

# State Plan

January 1, 2020

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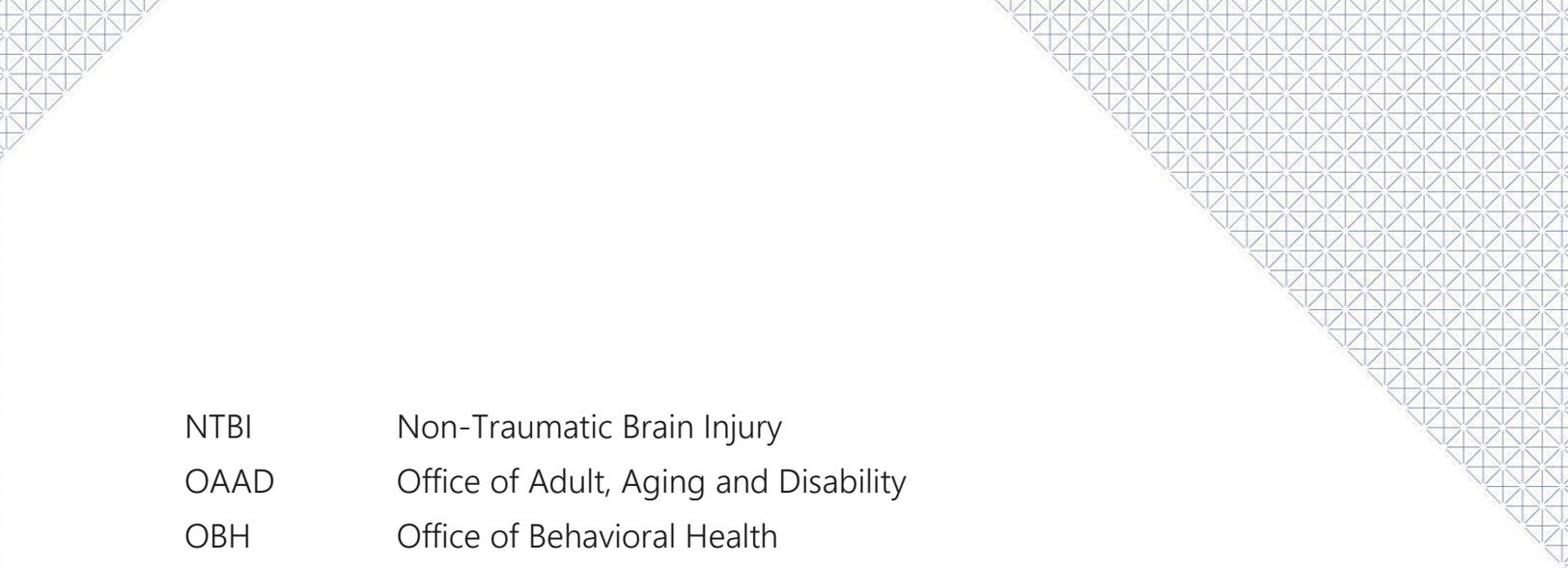
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## ACRONYMS

There are a number of acronyms referenced throughout this document. They are defined as follows:

ABI	Acquired Brain Injury
ACC	Accountable Care Collaborative
ACL	Administration for Community Living
BI	Brain Injury
BIAC	Brain Injury Alliance of Colorado
BIMW	Brain Injury Medicaid Waiver
BrainSTEPS	Brain Strategies Teaching Educators, Parents, and Students
CBIC	Colorado Brain Injury Collaborative
CBIP	Colorado Brain Injury Program (now known as MINDSOURCE – Brain Injury Network)
CDE	Colorado Department of Education
CDHS	Colorado Department of Human Services
CDLE	Colorado Department of Labor and Employment
CDPHE	Colorado Department of Public Health & Environment
CIL	Centers for Independent Living
CMHC	Community Mental Health Center
DHHS	U.S. Department of Health & Human Services
DVR	Division of Vocational Rehabilitation
HCPF	Colorado Department of Health Care Policy & Financing
I/DD	Intellectual and Developmental Disability



NTBI	Non-Traumatic Brain Injury
OAAD	Office of Adult, Aging and Disability
OBH	Office of Behavioral Health
OEF	Office of Employment First
RAE	Regional Accountable Entity
REDCap	Research Electronic Data Capture system
SAIL	Self-Advocacy for Independent Living
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TBI	Traumatic Brain Injury
YBIC	Youth Brain Injury Connections

## EXECUTIVE SUMMARY

MINDSOURCE - Brain Injury Network (MINDSOURCE) serves as the umbrella entity to: (1) manage the Colorado Brain Injury Trust Fund; (2) provide training and technical assistance regarding brain injury for public and private entities; and (3) manage local, state, and federal grants initiatives related to brain injury.

### Goals & Strategies

To develop the State Plan, MINDSOURCE created an Advisory Board to guide the work. Advisory Board members established goals to create and strengthen a system of services and supports that maximizes the independence, well-being, and health of people with brain injuries:

Goals	Strategies
Strengthen the infrastructure and capacity of MINDSOURCE and its partners to expand and improve services, resources, and supports throughout Colorado.	<ul style="list-style-type: none"><li>Find and expand new sources of revenue</li><li>Establish and promote common language and definitions for brain injuries</li><li>Ensure community providers have the training and tools to support people with a brain injury</li></ul>
Increase access to services via a user-friendly and non-redundant system of brain injury supports.	<ul style="list-style-type: none"><li>Implement a plan to ensure people living with brain injury, family members, and professionals have support across the life span of brain injuries</li><li>Build the capacity of systems/agencies to screen,</li></ul>

