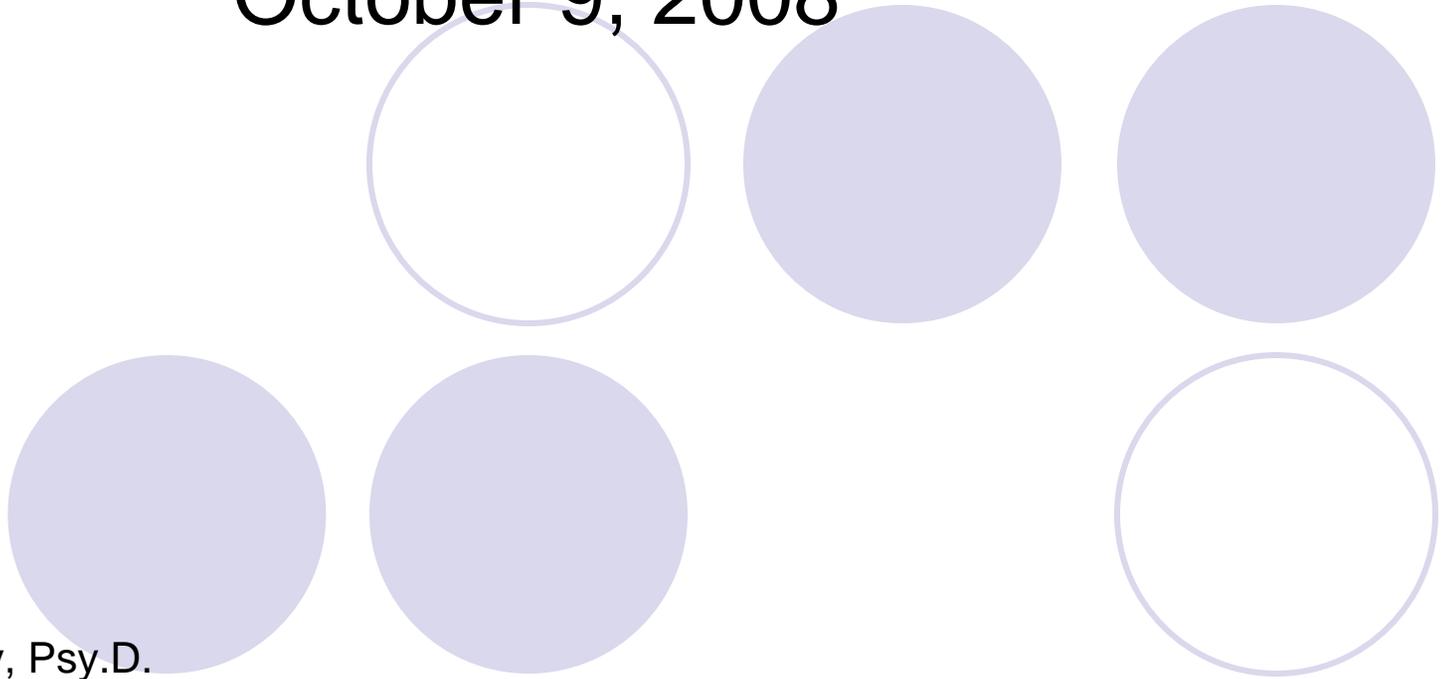


Facilitating Successful Transitions for Youth with Brain Injury

October 9, 2008



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What is brain injury?

An **acquired** brain injury (ABI) is an injury to the brain that has occurred since birth – a disruption of normal development.

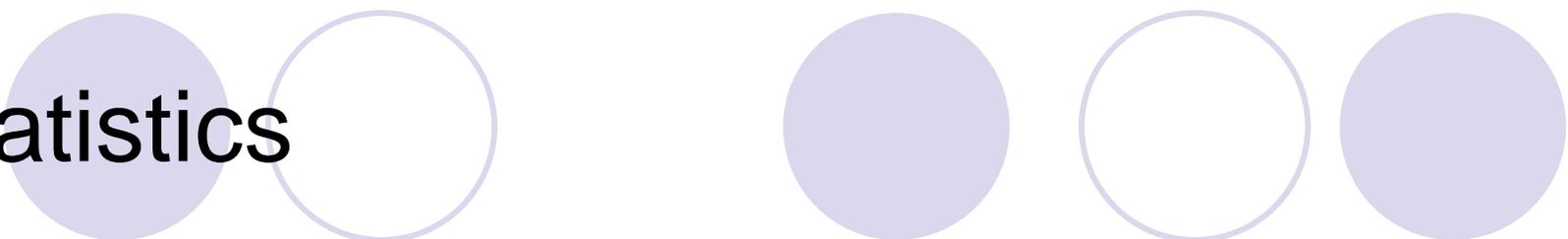
A **traumatic** brain injury (TBI) is an acquired brain injury that has resulted from trauma to the head/brain: open or closed



There **WAS** a period of normal development!

Every 15 seconds a person suffers a brain injury

- Based on national estimates, there are more annual incidences of Traumatic Brain Injuries than Multiple Sclerosis, Spinal Cord Injuries, HIV/AIDS and Breast Cancer put together. It is estimated that over 20% of our American Soldiers are returning home with a TBI.
- In this country there are:
- 3 million persons living with breast cancer and public spending is \$295 per person
- 900,000 persons living with HIV/AIDS and public spending is \$18,111 per person
- 5.3 million persons living with disability from TBI and public spending is \$2.55 per person



