

# Holland Bloorview

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## Kids Rehabilitation Hospital

### The Family Experience After a TBI Back to School 2013 Conference

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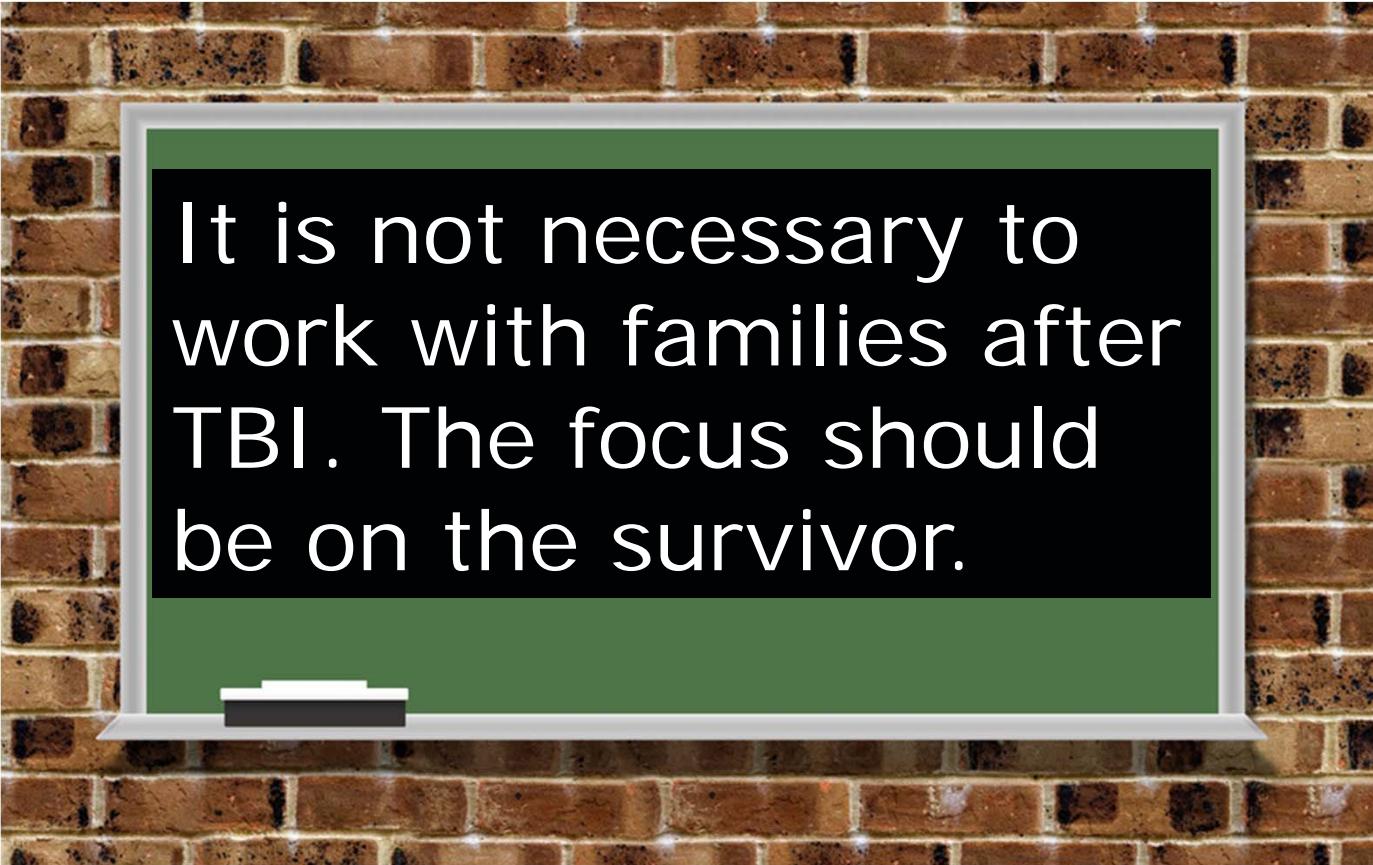
# Objectives

- Dispel common misperceptions and myths about families after TBI
- Highlight the need for family system intervention after brain injury
- Introduce two empirically-based family system interventions for families of adults and adolescents after brain injury

# Common Misperceptions and Myths about Families After Brain Injury



# MYTH #1

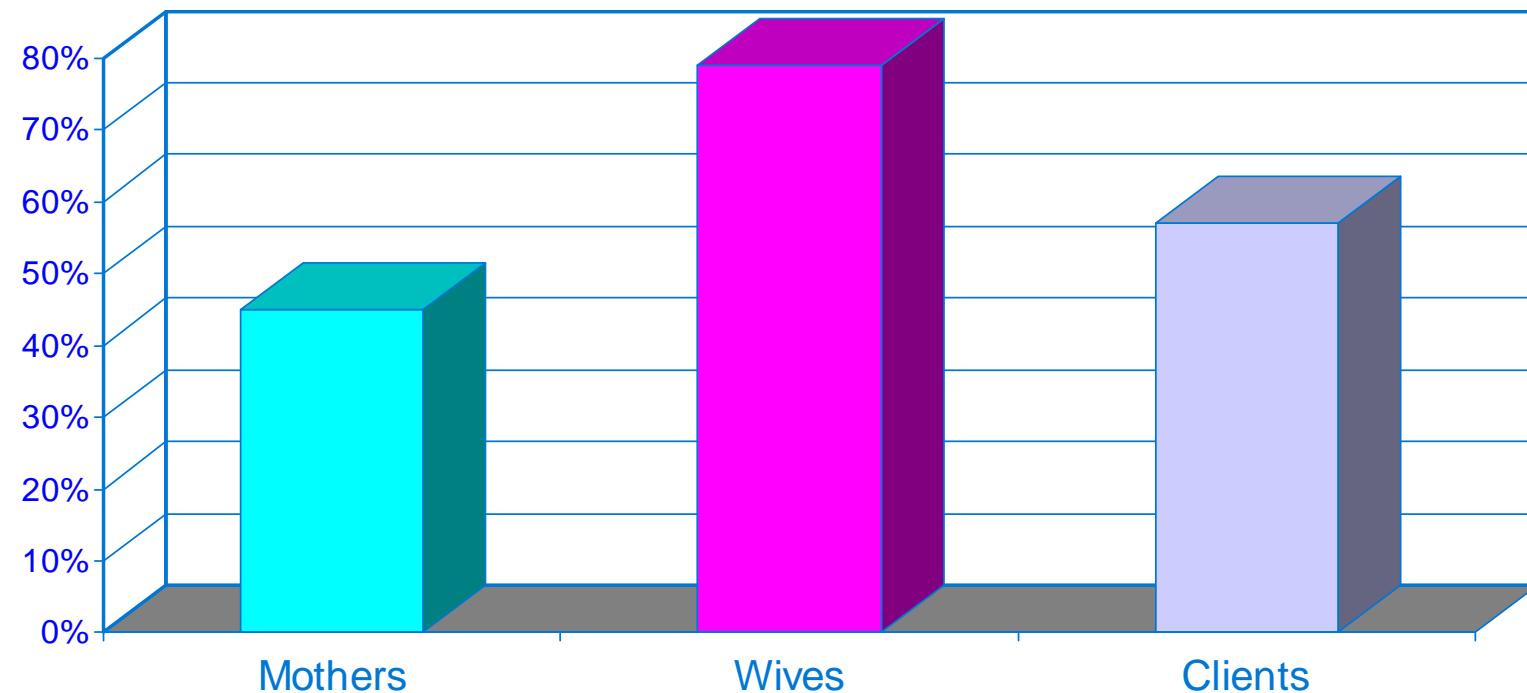


It is not necessary to work with families after TBI. The focus should be on the survivor.

