

Use a Strategy!
Learn to Compensate for
Thinking and Communication Challenges
after Acquired Brain Injury (ABI)

Stephanie Mayer Volker MS, CCC SLP

Coordinator Outpatient
Neurorehabilitation Team (ONRT)
Cincinnati Children's Hospital
Medical Center

Use a Strategy! Learn to Compensate after ABI

Presentation Goals

1. NOT just to give a list of compensatory tools after ABI (can Google them)
2. Explain the rationale for using compensatory tools
3. Provide an overview of important factors which impact successful use of strategies
4. Give hope that improved functional independence is always possible after ABI with the right use of compensatory tools

Presentation Overview

1. Progress beyond neurological recovery: compensating
2. Factors to consider in kids versus adults
3. Why use compensatory tools?
4. Compensatory “Tools/Options”
5. Choosing the right kind of compensatory “tool”
6. Individualized vs. “cookbook” approach
7. Resources

Progress beyond neurological recovery: Is this it? What about compensating?

Predicting recovery and long-term outcome following a brain injury is a complicated process, dependent on a number of factors, including:

- Severity and location of the neurological damage sustained
- Length of time elapsed since injury
- Pre-Injury language/cognitive abilities
- **Caregiver and Family support**
- The age at time of injury
- Change in symptoms over time and ability to **compensate**

Progress beyond neurological recovery: Is this it? What about compensating?

*“recovery from a
brain injury lasts a
lifetime”*

Positive or Negative Thought for You?

Progress beyond neurological recovery: Is this it? What about compensation?

- Is there an “end point” to recovery?
- Can a person make progress years after ABI?
- How many survivors/caregivers dreaded the “one year” anniversary?
- Can someone actually make a substantial amount of recovery beyond one year?

Progress beyond neurological recovery: Is this it? What about compensation?

Does progress always end when skill recovery slows/ends?

NO!!

Can a person make substantial, functional gains even when their skills remain the same?

YES!!

Progress beyond neurological recovery: Is this it? What about compensating?

Functional gains can be made without progress in skill development

Compensate!

Progress beyond neurological recovery: Is this it? What about compensating?

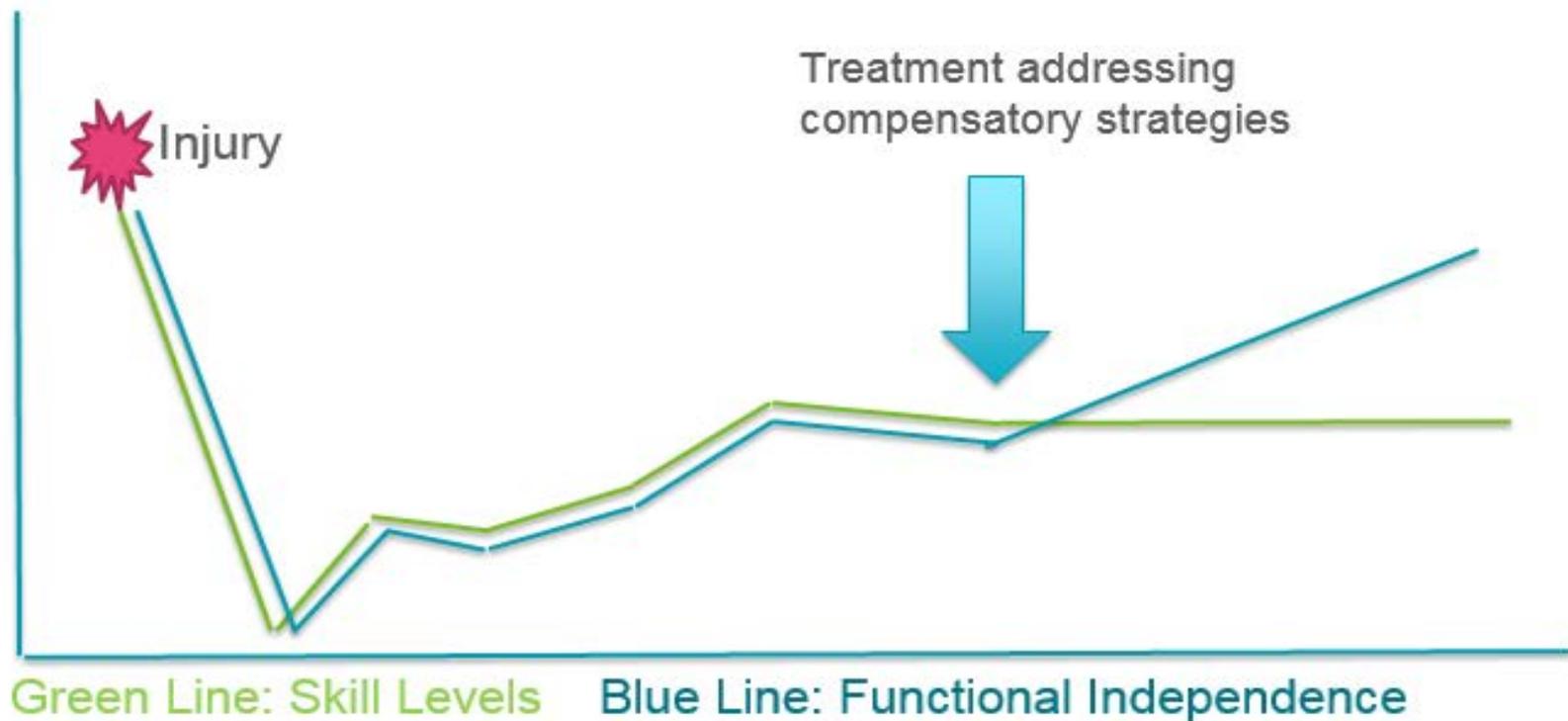
To compensate:

