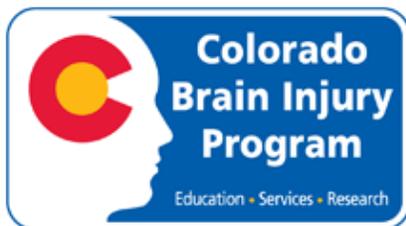


# COLORADO DEPARTMENT OF HUMAN SERVICES

## BRAIN INJURY PROGRAM



### Hard to Serve Study

August 4, 2017



Koné Consulting

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## REPORT NAVIGATION

The initial section of the report provides an overview of services and supports accessed by people with brain injury across the lifespan and across individual needs. This section analyzes themes related to equitable access to services and supports. The subsequent sections present key findings or gaps and recommendations organized by four primary domains:

1. Awareness/screening
2. Access to services
3. Availability of services
4. System coordination

Within each of these sections we explore three specific target populations:

1. Individuals with co-occurring complex medical and behavioral health needs
2. Youth, focusing particularly on students
3. Individuals seeking employment or using vocational rehabilitation services and supports

## EXECUTIVE SUMMARY

### PURPOSE

The Colorado Brain Injury Program Hard to Serve Study was initiated by the Colorado Brain Injury Program (CBIP) within the Colorado Department of Human Services in partnership with the Colorado Brain Injury Collaborative (CBIC) to analyze whether and how individuals with brain injury experience difficulties accessing supports, specifically when the individual has complex needs such as medical, mental health, and/or substance use disorder co-occurring with brain injury. The following key questions guided data collection and analysis:

1. What is the current infrastructure in place to support individuals with brain injury?
2. Which Coloradans with brain injury are experiencing difficulties accessing the services they need?
3. Where are the current gaps in services and what contributes to these barriers?
4. What best/promising practices can inform recommendations?

The goal of the hard to serve study is to provide information that can inform future funding, programming, and policy decisions to ensure Coloradans with brain injury have access to needed services and supports across their lifespans and regardless of the complexities of their health.

### KEY FINDINGS AND OPPORTUNITIES FOR IMPROVEMENT

A brain injury may begin as an acute medical injury but it can shift into a chronic health condition that endures over a lifetime and presents a wide array of symptoms and evolving needs that cross over into multiple service systems. Well-coordinated, person-centered care allows for individuals to get the holistic care they need to achieve better health and life outcomes. This report includes analysis around awareness/screening, access to services, availability of services, and system coordination, with a large number of detailed findings in the body of the report. Key findings include:

- **There is no standardized screening and identification protocol to identify brain injury.** Brain Injury is underdiagnosed or misdiagnosed and therefore treatment is postponed. This is true across systems, especially behavioral health, education, and vocational service providers.
- **Brain Injury is slow to capture public awareness.** This impacts prevention of brain injury and reinforces stigma at the community level. Lack of awareness also limits self-identification of the seriousness of brain injury, especially for mild injuries that may go overlooked, and delays intervention.
- **Providers need better training on the symptoms of brain injury to avoid differential diagnosis for individuals.** Behaviors related to a brain injury are often misidentified; therefore, interventions do not consider the brain injury, making them less likely to be successful. For individuals with co-occurring needs there are no clear lines to distinguish which symptoms are associated with which behaviors or diagnoses. This can lead to diagnostic overshadowing where these symptoms are attributed to the more prominent disability and are left untreated.
- **Access to services is prevented by cost and health insurance limitations.** Some individuals remain uninsured and those with coverage are burdened by out-of-pocket expenses, which prevents them from accessing care, and limits them to services and specific providers that are covered in their insurance

network, which may not offer specialized care for brain injury. Complementary medicine, executive functioning skills training, and family support services are highest in demand to access.

- **Divided payer and service structure creates access barriers.** One of the most influential gaps in service delivery and payer structures exists between **primary/medical care and behavioral health care**. This divide has created access limitations for people with brain injury who have more complex medical and/or behavioral health needs. Providers rely on diagnosis and medical necessity criteria to determine whether to provide care. Despite education and outreach, confusion persists on whether and how to delineate brain injury and behavioral health conditions. Access issues extend to **crisis and stabilization services**. Colorado recently implemented a statewide crisis response system, yet 77% of survey respondents indicated walk-in crisis as a service they “wish I could use.” Providers indicate a need for treatment alternatives to hospitals for when individuals are in crisis. Other service **system transitions** create opportunities for people to fall through the cracks and become under or un-served. Shifts that occur related to aging in and out of services, changing severity of needs, and movement between stability and crisis make it difficult to access services across systems. Services are driven by payer source instead of the individual’s needs.
- **Complexity associated with treating brain injury and co-occurring conditions creates access limitations.** Providers indicate complex needs as their biggest constraint to serving more individuals with brain injury. There is limited expertise in brain injury available for educators and providers with which to consult.
- **Disparate systems are hard for individuals and service providers to navigate.** Individuals are often involved in their care but are unaware of services that are available to them or don’t understand the process of how to get services. Referrals are often required but are not streamlined. System navigation is most difficult for those with complex medical needs or co-occurring behavioral health issues as well as youth transitioning to adulthood.
- **Holistic care coordination generally does not exist for people with brain injury.** People with brain injury tend to have many providers involved in their care but communication and information sharing isn’t consistent. Communication and information sharing between providers is limited because of information technology constraints and broader system silo issues. **Transition to adulthood** is a specific example of where improved care coordination could benefit people with brain injury. School services supporting transition to adulthood are not perceived as successful by students with brain injury or providers. The transition from school-based to adult systems is inconsistent. For example, there is no systematized process for referrals from school BrainSTEPS teams to case management provided by the Brain Injury Alliance of Colorado (BIAC).
- **Affordable housing and appropriate residential facilities remain an unmet need.** The cost of housing is a barrier and most survey respondents ranked low-income housing at the top of their wish list. Providers indicate appropriate residential facility placements are hard to find, especially during transitions from institutions back to the community. There are high rates of brain injury amongst the homeless population, including youth.
- **Long term employment services are limited for people with brain injury.** People with brain injury are employed at lower rates than the general disability population. Only 33% of survey respondents reported working full time or part time after injury. Survey respondents said the primary challenge with finding and keeping employment is changing individual needs because of the brain injury. The Division of Vocational Rehabilitation (DVR) can provide supported employment to people with brain injury, but need to identify an extended service provider. Because the Brain Injury as well as the Elderly, Blind and Disabled waivers do not include supported employment, it appears -- based on DVR data -- that individuals with brain injuries are infrequently connected to supported employment. Extended services

for this population require the customization of alternative resources, which may include Social Security Administration (SSA) work incentives/employment supports, private pay, natural supports, etc.

## RECOMMENDATIONS

There are many opportunities for Colorado to address system gaps and better meet the needs of people with brain injury. Key recommendations include:

- 1. Develop, implement, evaluate, and disseminate a best practice protocol for screening, identification, and assessment of brain injury statewide.** Routine screenings for lifetime history of brain injury should be prioritized in agencies and organizations that serve high risk populations such as co-occurring behavioral health, homelessness, domestic violence, etc. Incorporate lessons learned from the criminal justice system implementation grant being put into effect by the CO Brain Injury Program at CDHS. Schools should implement a consistent screening process to identify youth with brain injury needing special education or accommodations to maximize intervention effectiveness. DVR should integrate robust brain injury screening into eligibility process to improve the outcomes of people with brain injury looking for employment through connecting clients with more effective interventions, and allow DVR and other brain injury stakeholders to use the data to analyze the impact of interventions. Incorporate lessons learned from the Cross-System Behavioral Health Crises Response (CSCR) Pilot Program for persons with intellectual or developmental disabilities (IDD) around the importance of using assessments to connect symptoms and behaviors with the appropriate co-occurring condition to prevent diagnostic overshadowing in which brain injury is misidentified and left unsupported, and/or in which behavioral health conditions are untreated. Resolving confusion around diagnosis allows for use of best practices.
- 2. Increase public education and awareness about brain injury.** Broader understanding will help to increase acceptance and community integration of people with brain injury and decrease stigma. Increased awareness will support prevention of brain injury. Educating the public about brain injury will help people self-identify, particularly in cases where the injury is misdiagnosed or overlooked, which supports early and more effective intervention.
- 3. Support providers and educators by increasing the availability of brain injury specialists with which to consult and train across systems.** Identify local disability-competent providers and support professional development for providers and educators in the field. Use telemedicine to increase access to existing brain injury specialists or consultation. Telemedicine offers a more affordable way to access medical professionals and specialists in the field such as neurologists and neuropsychologists, including across systems for providers in non-medical fields such as behavioral health, education, and vocational rehabilitation. It can be especially helpful for those who live in the rural or frontier areas of Colorado with limited services and/or reliable transportation.
- 4. Continue efforts toward integrated care to assure individuals with complex needs are getting services.** Establish all-inclusive health care through integrating behavioral health and physical health care funding and service delivery models. Look to results from the Cross-System Behavioral Health Crises Response (CSCR) Pilot, which has been successfully catching people with less severe cognitive disabilities who had previously fallen through the cracks, to see ways to better integrate brain injury and behavioral health.

Data show that individuals with brain injury are more likely to suffer from behavioral health concerns, but are less likely to receive treatment. Aligning physical and behavioral health care delivery from the consumer's perspective under the Accountable Care Collaborative Phase 2 (ACC 2.0) should help, although funding streams will not be aligned. Within the transition to ACC 2.0, the Regional Accountable Entity (RAE) should analyze their work with school districts and youth/families to see how they can better serve youth with brain injury. The inclusion of high fidelity wraparound services within ACC 2.0 should incorporate youth with brain injury. Services should be available at a reduced cost for those who fall through the financial cracks. The state should consider setting performance targets for associated performance measures to track progress in this area.

5. **Remove remaining barriers to accessing behavioral health services.** Continue to offer trainings on best practices treating the behavioral health needs of individuals with brain injury. Conduct outreach and strengthen relationships between brain injury and behavioral health providers. Disseminate best practices in treating co-occurring brain injury and behavioral health to support consistency in treatment and identify lessons learned from the Cross-System Behavioral Health Crisis Response (CSCR) Pilot program. Implement performance measures to track progress in this area.
6. **Increase efforts to coordinate care over time and across an individual's continuum of needs.** Coordinated care should be streamlined and incorporate a holistic look at person's life, including housing, transportation, employment, physical health, behavioral health, social supports, and other factors impacting overall well-being. The problems faced by people with brain injury are lasting and require long-term, lifelong disease management approaches. People need more dynamic care teams to make connections between physical and behavioral health. Consider service coordinators across systems, including how to extend brain injury case management into this more holistic role. CBIP should be represented at the No Wrong Door Implementation Grant Planning Advisory Group to help coordinate pilot sites. Increase CBIP capacity through BIAC to provide in depth care coordination for a larger number of people and consider increasing intermittent follow up over a longer period of time for anyone suspected of brain injury.
7. **Continue advancements toward person-centered, patient driven care.** Increasing access and choice improves patient health outcomes as well as system coordination. Individuals should be able to self-direct their care based on their needs rather than funding. Consider using a common person-centered plan across services (physical health, behavioral health, vocational, etc.).
8. **Prioritize need for additional affordable housing and appropriate residential facilities.** There is a need for a wide spectrum of housing from an increase in Supported Living Program to permanent supportive housing programs set aside for individuals with disabilities. Consider interagency agreements with the Colorado Division of Housing in addition to the partnership with Colorado Choice Transitions (CCT) to coordinate housing efforts through all means possible. Look toward other states efforts to use Medicaid funding to pay for supportive services in permanent supportive housing programs.
9. **Increase access to crisis stabilization services, specifically crisis stabilization units.** Increase public awareness of existing crisis services and expand capabilities to serve people with complex needs in crisis stabilization units or create a Center for Excellence for intensive management of individuals with complex

needs. Offer brain injury consultation throughout crisis services to help crisis providers treat the behavioral health issues in the context of brain injury. Conduct research to improve treatment and support future policy development.