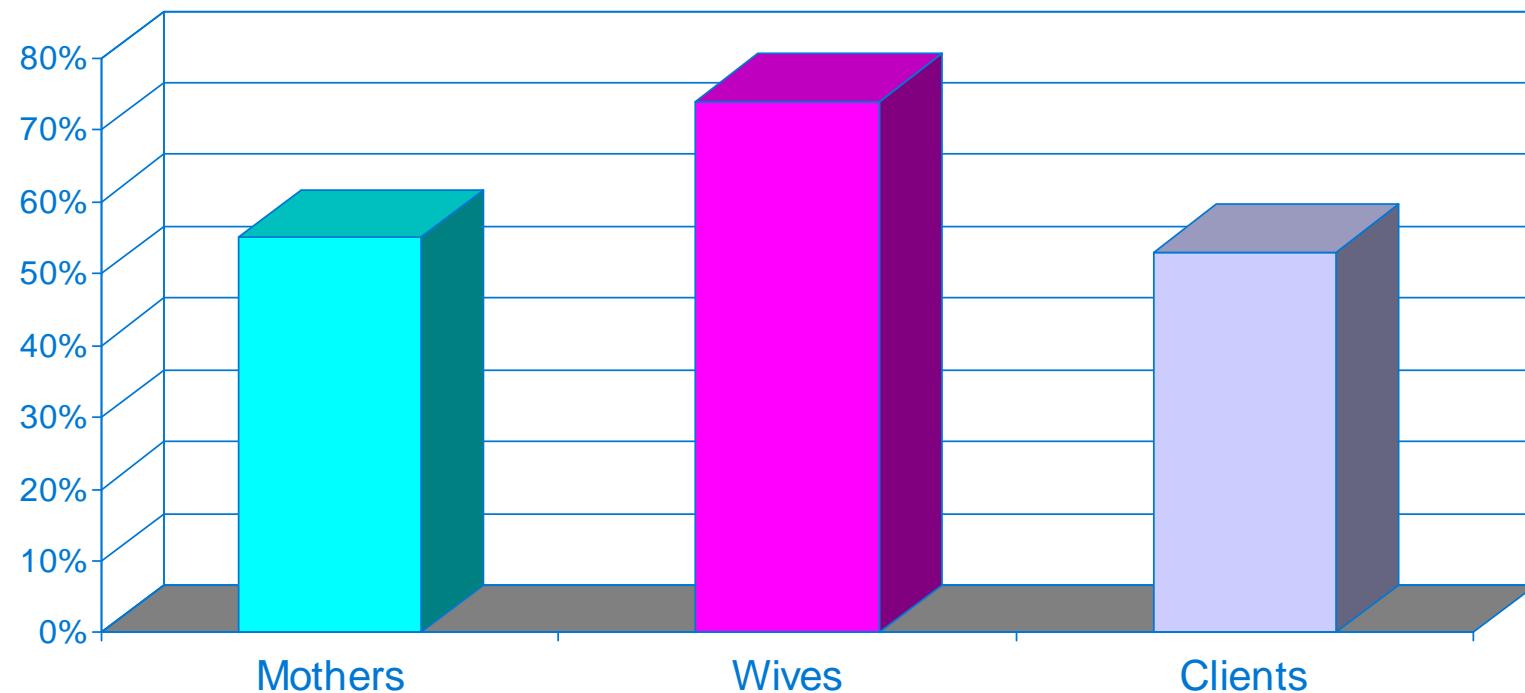
# Importance of Paying Attention to the Family Post TBI

- Family members are typically the major support for individuals post TBI
- Long-term negative effects on family functioning (Anderson et al., 2002; Gan & Schuller, 2002)
- Survivor outcome is linked to family outcome (Sander et al., 2002; Taylor et al., 1995)

