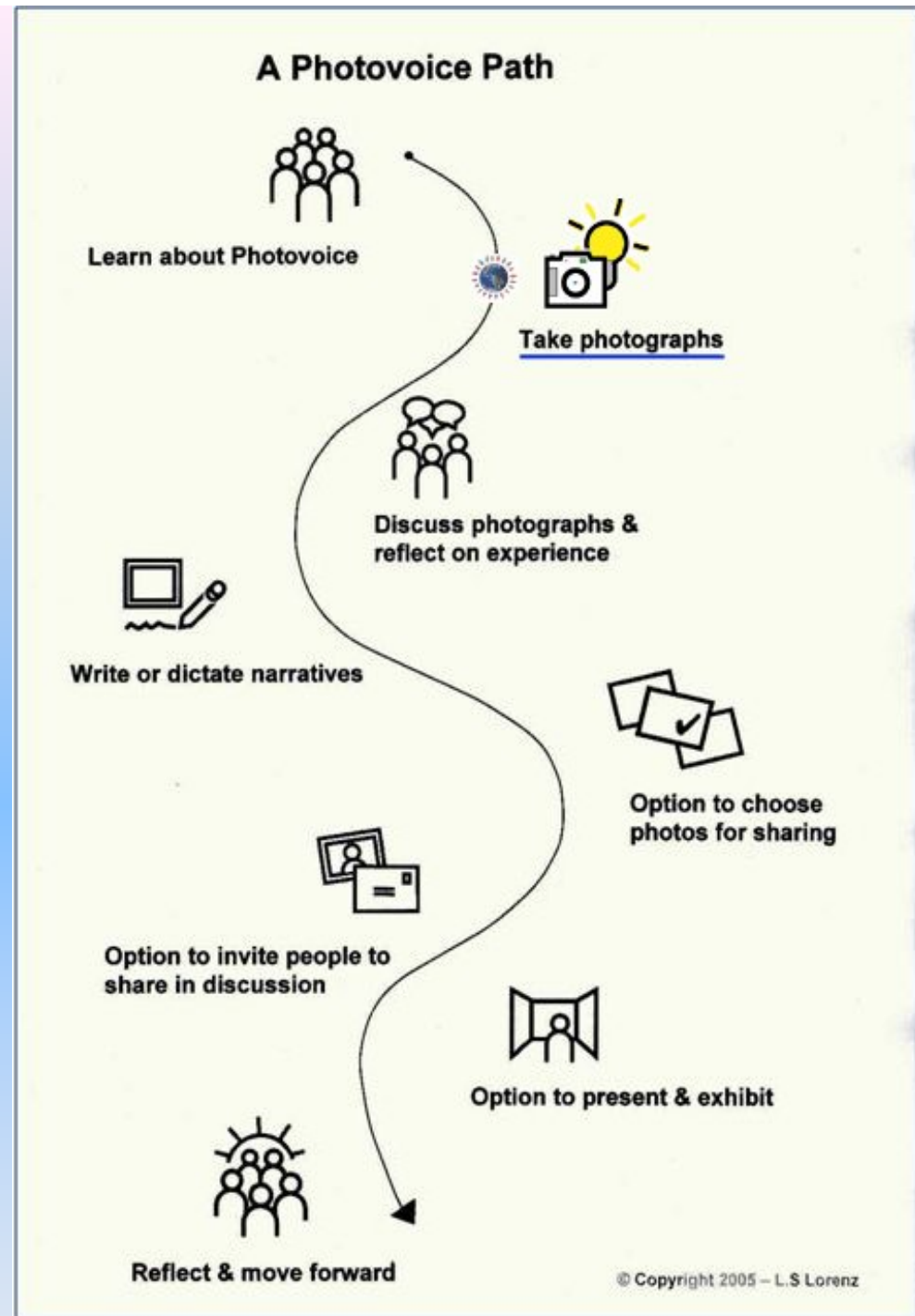


Photo-taking Options

- Use disposable cameras – or choose another option
- Let participants work alone, in teams, or as a family
- Provide 1 to 3 cameras or photo opportunities per person--15 and 50 photos per participant or team
- Emphasize photo content
- Allow participants to contribute family snaps or historical photos
- Allow participants to give the camera to others
- Encourage photos that are representational and metaphorical

“The disorder that I’m living with right now”