10. **Integrate peer support into the brain injury and employment systems.** Enhance peer support options for people with brain injury. Peer support is a best practice in person-centered recovery – people who know the most are the people who have experienced it. Peers can help people with brain injury navigate the re-identification process associated with navigating changed career and personal goals. Increased self-advocacy skills could also help people with brain injury more effectively lead their person-centered planning process. Peer support should be available through CBIP case management, Medicaid, and DVR to ensure broad accessibility.
11. **Improve system coordination for children and youth with brain injury as they transition through school and into adulthood by building on the BrainSTEPS initiative.** Educators and providers need to continue to follow up with children who had brain injury at younger ages so behavioral changes or other challenges related to executive functioning can be linked to the earlier injury. BrainSTEPS should define common metrics for use at district and statewide levels to determine impact of work in terms of system change and student outcomes. BrainSTEPS and concussion management teams can support this work by ensuring accurate data capture, and comparing Colorado’s identification and service outcomes to national data.
12. **Expand supported employment for people with brain injury.** The brain injury and elderly, blind, disabled waivers should include extended services and long term supports in collaboration with DVR for employment. Additionally, DVR providers, BIAC case managers, and other providers should work to better connect people with brain injury to existing supports that could help stabilize people so they are better able to find and maintain employment and/or serve as extended employment support. This may include Medicaid State Plan services, Social Security benefits and, for SSA beneficiaries, work incentives/employment supports, and natural supports. A coordinated service delivery system should be developed to ensure a continuum of care that includes employment.

## CONCLUSION

Brain injury is complex because there is no standalone brain injury system of services and supports. Brain injury is a chronic condition impacting all aspects of life, which can occur at any age. Because of this, brain injury needs to be a lens used across systems, so people with brain injury can be integrated into broader services and support structures, at work, and in their communities.

This analysis provides insight into service gaps experienced by people with brain injury, particularly individuals with complex medical needs or co-occurring behavioral health conditions, youth/students, and individuals seeking employment. Data show systemic gaps around awareness, screening, transitions for youth and adults, placement/residential options, and care coordination.

Beyond urban/rural geographic disparities impacting availability of services, data indicate disparities exist to a certain extent based on the severity of brain injury. Employment services are generally more accessible for individuals with less severe brain injury in youth and adulthood. This contrasts with Medicaid Waiver services,

which are primarily available only for those with the most severe injuries. Medicaid service access inequity is also impacted by waiver choice. Differing service definitions/requirements and service menus restrict access to some services, such as independent living skills training and supported employment.

The state is making progress in addressing gaps related to service system access and coordination through a wide variety of initiatives including the Cross-System Behavioral Health Crises Response (CSCR) Pilot Program for individuals with IDD, Olmstead-related initiatives including the Community Living Advisory Group (CLAG) and the Employment First Advisory Partnership, the Workforce Innovation and Opportunity Act (WIOA), BrainSTEPS, and ACC 2.0. Colorado has shown a great interest in continuing to bend the curve to improve outcomes for people with brain injury through improved awareness, access, service availability, and system coordination.

## OVERVIEW OF BRAIN INJURY

Brain injury is a significant public health concern that can have long-term and devastating impacts on individuals and communities. In addition to contributing to rates of permanent disability, the Center for Disease Control and Prevention (CDC) indicates that traumatic brain injuries (TBI) contribute to a third of injury-related deaths in the United States and costs of an estimated \$60 billion in medical care, rehabilitation and loss of work every year.<sup>1</sup>

Brain injury is unique in that it can happen to anyone at any time in their lifespan through a broad range of causes and at varying degrees of severity. A traumatic brain injury is defined as an alteration in brain function caused by an external force. An acquired brain injury, as defined by the World Health Organization, is damage to the brain which occurs after birth and is not related to a congenital or a degenerative disease.

The severity of brain injuries can be categorized as mild, moderate and severe which describes the level of initial injury and the length of time that consciousness was lost. While brain injury may begin as an acute medical injury it can develop into a chronic health condition with changing physical and behavioral health needs and an ongoing need for services to support stability throughout life and transitions.

There is still much to learn about brain injury, including better monitoring of trends, measuring the effectiveness of prevention efforts, and updating best practices and clinical guidelines for health care providers. Colorado has been working toward learning more about the prevalence of brain injury in the state to inform and equip leaders on opportunities to make systemic improvements to enhance services for individuals with brain injury.

## PURPOSE OF THIS STUDY

The Colorado Brain Injury Program Hard to Serve Study was initiated to analyze whether and how individuals with brain injury experience difficulties accessing supports, specifically when the individual has complex medical and/or behavioral health needs.

These key questions guided data collection and analysis.

1. What is the current infrastructure in place to support individuals with brain injury?
2. Which Coloradans with brain injury are experiencing difficulties accessing the services they need?
3. Where are the current gaps in services and what contributes to these barriers?
4. What best/promising practices can inform recommendations?

The goal of the study is to provide information that can inform future funding, programming, and policy decisions to ensure Coloradans with brain injury have access to needed services and supports across their lifespans and regardless of the complexities of their health.

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<sup>1</sup> Centers for Disease Control and Prevention. Traumatic Brain Injury & Concussion. Publications, Reports and Fact Sheets. [https://www.cdc.gov/traumaticbraininjury/pdf/bluebook\\_factsheet-a.pdf](https://www.cdc.gov/traumaticbraininjury/pdf/bluebook_factsheet-a.pdf)

## METHODOLOGY

### RESEARCH FOCUS

To better understand Colorado's available services for individuals with brain injury and gaps in the system that prevent some individuals from getting the services and supports they need for recovery, the Colorado Brain Injury Program Hard to Serve Study ascertains service needs and community perspectives in four key domains associated with the path to services:

1. Awareness/screening
2. Access to services
3. Availability of services
4. System coordination

In addition, the following subpopulations have been identified as having unique challenges associated with accessing needed services and supports:

1. Individuals with co-occurring complex medical and behavioral health needs
2. Youth, particularly students
3. Individuals seeking employment or using vocational rehabilitation services and supports

Additionally, underlying conditions such as demographics, geography, and severity of injury were researched to determine whether there were variations in access to services and supports for different populations.

### DATA COLLECTION

Researchers employed four data collection methods in this analysis: extant data review; key stakeholder interviews; an online survey for providers and consumers; and community forums.

### EXTANT DATA

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The extant data analysis sought to understand the current system and context in the core domains. The list of data sources and reports examined was developed by the researchers with input from the Colorado Brain Injury Program staff, steering committee members, and local community contacts and interviewees. The main sources included:

- Colorado Department of Human Services; Colorado Brain Injury Program and Office of Behavioral Health Evaluation Services
- Colorado Department of Health Care Policy and Financing
- The Brain Injury Alliance of Colorado
- Colorado Department of Public Health & Environment
- Colorado Department of Education
- Colorado Department of Labor and Employment; Division of Vocational Rehabilitation

## INTERVIEWS

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A broad group of community providers were interviewed to provide their input on services for people with brain injury in the State of Colorado. Interviewees were selected based on their expertise and referred by individuals knowledgeable about Colorado State service systems, organizations, leaders and initiatives. In addition, interviewees themselves were given the opportunity to suggest additional individuals to interview to capture a diverse group of stakeholders. Thirty individuals were interviewed between March 3 and June 14, 2017. See **Appendix A** for the interview protocol and **Appendix B** for a list of agencies represented in interviews.

## ONLINE SURVEY

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The survey was a web-based, electronic survey that reflected similar questions to those asked in the interviews, but in a more succinct format meant to deepen the analysis. Two separate surveys were administered, one for providers and one for individuals with brain injury and/or their family members. An anonymous link was emailed to the community providers who either participated in the kick-off meeting or were amongst the interviewees. They were encouraged to recruit through sharing the link with their networks. Ultimately, 452 responses were captured through the month of May 2017, including 244 providers and 208 individuals with brain injury and their family members. See **Appendix C** for a copy of the surveys and **Appendix D** for basic demographics of survey respondents.

## COMMUNITY FORUMS

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Two community forums were facilitated for providers, caregivers, and individuals with brain injuries to have in-depth conversations about brain injury service needs and opportunities for improvement. They were both hosted in the evening, the first was at Northern Colorado Rehabilitation Hospital in Johnstown, CO in hopes of capturing perspectives from a more rural location and included nine participants, including three consumers, one parent, three providers, and two state employees. The second was hosted at Craig Hospital in Englewood, CO in hopes of capturing perspectives from a more urban location and included 16 participants, including five consumers of services, one caregiver, one parent/provider, eight providers and one state employee. Participants in the forums were outreached through the same network of providers that conducted survey recruitment.

## ANALYSIS

The data obtained through each method were analyzed individually and then compared to identify recurring themes, including key findings and recommendations. Results from each tool are summarized by domain and subpopulation in this report.

## LIMITATIONS AND CONSIDERATIONS

The following issues, assumptions or constraints formed the context for this analysis:

- Brain injury services and support challenges encompass a large scope with a high degree of complexity. It is an ambitious task to define challenges to service and support access across a lifespan and severity of need in a usable format. This analysis could be much longer and more comprehensive, but possibly at the expense of readability and utility.

- The interview list was not inclusive of all potentially relevant key stakeholders. It was limited by the number of people who could be interviewed with available time and resources.
- The community survey was not inclusive of all providers or individuals with a brain injury in Colorado, nor was it a random sample representative of the state population. A network approach was used to recruit and disseminate the survey link. Those that received the survey likely had some connection to services as well as having access to resources and the skillset to complete the online survey and may not currently be considered hard-to-serve.
- The community forum participants were also not inclusive of all providers or individuals with a brain injury in Colorado. A network approach was used to outreach participants. Those that received the outreach material likely had some connection to services as well as access to transportation to reach the location the forums were hosted.

## COLORADO BRAIN INJURY ESTIMATES, EXISTING SERVICES, AND STRENGTHS

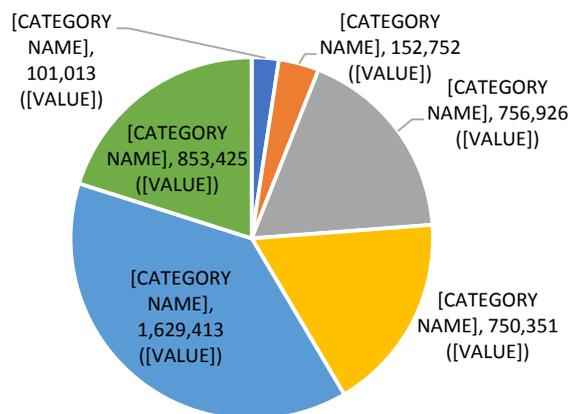
### COLORADO BRAIN INJURY ESTIMATES

This section provides an overview of currently known brain injury estimates (prevalence and receiving services) as well as services and supports in Colorado. These numbers are estimates as it is difficult to determine the full extent of brain injury prevalence due to under-screening, under-reporting, and the inherent complexity of and broad scope of brain injury services.

Craig Hospital has been conducting research on prevalence of TBI for adults in Colorado, and the associated outcomes. The research includes a statewide, population-based, random digit-dialed telephone survey of 2,701 adults which measured the lifetime history of TBI through a modification of the Ohio State University TBI Identification method. Based on their results, a weighted population estimate suggests that more than 1,000,000 (24%) of Colorado adults have a lifetime history of TBI if including mild injury with loss of consciousness (LOC), moderate, and severe injuries (as defined by LOC of 30 minutes or greater). If only looking at moderate and severe TBIs, 253,766 (6.0%) Coloradans are impacted.<sup>2</sup> This estimate does not include youth and individuals with non-traumatic brain injuries. While individuals with multiple and/or complicated mild brain injuries can have lifelong impairment, it is more likely that those with moderate to severe brain injury will. Therefore, the decision was made to be conservative in estimating need for support by focusing on individuals with moderate to severe brain injury. The following data reflect this.

