

## Developmentally Tailored Family-Centered Interventions to Improve Family and Survivor Intervention following TBI

Shari L. Wade Ph.D.  
Cincinnati Children's Hospital Medical Center and the  
University of Cincinnati College of Medicine

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## Collaborators

- H. Gerry Taylor, Ph.D., Case Western Reserve University and University Hospitals of Cleveland
- Keith Owen Yeates, Ph.D., Nationwide Children's Hospital and The Ohio State University
- Terry Stancin, Ph.D., Case Western Reserve University and MetroHealth Medical Center
- Armando J. Rotondi, Ph.D., University of Pittsburgh

## The Costs of TBI

- 2% of the U.S. population currently lives with disabilities resulting from TBI.
- Annual costs are estimated to be \$12.5 - 25 billion per year.
- Lifetime rehabilitation costs for an individual with severe TBI ranges from \$600,000 to \$1,900,000

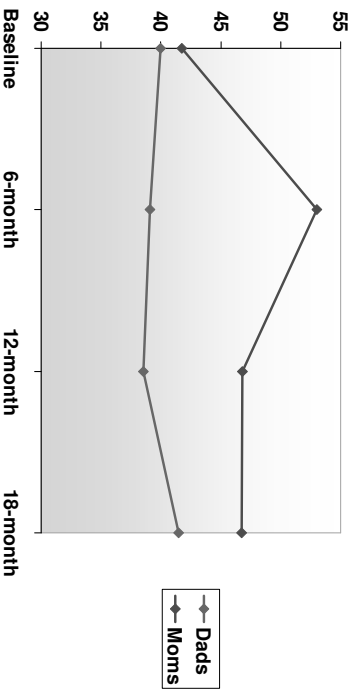
## The Psychosocial Consequences of TBI: Behavior and Relationships

- Executive function deficits and behavior changes can be the most persistent and profound consequences of TBI.
- Can range from apathy and withdrawal to emotional volatility and explosive anger.
- In children, secondary attention deficit hyperactivity disorder is common.
- Individuals with TBI often become socially isolated as a result of their behavioral difficulties and impaired self awareness.

## The Consequences for Families

- Elevated injury-related stress and burden.
- Parental psychological distress including anxiety and depression.
- Deterioration in family functioning that may persist many years following the injury.

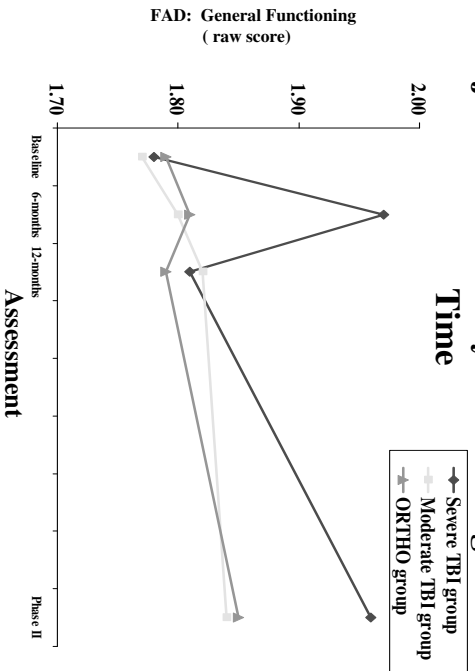
### Mother's vs. Father's Ratings of Parenting Disagreements over Time following Severe TBI



### Effects on Other Family Members

- Siblings
- Children
- Extended family

### Trajectories of Family Functioning over Time



### The Relationship between the Injured Individual's and the Family's Functioning

- There is a reciprocal relationship between the family's and the injured individual's functioning.
- Individuals from well functioning families show greater recovery.
- Individuals with more severe injuries and greater changes in behavior have more stressed families and caregivers.

### Predictors of Adaptation

Social environmental factors are more important than injury severity.