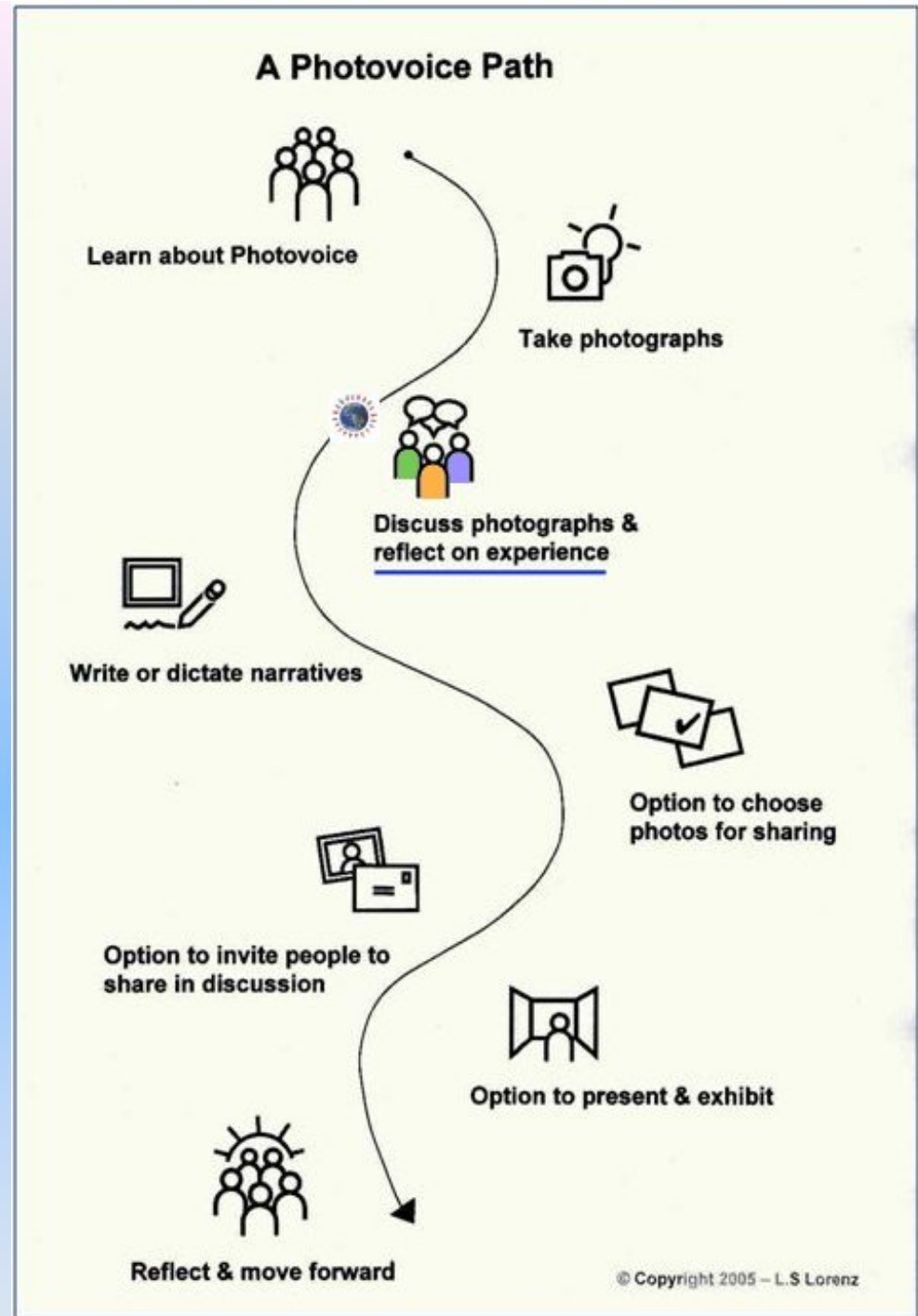


“Truth” versus “Narrative truth”

