School Re-entry After Traumatic Brain Injury (TBI): Giving Voice to the Family

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Landscape of TBI

- **Traumatic Brain Injury (TBI)** is a blow to the head or penetrating head injury that interferes with the brain's functioning (Brain Injury Association, 2014)

- Each year **1.7 million people** in the United States sustain a TBI including **475,000 children** (Schilling, 2012).

- **TBI is the leading cause of disability in children.** (Center for Disease Control, 2014).

Medical Model

Diagnosis to Discharge
Focus is on diagnosis of brain injury, identification of areas of vulnerability and creation of therapies for recovery

Patriarchal
Disability is a defect
Need to fix the handicap
institutions, special schools
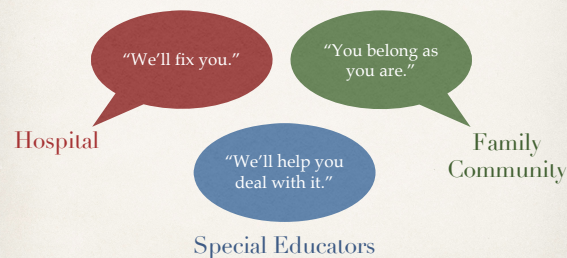
Social Model

Natural part of human existence
Fix the environment: natural, constructed, social, cultural

Community
Equality of opportunity, full participation, independent living, economic self-sufficiency
ADA, Rehabilitation Act Section 504, IDEA, UNCRPD


Approaches to Disability

Hospital — "We'll fix you."
Family Community — "You belong as you are."
Special Educators — "We'll help you deal with it."

Aspects of each sphere

	Communication	Teamwork	Stages
Hospital	Top Down Chain of Care	Surgeons, Doctors, Nurses, Therapists (Physical, Occupational, Recreation, Speech), Social Workers	ER-triage, Diagnosis, Surgery, Treatments, Discharge, Rehab Therapies
School	Top Down Policy to Instruction	School District Representative, Principal, Special Education Coordinator, Teachers, Speech Language Pathologists, Counselors	Assessment, IEP/504 Plan, Placement, Interventions, Review/Reassess
Family	Protection and Advocacy	Parents, Extended Family, Neighbors, Friends	Jumble of Grief: denial, anger, bargaining, depression, acceptance

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Conceptual Framework: From Models to Spheres of Support
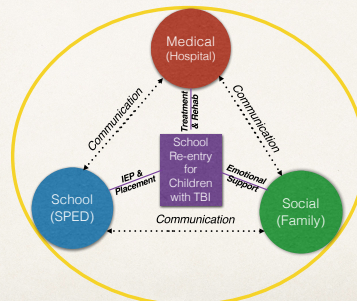
Literature Review
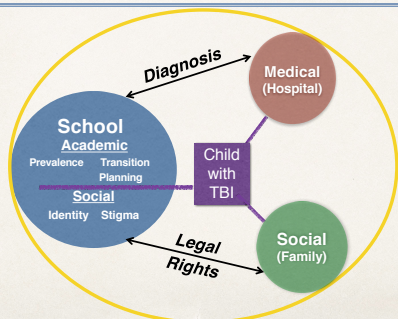
Research Findings:

Prevalence
- **6.4 million** students received special education services under IDEA. **0.4% were labeled under the TBI classification** (NCES, 2012).
- **Those classified represent only 1-2% of all children permanently disabled by TBI returning to school** (Schutz et al., 2010).

Transition
- **Problems with TBI tend to persist or worsen as children progress through school** (Glang et al., 2008).

Identity:
- **Personality changes after TBI can result in inappropriate behavior, which leads to social isolation** (Simpson et al., 2002).

Research Findings:
Prevalence

- According to the U.S. Department of Education's Office of Special Education Programs (OSPE), in the 1997-1998 school year **nearly 5 million students received special education services** under IDEA. **Only .02% were labeled under the TBI classification** (Ylvisaker et al., 2001).

- **Only one to two percent [of children permanently disabled by TBI returning to school] are classified as students with TBI**, qualifying them for the services they need for education (Schutz et al., 2010).
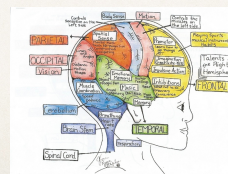

Research Findings:
Transition

- Deficits may only become fully apparent when development demands increase and once cognitive processes are expected to be fully developed, (Chevignard, et. al, 2010). Thus, **problems with TBI tend to persist or worsen as children progress through school** (Glang et al., 2008).

- In the days, weeks, and months following injury, **parents of children with TBI are emotionally overwhelmed and confused** by the health care system, insurance coverage and special education programs (Savage, 2005).