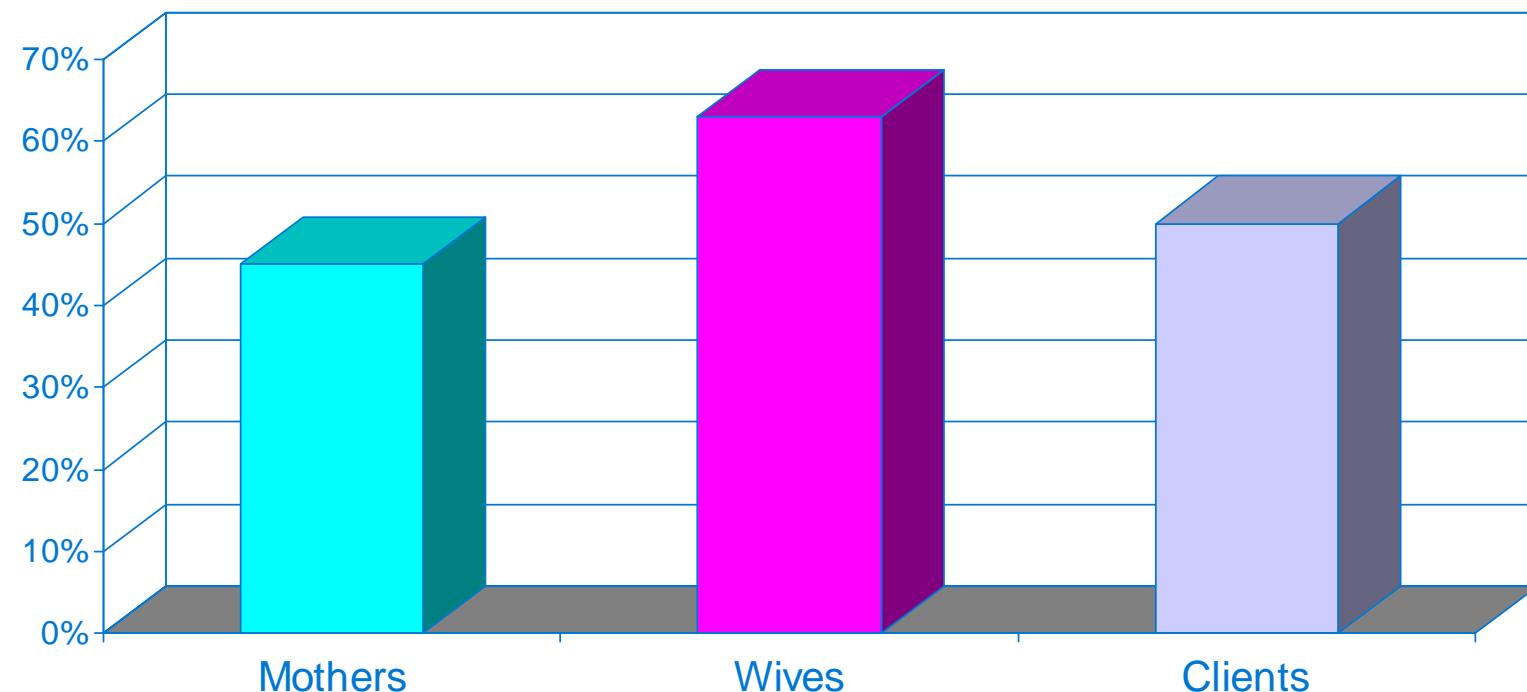
# Depression After Brain Injury



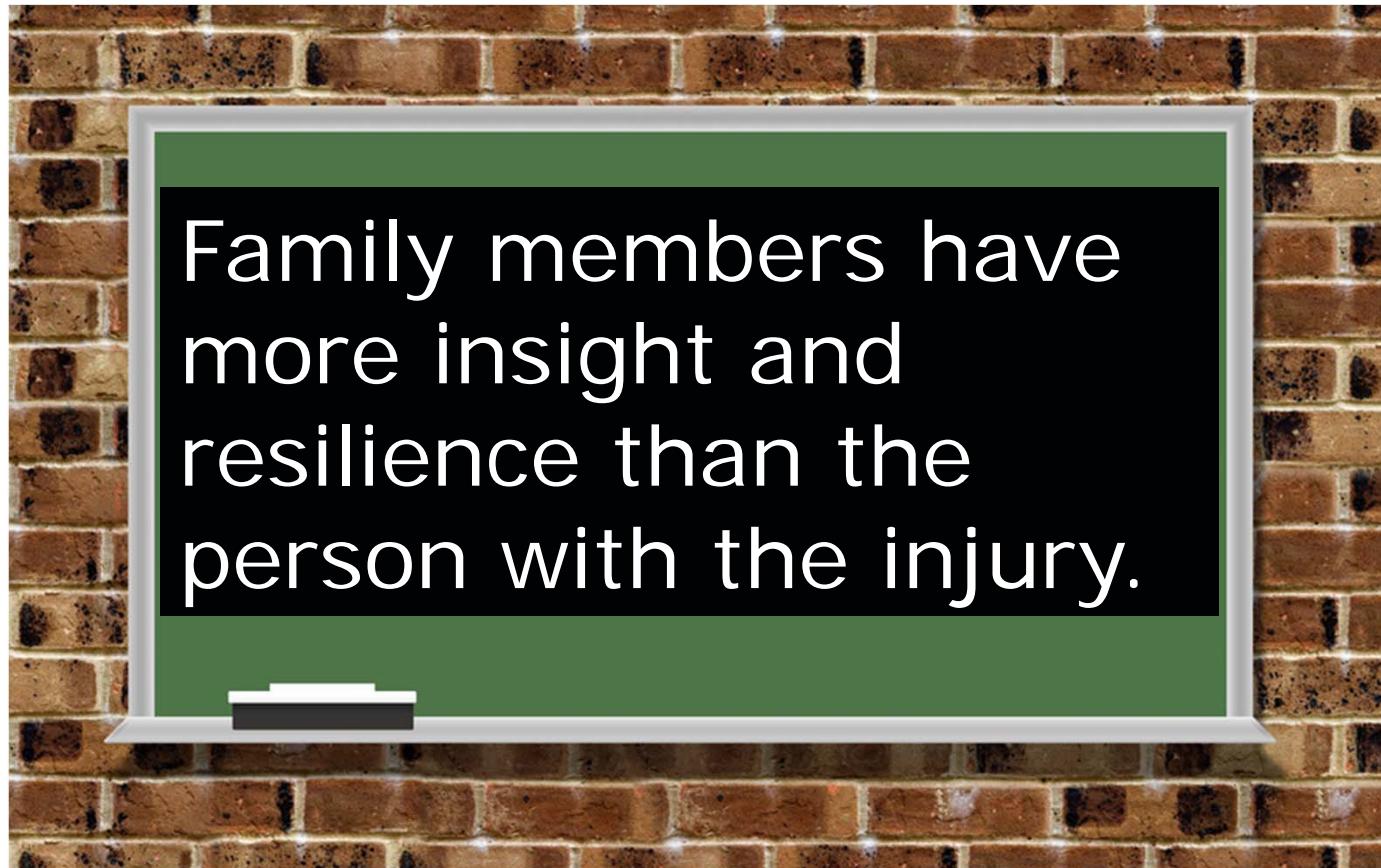
# Irritability After Brain Injury



# Anger After Brain Injury

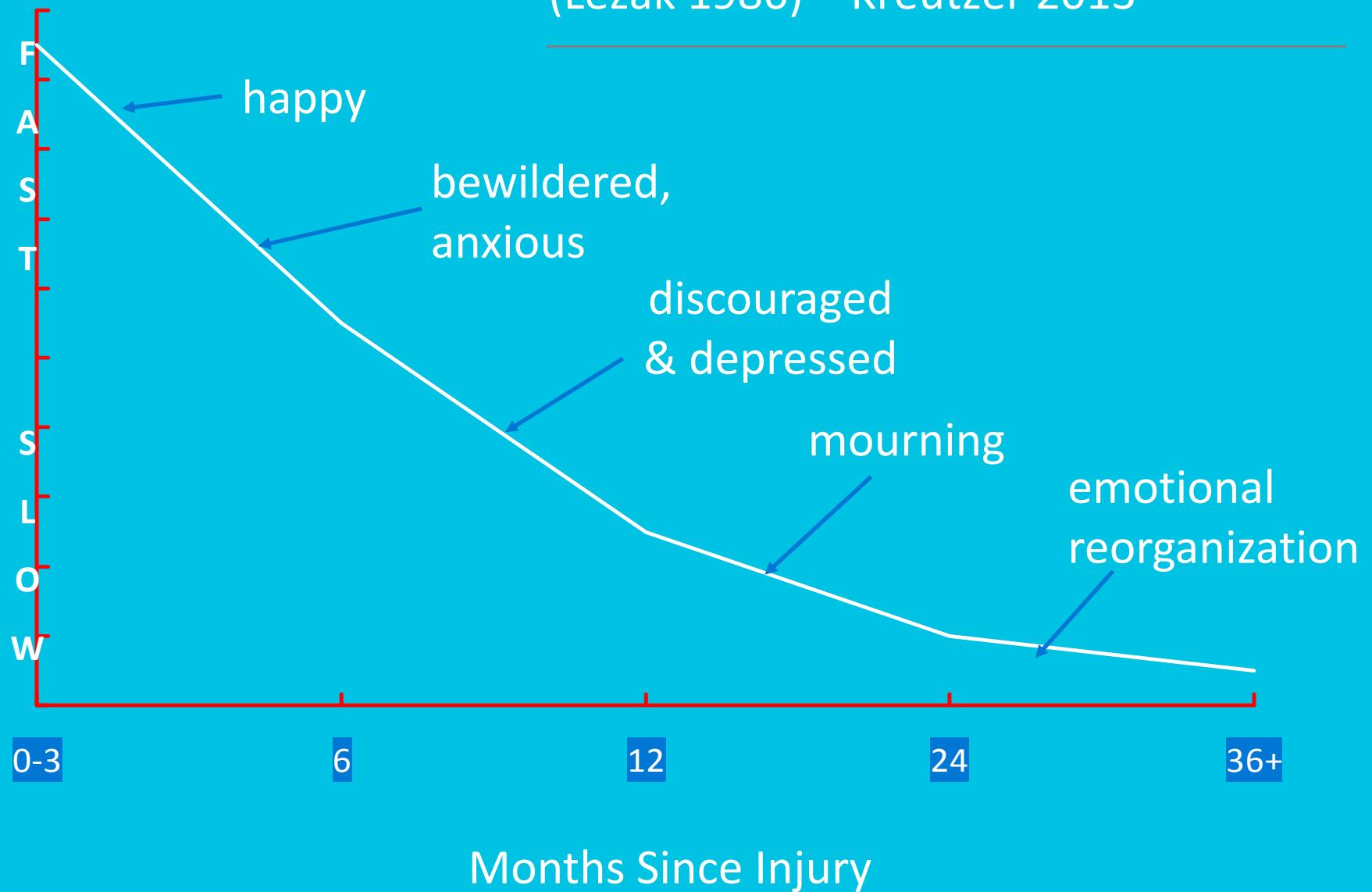


## Myth #2



Recovery Rate

## Family Reactions to Rates of Survivors' Improvement (Lezak 1986) – Kreutzer 2013



# Impact of TBI on Caregivers

- Family strain, psychological distress in 47% of relatives (Kreutzer et al., 1994)
- Negative life change in 67% of spousal or parent caregivers (Wallace et al, 1998)
- Symptoms of depression (73%) & anxiety (55%) in spouses (Linn et al., 1994)
- 47% of caregivers had altered or given up jobs @ 1 year post injury (Hall et al., 1994)
- Increased use of alcohol & medications (Hall et al., 1994)

