



Weaving a Web of Family Support After ABI

ABI Network Conference 2008

Caron Gan, RN, MScN, AAMFT Approved Supervisor

Investigative Team

Caron Gan – Bloorview Kids Rehab

Virginia Wright – Bloorview Research Institute

Kathryn Boschen – Toronto Rehabilitation Institute

Jeffrey Kreutzer – Virginia Commonwealth University

Judy Gargaro – Bloorview Kids Rehab

Funded by Bloorview Research Institute

Acknowledgements



Expert Panel

Anna Marie Batelaan
Pauline Berry
Jeanette Cato
Lies Ferriman
Bill Ferriman
Mary Ellen Keyes
Daniel Perry
Beverly Perry
Douglas Schmidt
Beverly Solomon

Test Clinicians

Rebecca Swift-Weir
Kathy Gravel
Valerie Lusted

Participant Families

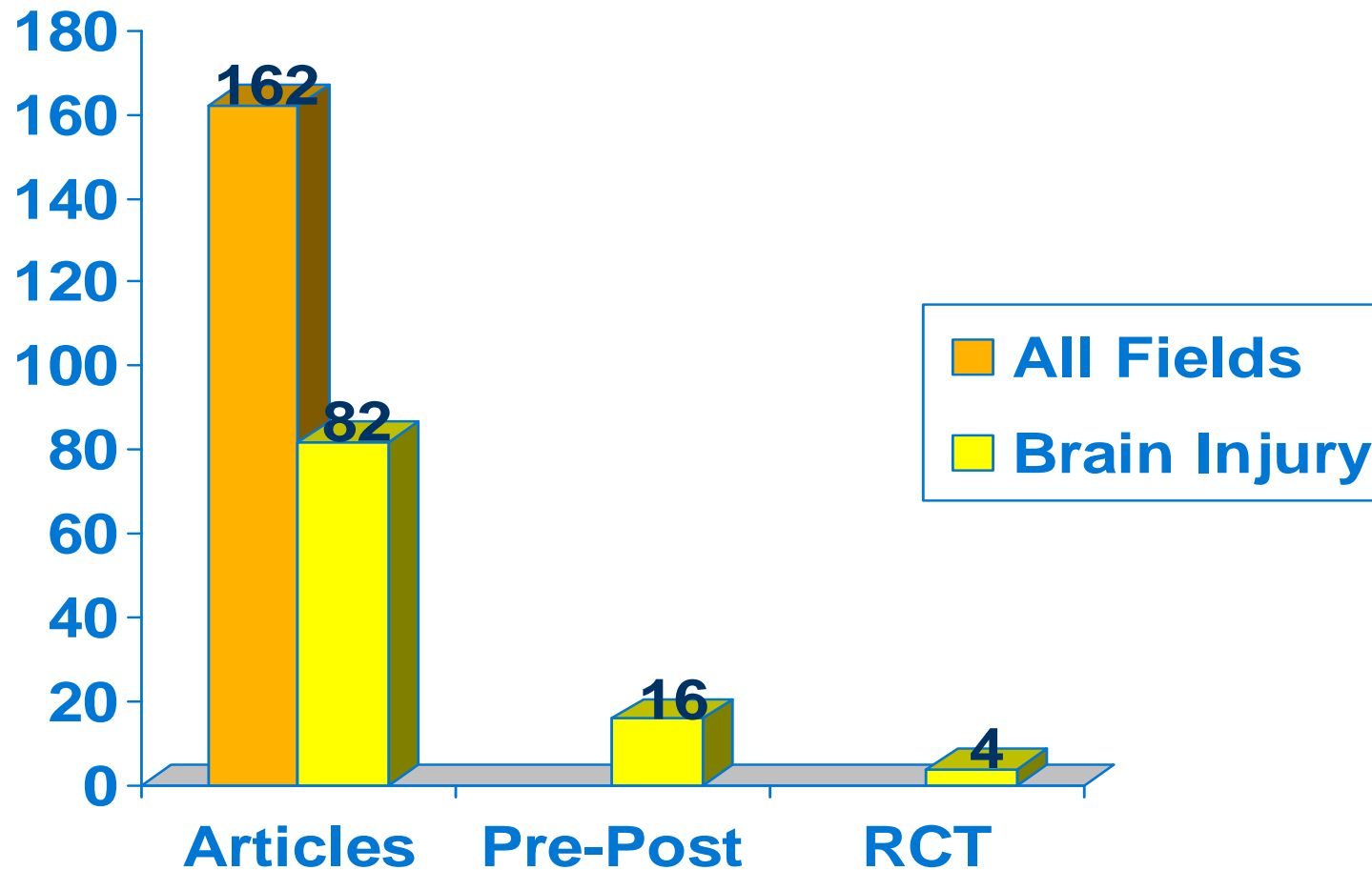
Virginia Commonwealth University

The Problem

- Impact of brain injury on the family system
- Increased strain, depression, burden, anxiety and psychological distress in family members
- Long-term negative effects on family functioning
- Relationship between family and individual outcomes
- Support, counselling, information, and educational needs
- Lack of evidence-based family interventions

The Research Evidence

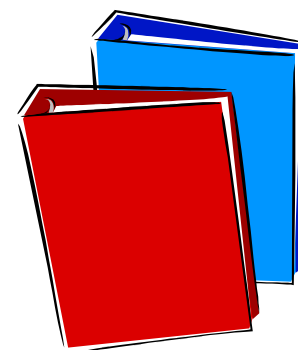
– Family Interventions After Brain Injury
(Boschen, Gargaro, Gan, Gerber, & Brandys, 2007)



The Brain Injury Family Intervention (BIFI)

(Kreutzer, Kolakowsky-Hayner, Demm, Meade, 2002)

- Guided by 30 years of research and clinical experience
- Structured family system intervention
- Focus on education, skill building, and support
- Five-session ten-week intervention
- Each session 1 ½ to 2 hours
- Manualized into a step-by-step protocol
- NIDRR grant to evaluate efficacy of BIFI – RCT Virginia Commonwealth University TBI Model System