Research Findings:
Identity and Stigma

- Members of the general community expect socially appropriate behavior from a child or adult with TBI as there is no obvious sign of disability…. **Personality changes after TBI can result in inappropriate behavior, which leads to social isolation** (Simpson et al., 2002).

TBI Recovery

Medical Treatment	School Services
Relieve Pressure/Swelling	Child Find
Monitor: Glasgow Coma Scale and MRI/CT Scans	Assessment
Rehabilitation Therapies	IEP/504 Planning
Counseling	Related Services

Research Question

How do the **parents** of a child with TBI **experience** his/her **school re-entry process**?

✤ What are the most and least challenging aspects of the re-entry process, and what makes them so?

Methods

Participants:
✤ 7 families from Western Washington and the Midwest
✤ 3 professionals from medical and social sectors in Seattle

Recruitment:
✤ Email flyer
✤ Selection: demographic phone calls
✤ Data Collections: Semi-structured interviews
      1 hour - audio recorded/transcribed

Data Collection:
Interview protocol with parents

✤ **Pre - injury:** child's identity including birth order, personality, intentional family values

✤ **Injury:** recounted events from notification, severity of diagnosis, hospital triage and care

✤ **Post - injury:** narrative of rehabilitation and transition to school including communication, planning, placement, success and challenges

Participants (all names have been changed)

	Age of Injury	Diagnosis	Cause	Home Life
Alice	14 yr	TBI	Brain Aneurysm	only child, low SES, struggling in school
Ben	12 yr	TBI paralysis	Hit by car	oldest of 4, parents divorced after accident
Clint	11 yr	Concussion	Youth Sports	youngest of 4, twin, parochial schooling
Danny	5 yr	Brain Tumor	headaches, seizures	oldest of 3, Catholic family, pursuing college
Elise	10yr	TBI	ATV accident	oldest of 4, parents work in school, college freshman
Frank	12 yr	TBI	Hit by car	youngest of 2, media coverage, emancipated

Comparative Re-entry Timelines
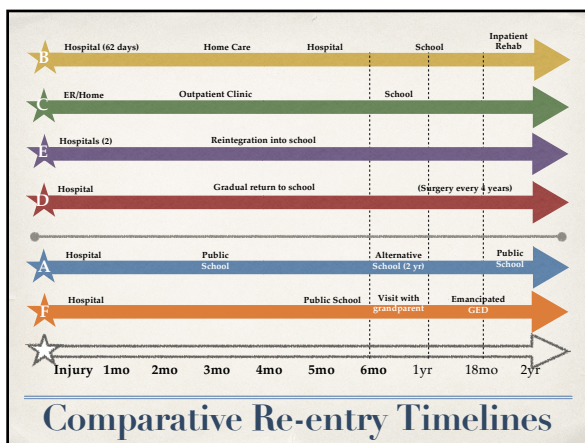
Data Analysis

Ground Theory fueled analysis

Coding
✤ First round: broad spheres of support and chronological events
✤ Second round: emotional climate, frequency, and description

Findings:

1. <u>Community is present</u> in each sphere.

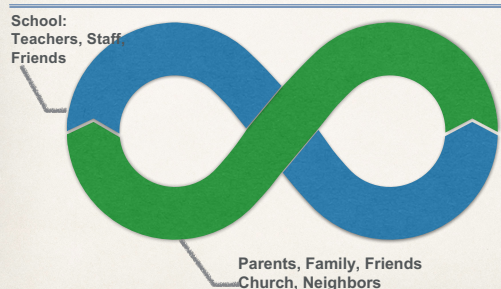2. <u>Parent engagement shifts</u> through the child's recovery process.

Findings:
Community

"And **when you're injured, you leave your community.** You literally are rushed into the ER and you are in this beautiful bubble where everyone is focused on saving your life. And then you move to another bubble, and there they are all focused on helping you through rehab. But it's a world. You are in a community right then, and it's very supportive.
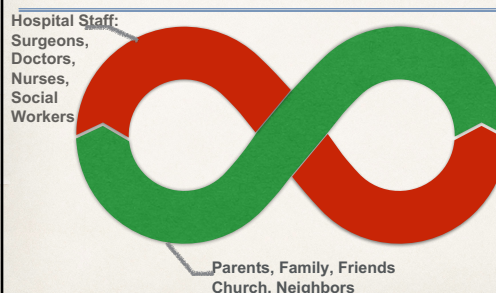
And then you leave all that. You go back home. And there's this huge gap between what you may be able to do right this moment and what you were able to do …before your injury. And **that gap is the difference between being part of community and not."**
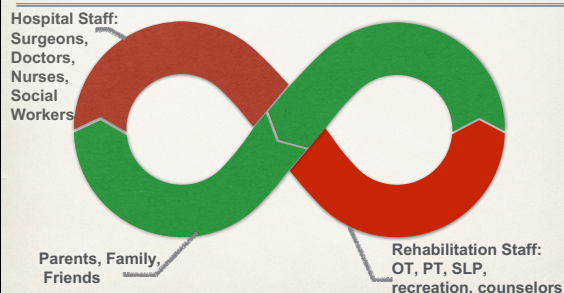
- Frank's Mom