### Craig Hospital research estimates over 250,000 adults in Colorado have a lifetime history of moderate or severe traumatic brain injury

Figure 1: TBI Prevalence by Injury Severity, 2016



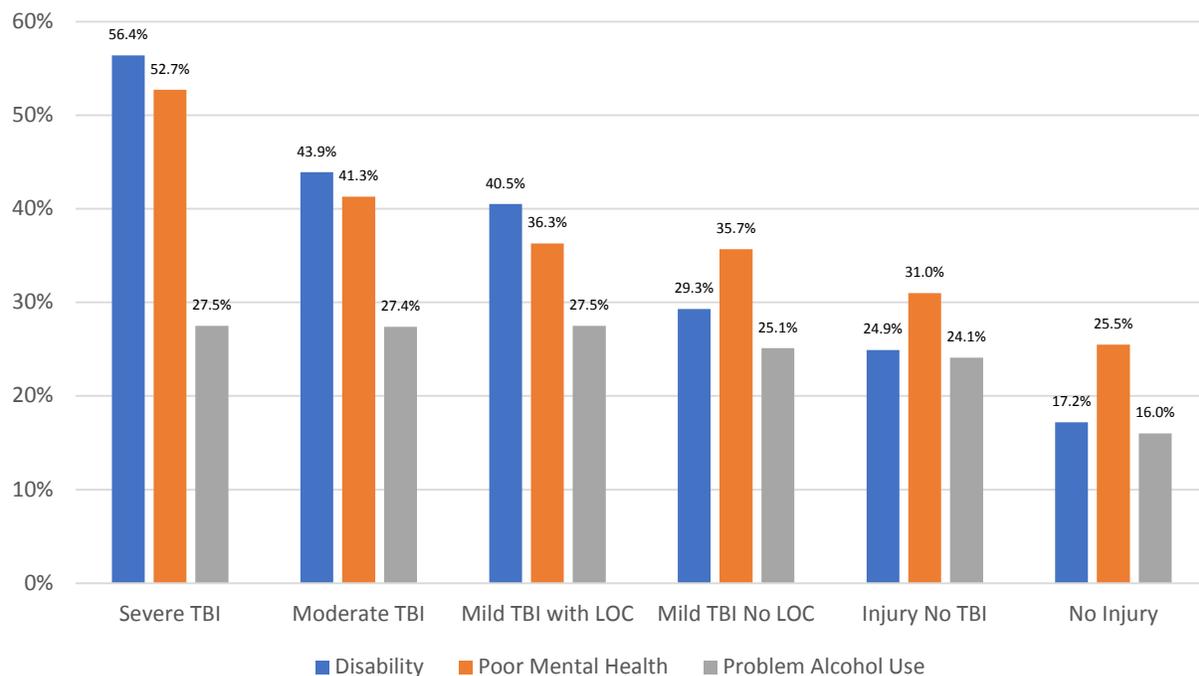
Source: Colorado Estimates of People with TBI by Planning Region, Craig Hospital.

<sup>2</sup> Colorado Estimates of People with TBI by Planning Region. Eagye, Whiteneck. Craig Hospital. November 4, 2016. <https://biacolorado.org/biac/wp-content/uploads/2017/01/Craig-Hospital-Research-1.pdf>

When analyzed by health outcome, 432,413 (42.6%) adults across mild with LOC, moderate, and severe injury severity levels are impacted by a disability; 389,229 (38.6%) experience two or more days a month of poor mental health; and 279,570 (27.5%) are impacted by negative alcohol use. The data do not conclude a causal relationship between these health outcomes and the TBI, but rather show a correlation between these factors. The figure below demonstrates how higher severity TBI is related to higher incidence of these three health outcomes.

### Individuals with more severe brain injuries are more likely to have disabilities and poor mental health

Figure 2: Negative Health Outcomes by TBI Injury Severity, 2016



Source: Colorado Estimates of People with TBI by Planning Region, Craig Hospital.

Prevalence varies by region, with mountainous regions having significantly higher rates of TBI compared to urban and eastern regions. However, the total number of people with brain injury is highest in the front range, aligned with overall population density. The table below includes the number and percentage of the total population in each planning region with a lifetime history of TBI with loss of consciousness, moderate TBI, and severe TBI.

## Brain injury is more prevalent in mountainous regions

Table 1: TBI Prevalence by Planning Region, Descending Order, 2016

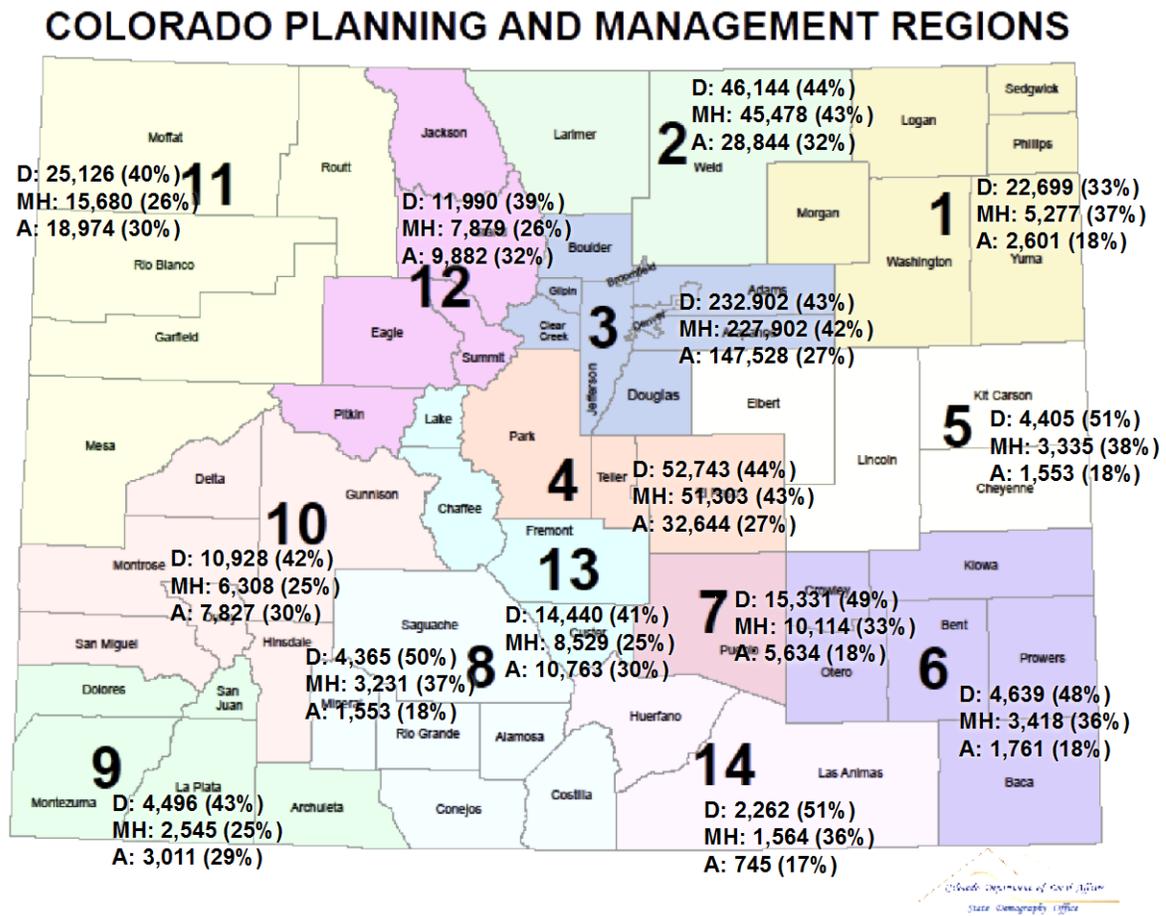
Region	Counties	# People w/ TBI	% Population
12	Eagle, Grand, Jackson, Pitkin, Summit	30,819	32.7%
13	Chaffee, Custer, Fremont, Lake	35,361	32.1%
11	Garfield, Mesa, Moffat, Rio Blanco, Routt	62,404	31.9%
10	Delta, Gunnison, Hinsdale, Montrose, Ouray, San Miguel	25,742	31.6%
9	Archuleta, Dolores, La Plata, Montezuma, San Juan	10,311	31.0%
6	Baca, Bent, Crowley, Kiowa, Otero, Powers	9,659	26.3%
5	Cheyenne, Elbert, Kit Carson, Lincoln	8,705	26.2%
1	Logan, Morgan, Phillips, Sedgwick, Washington, Yuma	14,403	26.0%
14	Huerfano, Las Animas	4,419	25.8%
8	Alamosa, Conejos, Costilla, Mineral, Rio Grande, Saguache	8,776	25.0%
7	Pueblo	31,314	24.8%
3	Adams, Arapahoe, Boulder, Broomfield, Clear Creek, Denver, Douglas, Gilpin, Jefferson	542,534	22.6%
4	El Paso, Park, Teller	120,463	22.1%
2	Larimer, Weld	105,783	21.9%

Source: Colorado Estimates of People with TBI by Planning Region, Craig Hospital.

The map below shows the total number of people with mild TBI with loss of consciousness, moderate TBI, and severe TBI impacted by a disability, two or more days per month of poor mental health, and problem alcohol use by planning region. The percentages represent the percentage of people with brain injury (mild with LOC, moderate, and severe) from Table 1, who impacted by negative health outcomes from Figure 2. In the map, “D” means disability; “MH” means poor mental health; and “A” means problem alcohol use. People with TBI in eastern Colorado appear to have higher rates of poor mental health and lower rates of problem alcohol use. The reverse looks to be true in western Colorado, which generally shows lower rates of poor mental health and higher rates of problem alcohol use. Higher disability rates appear to impact people with TBI in south central and southeastern Colorado.

## People with TBI regionally experience varied rates of negative health outcomes

Figure 3: Prevalence of Disability, Poor Mental Health, and Problem Alcohol Use for People with TBI by Planning Region, 2016



Source: Colorado Estimates of People with TBI by Planning Region, Craig Hospital.

### COLORADO BRAIN INJURY SERVICE ECOSYSTEM

Individuals with brain injury may experience a large diversity of needs depending on the severity of their injury and associated long term impacts. These needs may span an individual's whole life including issues related to stability, employability, and financial security.

**Table 2: Continuum of Care**

<b>Individual/Family Stability</b>	<b>Employability</b>	<b>Financial Security</b>
<ul style="list-style-type: none"> <li>• Food</li> <li>• Housing</li> <li>• Safety</li> <li>• Transportation</li> <li>• Physical and Mental Health</li> <li>• Child Education/Child Care</li> <li>• Child Health and Development</li> <li>• Social Supports</li> </ul>	<ul style="list-style-type: none"> <li>• Legal</li> <li>• Education</li> <li>• Training</li> <li>• Employment Skills and Experience</li> </ul>	<ul style="list-style-type: none"> <li>• Income</li> <li>• Financial Knowledge and Skills</li> </ul>

When this continuum of care or individual needs is translated into a service system, there is no single system or program addressing this breadth of issues holistically. People with brain injury can receive a variety of services and supports, which vary across their lifespan as well as by intensity/type of need (stability through crisis and short-term through chronic and complex). People will likely access services and supports across multiple programs. The summary figure below outlines services and supports potentially used by individuals with brain injury.

**Figure 4: Services and Supports Across Lifespan and Individual Needs**

	<b>Children/Youth</b>	<b>Adult</b>
<b>Higher Intensity</b>	<ul style="list-style-type: none"> <li>• Hospital</li> <li>• Psychiatric Residential Treatment Facility</li> <li>• Children’s Waivers (CES, HCBS)</li> <li>• HCP</li> <li>• Personal Assistance Services</li> <li>• Behavioral Health</li> <li>• Special Education</li> <li>• Brain Injury Case Management</li> <li>• Centers for Independent Living</li> <li>• 504 Plans</li> <li>• Vocational Rehabilitation (WIOA-Pre-ETS)</li> <li>• Early and Periodic Screening and Diagnostic Treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Hospital</li> <li>• Mental Health Institutes</li> <li>• Nursing Home</li> <li>• Assisted Living Facilities</li> <li>• Adult Waivers (Brain Injury, Elderly Blind Disabled, IDD, Community Mental Health)</li> <li>• Home Health</li> <li>• Private Duty Nursing</li> <li>• Behavioral Health</li> <li>• Veterans Affairs</li> <li>• Brain Injury Case Management</li> <li>• Housing Assistance</li> <li>• Centers for Independent Living</li> <li>• Aging and Disability Resource Centers, Area Agencies on Aging</li> <li>• Vocational Rehabilitation</li> </ul>
<b>Lower Intensity</b>		

Which services/supports individuals access depends on how they entered the system or their service pathway. Depending on the severity of the brain injury, a first step in the pathway could be a hospital emergency room and possibly inpatient hospitalization. Some may need additional intensive rehabilitation in a hospital or facility setting. A longer-term rehabilitation could take place in a skilled nursing facility. Then the individual would be discharged either to residential care or their own home with or without home and community based services (HCBS) to support them. Entrance to the Medicaid system for long term services and supports relies on a brain injury diagnosis, limited financial resources, and a high level of care need.