### Predictors of Adaptation

- Non-Modifiable
  - Pre-injury adaptation
  - Socioeconomic status
  - Race/Ethnicity
- Modifiable
  - Social supports and strain
  - Coping

<h3 style="text-align: center;">Clinical Implications</h3> <ul style="list-style-type: none"> <li>• Identify high-risk individuals based on multiple factors.</li> <li>• Follow families over time, as problems likely to persist or emerge.</li> <li>• Working with families is important for them as well as injured individual.</li> </ul>	<h3 style="text-align: center;">Barriers to Intervention</h3> <ul style="list-style-type: none"> <li>• TBI is a “low incidence” disorder.</li> <li>• Problems are multifaceted and vary from individual to individual.</li> <li>• Providers may be distant and/or difficult to access.</li> <li>• Families may not recognize the problems as arising from TBI.</li> </ul>
<h3 style="text-align: center;">The Family as Therapist</h3> <ul style="list-style-type: none"> <li>• Children spend little to no time in rehabilitation, but lots of time with their families</li> <li>• This makes families potentially powerful change agents</li> </ul>	<h3 style="text-align: center;">Family Problem Solving</h3> <ul style="list-style-type: none"> <li>• Teaches families a framework for problem-solving and addressing goals.</li> <li>• Individualized focus on the goals and difficulties identified by the family.</li> <li>• Incorporates education regarding changes following TBI and teaches strategies for dealing with those changes.</li> </ul>
<h3 style="text-align: center;">Why Problem Solving?</h3> <ul style="list-style-type: none"> <li>• Facilitates parent/family coping in response to injury and other stresses in their lives.</li> <li>• Provides the injured individual with an executive function heuristic for addressing post-injury challenges.</li> <li>• Flexible to accommodate the different kinds of issues facing survivors and their families.</li> </ul>	<h3 style="text-align: center;">The Evolution of Family Problem Solving Interventions</h3> <ul style="list-style-type: none"> <li>• Study 1 : Face-to-Face Family Problem Solving (FPS)</li> <li>• Study 2: Online Family Problem Solving (OFFPS)</li> <li>• Study 3: Counselor-Assisted Problem Solving</li> <li>• Study 4: Teen Online Problem Solving</li> <li>• Study 5: Parenting Skills for Younger Kids</li> </ul>

## What changed over time?

- From face to face to online
- More videos and interactivity
- More developmentally tailored (original projects targeted children ages 5-17; current projects focus on teens and younger children exclusively)
- Targeting a broader range of cognitive behavioral skills

## FPS: Core Content/Skills

- Cognitive reframing; managing stress (1 session).
- Problem solving to achieve your goals (1 session + practice at subsequent sessions).
- Positive behavioral supports/self-regulation (3 sessions)
- Communication skills ( 1 session)
- Responding to Crises (1 session)
- Up to 4 supplemental sessions based on family need.

## FPS: Evidence for Efficacy

Initial RCT: 32 families

- Significant improvements in internalizing symptoms in the treatment group vs. control group on the Child Behavior Checklist.
- No changes in parent psychological symptoms or parent-child conflict
- High levels of satisfaction and increased understanding of the child's injury and of strategies for handling attention and behavior problems.

## What Did We Learn?

- Families had a hard time getting to the hospital for sessions (50% received home-based sessions).
- A lot of information to cover in a short amount of time.
- Not geared to the varying developmental levels of participating children.

## The Next Generation: Taking Advantage of Technology

- Accessibility – make sessions “doable” and not a burden
- Simplified materials with greater opportunities for repetition and practice
- Developmental Considerations-more “Just for Kids”
- Increased emphasis on cognitive reframing/staying positive

## Online FPS

- Initial face-to-face session
- Subsequent sessions are delivered online
- Web-based materials include didactics, video clips modeling new skills, and exercises with feedback.
- Therapist (aka Coach) had synchronous 1:1 videoconferences with the families
- New materials for kids

## Differences from other Telehealth Approaches

- Initial face-to-face contact
- Combination of self-guided web-pages plus synchronous videoconferences with the therapist

## Advantages of this Approach

- High level of therapeutic alliance
- Presentation of materials in different formats (video, exercises, discussion)
- Repetition of key concepts

## Minimizing Costs by Using Off-the-shelf Technology

- Standard computers
- \$30-\$50 videocameras
- Free videoconferencing software (SightSpeed; Skype)
- Broadband access (\$30 - \$65 per month)