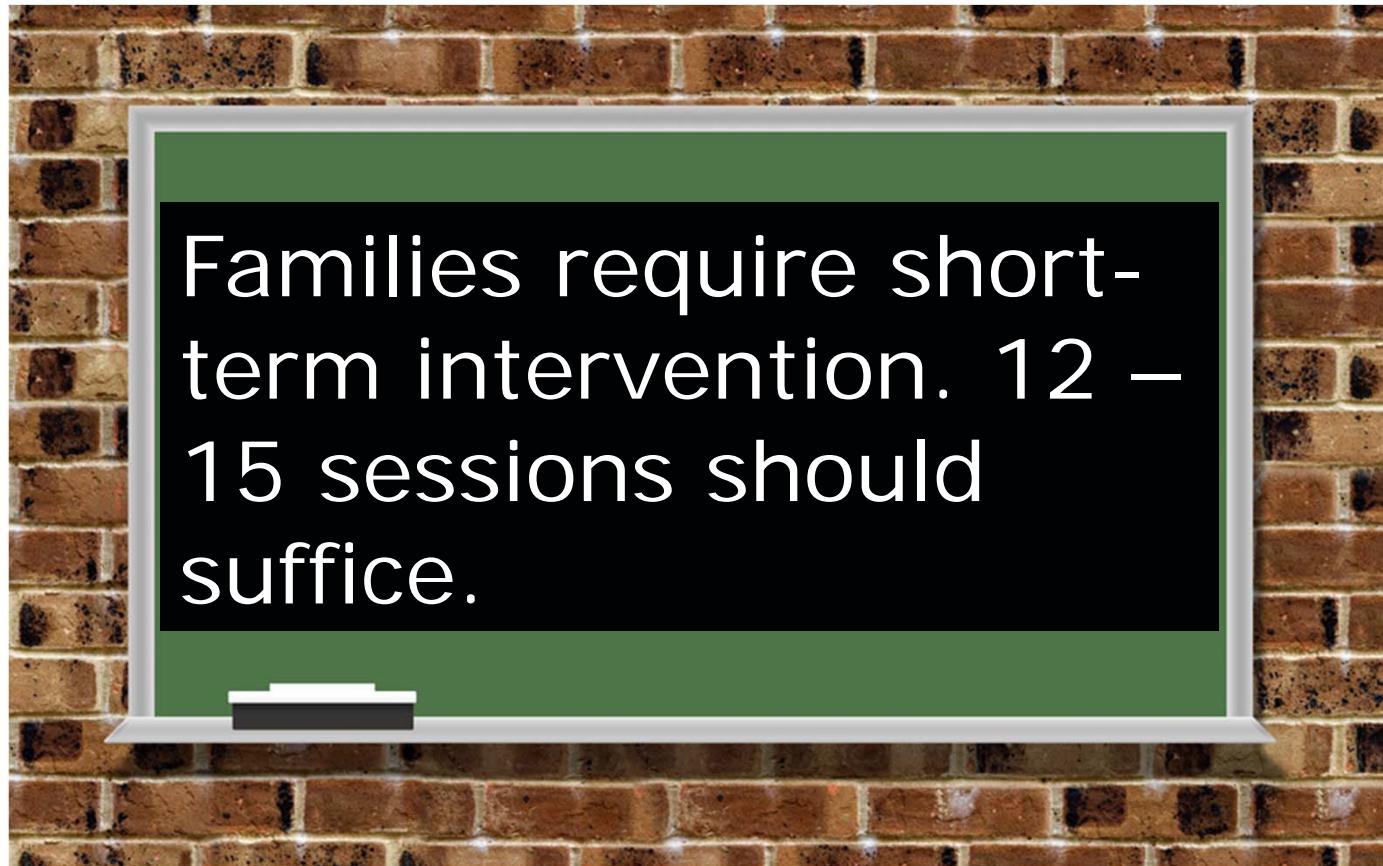
# Ten Problems Most Frequently Reported by Relatives (Brooks et al., 1986)

Problem	<u>Percent Relatives Reporting</u>	
	<u>1 year</u>	<u>5 years</u>
• Personality change	60	74
• Slowness	65	67
• Poor Memory	67	67
• Irritability	67	64
• Bad Temper	64	64
• Tiredness	69	62
• Depression	51	57
• Rapid mood change	57	57
• Tension & anxiety	57	57
• Threats of violence	15	54

# Family Needs After TBI

- Unmet needs around health information, professional support, and community support (Armstrong et al., 2002)
- Unmet health care needs associated with increased caregiver burden (Aitken et al., 2009)
- Physical and cognitive recovery stabilizes, psychosocial and behavioral difficulties emerge → increased stress on families (Anderson et al., 2005)
- 2/3 of parents report unmet needs around health information, medical support, family support and return to school 2 – 4 years post-rehab (Hermans et al, 2012)