- to make up for some defect or weakness
- to provide something good as a balance against something bad or undesirable



A compensation strategy or "work-around" goes **AROUND** the obstacle

Progress beyond neurological recovery: Is this it? What about compensation?



Progress beyond neurological recovery: Compensate for What?

COGNITIVE/THINKING SKILLS

- Attention
- Memory
- Processing Speed/Capacity
- Problem Solving and Critical Thinking
- Executive Function Skills
- Self-Awareness/Insight



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Keep in Mind: Kids versus Adults

Age at time of injury

- One of the most common misconceptions that exists is that an ABI sustained earlier in life leads to a more favorable outcome compared to an injury sustained later in life
- The conventional thinking regarding TBI in young people was that the child's brain was incredibly resilient to trauma because it was much more "plastic" than the adult brain, i.e., that other parts of the brain would take over for damaged parts

Keep in Mind: Kids versus Adults

“The earlier
the better”

“Young
brains heal
faster”

“They can
outgrow it”

“It happened
so long ago-
it no longer
matters

MYTHS
BUSTED

Keep in Mind: Kids versus Adults

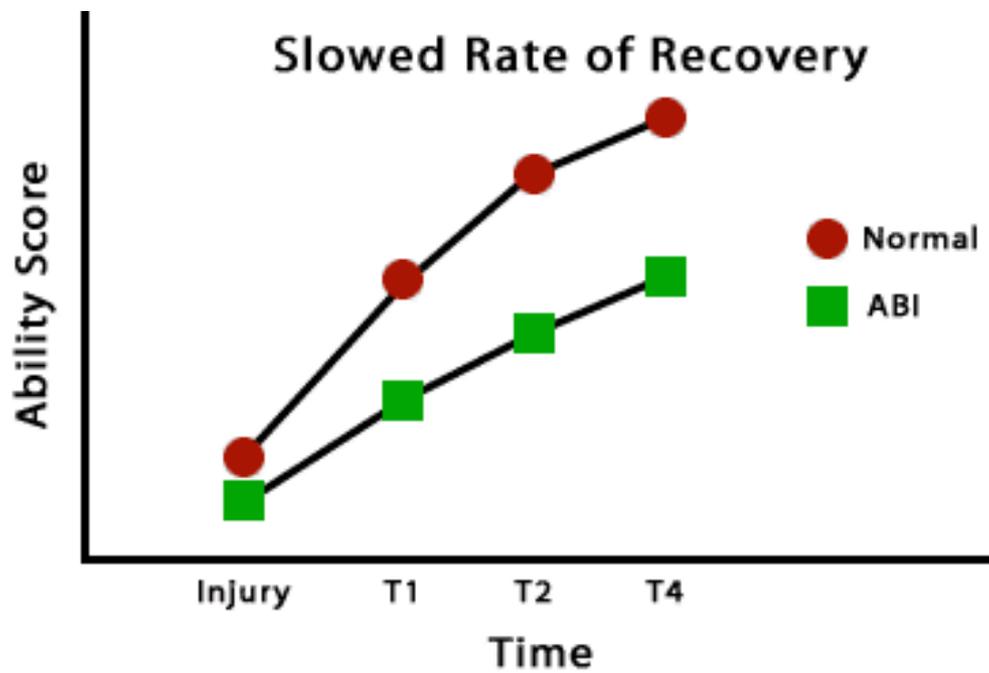
Kids and Adolescents have an injury to a still developing brain....

