Executive Summary: Listening to Kansans with Brain Injuries

- People with disabilities have higher rates of disease and chronic health conditions than people without disabilities. Yet people with disabilities can be healthy.

- In 2014, the Disability Rights Center of Kansas partnered with the University of Kansas Research and Training Center on Independent Living to gather information about the health care experiences of Kansans who have a brain injury (BI), also known as traumatic brain injury (TBI).

- This project conducted town hall meetings with BI support groups in Lawrence, Paola and Wichita, which were attended by BI survivors, their family members, other support persons and service providers.

- Based on the information provided by these participants, we offer recommendations to support better outcomes for people with BI in all areas of their health – including medical, dental, mental, behavioral and long-term care health needs.

- The recommendations proposed in this document address health care policies, programs and practices as ways to enhance culturally competent health care for brain injury survivors and minimize the economic and human costs of brain injuries.

Introduction: Gathering Information about Health Care Experiences

In 2014, the Disability Rights Center (DRC) of Kansas partnered with University of Kansas Research and Training Center on Independent Living (KU RTC/IL) to conduct a project to improve health outcomes for persons with brain injury (BI) in a more effective manner. Research shows that people with disabilities experience disparities in health status and receipt of health care services (1-3). For people with brain injury, there are also inequities in access to rehabilitation services (4).

The project used a town hall method to gather information about the health care experiences and outcomes of Kansans with brain injuries. This town hall process is based on a research model for grassroots community engagement that was developed by the Oregon Institute on Disability and Development (5).
KU’s RTC/IL previously collaborated with the Oregon Institute to use this process for engaging Kansans with all disability types in dialogue about their health care experiences.

The first stage in this tested process is identification of barriers to health care. Through discussion of what works and what doesn’t work in the health care experience of individuals, the common problems are identified. Then solutions to these barriers can be devised and implemented through community action and partnerships.

This document is a first step in offering recommended solutions to stakeholders in Kansas who have an interest in brain injury: people with brain injuries and their families, advocates, service providers, policymakers and health care professionals.

**Town Hall Meetings**

In the fall of 2014, we held three town hall meetings in different areas of the state to solicit input from Kansans regarding the availability and accessibility of culturally competent health care services for people with BI and those who support them.

A total of 70 people participated in these town hall events (Wichita – 25; Paola – 15; Lawrence – 30). Participants included people with brain injury, their parents, partners and other informal supporters, and disability service providers.

Rather than holding open public forums, we collaborated with existing brain injury support groups to recruit participants. This allowed us to recruit people who are interested in improving their health and quality of life. The known size of each group also guaranteed that each participant would have an opportunity to talk. The town hall meetings were one- to three-hours long, depending on the size of the group.

The town hall meetings were facilitated by staff members from the RTC/IL. These meetings focused on identifying what works (existing strengths) and what doesn’t work in each person’s experience of the health care system. Participants were asked to comment on four areas that are integral to receiving effective health care:

- **Transportation** – Simply getting to and from medical appointments, health promotion opportunities and related health activities can be a challenge for people with brain injury.

---

**What Is a Brain Injury?**

In this project, we worked with people who have survived any type of brain injury (BI). Brain injuries may be caused by a non-hereditary medical condition (stroke, tumor or prolonged lack of oxygen) or by an accident. These medical brain injuries are called “acquired.”

The term “traumatic brain injury” (TBI) describes injuries caused by an external blow to or penetration of the head, such as a motor vehicle accident, a fall, a sports injury or a gunshot.

Every brain injury is different because different areas of the brain may be affected. This is one of the difficulties for health care providers, who can face a complex array of neurological effects. Depending on the severity of an injury, survivors may experience changes in brain function that can have a dramatic effect on all aspects of their lives.