Goals	Strategies
	<p>assess and support people with brain injury</p> <p>Provide agencies and providers with appropriate training and tools to screen, assess, support and refer brain injury survivors to needed services</p> <p>Raise awareness of brain injury and brain injury services</p>
<p>Support people with brain injuries to navigate systems so they can explore options and access the services they need.</p>	<p>Promote self-advocacy for people living with brain injury and caregivers</p> <p>Empower people with brain injury to successfully access behavioral health and other services</p> <p>Promote meaningful productivity, whether through employment or other activities such as volunteering</p>

## THE STATE PLAN

### About MINDSOURCE

MINDSOURCE strives to enhance the quality of life for everyone in Colorado living with, or affected by brain injury, and their communities. MINDSOURCE serves as the umbrella entity for three distinct programs/functions: (1) MINDSOURCE manages the Colorado Brain Injury Trust Fund, which supports Client Services, Brain Injury Research and Education; (2) provides training and technical assistance regarding brain injury for public and private entities; and (3) manages local, state, and federal grants on special initiatives related to brain injury. MINDSOURCE is housed within the Office of Adult, Aging and Disability (OAAD) at the Colorado Department of Human Services (CDHS).

### Background

MINDSOURCE received a grant to develop a state plan to create and strengthen a system of services and supports that maximizes the independence, well-being, and health of people with brain injuries. The grant was awarded by the U.S. Department of Health and Human Services, Administration for Community Living (ACL) Traumatic Brain Injury (TBI) State Partnership Program. This state plan developed by MINDSOURCE will act as a blueprint that will guide the work of its programs and inform the work of other state agencies, as well as other partners. The period for the ACL grant is June 1, 2018 – May 31, 2021.

MINDSOURCE created an Advisory Board to guide the development of the state plan. The Colorado Brain Injury Advisory Board (Advisory Board) helped to identify gaps in services and supports, develop a responsive plan to address these gaps, and collaborated across private and public partners to meet the needs of people with brain injury and their family members. The Advisory Board is comprised of volunteer members who bring a wide variety of perspectives and expertise

including lived experience with brain injury, State agency representatives, community advocates, and providers. A list of Advisory Board members can be found in Appendix A.

The Advisory Board describes its work as

*The Colorado Brain Injury Advisory Board is identifying gaps and making recommendations to ensure that access to support is available in a system that works for everyone with a brain injury and their families.*

The Advisory Board will be responsible for monitoring the implementation of the state plan once it is developed. It is expected that the success of the plan will be dependent on several state departments, including: Judicial, Public Health and Environment, Education, Labor, Health Care Policy and Financing, and other offices/programs within Human Services as well as other community partners.

MINDSOURCE will share the experience, findings and plan with other states. Additionally, MINDSOURCE will offer consolidated curricula and training materials to all states and/or agencies that are interested.

## **Data: What We Know**

Acquired Brain Injury (ABI) is a broader definition that encompasses both traumatic and non-traumatic mechanisms of brain injury. Several entities have adopted this broader definition of brain injury. A working definition is as follows: "Acquired Brain Injury refers to damage to the brain from an internal or external source, that occurs post-birth and is non-congenital, non-degenerative, and non-hereditary, resulting in partial or total functional impairment in one or more areas such as attention, memory, reasoning, problem solving, speed of processing, decision making, learning, perception, sensory impairment, speech and language, motor and physical functioning, or psychological behavior." Non-traumatic brain injuries result from damage to the brain from internal factors while traumatic brain injuries are caused by external forces.

## Exhibit 1: Causes of Brain Injury

### More Common Than You Think

 <p><b>Acquired Brain Injury (ABI)</b></p>	<p>"Acquired Brain Injury" refers to damage to the brain from an internal or external source, including a traumatic brain injury, that occurs post-birth and is non-congenital, non-degenerative, and non-hereditary, resulting in partial or total functional impairment in one or more areas, including but not limited to attention, memory, reasoning, problem solving, speed of processing decision-making learning, perception, sensory impairment, speech and language, motor and physical functioning, or psychosocial behavior.</p>											
<p><b>There are two types of Brain Injury</b></p>	<p><b>1 Non-Traumatic Brain Injury</b> Non-traumatic brain injuries caused by damage to the brain through internal factors, such as a lack of oxygen, exposure to toxins, pressure from a tumor, etc...</p>	<p><b>2 Traumatic Brain Injury</b> An alteration in brain function, or other evidence of brain pathology, caused by an external force. There are two primary mechanisms of TBI; those involving impact to the head (Traumatic Impact), and those involving inertial forces which affect the brain (Traumatic Inertial).</p>										
<p><b>Causes of Brain Injury</b></p>	<table border="0"> <tr> <td data-bbox="428 957 496 1045">  Stroke         </td> <td data-bbox="630 957 737 1045">  Anoxic/Hypoxic         </td> <td data-bbox="829 957 898 1045">  Poison         </td> <td data-bbox="1027 957 1096 1045">  Virus         </td> <td data-bbox="1226 957 1294 1045">  Tumor         </td> </tr> <tr> <td data-bbox="496 1052 565 1140">  Fall         </td> <td data-bbox="691 1052 760 1140">  Motor Vehicle Accident         </td> <td data-bbox="886 1052 954 1140">  Struck by Object         </td> <td data-bbox="1081 1052 1149 1140">  Sports         </td> <td data-bbox="1276 1052 1344 1140">  IED         </td> </tr> </table>		 Stroke	 Anoxic/Hypoxic	 Poison	 Virus	 Tumor	 Fall	 Motor Vehicle Accident	 Struck by Object	 Sports	 IED
 Stroke	 Anoxic/Hypoxic	 Poison	 Virus	 Tumor								
 Fall	 Motor Vehicle Accident	 Struck by Object	 Sports	 IED								

Exhibit 1 illustrates the definition of acquired brain injury (ABI) along with ABI sub-definitions of non-traumatic brain injury (NTBI) and traumatic brain injury (TBI) which are each also described in the body of this report. It also provides cause of injury examples of both NTBI and TBI including stroke, fall, anoxic/hypoxic, motor vehicle accident, poison, struck by object, virus, sports, tumor, IED (improvised explosive device). This graphic was adapted from an original distributed by the Brain Injury Association of America (BIAA).