# Myth #3



# Family Burden

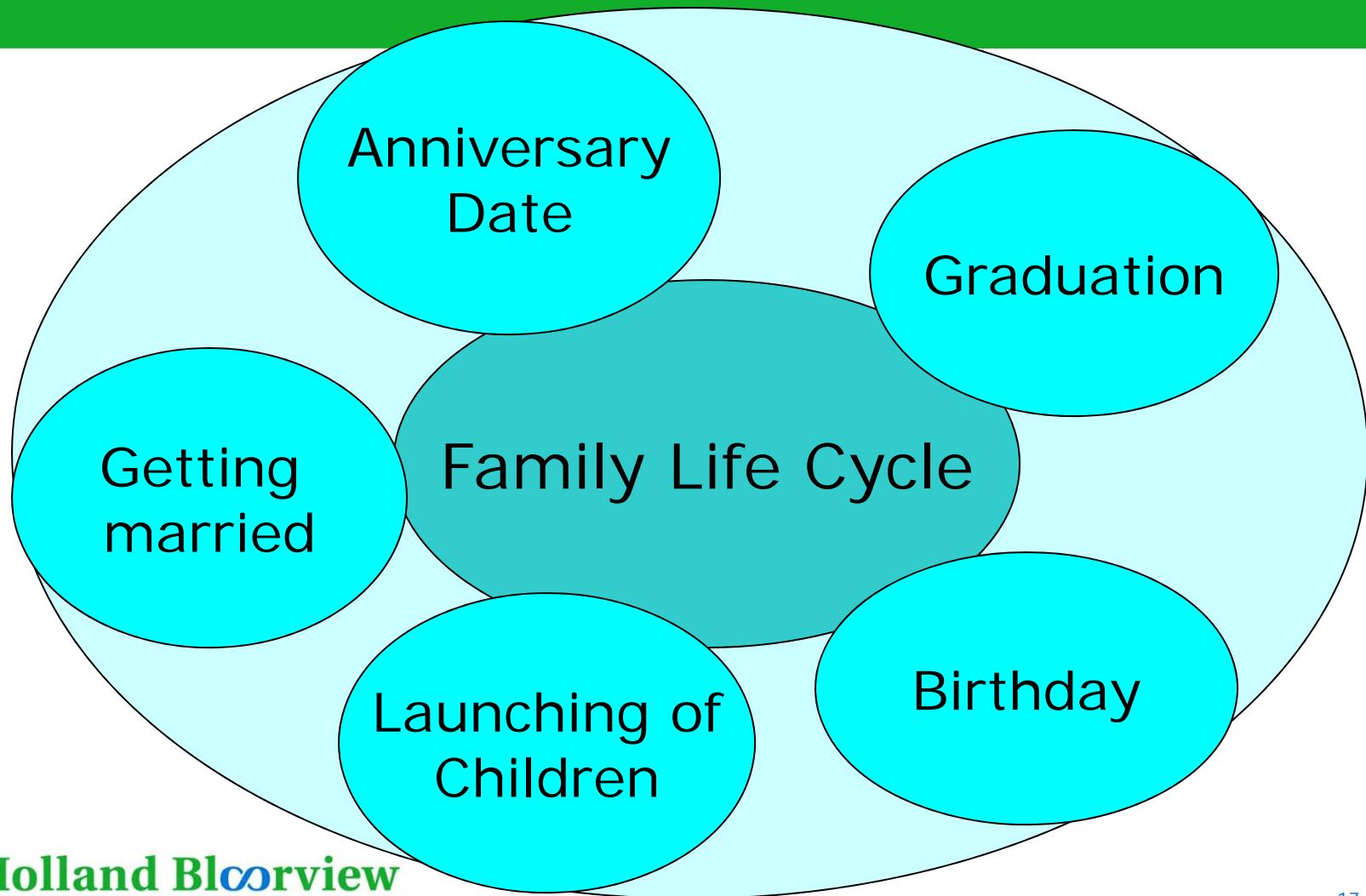
	<b>1 year</b>	<b>5 years</b>
<b>Low</b>	43%	10%
<b>Medium</b>	33%	33%
<b>High</b>	24%	56%



## Family Burden (cont'd)

- Family burden remained significant @ 7 years post-injury (Brooks et al., 1987)
- Physical changes cause the least burden
- Emotional, behavioral, and personality changes in survivor cause the most burden, NOT injury severity