## Online Family Problem Solving

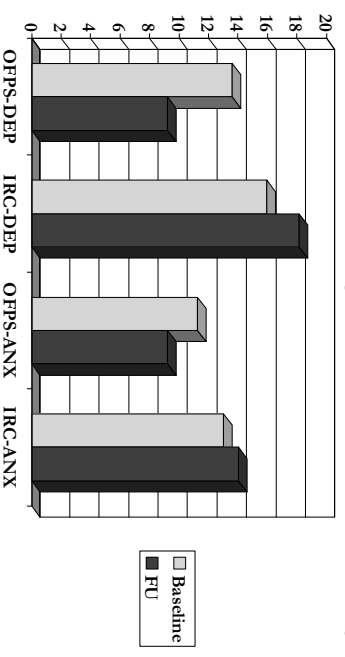
(Wade, Carey, & Wolfe, 2006)

- Children, ages 5 – 17, with moderate to severe TBI and their families
- Targeted outcomes included child behavior, parent depression and distress, parent-child interactions
- Children had to be < 24-months post injury and residing with their parents

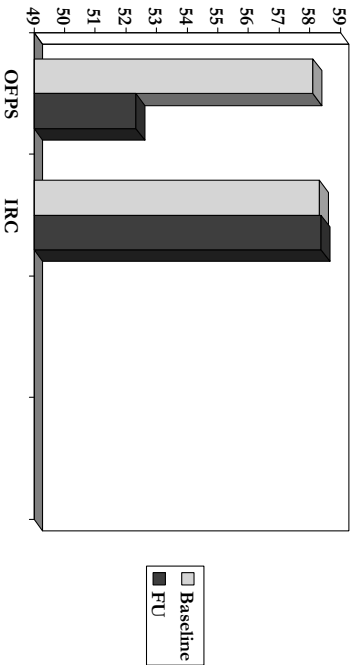
## Study Design

- Randomized Clinical Trial
- Online Family Problem Solving (OFPS) versus an Internet Resource Comparison group (IRC)
- All families receive computers, high speed internet access, and links to information and resources about brain injury
- Only families assigned to OFPS receive access to the OFPS website and synchronous videoconference sessions

## Findings from RCT (n = 40): Changes in Depression and Anxiety: Significant Differences in Depression and Anxiety



### Findings from RCT: Changes in Global Psychiatric Symptoms on the SCL-90

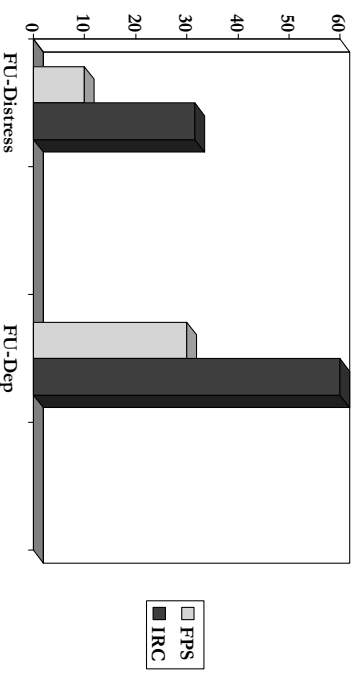


- Significantly greater improvements in self management in the OFPPS vs. the IRC group.
- Trends for greater improvements in overall social competence and behavior problems.
- Improvements in social competence and behavior were moderated by the child's age and SES respectively, with older children and those of lower SES benefiting more.

### Making it work for different people

- Age
- Family composition/participation
- Cognitive functioning
- Motivation
- Range and extent of problems
- Comfort with technology

### Clinically Significant Levels of Depression and Distress at Follow-up (p < .10)



### The Challenges of Adopting a Telehealth Approach

- The challenges of technology.
- Assessing and addressing varying levels of computer literacy.
- Meeting with families on their own turf.
- The dynamics of videoconferencing.
- If you build it, will they come?