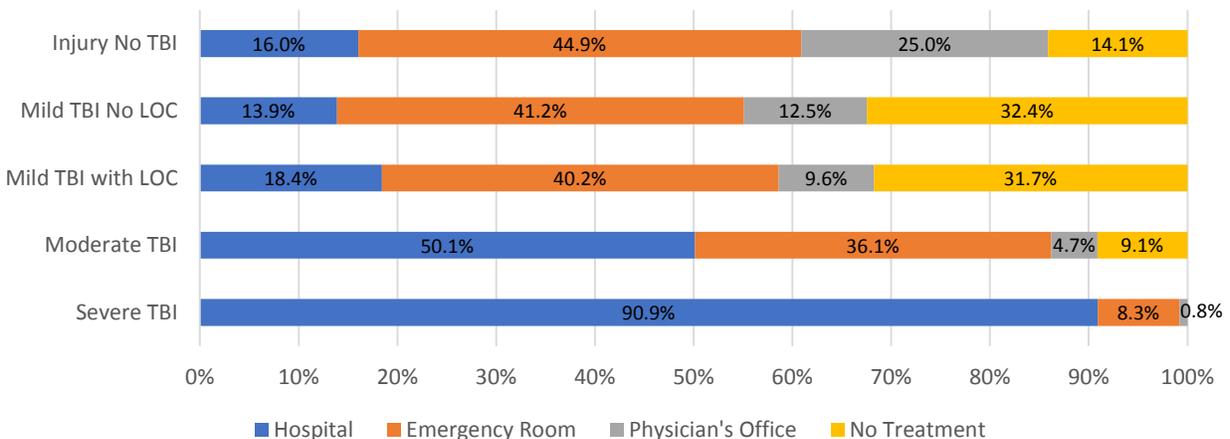
Service paths diverge for youth and adults, with schools and possibly healthcare providers playing central roles for youth/students, and adults relying on Medicaid, Older Americans Act, housing, employment, or other self-sufficiency programs depending on severity of injury/need and service system knowledge.

## INPATIENT/INSTITUTIONAL SERVICES AND SUPPORTS

Individuals who have experienced a moderate to severe brain injury are more likely to present at a hospital emergency department, and those with severe brain injury are most likely to be treated in an inpatient hospital setting. Individuals with mild brain injury may be seen in a hospital emergency department or in a clinic but often those injuries go unreported or undiagnosed. Craig Hospital’s research estimated that almost a third of people with mild brain injury did not seek medical care.

### The severity of a brain injury is related to whether and where an individual seeks care

Figure 5: Place of Care by TBI Severity of Injury, 2016



Source: *Prevalence of Self-Reported Lifetime History of TBI and Associated Disability: A Statewide Population-Based Survey, Craig Hospital.*

### Hospitalization

For those who have experienced a moderate or severe brain injury, the most common point of entry into services is through hospitalization. An average of 5,000 Coloradans who are hospitalized each year are diagnosed with a brain injury. Craig Hospital research indicates that 23% of Coloradans with all severities of TBI (including mild with no loss of consciousness) are treated in a hospital.

### Medical Rehabilitation Services

Individuals in need of acute rehabilitation may end up staying in one of Colorado’s rehabilitation hospitals such as Craig Hospital, Spalding Hospital, HealthSouth Rehabilitation Hospital, Boulder Community Hospital, Northern Colorado Rehabilitation Hospital, or Children’s Hospital. In addition to hospital settings, there are several rehabilitation facilities including Learning Services and Summit Rehabilitation. An average length of stay can range between 30-90 days depending on the severity of injury, rehabilitation goals and medical complications. Skilled nursing facilities and assisted living facilities also provide rehabilitation services to individuals with brain injury.

## RESIDENTIAL SERVICES

There are two types of residential services offered to individuals with brain injury through the Brain Injury Waiver in Colorado. Some with brain injury may end up in other residential settings through the Elderly, Blind and Disabled (EBD) waiver or the Developmental Disability (DD) waiver depending on geographic location, service preference, self-direction preference, or which services they were directed to first.

The [Supported Living Program \(SLP\)](#) is a specialized program designed for an individual whose independence can be maximized in the community by the provision of 24-hour staffing, structure and supportive services provided in a certified facility. SLPs are licensed as assisted living facilities. SLP providers commonly have waiting lists.

The [Transitional Living Program \(TLP\)](#) is similar to SLP in the provision of 24-hour staffing, structure and supportive services provided in a certified facility, however it is designed as a time limited (six months) transition after a recent injury to improve an individual's ability to live in the community so s/he can return to independent living.

Additional residential settings available for individuals with brain injury include [Alternative Care Facilities \(ACF\)](#), which provide assisted living and are available to adults who are eligible under the EBD Waiver or the Community Mental Health Supports (CMHS) Waiver.

For individuals with a brain injury who are also eligible for the DD Waiver, an additional option would be living arrangements through group homes/host homes which provide 24-hour, seven days a week supervision through [Residential Habilitation](#) and Day Habilitation Services and Supports.

A living situation option for children is through the [Children's Habilitation Residential Program \(CHRP\)](#) Waiver which provides residential services for children and youth in foster care who have a developmental disability and very high needs that put them at risk for institutional care. CHRP waiver services help children and youth learn and maintain skills needed to live in the community.

**Table 3: Residential Services for Individuals with Brain Injury**

<b>Residential Service/Program</b>	<b>Age Served</b>	<b>Level of Care</b>	<b>Waiver Program</b>
<b>Supported Living Program (SLP)</b>	18 or older	24-hour support in a facility	Brain Injury
<b>Transitional Living Program (TLP)</b>	18 or older	24-hour support in a facility	Brain Injury
<b>Alternative Care Facilities (ACF)</b>	18 or older	24-hour support in a facility	EBD and CMHS
<b>Residential Habilitation Services and Supports</b>	18 or older	24-hour support in a group residential setting	Developmental Disability
<b>Children's Habilitation Residential Program (CHRP)</b>	Under 21	24-hour support in a facility	CHRP

## COMMUNITY-BASED SERVICES

Serving individuals in the least restrictive environments in their community is required by the Americans with Disabilities Act and Olmstead, and is a known best practice for recovery. However, for individuals with brain injury

and their caregivers, it also increases the complexity of navigating several different program funding streams and service providers to piece together the necessary supports for recovery and living independently in the community. The services listed below are commonly used by people with brain injury in home and community-based settings.

The Colorado Department of Human Services (CDHS) is the lead state agency to coordinate efforts around brain injury services through the Colorado Brain Injury Program (CBIP). CBIP provides technical and policy assistance and capacity building, and manages the TBI trust fund, which is dedicated to education and awareness, services (case management), and research. [Brain injury case management services](#) are contracted through the Brain Injury Alliance of Colorado (BIAC) as of July 1, 2016. Brain injury case management services are offered statewide with regional in-person case managers available in addition to phone support.

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## MEDICAID

The Colorado Department of Health Care Policy and Financing (HCPF) is the Medicaid agency. Medicaid provides a wide range of services and support for individuals with limited financial resources. People with the ability to privately pay for medical or long term care generally would not access Medicaid. However, Medicaid is commonly used for people with disabilities needing long term services and supports because of the high cost of care and challenges with maintaining financial self-sufficiency associated with a disability.

Colorado Medicaid provides services through State Plan and waiver services. State Plan services, such as home health, private duty nursing, and behavioral health care, may help people with brain injury maintain independence. Medicaid also pays for nursing facility services through the State Plan. Youth with brain injury may receive services through the Early and Periodic Screening and Diagnostic Treatment (EPSDT) State Plan.

Waivers provide a broader range of services and supports, which may be targeted at specific populations or disabilities. Colorado waivers include the Brain Injury Waiver, Elderly, Blind, and Disabled Waiver, Community Mental Health Supports Waiver, Spinal Cord Injury Waiver, Supportive Living Services (IDD) Waiver, Developmental Disabilities (IDD) Waiver, Children's Extensive Supports (IDD) Waiver, Children with Life-Limiting Illnesses Waiver, Children with Autism Waiver, Children's Habilitation Residential Program (IDD) Waiver, and Children's HCBS Waiver. People with brain injury may be served through any of these waivers provided if they meet the qualifying eligibility criteria.

The [Brain Injury \(BI\) Waiver](#) helps people with a brain injury who need extra support to live in their communities. Those who qualify for the brain injury waiver must be 16 years or older, have a brain injury diagnosis that occurred before turning 65 years old and who would otherwise require a nursing facility or hospital level of care. The services used by the most people through the brain injury waiver are the supported living program and independent living skills training (ILST). Due to a lack of providers, ILST services are primarily limited to the metropolitan regions of the state, and often have associated provider waiting lists. Medicaid Buy-In for Working Adults with Disabilities (buy-in) has recently been added to the brain injury waiver. One alternative for self-direction is included in this waiver (Consumer Directed Attendant Support Services).

The [Elderly, Blind and Disabled \(EBD\) Waiver](#) serves people ages 65 and older who have a functional impairment, people who are blind, people ages 18-64 with physical disabilities, or people who have a diagnosis of HIV or AIDS and require long term services and supports to remain in a community setting. EBD waiver services are available statewide and allow buy-in and two self-direction options (Consumer Directed Attendant Support Services and In Home Services and Supports). The [Community Mental Health Supports \(CMHS\) Waiver](#) provides assistance to

people with a mental illness that require long term services and supports to remain in a community setting. The services are generally identical to those available through the EBD waiver, except for one self-directed option, In-Home Support Services.

The [Persons with Spinal Cord Injury \(SCI\) Waiver](#) is designed for people with spinal cord injury meeting hospital or nursing home level of care. The SCI Waiver serves fewer than 100 people. Services are similar to those available on the EBD waiver, with the addition of complementary and integrative health services (chiropractic, acupuncture, and massage). People who have co-occurring spinal cord and brain injuries must select one of the two waivers through which to receive services.

The [Developmental Disabilities \(DD\) Waiver](#) provides access to 24-hour, seven days a week supervision through Residential Habilitation and Day Habilitation Services and Supports. Eligible individuals must be 18 or older, in need of 24/7 services and supports to live safely and participate in the community, and meet intermediate care facility for individuals with intellectual disabilities (ICF-IID) level of care. The service provider is responsible for living arrangements, which typically range from host homes with 1-2 persons, individualized settings of 1-3 persons and group settings of 4-8 persons, as well as residential support for people who live with and are provided services by members of their family. The [Supported Living Services \(SLS\) Waiver](#) provides services to adults with developmental disabilities who can live independently or receive high level of support from non-Medicaid sources. Eligible individuals also need to meet ICF-IID level of care. Adults in these two waivers can receive supported employment services.

Services for children and youth with brain injury are primarily provided through school-based services such as special education (Individualized Education Plan) or reasonable accommodations made in learning environments (504 plans). Children under 16 are not eligible for the BI Waiver. Some children with brain injury qualify for intellectual and/or developmental disability services provided through the [Children's Extensive Support Waiver \(CES\)](#). These children must meet additional targeted criteria and be at risk of institutionalization.

The [Children's HCBS Waiver](#) provides services for disabled children, birth through age 17 in their home or community who would otherwise be ineligible for Medicaid but are at risk of hospitalization or nursing facility placement.

Comprehensive [behavioral health services](#) are available statewide to all Health First Colorado (Medicaid) members through a capitated state plan managed through a network of five regional behavioral health organizations (BHOs). These behavioral health services are not waiver services, but rather provided through the Medicaid State Plan. To qualify, a person must have a qualified behavioral health diagnosis. Some of the services provided through BHOs are similar to waiver services and are also incorporated in Table 4 below: case management services, clubhouse/drop-in centers, drug screening & monitoring, emergency services, individual and group therapy, medication management, recovery services, respite services and vocational services. However, the following are unique to behavioral health services.