# Episodic Loss Reaction

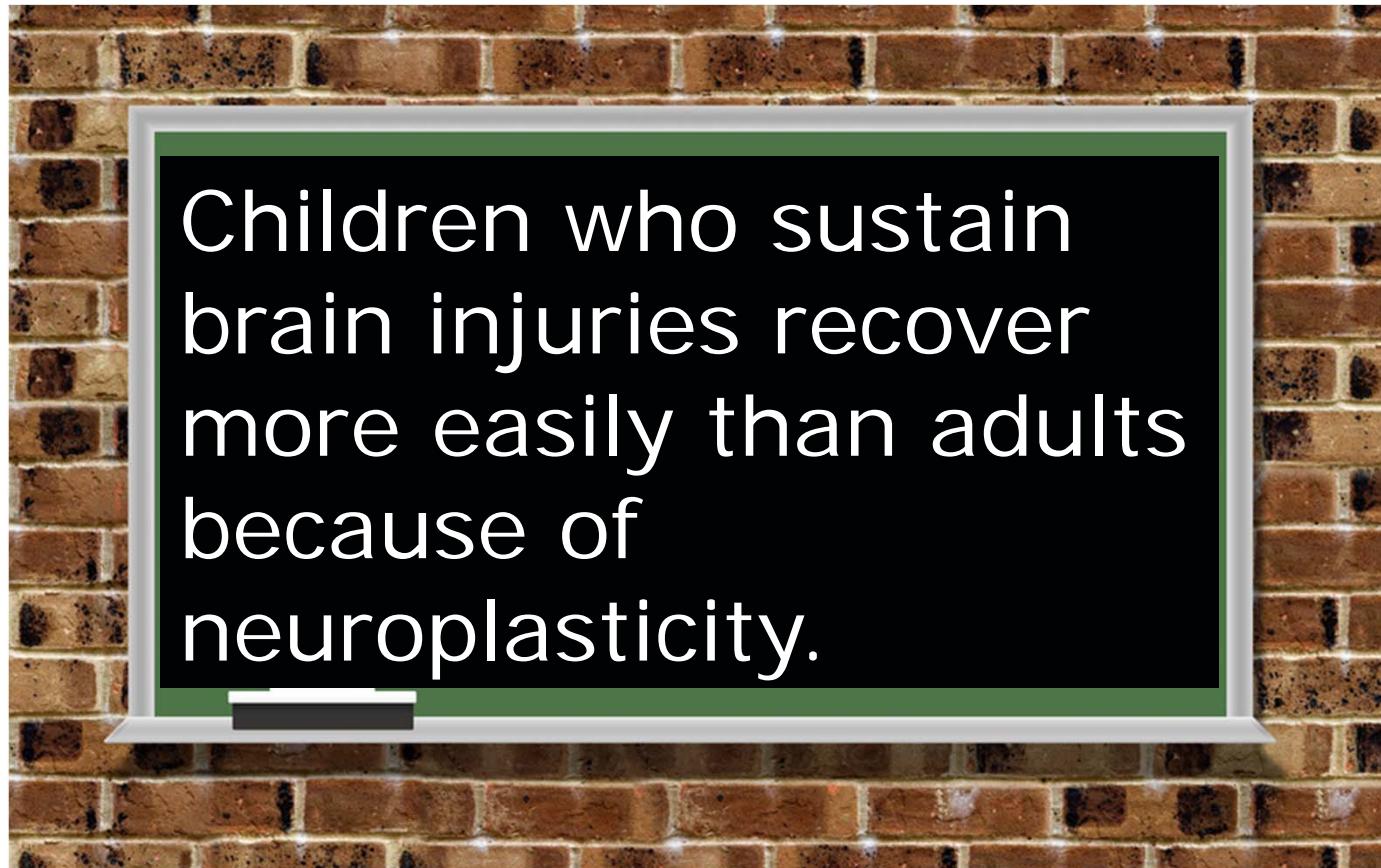


# Need for Life Course Perspective After Pediatric TBI

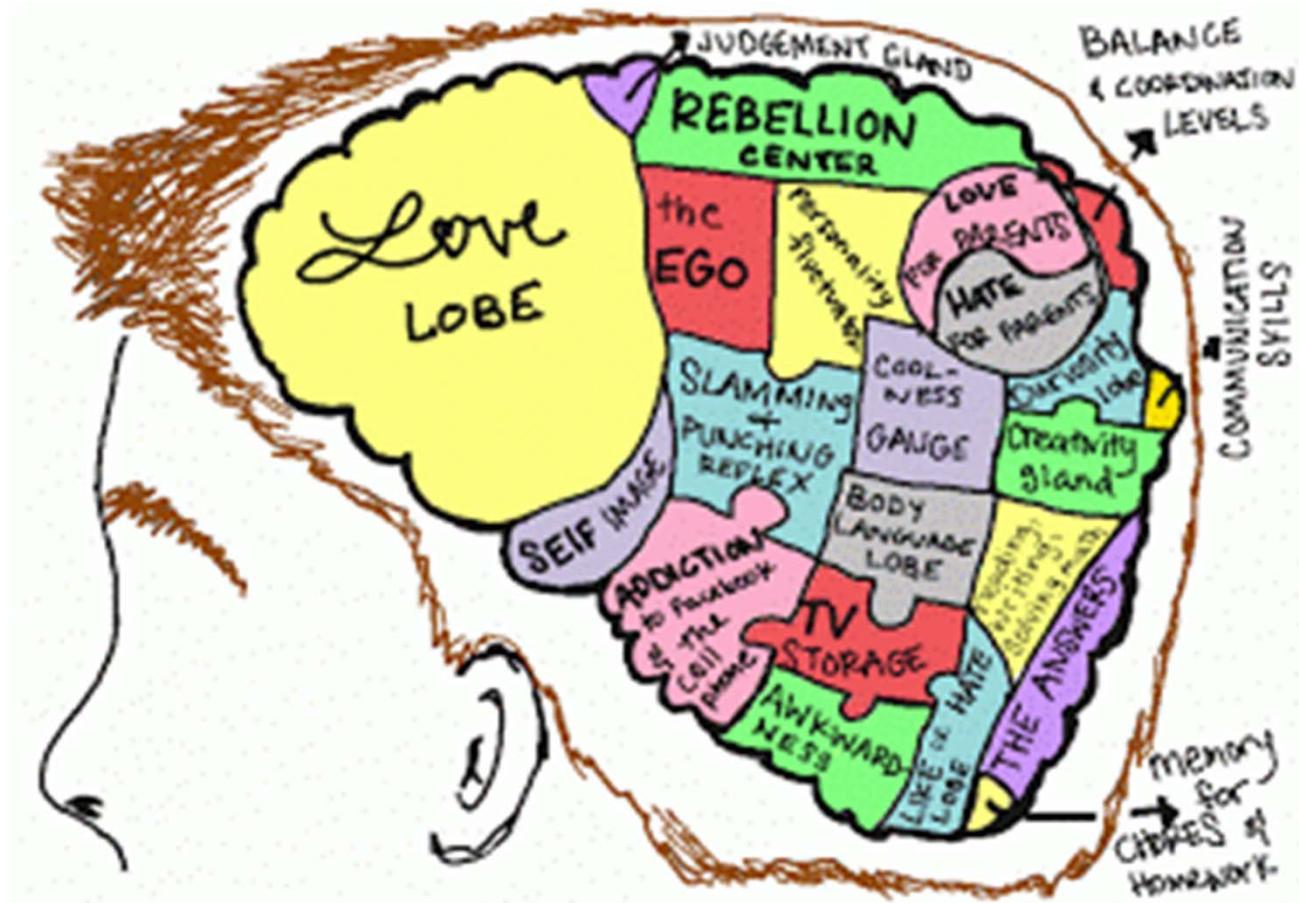
- Children's brains are still developing
- Recovery patterns differ from those of adults
- Children often "grow into" their disabilities
- Adolescence is a time of heightened vulnerability
- Attainment of life skills and transition to adulthood more challenging

(Gan et al, 2012)

## Myth #4



# Adolescent Brains – Works in Progress



# Timing of TBI in Childhood

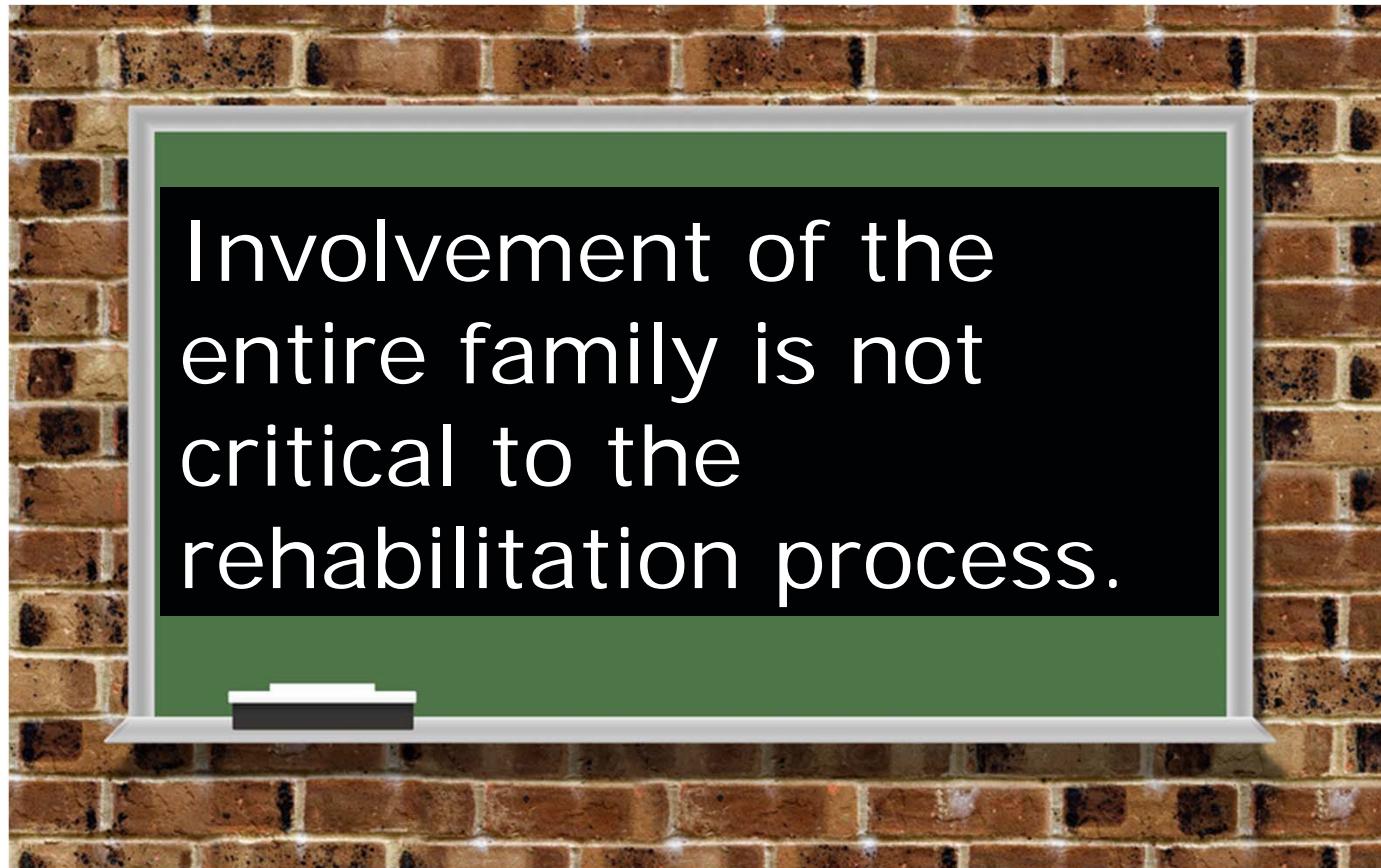
- Recovery is influenced by age of injury
- **Children injured in middle childhood (7 – 9 years) appear to be particularly vulnerable**
- Preschool age (3 – 6 years) and infancy (2 mo. – 2 years) are also times of vulnerability
- Sustaining a TBI in late childhood (10 – 12 years) displayed best outcomes

(Crowe et al, 2012)

# Impact of Pediatric TBI on Families

- Significant levels of anxiety and depression in 40% of parents (Wade et al., 1998)
- High levels of psychological distress and family burden (Anderson et al., 2005)
- Injury related burden persisted up to 6 years post injury (Wade et al., 2006)
- Struggles with work and finances are significant family stressors (Aitken 2009)