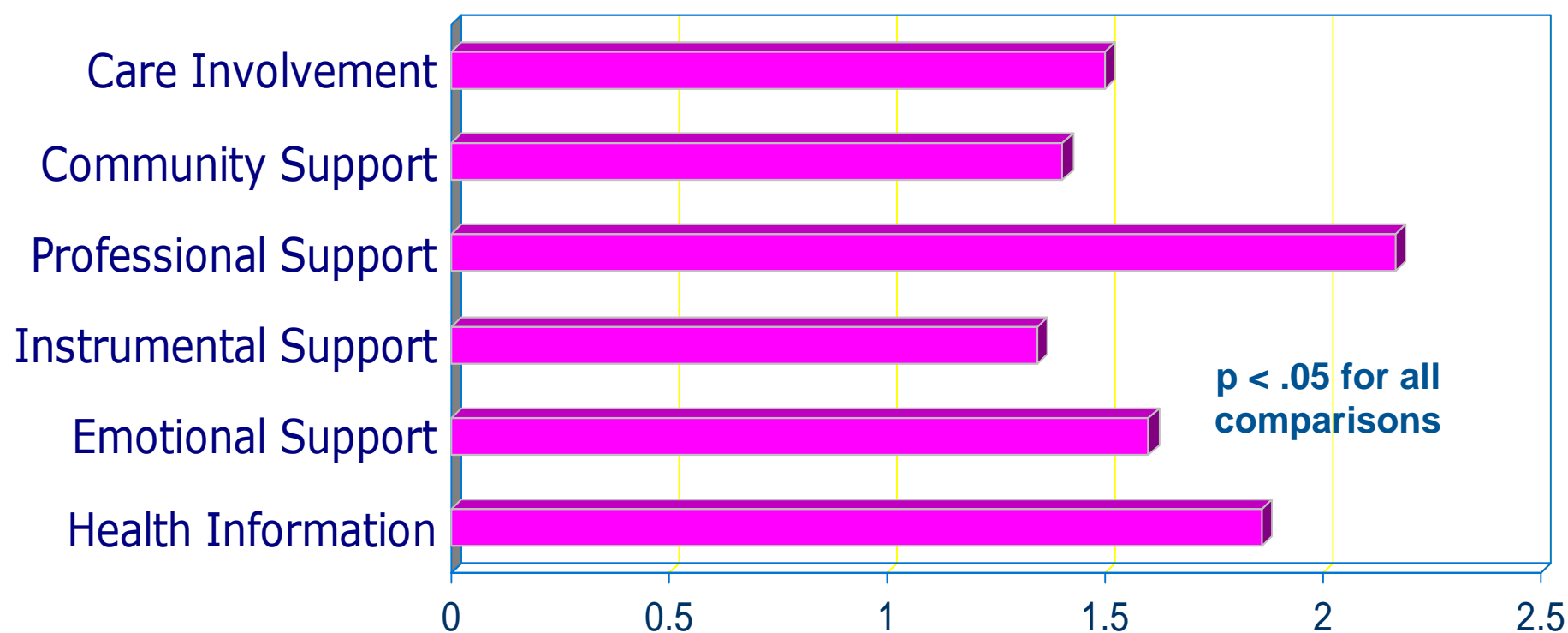


BIFI Goals

1. Information about common challenges after ABI
2. Impact on family members and the family as a system
3. Problem solving skills
4. Coping strategies
5. Strengths and progress
6. Effective communication skills
7. Foundation of knowledge and strategies to move forward

FNQ Subscale Score Post-Intervention Changes

(change in mean number of met needs)