Participants in the town hall meetings identified these common symptoms:

- **Memory loss** – affecting short- and/or long-term memory
- **Cognitive problems** – slowness in thinking, difficulty understanding or processing information, trouble concentrating, distractibility
- **Physical changes** – vision loss or disturbances, seizures, paralysis, headaches, difficulty speaking, balance issues, sleep disturbance, nausea, sensory loss (smell, hearing, taste)
- **Emotional and behavioral issues** – depression, mood swings, agitation, aggression, impulsivity
- **Executive function issues** – difficulty making decisions

In the words of one survivor: “With TBI, a lot of the people that we’re talking about have normal lives, go to normal jobs, they do normal things, then they get hit in the head, and the next day they’re not normal. And there’s a lot of emotional aspects to get over and to deal with. And a lot of times when you get a TBI, your filters get knocked off. And so – so now you’re not only physically disabled but you’re socially disabled. Depression.”
Improving Access to Health Care for Kansans with Brain Injuries

Rehabilitation therapies provided by the Medicaid Traumatic Brain Injury (TBI) Waiver for home and community-based services (HCBS) or through private pay contribute greatly to ongoing recovery after a brain injury survivor is discharged from formal rehabilitation programs or facilities. Cognitive therapy, occupational therapy, physical therapy and speech therapy are supported by the HCBS waiver. In addition, the waiver will provide a transitional living specialist (TLS) who works one-on-one with the TBI survivor to perform cognitive exercises related to daily activities and support the individual’s goals for independence, such as money management. Minds Matter and Community Works were praised as providers of these services.

Physicians and other health care providers who have newer training and attitudes about brain injury provide innovative care that meets the individual needs of survivors.

Physicians and rehabilitation professionals who understand the latest science of brain injury encourage survivors to pursue lifelong rehabilitation. These providers also work with survivors to meet their special communication needs, such as allowing audio recording of a medical visit and breaking information into small segments.

“Now we know how plastic the brain is and that even years, 25 years after a head injury, they have ways of finding out more precisely where the injury was and how to cause the brain to build new connections, new neurons – and that’s what we’re working with this physician group for. So I just want to encourage people who maybe thought they were at an end point, and that may not be true.”

– Family member of a BI survivor

Health care providers who are not brain injury experts will conduct research to meet the survivor’s needs.

Some providers who do not already have specialized knowledge on brain injury will work to find solutions to a survivor’s unique problems. Participants mentioned two optometrists (one who learned to provide vision therapy for adults), several dentists, and a psychiatrist who expanded their skills to meet their patients’ needs.
Health care providers share information with and about a patient through electronic records and other methods.
Tools like mychart.com enable coordination of health care services among providers and greater participation in one’s own health care.

Providers and their staff use effective communication tools and display receptive attitudes in relation to common cognitive and memory issues for BI survivors.
Survivors appreciate text and phone messages to confirm appointments, printed information that is clearly broken into small segments, slow speech with clear enunciation, and courteous behavior.

Pharmacies provide services that meet BI survivors’ needs.
Pharmacists offer counsel on medications, refill reminders, medication dispensers and more to help survivors fulfill and adhere to their medication regimens. A variety of free and low-cost medication programs are available.

Public transportation, paratransit services and transportation offered by private organizations meet people’s needs in combination with transit provided by family and friends.
Most brain injury survivors do not resume driving after their injury, though some have been able to get a driver’s license with approval from a neurologist after rehabilitation.

Peer support groups and community organizations provide important cognitive and life supports.
Survivors, their family members and service providers gather regularly in support groups to share information about medications, health care providers and daily living strategies. Centers for independent living and churches also provide resources and support.

What Doesn’t Work
Many survivors did not know about the existence of the Medicaid Traumatic Brain Injury (TBI) home and community-based services (HCBS) Waiver, while others who are on the waiver say support for services that enable their ongoing recovery progress is too limited. While the TBI Waiver helps address survivors’ needs for health care and specialty services for brain injury rehabilitation, participants said the authorized amount of support for cognitive therapy is inadequate. Survivors also cite frequent problems finding and retaining a reliable transitional living specialist (TLS).

The current TBI Waiver does not cover two important groups: people with other acquired brain injuries and children under the age of 16. People who have a non-traumatic brain injury, such as those caused by a stroke, partial drowning or tumor, and children younger than 16 could benefit greatly from the services provided by this waiver. Even if they are on another waiver, people in these groups do not receive the targeted waiver-only therapies that help people with BI improve their functioning.

Medicaid coverage has significant gaps. Many physicians and dentists do not accept Medicaid, complicating the search for a knowledgeable provider or specialist. For dental care, only cleanings are covered. In addition, some survivors waited up to five months to receive Medicaid coverage, and this lack of coverage delays discharge from rehabilitation facilities.