# Myth #5



Increased  
parental stress

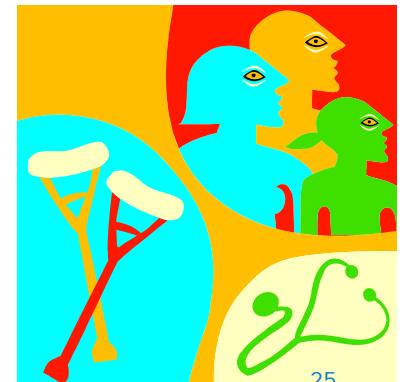


Poorer family  
outcome

Behavior  
problems in  
child with ABI

# Impact of TBI on Family System

- Disruption of family roles
- Shifting responsibilities
- Safety issues
- Family strain
- Financial strain
- Social isolation
- Prolonged caretaking demands



# Impact on Spousal/Marital System

Decline in sexual functioning  
Loss of companionship  
Caregiver strain

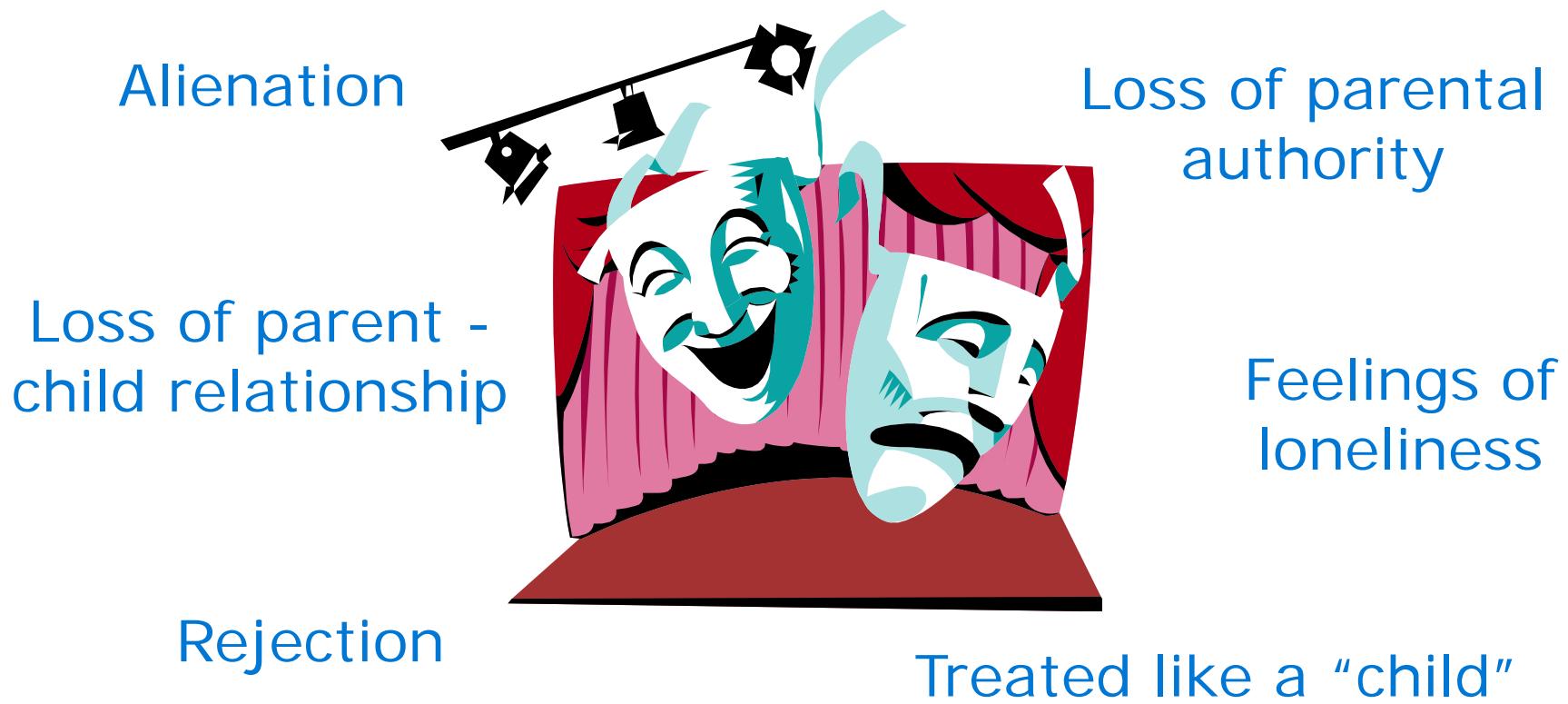


Increased dependency

Loss of intimacy

Loss of partnership

# Impact on Parenting (injured parent)

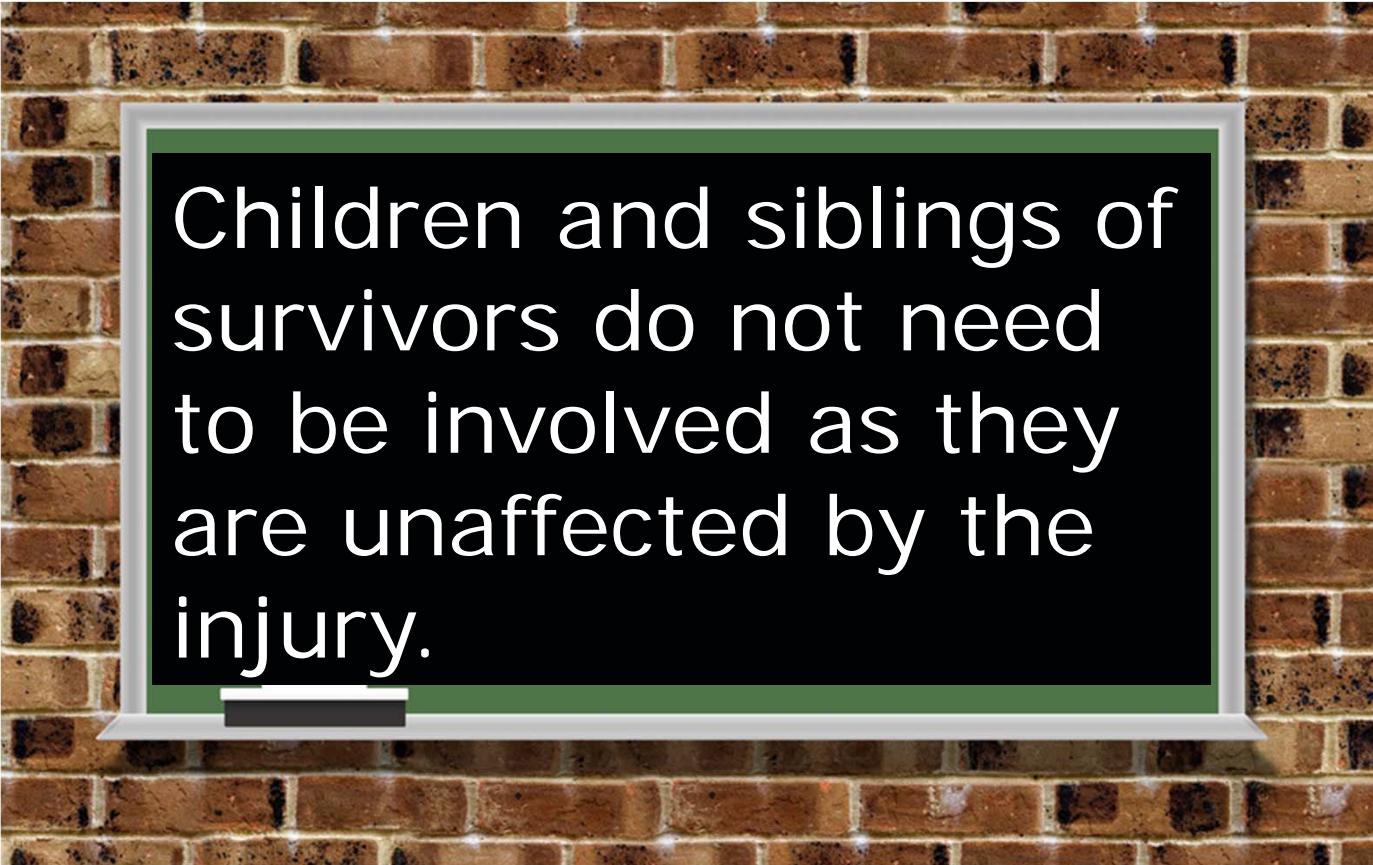


# Impact on Parenting (non-injured parent)

- Divided loyalties
- Juggling multiple demands
- Disruption of power balance
- Feeling overwhelmed
- Discipline problems
- “I feel like a single parent”
- “It’s like having another child”



# Myth #6



Children and siblings of survivors do not need to be involved as they are unaffected by the injury.

# Sibling Response to Pediatric TBI

- 46% - emotional reactions, school problems or aggressive personality changes (Harris et al., 1989)
- Increase in personal responsibilities, family distress, concern for the future (Willer et al., 1990)
- Need for support, information about ABI, direction, and communication (O'Hara et al., 1991)
- Increased psychological distress and less effective problem solving (Orsillo et al., 1993)
- Loss of parental affection (Peretti et al., 1995)

# Sibling Adjustments

- Needs often unrecognized
- May be target of inappropriate behaviour
- Added responsibilities
- Role reversal
- Limited supports



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# Effects of Parental Brain Injury on Children

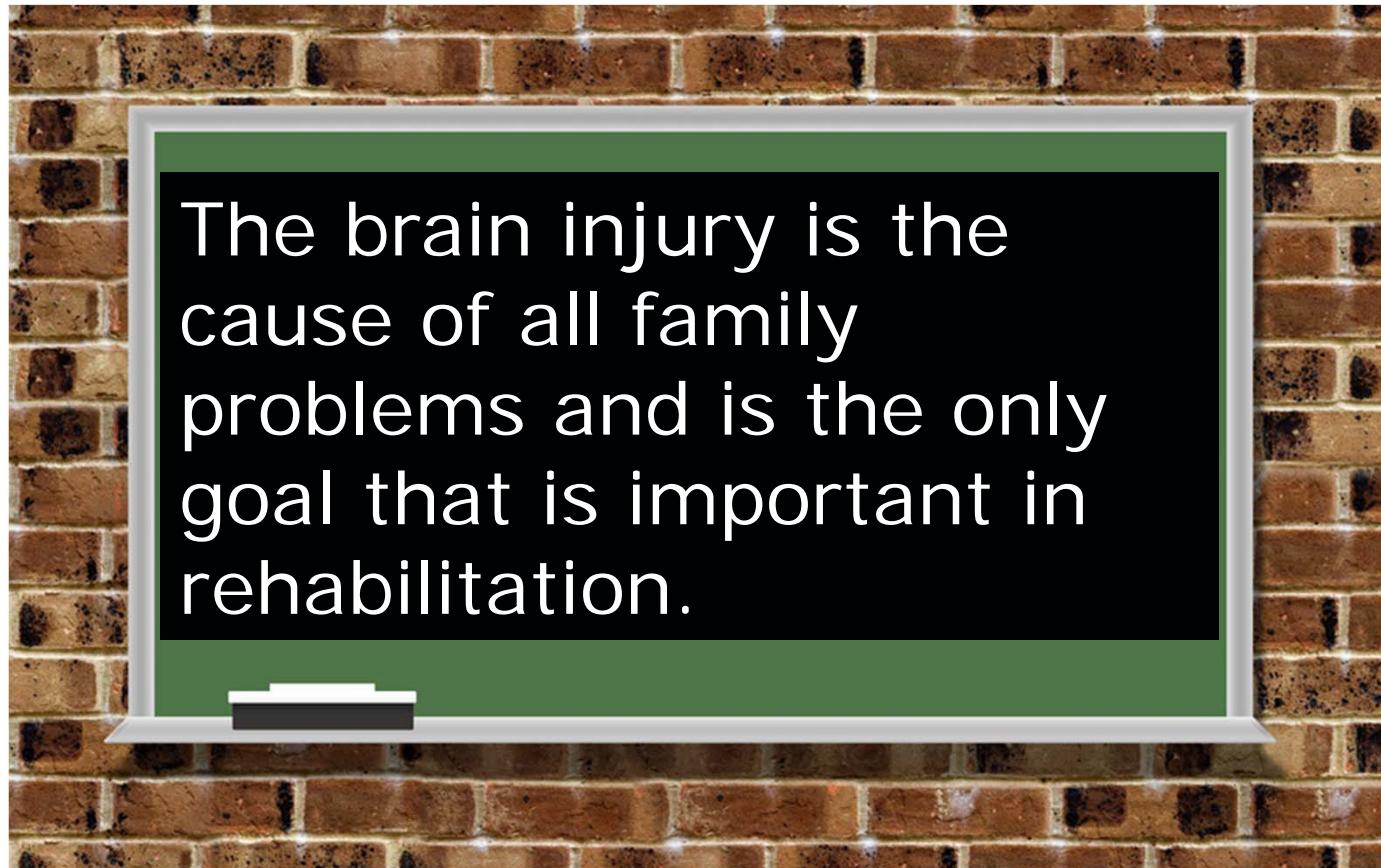
- Negative behavioral change in 90% of sample (Pessar et al., 1993)
- Parents perceived as more lax in discipline (Uysal et al., 1998)
- Non-injured parent less actively involved