- Assertive Community Treatment
- Inpatient Hospital Psychiatric Care
- Psychiatric services
- Outpatient hospital psychiatric services
- Residential services
- Social detoxification services
- Prevention/early intervention activities
- School-based and day treatment services for children/youth

The table below provides an overview of the services available through the Medicaid programs highlighted above.

**Table 4: Community Based Services Available through a Selection of Medicaid Waivers and Behavioral Health Organizations**

Service/Program	Brain Injury Waiver	EBD Waiver	DD Waiver	Children's HCBS Waiver	CES Waiver	Community Mental Health Supports Waiver	*Behavioral Health Organization Services
Adapted Therapeutic Recreation & Fees					X		
Adult Day	X	X				X	Clubhouse/ Drop-in Centers
Alternative Care Facilities		X				X	
Assistive Technology			X				
Behavioral Management	X		X		Behavioral Services		Recovery services
Case Management	X	X	X	X	X	X	X
Community Connection					X		
Community Transition		X					
Consumer Directed Attendant Support Services (CDASS)	X	X				X	
Day Habilitation			X				
Day Treatment	X						
Dental			X				
Home Modifications	X	X	X		X	X	
Homemaker	X	X	X		X	X	
Independent Living Skills Training	X						
In-Home Support Services (IHSS)		X		X			
Medication Reminder	X	X					Medication Management
Mental Health Counseling	X						Individual and Group Therapy
Mentorship			X				
Non-Medical Transportation	X	X	X		Travel Services	X	
Personal Care	X	X	X		X	X	
Personal Emergency Response System	X	X	X			X	Emergency Services
Prevocational			X				
Professional			X				
Residential Habilitation			X				
Respite Care	X	X	X		X	X	Respite Services
Specialized Medical Equipment	X	X	X		X	X	
Substance Abuse Counseling	X						Drug screening and monitoring
Supported Employment			X				Vocational Services
Supported Living	X						
Transitional Living	X						
Vehicle Adaptations			X		X		
Vision Therapy			X		X		

## OTHER RELEVANT MEDICAL SUPPORTS

Children with special health needs may also access services through HCP (previously called the Health Care Program for Children with Special Needs), a program through the Department of Public Health & Environment which provides information and referral, individualized care coordination, and access to specialty care through nurse-led teams.

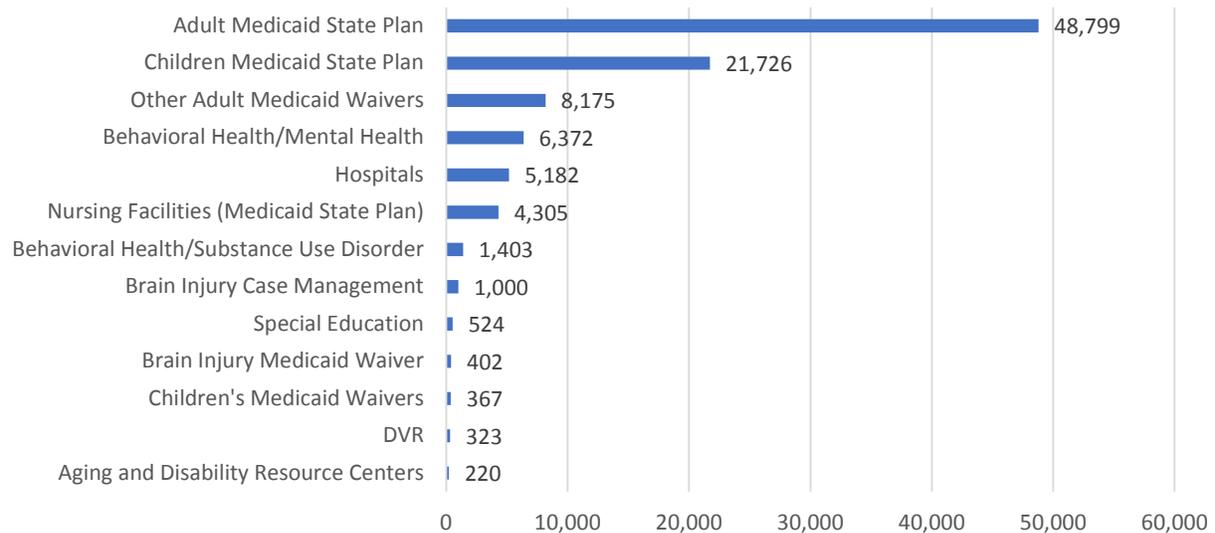
## ESTIMATES OF INDIVIDUALS WITH BRAIN INJURY IN HEALTH/HUMAN AND EDUCATION SYSTEMS

Only a subset of the population of people with brain injury access services and supports. Existing data for publicly funded supports show a maximum of 98,798 people with a brain injury diagnosis connecting to services through hospitals; brain injury case management; Medicaid waivers, including the Brain Injury Waiver; Medicaid State Plan services, including nursing facilities; Medicaid behavioral health services, including mental health and substance use disorder; special education, Division of Vocational Rehabilitation, and Aging and Disability Resource Centers. One could fairly assume that some individuals access supports through multiple systems, so the actual number of individuals connecting to supports may be markedly lower.

The following figure shows the number of people with a brain injury diagnosis in each service category for the most recent year available, generally SFY 2016. Individuals may fall within more than one category of service. This table is not intended to say that people receiving services are having their needs related to their brain injury fully met. Efficacy of services/interventions is not known with available data. Data are unavailable to further estimate this population because brain injury diagnosis is commonly not collected or documented.

## Almost 100,000 people with brain injury diagnosis in Colorado Health, Human, and Education Service system annually

Figure 6: Number of People with Brain Injury Diagnosis in Health, Human, and Education Services, 2016



Source: Colorado Department of Healthcare Policy and Financing; Colorado Office of Behavioral Health Evaluation Services; Colorado Department of Human Services; and Colorado Department of Public Health & Environment.

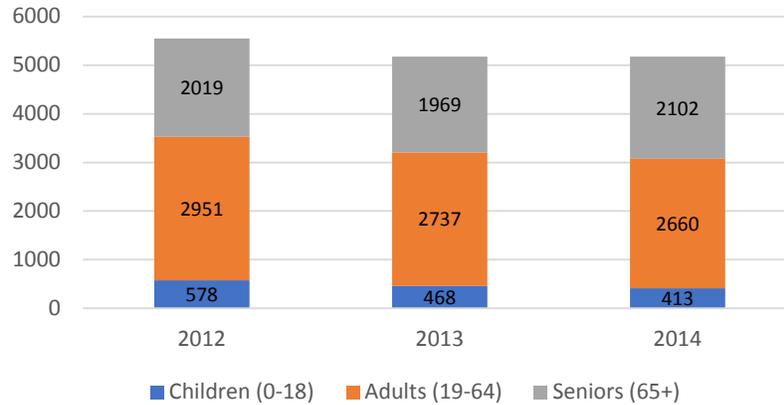
### HOSPITALIZATION

According to the Colorado Health Information Dataset on injury hospitalizations, 5,182 individuals were hospitalized for a brain injury in 2014, which accounts for 17% of all injury hospitalizations.<sup>3</sup> Approximately 51% these individuals were within the age range of 18-64 years old, while 40.5% were over the age of 65, and 8% were children under the age of 18. The rate of brain injury hospitalizations in Colorado had remained steady for the previous two years.

<sup>3</sup> Colorado Department of Public Health & Environment. Colorado Health Information Dataset. Injury Hospitalization Data. Accessed May 2017.

## Over 5,000 Coloradans are hospitalized for brain injury annually

Figure 7: Brain Injury Hospitalizations in Colorado, 2012-14



Source: CO Department of Public Health & Environment. Colorado Health Information Dataset. Injury Hospitalization Data.

### CASE MANAGEMENT

Through a contract with CBIP and funding from the Colorado TBI Trust Fund, Rocky Mountain Human Services provided case management services for adults through FY2016. In that timeframe, approximately 1,000 adults were served annually. Just under half of client goals were attained. Clients received both in-person and phone based support.

## Approximately 1,000 people with brain injury receive brain injury case management support annually

Table 5: Brain Injury Case Management Overview, FY 2014-16

	FY2014	FY2015	FY2016
<b>Unduplicated Count</b>	919	1,048	1,000
<b>Care Coordination Budget</b>	\$796,061	\$827,698	\$758,159
<b>Goals Attained</b>	111 (48%)	254 (46%)	587 (49%)
<b>Case Management Waiting List</b>	3-6 months	6 months	6 months

Source: Rocky Mountain Human Services, Brain Injury Support, Annual Report, FY2014 – FY2016.

These case management services are currently provided by the Brain Injury Alliance of Colorado (BIAC). As of July 2017, BIAC was serving around 1,000 individuals. BIAC receives approximately 70-100 referrals a month from a wide variety of sources including hospitals, the criminal justice system, self-referrals, schools, Division of Vocational Rehabilitation, medical providers, and behavioral health providers.

## MEDICAID

Health Care Policy and Financing pulled 2016 data on the number of people with brain injury-related diagnoses, including all severity levels and head/jaw injuries, receiving Medicaid State Plan or waiver services. This broad sweep errs on the side of inclusivity, so may overestimate the number of people impacted by brain injury receiving Medicaid waiver services. These data do not indicate that people's needs related to brain injury are being fully served. Rather, it is a head count of where people with brain injury diagnosis exist in the Medicaid system.

Colorado's Brain Injury Waiver has grown over the past three fiscal years, and served just over 400 people in FY2016. Approximately 40% receive supported living or long term assisted living supports, and the remaining 60% live more independently in the community.

### Approximately 400 Coloradans are served through the Brain Injury Waiver

Table 6: Brain Injury Waiver Unduplicated Participants and Expenditures, 2014-16

	FY2014		FY2015		FY2016	
	Participants	Expenditures	Participants	Expenditures	Participants	Expenditures
<b>Residential</b>	129	\$10,808,182	165	\$12,422,646	170	\$13,432,173
<b>Total</b>	314	\$14,356,583	372	\$16,923,914	402	\$18,945,428

Source: Colorado Department of Health Care Policy and Financing.

Additional people with brain injury receive services through other Medicaid waivers. In particular, the EBD Waiver is used by more people with brain injury than the BI Waiver because services are more available statewide; it includes two options for individuals to self-direct services, and is available for people who have sustained a brain injury after age 65. Of the total adult waiver population of approximately 37,000 individuals, 8,175 or 22% have a diagnosis that could potentially qualify them for the BI Waiver, which including all severity levels and types of brain injuries. Children's waivers serve 367 youth with brain injury out of approximately 3,500 total children, or 10%. Approximately 50% of youth are in the IDD Waiver, compared to 12% of the adult waiver population.

### Potentially, almost 9,000 people with brain injury in Medicaid Waivers

Table 7: Number of People with Potentially Qualifying Brain Injury Diagnoses in Medicaid Waiver Services, 2016

Waiver Service Area	# People w BI
Brain Injury Waiver	402
Other Adult Medicaid Waivers	8,175
Children's Medicaid Waivers	367
<b>Total</b>	<b>8,944</b>

Source: Colorado Department of Health Care Policy and Financing.

More than 82,000 people with a brain injury diagnosis receive Medicaid State Plan services. Data are not available to indicate specific services used by adults in the general category of adult Medicaid State Plan services. Data conversion issues associated with the Medicaid Management Information System implementation have created challenges in further analyzing Medicaid data for the brain injury hard to serve study.

## Potentially, over 80,000 people with brain injury in Medicaid State Plan services

Table 8: Number of People with Potentially Qualifying Brain Injury Diagnoses in Medicaid State Plan Services, 2016

State Plan Service Area	# People w BI
Adult Medicaid State Plan (excluding nursing facilities)	48,799
Children Medicaid State Plan	21,726
Behavioral Health/Mental Health	6,372
Nursing Facilities	4,305
Behavioral Health/Substance Use Disorder	1,403
<b>Total</b>	<b>82,605</b>

Source: Colorado Department of Health Care Policy and Financing.