- The brains of children, adolescents and young adults are not static, but rather develop in leaps and spurts throughout childhood and well into the mid-twenties of young adulthood.
- Any injury in the developing brain can impact how the brain develops later on....
- Example: a Computer Hard Drive which hasn't yet received all the data and experiences a power surge



Keep in Mind: Kids versus Adults

Slow Rate of Skill Development

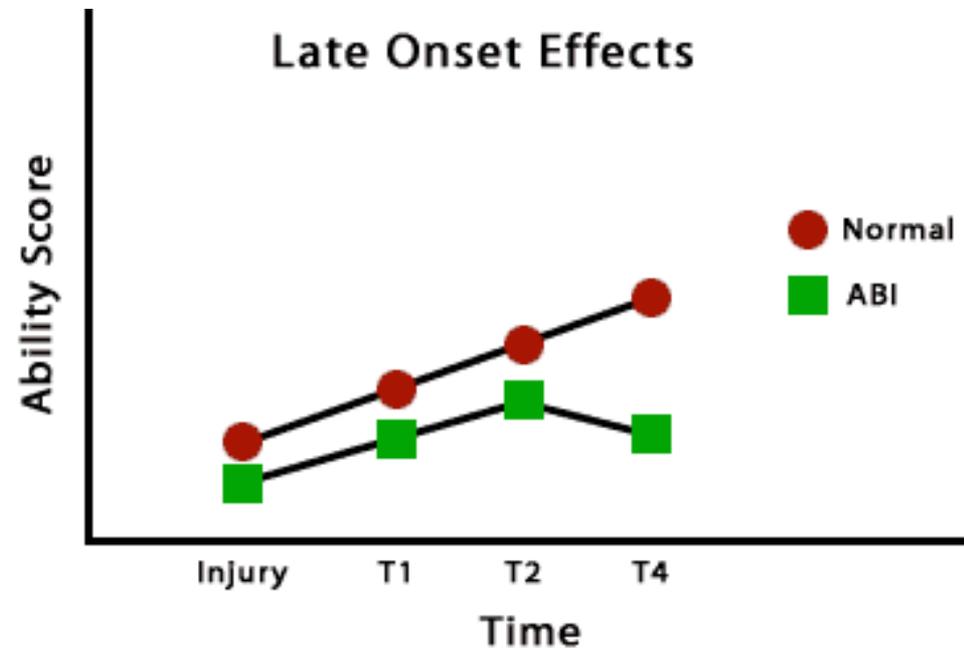


- Some injured children will develop skills but at a slower rate than normal with a decreased likelihood of ever "catching up."
- Shawna was a nine-year-old third grader when she was diagnosed with a brain tumor and underwent chemo and radiation. Her pre-injury history was remarkable for being diagnosed with an attention deficit disorder. Following her treatment, she developed neurocognitive late effects, and as she aged she had more and more challenges keeping up with her same age peers due to reduced development of higher level cognitive functions

Keep in Mind: Kids versus Adults

“Growing Into Symptoms”

- Some show early medical and neurological recovery and then "grow into" their symptoms with the passage of time
- Peter sustained a moderate TBI in a motor vehicle/bicycle accident as a seven-year-old second grader. His pre-injury history was completely normal. Once he returned to school, he kept pace with his peers up until the sixth grade, at which time problems in organization and planning of schoolwork and activities (executive functions) became apparent.



Keep in Mind: Kids versus Adults

The bar keeps getting raised....

- As children and adolescents grow up with a history of chronic illness or injury, the impact of their deficits and their ability to compensate will change
- As young people's brains develop, the world around them also becomes more complex and sophisticated. Learning in school becomes more difficult, social and behavioral expectations increase, and the expectations of independence levels increase
- They are not getting worse, but the functional impact of their deficits can become more obvious and detrimental, i.e. they are "growing into their symptoms"
- **THIS CAN OCCUR IN ADULTS TOO AS THEY FACE TRANSITIONS IN LIFE**



Keep in Mind: Kids versus Adults

Adults

Functional Goals May Include:

- Successful employment
- Parenting
- Spousal relationships
- Independent living
- **Transitions**

Kids

Functional Goals May Include:

- Success in school
- Independence (up to a point)
- Social Relationships
- **LOTS of transitions as they age**

Keep in Mind: Kids versus Adults

Different Support Systems

- Children may have more resources available to them than adults due to pediatric vs. adult healthcare, school systems, access to developmental disability programs
- Most children were already being taken care of and were dependent on their parents so their family support system is already in place. Adults were self-sufficient and now may need a caregiver.
- An emotional challenge and grieving process for all involved
- **CAREGIVER SUPPORT BIGGEST OUTCOME PREDICTOR**