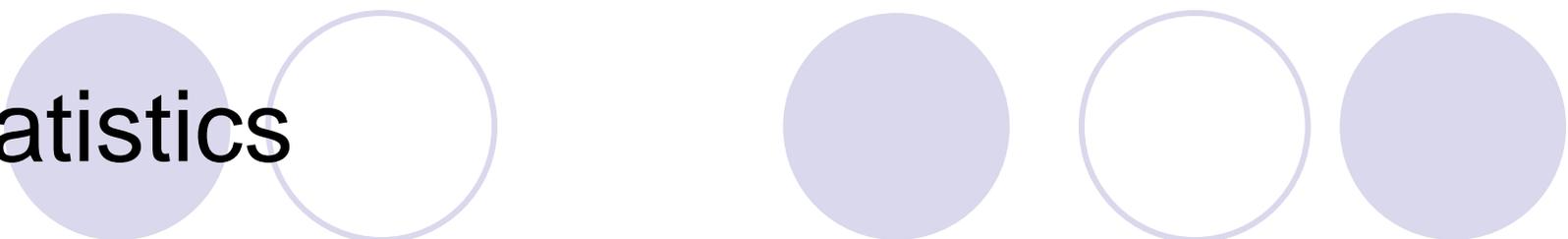
Statistics

Pediatric brain injury – the single most cause of death and disability in children, up to 90% of injury-related deaths are associated with head trauma

Between 60-82% of all admissions to hospitals are head traumas

165,000 children will be hospitalized each year with a BI

From hospital fewer than 2% are recommended for special education (though 19% have cognitive limitations) (National Pediatric Registry)



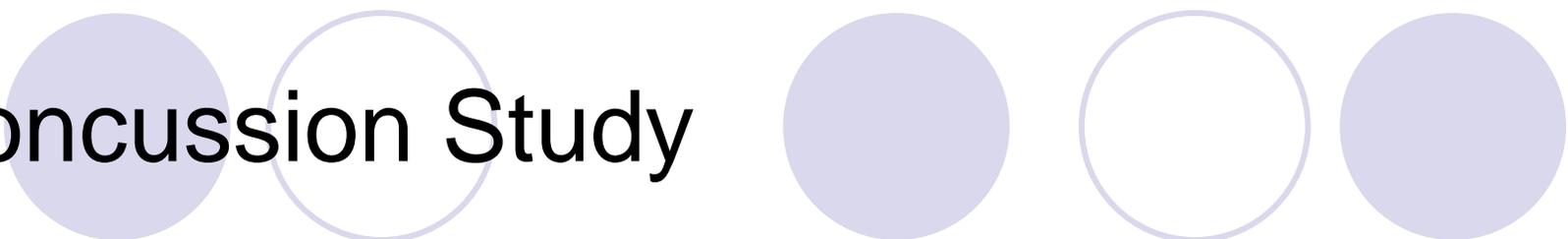
Statistics

Mild Brain Injury:

CDC reports over 300,000 sports-related mild BI per year (also known as a “concussion”) — this number only includes LOC

Each year, approximately 1 million children require emergency care as a result of a brain injury (National Head Injury Foundation, Inc.)

Concussion Study

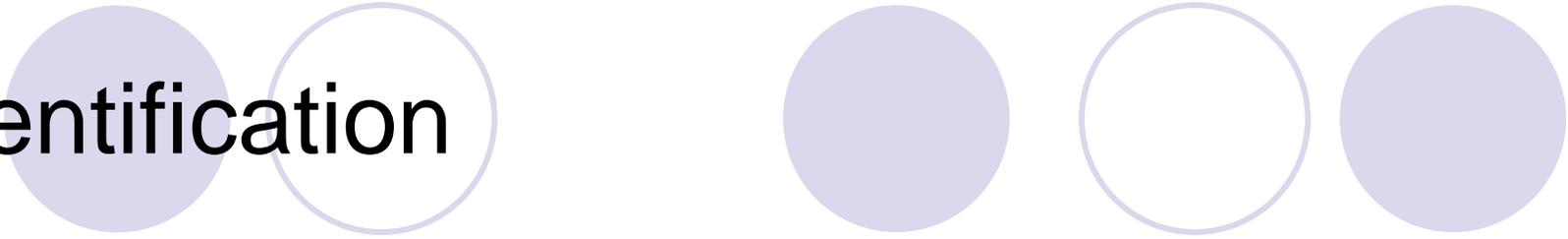


June 2007 completed a 3 year study on concussions in student athletes for CDC.

Concussion = mild TBI

In 1 high school, over 3 years = approximately 120+ concussions

WikiAnswers: $13,500 \text{ HS} \times 40 = 540,000?$



Identification

Proper identification of BI is essential in facilitating a successful transition

If you do not appropriately identify...you cannot set up the necessary parameters for Transition

Barriers to Identification



Moderate to severe brain injury:

- Families are deeply grieving
- Criteria for special education is exclusive of non-traumatic brain injury (acquired brain injury)
- Many children with a moderate to severe TBI qualify and receive an IEP or 504 upon discharge. This at least keeps “Transition” on the radar.

Where Are the Children? Barriers to Identification



Mild to moderate brain injury:

- Brain injury often goes undiagnosed
- The effects of brain injury can be very subtle
- Lingering effects of BI may not emerge in earnest until after 12 months
- Families and school personnel have limited knowledge about brain injury



The Importance Of Accurate Identification

- Student receives appropriate interventions
- Prevent a cycle of failure
- Allows the student to begin developing self advocacy skills
- Accurate identification ensures more appropriate funding and subsequent service provision
- If you cannot identify BI, how can you facilitate a successful transition?

