Hope & Healing: How the Brain Injury Registry & Resource Facilitation Create Successful Outcomes

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Overview

What and Why?

So What?

Now what?
“Public health is the constant redefining of what is unacceptable.”

Ed Ehlinger, MD, MPH,
Commissioner MDH, April 2011
Public Health Approach

**Primary Prevention**
- Identifying risk (and protective) factors to prevent disease or injury

**Secondary Prevention**
- Early diagnosis & appropriate management

**Tertiary Prevention**
- Medical care & self-management to reduce disability
144.662 TRAUMATIC BRAIN INJURY AND SPINAL CORD INJURY REGISTRY.
The commissioner of health shall establish and maintain a central registry of persons who sustain traumatic brain injury or spinal cord injury. The purpose of the registry is to:
(1) collect information to facilitate the development of injury prevention, treatment, and rehabilitation programs; and
(2) ensure the provision to persons with traumatic brain injury or spinal cord injury of information regarding appropriate public or private agencies that provide rehabilitative services so that injured persons may obtain needed services to alleviate injuries and avoid secondary problems, such as mental illness and chemical dependency.

History: 1991 c 292 art 2 s 6
144.664 DUTIES OF COMMISSIONER.

Subdivision 1. Studies. The commissioner shall collect injury incidence information, analyze the information, and conduct special studies regarding traumatic brain injury and spinal cord injury.

Subd. 2. Provision of data. The commissioner shall provide summary registry data to public and private entities to conduct studies using data collected by the registry. The commissioner may charge a fee under section 13.03, subdivision 3, for all out-of-pocket expenses associated with the provision of data or data analysis.

Subd. 3. Notification. Within five days of receiving a report of traumatic brain injury or spinal cord injury, the commissioner shall notify the injured person or the injured person's family of resources and services available in Minnesota, pursuant to section 144.662, clause (2).

Subd. 4.[Repealed, 1999 c 86 art 2 s 6]

Subd. 5. Rules. The commissioner shall adopt rules to administer the registry, collect information, and distribute data. The rules must include, but are not limited to, the following:

1. the specific ICD-9 procedure codes included in the definitions of "traumatic brain injury" and "spinal cord injury;"
2. the type of data to be reported;
3. standards for reporting specific types of data;
4. the persons and facilities required to report and the time period in which reports must be submitted;
5. criteria relating to the use of registry data by public and private entities engaged in research; and
6. specification of fees to be charged under section 13.03, subdivision 3, for out-of-pocket expenses.

History: 1991 c 292 art 2 s 8; 1994 c 483 s 1; 1997 c 205 s 22
Timely service information

(Resource Facilitation – getting information and services to persons injured and their families so they will do better, heal more quickly and completely, have less frustration, etc.)

Epidemiology/Prevention
Making it work – the process

Multi-disciplinary review committee – five meetings over six months (1991)

Public review and input

Rules adopted (1992)

Registry started with in-patient admissions; goal to expand as resources allowed and advisory group directed

We believe the time may be now! (2018)
How would life improve for persons with TBI in Minnesota if MDH included non-hospitalized brain injuries on the TBI Registry? What is it we still need to know? What are the stories that need to be told?

Logistically, how might we do this (have ED and urgent care TBI cases be reported to the Registry)?

Is this an opportunity to test the electronic medical record reporting process?

What about a pilot project (perhaps with one or two emergency departments) to test how this might work?
TBI – Traumatic Brain Injury

- altered or loss of consciousness,
- loss of memory, and/or
- neurological dysfunction

Milestones:

- state-mandated TBI/SCI registry, 1991
- death certificates, 1993
- statewide hospital discharge data, 1998
- APCD, 2018
- ED and urgent care treated TBI, 2018?
What, So What and ... **Now What!**
Resource Facilitation
Resource Facilitation

A bridge of support from hospital to home

- Helping individuals and families move forward in their recovery and rehabilitation.
- Helping individuals and families understand and overcome or adjust to the short term and long term effects of brain injury or stroke.
- Helping people get ‘back to life’.
New Client Referrals

30% of Hospitalized treated individuals with brain injury say yes to help or Resource Facilitation.

1500 New Client Referrals every year out of approximately 5000 Hospitalized with BI every year.
New Clients

Sent a welcome packet, letter of introduction and basic brain injury packet.
Provided name and number to call sooner.
Resource Facilitator will be calling shortly.
Individuals are given information on program and ways to receive support.
Scheduled Calls

Initial call made 6 weeks after hospital discharge or 48hr call for Registry referrals. Additional calls are made at (3-6 month intervals) 6 months, 12 months, 18 months and 24 months.
Structured Interview

1. How was brain injury caused?
2. Hospitalization and rehabilitation provided?
3. Health insurance & Primary Doctor?
4. Employment and School or College?
5. Relationships, Social and Leisure?
6. Family Support?
7. Memory?
8. Physical Health?
Let’s talk
Interview

Time to build a relationship.
Opportunity for a person to tell their story.
Receive support and affirmation about their experience
Receive education on brain injury
Community referrals and information
Life Changes

After brain injury it may change more
RF provides proactive education about common areas of change.
Ways to compensate for changes.
Education to share with friends and family.
How to get professional assistance support and how to navigate systems.
Reported Changes

Cognitive Fatigue
Memory Changes
Balance and Coordination
Increased Frustration or Stress
Headaches
Referrals Provided

Medical Rehabilitation (OT, PT & Speech)
Support Group
Counseling
Neuropsychological Testing
Housing and Home Supports
Supporting Families

Helping connect families and individuals to classes about brain injury.

Family Conferences

Community Events/ Walk for Thought

Support Groups
Success Stories

The impact of checking in on me and getting help to me while I was in crisis was huge. I am getting my own apartment tomorrow and appreciate Resource Facilitations help.”
Success Stories

Resource Facilitation taught me about my rights regarding employment, and it gave me access to doctors who were knowledgeable.”
Thank you!

Questions?

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