Currently, statistics related to the incidence or prevalence of non-Traumatic Brain Injury in Colorado are not available. However, this is something the State of

Colorado is working toward understanding. The Traumatic Brain Injury National Data Center has indicated that over 500,000 adults in Colorado have sustained a TBI and are living with disability-related impairments. Colorado ranks 9th in the nation for fatalities and 13th in the nation for hospitalizations due to a TBI.

## Methodology

After the kick-off meeting in July 2018, the facilitator of the Advisory Board held one-on-one conversations with each of the members to understand their perspective on what the group could and should accomplish.

The Advisory Board has held a series of meetings throughout the development of this plan:

### Exhibit 2: Advisory Board Meeting Activities

Date	Advisory Board Activities
July 2018	<ul style="list-style-type: none"> <li>• Advisory Board Members met each other and were introduced to Brain Injury 101</li> <li>• Advisory Board Members were informed of their roles, responsibilities, and expectations</li> </ul>
September 2018	<ul style="list-style-type: none"> <li>• Advisory Board Members were introduced to the research that has been completed over the past two years including:               <ul style="list-style-type: none"> <li>○ 2008: A Needs &amp; Resources Project documented quantitative and qualitative information that would translate to better supports and services</li> <li>○ 2009: A work group established after Governor Ritter signed an Executive Order specifying aligned efforts with brain injury stakeholders to identify critical</li> </ul> </li> </ul>

Date	Advisory Board Activities
	<p>elements for improving services</p> <ul style="list-style-type: none"> <li>○ 2015: The Brain Injury Alliance of Colorado completed a needs assessment to understand how clients with brain injuries access case management and other services</li> <li>○ 2015: The Colorado Brain Injury Program/Youth Needs Assessment was released</li> <li>○ 2017: The Koné Study analyzed whether and how people with brain injury experience difficulties accessing supports</li> <li>● Advisory Board members brainstormed on the long-term vision for the Board and how Colorado will be different in 2030 because of their work</li> </ul>
November 2018	<ul style="list-style-type: none"> <li>● The Advisory Board reviewed the Needs Assessment Summary that documented all of the research completed over the past decade</li> <li>● The Advisory Board learned about other state plans, including Hawaii, Missouri, and Iowa</li> <li>● Members split into self-selected working groups and began to draft goals and strategies</li> </ul>
January 2019	<ul style="list-style-type: none"> <li>● Working groups shared their goals and strategies with the full Advisory Board</li> <li>● Small groups were asked to prioritize the proposed strategies</li> </ul>
March 2019	<ul style="list-style-type: none"> <li>● The Advisory Board discussed the existing resources that</li> </ul>

Date	Advisory Board Activities
	<p>can be leveraged during the implementation of the plan</p> <ul style="list-style-type: none"> <li>Working groups reviewed their revised goals and strategies and made changes as needed</li> </ul>
April 2019	<ul style="list-style-type: none"> <li>A focus group was held with partners that work closely with MINDSOURCE to glean initial reactions and recommendations for the Advisory Board to consider.</li> </ul>
May 2019	<ul style="list-style-type: none"> <li>The Advisory Board was trained on Person-Centeredness and Cultural Competency</li> <li>Working groups shared changes to their work plan and discussed objectives as a result of the feedback received from the focus group in April 2019.</li> </ul>
August 2019	<ul style="list-style-type: none"> <li>The Advisory Board heard and discussed the feedback received from participants of the focus groups that were held in June and July 2019 (see note below this exhibit) as well as input gleaned from on-line surveys. As a result, they updated the language and clarified some of the items included in the state plan</li> </ul>

One focus group was held in Denver in April 2019 to solicit initial input from partners that work closely with MINDSOURCE. Throughout June and July 2019, four additional focus groups were held: one each in Pueblo, Windsor (Fort Collins), Grand Junction, and Frisco. Three focus groups were also held by telephone. A total of over 40 people attended these focus groups. Focus group attendees represented brain injury survivors, family members, providers, and medical professionals. An online survey was also disseminated, and approximately 85 people opened and started the survey. Overall, people were enthusiastic that there is a plan that is realistic and measurable. They are appreciative of the efforts to streamline services,

and noted that the collaboration of different agencies on the Advisory Board means that the plan is multi-faceted and comprehensive. The full summary of the survey and focus group findings can be found in Appendix B.

## **Goals & Strategies**

The Advisory Board was tasked with creating a plan to address the identified gaps in the system. Per the Koné Study that was completed in 2017, there are several barriers that create difficulties in accessing supports:

- There are no standardized screening and identification protocols to identify a brain injury.
- There is little public awareness about brain injuries, which impacts prevention and reinforces stigma.
- Providers need better training on the symptoms of brain injury to avoid differential diagnoses for individuals.
- Access to services is prevented by cost and health insurance limitations due to high out-of-pocket expenses.
- Divided payer and service structure create access barriers, especially between primary/medical care and behavioral health care.
- Disparate systems are hard for individuals and service providers to navigate, and make it difficult to understand what services are available and how they can be accessed.
- There is little-to-no coordination among service providers. Communication and information sharing aren't consistent, often because of technology constraints and broader system silo issues.

- Affordable housing and appropriate residential facilities are nearly impossible to find. This results in high rates of homelessness among people with a brain injury, including youth.
- Long-term employment options are limited due to an individual's changing needs because of the brain injury.