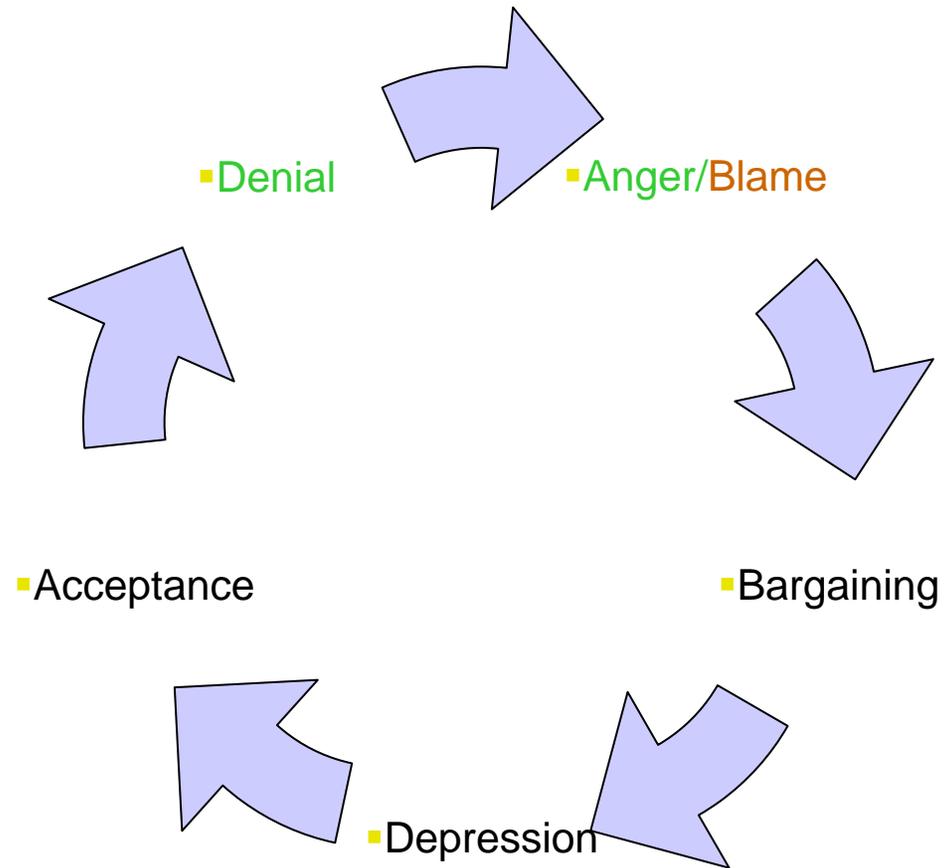
What makes Transition challenging for children/families with a brain injury?

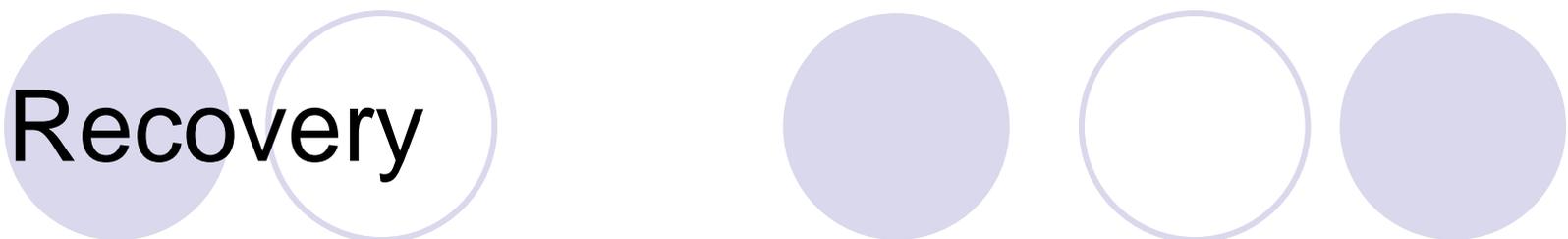
1. Reason – How child received their injury
2. Recovery – Non-linear recovery
3. Reality – Remediation versus compensation

1. Reason: Most common causes of brain injury

- Infants – physical abuse, “shaken baby syndrome”
- Young children – passengers in motor vehicles
- School-aged children – bicycle and pedestrian collisions with automobiles
- Adolescents – auto accidents (both drivers and passengers)

