

South Dakota Brain Injury Targeted Needs Assessment Report: Supports & Services Professionals

Report on the 2021 Brain Injury Needs Assessment Survey

February 24, 2022 (revised)

Submitted to:



Submitted by:



5030 Cherry St., Room 120

Kansas City, Mo 64110

Kelli N. Barton, Ph.D., Director, Health and Aging

Emma Swinford, M.P.H., M.S.W., Senior Research Assistant

Published January 2022

© Copyright 2022 by The Curators of the University of Missouri, a public corporation.

Authors: **Kelli N. Barton, Ph.D.**, bartonkn@umkc.edu
Emma Swinford, M.P.H., M.S.W., eswinford@umkc.edu

This report is based on work supported, in whole or in part, by funding from the South Dakota Department of Human Services through a contract with the University of South Dakota Center for Disabilities and awarded to UMKC Institute for Human Development, UCEDD. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official positions of Funder and Funding Sources.

This report is published by the
UMKC Institute for Human Development, UCEDD
University of Missouri-Kansas City
ihd.umkc.edu · 816-235-1770

Suggested citation:

Barton, K. N., and Swinford, E. (2022). South Dakota Brain Injury Targeted Needs Assessment Report: Supports & Services Professionals. Kansas City, MO: Institute for Human Development, University of Missouri-Kansas City.

This report is available in alternate formats upon request. UMKC does not discriminate on the basis of race, color, ethnic or national origin, sex, sexual orientation, gender identity, religion, age, ancestry, disability, military status, veteran status, in admissions, educational programs or activities and employment. The University complies with all federal and state laws and University of Missouri System policy regarding nondiscrimination and affirmative action, including Title IX of the Education Amendments of 1972, Section 504 of the Rehabilitation Act of 1973, Title VII of the Civil Rights Act of 1964 and the state of Missouri Human Rights Act Chapter 213 RSMO.

Electronic versions of this report are available at ihd.umkc.edu

Table of Contents

Table of Tables	4
Table of Figures.....	4
Methodology.....	5
Results	5
Sample	5
Knowledge of Brain Injury Supports and Services	8
Adequacy of Supports and Services	10
Medical/Hospital Services	11
Rehabilitation Services.....	12
Community Supports and Services	12
Services Adequacy Comparison	14
Barriers to Accessing Supports and Services.....	15
Brain Injury-Related Training	16
Community Trainings.....	16
Professional Trainings	17
Staff Trainings.....	17
Access to External Trainings	17
Mode of Training.....	18
Training and Information Needs.....	18
Strengths of System	19
Additional Comments.....	20
Conclusion	21
References	22
Appendix A: Ratings of Service Adequacy, Full Table (sorted by ‘very inadequate’)	23

Table of Tables

Table 1. Which position best describes you? (n=200).....	5
Table 2. How were brain injuries identified? (select all that apply) (n=194).....	7
Table 3. Medical/Hospital Services Adequacy: ‘I don’t know’ Reponses	11
Table 4. Rehabilitation Services Adequacy: ‘I don’t know’ Reponses.....	12
Table 5. Community Supports and Services Adequacy: ‘I don’t know’ Reponses.....	13
Table 6. In your opinion, what barriers to individuals with brain injury and their families face in accessing services and supports? (n=198).....	15
Table 7. Type of Community Training Provided (n=38).....	17

Table of Figures

Figure 1. How long have you been in your current position? (n=199).....	6
Figure 2. Please estimate the number of individuals with brain injury that YOU served or had contact with in the last year: (n=197).....	7
Figure 3. Indicate what type of services you and/or your organization provide (select all that apply) (n=198)	8
Figure 4. Please rate your knowledge of available services and supports for individuals with brain injury and their families (n=200)	9
Figure 5. Knowledge Level by Profession, Summary (n=198).....	10
Figure 6. Knowledge Level by Profession, Detailed (n=198).....	10
Figure 7. Medical/Hospital Services Adequacy Ratings.....	11
Figure 8. Rehabilitation Services Adequacy Ratings	12
Figure 9. Community Supports and Services Adequacy Ratings.....	14
Figure 10. Training Opportunities	16
Figure 11. What is your preferred method to obtain additional training or information?	18

Methodology

The *2021 South Dakota Brain Injury Professional Survey* is a modified version of a targeted needs assessment developed in Missouri in 2017 with support from the U.S. Administration for Community Living, Department of Health and Human Services (grant # 90TSG0017-02-00). The 2017 survey included items assessing TBI-related knowledge and training needs among professionals, as well as their perceptions of barriers and gaps in supports and service for survivors. South Dakota’s Brain Injury Networking group reviewed the adapted version of the survey and provided feedback on suggested modifications. Changes to the original survey include: (1) modifying the language to expand the focus beyond TBI to all acquired brain injury and (2) streamlining the section on adequacy of supports and services for survivors to focus on services as they currently exist and eliminating items comparing past and current services.

The research team at UMKC-IHD secured project approval through the UMKC Institutional Review Board (project # 2072183) and established a REDCap online survey link. The target population for the 2021 survey was professionals who provide supports and services commonly accessed by brain injury survivors and their families. The Brain Injury Networking group and other project partners broadly disseminated the online survey link to a diverse network of professionals statewide. The survey was available for approximately 5 weeks in October and November 2021.

Results

Sample

A total of 200 professionals and community service providers completed the *2021 South Dakota Brain Injury Professional Survey*. Nearly half (47.0%) of the respondents identified as community service providers and professionals, such as mental health personnel, caseworkers, and social workers (Table 1). The remaining respondents identified as educators/school personnel (18.5%), rehabilitations personnel (17.5%), and medical personnel (17.0%).

Table 1. Which position best describes you? (*n*=200)

Profession	<i>N</i>	Percent
Community Service Providers and Professionals	94	47.0
Mental Health Personnel	28	29.8
Other Advocate	25	26.6
Caseworker	15	16.0
Vocational Rehabilitation	13	13.8
Social Worker	8	8.5
Attorney	3	3.2
Department of Corrections Personnel	1	1.1
In-Home Care Provider	1	1.1
Educator/School Personnel	37	18.5

Other	17	45.9
Teacher	10	27.0
Administrator	8	21.6
Coach/Director	2	5.4
Rehabilitation Personnel	35	17.5
Other	21	60
Occupational Therapist	5	14.3
Administrator	4	11.3
Physical Therapist	3	8.6
Speech Therapist	2	5.7
Medical/Hospital Personnel	34	17.0
Other	13	39.4
Nurse	10	30.3
Other Physician	3	9.1
Psychologist	3	9.1
Advanced Nurse Practitioner	2	6.1
Discharge Planner	1	3.0
Emergency Room Physician	1	3.0

Figure 1 shows the length of time respondents have been working in their current position. Over a third (35.2%) indicated that they have been in their position for 10 years or more and about another third (31.2%) have worked in their position between 5-10 years. About a quarter (25.6%) had been working in their position between 1-5 years and 8.0% had been in their position less than a year.