Limited availability of specialists in rural areas is a major problem.
Residents of rural areas must travel to urban centers to receive important therapy services.

Health care professionals, including neurologists and other specialists, do not have a good understanding of brain injury and set low expectations on the potential for recovery.
In some cases, a person’s brain injury is not correctly diagnosed or treated because medical providers focus on visible physical injuries instead. Prescription drugs can be especially problematic. Some survivors suffered negative results when doctors prescribed certain drugs without knowing how those medications interact with brain injury. The psychological symptoms of brain injury are also difficult to negotiate with providers, who may assume the survivor is depressed or suicidal.
Psychiatric and antipsychotic drugs are frequently prescribed, though the science of these drugs for brain injury survivors is not clear. Trial and error is common in the use of medications, though that is not a negative if the physician is willing to work closely with the survivor. In addition, lack of knowledge about how pain medicine interacts with brain injury can lead to denial of treatment for pain, whether the pain is a result of the event that caused the brain injury or a separate medical condition.

“I got titanium in my leg, my collarbone shot through my shoulder, and I had a pressure gauge sticking out of my head, you know, but they want to talk to me that I may be bipolar so they want to put me on bipolar medicine.”

– BI Survivor

Family members do not receive adequate information or training to provide care after a survivor is released from the hospital or rehabilitation facility following a brain injury.

Families want: education about what kind of care team is needed after discharge; training in how to deal with mental and physical changes (from memory problems to how to feed someone who can’t chew); and resources to address physical and social disability (help dealing with emotions, agitation, stress, frustration).

“But the physician, before they turn this person loose to them [family] needs to say, ‘Hey, you need to be aware of this, that and the other.’ And that just doesn’t happen. It’s like, take them home, you’re done."

– Family Member of BI Survivor

Providers don’t communicate with survivors in an effective way.

Physicians and others may speak to the support person instead of speaking directly to the patient, and some don’t address the cognitive and visual needs of those with brain injury (e.g., break information into small segments, use short sentences, write instructions clearly).

Physicians, therapists and pharmacists don’t communicate about a shared patient.

Survivors and families would appreciate more information sharing among their providers, with special concern about medication interactions and dosages.

Physical access to health care facilities is compromised by usage and design.

People park in the van access aisles next to accessible parking spots and snow is often shoveled into accessible spots in the winter. Once inside health care facilities, doors are often too heavy or doorknobs are difficult to turn for those with dexterity issues. Overly stimulating visual factors (patterned carpets, fluorescent lights) also cause problems for BI survivors.

BI survivors experience stigma and lack of understanding.

Some health care providers as well as the general public project an attitude that BI survivors are lazy or difficult to deal with. Misinterpretation or misunderstanding of a survivor’s behavior may jeopardize his or her overall safety and well-being. For that reason, some survivors wear a medical alert bracelet so that police or emergency personnel will not confuse their symptoms with being drunk.

Recommendations to Improve Health Care Access and Delivery

Based on both the positive and negative experiences described above, we suggest a number of system improvements. These recommendations emphasize changes that would benefit people with BI and create more efficiency in both human and economic long-term costs. They focus on:

- Accurately diagnosing brain injury to improve recovery time and processes
- Preventing deterioration in health conditions and/or costly hospitalizations
- Maintaining or improving the individual’s current level of function
- Creating a health care environment that meets the unique needs of people with brain injuries

The recommendations are directed to three groups of stakeholders who each play an important role in the health of Kansans with brain injuries:

(A) State policymakers
(B) BI survivors, families, advocates and service providers, who could work in partnership with state policymakers and health care organizations to make changes.
(C) Health care providers and brain injury researchers
A. Recommendations for Policymakers

Encourage the State of Kansas to provide the following enhanced Medicaid & HCBS services, which emphasize prevention, improved recovery and maintained function.

- Improve Medicaid reimbursement rates for physicians and dentists to expand access to specialists and dentists for brain injury survivors.

- Make specialized brain injury services available as state plan services so all Medicaid beneficiaries can access them based on medical necessity to support long-term recovery goals. This option is an enhancement to the Medicaid state plan. It would keep the current TBI Waiver as is and expand the Medicaid state plan to include specialized brain injury services for those currently not covered by the TBI Waiver. These services include cognitive therapy, transitional living specialists, and brain-injury specific physical and occupational therapies. If these services were covered under the Medicaid state plan, people who are not on the TBI Waiver but have a brain injury could also improve their functioning.