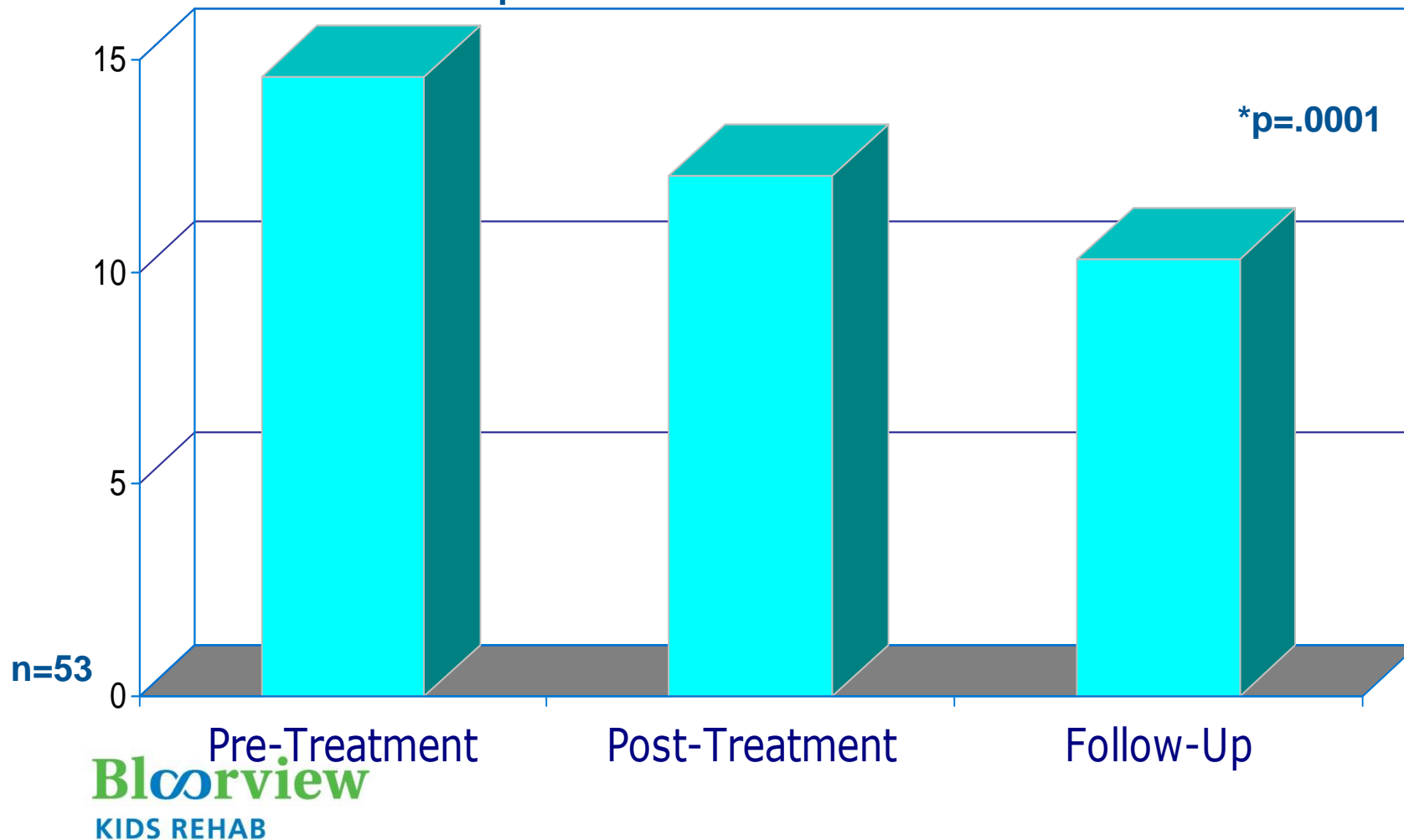


n=53

change pre- vs. post-treatment

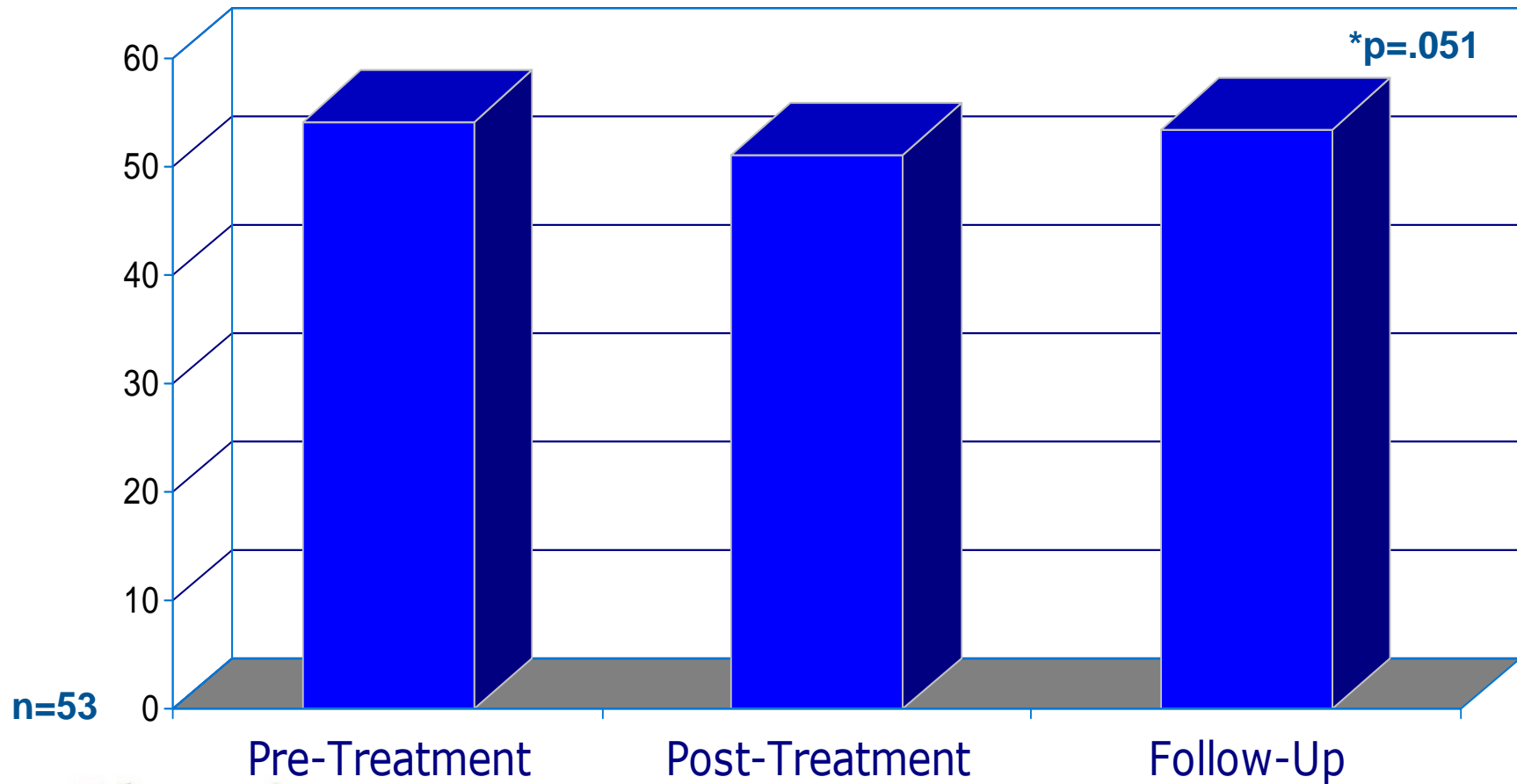
Service Obstacle Scale

****lower scores denote fewer perceived obstacles**



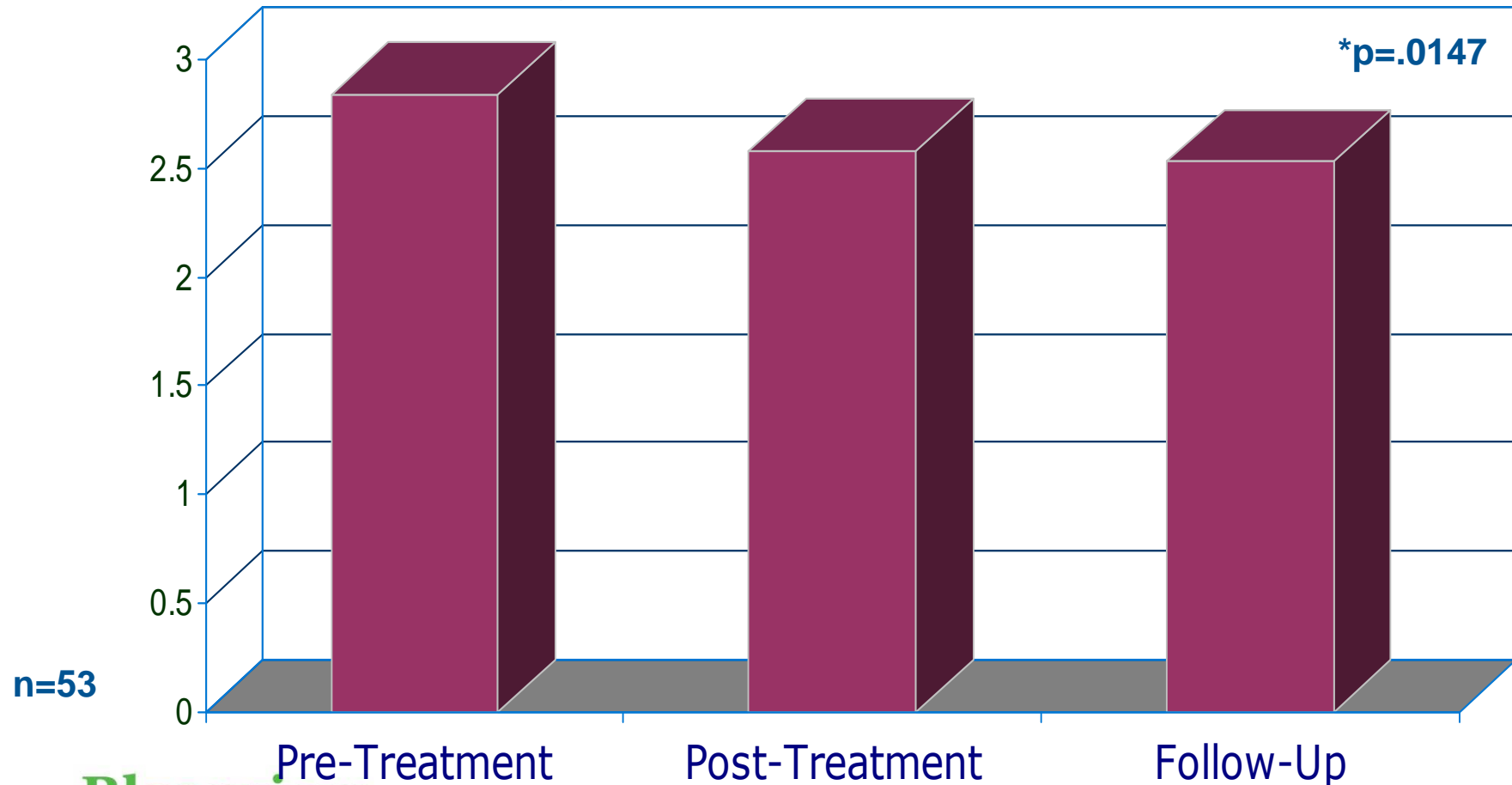
Depression Subscale Brief Symptom Inventory

****lower scores denote lower levels of emotional distress**



Neurobehavioral Functioning Inventory Depression Scale

family members' ratings of the client



Applicability of BIFI to Adolescents?

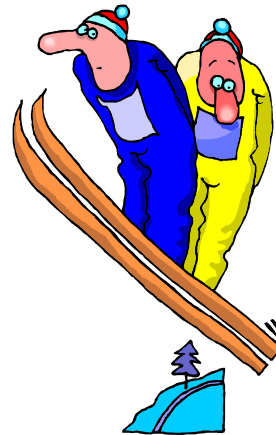
- Recovery patterns differ
- Growing into injury
- Developmental issues
- Transition to adulthood



Entering the World of Adolescents # * !