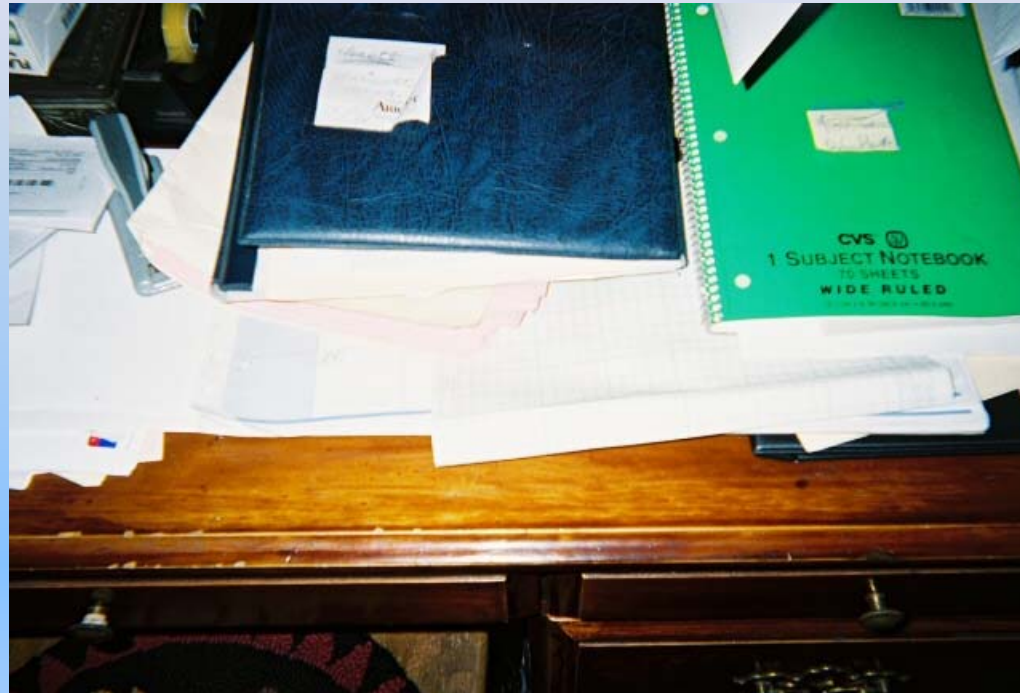
Source: Spaulding Rehabilitation Hospital Participant, 2006

A Photovoice Path

Photovoice: Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)



Sample Representational Photo



Source: Pre-pilot
study 2005
Photographer:
Laura Foley

Paperwork...is a great obstacle for me...it's also a symbol for the disorganization I feel in my mind. There's a sifting process her for me, because paperwork was never a forte for me, even prior to the brain injury. How much of it is just my own pre-existing trait, and how much is the disability? Maybe here it's like 50-50.



