

Meeting the Challenge of Brain Injury Through Resource Facilitation

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+ Inlatable loss of self-esteem...

- Inlatable raft/Scheels
- 3.75 hours
- Lack of insight
- No instructions
- Shoreline?





Beginnings of Resource Facilitation



- **Resource Facilitation:** assist in building personalized support teams providing information, resources, and referral services to individuals and their families
- (1992 - 2020): Resource Facilitation in its infancy and growth through the years
- (1995 – 2020): Facilitated Brain Injury Support Groups in Kansas and Nebraska
- (2008 – 2020): contracted with BIA-NE as a Nebraska Brain Injury Ombudsperson; 2016 - Resource Facilitator
- 2016 – Chris Stewart hired as Resource Facilitator

“What we do for ourselves, dies with us. What we do for others, lives forever.”

-Ann Boriskie, founder of braininjurypeervisitor.org

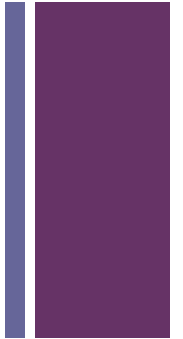
+ “Our lives begin to end the day we become silent about things that matter.”





Case Vignette #1

“A major problem for survivors of TBI (traumatic brain injury) is that they pass rehabilitation but fail life” (Hux, 2003).



Brain Injury Resource Facilitation:

A. Intake and Referral

1. TBI Registry/ referrals/cold calls/people we meet
2. Listening to individual and identifying where they are at within their recovery
3. Mayo-Portland Adaptability Inventory (short version)
4. Establishing the individual's short and long-term goals
5. Offering resources to individual/family

B. Case Management

1. Assessment, Treatment Planning, Linking, Advocacy, and Monitoring.

C. Awareness and Education

1. BI Symptom Checklist



“When your greatest heartache becomes your greatest ministry, grace comes full circle.”

-Bethany Haley Williams





Leading Causes of Disability Worldwide and Nationwide:



- Traumatic brain injury (TBI), according to the World Health Organization, will surpass many diseases as the major cause of death and disability by the year 2020. (Hyde, 2007)
- Worldwide, in 2016, there were approximately 27 million new cases of Traumatic Brain Injury which represented a 3.6% increase from 1990. In the same year, prevalence was 55.5 million individuals, representing an 8.4% increase from 1990 (Global Burden of Disease, 2019).
- Each year, the number of new cases of Traumatic Brain Injury in the United States is approximately 2.8 million (CDC, 2015).



Brain Injury is Multifaceted...

- Every injury and individual is different
- Same symptoms, but different ways to approach them
- Everyone does not have the same resources/
rehabilitation/socio-economic status/culture/coping
strategies/family-friend support/education/age
- Neuropsychiatric and mental health
- Insurance needs
- Lifetime of different concerns





Nebraska - 2010 Needs and Resources Assessment (Schmeckle Research Inc.)

- Everyday in Nebraska: at least one person dies from a traumatic brain injury (TBI), three people are hospitalized and over 24 people a day visit the emergency department because of TBI.
- More than 300,000 people have suffered a brain injury including concussions and more than 36,527 individuals live with a disability caused by a traumatic brain injury.
- The monetary cost associated with TBIs in Nebraska was over \$413,000,000 in 2009. Includes fatal/nonfatal injuries, medical costs and productivity losses.
- Estimated lifetime costs per individual with a brain injury are:
 - Mild brain injury - \$85,000
 - Moderate brain injury - \$941,000
 - Severe brain injury - \$3 million
- In the last five years, steady increase in emergency department visits, hospitalizations and deaths caused by a traumatic brain injury. Emergency visits for brain injury in Nebraska are higher than national average.
- Most frequent cause of TBI is a fall, especially in those under one year old and over 65. Males, 25-44, have the highest incident of brain injury due to being struck in the head, struck against something or involvement in a car crash.
- Lives are changed by a traumatic brain injury, most notably physical health, emotional well-being and loss of income. The entire family is affected.





Outcomes in Nebraska

(July, 2016-June, 2020)

- 26% of those served were less than 6 months post injury, while 11.3% were more than 20 years post injury. This indicates those with Brain Injury have chronic needs, beyond what is provided at the acute care level.
- The average age of the individual with Brain Injury is 43 years old and the majority, or 39.8% of our clients fall within the 40-59 age bracket.
- The top five reported causes of Brain Injury were: motor vehicle crash, fall, assault, stroke, and medical/disease
- 44.8% of Resource Facilitation clients are reportedly unable to work due to their Brain Injury. About one-in-four (25.5%) are employed.