Cycle of Grief



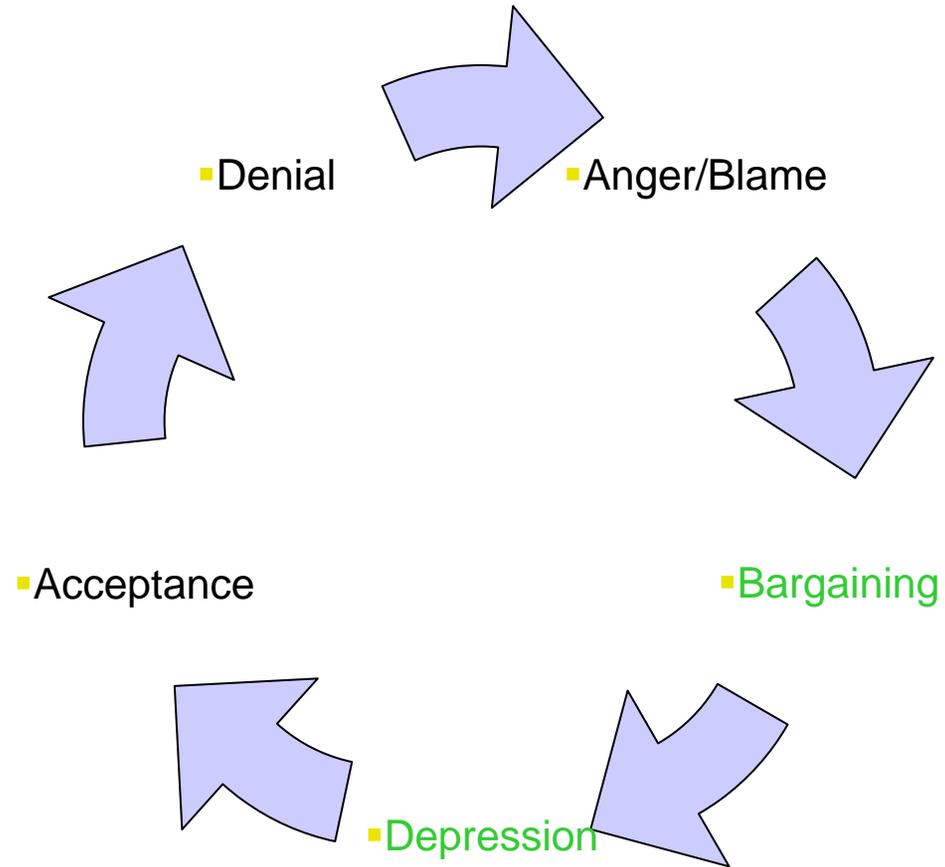


2. Recovery

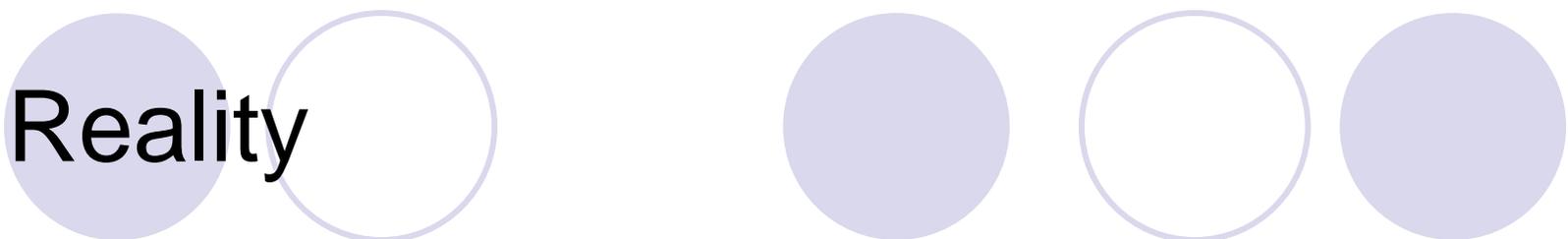
Rate of recovery from BI is generally rapid and steep at first. Recovery then generally stalls and slows... may plateau at about 2 years.

Trajectory of recovery from BI is non-linear. Skills that do return range from full recovery to splintered recovery to minimal recovery.

Cycle of Grief



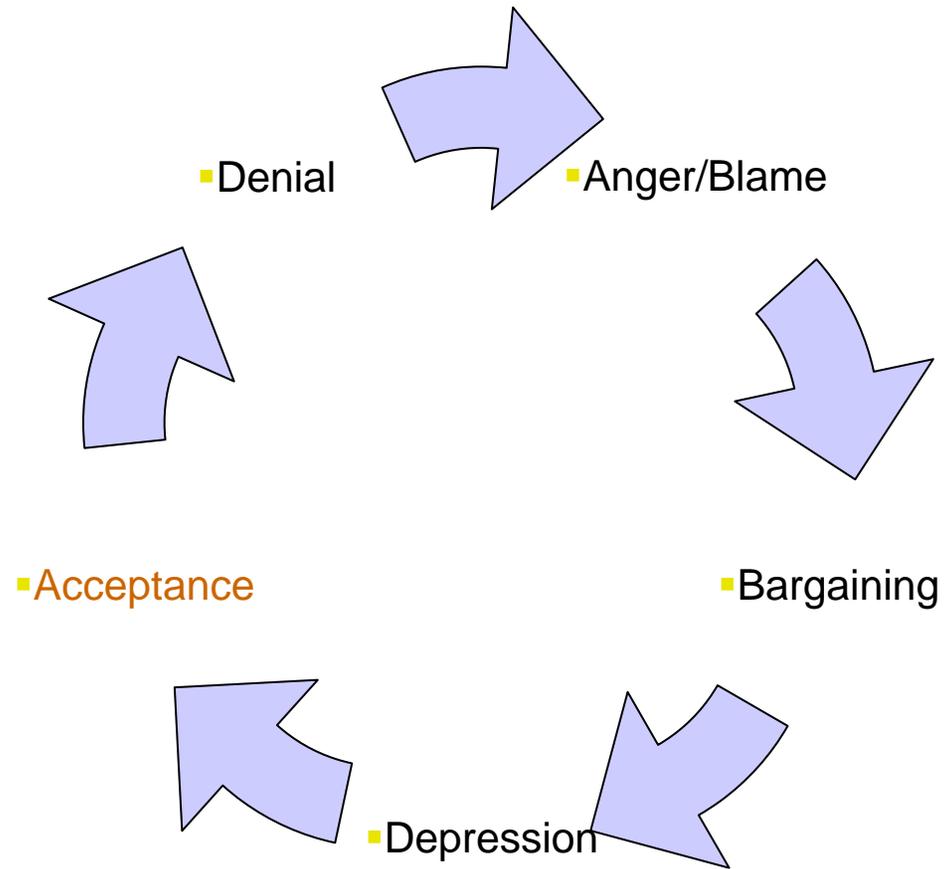
3. Reality



Balance between remediation and compensation:

Acceptance - depends upon state of denial, anger/blame, bargaining and depression