When asked about the population they serve, most respondents (98.5%) reported that they provide services and supports to others in addition to people with brain injury; the remaining 1.5% reported that they serve only brain injury survivors and their families.

Figure 1. How long have you been in your current position? (n=199)

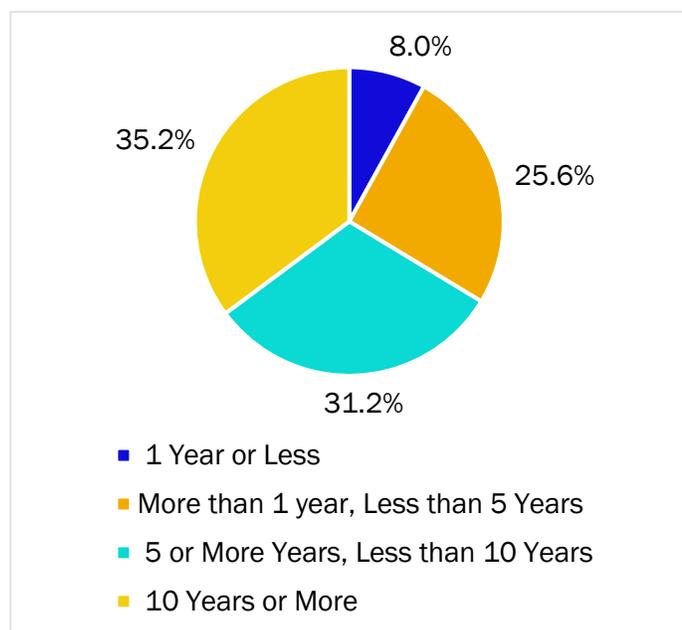


Figure 2 displays the estimated number of brain injury survivors served by respondents in the past year. About 75% of respondents reported they had served or been in contact with 10 or fewer survivors in the past year, followed by 20% reporting contact with 11-50 survivors and 5% reporting contact with more than 50 survivors in the last year.

Figure 2. Please estimate the number of individuals with brain injury that YOU served or had contact with in the last year: (n=197)

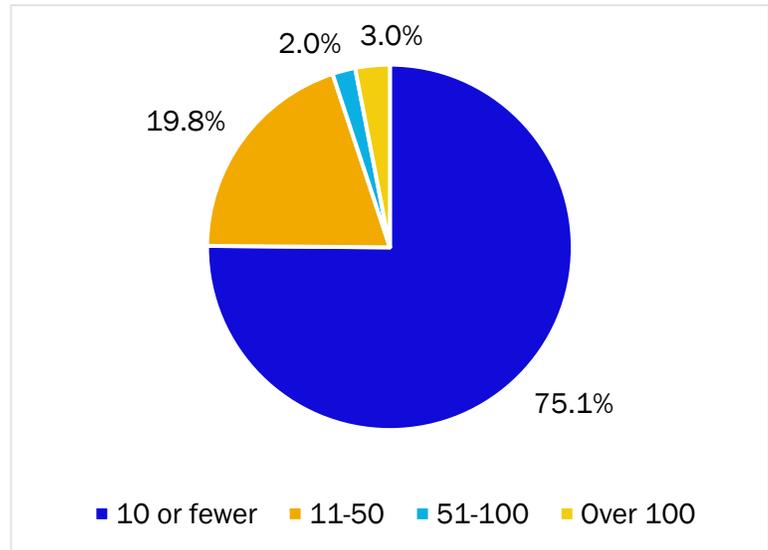


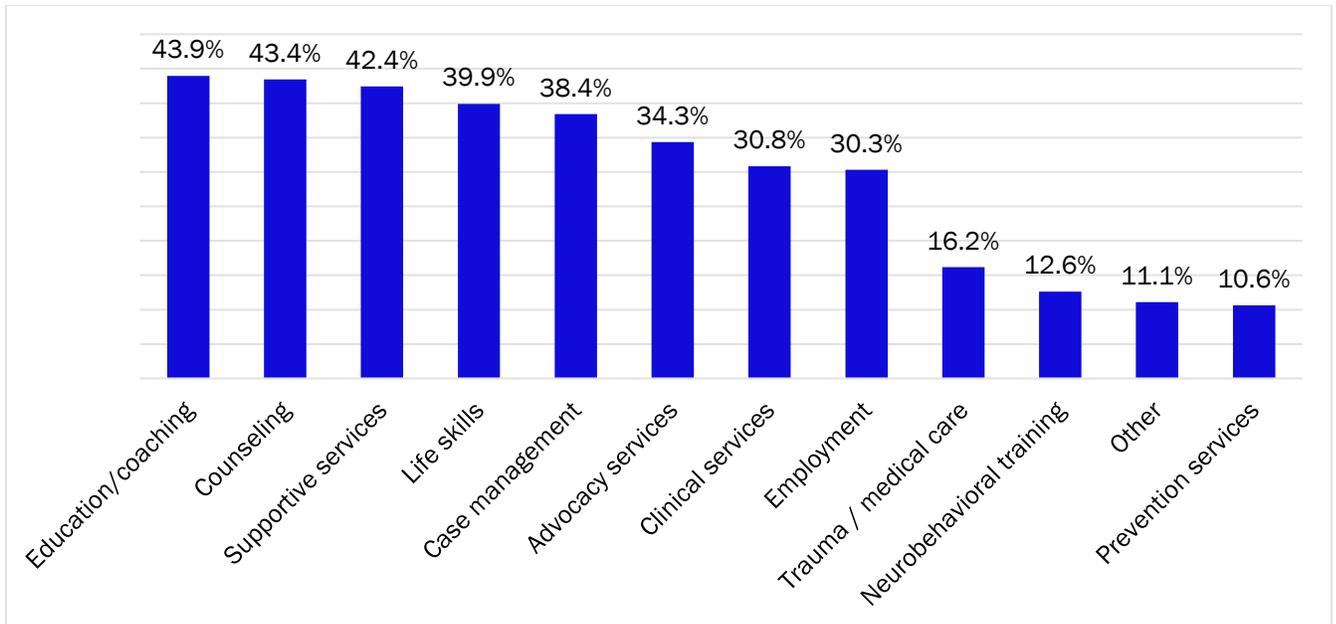
Table 2 shows how brain injuries were identified (respondents could select all responses that apply). The vast majority (over 80%) of respondents reported that brain injuries were identified by outside professionals. This was followed by referral sources (36.6%) and other professionals within respondent's organization (28.4%). Less than 10% of respondents reported that they identified brain injuries themselves.

Table 2. How were brain injuries identified? (select all that apply) (n=194)

Method	n	%
By Outside Professionals	157	80.9
By Referral Sources	71	36.6
By Other Professionals Within My Organization	55	28.4
By me	19	9.8
Other	11	5.7

In Figure 3, the types of services respondents reported that they or their organization provide to brain injury survivors are outlined. About 44% of respondents' organizations offer education or coaching, followed by counseling services (43.4%), supportive services (42.4%), life skills services (39.9%), and case management (38.4%).