It is common for adolescents to:

- Argue for the sake of arguing
- Be self-centred
- Challenge authority
- Be moody
- Behave impulsively
- Take unnecessary risks



Whatever It Takes (WIT) Model of Family Intervention

- Monroe (1990)
- Based on work with highly dysfunctional families
- Principles of behavioural conditioning
- Family systems orientation
- Shortcomings – poorly designed, non-experimental
- Single case study – shows some promise



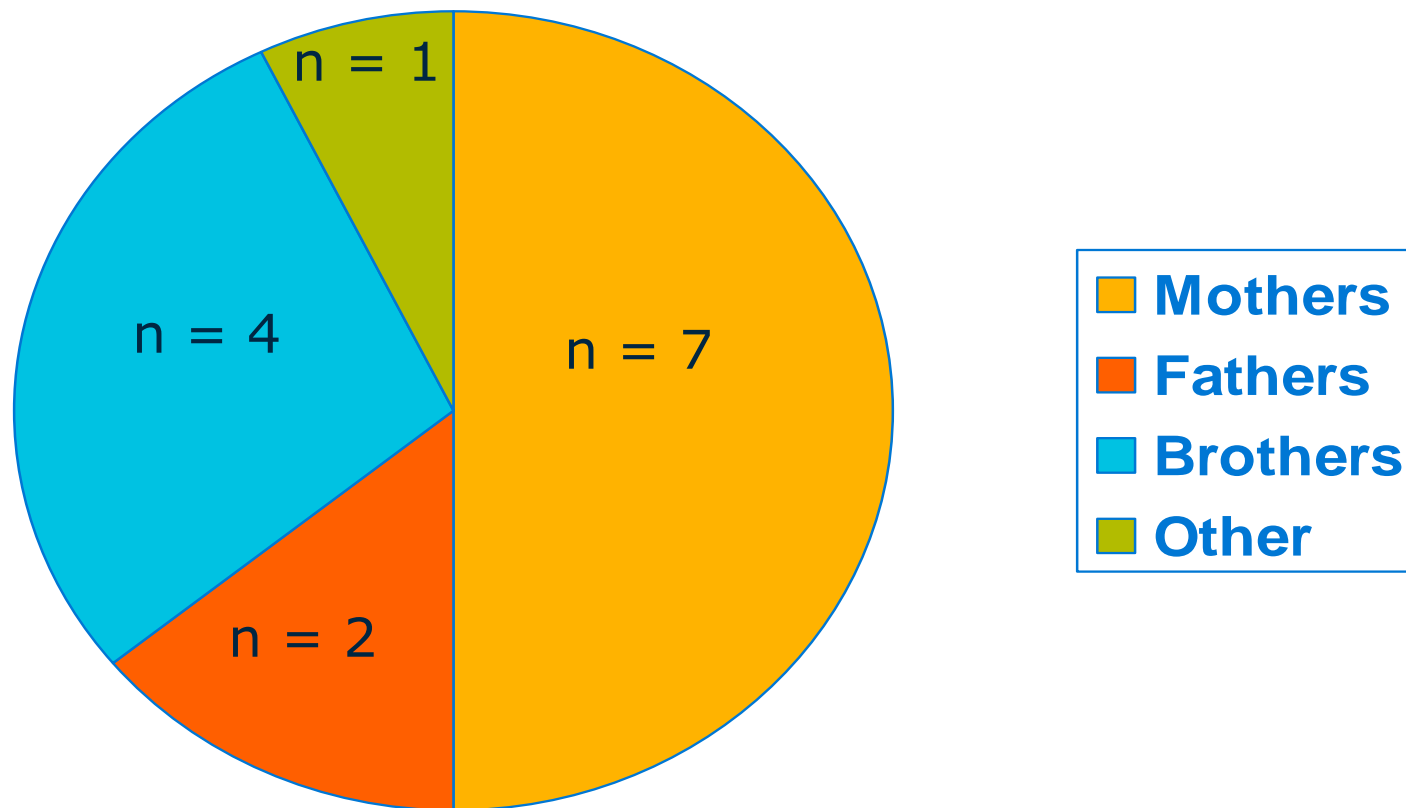
What we did....

- Developed an **adolescent version** of the BIFI
 - Families with an adolescent with ABI (13 – 19 years)
- Modified the adult BIFI to have an adolescent focus
 - Generated new topics – expert panel
 - Modified some original topics
 - Modified curriculum to be more youth friendly
- Feasibility testing: 3 test clinicians, 8 adolescents with ABI and 14 family members
- Developed 1st edition of BIFI-A clinician manual

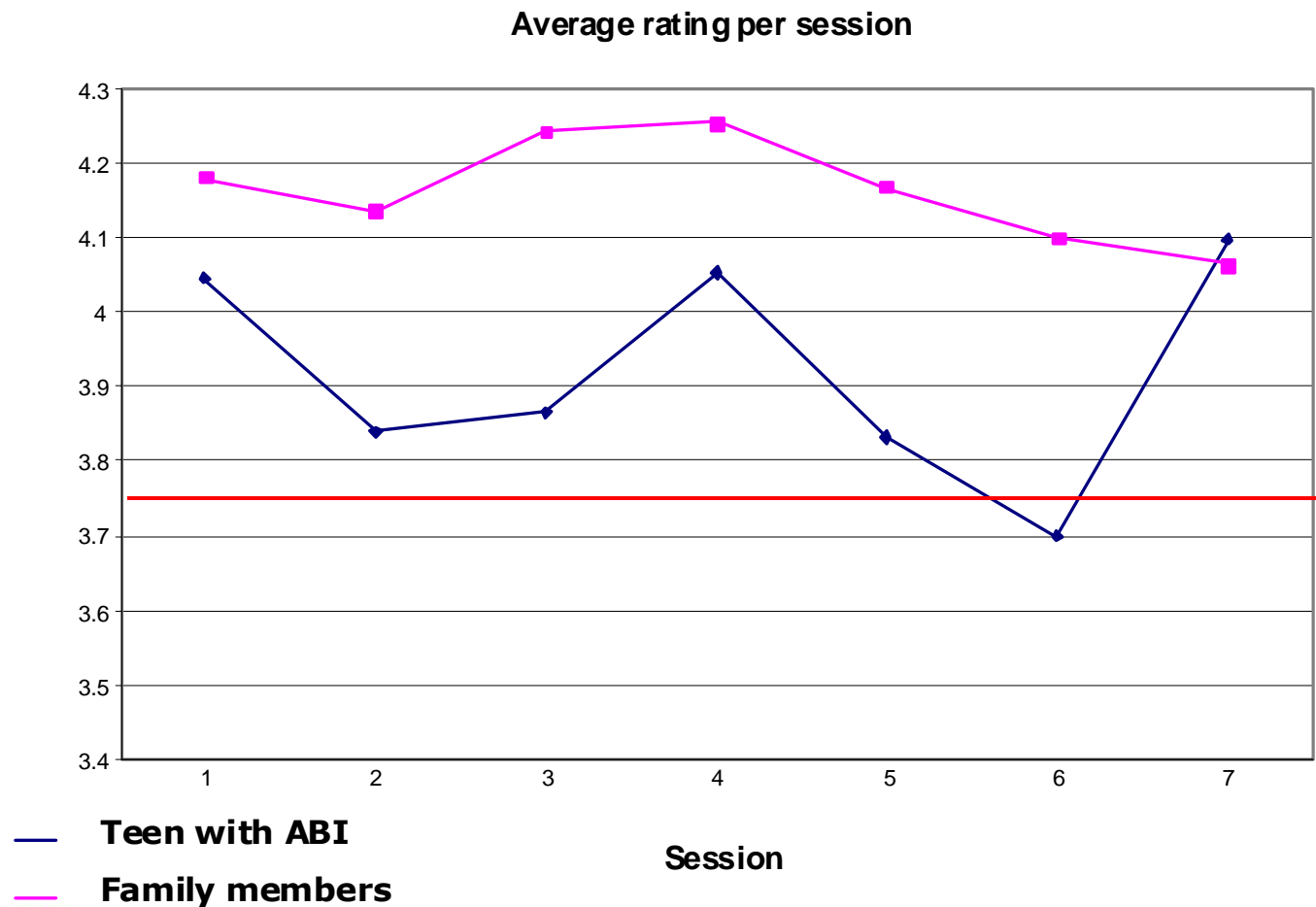
Feasibility testing – Teen participants

- 5 males, 3 females
- Ages 13 – 18 (mean 14.63 years)
- Time post injury - .5 to 14 years
- Cause of injury
 - Pedestrian 2
 - Fall 2
 - Skateboard 1
 - Aneurysm 1
 - Stroke 1
 - Encephalitis 1

