

South Dakota Acquired Brain Injury (ABI) Needs Assessment Survey

Survivor & Family Needs Questionnaire

The Center for Disabilities at the University of South Dakota has contracted with the University of Missouri--Kansas City Institute for Human Development to conduct a statewide needs assessment. The information gathered will be used to help South Dakota develop a plan to improve services and supports for people living with Acquired Brain Injury (ABI) and their families. Acquired Brain Injury is any damage to the brain that happens after birth, including a Traumatic Brain Injury (TBI, all ranges of severity including concussion). Your opinions and responses are very important to this effort. We anticipate it will take approximately 15 to 25 minutes to complete. Thank you for participating--we very much appreciate your time in completing this important survey.

The survey is anonymous and you will not be individually identified. Participation in the survey is voluntary and you may choose not to answer any specific questions..

Please send your completed survey to Dr. Eric Kurtz with the South Dakota Center for Disabilities: Eric.Kurtz@usd.edu or 1400 West 22nd Street, Sioux Falls, SD 57105

Demographics

Which best describes you (person completing survey)?

- I am a person with an Acquired Brain Injury (ABI), if under age 18 please complete with parent/guardian
- I am a family member of a person with ABI (responding on behalf of a survivor of ABI)
- Other

If other, please specify

What caused the brain injury?

- Traumatic Brain Injury (TBI)
- Acquired Injury
- Progressive Neurological Disorder

If Traumatic Brain Injury (TBI), please specify the type

- Falls
- Struck by a vehicle (as a pedestrian) or falling debris
- Motor vehicle crashes including motorcycles and all-terrain vehicles
- Domestic violence
- Gang violence
- Shaken Baby Syndrome
- Blast injury caused by explosion
- Not Applicable

If Acquired Injury, please specify the type

- Stroke
- Infections such as meningitis or encephalitis
- Anoxia or hypoxia from drowning, asphyxiation, strangulation, or aspiration
- Exposure to toxins in cleaning products, pesticides, lead, or mercury
- Drugs such as cocaine, methamphetamines, inhalants, or MDMA
- Not Applicable

If Progressive Neurological Disorder, please specify the type

- Arteriovenous Malformation (AVM)
- Brain Tumor
- Cerebellar Hypoxia
- Cerebellar Aneurysm
- Creutzfeldt-Jakob Disease
- Dementia
- Encephalitis
- Encephalopathy
- Epilepsy
- Gerstmann's Syndrome
- Guillain-Barre Syndrome
- Huntington's Disease
- Hydrocephalus
- Mayamoya Disease
- Meningitis
- Multiple Sclerosis
- Neurotoxicity
- Parkinson's Disease
- Prosopagnosia
- Wernicke-Korsakoff Syndrome
- Not Applicable

Which best describes you (brain injury survivor)?

- Child with BI (0-14 years old)
- Youth with BI (15-22 years old)
- Adult with BI (22-49 years old)
- Adult with BI (50-64 years old)
- Older Adult with ABI (65 years or older)

Are you (brain injury survivor) a military service member?

- Current military service member
- Former military service member
- Never a military service member

Gender of brain injury survivor:

- Male
- Female
- Other (e.g. transgender)

Race of brain injury survivor (select all that apply):

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other

If race is other, please specify

Ethnicity

- Hispanic or Latino
- Not Hispanic or Latino

First 3 digits of the zip code in which the brain injury survivor currently lives:

_____ (example: for the zip code is 57101, enter 571)

Payor source at the time of injury

- Private Insurance
- State financial assistance
- None
- Other

If payor source is other, please specify

If state financial assistance was received, what type of assistance did you receive?

- Medicaid
 Title III Assistance
 Waiver
 Assistance received but funding unknown
 Not Applicable

If a waiver was received, what was the waiver type?

- HOPE Waiver with Long Term Services and Supports
 ADLS Waiver with Rehabilitation Services
 CHOICES Waiver with Developmental Disabilities
 Family Support Waiver with Developmental Disabilities
 Waiver received but specific type unknown
 Not Applicable

Did you switch waivers during this time?

- Yes
 No
 Not Applicable

If you switched waivers, please explain

Any additional comments before proceeding?

Brain Injury and Other Health Conditions

In what year did the injury occur?

_____ (example: 1982)

Age at the time of injury?

How long after the injury were you (brain injury survivor) diagnosed with the ABI?

- Same day
 First week
 Within 6 months
 6 months to 1 year
 1-5 years
 Over 5 years

Were you hospitalized for BI?

- Yes
 No

If yes, how long were you hospitalized for?

- Less than a day
 1-3 days
 3 days - 1 week
 More than a week
 Not Applicable

Please indicate any disabilities or significant health conditions that you (brain injury survivor) already had before your injury as well as those developed after injury (select all that apply)

	Had before brain injury	Developed after brain injury	Does not apply
Behavior/personality change (e.g. acting out, aggression, social inappropriateness)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chronic pain (e.g. headaches)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive (memory, processing, problem solving)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Language (e.g. communication, expression, and understanding)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical (balance, other mobility)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Post Traumatic Stress Disorder (PTSD)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seizure disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sensory (vision, hearing, taste, smell)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Substance use disorder (alcohol)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Substance use disorder (drugs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other mental health conditions (e.g. anxiety)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self harm/injury	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please specify any other conditions experienced before your injury _____

Please specify any other conditions you developed after your injury _____

Has the injury affected any of the following areas of your (brain injury survivor) life?