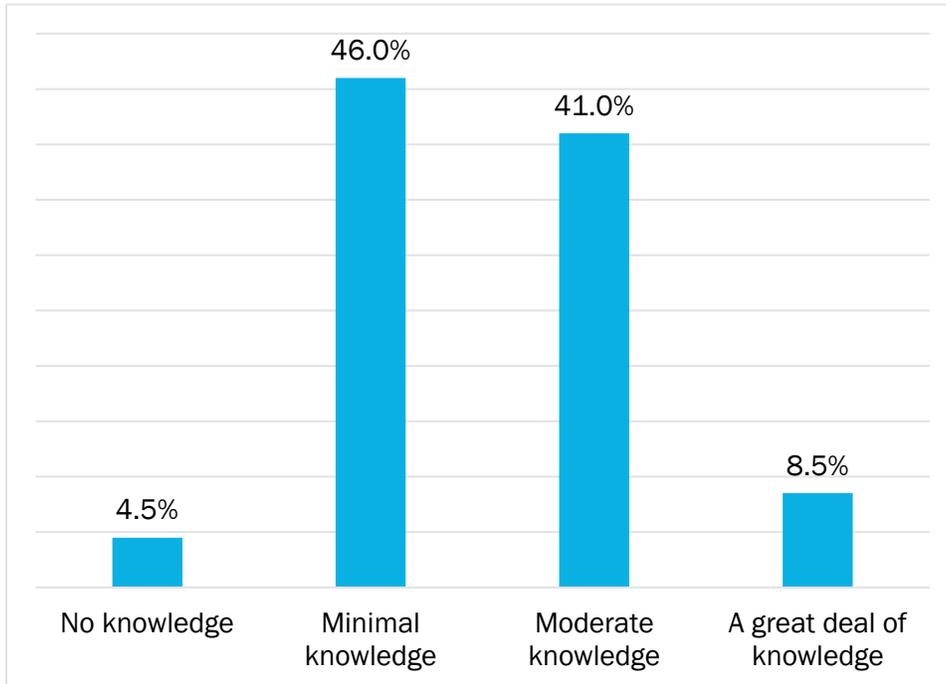
Figure 3. Indicate what type of services you and/or your organization provide (select all that apply) (n=198)



Knowledge of Brain Injury Supports and Services

As shown in Figure 4, half of the survey respondents reported that they had either minimal or no knowledge of available supports and services for individuals with brain injury and their families. Forty one percent reported having moderate knowledge and only 8.5% reported having a great deal of knowledge related to available supports and services for brain injury survivors and their families.

Figure 4. Please rate your knowledge of available services and supports for individuals with brain injury and their families (n=200)



Figures 5 and 6 show knowledge of available services by respondents' identified profession. Overall, at least a quarter of professionals in each category reported having minimal or no knowledge of available supports and services for brain injury survivors. Almost three quarters of educators/school personnel and over half of community service providers and professionals indicated having no or minimal knowledge of brain injury-related services and supports. Conversely, about 74% of rehabilitation personnel and 67% of medical/hospital personnel reported having moderate or a great deal of knowledge. Of those, only 15% of medical/hospital personnel and 20% of rehabilitation personnel reported having a great deal of knowledge.

Figure 5. Knowledge Level by Profession, Summary (n=198)

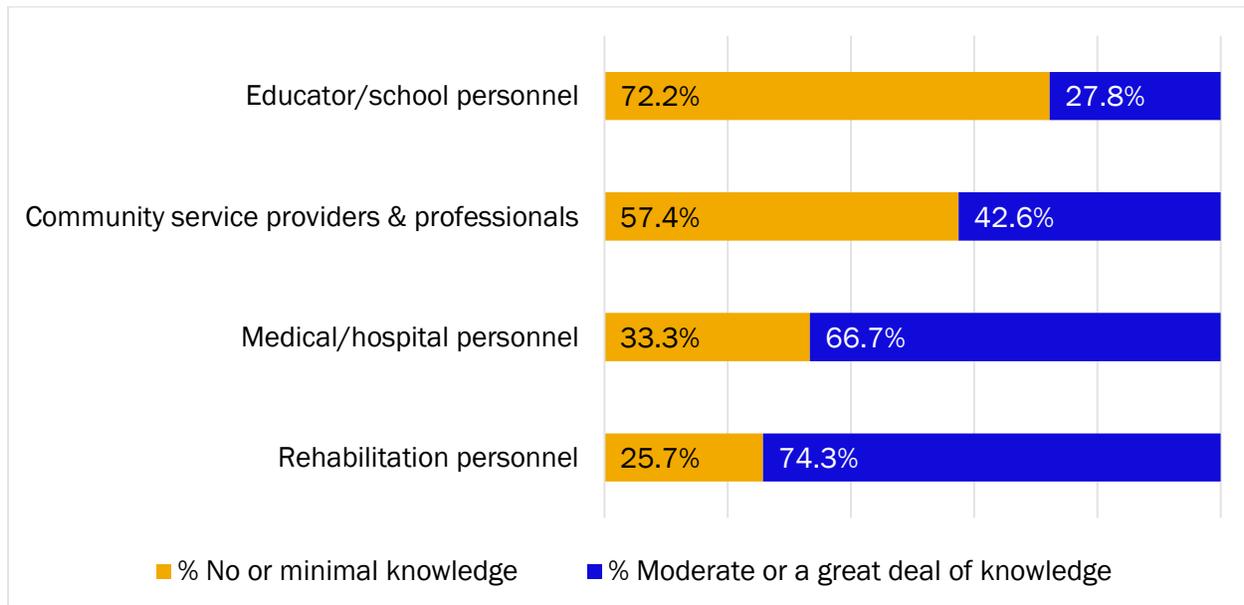
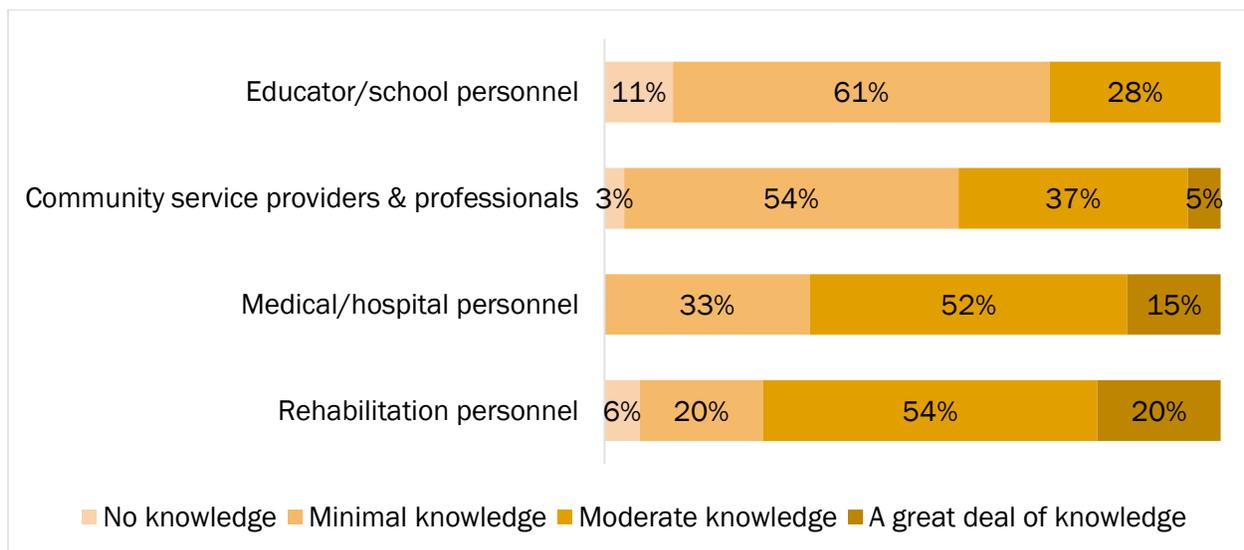