In developing its goals and strategies, the Advisory Board agreed that their work should have a broad impact. In addressing the gaps in services that have been identified, the Advisory Board focused on developing strategies that would touch as many people as possible. Advisory Board members self-selected into three working groups that established goals to create and strengthen a system of services and supports that maximizes the independence, well-being, and health of people with brain injuries:

- *Goal One:* Strengthen the infrastructure and capacity of MINDSOURCE and its partners to expand and improve services, resources, and supports throughout Colorado.
- *Goal Two:* Increase access to services via a user-friendly and non-redundant system of brain injury supports.
- *Goal Three:* Support people with brain injuries to navigate systems so they can explore options and access the services they need.

Exhibit 3 provides an overview of the strategies that MINDSOURCE will use to achieve these goals. The original goals and strategies developed by each working group can be found in Appendix C.

### Exhibit 3: State Plan Goals & Strategies

Goals	Strategies
Strengthen the infrastructure and capacity of MINDSOURCE and its partners to expand and improve services, resources, and supports throughout Colorado.	<ul style="list-style-type: none"> <li>Find and expand new sources of revenue</li> <li>Establish and promote common language and definitions for brain injuries</li> <li>Ensure community providers have the training and tools to support people with a brain injury</li> </ul>

Goals	Strategies
<p>Increase access to services via a user-friendly and non-redundant system of brain injury supports.</p>	<p>Implement a plan to ensure people living with brain injury, family members, and professionals have support across the life span of brain injuries</p> <p>Build the capacity of systems/agencies to screen, assess and support people with brain injury</p> <p>Provide agencies and providers with appropriate training and tools to screen, assess, support and refer brain injury survivors to needed services</p> <p>Raise awareness of brain injury and brain injury services</p>
<p>Support people with brain injuries to navigate systems so they can explore options and access the services they need.</p>	<p>Promote self-advocacy for people living with brain injury and caregivers</p> <p>Empower people with brain injury to successfully access behavioral health and other services</p> <p>Promote meaningful productivity, whether through employment or other activities such as volunteering</p>

A broad overview of the work that will be done by MINDSOURCE and its partners each year is outlined below. There is a more in-depth action plan that is being used internally.

## **FY 2020 (July 2019 – June 2020):**

The first six months of the state plan begins in January 2020 – which is half-way through the fiscal year for MINDSOURCE. This time will be focused on laying the groundwork for future implementation. MINDSOURCE and its partners will:

- Identify underserved populations through a demographic analysis to conduct targeted outreach and understand where efforts need to be focused to raise awareness.
- Identify what entities serve underserved populations (e.g., Criminal and Juvenile Justice-Involved, Native Americans, Veterans) and begin to develop strategic partnerships with those organizations.
- Define self-advocacy (per a strategy in Goal #3) and identify existing resources that could be shared with others for educational and support purposes.
- Monitor the trials and research study being conducted by Craig Hospital, Self-Advocacy for Independent Life (SAIL), for its possible use in implementation of providing self-advocacy resources.
- Hold conversations with other State Agencies and partners to learn how to prioritize their policy work that will sustain and/or broaden the infrastructure within the Colorado brain injury community. This will lead to the development of memorandums of understanding (MOUs) and/or formal commitments with those agencies and partners.
- Review the Regional Accountable Entity (RAE)<sup>1</sup> policies (appendix H in the RAE contracts) to explore how to offer training and materials to providers/people with brain injuries on how to access behavioral health and other services.

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<sup>1</sup> The Regional Accountable Entities (RAEs) are community-wide systems for effective care management for Colorado's Medicaid program.

Understand protocols on the cultural competency and person-centeredness trainings that are offered to RAE providers.

### **FY 2021 (July 2020 – June 2021):**

The first full fiscal year in which MINDSOURCE will be implementing its state plan will be one that will require engaging many partners, as well as developing and disseminating key resources. To expand and improve services and supports throughout Colorado, MINDSOURCE and its partners will:

- Identify and secure additional funding based on priorities outlined by Advisory Board to support continued implementation of the state plan.
- Work across Colorado state agencies to adopt common language, such as a person-centered definition list. MINDSOURCE will partner with those other agencies to promote that common language.
- Find at least one state agency partner with whom to co-brand common definitions and incorporate into policy.
- Identify and review existing trainings for providers who support people with brain injuries (e.g., behavioral health) to ensure those trainings include best practices and are culturally appropriate and person-centered.
- Promote and deliver trainings that support people with a brain injury to behavioral health providers.

To increase access to services, MINDSOURCE and its partners will:

- Conduct a survey to determine if and how agencies screen for brain injury, and if they feel equipped to support people with brain injury. MINDSOURCE will also seek to identify and understand barriers that agencies face when trying to complete screenings and assessments.

- Develop outreach templates that would offer support to agencies in meeting their obligations to serve and/or accommodate people with brain injuries.
- Conduct a culturally-competent and person-centered survey of individuals to determine where people with brain injury seek support, if they were rejected for any services, and for what reason(s). Ask survey respondents to identify how many agencies they have worked with that have provided accommodations for identified brain injuries.
- Determine which agencies are currently screening and assessing for brain injury. Prioritize those that are not currently screening and assessing but could benefit from doing so -- especially those that interact with a high prevalence of people with brain injury (e.g., jails, crisis centers, etc.).
- Create an outreach plan for those agencies that support people with brain injury (or that interact with a high prevalence of people with brain injury) and conduct an analysis to implement screening, assessment, support and referral protocols.
- Expand on existing efforts to develop MOUs with hospitals and other key referral sites where there is a high prevalence of people with brain injury (e.g., criminal and juvenile justice, homeless, intimate partner violence, etc.) to raise awareness of brain injury services.

To support people with brain injuries to navigate systems, MINDSOURCE and its partners will:

- Assure self-advocacy training options include awareness and explanation of how to access ombudsman and other advocacy and peer supports, including appeals and grievance procedures.
  - Educate and increase awareness on the part of people with brain injuries of their right to receive culturally competent and person-centered services typically involving informed choice and options from which to choose.