### BEHAVIORAL HEALTH

In FY2016, approximately 3,000 individuals with brain injury received services through behavioral health organizations, a statewide program that provides comprehensive mental health and substance use disorder services to all Health First Colorado (Medicaid) members. According to the Office of Behavioral Health Evaluation services, people with brain injury represent about 3.5% of those receiving behavioral health services through Behavioral Health Organizations. Rates of services have been increasing over time with 1,562 individuals with brain injury accessing behavioral health services in 2014 and 2,936 individuals with brain injury accessing behavioral health services in 2016.

### A growing number of people with brain injury are accessing behavioral health services

Table 9: Behavioral Health Brain Injury Clients, Age Groups by Fiscal Year

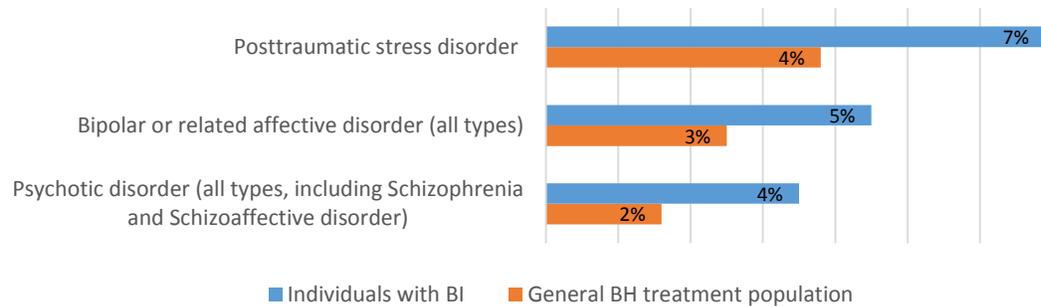
Age	FY2014	FY2015	FY2016	Total
<b>0-17 years</b>	158 (10.1%)	171 (9.1%)	235 (8.0%)	564 (8.9%)
<b>18-64 years</b>	1,354 (86.7%)	1,658 (88.5%)	2,625 (89.4%)	5,637 (88.5%)
<b>65 and older</b>	50 (3.2%)	45 (2.4%)	76 (2.6%)	171 (2.7%)
<b>Total</b>	1,562	1,874	2,936	6,372

Source: State of Colorado, Office of Behavioral Health Evaluation Services, 2017.

More men with brain injury received behavioral health services than women (61% mental health services and 70% substance use services) and the majority of those served identified their race as White (77%).

When compared to the general behavioral health treatment population, individuals with brain injury have higher rates of **mental health** diagnosis, specifically Posttraumatic stress disorder, Bipolar disorder and Psychotic disorder.

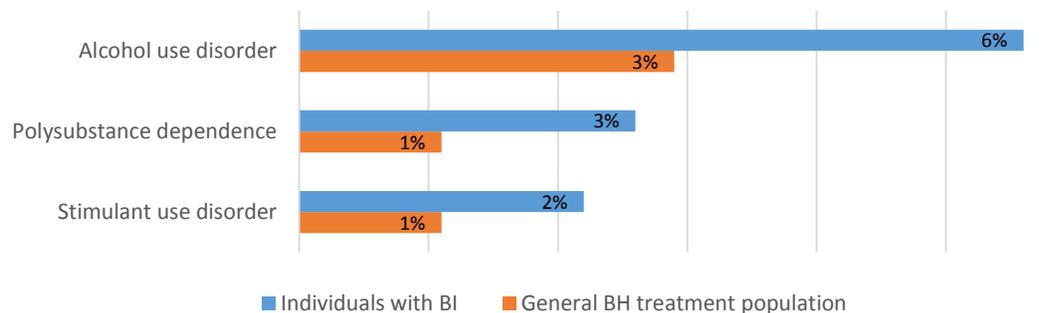
**Figure 8: CCAR Primary Mental Health Diagnosis Comparison of Individuals with BI to General BH Treatment Population**



Source: This figure uses data compiled by the State of Colorado-Office of Behavioral Health Evaluation Services. FY 2014-16.

When compared to the general behavioral health treatment population, individuals with brain injury have higher rates of **substance use** diagnosis, specifically alcohol use disorder, polysubstance dependence and stimulant use disorder. Compared to the overall BH treatment population, 37% of individuals with brain injury received previous or concurrent substance use treatment.

**Figure 9: CCAR Substance Use Diagnosis Comparison of Individuals with BI to General BH Treatment Population**



Source: This figure uses data compiled by the State of Colorado-Office of Behavioral Health Evaluation Services. FY2014-16.

However, individuals with brain injury accessing substance use disorder services remains a small percentage of those with brain injury accessing behavioral health services overall.

**Table 10: Substance Use Disorder Brain Injury Clients, Age Groups by Fiscal Year**

Age	FY2014	FY2015	FY2016	Total
<b>0-17 years</b>	11 (2.0%)	< 10 (1.5%)	< 10 (1.6%)	24 (1.7%)
<b>18-64 years</b>	549 (97.5%)	444 (97.8%)	377 (97.7%)	1,370 (97.6%)
<b>65 and older</b>	< 10 (0.5%)	< 10 (0.7%)	< 10 (0.8%)	< 10 (0.6%)
<b>Total</b>	~563	~454	~386	~1,403

Source: State of Colorado, Office of Behavioral Health Evaluation Services, 2017.

## STUDENTS AND SPECIAL EDUCATION

Youth with brain injury, just like adults, have a chronic condition which requires support in all aspects of their lives. Also like adults, youth may have a wide range of needs from their brain injury – physical, behavioral, developmental, social, educational vocational, and others – which will likely change over time.

Youth with brain injury are undercounted in special education numbers, comprising 0.6% of the total population from 2010 to 2015 and 0.5% in 2016. This is comparable to the national rate of 0.4% TBI compared to the total special education population.<sup>4</sup> One reason is they are not consistently classified as having brain injury in IEPs. This is particularly true in cases where the school is unaware of a brain injury but are identified as needing special education services, where there is no medical documentation of the injury, or the brain injury is non-traumatic. These students are generally categorized under “Other Health Impairment” to ensure they receive services based on functional need. Other students may have a primary disability category of “Learning Disability” with a secondary or tertiary disability of brain injury. Schools are only required to report primary disability category to the state, so there are no statewide estimates accounting for these students. Mild brain injuries occurring outside of school-based events (e.g. ski accident) are the most likely to be unknown by schools because families and/or medical providers do not report them.

### Youth with brain injury underestimated, comprising less than 1% of special education population

Table 11: Students Served by Disability, FYs 2010-16

Primary Disability Description	2010	2011	2012	2013	2014	2015	2016
Intellectual Disability	2,986	2,958	2,879	2,832	2,636	2,563	2,543
Serious Emotional Disability	6,679	6,546	6,364	6,039	5,713	5,551	5,474
Specific Learning Disability	31,131	32,991	34,254	35,405	36,739	37,899	39,022
Hearing Impairment, including Deafness	1,467	1,427	1,407	1,375	1,372	1,364	1,319
Visual Impairment, including Blindness	329	320	326	325	312	293	273
Physical Disability	9,926	10,177	10,502	9,584	6,696	2,989	
Autism Spectrum Disorders	3,786	4,367	4,878	5,280	5,774	6,525	7,111
Traumatic Brain Injury	481	497	523	550	537	524	524
Speech or Language Impairment	19,433	19,141	19,136	18,841	18,206	17,513	17,422
Deaf-Blindness	27	21	15	16	21	27	26
Multiple Disabilities	3,258	3,371	3,486	3,589	3,826	3,967	4,087
Developmental Delay	4681	4908	5043	5382	6,451	7,857	8,992

<sup>4</sup> Disability Statistics & Demographics Rehabilitation Research & Training Center, “2016 Annual Disability Statistics Compendium,” Table 9.3d Special Education—Students Ages 6 to 21 Served under Individuals with Disabilities Education Act, Part B, by Select Diagnostic Categories: Fall 2014.

Primary Disability Description	2010	2011	2012	2013	2014	2015	2016
Orthopedic Impairment (New 2012)	n/a	n/a	*	76	209	359	443
Other Health Impairment (New 2012)	n/a	n/a	18	1,094	3,749	7,134	10,203
<b>State Total</b>	<b>84,184</b>	<b>86,724</b>	<b>88,832</b>	<b>90,388</b>	<b>92,241</b>	<b>94,565</b>	<b>97,439</b>

Source: Colorado Department of Education, Special Education Data Reports,  
[http://www.cde.state.co.us/cdesped/sped\\_datareports](http://www.cde.state.co.us/cdesped/sped_datareports).

## VOCATIONAL REHABILITATION

People must have a documentable disability that creates employment challenges which can be addressed through Department of Vocational Rehabilitation (DVR) services to be eligible. DVR records primary and secondary disabilities impacting a person's functional ability to work through their eligibility process. The number of people recorded as having a brain injury served by DVR has grown in the last three years, however represents a small percentage of the overall DVR caseload which exceeds 7,000 individuals.

### Increasing number of people with Brain Injury served by Vocational Rehabilitation Services

Table 12: Counts of Cases with TBI, Supported Employment with Rehab Rate, FY2015-17

	FY2015	FY2016	FY2017
<b>Primary TBI Total</b>	245	266	358
<b>Primary TBI Rehab Rate</b>	30.7%	53.5%	43.5%
<b>Secondary TBI Total</b>	73	69	109
<b>Secondary TBI Rehab Rate</b>	8.7%	19.7%	15.3%
<b>Supported Employment Total</b>	22	29	37
<b>Supported Employment Rehab Rate</b>	8.7%	13.1%	11.6%
<b>Case Count Total</b>	308	323	449
<b>Case Count Rehab Rate</b>	35.1%	57.3%	48.3%
<b>All Disabilities Rehab Rate</b>	59.0%	62.7%	54.5%

Source: Colorado Division of Vocational Rehabilitation

## AGING AND DISABILITY RESOURCE CENTERS

For the two fiscal years for which statewide TBI diagnosis data is available, Aging and Disability Resource Centers served over 200 people with brain injury through information and assistance or options counseling.

### More than 200 individuals with TBI served annually through ADRCs

Table 13: Number of Individuals with TBI Served by ADRCs, 2015-16

	FY2015	FY2016
<b>Unduplicated Count</b>	210	220

Source: Colorado Department of Human Services.

## COLORADO STRENGTHS

The challenges that accompany brain injury and providing access to quality services across an individual's life span and through changing needs are vast. Despite this, Colorado is already working towards making improvements in their service system, including the work that has happened for this study.

Colorado is attempting to address system coordination across healthcare service domains through integrating primary care and behavioral health care to create more a more patient-centered, coordinated and holistic model of healthcare through [Integrated Health Homes](#) with the second phase of the accountable care collaborative (ACC 2.0).

Another recent cross-system response was initiated by legislative action to create a [Cross-System Behavioral Health Crises Response \(CSCR\) pilot program for individuals with intellectual and developmental disabilities \(IDD\)](#). The pilot program provides crisis intervention, stabilization, evaluation, treatment, in-home therapeutic respite, site-based therapeutic respite and follow-up services to integrate with the Colorado mental health crisis program. This pilot is working to address issues experienced by people with IDD and behavioral health needs similar to those identified and experienced by people with brain injury and behavioral health needs as defined in this report.

Colorado recently launched a statewide mental health crisis line, the [Colorado Crisis and Support Line](#), offering 24/7/365 confidential support over the phone with a trained mental health professional in addition to 11 walk-in crisis centers around the state, mobile care when a mental health professional may need to go into the community as well as respite services for those needing safe, peer-managed stabilization and support through a one to 14-day voluntary place to stay.

Colorado has also responded to over-utilization of services through the [Client Overutilization Program \(COUP\)](#), a statewide Medicaid surveillance program that safeguards against unnecessary or inappropriate use of care or services. The Client Overutilization Program works with community partners, such as [Community Assistance, Referral, and Education Services \(CARES\)](#), a program developed through the Colorado Springs Fire Department to identify and redirect high utilizers of the emergency medical system to more appropriate care that leads to better patient outcomes. Colorado Springs also responded to community mental health needs through a [Community Response Team \(CRT\)](#) that can perform psychiatric evaluations in the community and medically clear patients for admittance to behavioral health treatment facilities. Currently, providers do not screen for brain injury in these programs.