Figure 6. Knowledge Level by Profession, Detailed (n=198)



Adequacy of Supports and Services

Survey respondents who indicated that they had minimal, moderate, or a great deal of knowledge about available brain injury-related supports and services ($n = 191$) were asked about the adequacy of 25 specific services across three areas: *medical/hospital services*, *rehabilitation services*, and *community services and supports*. Respondents rated the adequacy of the service on a 4-point Likert scale (1=very inadequate, 2=somewhat inadequate, 3= somewhat adequate, 4=very adequate) or had the option to select 'I don't

know.’ In this section, services are first discussed by service area, followed by a broader comparison of all services.

Medical/Hospital Services

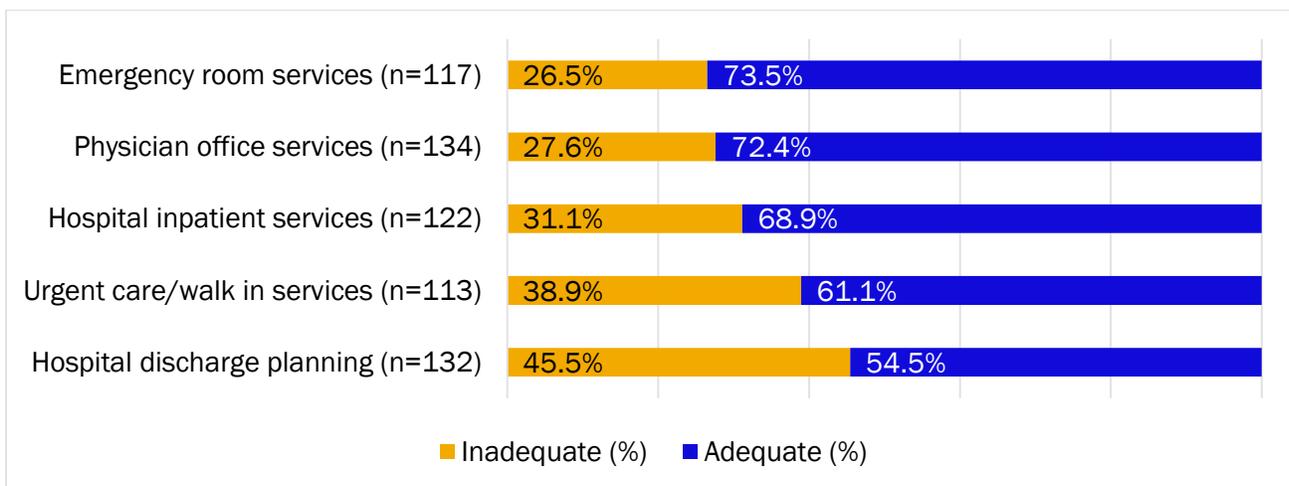
Survey respondents who reported having any knowledge about available supports and services for brain injury survivors and their families were asked to rate the adequacy of five medical/hospital services, as they relate to brain injury survivors. In this category, between 24% and 40% of respondents did not provide an adequacy rating and instead selected ‘I don’t know’ for each of the listed services (Table 3).

Table 3. Medical/Hospital Services Adequacy: ‘I don’t know’ Responses

	Don't know
Urgent care/walk in services (n=187)	39.6%
Emergency room services (n=186)	37.1%
Hospital inpatient services (n=186)	34.4%
Hospital discharge planning (n=186)	29.0%
Physician office services (n=187)	28.3%

Figure 7 shows the percentage of ‘adequate’ (‘somewhat adequate’ or ‘very adequate’) and ‘inadequate’ (‘somewhat inadequate’ or ‘very inadequate’) ratings for the five medical/hospital services, among respondents who provided a rating.

Figure 7. Medical/Hospital Services Adequacy Ratings



Among the medical/hospital services, about 46% of respondents rated hospital discharge planning services as ‘inadequate,’ followed by urgent care/walk in services (38.9%), hospital inpatient services (31.1%), physician office services (27.6%), and emergency room services (26.5%).

Rehabilitation Services

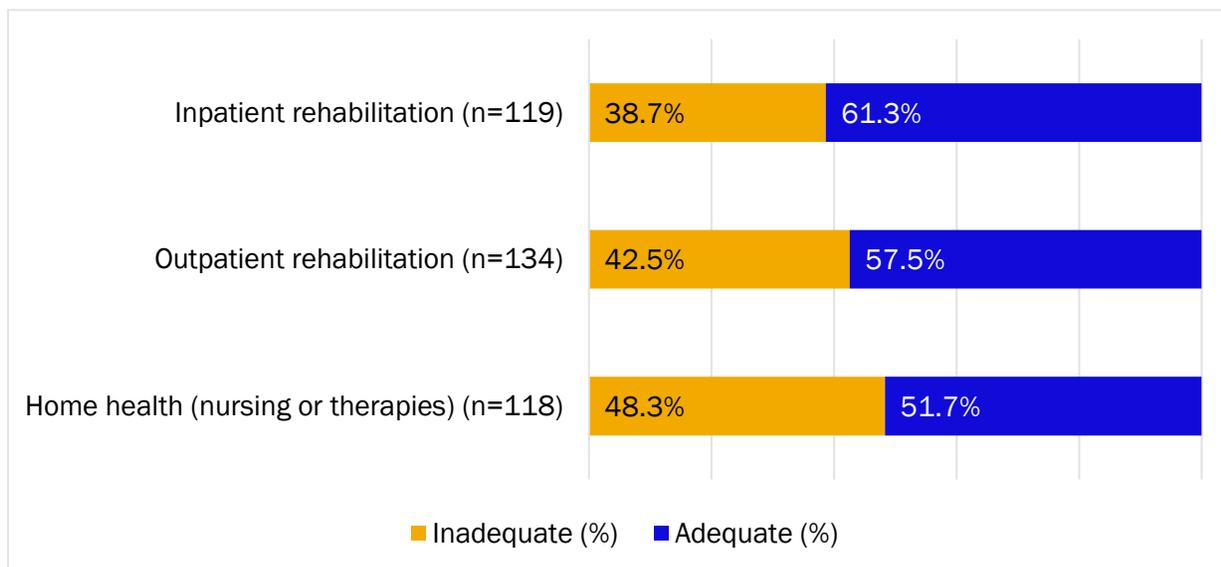
Survey respondents who reported having any knowledge about available supports and services for brain injury survivors and their families were asked to rate the adequacy of three rehabilitation services, as they relate to brain injury survivors. In this category, between about a quarter and a third of respondents did not provide an adequacy rating and instead selected ‘I don’t know’ for each of the listed services (Table 4).