- Provide Self-Advocacy workshops around the State. This includes developing and implementing accessible (including online) trainings and other materials (such as tip cards) for users of behavioral health services with instructions on the language to use when asking for services.
- Provide information and trainings on the benefits, challenges, skills for success, and opportunities for productive volunteer activity after a brain injury, including trainings for both people with brain injury, and volunteer agencies in the community.
- Work with the Division of Vocational Rehabilitation and the Office of Employment First (OEF) at JFK Partners within the University Centers for Excellence in Developmental Disabilities (UCEDD) to expand opportunities to enhance employment supports for people with brain injury who want to participate in the workforce.

### **FY 2022 (July 2021 – June 2022):**

As it continues to implement the state plan, MINDSOURCE will need to continue to procure financial commitments, and secure funds as it seeks to expand and improve services, resources and supports.

To increase access to services, MINDSOURCE and its partners will:

- Develop a culturally competent and person-centered implementation guide that agencies can use to develop a screening, assessment, support, and referral protocol that includes data collection, data sharing, training, and policy creation.
- Conduct training to prioritized sites to ensure effective screening, identification, support and referral occurs.
- Develop culturally competent and person-centered materials for outreach, e.g., handouts on brain injury, to increase the awareness of brain injury.
- Develop and promote trainings to psychiatrists.

To support people with brain injuries to navigate systems, MINDSOURCE and its partners will:

- Engage people with brain injuries to assist in delivering self-advocacy workshops.
- Increase awareness on the part of individuals with brain injuries of their right to receive culturally competent and person-centered services typically involving informed choice and options from which to choose.
- Assure self-advocacy training options for youth and adults with brain injuries (as well as caregivers) to include awareness of, and how to access ombudsman and other advocacy and peer supports as well as appeals and grievance procedures.
- Provide information to people with brain injuries about working while receiving benefits (e.g., SSA) and options for employment such as self-employment, re-training, etc.

### **FY 2023 (July 2022 – June 2023):**

The last year of the plan will focus on maintaining the work that has been completed thus far, as well as continuing to raise awareness. MINDSOURCE and its partners will:

- Research, develop and implement an effective public awareness campaign regarding common language and definitions, and disseminate materials to at least 350 providers and agencies.
- Maintain an updated list of which agencies are utilizing screening and assessment protocols (MINDSOURCE), and disseminate it as a resource.
- Work with agencies and partners to put screening, assessment, support and referral protocols into policy and procedures to ensure sustainability.

- Create and implement a media plan to increase awareness of the need for identification and access to services.

MINDSOURCE, along with the Advisory Board, will review and revise the goals and strategies every other year to ensure that they are still relevant, given the ever-changing environment.

### **Staffing & Finances**

MINDSOURCE is the lead entity responsible for ensuring that the activities included in this plan are accomplished. With a staff equivalent of three full-time employees (FTEs), MINDSOURCE needs to be realistic about what it is able to accomplish in the next three years while also seeking opportunities to expand FTE allocation in coordination with OCAI. Although not all of the work will be completed by MINDSOURCE, as there are several partners on which success will depend, those partners also have other priorities.

MINDSOURCE will have to work closely with its partners to determine how best to integrate the state plan into the work of those partners.

Over the course of the next few years, MINDSOURCE will need to significantly increase its overall funding. This will help to assure broad access to client services by people with brain injury, including those with a non-traumatic brain injury (which is the result of legislation recently passed). Referrals are expected to increase.

Specific to the activities outlined in this State Plan, MINDSOURCE will need to secure an additional \$60K to successfully implement this plan in FY 2021. The extra monies will support the dissemination and analysis of two surveys, as well as materials to build the capacity of agencies to screen, assess and support people with brain injury. Once the materials are developed, trainings will be provided, which are also included in this \$60K.

In FY 2022, MINDSOURCE anticipates needing to secure approximately \$40K to help with a website and webinar platform, as well as travel to provide additional trainings. These are items related specifically to this State Plan.

## **Monitoring**

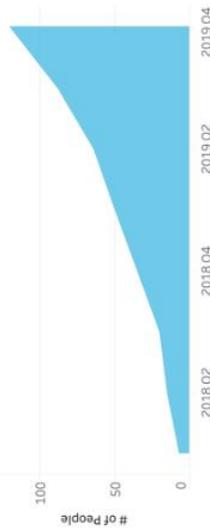
Once the state plan has been finalized and approved, the Advisory Board will be responsible for monitoring the plan to ensure that progress towards goals is being made. The Advisory Board will meet on a quarterly basis, and will use a dashboard similar to the illustration in Exhibit 4 on page 22 to measure progress.

## Exhibit 4 : MINDSOURCE State Plan Dashboard

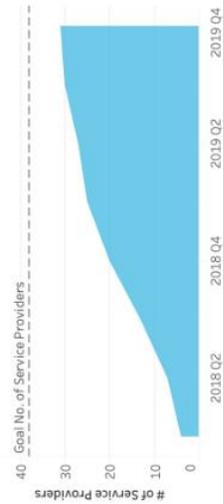
Note: This is for demonstrative purposes and does not reflect real data.