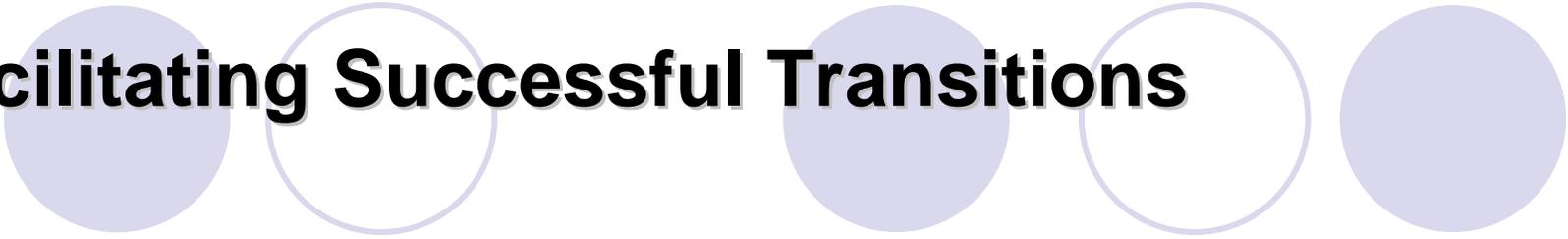
Cycle of Grief



Transitions



Facilitating Successful Transitions



- Transition from person without a disability to a person with a disability
- Transition from a medical setting back to school
- Transition from grade to grade
- Transition from elementary to Middle school and Middle school to High School
- Transition from secondary to post-secondary settings

Transition from Medical Setting back to School - **Issues**

- Grief, stress, overwhelmed – **information overload** (TCH data upon discharge)
- Person with injury, families and school personnel have to learn SO much about brain injury
- Fear - don't know what to expect next
- Prioritize – “hierarchy of needs”





Transition from a Medical Setting

- Grieving is acute! Often still in early cycle of denial and /or anger/blame.
- Have either the BI Team or a liaison from the school attend the discharge meeting at the medical setting
- Help the family navigate the uncharted territory of IDEA and/or 504 (families often refuse services in “hope” child will get better)
- Identify the team of people that will be supporting the student as they return to school



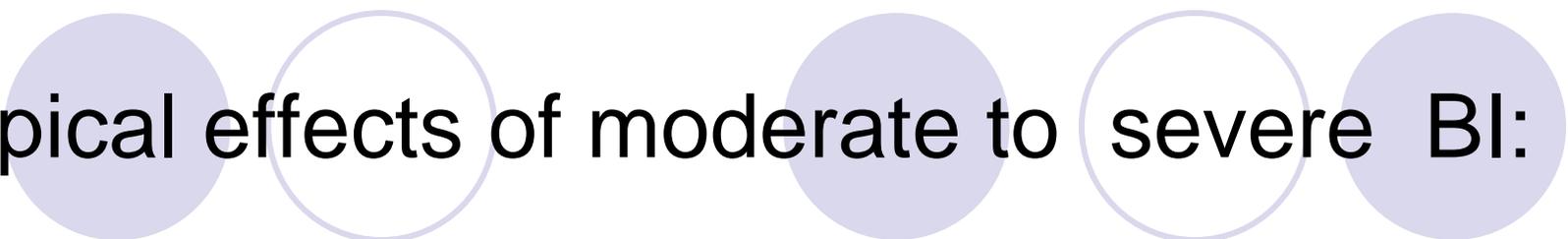
Transition from a Medical Setting

- With the help of the BI Team and/or outside BI expert - provide an in-service for the student's classmates. This generally includes the parents and the student. "Grow and Glow"
- With the help of the BI team and/or outside BI expert - provide an in-service for school personnel, including administrative personnel, teachers, lunchroom and recess aides if possible.
- Allow the student to visit the school prior to their return to classes



Transition from a Medical Setting

- OT, SLP, PT and Psych should coordinate with outside providers (services by school OT, PT, SLP, Psych have a different focus)
- In severe cases of BI and usually upon discharge from a hospital, an IEP is necessary
- If prior IEP in place, make every attempt to change existing IEP to reflect brain injury
- Once the transition has occurred, if lingering academic, behavioral or emotional concerns persist, have the school district BI Team or Behavior Team consult



Typical effects of moderate to severe BI:

Tend to see:

- Mental Fatigue
- Motor problems
- Feeding problems
- Cognitive problems – concrete thinking
- Emotional and Behavior regulation
- Seizures

Typical effects of mild to moderate BI

- Mental fatigue
- Slowed processing speed
- Difficulty transferring “new learning” into memory – affects sequential thinking
- Problems with Executive Function
- Social Skill problems

How BI issues “manifest” in the classroom

- Mental fatigue
- Slowed processing speed
- Difficulty transferring “new learning” into memory – affects sequential thinking
- Problems with Executive Function
- Social Skill problems
- Head down, tired, “lazy”
- Dragging work out
- Inconsistent learning – “you had it yesterday and not today, faking”
- Behavior problems, ADHD, messy,
- Can’t get along with others

“The Outside to the Inside, Including Students with Brain Injury”

Ctr. for Disabilities and Development, Univ. Of Iowa Health Care

Transition from Medical Setting back into School:

- Establish a leader
- Assess the problem
- Hypothesize the core underlying the problem
- Prioritize the problem(s)
- Apply an intervention
- Assess whether your intervention is successful

Ordering information: 319-356-1523 or email
Linda-Murray@uiowa.edu

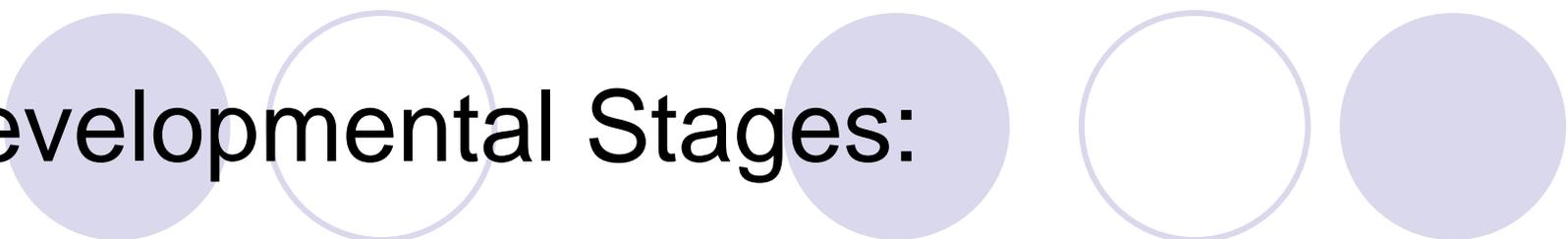
Take development into account

What is the appropriate developmental achievement?