Family participants (n = 14)

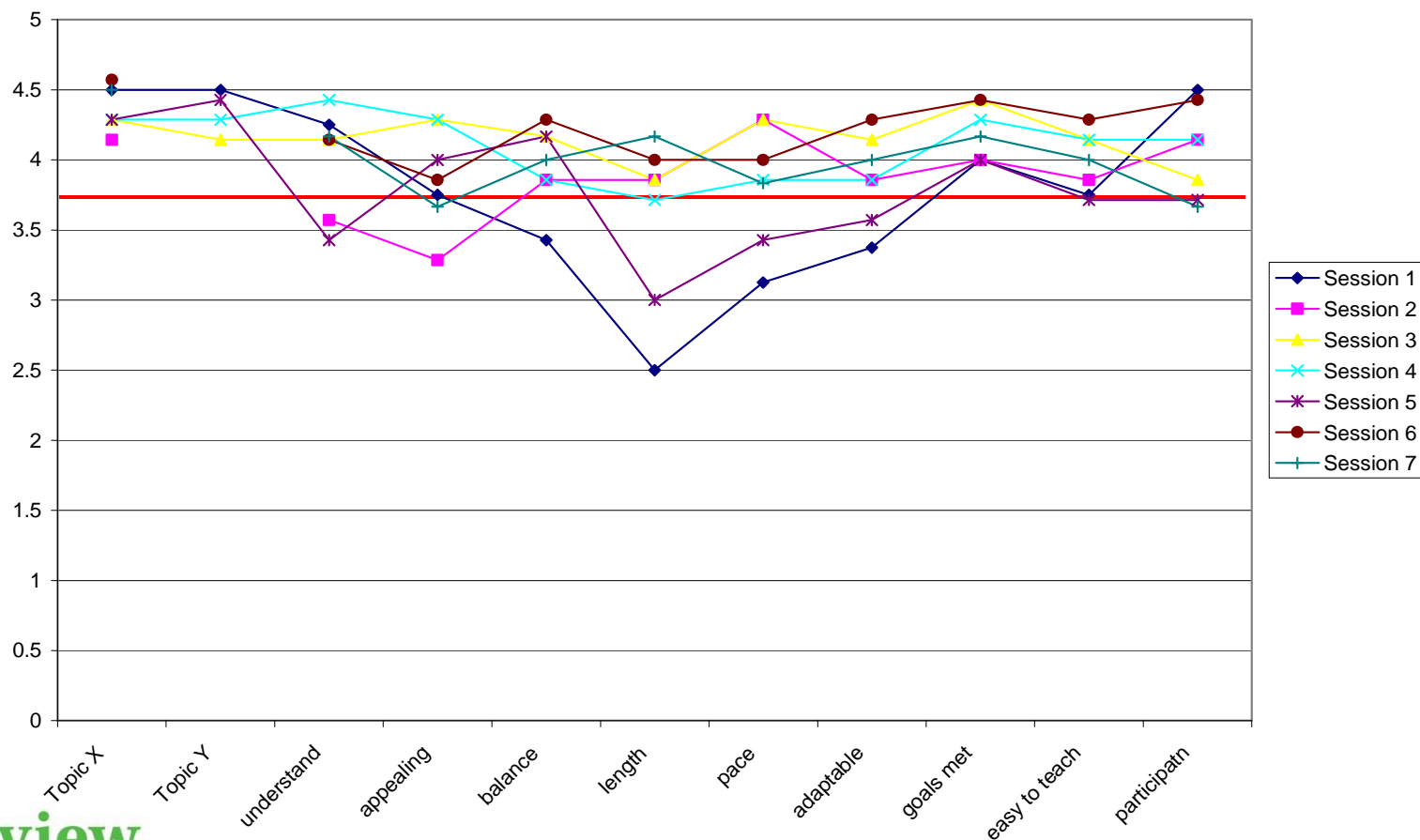


Average rating per session (family participants)



Clinician ratings

Clinician Summary



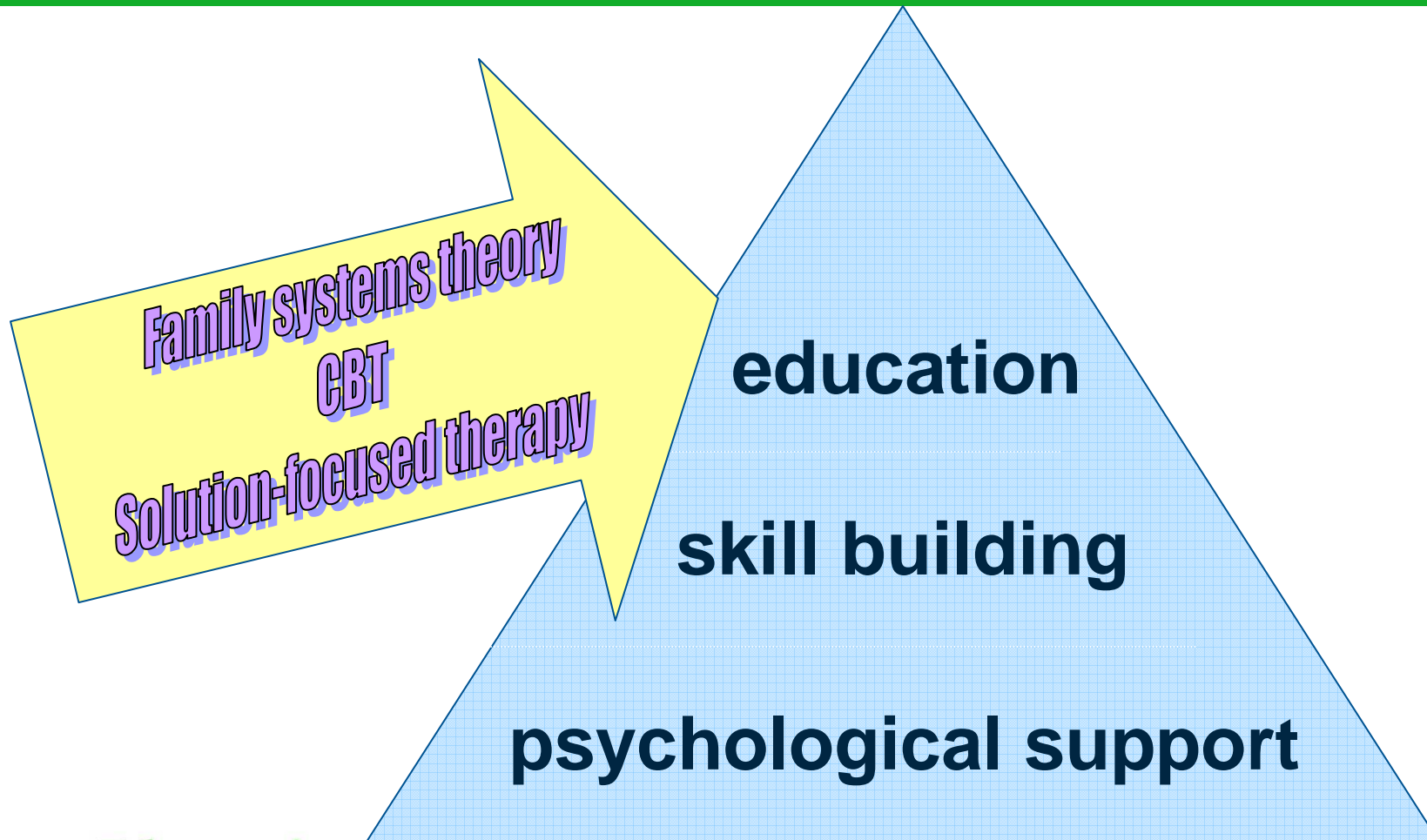
What we learned from feasibility testing

- Sessions “too long”
 - Keep it to 1 topic/session
- “Some of the talk is boring and pointless”
 - Need for interactive exercises to keep teen and sibling engaged
- Decrease paper/pencil tasks
- Simplify handouts
- No homework!