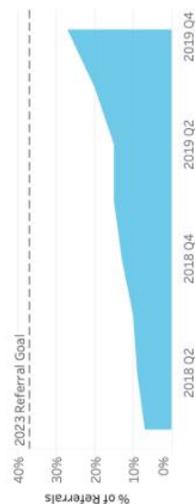
Impact: Annual increase in number of individuals receiving SAIL training



Outreach: Increase number of local service providers by 50% to screen and assess individuals across the lifespan of brain injury



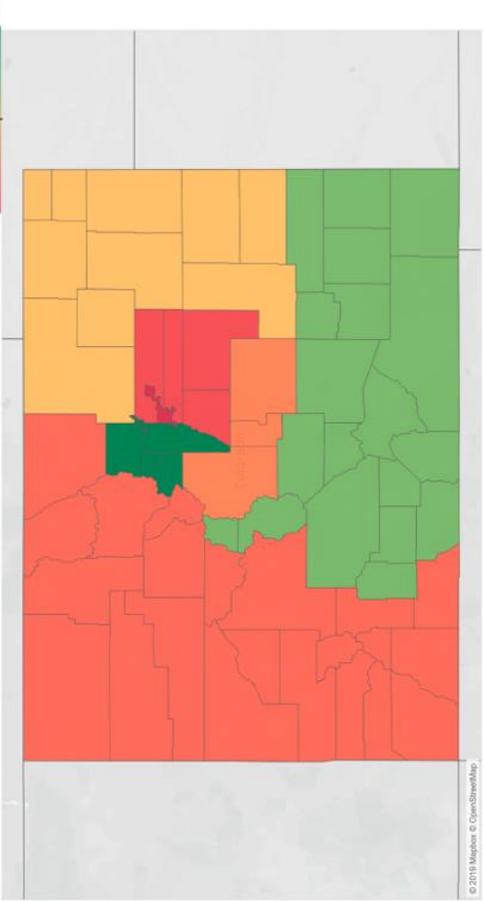
Outreach: Increase referrals to MINDSOURCE-funded services for people with identified brain injuries by 10% by June 2023



Financial: Increase MINDSOURCE revenue by \$450,000 in additional funding by July 1, 2022



Outreach: Brain Injury-Trained Community Providers by Regional Accountable Entity (RAE) Region



## **Conclusion**

In implementing this state plan, MINDSOURCE will have created and strengthened a system of services and supports that maximizes the independence, well-being, and health of people with brain injuries. MINDSOURCE will be the leader that other states will look to as they seek to enhance the quality of life for everyone living with, or affected by brain injury, in their state and communities.

## Appendix A

MINDSOURCE is grateful to the Advisory Board members and subject matter experts who were crucial to the development of this plan:

- Diane Byrne
- Brinda Dungan
- Ian Engle
- Denice Enriquez
- Anna French
- Ronen Friedman
- Barbara Gabella
- Ben Genzel
- Liz Gerdeman
- Lenny Hawley
- Steve Heidenreich
- Joy Henika
- Patricia Henke
- Heather Hotchkiss
- Russha Knauer
- Bill Levis
- Maria Martinez
- Anne Meier
- Kari Snelson
- Peggy Spaulding
- Janet Tyler
- Joshua Vensor

- Louisa Wren

## Appendix B

Below is a summary of the themes resulting from the stakeholder input to the draft state plan that was received over the course of June and July 2019.

### Online Survey:

- Approximately 85 individuals opened and started the survey. Of those respondents, 44% identified themselves as a provider, 24% acknowledged that they are a person with a brain injury, 14% said that they are a member of the general public, and 11% indicated that they are a family member or friend of a person with a brain injury. The remaining respondents indicated that they were advocates, researchers, government workers, probation officers and a handful of other representatives.
- Almost 75% of the respondents are from a metropolitan area, 20% are from rural Colorado, and 6% represent frontier Colorado.
- The vast majority of respondents (approximately 95%) are between 25 and 64 years old, and 82% identify themselves as female.
- Of the 43 respondents who did read the draft State Plan, 19% indicated that they loved it, 54% indicated that they liked it, and 26% said it was "okay." Only one respondent did not like the draft State Plan.

### Focus Groups:

- In June and July 2019, there were four focus groups held: one each in Pueblo, Windsor (Fort Collins), Grand Junction, and Frisco. Three focus groups were also held by telephone. A total of over 40 people attended these focus groups. Focus group attendees represented brain injury survivors, family members, providers, and medical professionals.

## *Themes:*

People are enthusiastic that there is a plan that is realistic and measurable. They are appreciative of the efforts to streamline services, and they expressed that the plan is ambitious. When asked what excited people about the draft State Plan, there were several other themes:

- The collaboration of different agencies on the Advisory Board means that the plan is multi-faceted and comprehensive.

Raising awareness and educating professionals is seen as being a key piece of the work over the next few years, and respondents embraced those strategies in the draft plan. There is consensus that training service providers will lead to improved access to services. Raising awareness will result in more people with a brain injury being identified/diagnosed sooner. Furthermore, providing training/education will strengthen the infrastructure of the community and ensure that there are tools in place to support survivors.

- Respondents indicated that, although the State Plan includes options for providing information about brain injury to the general public, this should represent an even greater focus. Initiatives such as public service announcements can help people to understand symptoms that might represent brain injury, such as aneurysms, strokes, etc. Also, additional public education will reduce/remove the stigma.
- Respondents are excited about establishing a common language that everyone is using.
- Colorado could have “THE” model of care that all other states look to as a best practice. This draft State Plan is a step in that direction.

When asked what people found confusing about the draft State Plan, the following was shared:

- The role of MINDSOURCE in this work is not clear. There needs to be clarification on how MINDSOURCE interacts with the other stakeholders, and generally, what the organization does.
- The language in the draft plan is sometimes confusing and feels “jargon-y.” Efforts to simplify the language would help.
- There were a lot of questions around how the plan will be implemented – especially with only 3 full-time employees. If the implementation will take longer than 3 years, that should be clarified.