Table 4. Rehabilitation Services Adequacy: ‘I don’t know’ Responses

Services	Don't know
Home health (nursing or therapies) (n=185)	36.2%
Inpatient rehabilitation (n=186)	36.0%
Outpatient rehabilitation (n=183)	26.8%

Figure 8 shows the percentage of ‘adequate’ (‘somewhat adequate’ or ‘very adequate’) and ‘inadequate’ (‘somewhat inadequate’ or ‘very inadequate’) ratings for the three rehabilitation services, among respondents who provided a rating.

Figure 8. Rehabilitation Services Adequacy Ratings



Among the rehabilitation services, about 48% of respondents rated home health services as ‘inadequate,’ followed by outpatient rehabilitation (42.5%), and inpatient rehabilitation (38.7%).

Community Supports and Services

Survey respondents who reported having any knowledge about available supports and services for brain injury survivors and their families were asked to rate the adequacy of 17 community supports and services, as they relate to brain injury survivors. The percentage of respondents who did not provide an adequacy rating and instead selected ‘I don’t know’ for

each of the listed services ranges from about 19% (mental health counseling) to almost 47% (legal services, Table 5).

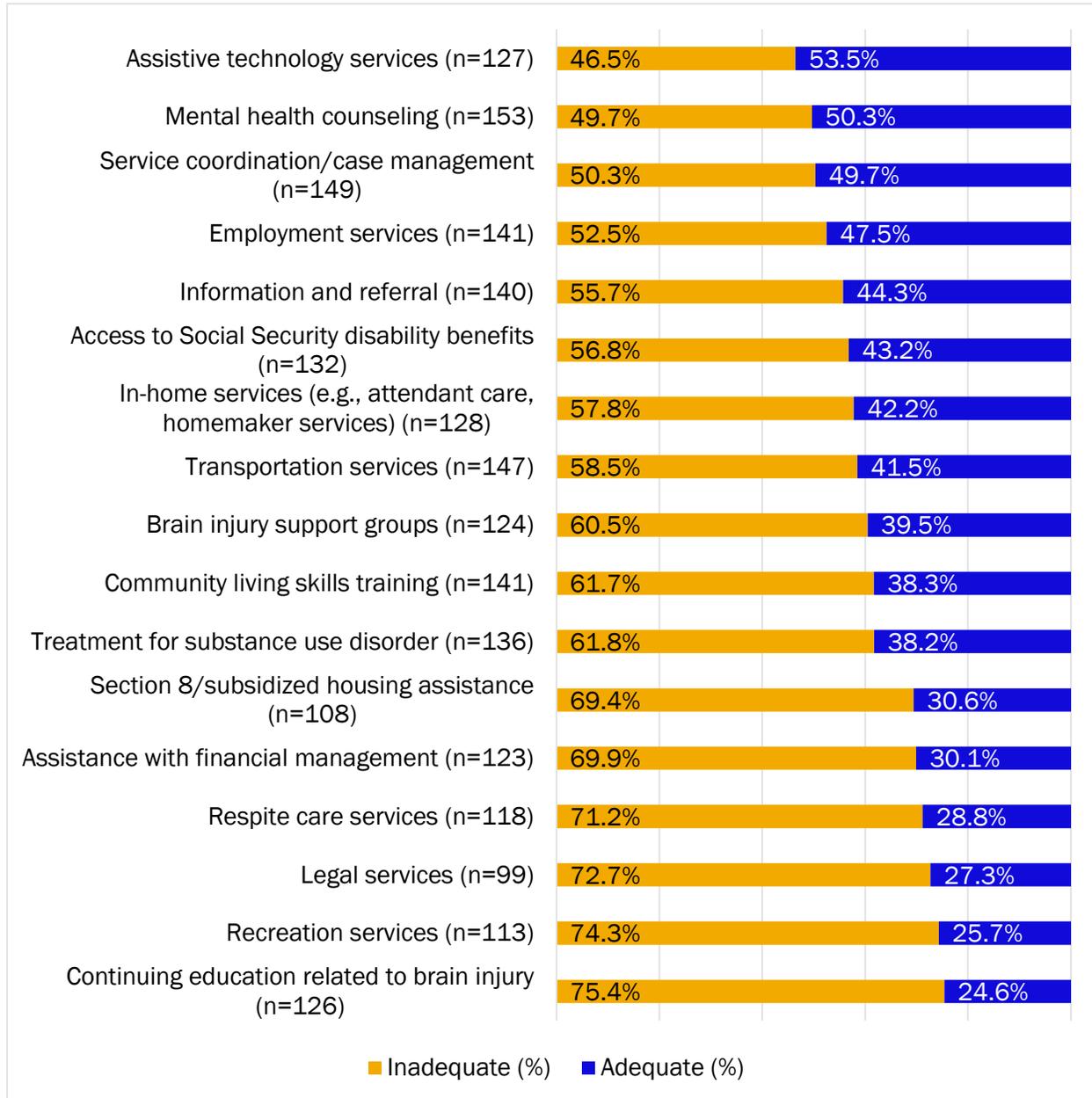
Table 5. Community Supports and Services Adequacy: 'I don't know' Responses

Services	Don't know
Legal services (n=186)	46.8%
Section 8/subsidized housing assistance (n=188)	42.6%
Recreation services (n=186)	39.2%
Respite Care Services (n=187)	36.9%
Assistance with financial management (n=188)	34.6%
Brain injury support groups (n=188)	34.0%
Continuing education related to brain injury (n=187)	32.6%
Assistive technology services (n=186)	31.7%
In-home services (e.g., attendant care, homemaker services) (n=187)	31.6%
Access to Social Security disability benefits (n=186)	29.0%
Treatment for substance use disorder (n=187)	27.3%
Information and referral (n=188)	25.5%
Community living skills training (n=187)	24.6%
Employment services (n=186)	24.2%
Transportation services (n=186)	21.0%
Service coordination/case management (n=186)	19.9%
Mental health counseling (n=188)	18.6%

Figure 9 shows the percentage of 'adequate' ('somewhat adequate' or 'very adequate') and 'inadequate' ('somewhat inadequate' or 'very inadequate') ratings for the 17 community supports and services, among respondents who provided a rating.

Among the community supports and services, over 75% of respondents rated continuing education related to brain injury as 'inadequate,' followed by recreation services (74.3%), legal services (72.7%), and respite care services (71.2%). Just over half of respondents rated assistive technology services as 'adequate,' which was the service in this area most frequently rated as either somewhat (47.2%) or very (6.3%) adequate.

Figure 9. Community Supports and Services Adequacy Ratings



Services Adequacy Comparison

Appendix A displays all services (sorted by highest percentage of ‘very inadequate’ ratings).