BIFI-A (First Edition)

- Twelve sessions
 - Assessment
 - 10 topics
 - Wrap-up
- Each session is ~ 60 minutes
- Family discussion, worksheets, vignettes, role plays, and interactive exercises
- Sessions implemented hierarchically
- Pace and topics tailored to suit individual family needs

BIFI-A Primary Components



Topic 1: What happens after brain injury?

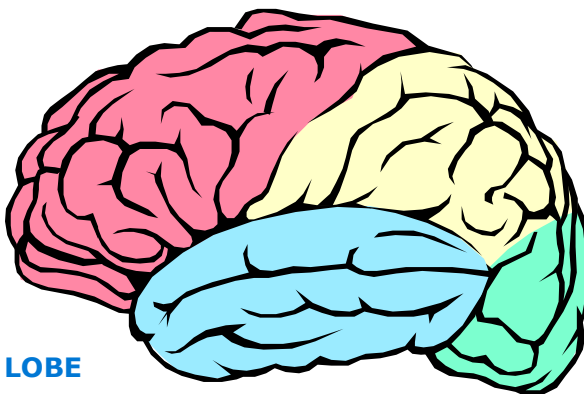
- Incredible brain facts
- What are common changes after brain injury?

FRONTAL LOBE

Attention and concentration
Emotional control
Judgment
Initiation (starting things)
Impulse control
Planning and organizing

TEMPORAL LOBE

Memory
Hearing
Understanding language
Sequencing
Recognizing faces



PARIETAL LOBE

Sense of touch
Knowing right from left
Knowing size, shapes, and colours
Naming objects
Eye-hand coordination

OCCIPITAL LOBE

Vision
Recognizing objects or words
Identifying colours
Reading and writing

Topic 2: Brain injury happens to the whole family

- Personal reactions to the injury
- Impact on the family system
- Every family member needs support



FAMILY CHANGE QUESTIONNAIRE

Family member: How did you feel when you first learned that your family member had a brain injury?

Teen with ABI: How did you feel when you first learned that you had a brain injury?

How did you feel when you began to learn that the brain injury might not fully go away? _____

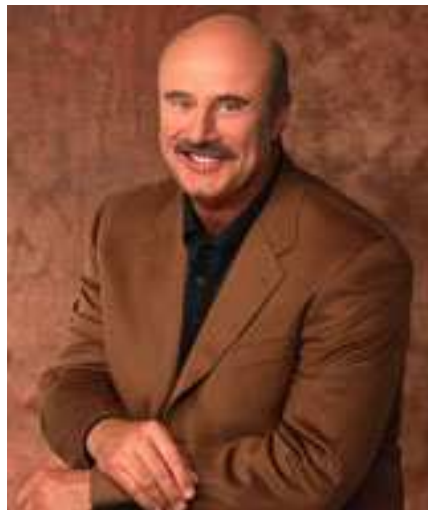
How has the brain injury affected your life? (e.g., work, chores, school, friends, activities, money)

Which changes have been the hardest for you?

How has the brain injury affected your plans for the future?

Topic 3: Being a teen and achieving independence

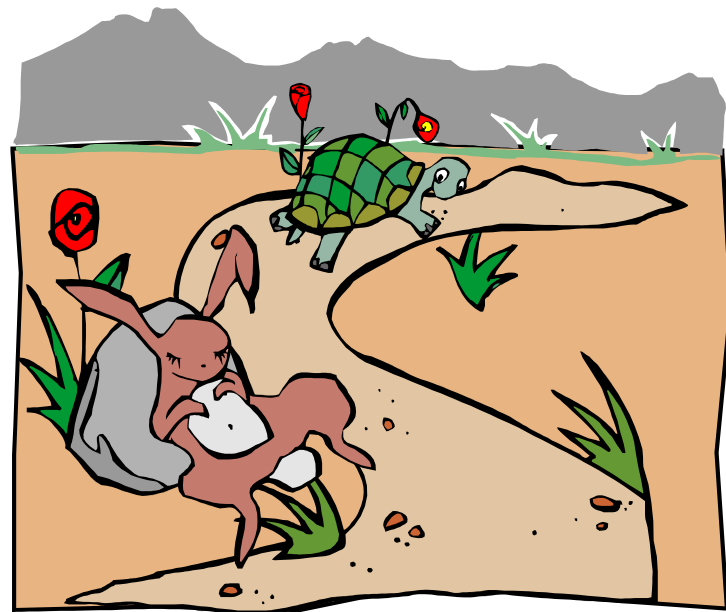
- Is it brain injury or adolescence?
- Normal adolescent development
- Challenges facing adolescents with ABI and their families
- Ways of supporting independence
- *Dr. Phil*



Topic 4:

Emotional and physical recovery are two different things

- Difference between emotional and physical recovery
- Pace and process of recovery
- Obstacles to recovery
- *A Lot on My Plate*



Topic 5: Coping with loss and change

- Grieving process after brain injury
- Reactions to loss and change
- Strategies for coping





worried



pleased



stressed



angry



scared



happy



disappointed



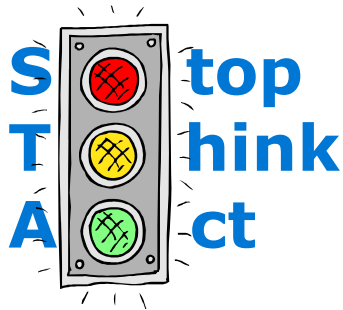
confused



tired

Topic 6: Managing intense emotions

- Common emotions experienced post-injury
- Skills for emotional expression
- Strategies for managing anger and intense emotions