How has the ABI/TBI disrupted the path of development?

Where has the child gotten “stuck”?





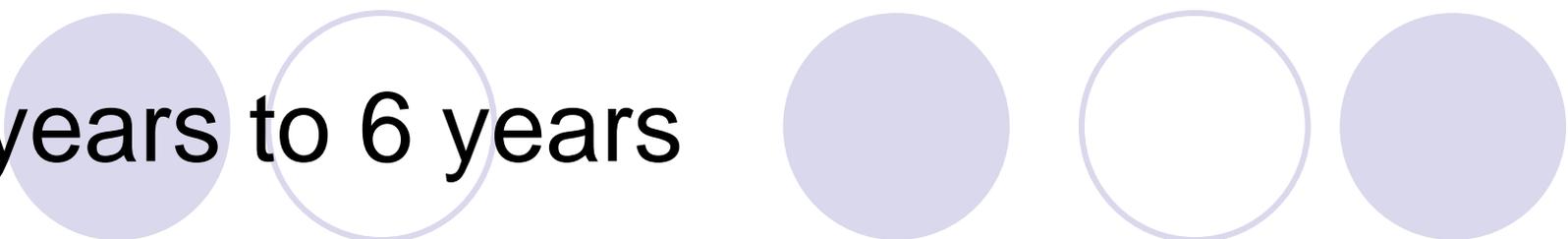
Developmental Stages:

BrainSTARS – Jeanne Dise-Lewis, Ph.D.

Birth – 3 years: mastery skills: sensory/motor,
sleep-wake

A BI here often leads to:

- poor self-regulation
- slow language
- poor understanding of cause and effect
impulsivity
- Trouble with transitions



3 years to 6 years

Mastery skills: cause and effect, primitive emotion regulation empathy, judgment, inhibition, friendships

A BI here often leads to:

- Reduced ability to learn from consequence
- Poor organization of behavior
- Difficulty dealing with change
- Possible aggressive behavior and tantrums
- Poor acquisition of preschool concepts



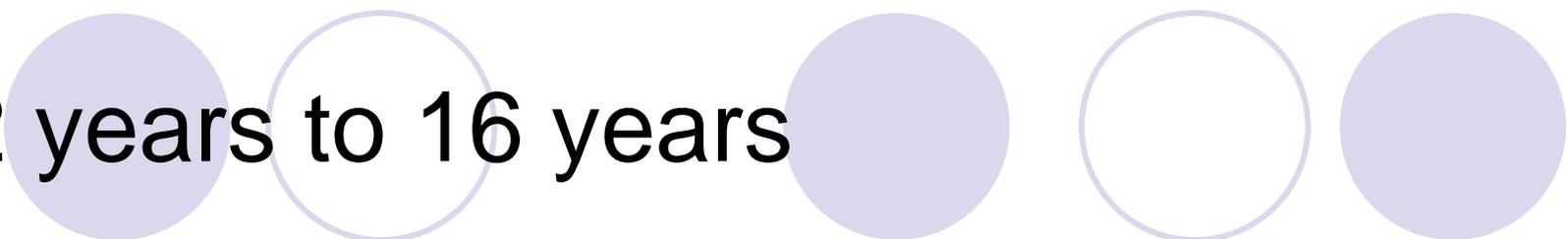
6 years to 12 years

Mastery skills: multiple cause and effect, mastery emotion, behavior and social skills

A BI here often leads to:

- Academic difficulties
- Uneven academic profile
- Organizational deficits
- Mental inflexibility
- Poor frustration tolerance
- Inability to “read” others

12 years to 16 years



Mastery skills: abstract reasoning,
autonomy, identity formation

A BI here often leads to:

- Difficulty with abstract, cognitive organization
- Judgment and reasoning problems
- Reduce ability to assume responsibilities
- Dependence on others



16 years to 19 years

Mastery skills: complex reasoning and judgment, independence, vocation, emancipation

A BI here often leads to:

- Rigid thinking
- Slow mental processing
- Insecure self-image
- Defensiveness regarding deficits
- Interference in drive toward independence

Executive Functions:

- Attention
- Planning
- Judgment
- Organization
- Problem-solving
- Emotion Regulation (lability)
- Social Skills





Transitions within schools: Specific barriers in schools that make transitions difficult:

No school person/program owns TBI:

Case manager does not follow TBI

Program does not follow TBI

Myth of Rehab Center for TBI students:

School **IS** the Rehab Center

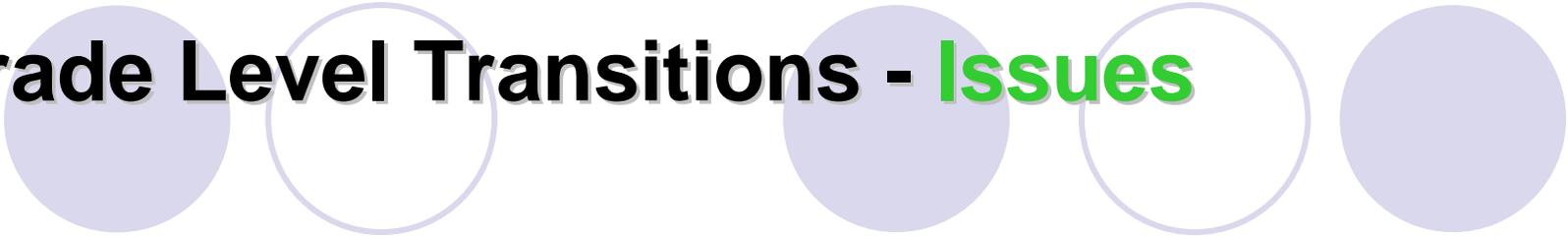
Transition from grade to grade - Issues

“Every September I feel like we have to start over again, things that helped my child in school last year have to be worked out again”. Parent (Wolcott, Lash, Pearson, 1993)