Sample Metaphorical Photo

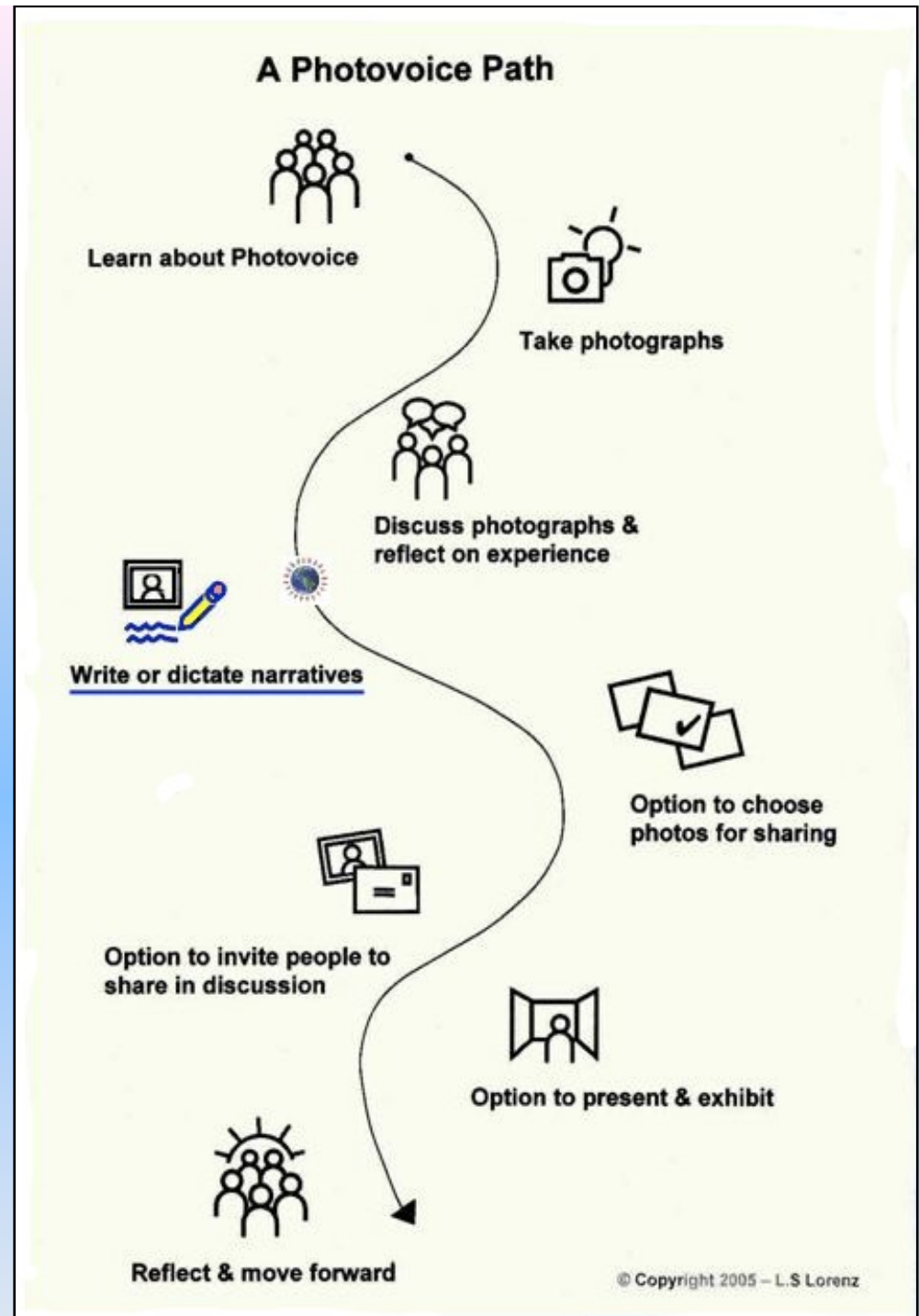
...that's how I felt...right after my accident, that there was no connection and there were so many missing links as I tried to begin living again...it was kind of like living in the middle of nowhere...When I saw that, well, that seemed like a perfect way to sum it all up, you know

Source: Pre-pilot study 2005

Photographer: Laura Foley

A Photovoice Path

Photovoice: Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997)



The Journey

‘It’s a muddy, ruddy, hands-and-knees crawl up to the first rung of the ladder that begins to make some semblance of sense—and then you get to begin to really struggle. The climb does not and will not end. There is no final healed bone or mended tear of the skin to get over. Sometimes weekly, and sometimes daily there is a new step to attempt to get to your “new self.” You can’t even ever hope to get back to your “old self.” Oh well Maybe there will be a good view on this journey that I hadn’t expected...’