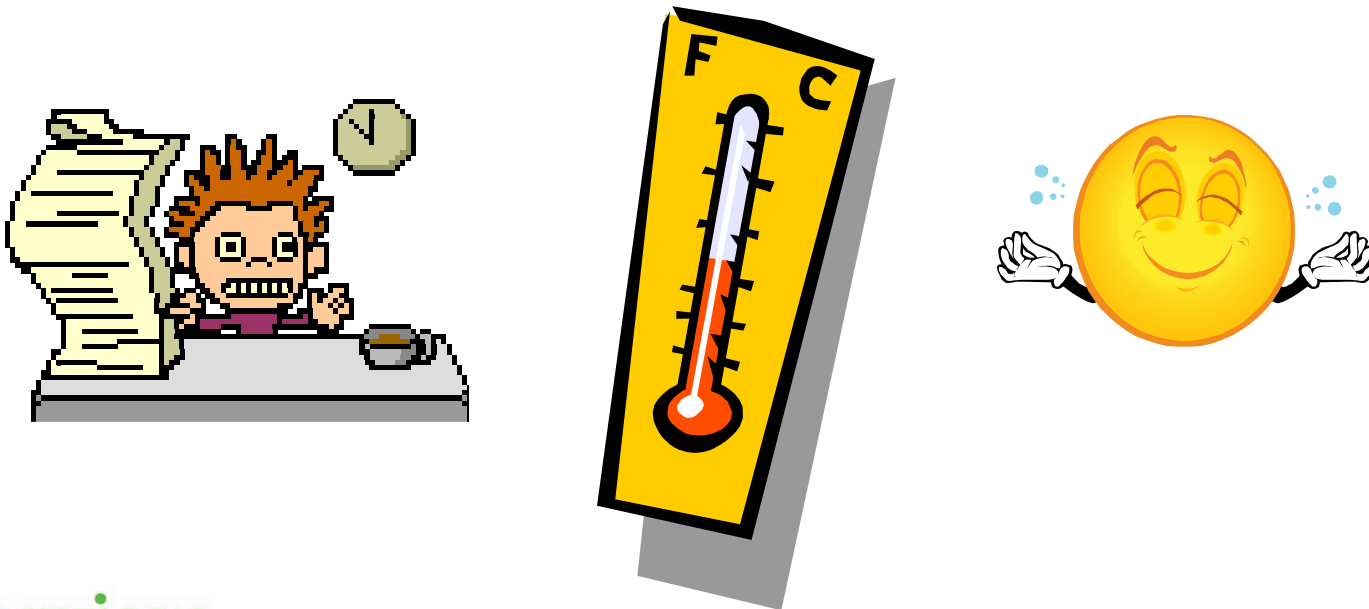
10, 9, 8, 7, 6, 5, ...



Topic 7:

Managing stress and taking care of self

- Early warning signs of stress
- Ways of monitoring stress
- Strategies for effective stress management and self-care



Topic 8:

Setting s.m.a.r.t. goals & tracking progress

- Difference between poor goals and s.m.a.r.t. goals
- Tracking progress
- Setting s.m.a.r.t. goals

Specific

Measurable

Achievable

Realistic

Timelines



Steps to Success - My S.M.A.R.T. Goal is:

I think I can achieve this goal in _____ weeks/months

Completed ☐

Completed ☐

Completed ☐

Completed ☐

This is what I
have done so
far:

Step 1- I will
have achieved:

Step 2- I will
have achieved:

Step 3- I will
have achieved:

Step 4- I will
have achieved:

Now



Future

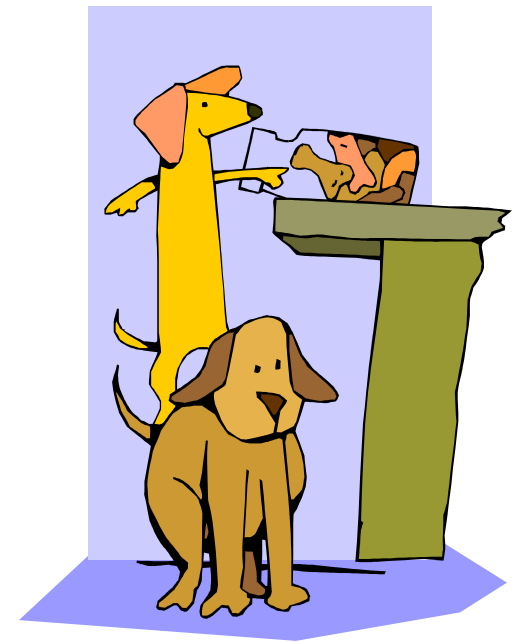
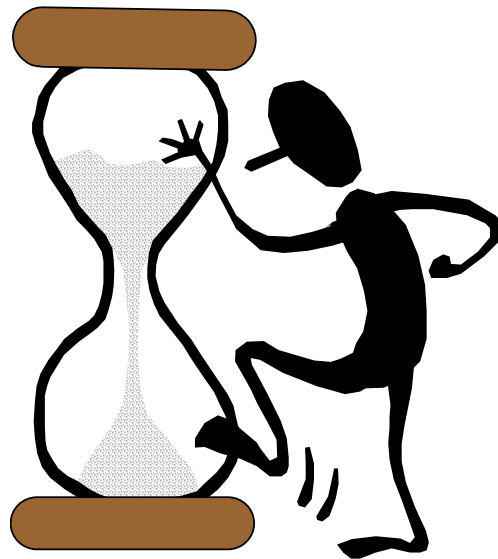


BIFI-A: Setting s.m.a.r.t. goals and tracking progress

Topic 9:

Learning patience and solving problems

- Identify problem solving personality
- Skills for effective problem solving
- Practical strategies for remaining patient



Worksheet #31: Problem Solving Personality Questionnaire

Circle True if the statement describes you and False if not.

- | | | |
|----------|----------|--|
| T | F | 1. I tackle problems head on. |
| T | F | 2. I have so many problems to work on I usually don't know where to start. |
| T | F | 3. I am usually not patient. |
| T | F | 4. I usually have clear goals. |
| T | F | 5. I usually let other people solve my problems for me. |
| T | F | 6. I am a creative problem solver and a positive thinker. |
| T | F | 7. Most of the time I don't have a back-up plan if things don't work out. |
| T | F | 8. I try to get good advice from others. |
| T | F | 9. I'm good at setting priorities and working on only one problem at a time. |
| T | F | 10. I usually don't ask for help. |

Topic 10: School and transition planning

- Common challenges in returning to school after ABI
- Strategies to support successful school transitions
- Resources to support transition to adulthood