Colorado is also making efforts to improve long-term care in community settings through [Colorado Choice Transitions](#), a demonstration program of the national Money Follows the Person Initiative, designed to assist Health First Colorado members who are interested in transitioning out of long-term care facilities back into home and community based settings.

The [Community Living Advisory Group](#) was established to make recommendations to improve the Long-term Services and Supports (LTSS) delivery system and the [Community Living Implementation Plan](#) is Colorado's response to the Olmstead Decision to implement those recommendations into practice. Colorado has also secured federal funding for a [No Wrong Door](#) Implementation grant to develop a statewide model to address access challenges experienced by individuals seeking long term services and supports. The state is also using an [Employment First Advisory Partnership](#) to integrate Employment First principles into their Olmstead plan. The advisory group includes individuals from the Colorado Departments of: Education, Health Care Policy and Financing, Human Services, Higher Education, and Labor and Employment; in which the purpose is to provide specific Employment First recommendations to the Colorado legislature.

Colorado is also identifying and responding to needs in the criminal justice system through the [TBI Implementation Grant](#), a partnership with CBIP to improve the screening and identification of TBI within the criminal justice,

develop a well-informed brain injury workforce across criminal justice personnel, streamline the system of support, and evaluate a comprehensive statewide method of delivering resource facilitation to the corrections population.

Colorado schools are building capacity through brain injury consultants in the school district who are developing a system of supports called [BrainSTEPS](#) to respond to students with brain injuries and monitoring their return to learning environments. BrainSTEPS is a new Colorado Department of Education initiative jointly funded by CBIP and the Colorado Department of Education, which is working to improve capacity to support students with brain injury in the school system, as well as coordinating broader community-based services and supports for youth and families.

## OTHER STATE SERVICE MODELS

Brain injury is both an acute medical as well as a chronic condition impacting potentially every aspect of an individual's life, including family/relationships/parenting, education/training, employment, transportation, housing, food, social, legal, safety, behavioral, and financial. Ideally, any system should incorporate a full continuum of care to address associated needs, including trauma and emergency services, inpatient and outpatient rehabilitative services, long term services and supports (home and community based as well as institutional), behavioral health services, special education and accommodation services for youth, case management, and advocacy.

States generally provide brain injury services and supports through a combination of Medicaid waivers, Medicaid State Plan, and state-funded services and supports, which may include brain injury trust funds. There is no silver bullet in terms of how to structure a service system. Rather, every state cobbles together what is possible based on political will, budgets, and other factors, and works to ensure the system meets people's needs and can be navigated.

Colorado's system is heavily reliant on discrete Medicaid waivers, with limited Medicaid State Plan services outside of behavioral health, home health, and private duty nursing. The benefit of this approach is cost containment and the ability to provide targeted services in limited geographic areas. Cash funds generated from surcharged on specific traffic violations flow through the Colorado Brain Injury Program to support care coordination for people with brain injury.

Examples from other states include:

- **State Plan Community-Based Neurobehavioral Rehabilitation Services.** Iowa implemented this service for people with brain injury co-occurring with a mental health diagnosis as an alternative to out-of-state facility-based neurobehavioral rehabilitation, institutionalization, hospitalization, incarceration, or homelessness. Services funded before the State Plan promulgation yielded cost savings compared to out-of-state placement.
- **Institutional Transition Coordination.** Maryland's Brain Injury Resource Specialists help people with brain injuries wanting to transition out of institutions or at risk of institutionalization to access needed services and supports, in addition to providing enhanced transition case management to Money Follows the Person participants enrolling in the state's adult TBI Waiver.
- **State Plan Personal Assistance Services/Community First Choice Option.** Some states provide personal assistance services through their State Plan. States do not have to require that clients meet level of care requirements for these services, although they may. Increasingly states provide personal assistance services through a 1915(k) Community First Choice (CFC) Option, which does require level of care

determination for eligibility. In Montana, Section 19 waiver services are wrapped around CFC and other State Plan services for individuals with brain injury.

- **Standalone and Integrated Waiver Services.** Eighteen states have existing or pending waivers for people with brain injury. Three of the 18 have two brain injury waivers – Kansas (ABI and TBI), Kentucky (long term care and not), and Massachusetts (residential habilitation and non-residential habilitation). This is a decrease from 2007, when 23 states operated brain injury waivers.<sup>5</sup> Other states generally serve people with brain injury mixed in with broader waiver groups, such elderly, blind, disabled or behavioral health.
- **Holistic, Person-Centered Plans and Care Coordination.** As Medicaid programs implement person-driven, person-centered planning processes in accordance with Section 2402 of the Affordable Care Act, states are learning how to coordinate planning and plan execution across varied and uncoordinated stakeholders. Tennessee has Service Coordinators located in various nonprofits across the state to develop comprehensive care plans, provide referrals, and coordinate services. Colorado’s CSCR Pilot Program and MFP programs provide examples of broader care coordination efforts. A small number of Temporary Assistance for Needy Families (TANF) Programs are taking the lead on broader health and human services coordination through person-centered planning processes. They are looking to ecological systems theory placing the individual, family, and/or child in the center, and the environmental systems with which the family interacts wrap around the individuals. Efforts to improve economic and person-related outcomes by increasing access to more comprehensive services addressing multiple needs of adults and children in a household, coordinated across multiple service systems have grown from this foundation. Montana, Washington, Washington DC, and Utah provide TANF examples.
- **Education Support for Youth.** Oregon’s Brain Injury Education Support and Training (BEST) team supports youth ages 0-21 through regional training and consultation of school district personnel in knowledge-based and evidence-based methods to support students with brain injury and their families. Tennessee’s Project BRAIN provides education and training for school personnel, families, and health professionals who support students with TBI as well as a brain injury transition liaison in three children’s hospitals. Pennsylvania’s BrainSTEPS, brain injury school consulting program was the model adopted by Colorado, which has been recognized by the Centers for Disease Control as a national model for education consultation supporting students and school teams to develop and implement educational supports and services for students with brain injury.
- **Domestic Violence Services and Supports.** Pennsylvania’s Coalition Against Domestic Violence has developed tools to enhance domestic violence advocacy services and skills in working with survivors of TBI as a result of domestic violence.

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<sup>5</sup> Rutgers Center for State Health Policy, Institute for Health, Health Care Policy, and Aging Research, “Issue Brief: A Survey of Medicaid Brain Injury Programs,” March 2008, <http://www.cshp.rutgers.edu/downloads/7730.pdf>.

## COLORADO SERVICE SYSTEM GAPS AND OPPORTUNITIES FOR IMPROVEMENT

As identified previously, there is a significant difference between the Craig estimates of Coloradans with a lifetime history of brain injury and the estimated number of individuals receiving brain injury services. Though some may not need or be seeking services, others may need services and are falling into service gaps. The results from interviews, survey respondents and community forum participants all validated the challenges faced by individuals with brain injury in obtaining services. The system has gaps at the community level as well as institutional care.

### SUMMARY OF FINDINGS

Overall themes that emerged include lack of **awareness** of brain injury, service **access** barriers, unmet **availability** of services, and challenges in **system coordination**. The following is an overview of the findings for each of these categories. Supporting data and information will follow.

#### AWARENESS

- **There is no standardized screening and identification protocol being utilized to identify brain injury.** Brain Injury is underdiagnosed or misdiagnosed and therefore treatment is postponed. This is true across systems, especially behavioral health, education, and vocational service providers.
- **Brain Injury is slow to capture public awareness.** This impacts prevention of brain injury and reinforces stigma at the community level. Lack of awareness also limits self-identification of the seriousness of brain injury, especially for mild injuries that may go overlooked, and delays intervention.
- **Providers need better training on the symptoms of brain injury to avoid differential diagnosis for individuals.** Behaviors related to a brain injury are likely to be misidentified and interventions will not consider the brain injury, making them less likely to be successful. For individuals with co-occurring needs there are no clear lines to distinguish which symptoms are associated with which behaviors or diagnoses. This can lead to diagnostic overshadowing where these symptoms are attributed to the more prominent disability and are left untreated.
- **People with brain injury are involved in their care but unaware of services.** Not having a clear path to services postpones treatment and may lead individuals toward inappropriate use or over-utilization of ineffective or more expensive services.

#### ACCESS TO SERVICES

- **Access to services is prevented by cost and health insurance limitations.** Some individuals remain uninsured and those with coverage are burdened by out-of-pocket expenses, which prevents them from accessing care, and limits them to services and specific providers that are covered in their insurance network, which may not offer specialized care for brain injury. Complementary medicine, executive functioning skills training, and family support services are highest in demand to access.
- **There remain barriers to accessing community behavioral services.** More people with brain injury are receiving behavioral health services but there remains an unmet need. Some people with brain injury have been denied access to services.

- **Complexity associated with treating brain injury and co-occurring conditions creates access limitations.** Providers indicate complex needs as their biggest constraint to serving more individuals with brain injury. There is limited expertise in brain injury available for educators and providers with which to consult.
- **Divided payer and service structure creates access barriers.** One of the most influential gaps in service delivery and payer structures exists between **primary/medical care and behavioral health care**. This divide has created access limitations for people with brain injury who have more complex medical and/or behavioral health needs. Providers rely on diagnosis and medical necessity criteria to determine whether to provide care. Despite education and outreach, confusion persists on whether and how to delineate brain injury and behavioral health conditions. Access issues extend to **crisis and stabilization services**. Colorado recently implemented a statewide crisis response system yet 77% of survey respondents indicated walk-in crisis as a service they “wish I could use”. Providers indicate a need for treatment alternatives to hospitals for when individuals are in crisis. Other service **system transitions** create opportunities for people to fall through the cracks and become under or un-served. Shifts that occur related to aging in and out of services, changing severity of needs, and movement between stability and crisis make it difficult to access services across systems. Services are driven by payer source instead of the individual’s needs.
- **Long-term services and supports are needed but more difficult to access.** People with brain injury indicate services are harder to access years after their injury than in the months following injury, despite the need for managing a chronic condition throughout a lifetime. Interestingly, providers indicated access to services was more difficult immediately following injury rather than in the long-term.
- **Location of services and transportation needs remain barriers to accessing services.** Location of services presents more challenges in rural and frontier counties. Reliable transportation is also a challenge, including limitations of already existing public transportation systems and non-medical transportation providers in metropolitan areas not providing enough flexibility or reliability when utilizing their services.
- **The severity of brain injury impacts a student’s access to school-based services.** Youth with mild brain injury are less likely to access services. Students getting injured through non-school events who don’t go to doctor/hospital are often not being identified, and thus go unserved. More severe injuries have a clearer path, generally because of a medical diagnosis but also indicate unmet needs. Therapies, special education/individualized education plans (IEPs), Counseling and Educational Consultation are the most used and most in-demand educational services.
- **Behavioral health coordination with schools exists, but serves fewer students with brain injury.** Students with brain injury are receiving behavioral health services at lower numbers than the general student population. Youth with brain injury exhibiting aggressive behavior have fewer placement/stabilization options than adults with brain injury.
- **People with brain injury have limited access to employment services and supports.** Survey respondents show many more people “wishing they could use” vocational services than currently or previously using them. This was particularly true for people with severe brain injury. DVR is less likely to provide supported employment services to people with brain injury because of limited access to extended employment support services through other payer sources, which may decrease overall access to needed employment supports.

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## AVAILABILITY OF SERVICES

- **Affordable housing and appropriate residential facilities remain an unmet need.** The cost of housing is a barrier and most survey respondents ranked low-income housing at the top of their wish list. Providers indicate appropriate residential facility placements are hard to find, especially during transitions from institutions back to the community. There are high rates of brain injury amongst the homeless population, including youth.
- **Brain injury specialists are limited.** Brain injury specialists are needed in behavioral health, education, and vocational rehabilitation services.
- **There is insufficient peer support and substance use inpatient treatment for people with brain injury.** Survey respondents and community forum participants indicate a gap in services when it comes to these specific supports.
- **Students with severe brain injury will likely not qualify for SWAP.** DVR's Student Work Alliance Program (SWAP) is for students with mild to moderate disabilities on a fast track to employment, primarily focused on students with learning disabilities. DVR is in the process of determining how to implement Pre-Employment Transition Services (Pre-ETS), and incorporate more students with severe disabilities, including those with severe brain injury.
- **Long term employment services are limited for people with brain injury.** People with brain injury are employed at lower rates than the general disability population. Only 33% of survey respondents reported working full time or part time after injury. Survey respondents said the primary challenge with finding and keeping employment is changing individual needs because of the brain injury. The Division of Vocational Rehabilitation (DVR) can provide supported employment to people with brain injury. However, because the Brain Injury as well as the Elderly, Blind and Disabled Waivers do not include supported employment, it appears -- based on DVR data -- that individuals with brain injuries are infrequently connected to supported employment. Extended services for this population require the customization of alternative resources, which may include SSA work incentives/employment supports, private pay, natural supports, etc., but need to identify an extended service provider, which requires thinking outside the box since it is not included in the Brain Injury or Elderly, Blind, Disabled Medicaid Waivers.