When asked what was glaringly missing from the draft State Plan, as well as questions that surfaced after reading the plan, the following themes emerged:

- There needs to be additional efforts to address the needs of people with brain injury in less-populated (e.g., rural and frontier) areas. Identifying and accessing providers in rural communities is near impossible. Furthermore, it could be helpful to have “levels of modalities.” For example, support services could be provided via a “livestream” or a recording in a person’s house rather than “in person” services being the only option.
- There needs to be an investment in care coordination. For instance, each region could have a fully-funded full-time employee to support care coordination for survivors and their family members. It would be helpful to explore how that type of position could be sustainable; it will likely always rely on grant dollars.
- The Plan should better address the difficulties that individuals face in getting connected to supports in the 1-2 years following the brain injury. Individuals (and overwhelmed caretakers) often need someone to provide direction. Individuals need a “road map” of how to access supports after a brain injury. For example, specifically provide information on how to access applications for

disability; determining providers that take Medicare/Medicaid; vocational rehabilitation; locating cognitive therapy; legal services; and managing finances.

- It would be helpful to engage additional external partners and experts to provide insight into this work. Furthermore, partnerships with schools – to include educating school staff such as nurses and coaches – are not reflected in the draft Plan.
- Survivors and their family members want to connect to peers to lessen isolation and share information/experiences with one another. Overall, there needs to be more support for families, and there needs to be education for them so that they know how to access services for themselves and their loved ones.
- Long-term services are cost prohibitive. It is unclear if/how this is addressed in the Plan.
- The gaps of health equity are not reflected in the State Plan. Will MINDSOURCE look at the social determinants of health and identify ways in which to better reach the underserved? If so, be more explicit about that.
- It is not clear if/how the “brain injury waiver” fits in.
  - Where do insurance companies – or the “insurance system” – fit into this Plan?
- Although education of the medical community is included in the Plan, this needs to be reiterated as a huge need (especially screening and assessment). Often, medical professionals do not know how to diagnose or refer individuals to resources.
  - Training and education need to be expanded to the law enforcement community. They are often the first on the scene of an accident/situation, but do not always know when it’s “not okay” to let someone walk away without a medical review. Protocols to identify if/when there might be a possible brain injury would be effective.

- There could be opportunities to better leverage technology.
- There is an additional need for long-term supportive (and affordable) housing.
- There was concern about not having a process to follow up with the survivor to determine the results of self-advocacy. For example, was the survivor able or willing to proceed with recommendations? Why or why not? What worked for the individual and what didn't? Why didn't it work? Complexity? Transportation? Communication? Etc.

Other work or initiatives that stakeholders want the MINDSOURCE Advisory Board to be aware of include:

- The "Clubhouse" model at Aspen Pointe, which provides volunteer work, peer support and employment opportunities to its clients.

## Appendix C

The original goals and strategies identified and developed by the Advisory Board is found below. The purpose of sharing this is to capture the history of where the Advisory Board *started* in its thinking and approach to the state plan.

### MINDSOURCE Working Groups

Original Bucket: Infrastructure

Restated Goal (Overarching outcome you are trying to achieve): Strengthen Infrastructure

Strengthen Infrastructure Share your strategies in prioritized order:

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Ideal Target Timeline (Start – Completion)
Well trained Community Providers supporting individuals with BI.	Gather Information in available existing training Review to make sure it includes a best practice component Promote training opportunities to behavioral health providers	Train 50 new behavioral health providers per Regional Accountable Entity (RAE) region (7 regions, so 350 providers) Create a resource that lists who has been trained	CY19 – CY20  Ongoing
Structure to Support	Determine best resources/sites for best BI	Have the resources, sites and	December 2019

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Ideal Target Timeline (Start – Completion)
Communication <ul style="list-style-type: none"> <li>• Best Practice Info</li> </ul>	practice on local and national levels Create resource page and explain logic behind why these sources were chosen	explanation of logic up on the MINDSOURCE Resource page	
Structure to Support Communication <ul style="list-style-type: none"> <li>• Common language/ definitions</li> </ul>	Develop press release following 2019 legislature that announces new common BI terminology	Send press release Create a preferred definition list on MINDSOURCE Resource page	November 2019 *Dependent on passage of legislation
Funding Diversification and growth of revenue streams	Define current funding sources Analyze how much money we need to support Trust Fund infrastructure Partner with State officials to determine legislative funding possibilities and partner with Governor’s executive staff to examine agency specific funding dedicated to BI related efforts	Procure funding of \$XX to support infrastructure needs	June 2020

Original Bucket: Ancillary Services

Restated Goal (Overarching outcome you are trying to achieve): Improve ancillary services for individuals with brain injury.

Strategies in prioritized order:

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start-Completion)
Improve ancillary services for individuals with brain injury.	<p><i>Work to incorporate the concept of self- advocacy across service interventions (e.g. peer support, case management, support groups, etc.) -- so that individuals are better able to successfully access and participate in ancillary services to include employment supports, behavioral health, housing support, higher education and others they prioritize as options for their lives.</i></p> <ul style="list-style-type: none"> <li>• Define self-advocacy for our purpose in the state plan</li> <li>• Examine availability of self-advocacy within various, existing services</li> </ul>	<ul style="list-style-type: none"> <li>• Evaluations demonstrate (through pre/post) what individuals with brain injuries do differently as a result of self-advocacy training</li> <li>• Consider pulling from self-advocacy measures in Craig Hospital’s materials (Lenny will share with workgroup – re-visit at upcoming meeting)</li> </ul>	Jan 2020 - June 2021?