IPRC



resource

accommodations

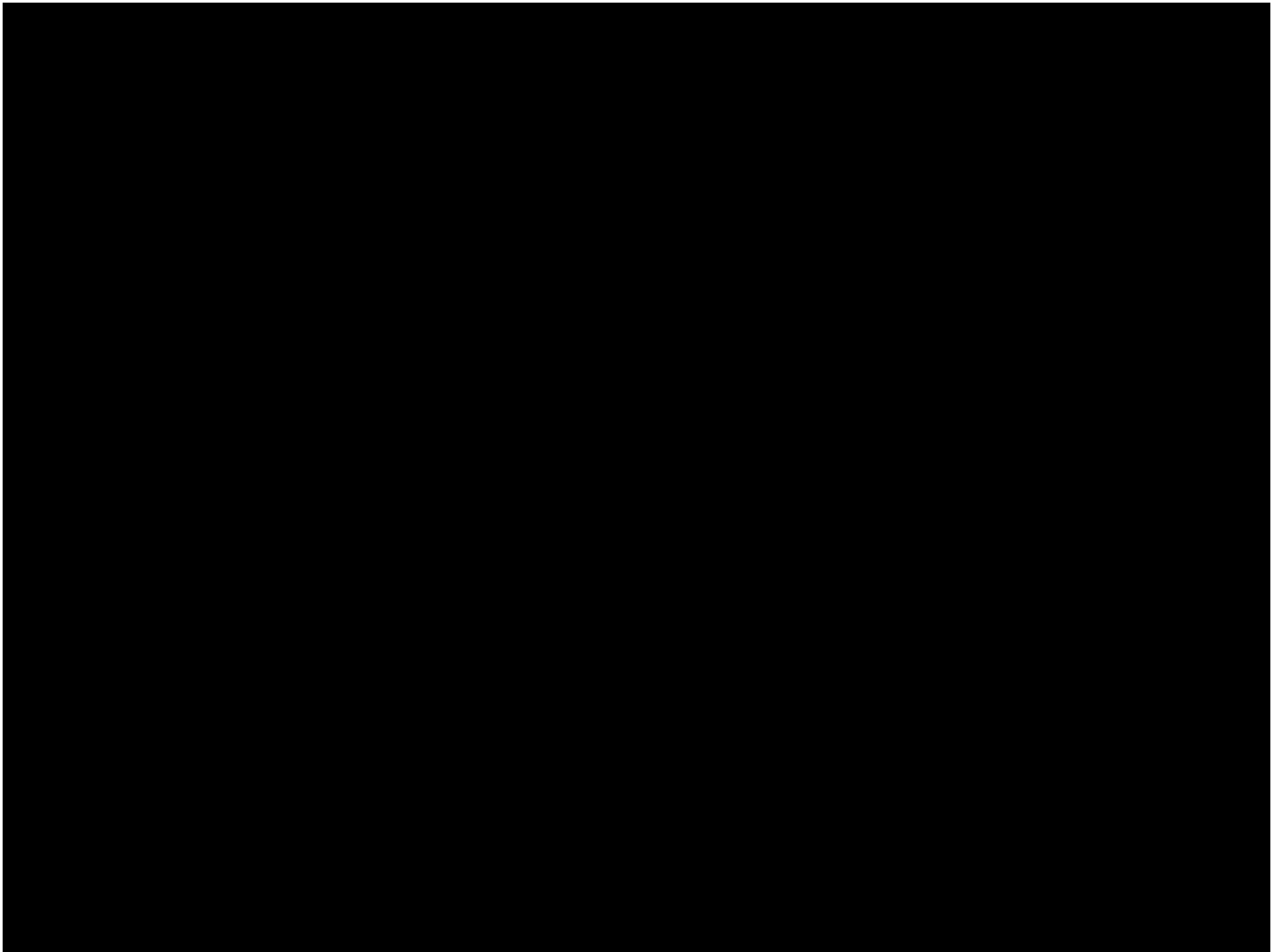
Bloorview
KIDS REHAB



Wrap-Up

- Individual and family strengths
- Focusing on accomplishments and progress
- Ways to keep getting better
- Celebration of successes





What family members said about BIFI-A ...

Helped me deal with stress in a healthy way

We can set goals and work on them – don't have to do it alone

Learn how other family members feel about things



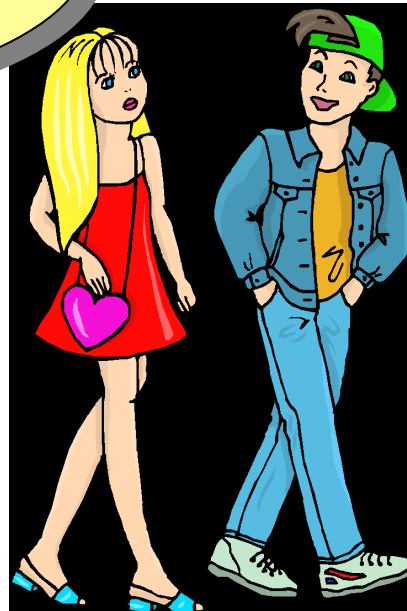
What adolescents with ABI said about BIFI-A ...

Liked coming together to learn about ABI

That my mom was overprotective because she worried about me

Learned that my mom and dad get stressed too

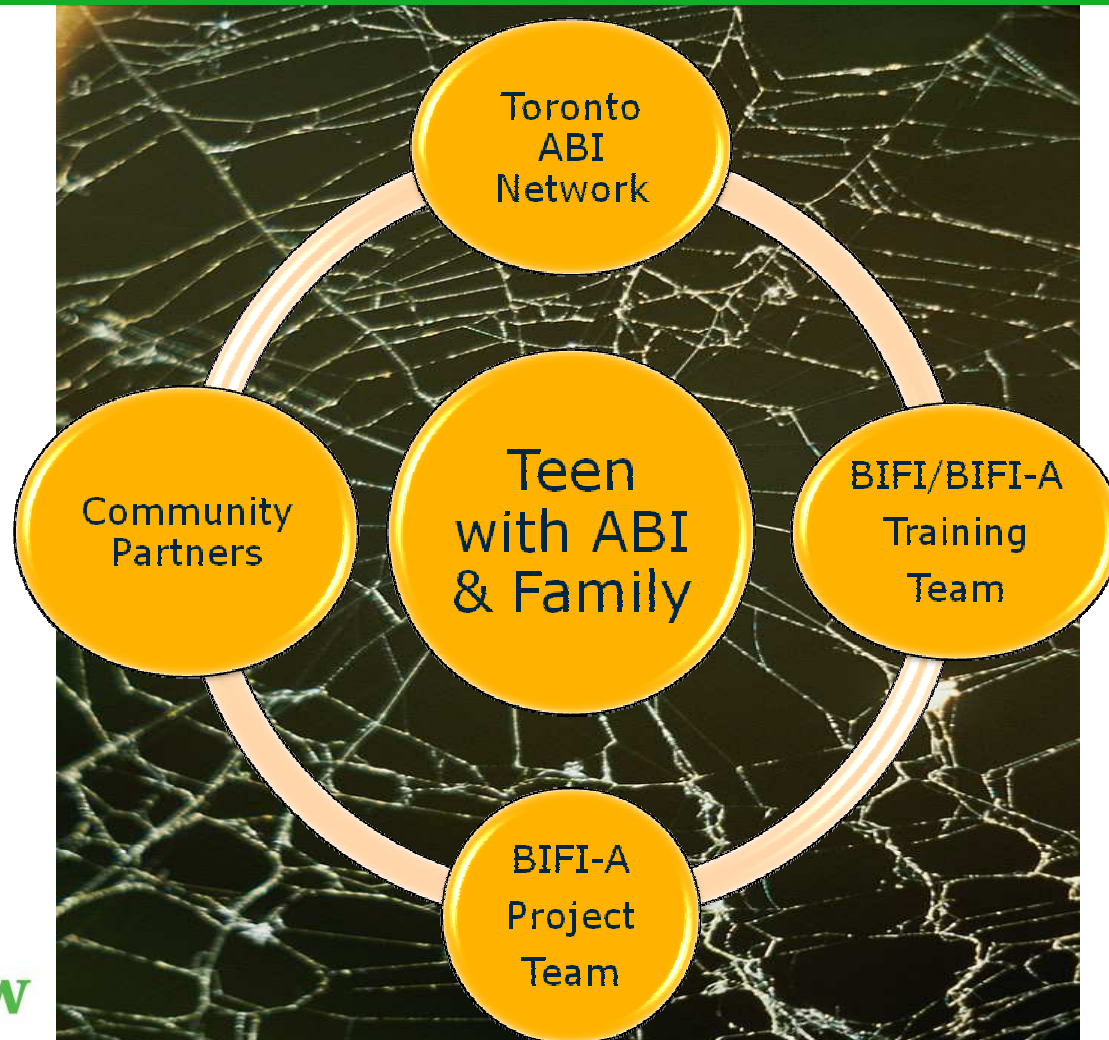
It was infamacious!



Lessons learned from BIFI-A feasibility testing

- Importance of clinicians having family therapy skills, mental health training, or access to clinical supervision
- “Only those trained in psychological counselling should facilitate these discussions”

Where do we go from here?



Bloorview

KIDS REHAB



Thank you

Caron Gan, RN, MScN, AAMFT Approved Supervisor
Registered Marriage and Family Therapist
Family Support Service
Brain Injury Rehabilitation Team
Bloorview Kids Rehab
Toronto, Ontario M4G 1R8

Phone: 416-425-6220, extension 3514
Fax: 416-424-3880
E-mail: cgan@bloorview.ca