	No change	Is better	Is worse
Marriage/ Romantic Relationship	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interpersonal/ Social	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Income	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Living Situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General Health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Parenting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychological Status	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any additional comments before proceeding?

Where You Live

Where do you (brain injury survivor) currently live?

- Assisted living facility
- Group home
- Residential care facility
- Nursing facility
- Own apartment/ home with caregiver assistance
- Own apartment/ home without caregiver assistance
- In a family member's home
- Other

If other, please specify

Where do you (brain injury survivor) want to live?

- Assisted living facility
- Group home
- Residential Care Facility
- Nursing facility
- Own apartment/ home with caregiver assistance
- Own apartment/ home without caregiver assistance
- In a family member's home
- Other

If other, please specify

If you are not living where you want to live, why not?
(Mark all that apply)

- Not applicable
- Unable to get the in-home services I need (e.g. personal care, homemaking services)
- Unable to get the medical care I need
- Unable to get the rehabilitation therapy I need (e.g. physical, speech, occupational)
- Unable to get access to transportation
- Unable to find residential housing for TBI survivors
- Unable to live with people in same age range
- Insufficient financial resources
- Lack of access to accessible and affordable housing
- Lack of employment
- Mental Health
- Need help coordinating and planning for services
- Need specialized training and services (e.g. cognitive training, behavioral supports, community living skills training)
- Other

If other, please specify

If you live in a nursing facility, how long have you lived there?

- Less than 3 months
 3 to 6 months
 6 months to 1 year
 1 year to 3 years
 3 to 5 years
 5 years or more
 Not Applicable

If you live in a long term care facility, where did you move there from?

- Acute rehabilitation program
 Group home
 Hospital
 Your home
 Other
 Not Applicable

If other, please specify

Any additional comments before proceeding?

Services and Supports

Following your injury, did anyone provide you with information or advise you about services available for people with brain injury?

- Yes
 No

If yes, was this information provided before you left the hospital or doctor's office?

- Yes
 No
 Not Applicable

Who provided you with information or advised you? (Mark all that apply):

- Attorney
 Brain Injury Association (BIA)
 Family/ friends
 Medical professional (doctor, PA, nurse)
 Rehabilitation staff/ vocational rehabilitation
 Social worker/ service coordinator/ counselor/ case manager
 Other
 Not Applicable

If other, please specify

Medical and Hospital Services

Did you receive emergency room care at time of injury?

- Yes
 No

If yes, please rate your level of satisfaction with the emergency room care:

- Very Dissatisfied
 Dissatisfied
 Satisfied
 Very Satisfied
 Not Applicable

Did you receive urgent care or walk-in clinic services at time of injury?

- Yes
 No

If yes, please rate your level of satisfaction with the urgent care or walk-in clinic services:

- Very Dissatisfied
 Dissatisfied
 Satisfied
 Very Satisfied
 Not Applicable

Did you receive doctor's office services at time of injury?

- Yes
 No

If yes, please rate your level of satisfaction with the doctor's office services:

- Very Dissatisfied
 Dissatisfied
 Satisfied
 Very Satisfied
 Not Applicable

Were you admitted to a hospital at the time of injury?

- Yes
 No

If yes, please rate your level of satisfaction with the hospital services:

- Very Dissatisfied
 Dissatisfied
 Satisfied
 Very Satisfied
 Not Applicable

If admitted to the hospital, did you receive discharge planning services before you left the hospital? (Someone giving you information about the care you would need at home and helping to arrange services)

- Yes
 No
 Not Applicable

If discharge plans were provided to you by the hospital, what kind?

- Discharge to home with home-based rehabilitation services
 Discharge to home with travel outpatient therapy and services
 Discharge to nursing home or facility
 Discharge to residential brain injury rehabilitation program
 Discharge to home with no services
 Not Applicable

If discharge planning services were received, please rate your level of satisfaction with those services:

- Very Dissatisfied
 Dissatisfied
 Satisfied
 Very Satisfied
 Not Applicable

Rehabilitation Services

Please tell us about any rehabilitation services related to brain injury that you are currently receiving or have received in the past. Rehabilitation offers therapy for speech, physical movement, thinking problems (e.g. memory, problem solving), emotional issues, sensory issues, occupational therapy, and taking care of yourself.

Currently receiving services

Received services in the past

Needed services but did not receive

Did not need

Acute Trauma Facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inpatient Rehabilitation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home Health (nursing or therapies)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outpatient Rehabilitation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nursing Facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you receive rehabilitation services in South Dakota, or in another state?

