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

Social Model
- **Natural part of human existence**
  - Fix the environment: natural, constructed, social, cultural

Approaches to Disability
- **Hospital**
  - “We’ll fix you.”
- **Family**
  - “You belong as you are.”
- **Community**
  - “We’ll help you deal with it.”

Aspects of each sphere

Conceptual Framework: From Models to Spheres of Support
- Medical (Emergency)
- School (SPED)
- Social (Family)

<table>
<thead>
<tr>
<th>Aspects of each sphere</th>
<th>Communication</th>
<th>Teamwork</th>
<th>Stages</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hospital</strong></td>
<td>Top Down Chain of Care</td>
<td>Surgeon, Doctor, Nurses, Rehabilitation, Diagnosis, Therapy, Pathologists, Social Workers</td>
<td></td>
</tr>
<tr>
<td><strong>School</strong></td>
<td>Top Down Policy to Instruction</td>
<td>Principal, Special Education Coordinator, Teachers, Speech Language Pathologists, Counselors</td>
<td></td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td>Protection and Advocacy</td>
<td>Parents, Extended Family, Neighbors, Friends</td>
<td></td>
</tr>
</tbody>
</table>

- Ill-silage, Diagnosis, Surgery, Treatment, Discharge, Rehabilitation, Return to Normal

- Assessment, IEP/504 Plan, Placement, Interventions, Return to Normal

- Jumble of Grief: denial, anger, bargaining, depression, acceptance
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
- Relieve Pressure/Swelling
- Monitor: Glasgow Coma Scale and MRI/CT Scans
- Rehabilitation Therapies
- Counseling

School Services
- Child Find
- Assessment
- IEP/504 Planning
- 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):

<table>
<thead>
<tr>
<th>Age of Injury</th>
<th>Diagnosis</th>
<th>Cause</th>
<th>Home Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>TBI</td>
<td>Brain Aneurysm</td>
<td>only child, low SES, struggling in school</td>
</tr>
<tr>
<td>Ben</td>
<td>TBI</td>
<td>Hit by car</td>
<td>oldest of 4, parents divorced after accident</td>
</tr>
<tr>
<td>Clint</td>
<td>Concussion</td>
<td>Youth Sports</td>
<td>youngest of 4, Irish, parochial schooling</td>
</tr>
<tr>
<td>Danny</td>
<td>Brain Tumor</td>
<td>Headaches, seizures</td>
<td>oldest of 3, Catholic family, pursuing college</td>
</tr>
<tr>
<td>Elise</td>
<td>TBI</td>
<td>ATV accident</td>
<td>oldest of 4, parents work in school, college freshman</td>
</tr>
<tr>
<td>Frank</td>
<td>TBI</td>
<td>Hit by car</td>
<td>emancipation, coverage, emancipated</td>
</tr>
</tbody>
</table>

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. Community is present in each sphere.
2. Parent engagement shifts through the child’s recovery process.

"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: Post Injury

Rehab Staff: OT, PT, SLP, Counselors
Parents, Family, Friends
Hospital Staff: Doctors, Nurses
School Staff: Teachers, IEP, Friends

Injury Post-Injury

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 an 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

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

Rebuild Recover Reintegrate
Rebuild Recover Reintegrate
Rebuild Recover Reintegrate
Rebuild Recover Reintegrate

Frequency of “RE” Post-Injury

Number of times stated

<table>
<thead>
<tr>
<th>Rebuild</th>
<th>Recover</th>
<th>Reintegrate</th>
<th>Return</th>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>3</td>
<td>5</td>
<td>8</td>
</tr>
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</table>
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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