Almost half of the survey respondents who reported having at least some knowledge about available supports and services for survivors did not provide an adequacy rating for legal services and instead selected ‘I don’t know.’ This was followed by Section 8/subsidized housing assistance (42.6%), urgent care/walk in services (39.6%), and recreation services (39.2%). The categories with the lowest percentage of “I don’t know” responses were mental health counseling (18.6%) and service coordination/case management (19.9%).

Between about half and three quarters of respondents rated the listed community supports and services as ‘inadequate’ (either ‘somewhat’ or ‘very’). Over 25% of respondents rated 13 of the 17 the listed community supports and services as ‘very inadequate.’ Services most frequently identified as ‘very inadequate’ include: legal services (44.4%), recreation services (40.7%), respite care services (39.8%), assistance with financial management (39.0%), continuing education related to brain injury (37.3%), and transportation services (34.0%).

Services most frequently rated as ‘adequate’ (either ‘somewhat’ or ‘very’) include: emergency services (73.5%), physician services (72.4%), and hospital inpatient services (68.9%). Services most frequently identified as ‘very adequate’ include: inpatient rehabilitation (27.7%), emergency room services (25.6%), hospital inpatient services (23.8%), and physician office services (20.9%).

Barriers to Accessing Supports and Services

Respondents were asked about common barriers brain injury survivors and their families experience when accessing supports and services. As shown in Table 6, respondents most frequently identified a lack of knowledge of services and services as a barrier to access (80.3%), followed by an inability to pay for needed services (73.7%) and resources not being located near the homes of survivors (70.7%).

Table 6. In your opinion, what barriers to individuals with brain injury and their families face in accessing services and supports? (n=198)

Barrier	%
Unaware of services and resources	80.3%
Inability to pay for needed services	73.7%
Services and resources not located near their homes	70.7%
Cognitive limitations	68.2%
Difficulty understanding paperwork	64.1%
Inadequate insurance	60.1%
Lack of support/patient advocacy	57.1%
Inadequate support to live in setting of choice	56.1%
Need help with financial management	55.6%
Lack of transportation	53.0%
Lack of insurance	51.5%
Inadequate support to find employment	46.0%
Difficulty with enrollment/admissions	44.9%
Physical limitations	44.9%
Difficulty with English language	7.6%
Other	9.1%

Given that many of the identified barriers are related, broader themes also emerge. Several of the commonly identified barriers are related to gaps in available knowledge or difficulty understanding what services are available and how to connect with—or even physically access—these services. Examples of these types of barriers include: unaware of services and resources (80.3%), cognitive limitations (68.2%), difficulty understanding paperwork (64.1%), difficulty with enrollment/admissions (44.9%), and physical limitations (44.9%). Many of the identified barriers to seeking care, services and supports also center around financial concerns, including: inability to pay (73.7%), inadequate insurance (60.1%), help with financial management (55.6%), and lack of insurance (51.5%). Other obstacles that respondents identified included a need to serve individuals who had sustained a brain injury in adulthood and a lack of rehabilitation services tailored to individuals with brain injury.

Brain Injury-Related Training

Respondents were asked about the availability of brain-injury related trainings targeting professionals as well as to the broader community.

Community Trainings

About one in five (18.9%) respondents indicated that their organization provides education or training on brain injury to the community (Figure 10).

Figure 10. Training Opportunities

Does your organization provide education or training to the community on brain injury?		
	N	Percent
Yes	38	18.9
No	130	64.7
Unsure	33	16.4
Did you receive brain injury training as part of your professional/job training?		
	N	Percent
Yes	80	39.8
No	121	60.2
Does your organization currently offer brain injury training and information to staff (not from outside source)?		
	N	Percent
Yes	38	19.0
No	127	63.5
Unsure	35	17.5
Do you or other staff within your organization access training or information regarding brain injury from external sources?		
	N	Percent
Yes	91	45.7
No	49	24.6
Unsure	59	29.6

The most common type of community training had content focused on *available supports and services for individuals with brain injury and their families* (76.3%), followed by *general*

knowledge about brain injury (73.7%) and specific knowledge about the needs of people with brain injury (65.8%, Table 7).

Table 7. Type of Community Training Provided (n=38)

Type of Training	n	%
Available services and supports for individuals with brain injury and their families	29	76.3%
General knowledge about brain injury (e.g. causes, types)	28	73.7%
Specific knowledge about the needs of people with brain injury	25	65.8%
Promoting skills for independence	22	57.9%
Employment	19	50.0%
Understanding and managing communication and cognitive changes	19	50.0%
Understanding and managing behavioral changes	18	47.4%
Screening / identification of possible brain injury (including concussions)	15	39.5%
Understanding and managing medical and physical changes	15	39.5%
Housing	13	34.2%
Interpersonal	12	31.6%
Other	6	15.8%

Professional Trainings

Over half of survey respondents (60.2%) indicated that they had not received brain injury-related training as part of their professional or job training (Figure 10). The most common type of training respondents received was related to *general knowledge about brain injury* (84.8%), followed by *understanding and managing communication and cognitive changes* (57.0%), *specific knowledge about the needs of people with brain injury* (53.2%), and *understanding and managing behavioral changes* (51.9%, full results not shown).

Staff Trainings

Just under 20% of respondents reported that their organization currently offers brain injury-related training and information to staff (another 18% reported that they were unsure were unsure, Figure 10). *General knowledge about brain injury* was the most common type of staff training (84.2%), followed *specific knowledge about the needs of people with brain injury*, *understanding and managing behavioral changes* and *understanding and managing communication and cognitive changes* (65.8% for all three topic areas, full results not included).