Schmeeckle Research Inc., 2020





Outcomes (continued):



- The top 3 concerns at intake related to health and self-direction/care are: Memory (58.8%), Activities of Daily Living (53.3%), and Mental Health (52%).
- **Concerns and Improvements in Health Areas (n=71):** Physical health (33), Home safety (19), Fatigue (33), Mental health (40), and Seizures (6), were identified as concerns for some clients served by Resource Facilitation. Although these issues are still being worked on, there was an overall improvement rate of 62.6%.
- **Concerns and Improvements in Self-Direction/Care (n=70):** ADL's (27), Leisure Activities (30), Personal Care Attendant (11), Initiation (34), Family (32), Friends (31), and Memory (41), were identified as concerns for some clients served by Resource Facilitation. Although these issues are still being worked on, there was an overall improvement rate of 56.3%.

+ Case Vignette #2

“There are only two ways to live your life. One is as though nothing is a miracle. The other is as if everything is.”

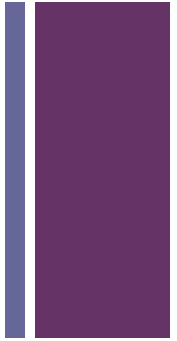
-Albert Einstein





Think About It...

- More than half of homeless persons or those with unstable housing suffer TBI at some point of their life, a rate which far exceeds the general population (Stubbs JL, Thornton AE, Sevick JM, et al., 2019)
- Researchers estimate that up to 60% of incarcerated individuals are living with traumatic brain injury (TBI) in our prisons (Shulein O, Klemme, R, Johnson, K,, Harniss, M, 2014)
- TBI is associated with an increase in the relative risk of developing numerous mental health issues including:
 - Mood and Anxiety Disorders/PTSD
 - Manic Syndromes
 - Psychotic Disorders
 - Obsessive Compulsive Disorders
 - Substance Abuse/Addictions
 - Neuropsychiatric Disorders (Schwarzbald M, Diaz A, Martins E, et al, 2008)





Unmet Needs in Nebraska

(2010 Needs and Resource Assessment, Schmeeckle)



Gaps in Most Needed Services

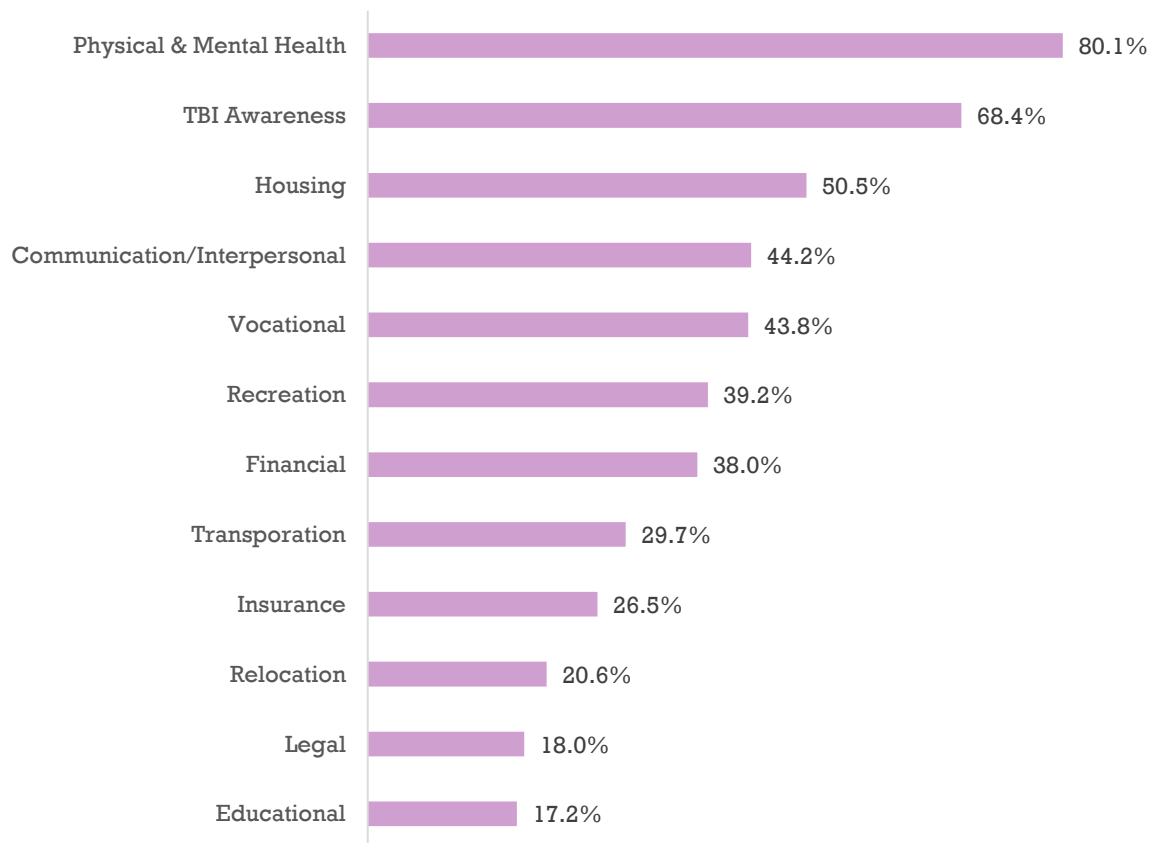
- 1. Cognitive training
- 2. Counseling
- 3. Behavioral supports
- 4. Community skills training
- 5. Employment support
- 6. Educational services