  This includes people who are served by other waivers but also have a brain injury, Kansans with non-traumatic brain injuries, children under 16, and people who qualify for Medicaid who would benefit from specialized brain injury services but who do not meet the strict definitional limits of the TBI Waiver. As one example, a Kansan who is in a terrible car crash and acquires both quadriplegia and a brain injury must currently choose between going on the Physical Disability (PD) Waiver to accommodate his physical disabilities or the TBI Waiver to rehabilitate his brain injury.

  - If such a state plan amendment is not an option, alternatively, the state could:
    1. Expand the TBI Waiver to include people with other acquired (non-traumatic) brain injuries (such as stroke, lack of oxygen to the brain, etc.).
    2. Expand the TBI Waiver to include children under age 16.
    3. Amend the TBI Waiver to allow those who qualify for other waivers to also receive waiver services to rehabilitate their brain injury.
    4. Amend waiver capacity to accommodate the above three changes.

- Expand Medicaid adult dental coverage to include procedures beyond cleanings. Comprehensive oral health care contributes to a person’s overall health and also supports employment by reducing stigma.

- Streamline Medicaid application process to ensure timely coverage after an injury.

- Ensure that a network of brain injury service providers is available throughout the state. In some parts of the state, these specialized services are not readily available, which dramatically reduces the number of Kansans benefiting from these services and makes these areas clearly “underserved” in regards to brain injury services.

- Fund brain injury peer support and advocacy groups to leverage the effectiveness of volunteer groups. This support would be similar to state funding currently provided for consumer-run organizations such as the Self-Advocates Coalition of Kansas for people with intellectual and developmental disabilities and consumer-run organizations for Kansans with mental illness.

Encourage the Kansas Department of Revenue to add information about accessible parking regulations to driver’s license exams.

- Require drivers to know that striped access aisles next to accessible parking spaces must remain open to accommodate vehicles that are equipped with a lift or ramp.
B. Recommendations for BI survivors, families, advocates and service providers

These recommendations entail working with peer support groups and local, regional and state organizations to develop policies, programs, practices and products that address weaknesses in major areas of health care access.

Increase access to transportation.
- Work with local transportation providers to expand routes, improve planning for pick-up and flexibility for people with brain injury.

Educate health care providers about ways to improve access to their facilities, equipment and services.
- Publicize Americans with Disabilities Act Guidelines, such as fact that inside doors should weigh no more than five pounds.
- Promote tax incentives and deductions for purchasing accessible scales and adjustable height exam tables and making building alterations. One tool for this is “Disability Resources for Health Care Providers” ([http://www.rtcil.org/~rtcil/resources/Healthcareproviders.shtml](http://www.rtcil.org/~rtcil/resources/Healthcareproviders.shtml))
- Encourage medical facility owners/managers to instruct maintenance personnel that accessible parking spaces and routes of travel should be clear in all weather conditions.

Enhance health care providers’ communication with, knowledge about and attitudes toward people with brain injuries.
- Inform providers of effective ways to communicate with brain injury survivors (e.g., chunk information in small segments, repeat main ideas, allow audio recording of visits, speak slowly, provide large print educational materials with minimal design features, etc.).
  - As an individual, discuss your unique communication needs with your own providers.
  - As a group, create or reproduce informational materials about common communication issues and disseminate to physicians.
- Develop a program in which culturally competent doctors and dentists peer mentor others.
- Recognize effective health care providers and their staff members by presenting them with the certificate “For Excellence in Caring for People with Disabilities” ([pictured at right, available from DRC and RTC/IL](http://www.rtcil.org/~rtcil/resources/Healthcareproviders.shtml)).