### Developmentally Tailored, Web-based Intervention Programs: A Closer Look

- Teen Online Problem Solving
- Internet Interacting Together Everyday After Traumatic brain injury (I-INTERACT)

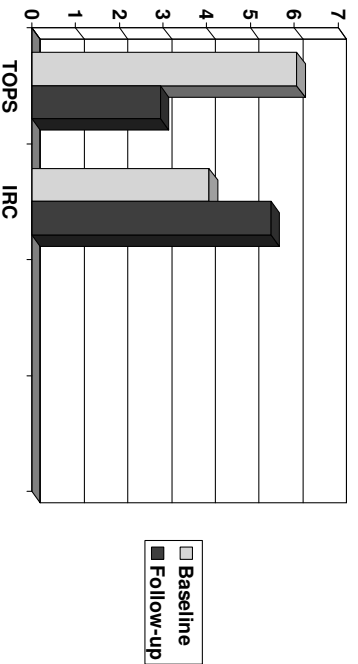
## Teen Online Problem Solving

- Builds on OFPPS
- Additional sessions on anger management, language pragmatics, nonverbal communication, and social problem solving.
- Greater emphasis on self-monitoring and self-regulation versus the parents providing the structure.

## TOPS Core Sessions

- Getting Started
- Staying Positive
- Solving Problems
- Getting Organized
- Staying in Control (self regulation)
- Staying in Control (anger management and I-messages)
- Nonverbal Communication and Active Listening
- Making and Keeping Friends
- Crisis Management
- Planning for the Future

## Parents and Teens Working Together = Less Conflict



## Working with Teens with TBI

- Executive function deficits
- Dealing with affective lability and anger issues
- Reading social situations and dealing with social isolation
- Severe cognitive limitations

## Case Example 1: Dealing with Executive Function Deficits

- Paul is a 14 year with a moderate TBI
- Had some learning problems before the injury
- Since the injury, organizational issues have increased-he often forgets to turn in homework, fails to plan ahead for assignments
- School has labeled problem as a lack of motivation

## TOPS in Action

- Provides the information and scaffolding to help parent and teen connect current problems to the injury
- Problem-solving process provides a framework for monitoring the problem, implementing a solution, and evaluating its success.
- Engages school in a non-confrontational way

## Advantages of TOPS Approach

- Parents and teens work as a team, rather than adversaries
- Teen has choice and control in terms of what to try first
- The process models successful negotiation as well as systematic problem solving

## Case Example 2: Dealing with Impulsivity and Emotional Liability

- Kaden is a 15 year with a moderate TBI
- He was injured by throwing himself out of a moving car
- Since the injury, he quickly loses his temper and has been suspended from school for fighting.

## TOPS in Action

- Teaches teen to Stop and Think before acting, emphasizing inhibition as a solution
- Cognitive reframing--don't assume that the world is out to get you
- Problem solving process allows teen and family to identify alternatives to aggression

## Case Example 3: Dealing with Internalizing Symptoms and Social Isolation

- Megan is a 16 year old girl with a severe TBI
- She was socially isolated before the injury, but has become more so since
- Low self-esteem and depressive symptoms with questionable auditory hallucinations telling her that she is bad

## TOPS in Action

- Teaches strategies for staying positive including cognitive reframing and stress management
- Addresses language pragmatics including interpreting social cues and sending the right signals
- Problem solving process flexible and can focus on getting out more and making friends

## Case Example 4: Dealing with Significant Cognitive Limitations

- John is a 17 year old boy with a severe TBI
- Still has significant cognitive impairments as a consequence of the injury
- Behavioral perseverance is a problem for John's family

## TOPS in Action

- Family plays a critical role in cueing John around problem behaviors and reinforcing him when he is able to successfully inhibit or alter his behavior.

## Impact of Telehealth Approaches on the Adolescent

- Much more comfortable on their own turf.
- Avoids the stigma of attending sessions in a mental health clinic.
- More distractions-may be easier to tune out.
- Teen can assume a power role since he/she is usually more technologically sophisticated than the parent.

## I-INTERACT: Addressing the Needs of Younger Children

- Young children have a harder time attended to a talking head on the computer
- More easily distracted
- Unlikely to internalize the EF heuristics
- Parents can serve as therapists for young children reinforcing behavior and modeling and reinforcing language

## I-Interact: Internet-based Interacting Together Everyday-Recovery After Childhood TBI

### Goals

1. Determine feasibility of delivering a parenting skills program with live coaching via the web.
2. Gather preliminary evidence regarding the efficacy of I-Interact in changing parent and child behaviors.