Community: Pre-Injury

School:
Teachers, Staff,
Friends

Parents, Family, Friends
Church, Neighbors

Community: Injury

Hospital Staff:
Surgeons,
Doctors,
Nurses,
Social
Workers

Parents, Family, Friends
Church, Neighbors

Community: Injury

Hospital Staff:
Surgeons,
Doctors,
Nurses,
Social
Workers

Parents, Family,
Friends

Rehabilitation Staff:
OT, PT, SLP,
recreation, counselors

Community: Post Injury

Rehab Staff:OT, PT,
SLP, Counselors

Hospital Staff:
Doctors,
Nurses

Parents, Family
Friends

School Staff:
Teachers, IEP,
Friends

Community: Post Injury

Rehab Staff: OT, PT, SLP, Counselors

Parents, Family, Friends

Injury

Post-Injury

Hospital Staff: Doctors, Nurses

School Staff: Teachers, IEP, Friends


Findings:
Post - Injury

"I never would have kept that kid in that school except that's where [he] wanted to be. That's where his friends were. His, friends, but they didn't never communicate, never invited him anywhere. But it was really important to him. And people with brain injuries, it's hard enough. But **the social part of being a kid with a injury is so huge.** …**The hardest thing you find is [being] social, it's not the academics.** The kid, what he wants and identifies [is] the need socially. And we kept him there [in that school] for that reason."

- Ben's Mother

Learning curve of advocacy

● Hospital   ● School   ● Parent Voice

Level of Agecy

Injury   Rehab   School Re-entry   Post-Injury
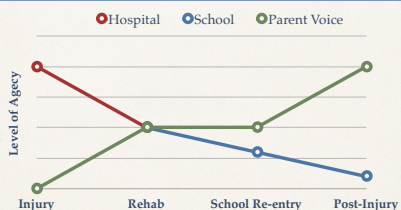
Parents gain stronger voices throughout the recovery process. Child and family go through steep learning curve of advocacy.

Learning curve of advocacy

"I remember the educator at [the hospital] say to me, you're going to have to be an advocate and fighter for your son.

And honestly, I looked at her and said, you've got to be kidding me. I need a fighter for us. I can't fight the world.
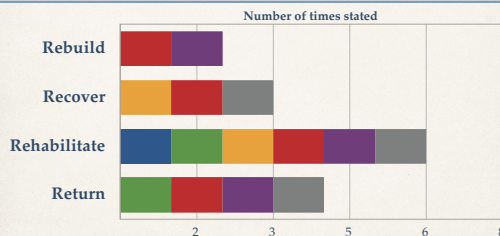
Aren't you guys going to advocate? Aren't you going to advocate for us? She laughed. No, no, the reality is you're going to have to fight."

- Frank's Mom

Discussion:
The RE experience

reintegrate
recover
restart
rejuvenate
rebuild
refresh
reenter
relax
rewire

Frequency of "RE" Post-Injury

Number of times stated

	2	3	5	6	8
Rebuild					
Recover					
Rehabilitate					
Return					

Discussion:
Identity Tug of War

Labels, Names and Stigma are placed on children with TBI after their injury.

"**He was identified I'm sure as the kid that had the brain tumor.** I mean there's still probably people that refer to him as the kid with the brain tumor. I mean, there are people that still talk about that. And he has this core group of kids that have sort of been his personal bodyguards that have just kept other kids away just in case they're going to harm him. And he's got this very, very close bond with them."

- Danny's Mom

Identity Tug of War

Inspiration vs. Belonging: **kids want friends**, but sometimes they are placed on pedestals as TBI Survivors.

"I never use the word [survivor]. I just say [she] **had** a TBI. I don't even say **"has"** anymore. I know she still has effects from it and she will always have that…We didn't change our expectations for [her]. We only accommodated. We're telling her we understand she's frustrated and we're offering her help finding how she can deal with that."

- Elise's Mom

Limitations

✦ Recruitment: narrow channels of outreach

✦ Broad spectrum of diagnosis

✦ Early interviews were piloting that lead to more concrete interviews

✦ Families selected by proximity across several school systems

Further Research

✦ First person Voice of Child with TBI

✦ Public vs. Parochial School Experiences

✦ Teacher training, preparation, experience

✦ Depth and Frequency of Hospital and School Communication

Thank You
Questions?

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