Learn how to engage more actively in your or your family member’s health care.
- Request a copy of health care providers’ notes. This promising practice is discussed in “Inviting Patients to Read Their Doctors’ Notes” ([http://www.rwjf.org/en/research-publications/find-rwjf-research/2012/10/inviting-patients-to-read-their-doctors--notes.html?cid=XEM_A6442](http://www.rwjf.org/en/research-publications/find-rwjf-research/2012/10/inviting-patients-to-read-their-doctors--notes.html?cid=XEM_A6442)).
- Prepare questions to ask health care providers by visiting the “On Choosing Wisely” website. This compilation of “Five Things Physicians and Patients Should Question” ([http://choosingwisely.org/?page_id=13](http://choosingwisely.org/?page_id=13)) gives lists developed by medical specialists in many fields.
- Use patient empowerment materials provided by the Agency for Health Care Research and Quality. Resources in “Questions Are the Answer” ([http://www.ahrq.gov/questions/](http://www.ahrq.gov/questions/)) are also available in Spanish.

(continued)
(Continued) B. Recommendations for BI survivors, families, advocates and service providers

- Use peer support groups and online resources to learn about responsive health care providers in your area, effective medications, helpful cognitive supports, etc. Examples of shared information:
  - Some people wear a medical alert bracelet/necklace in case they are stopped by police, who may confuse brain injury symptoms such as slow speech and a limp with being drunk or drug impaired.
  - Nuedexta is a new drug that helps with the PseudoBulbar Affect (PBA), a neurologic condition that causes survivors to burst out crying or laughing.
  - One person located a needed specialist through the Brain Injury Association of America website (http://www.biausa.org).

Create supportive group living settings for people with brain injury, similar to those for people with intellectual and developmental disabilities. This type of independence contributes to overall physical, social and emotional well-being.

C. Recommendations for Health Care Providers and Brain Injury Researchers

Research and employ the latest information about brain injury and rehabilitation in providing care.

- Distinguish a person’s head injury from other physical injuries sustained in an accident or health incident to guarantee that each diagnosis is treated appropriately.

- Work closely with survivors to find effective medications that have tolerable side effects.

- Affirm the importance of maintenance as an indication of success, even when an injury is permanent (e.g., function of an injured arm and leg can be maintained rather than lost).

- Understand that head injury survivors think and plan differently post-injury.

- Recognize that effective care for person with brain injury is an art as well as a science, with most of the art focused on communication with the survivor.

Educate survivors and family members about the type of care team that is needed after discharge from a hospital or rehabilitation facility.

- Provide resources for families to address the physical, cognitive and emotional aspects of recovery.

- Encourage an expectation of lifelong progress in recovery. In many cases, maintenance can be progress.

Complete trainings for physicians, nurses, medical students and other health care providers about people with disabilities.

- Online course on Kansas TRAIN: “Health Care Access for Persons with Disabilities” (Course #1025624, free and open to all interested persons at https://ks.train.org).

- KU School of Nursing online graduate-level course: “Caring for People with Disabilities.”

Research alternative therapies that may supplement traditional therapies (nutritional methods, homeopathy, spirituality in a non-religious sense).

Research possible risks to BI survivors and the brain in general from environmental factors (such as cell phones) and medical or dental procedures.

Engineer a rear-view mirror that spans the entire car to address peripheral vision deficits of drivers who have brain injury.
Conclusion
Through this grassroots project, the DRC of Kansas and KU’s RTC/IL listened to Kansans with brain injuries in order to identify approaches for improving their health care experiences and outcomes.

We know that no two brain injuries are identical. Each person with a brain injury has a different experience and set of health care needs, but this project brings important common themes into focus. By collecting a wide array of personal experiences from Kansans, we can highlight their shared experiences.

The voices of Kansans heard in this project and the resulting recommendations provide new information for developing state policies, provider practices and tools that may reduce the human and economic costs of brain injury.

Efforts to improve the overall health of Kansans with brain injuries can benefit from an ongoing study of local and regional support structures. This type of study is essential to success in achieving and maintaining the goal of improved overall health for Kansans with brain injury.

For More Information
Disability Rights Center of Kansas
635 SW Harrison St., STE 100
Topeka KS 66603
Toll Free Voice: 1-877-776-1541
www.drckansas.org

References


Produced by:
Research and Training Center on Independent Living
The University of Kansas,
(785) 864-4095
rtcil@ku.edu
www.rtcil.org

The authors would like to acknowledge the many contributors (survivors, family members, caregivers) as well as the recruitment assistance provided by the Brain Injury Association of Kansas and Greater Kansas City and the brain injury support groups of Wichita, Lawrence and Paola.

The contents of this report were developed under a grant from the Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) grant #H133B060018. However, these contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.