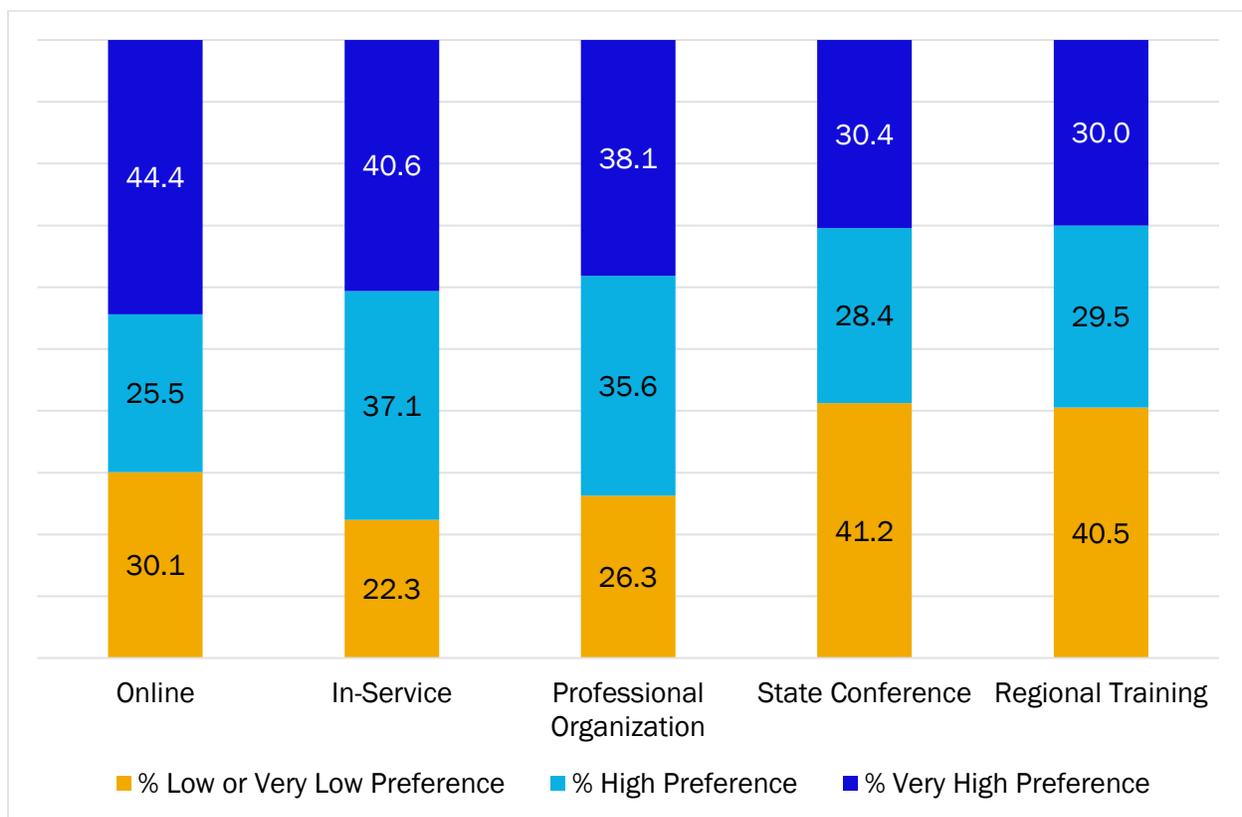
Access to External Trainings

About 46% of respondents reported that they, or other staff within their organization, access training or information regarding brain injury from outside sources (Figure 10). *General knowledge about brain injury* was the most common type of information or training accessed (76.1%), followed by *understanding and managing behavioral changes* (55.7%) and *understanding and managing communication and cognitive changes* (51.1%, full results not included).

Mode of Training

When asked about how they prefer to obtain training or information about brain injury, 44.4% of respondents indicated a ‘very high preference’ and 25.5% indicated a ‘high preference’ for online training (Figure 11). About 40% identified a ‘very high preference’ for in-service training and 37.1% indicated a ‘high preference,’ making this the option with the most positive responses (77.7%). Professional organizations were also a preferred way of obtaining information (38.1% identified a ‘very high preference’ and 35.6% identified a ‘high preference’). State conferences and regional trainings were the least preferred methods of receiving additional brain injury information.

Figure 11. What is your preferred method to obtain additional training or information?



Training and Information Needs

Respondents were asked what additional training or information was needed to improve their or their organization’s capacity to serve those with brain injury. Nearly 90 respondents wrote in their training and information needs and several are highlighted in this section. Some respondents indicated specific training needs (brain injuries and mental health, affordable housing, diagnostic and rehabilitation processes, interventions for students, local community resources, and communication, for example) while others indicated that any type of brain injury-related education would be beneficial (e.g. “Brain injuries are complex and no one size fits all. Any training/information is helpful.”).

Additional feedback on training and information needs:

- *“How to communicate and manage behaviors and cognitive deficits. Resources available to them beside LTSS services. Options for them when they need extensive oversight and there is not facility that will take them.” - Community Service Provider or Professional*
- *“Training on all of it. What service ARE available. How do you access them with limited information. What works for individuals under 21 and not in school. How to get them employed. Any and all topics on available services to help TBI survivors.”*
- *“Ways to recognize if someone has a brain injury and accommodations that may help that person be successful.”- Community Service Provider or Professional*
- *“More specific community resources to assist with TBI recovery. Only one rehab facility in South Dakota and funding is difficult with really no transition services into communities.” - Community Service Provider or Professional*

Strengths of System

Respondents were also asked to identify what is working well for brain injury survivors and their families in South Dakota. Almost 100 respondents wrote in answers. Interestingly, while many responses identified strengths of South Dakota’s brain injury service and support systems, many responses were coupled with suggestions or explanations of challenges:

- *“The Benefits Planning process is doing a lot of good things. I think Vocational Rehabilitation is doing a good job but I would encourage them to think about longer term supports and really focusing on the expressed interests and desires of the client.” -Community Service Provider or Professional*
- *“The family and the special education dept. work very well together and stay in constant contact. The training available for students on brain injury is non-existent. School administration has limited understanding of the needs of said student and are therefore inadequate.” -Educator/School Personnel*
- *“In larger areas, there are centers with all of the support services available. In the rural areas, there is little support or not highly trained professionals to help people in their communities get adequate care.” -Community Service Provider or Professional*

Other comments identified specific programs, centers, and strategies to address the needs of individuals with brain injury and their families:

- *“The Brain Injury Center in Rapids is a fabulous resource.” - Community Service Provider or Professional*
- *“There is a good inter-relationship between various agencies in the area.” -Educator/School Personnel*
- *“The emphasis on identification and response to suspected concussions by the SDHSAA.” -Educator/School Personnel*

Additional Comments

About 70 respondents wrote in answers with thoughts on how to improve statewide services and supports for individuals with brain injury and their families. **Funding** was a commonly mentioned theme, with respondents indicating a need for financial support for brain injury services, supports, staffing, and training:

- *“Funding is the biggest barrier for individuals to receive necessary supports. The State of SD needs to begin a comprehensive accounting of the number of brain injuries sustained by South Dakotans each year in order to better assist with creating funding sources. Residents should have access to in-state rehabilitation services instead of these supports being provided by facilities in other states.”* - Medical/Hospital Personnel
- *“I think the primary need is for a long-term funding source such as a Medicaid waiver for people with brain injuries. The waiver should be sufficiently studied to provide for truly individualized services with an emphasis on avoiding congregate care.”* - Rehabilitation Personnel
- *“Free trainings. Non-profit [is] not likely to allow all staff to attend training if having to cover cost, would likely hand select 2-3 staff to attend, & then report back minimal info... definitely has not been effective in the past.”* - Community Service Provider or Professional

Respondents also indicated that there is a need to increase **community awareness of brain injury and expand collaborative efforts** between organizations serving individuals with brain injury and their families:

- *“Improved awareness and community support is need to better understand the global impact of brain injury and the emotional and psychosocial needs of the family members as well.”* - Medical/Hospital Personnel
- *“Most students with brain injury need support from medical, community, human services, social services and more. These entities should be working together to offer support on all fronts.”* -Educator/School Personnel
- *“I think all Case Managers should be educated on the real limitations that these individuals have. But to also consider the family members that give up their livelihood so their family member can have a quality of life. They do not belong in nursing homes unless the level of care warrants.”* -Community Service Provider or Professional