Most Important Needs

- 1. Cognitive training
- 2. Sources of funding
- 3. Primary medical care
- 4. Physical therapy
- 5. Counseling (individual and family)
- 6. Information resources
- 7. Occupational therapy

+ Barriers

**Percentage of Clients Experiencing Barriers in the Following Areas at Intake (n=582)
(July '16 - June '20)
Schmeckle Research Inc.**





Successful Outcomes for Barriers

(n=450); July '16 – June '20

Schmeckle Research Inc.

At time of intake, experienced a barrier in the following areas:	Number of clients experiencing a barrier	Number of clients with a successful outcome	Success rate
Insurance	154	99	64.3%
TBI Awareness	398	173	43.5%
Financial	221	71	32.1%
Legal	105	32	30.5%
Educational	100	29	29.0%
Relocation	120	34	28.3%
Physical and Mental Health	466	120	25.8%
Housing	294	66	22.4%
Vocational	255	50	19.6%
Recreation	228	44	19.3%
Communication/Interpersonal	257	47	18.3%
Transportation	173	18	10.4%
Total Barriers	2,771	783	28.3%





Case Vignette #3

**“I can be changed by what happens to me.
But I refuse to be reduced by it.”**

-Maya Angelou



+ Provision of Hope...

“People don’t care how much you know until they know how much you care.” -Theodore Roosevelt

Resource Facilitation: Responsibilities

- Trust and Respect
- Self-Direction
- Open Door Policy
- Confidence
- Listening
- School
- Employment
- Volunteering/Interests
- Advocacy
- Neuropsychological Assessment - if warranted
- Extensive Brain Injury Knowledge
- Educating individual, family/caregivers/professionals and oneself
- Boundaries
- Resources
- Case Management
- Referrals/BI professionals
- Follow-up/Follow-through
- Relationships with other professional BI providers
- Support for individual and family

+

“...everything can be taken from a man but one thing: the last of the human freedoms – to choose one’s attitude in any given set of circumstances and to choose one’s own way.”

-Viktor E. Frankl



+ Case Vignette #4



+ Methods we use to Teach

- If there is something to be remembered, write it down
- If there is a plan to be enacted, spell each step out and write it down
- Speak slowly; allow for increased processing speed time
- Do not interrupt
- Use concrete examples/not hypotheticals
- Limit amount of information given/use chunking
- State expectations clearly
- Ensure understanding by asking individual to repeat and watch for gestures or understanding or confusion
- Model/remain calm in all situations to reduce anxiety



+

Our Individuals and Families educate us



***"To every thing there is a season, and
a time to every purpose under
the heaven:"***

Ecclesiastes 3:1 (KJV)



In the end, to heal, everyone needs a renewed sense of purpose...



- Brain Injury Alliance of Nebraska Engagement Groups are individuals and family members using their personal experiences for the purpose of growing awareness and supports for others, including:
 - BRAIN Talks (Basic, Resource, Advocacy, Innovation and Networking): through individuals sharing personal experiences for community groups.
 - Unmasking project and Exhibit: Individuals synthesize their journeys through the creation of masks that are available for exhibition throughout the state.
 - Expanding Resources: Sharing and creating supports in communities to increase awareness and available options.
 - Advocacy: to educate and enlighten change makers.

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

-Margaret Mead

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THANK YOU!

**“Do all the good you can, by all the means you can, in
all the places you can, as long as you ever can.”**

-John Wesley