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start-Completion)
	<p>and supports that reach people with brain injury (self-management/skills building, peer support, support groups, etc.)</p> <ul style="list-style-type: none"> <li>• Where in existence, examine cultural appropriateness, statewide availability, technology options, funding barriers, etc.</li> <li>• Determine and implement components of effective self-advocacy training – person-centered, culturally appropriate, statewide, maximizes technology options</li> </ul>		
<p>Improve ancillary services for individuals with brain injury.</p>	<p>Improve access to and understanding of brain injury within Regional Accountable Entities (RAEs) and their associated, community service providers.</p> <ul style="list-style-type: none"> <li>• Develop training</li> </ul>	<ul style="list-style-type: none"> <li>• Reduction in the instance of individuals with brain injury being denied services, particularly behavioral</li> </ul>	<p>Currently in process.</p>

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start-Completion)
	<p>opportunities for users, direct service providers and managers within the Health First Colorado (Medicaid) systems of case (RAEs as well as RAE network providers).</p> <ul style="list-style-type: none"> <li>○ Gain top-level support by training managers on the cost savings and improved outcomes that come with early identification and integrated, supportive services for individuals with brain injury using current contract language re: serving individuals with brain injury as a framework.</li> <li>○ Develop and implement systemic, on-going training for</li> </ul>	<p>health services, on the basis of brain injury.</p> <ul style="list-style-type: none"> <li>● Improved RAE service delivery outcomes of individuals with brain injury.</li> </ul>	

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start-Completion)
	<p>all categories of direct service providers on brain injury and effectively serving individuals with brain injury.</p> <ul style="list-style-type: none"> <li>○ Develop widely accessible (likely on-line) training for users of RAE services with instruction on language to use when asking for services (to lower the risks of being screened out), what to expect, how to locate, classifications of practitioners, etc.</li> </ul>		
Improve ancillary services for individuals with brain injury.	Address productivity for individuals with brain injury -- creating a stronger sense of fulfillment, active engagement in community (through employment, volunteering [including on-line], participating on	For individuals with brain injury, increased: <ul style="list-style-type: none"> <li>● sense of fulfillment</li> <li>● life satisfaction</li> <li>● sense of life</li> </ul>	Jan. 2020 - June 2021

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start-Completion)
	<p>boards), and increased life satisfaction, sense of life purpose, sense of independence, and balance. An additional benefit is that these types of activities can help create natural peer supports.</p> <ul style="list-style-type: none"> <li>• Examine opportunities to educate individuals with brain injury on what it means to be “productive” -- not one size fits all. Peer programs may be a resource for helping individuals understand what productivity can include.</li> <li>• Review resources currently in existence at Craig Hospital <ul style="list-style-type: none"> <li>○ 1) information for agencies re: volunteers with brain injury (assure sensitivity)</li> </ul> </li> </ul>	<p>purpose</p> <ul style="list-style-type: none"> <li>• sense of balance</li> </ul> <p>Increase of successful DVR employment outcomes of individuals with brain injury.</p>	

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start-Completion)
	<ul style="list-style-type: none"> <li>○ 2) information for individuals with brain injury about volunteerism -- how to get started, how to locate opportunities.</li> <li>● Explore opportunities to enhance employment supports for those who want to be productive through work and involvement with DVR. NOTE: Vendor options improving, continued employment supports through BI waiver are being discussed this year. Possible options:               <ul style="list-style-type: none"> <li>○ Train employers about brain injury.</li> <li>○ Expand entrepreneurship options.</li> <li>○ Incorporate peer supports into employment.</li> </ul> </li> </ul>		

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start-Completion)
	<ul style="list-style-type: none"> <li>○ Examine increased use of supported employment, customized employment for individuals with brain injury -- utilizing creative methods for extended supports as needed (e.g., SSA work incentives).</li> <li>● Emphasize job retention strategies for individuals with brain injury.</li> <li>● Examine CIL involvement for job retention supports in communities.</li> </ul>		

Original Bucket: Seamless Support

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Restated Goal (overarching outcome we are trying to achieve): Create a user-friendly and non-redundant system of brain injury supports for survivors, family members and professionals; ensuring that support reaches individuals across the life span of brain injuries in communities across Colorado

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start – Completion)
Create a user-friendly and non-redundant system of brain injury supports for survivors, family members and professionals; ensuring that support reaches individuals across the life span of brain injuries in communities across	Assess evidence based and research informed care and case management practices for individuals with brain injury.	<ul style="list-style-type: none"><li>• Research and share brain injury specific evidenced-based and research-informed care and case management practices, continuum of care programs, and transition services</li><li>• Research and share non-brain injury specific evidenced-based and research-informed care and case management practices, continuum of care programs, and transition services</li><li>• Compare the two sets of research to determine what can be applied to</li></ul>	6 months; July, 2019

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start – Completion)
Colorado		the brain injury field	
	Identify systemic screening, assessment and support strategies that currently employed by agencies.	<ul style="list-style-type: none"> <li>• Identify best practices for screening for brain injury               <ul style="list-style-type: none"> <li>○ Identify systems and / or agencies that currently screen for brain injuries</li> <li>○ Identify systems and / or agencies that are not currently screening for brain injuries</li> <li>○ Identify which agencies should be screening for brain injuries</li> </ul> </li> <li>• Assessment               <ul style="list-style-type: none"> <li>○ Identify systems and / or agencies that currently assess for brain injuries</li> <li>○ Identify systems and / or agencies that are not currently assess for brain injuries</li> <li>○ Identify which</li> </ul> </li> </ul>	9 months; September, 2019

Goals (Primary outcome we are seeking)	Strategies (Approach to achieve goal)	Objectives (How we know we are successful)	Idea Target Timeline (Start – Completion)
		agencies should be assessing for brain injuries	
	Develop systemic and agency recommendations	<ul style="list-style-type: none"> <li>• Identify agencies that may benefit from implementing these recommendations, including return on investment               <ul style="list-style-type: none"> <li>○ Screening</li> <li>○ Assessment</li> <li>○ Data collection</li> <li>○ Data sharing</li> <li>○ Systems of care</li> </ul> </li> </ul>	March, 2020
	Create an implementation plan	<ul style="list-style-type: none"> <li>• Create an implementation plan for agencies to use</li> <li>• Create a mechanism to monitor progress of implementation plans</li> </ul>	July, 2020