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Goal of Using Compensatory “Tools”

Treatment for “life”

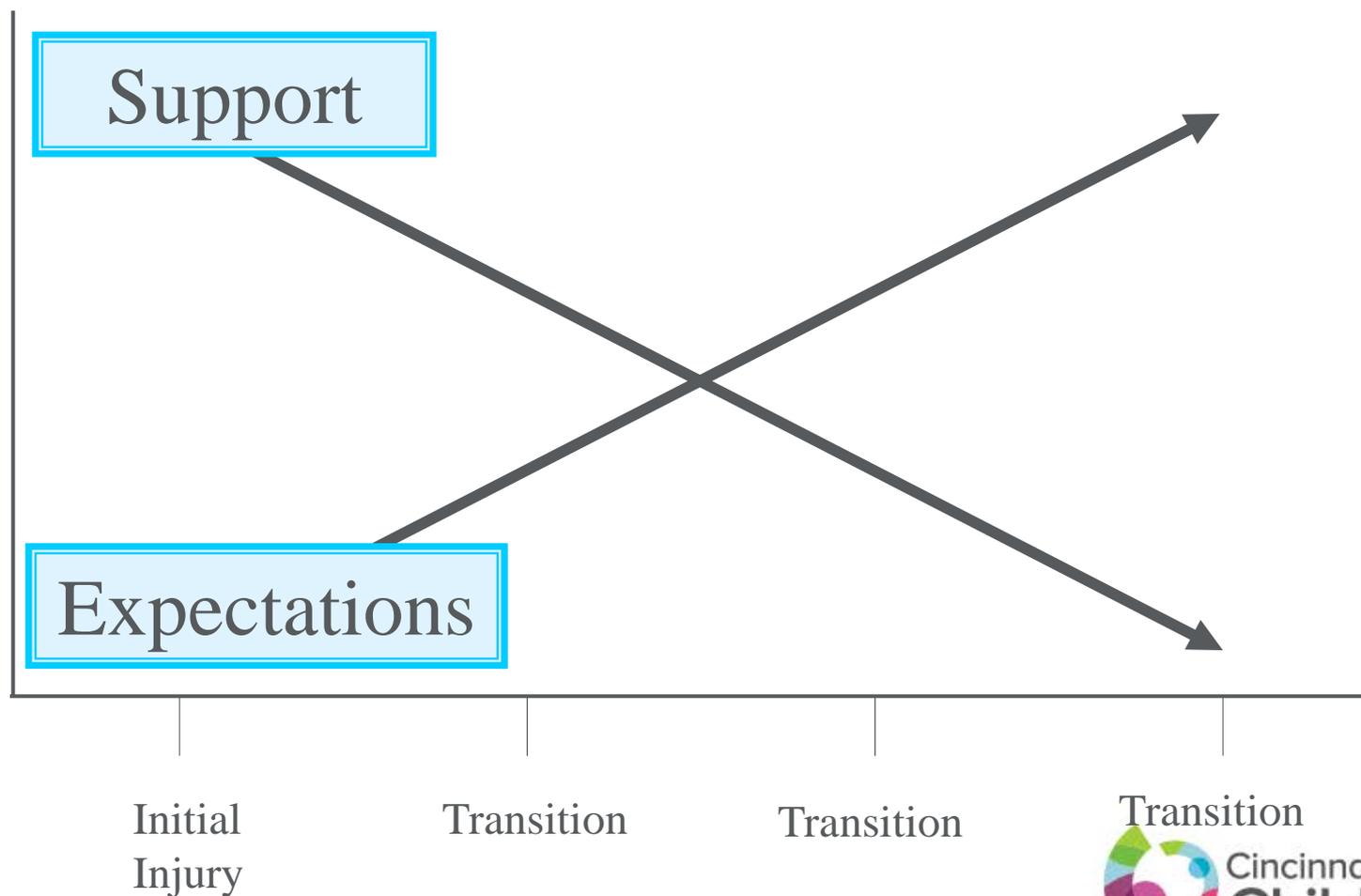
- ABI can be a developing disability in which the impact changes over time as the bar is raised
- Survivors’ needs may change with time due to the changes in demands and the deficits they demonstrate at any given time
- Therapy should target real “life”, very functional goals, ex. “I want to be able to.....”
- Compensatory “tools” help achieve these goals even when the bar keeps moving

Goal of Using Compensatory “Tools”