- In state
 Out of state
 Both

Please rate these services (select "Not Applicable" if services were not needed or received)

	Not Applicable	Very Dissatisfied	Dissatisfied	Satisfied	Very Satisfied
Acute Trauma Facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inpatient Rehabilitation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home Health (Nursing or Therapies)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outpatient Rehabilitation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nursing Facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Any additional comments before proceeding?

Community Services and Supports

Please tell us about any community services or supports related to brain injury that you are currently receiving or have received in the past.

	Currently receiving	Received services in the past	Needed services but did not receive	Did not need
Employment Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In-Home Services (e.g. attendant care, homemaker services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Service Coordination or Case Management Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment for Substance Use Disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental Health Counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use of Assistive Technologies (such as a communication board or wheelchair)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Caregiver/Respite Care Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain Injury Support Groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance with Financial Management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreation Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Legal Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Section 8 or Other Housing Assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance Applying for Social Security Disability Benefits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Continuing Education Related to ABI (seminars, workshops, conferences, classes, or newsletters)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Living Skills Training (such as cooking or money management)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information and Referral Services (information about how to find the services you need)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other assistance for subsequent disability (such as vision impairment)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisted Living Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Living Home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services Adult Day Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ongoing Physician Follow-Up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services provided by a Community Support Provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Companion Care Services at Home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nutrition Program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please rate the following community services and supports services that you have used (select "Not Applicable" if services were not needed or received)

	Not Applicable	Very Dissatisfied	Dissatisfied	Satisfied	Very Satisfied
Employment Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In-Home Services (e.g. attendant care, homemaker services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Service Coordination or Case Management Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Treatment for Substance Use Disorder	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mental Health Counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use of Assistive Technologies (such as a communication board or wheelchair)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caregiver/Respite Care Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain Injury Support Groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance with Financial Management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreation Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Legal Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Section 8 or other Housing Assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assistance applying for Social Security Disability Benefits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Continuing Education related to ABI (seminars, workshops, conferences, classes, or newsletters)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Living skills Training (such as cooking or money management)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information and Referral Services (information about how to find the services you need)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisted Living Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Living Home Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Adult Day Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ongoing Physician Follow-Up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services provided by a Community Support Provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Companion Care Services at Home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nutrition Program	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please describe why you provided these satisfaction ratings

Any additional comments before proceeding?

Additional Needs

Do you have any other comments about services that you need?

What challenges do you have in getting the services you need related to ABI? (Mark all that apply):

- Difficulty understanding process or paperwork
- Difficulty with English language
- Difficulty with enrollment/admissions
- Do not have insurance
- Do not have support to get a job
- Do not have support to live where I want to live
- Inability to pay for needed services
- Insurance does not cover needed services
- Lack of support/patient advocacy
- Lack of transportation
- Need help with financial management
- Services and resources not located locally
- Unaware of services and resources
- Not eligible for services
- Other

If other challenges, please specify

Have you met professionals who need to learn more about ABI?

- Yes
 No

If yes, who are these professionals? (Mark all that apply)

- Medical/Hospital Personnel
- Community Service Providers & Professionals
- Educator/School Personnel
- Rehabilitation Personnel
- Military Service Personnel
- Other

If other professionals, please specify

What type of medical/hospital personnel need to learn more about ABI?

- Discharge planner
- Emergency room medical provider
- Family medical provider
- Nurse
- Psychologists/neuropsychologists
- Other
- Not Applicable

If other, please specify

What type of community service providers & professionals need to learn more about ABI?

- Adult brain injury program providers
- Attorney
- First responders
- In home care provider
- Law enforcement personnel
- Mental health professional
- Social worker
- Vocational rehabilitation personnel
- Other
- Not Applicable

If other, please specify

What type of educator/school personnel need to learn more about ABI?

- Coach
 - Principal
 - School nurse
 - Teacher
 - Other
 - Not Applicable
-

If other, please specify

What type of rehabilitation personnel need to learn more about ABI?

- Administrator
 - Occupational therapist
 - Physical therapist
 - Speech therapist
 - Other
 - Not Applicable
-

If other, please specify

What additional training or information do these professionals need to improve their capacity to serve people with ABI and their families? (Mark all that apply):

- Available services and supports for individuals with ABI and their families
 - Employment
 - General knowledge about ABI (e.g. causes, types)
 - Housing
 - Interpersonal
 - Promoting skills for independence
 - Specific knowledge about the needs of people with ABI
 - Understanding and managing communication and cognitive changes
 - Understanding and managing emotional and behavioral changes
 - Understanding and managing medical and physical changes
 - Other
 - Not Applicable
-

If other, please specify

What do YOU feel needs to be done to improve statewide services and supports for people with ABI and their families?

What services and supports worked well for you and your family (select all that apply)?

- Support/Patient Advocacy services
- Services and resources located locally
- Awareness of services and resources
- Support to get a job
- Support where you live
- Services covered by insurance or state assistance
- Transportation
- Coordination and planning of services
- Specialized training and services
- Services that were age appropriate
- Other

If other services and supports worked well, please specify

Any final comments that you would like to add?