Source: Brain Injury X-Posed 2006

Photographer: Peggi R



Outreach Considerations

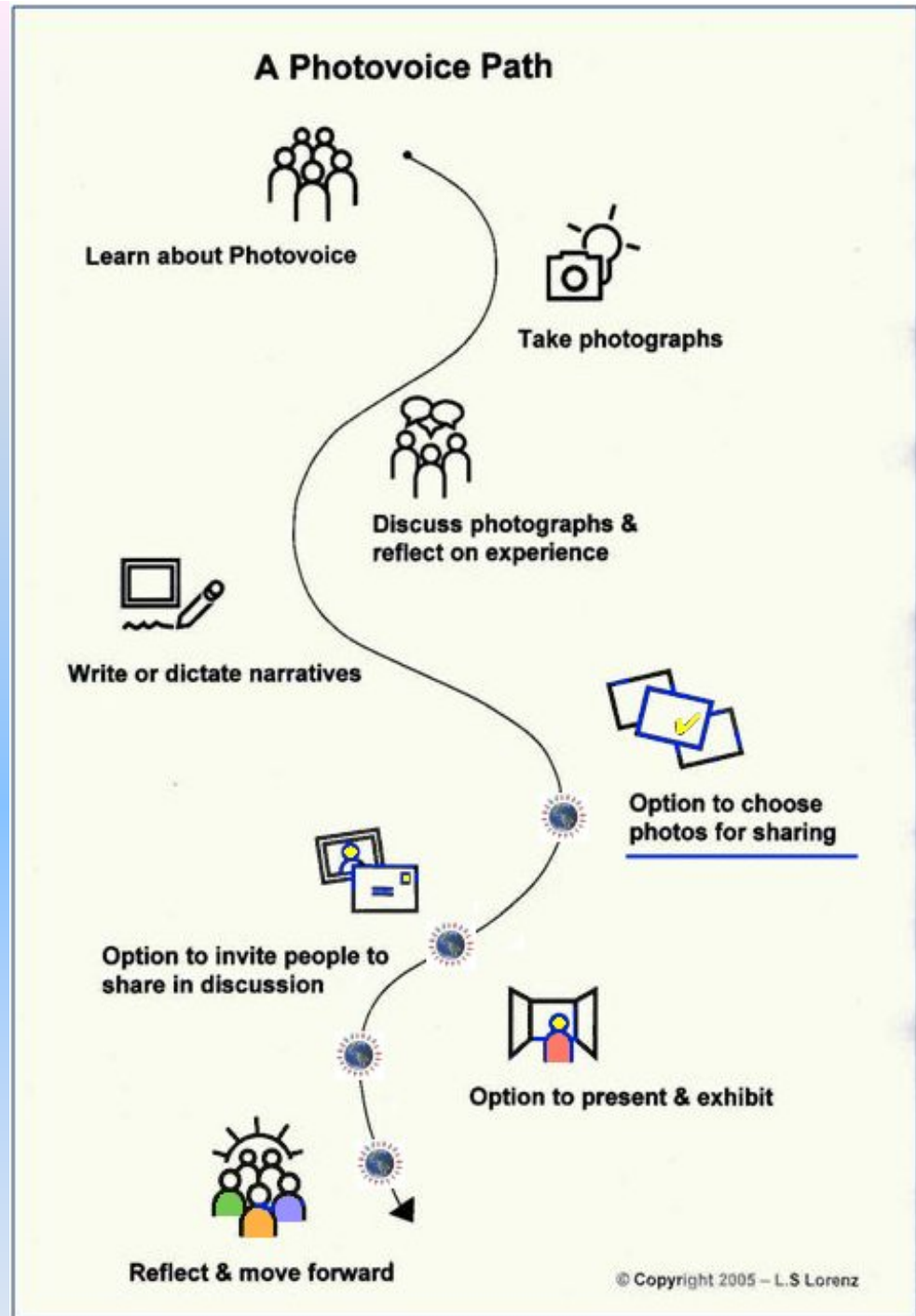
WHO do you want to reach?

WHAT are your messages?

WHY? What action(s) do you want them to take?

HOW? What types of media and products will reach them?

Photovoice helps people with TBI to be experts, teachers, and helpers





Brain Injury X-Posed Exhibit, Sherborn Library, Sherborn, MA, 2008
Source: Photovoice facilitator

Doing Your Own Photovoice Project

- Lorenz, L. S. and B. Webster. *Doing your own photovoice project: A guide*.
[http://www.brainline.org/multimedia/presentations/photovoice/Photovoice Facilitators Guide.pdf](http://www.brainline.org/multimedia/presentations/photovoice/Photovoice_Facilitators_Guide.pdf)
- **Contents:** Getting started, Photovoice tips, Photo-taking Questions, Photo-taking Tips, Photovoice Ethics: Safety and respect, Consent forms, Discussion questions, Building on your project, Exhibit options.
- See the “Brain Injury X-Posed” **photos and captions:**
<http://www.brainline.org/multimedia/photovoice.html>,
<http://www.lslorenz.com/currentprojects.htm>, and
<http://www.biama.org/whatdoes/photovoiceindex.html>

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Learn What Is Available

- Varies greatly state to state
- More awareness and support for TBI survivors now because of wars in Iraq and Afghanistan
- NASHIA – 2005 Guide to State Gov't BI Policies, Funding and Services
- BIAA – National Directory of Brain Injury Services
- Local hospitals – May provide low cost services, community services, or participation in research
- Arts and other organizations – can provide support group expertise