- What is the mechanism by which a Transition meeting naturally happens?
Lack of communication from level to level
- Lack of time necessary for training and collaboration. Teachers understanding the effects of BI (and not the “classroom manifestation” of helps)
- Teacher selection process – teachers often not determined until beginning of year
- End of year madness – Start of the year madness



Grade Level Transitions - Issues



- With each new level of education expectations grow larger and demands grow greater (4th grade on, demands get abstract and more intense)
- There is less and less external structure provided
- The student is faced with an increasingly diverse schedule with different teachers with different teaching styles
- Student has to deal with increasing daily transitions, larger buildings, social judgment

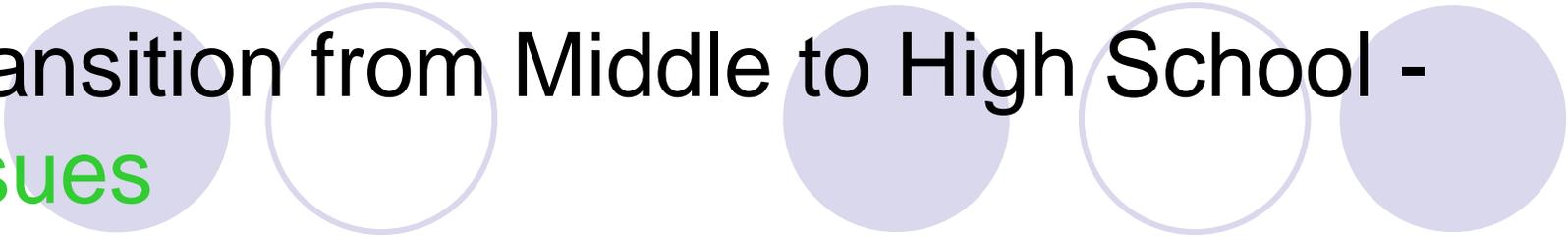
Transition from Elementary to Middle School - **Strategies**

- Learn what teaching style works best and request the teacher that best matches that style
Keep in mind...teacher selection and placement is often NOT set by the end of the year!
- IEP “Transition Meeting” – often done in the spring, can be done at the beginning of the year with the receiving teacher
- “Grow and Glow” – (level of **denial** by student?)
- Back and Forth book – (level of organization?)

Elementary to Middle School - Strategies

- Develop a mentoring program, match an individual with a BI with a student a grade level higher (for younger children)
- Allow the student to practice for the transition, visit the new school
- Ensure the case manager has some understanding of brain injury. The case manager continues to educate the general education teacher(s). Education makes a difference!
- Designate a teacher or another staff in the building that the student knows to go to if she/he has concerns
 - see if mental health in the school can get involved

Transition from Middle to High School - Issues



Up to 7 or 8 teachers, elective teachers

More abstract work

More independence required, less tolerance of
disorganization

More social judgment required, more subtle social
demands

Vocational needs and life skills need developing

Middle School to High School - Strategies

- Conduct an IEP “Transition meeting” with the middle school case manager, high school case manager, parent and student. Regular Ed teachers often are not in attendance
- Request a “Transition 504 Meeting” – 504 meetings often do not happen without a request
Keep in mind that the “accommodations” on a 504 Plan generally fall on the student to advocate for and to initiate
- If student has an IEP, make sure that the HS case manager has some understanding of BI. It is the case manager that is responsible for educating the 7 other regular education teachers on student’s needs

Middle School to High School - Strategies



- Develop a strategy for communication between school and home that is developmentally appropriate (e.g. email, communication book, planner, behavior plan)
- Begin teaching the student skills that will be necessary at higher grade levels as soon as possible (e.g. use of a planner)
- Involve the mental health professionals/counselors on emotional, behavioral and social support of the student
- Student's level of **acceptance** determines ability to self-advocate

Middle School to High School - Strategies



- Consider the use of an “academic coach” for organization and study skills if necessary
- SWAP Team – with a documented disability, SWAP team will help students find and keep jobs. Can start this in high school
- School district “Transition Program” – if staffed into special education, responsible for services until age 21 years

School District Teams

- Brain Injury Team
- Behavior Team
- SWAAC
- Mental Health professionals in buildings



Transition from Secondary to Post-secondary Settings - Issues

“85% of families with children with special needs (14-17) report that they did not receive guidance and support in transition to adulthood” (presentation, Anne-Marie Braga, June 16, 2005)

- Transition planning not actively occurring at the school level, the student is often not actively involved in planning for transition
- Transition planning occurs too late (**Indicator 13**)
- Parents are not familiar with transition process and have fear related to this process

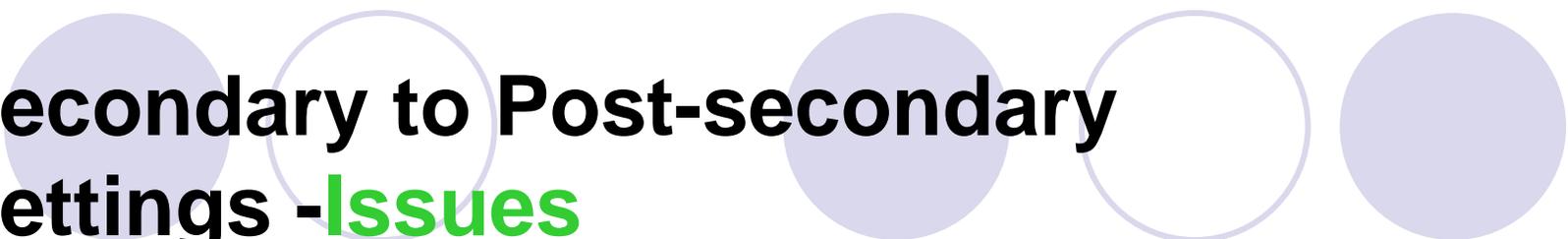


Secondary to Post-secondary Settings

- Issues

“In a sample of 98 adolescents with TBI in Oregon and Washington, only 9% were enrolled in post-secondary education or training programs two years after completing high school, and only one third were working 20 hours or more per week” (Glang et al, 2004).