- Increased depression

# Children Who Have a Parent With Brain Injury

- Fear around personality & behavioral changes
- Role changes - increased responsibilities
- Compromised social relationships
- Fewer positive interactions with injured parent
- Loss - one or both parents



# Myth #7



# It's rarely just the ABI!



# How can we be proactive around the needs of families after TBI?

- Involve other members of the family around TBI education
- Provide information and education around the common experiences of families after TBI
- Link families to local and provincial brain injury resources (i.e. BIST, OBIA)
- Encourage families to attend support groups and caregiver workshops
- Assess the needs of the family system and every family member, including the children in the family
- Put in separate claim for family members

# Empirically-Based Brain Injury Family System Intervention Programs

- **Brain Injury Family Intervention (BIFI)**

Kreutzer, Stejskal, Godwin, Powell & Arango-Lasprilla. A mixed methods evaluation of the Brain Injury Family Intervention. *NeuroRehabilitation* 2010; 27:19-29.

- **Brain Injury Family Intervention for Adolescents (BIFI-A)**

Gan, Gargaro, Kreutzer, Boschen & Wright. Development and preliminary evaluation of a structured family system intervention for adolescents with brain injury and their families. *Brain Injury* 2010; 24(4): 651–663.

# Brain Injury Family Intervention Training (BIFI/BIFI-A): An Evidence-Based Approach

## April 24 – 25, 2013

This two-day intensive workshop focuses on clinical intervention skills for professionals (e.g., social workers, psychologists, therapists, rehabilitation counselors) who work with families of persons who have sustained a brain injury.



# Holland Bloorview

## Kids Rehabilitation Hospital

*From disability to possibility*

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## Select References

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