## The I-Interact Intervention

- Initial face-to-face session and 10 online sessions providing didactic information about parenting skills (i.e., using labeled praise), stress management, and the cognitive and behavioral changes associated with TBI.
- Synchronous coaching sessions using Skype and blue-tooth earpieces.

## Intervention Model

- Every week parents logged onto the website to
- **learn** about positive parenting skills through didactics, video examples, practice exercises
  - Every week parents met with a therapist using videoconferencing technology (Skype) to
  - **review** positive parenting skills
  - **be observed** while playing with the child to identify positive parenting skill strengths & areas for improvement (DPICS III coding)
  - **practice** positive parenting skills while playing with the child & being coached through a Bluetooth earpiece.

## Session Content

- Positive parenting skills
- Stress management
- Antecedent behavior management
- Giving good commands
- Anger management
- Using Timeout
- Cognitive consequences
- Positive parenting skills in real life

## PRIDE SKILLS

- **P**raise the child for behaviors you like
- **I**mitate the child's play
- **R**eflect what the child says
- **D**escribe what the child is doing
- **E**nthusiastically engage in the play

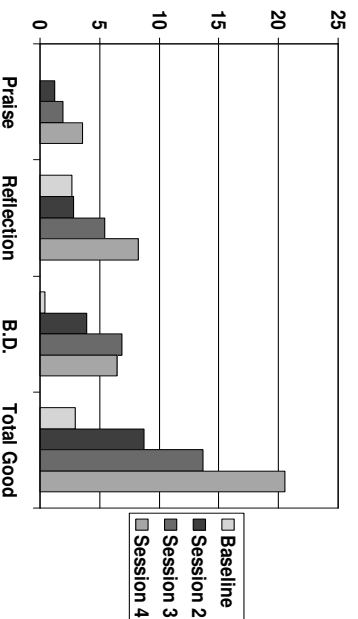
## What Not To Do

- No Questions
- No Commands
- No Criticism

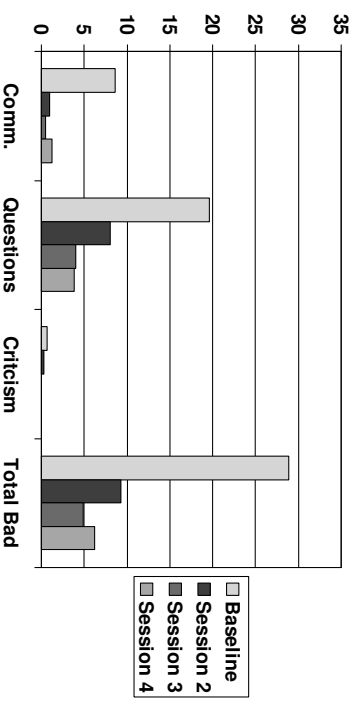
## Examples of Pre-Post Changes



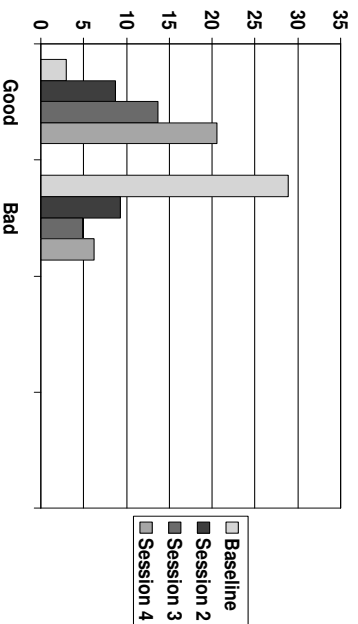
## Changes in Positive Parenting Behaviors: Baseline – Session 4



## Changes in Negative Parenting Behaviors: Baseline to Session 4



## Overall Changes in Positive and Negative Parenting: Baseline to 4



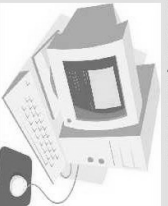
A screenshot of the i-Interact login page. It features a text input field containing the name 'Karen', a password input field with asterisks, and a 'Submit' button. Above the fields is the text 'Please log-in to begin'.