- Students are not prepared when they graduate and have not learned skills necessary for post-secondary employment or education
- Students do not know what they want to do when they grow –up
- Students and families are not realistic about post-secondary options – (level of **denial** affects the ability to switch from remediation to compensation)



Secondary to Post-secondary Settings - **Issues**

- Uncertainty about appropriate goals, underestimating or overestimating abilities (**compensation versus remediation**)
- Lack of awareness regarding adult support services, vocational rehab., independent living skills training, residential supports. Supports for BI? Supports for other disabilities? Which disability gets more services? **MH services?**
- Lack of coordination between school and community based entities
- Waitlist, strict eligibility criteria and timeframes for eligibility

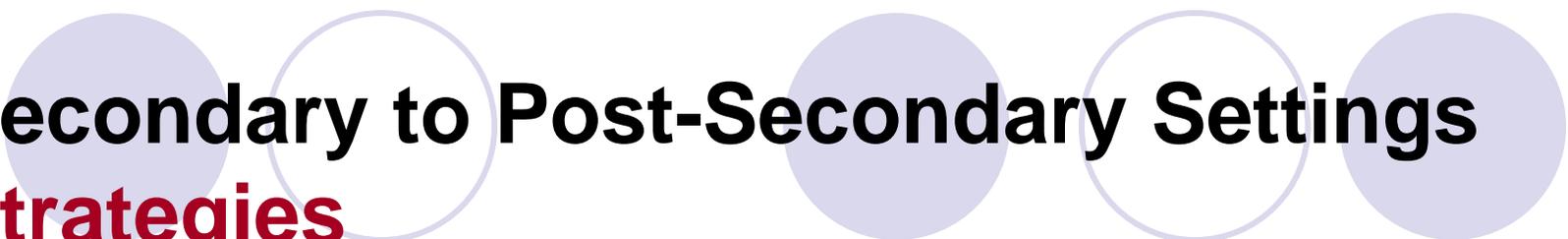


Secondary to Post-Secondary Settings- **Strategies**

- Become knowledgeable about adult support services available in your community
- Never too early to begin planning for post-secondary transition
- Take advantage of the years in high school to develop a post-secondary education or vocational goal and life skills **(in the natural environment, ie riding the bus)**
- Access employment programs offered by high schools

Secondary to Post-Secondary Settings Strategies

- All transition planning needs to be centered around the student for it to be successful/teach self-advocacy skills
- Establish a formal or informal network of families facing post-secondary transitions
- Develop a team to ensure transition plan is successfully implemented. Set **SMART** goals.
- Teams should include representatives from both school and adult service providers



Secondary to Post-Secondary Settings Strategies

- Activities related to “job readiness” need to be functional and take place in the environment that the task will be expected to occur
- Provide individual with honest and consistent feedback.
- Allow individual to explore grief around the loss of dreams as well as facilitate the evolution of new goals and dreams.
- Conduct community-based observations for post-secondary education or vocational goals.

Rule of Thumb

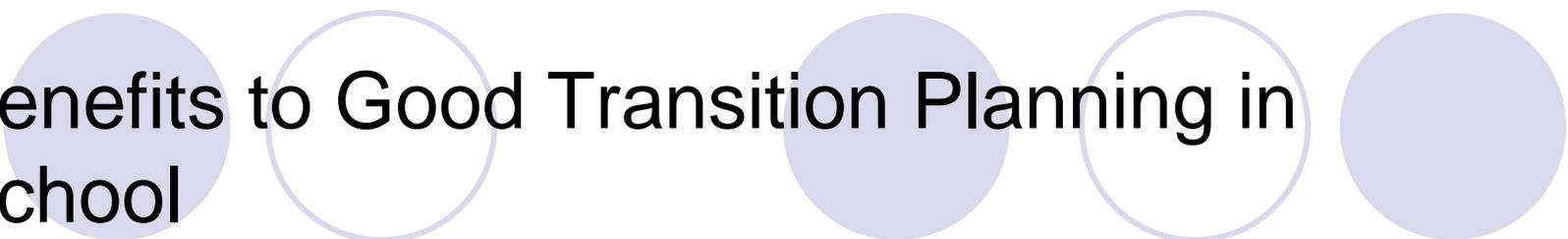


Work backwards:

What do you want the student to accomplish in the future?

Begin to teach it now!

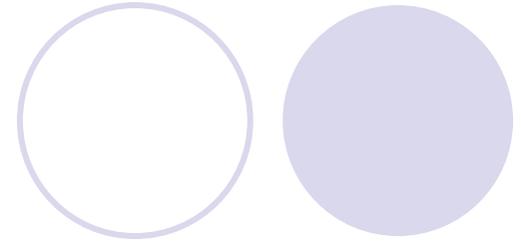
Keep on track developmentally – *concrete to abstract thinking, dependence to independence, external to internal locus of control*



Benefits to Good Transition Planning in School

- Increases chances of success as an adult, reduces the cycle of failure
- Increases student's confidence as they exit high school
- Decreases parental fear as student exits high school

Questions?



The End!