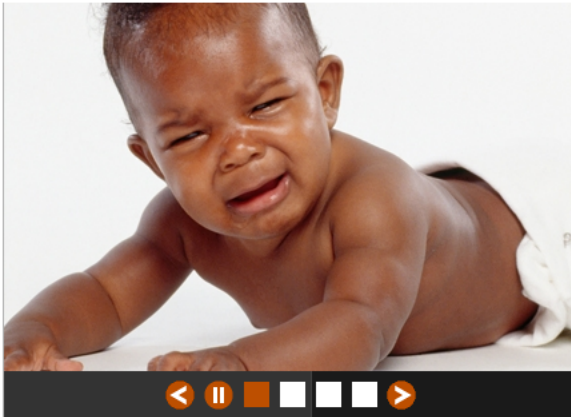
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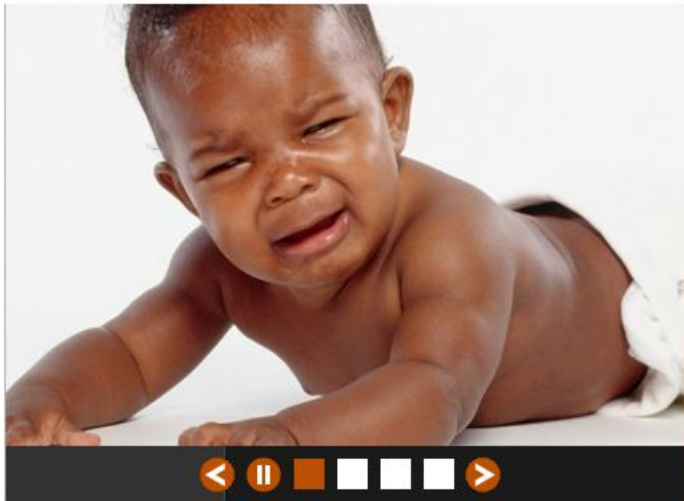
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The *Journal of Head Trauma Rehabilitation* announcement can be found [here](#).

*** Please see below for information regarding the new, fully electronic CBIS/CBIST application, testing, certification and renewal process which goes into effect November 1, 2010***

Welcome to the ACBIS Website!

The Academy of Certified Brain Injury Specialists (ACBIS) offers a voluntary national certification program for both entry-level staff and experienced professionals working in brain injury services. ACBIS provides staff and professionals the opportunity to learn important information about brain injury, to demonstrate their learning in a written examination, and to earn a nationally recognized credential.

ACBIS offers two certification options representing distinct levels of experience and supervisory skills: Certified Brain Injury Specialist (CBIS) and Certified Brain Injury Specialist Trainer* (CBIST). Certification is based on a comprehensive training manual that covers the following topics:

- Incidence and epidemiology of brain injury
- Continuum of services
- Brain anatomy and brain-behavior relationships
- Functional impact of brain injury
- Effective treatment approaches
- Children and adolescents with brain injury
- Health and medical management
- Family issues
- Legal and ethical issues

Certification is not restricted to any one profession or discipline. Rather, it is intended for anyone who delivers services specific to brain injury. [Please read Certification Disclaimer.](#)

*Previously known as Clinical Examiner and, most recently, ACBIS Trainer.

ACBIS Announcements

IMPORTANT - Please Read (Effective 11/1/2010)

- The paper application processes have been entirely replaced by online forms. For further information please click the appropriate category:

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Our books, manuals, tip cards and tool kits describe the symptoms, treatment, cognitive rehabilitation and recovery of individuals with brain injuries acquired due to trauma, blast injuries and concussion. Based on the latest brain injury research and best practices for clinicians, we have taken out the jargon and produced practical user friendly materials. They are written for clinicians, therapists, educators, advocates, caregivers and families for use in hospitals, rehabilitation programs, schools, private practice, community agencies and home settings.

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Every brain injury is different. The causes and consequences of brain injury are different for children, adolescents, adults and veterans. So we have produced special books, tip cards, manuals and tool kits just for them.

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Conclusion

- THI/TBI can change and challenge the entire family system
- A diagnosis can confuse the present, negate the past, and distort or destroy future dreams
- You can help families by
 - ✓ facilitating the process of learning, coping, adjusting, surviving, and living with THI/TBI
 - ✓ Providing relevant information, support, and tools
 - ✓ Validating family experience and helping them cope
 - ✓ Helping families recognize their strengths

Russell, 2009

Final Note

- Start – and end – with a healthy respect for each family's individuality



Thank you!

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