### What will we do?

Through this program, you will learn a set of positive parenting skills that has been shown to reduce behaviors such as over activity, meanness, and tantrums, and improve behaviors like listening and following directions.

*You will learn these skills by:*

- 1) going online and completing the educational sessions
- 2) meeting with your coach online using the web camera while you practice these skills with your child.



A screenshot of the i-Interact website's welcome page. The page title is 'Welcome to i-Interact'. Below the title, it reads 'Internet-based Interacting Together Everyday: Recovery After Childhood TBI'. There are three main sections: 'Resources' with a right-pointing arrow, 'For those of you in the intervention group of our study, please click the Start Sessions button to access the session material.' with a right-pointing arrow, and 'Please feel free to Contact Us.' with a right-pointing arrow. A small image of a family is visible in the bottom right corner.

### Parenting and Recovery from Brain Injury



A traumatic brain injury, which may be referred to as TBI in this program, affects every child differently. Some children experience changes in memory, attention, and learning, while others have more difficulty controlling their emotions and behavior.

In this program, you will learn positive parenting skills which may help you to deal with these changes. These skills may also help you to become a more effective parent, even after your child has fully recovered from TBI.

### What will I learn in the Educational Sessions?

The online educational sessions include information, videos, and exercises to teach you about these positive parenting skills.



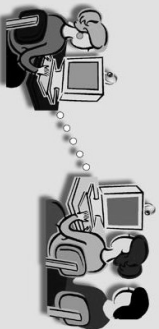
In addition, the educational sessions will help you learn more about childhood brain injury and what you can do to help with specific problems (such as memory).

You will also learn how to stay positive and manage your stress.

[Click here for the example Educational Session Video](#)

## What will I learn during the Coaching Sessions?

A coaching session is a time when you will meet with the therapist in a video conference online. During this time, the therapist will reinforce the positive parenting skills that you learn in the educational sessions by teaching you to apply and master these skills.



[Click here for the example Coaching Session Video](#)



## Positive Parenting Skills

*Follow Your Child*

*Follow Your Child will:*

- Teach you how to talk or **communicate** with children who are very active.
- Teach you ways to **teach your child without frustration** for either of you.
- Encourage your child to **feel better** about him or herself.
- Teach your child **social skills**, like sharing, which children need to get along with other children and keep friends.
- Help foster a **secure, warm relationship** between you and your child.

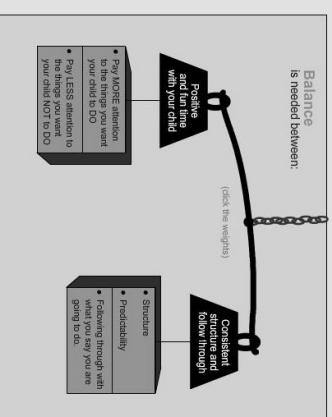
We will focus just on Follow Your Child for the first several weeks.



## Case Example 1: Need for consistent & positive parenting

- K. was a 5 year old boy whose oppositional and disruptive behavior greatly worsened post-TBI
- Exhausted by his behavior parents only reacted, often relenting for a moment's peace and never reacting the same way twice.
- Parents & child stopped enjoying each other, "dreading" each new day.

## Overview of Positive Parenting Skills



## Positive Parenting Skills

*Lead Your Child*

After you feel comfortable with the skills in Follow Your Child, Lead Your Child will be taught. During this phase, you will continue to practice the Follow Your Child skills you have learned. You will also learn how to properly give small commands to your child as well as how to react when your child disobeys.



*Why do we learn Follow Your Child first?*

As you and your child establish a more secure, warm relationship through Follow Your Child, you will find it easier to give commands, and your child will be more motivated to cooperate with you. Lead Your Child is built on a strong foundation of Follow Your Child.



## I-INTERACT in Action

- Parents learned to prevent problem behaviors through antecedent behavior controls (e.g. preventing boredom at the grocery store by letting him help choose items)
- Parents practiced "consistency, predictability, follow-thru" all throughout each day.