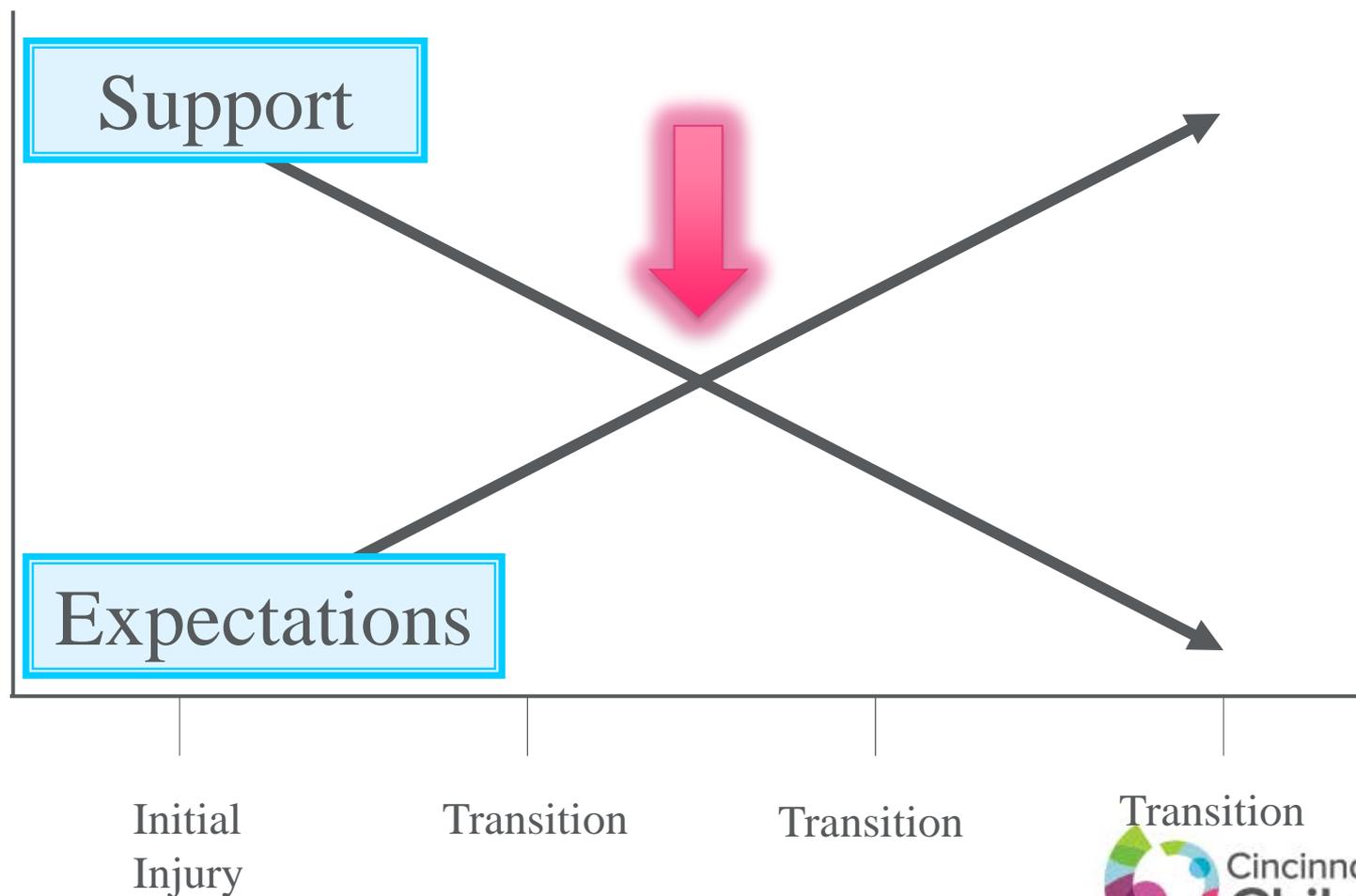
Treatment for “life”

- Those who have sustained an ABI and have a need for cognitive rehabilitation may not fit the traditional model of therapy services, ex. Weekly for 6 months after the injury
- In our program, we use a variety of models such as a changing frequency, consultative, burst/intensive, group and individual, breaks from therapy and return as needed for current challenges
- I never really ever “truly” discharge anyone if there is potential for use of compensatory tools to make progress