Some respondents suggested **specific services and supports** that are needed to best support individuals with brain injury, their families, and professionals working with this population:

- *“Desperate need for more TBI services across the state, including residential rehabilitation settings specific to TBI. Peer support, understanding how the impact/effects of TBI is different for each person. Schools need to understand how to work with students who have a TBI and that the smallest injury to a head on the playground can cause a TBI.”* - Community Service Provider or Professional

- *“Support groups are needed.” -Educator/School Personnel*
- *“Resource handbooks.” -Community Service Provider or Professional*
- *“The fantasy is that the legislature would elevate funding of brain injury services, creating a community integrated living arrangement CILA (small group home) model that could be implemented in communities across the state (not requiring clients to have to move to larger areas to receive services.)” -Medical/Hospital Personnel*
- *“We have many homeless individuals who either become homeless due to a TBI or end up getting a TBI due to their homelessness and violence on the streets (hitting their head due to intoxication). We need services specifically for those individuals.” - Community Service Provider or Professional*

Others mentioned challenges with providing services in rural regions of the state and offered comments about **geographic and access barriers**:

- *“It's a big state but everything is in Sioux Falls or Rapid. Spread services out or have more satellite and mobile resources. Not everyone can do virtual but even that could be expanded. Better education for general public - people I think transportation is a huge issue in the Rapid City area right now.” -Rehabilitation Personnel*
- *“So many people have to go out of state for TBI services. It is a burden for families.” - Medical/Hospital Personnel*

Conclusion

Responses from the 200 professionals who completed the 2021 South Dakota Brain Injury Needs Assessment offer perspective on the current landscape of brain injury supports and services in the state. About half of respondents identified as community service providers and professionals and most reported limited exposure to working with individuals with brain injury (almost all work with others in addition to people with brain injury and 75% had been in contact with fewer than 10 brain injury survivors in the past year). Half of respondents reported having minimal or no knowledge of brain injury supports and services, though knowledge levels varied by profession.

Ratings of service adequacy also varied. Between about half and three quarters of respondents rated the listed community supports and services as ‘inadequate’ (either ‘somewhat’ or ‘very’), whereas hospital/medical services, like emergency room services, were more frequently rated as ‘adequate.’ Services most frequently identified as ‘very inadequate’ include: legal services, recreation services, respite care services, assistance with financial management, continuing education related to brain injury, and transportation.

Brain injury survivors and their families face numerous obstacles in accessing supports and services, the most frequently identified was lack of knowledge of what is available to them. Respondents also reported a critical need for additional professional trainings and educational opportunities, both for professionals as well as the broader community. Feedback included suggestions on how to improve statewide services and supports for brain injury survivors and their families.

References

- Brain Injury Association of America (2021). *What is the difference between an acquired brain injury and a traumatic brain injury?* <https://www.biausa.org/brain-injury/about-brain-injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury>.
- Centers for Disease Control and Prevention. (2015). *Report to Congress on Traumatic Brain Injury in the United States: Epidemiology and Rehabilitation*. National Center for Injury Prevention and Control; Division of Unintentional Injury Prevention. Atlanta, GA.
- Crowley, M. (2021). *Best practice for using TBI registries to connect people to services: A national guide*. Washington, D.C.: Administration of Community Living, Department of Health and Human Services.
- Frieden, T. H. (2015). *Report to Congress on Traumatic Brain Injury epidemiology and rehabilitation: Recommendations for addressing critical gaps*. Centers for Disease Control and Prevention and National Institute of Health. Retrieved from https://www.cdc.gov/traumaticbraininjury/pdf/TBI_Report_to_Congress_Epi_and_Rehab-a.pdf.
- Kolakowsky-Hayner, S. H.-A. (2012). Ageing and traumatic brain injury: age, decline in function and level of assistance over the first 10 years post injury. *Brain Injury*, 26(11), 1328-1337.
- Raymont, V. S. (2011). "Studying injured minds" The Vietnam head injury study and 40 years of brain injury research. *Frontiers in Neurology*, 2(15).
- Sarmiento, K. , Thomas, K. , Daugherty, J. , Haarbauer-Krupa, J. & Waltzman, D. (2020). State-Level Numbers and Rates of Traumatic Brain Injury-Related Emergency Department Visits, Hospitalizations, and Deaths by Age, 2014. *Journal of Head Trauma Rehabilitation*, 35 (6), E469-E480.

Appendix A: Ratings of Service Adequacy, Full Table (sorted by 'very inadequate')

Service Type	Service	n	don't know (%)	rated adequacy (n)	very inadequate (%)	somewhat inadequate (%)	somewhat adequate (%)	very adequate (%)	inadequate (%)	adequate (%)
Community	Legal services	186	47%	99	44%	28%	26%	1%	73%	27%
Community	Recreation services	186	39%	113	41%	34%	24%	2%	74%	26%
Community	Respite care services	187	37%	118	40%	31%	26%	3%	71%	29%
Community	Assistance with financial management	188	35%	123	39%	31%	28%	2%	70%	30%
Community	Continuing education related to brain injury	187	33%	126	37%	38%	21%	4%	75%	25%
Community	Transportation services	186	21%	147	34%	24%	33%	8%	59%	41%
Community	Section 8/subsidized housing assistance	188	43%	108	32%	37%	24%	6%	69%	31%
Community	Treatment for substance use disorder	187	27%	136	29%	33%	32%	6%	62%	38%
Community	Brain injury support groups	188	34%	124	28%	32%	30%	10%	60%	40%
Community	Employment services	186	24%	141	28%	25%	38%	9%	52%	48%
Community	Community living skills training	187	25%	141	27%	35%	32%	6%	62%	38%
Rehab.	Outpatient rehabilitation	183	27%	134	27%	16%	37%	20%	43%	57%
Community	Access to Social Security disability benefits	186	29%	132	27%	30%	35%	8%	57%	43%
Community	Service coordination/case management	186	20%	149	26%	24%	40%	9%	50%	50%

Rehab.	Home health (nursing or therapies)	185	36%	118	24%	25%	36%	15%	48%	52%
Community	In-home services	187	32%	128	22%	36%	34%	8%	58%	42%
Community	Information and referral	188	26%	140	21%	35%	38%	6%	56%	44%
Community	Mental health counseling	188	19%	153	20%	29%	42%	8%	50%	50%
Rehab.	Inpatient rehabilitation	186	36%	119	18%	20%	34%	28%	39%	61%
Med./Hosp.	Hospital discharge planning	186	29%	132	16%	30%	39%	15%	45%	55%
Community	Assistive technology services	186	32%	127	15%	31%	47%	6%	46%	54%
Med./Hosp.	Urgent care/walk in services	187	40%	113	12%	27%	42%	19%	39%	61%
Med./Hosp.	Hospital inpatient services	186	34%	122	11%	20%	45%	24%	31%	69%
Med./Hosp.	Emergency room services	186	37%	117	10%	16%	48%	26%	26%	74%
Med./Hosp.	Physician office services	187	28%	134	7%	20%	51%	21%	28%	72%