## I-INTERACT in Action, cont'd

- Parents had “Special Play Time” with the child most days.
- The child learned it was more fun to cooperate
- Both child and parents learned how to enjoy one another.
- “I never would have imagined that 5 minutes a day could change our family’s life”

## Case Example 2: Need for TBI information & self-care

- J. was a 7 year old boy who struggled with self-regulation and attention, often resulting in defiance.
- J.’s parents were aware that his high intelligence & solid academic skills were in stark contrast to his disruptive behavior.
- Parents tried several behavior management strategies day-in and day-out without success.

## I-INTERACT in Action

- Parents experienced emotional relief by learning the organic nature of J’s behavior.
- Parents learned to practice self-care and marriage-care leading to more positive thinking and problem solving.
- Parents discovered J.’s unpredictable behavior was par for the course; a bad day is sometimes just a bad day (vs. an ominous start of a new behavior problem).

## I-INTERACT in Action, cont’d

- J. enjoyed Special Play Time when he could lead without parent directives.
- Parents’ ratings of behavior problems did not decrease significantly, but their distress related to behavior problems did improve.

## Case Example 3: Need for School Advocacy Skills & Structure/Safety in the Home

- 4 year old African American girl M. is 1 of 4 young children residing with her unemployed mother. M. fell out a 2<sup>nd</sup> story screenless window in Section 8 housing resulting in her TBI.
- M. is often non-compliant, sometimes resulting in safety concerns (e.g. sliding down bannister)
- Mom requires childcare so that she can complete her GED & Associate’s degree to provide for her family.

## I-INTERACT in Action

- School & Mom requested information and suggestions for dealing with M’s frequent & severe temper tantrums at school.
- Using program content, the therapist trained Mom to be M’s school advocate.
- After consulting via phone, the principal was given access to the website to learn about TBI and behavior management strategies.
- Since then, Mom has missed no classes as she has not been called to pick M. up early.

<p><b>I-INTERACT in Action, cont'd</b></p> <ul style="list-style-type: none"> <li>• Mom is learning to structure her daily routine to make 5 minutes of Special Play Time &amp; undivided attention for M.</li> <li>• Mom and M. greatly enjoy their SPT together, resulting in excellent compliance and emotional self-regulation.</li> <li>• By learning problem solving skills, Mom has developed creative strategies to maximize home safety hopefully reducing the chances of future injury for M. and her siblings.</li> </ul>	<p><b>Impact of Telehealth Approaches on the Therapist</b></p> <ul style="list-style-type: none"> <li>• Fewer nonverbal cues.</li> <li>• May need to change style (can't do structural family therapy).</li> <li>• Maintaining boundaries on the family's turf.</li> <li>• Need for flexibility.</li> </ul>
<p><b>Telehealth approaches and parents</b></p> <ul style="list-style-type: none"> <li>• Technology can be overwhelming particularly for parents who are not computer literate.</li> <li>• Flexibility of the approach may reduce rather than increase adherence for some parents.</li> </ul>	<p><b>The Darkside of Technology</b></p> <ul style="list-style-type: none"> <li>• The use of videoconferencing can exacerbate problems with attention and engagement for some teens and children.</li> <li>• Technological problems can contribute to family frustration and nonadherence, although this seems to be independent of SES and prior computer comfort.</li> <li>• Rural families with fewer resources/options may be more tolerant of difficulties.</li> </ul>
<p><b>Conclusions and Future Directions</b></p> <ul style="list-style-type: none"> <li>• These telehealth approaches appear to be well-received and beneficial to families and survivors of TBI.</li> <li>• On the whole, the advantages of using a web-based approach coupled with videoconferencing outweighs the disadvantages in most cases.</li> </ul>	<p><b>Rehabilitation Research and Training Center for Pediatric TBI Interventions</b></p> <ul style="list-style-type: none"> <li>• This NIDRR-funded center will allow us to conduct two large, multi-site RCTs of the efficacy of TOPS and I<sup>2</sup></li> <li>• Participants recruited from 4 sites in Ohio + Children's Hospital of Denver (total 155 kids in TOPS and 120 in I<sup>2</sup>)</li> <li>• These studies will help us to understand who needs the full model and who might benefit from just website access or an abbreviated program.</li> </ul>

## Sharing/Collaboration

- Happy to give professionals interested in using the programs we've developed access so they can use them in their own settings.
- Feedback about new uses and applications is very important for subsequent modifications.