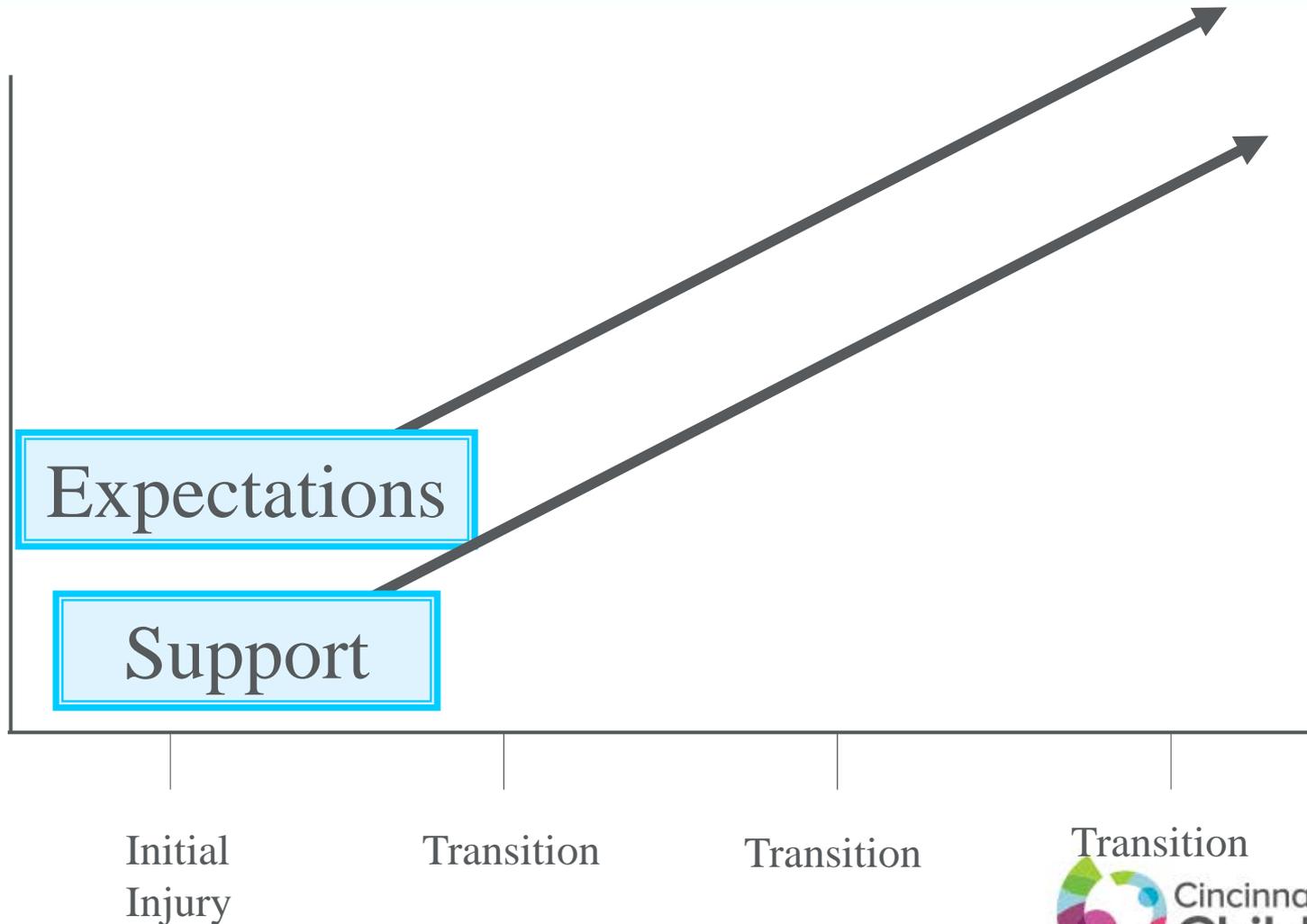
Goal of Using Compensatory “Tools”



Goal of Using Compensatory “Tools”



Goal of Using Compensatory “Tools”



Goal of Using Compensatory “Tools”

Improved Functional Outcomes by Learning to Compensate

- Significant progress can be made in therapy (or without) even if the likelihood of further skill progress is limited
- This is exactly when to begin to think about training in the use of strategies or developing accommodations to compensate for persistent deficits
- This type of thinking is sometimes a direct opposite of what some therapists are used to (shouldn't be if a rehab therapist)

Goal of Using Compensatory “Tools”

Compensation for Persistent Deficits

- Teach/train survivor and caregiver support system to compensate for deficits
- The problem is still there, but the functional impact of it is minimized
- I argue that the BEST progress and outcomes can come from shifting to this approach

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What's in the Compensatory TOOLBOX?

Accommodations

- Provided by others

External Aids/Assistive Technology

- Can be “touched”
- Can be used with help (cues from another person)
- Can be used independently by survivor *if have motivation and self awareness*

Self Directed Strategies

- Are used independently by survivor
- *NEED motivation and self-awareness*

What's in the Compensatory TOOLBOX?

Accommodations

- Are provided by others to help increase the survivor's independence
- Can be provided by caregivers, aids, teachers, job trainers, friends
- Can be tangible (touched) or verbal (prompts/cues)
- Do NOT need self-awareness, but need acceptance of help
- Can be:
 - A change to the environment
 - A modification to expectations
 - Support from others to reduce the impact of a deficit

What's in the Compensatory TOOLBOX?

Accommodations Examples

1. Changing the environment: seating, routine, remove distractions, reduce noise, pre-organize materials, set up a schedule, change people
2. Modify expectations: ½ days, rest breaks, less work, different curriculum, test formats, increased time to complete
3. Supports: communication style (slowed rate of speech), arrangement of materials (bag of outfits), instructional techniques such as advance organizers, small group instruction, errorless learning, repetition

What's in the Compensatory TOOLBOX?

Self-Directed Strategies and Independent Use of External Aids/Assistive Technology: **Must Haves**

1. Self-Awareness (Metacognition)- Insight and Awareness (more on this later)
2. Initiation (don't confuse lack of initiation with laziness)
3. Motivation/Desire (Don't confuse with self-awareness)
4. A functional outcome goal to strive toward
 - If the above 1-4 are not present, then I would only target use of accommodations (provided by others) or prompted use of external aids/assistive technology
 - BIG 4

What's in the Compensatory TOOLBOX?

External Aids/Assistive Technology

- Can be provided by others, prompted cued to use by others, OR used independently
- If used independently need to have good self-awareness, initiation, and motivation to use
- Can be Low Tech (External Aids)
- Can be High Tech(Assistive Technology)

What's in the Compensatory TOOLBOX?

External Aids/Assistive Technology

** remember can be used with prompts or independently

1. Examples of Low Tech (External Aids):

- Calendar, visual schedules, checklists, organizational system in the home, binder system in school, folders, white boards, post it notes

2. High Tech (Assistive Technology)

- Smart Phone, Siri/Cortana, Alarm Reminders, Speech to Text, Text to Speech, Audio books, Google Extension, Apps, Smart Home Devices (Alexa, Google Home), Smart Pen

What's in the Compensatory TOOLBOX?

Self-Directed Strategies

1. Ways of doing something differently in order to be more independent
2. Requires the BIG 4 (initiation, goal, self-awareness, motivation)
3. Survivors who use self-directed strategies or use external aids/technology independently can significantly improve their own success and independence level even when they have persistent deficits
4. Can be used for both communication and cognitive challenges

What's in the Compensatory TOOLBOX?

Self-Directed Strategies

Examples

- Self-Advocacy- asking for help or requesting certain accommodations or supports when needed
- Compensatory Memory Strategies- repetition, association, mnemonic devices (tricks), chunking, “trip over it”, “everything has a place and everything in its place”
- Comprehension Strategies- Ask for repetition, Restate, Clarification, Can you slow down?
- Attention Strategies- Block distractions, laser focus, sticktoitability

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How to Choose the Right Kind of “Tool”

What is Self-Awareness (metacognition)?

- May also have heard it called “insight”
- The ability to stand back and take a bird’s eye view of yourself in a situation, to observe how you problem solve.
- Includes self-monitoring and self-evaluation skills (how am I doing or how did I do?)
- Requires **attention** to self and performance, the ability to **remember** all of the information in order to process it, and good **reasoning** and logic to evaluate
- **What are common deficits s/p ABI?**

How to Choose the Right Kind of “Tool”

Self-Awareness

- Acknowledgement of strengths and limitations, in particular the ability to understand the nature of impairment and appreciate its implications.
- Awareness of cognitive physical, social, and communicative functions and functional outcomes
- Cognitive process requiring integration of information from both external reality and inner experience.
- Includes the ability to self-monitor and self-correct behavior, and is among the highest cognitive functions
- Changes in children with developmental progression

How to Choose the Right Kind of “Tool”

Self-Awareness Analysis

- **Intellectual Awareness:** cognitive capacity to understand that a particular function is diminished
- **Emergent Awareness:** ability to recognize a problem when it is actually occurring during an activity
- **Anticipatory Awareness:** ability to anticipate that a particular problem may be experienced in a particular task or situation and to acknowledge the possible implications deficits may have on functional performance (ONLINE)
- ONLINE involves the ability to detect errors during actual performance, anticipate likely problems and initiate compensatory strategies aimed at overcoming these possible problems

How to Choose the Right Kind of “Tool”

Self-Awareness Analysis

- **No Awareness (Lack of):** There is nothing wrong, I am the same, I don't need help, I can do it myself, I did great
- **Intellectual Awareness:** Yeah, I can't remember things so well
- **Emergent Awareness:** I can't remember things well and am not doing well at work/school because of my memory
- **Anticipatory Awareness:** When I am at work I can't take in all of the information that my boss tells me during a staff meeting so I:
 - Record the meetings with my Smart Pen, Notability App on iPhone
 - Ask him to slow down
 - Request he use visuals support my memory
 - Check back/restate
 - Take notes

How to Choose the Right Kind of “Tool”

Lack of Self-Awareness

- Very, very common in ABI
- Clinical term is anosognosia
- ‘Lack of insight’ describes a common outcome of brain injury. ... If you heard a person had ‘anosognosia’ would you think and respond differently, than hearing a person has a ‘lack of insight after brain injury’?
- *If your scale was involved in a crash while moving houses and had sustained damage- would you use that scale to weigh yourself and trust the number?*



How to Choose the Right Kind of “Tool”

Lack of Self-Awareness Vs. Denial

- Do not confuse lack of self-awareness with denial
- Lack of self-awareness is due to neurological damage sustained in the brain
- Denial can be a normal psychological response to help a person deal with something can't face yet
- Denial can be present in survivor and in caregiver
- Acceptance to the “new reality” after an ABI can take 2-3 years (average range)
- This can present a challenge when there is a time limit on provision of therapy to work on compensatory tools

How to Choose the Right Kind of “Tool”

Building Self-Awareness

- Self-Awareness CAN BE IMPROVED and is often a goal of cognitive rehabilitation treatment addressing compensatory tools
- Often caregivers are the key to help build self-awareness
- May need to use “supported failure” and allow the survivor to experience consequences of the deficit and recognize what will happen without the help of others
- This is a delicate process and should be guided by a therapist trained in cognitive rehabilitation

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Compensate?

WHY?

HOW?

WHEN?

WITH WHAT?

FOR WHAT?

WITH HELP?

WITHOUT HELP?

Individualized versus a “cookbook” approach

- “One size does not fit all”
- “Once you have seen one brain injury, you have seen one brain injury”
- The key to successful compensatory tool development is to take into account all of the factors that should be considered
- A standardized “Tips for Memory after TBI” may not work for everyone
- It is key to understand all of the variables involved

Individualized versus a “cookbook” approach

- All brains are different
- All injuries are different
- All personal goals are different
- All support systems are different
- All expectation levels are different
- All experiences in recovery are different
- All access to resources and supports are different

You get the point

Resources to Learn More to Get Started

- Best to consult with a cognitive rehabilitation therapist who can help
- Even a few consultative sessions can really make an impact
- But if therapy is not a possibility... do some reading, talk to other survivors, attend support groups, Google, and..... give it a try
- Can do it gradually
- Try “liking” an educational resource on Facebook, sign up for weekly emails from websites, make a goal to work on it one hour a week

Resources to Learn More to Get Started

Specific to ABI (vetted and “expert” content)

- Project Learnet: www.projectlearnet.org
- Brainline: www.brainline.org
- Brainline Kids: <https://www.brainline.org/children-tbi>
- Brain Injury Association of America: www.biausa.org
- Family Caregiver Alliance:
<https://www.caregiver.org/traumatic-brain-injury>
- Google diagnosis specific sites for stroke, epilepsy, brain tumor, etc.
- There are a lot of survivor sites, Google them

Resources to Learn More to Get Started

Not ABI specific, but compensatory tool specific

- www.Understood.org
- Smart But Scattered by Peg Dawson and Richard Guare
- Smart But Scattered for Teens by Peg Dawson, Richard Guare and Colin Guare
- The Smart But Scattered Guide to Success: How to Use Your Brain's Executive Skills to Keep Up, Stay Calm, and Get Organized at Work and at Home by Peg Dawson and Richard Guare
- All 3 available at www.amazon.com/Smart-but-Scattered-Revolutionary-Executive/dp/1593854455

Resources to Learn More to Get Started

Specific to the School Setting

- Center on Brain Injury Research and Training:
<http://cbirt.org/resources/educators/>
- BrainStars:
<http://www.brainline.org/content/2011/09/brainstars.html>
- Brain Injury In Children and Youth: An Educator's Manual:
https://www.cde.state.co.us/cdesped/tbi_manual_braininjury

Specific to the Work Setting

- Understanding Brain Injury: A Manual for Employers:
<http://www.ndrn.org/images/Documents/webcats/mc1298.pdf>

WRAP UP THANK YOU!

Stephanie Volker MS CCC-SLP
Cincinnati Children's Hospital
Coordinator Outpatient NeuroRehab Team
Stephanie.Volker@cchmc.org