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## SERVICE COORDINATION

- **Disparate systems are hard for individuals and service providers to navigate.** Individuals are often involved in their care but are unaware of services that are available to them or don't understand the process of how to get services. Referrals are often required but are not streamlined. System navigation is most difficult for those with complex medical needs or co-occurring behavioral health issues as well as youth transitioning to adulthood.
- **Holistic care coordination generally does not exist for people with brain injury.** People with brain injury tend to have a lot of providers involved in their care but communication and information sharing isn't consistent. Communication and information sharing between providers is limited because of information technology constraints and broader system silo issues. **Transition to adulthood** is a specific example of where improved care coordination could benefit people with brain injury. School services supporting transition to adulthood are not perceived as successful by students with brain injury or providers. The transition from school-based to adult systems is inconsistent, with no formal handoff from BrainSTEPS teams to BIAC case management.

- **Employment services do not consistently have shared person-centered plan or care coordination for people with brain injury.** Outside of the typical, collaborative partnerships with the Office of Behavioral Health or Medicaid DIDD for individuals with behavioral health or developmental disabilities, there are not programmatic partnerships for other types of supported employment service delivery, including services to individuals with brain injuries. There is often not a team participating in the creation or employment plan execution for individuals with brain injuries. BIAC, Brain Injury Waiver case managers, and DVR counselors do not have clear care management roles and responsibilities.

## AWARENESS: FINDINGS AND DATA

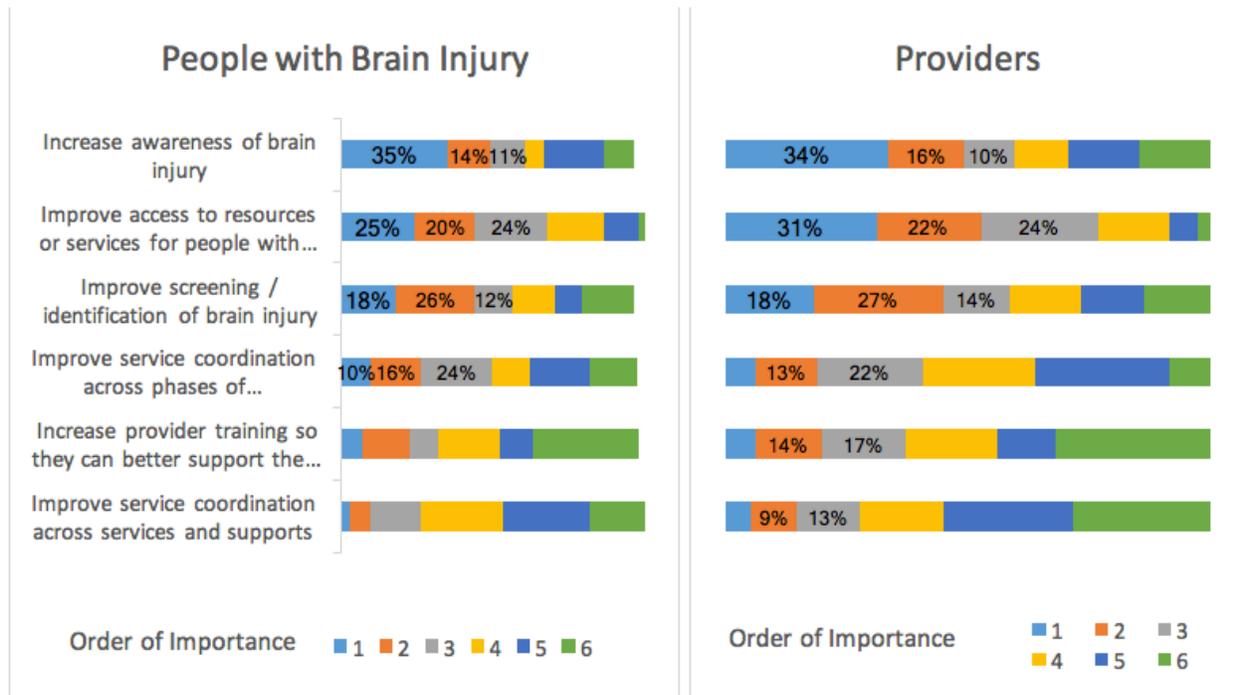
Lack of awareness and understanding of brain injury limits prevention, identification, service delivery and coordination, and health outcomes. All stakeholders benefit from awareness, training, and support, including individuals with brain injury, their families, schools, providers, care coordinators, advocates, policy makers, and the community at large.

### BRAIN INJURY IS SLOW TO CAPTURE PUBLIC AWARENESS

People with brain injury and providers identified lack of public awareness as a challenge to overcoming brain injury. Without a better understanding of the seriousness of brain injury, individuals can't make informed decisions about how they can prevent brain injury. Increased national attention on brain injury due to veterans and athletes has meant a broader general understanding of brain injury, but there remains work to do. Limited public awareness and understanding also reinforces stigma around acknowledging and addressing brain injury. Lack of awareness limits identification of brain injury, especially for mild injuries that may go overlooked, and delays intervention and treatment.

## Increased awareness of brain injury seen as most impactful change by individuals with brain injury and providers

Figure 10: Changes that Would Most Positively Impact People with Brain Injury – People with Brain Injury and Providers



Source: Colorado Brain Injury Hard to Serve Study, Consumer and Provider Survey, 2017

### THERE IS NO STANDARDIZED SCREENING AND IDENTIFICATION PROTOCOL IN PLACE TO IDENTIFY BRAIN INJURY

A person with brain injury and their provider must be aware of the brain injury to determine the appropriate course of treatment and how to address broader service and support needs. Identification of a brain injury is the first step toward recovery, but is hampered by inconsistent screening for brain injury. Undiagnosed or misdiagnosed brain injury means people struggle for longer periods of time and potentially endure additional injuries and negative health outcomes while lingering between crisis and stabilization. Mild brain injuries are more susceptible to being overlooked.

“Often patients are unaware of what they may be experiencing and/or the knowledge to seek out services.”

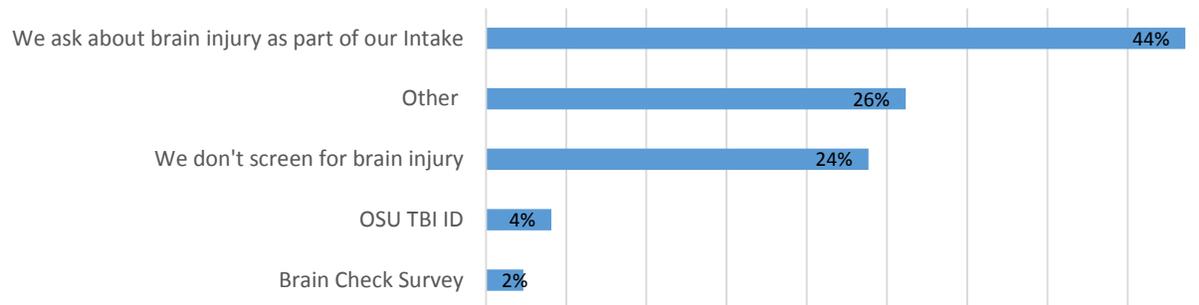
### Improved screening and identification of brain injury ranked top three for positively impacting Coloradans with brain injury

People with brain injury and providers both ranked screening and early identification among the top three approaches that would most positively impact people with brain injury. Lack of screening or inconsistent screening

is a challenge across service systems. Medical settings tend to do a better job at screening, such as a standard questionnaire in the emergency department, but there is no common assessment across providers.

Nearly one quarter of providers (24%) indicated that they don't screen for brain injury at all. Forty-four percent of provider survey respondents indicated that brain injury is something that is asked about as part of their intake process but there is no standardized screening protocol used across agencies.

**Figure 11: Screening Methods Currently Used by Providers**



*Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017*

Several other identified methods of confirming brain injury diagnosis were identified through those that wrote in descriptive responses in the “Other” category, including reviewing medical records and using the HELPS questionnaire.

## BEHAVIORAL HEALTH PROVIDERS DO NOT PROVIDE COMPREHENSIVE SCREENING DURING INTAKE FOR OUTPATIENT SERVICES

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Despite the relationship between brain injury and behavioral health issues, screening for brain injury during behavioral health assessment is not consistent. Current practices allow for brain injury to get overlooked or misdiagnosed. Some intake specialists do a better job of assessing for brain injury than others. Currently this process ranges from documenting personal reports, acquiring general medical background, or using one of several known brain injury screening tools.

Documentation of a brain injury is also not consistent and ranges from entering it as a diagnostic code or into case notes, which makes it challenging to query reports that accurately reflect population level impacts of brain injury amongst those receiving behavioral health services.

## SCHOOLS DO NOT USE BRAIN INJURY SCREENING PROCESS/TOOL OUTSIDE OF SPORTS CONCUSSION MANAGEMENT

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Schools commonly rely on brain injury diagnoses or medical documentation from medical providers. When this documentation is absent because a student either did not see a doctor because of the injury or the provider and/or family did not share the information with the school district, school teachers may intervene to provide accommodations or special education when students struggle. Educators are often not using the best practice

screening protocol identified in [cokidswithbraininjury.com](http://cokidswithbraininjury.com). Per provider survey responses, schools rely on self-reporting, with many schools not even asking about brain injury.

Coaches receive annual concussion education, and students removed from sports/activity participation due to head trauma must obtain a written release from a licensed practitioner before resuming participation. Concussion education includes information on how to recognize the signs and symptoms of a concussion. Coaches are encouraged to use a graded symptom checklist with four domains of symptoms – physical, cognitive, emotional, and maintenance. The Colorado Department of Education is responsible to ensure school districts understand the legal requirements related to student athletes.<sup>6</sup>

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## EDUCATION OUTCOMES DEPENDENT ON EARLY IDENTIFICATION AND INTERVENTION

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Students may have increased brain injury-related needs years after the injury occurred. Since brain injury impacts executive functioning, symptoms may appear as these skills are increasingly required for academic and social success. Students with unidentified brain injury exhibiting needs later in their lives are in danger of receiving inappropriate or less effective services and supports. This also applies to students who sustained brain injuries earlier in life. It can be hard for educators to link negative behaviors with a previous brain injury, especially if significant time has elapsed. Violent behavior is often not seen as out of a child’s control because of a brain injury. Children may be misdiagnosed as having an emotional disability, learning disability, or as making a behavior choice.

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## BRAIN INJURY UNDER-COUNTED IN VOCATIONAL SERVICES DUE TO INCONSISTENT SCREENING

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A DVR counselor determines eligibility for adult vocational services through an intake process. People must have a documentable disability that creates employment challenges which can be addressed through DVR services to be eligible. Counselors document the primary and secondary disabilities that result in the most functional capacity loss when determining eligibility. It is common for DVR to see TBI and mental health co-occurring in clients.

DVR uses a standardized intake process; however, brain injury is not consistently screened for. Rather counselors rely on the client to report they have had a brain injury. Per vocational/employment provider survey respondents, more counselors ask about brain injury at intake than do not. Counselors may also recognize a brain injury based on interactions once a case is open. If verified, it is recorded in a person’s case file. However, counselors may prioritize brain injury lower than other disabilities for an individual, reducing the query-able data to estimate the number of people with brain injury receiving DVR services in Colorado.

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## SCREENING GIVES US A BETTER UNDERSTANDING OF WHO IS IMPACTED BY BRAIN INJURY

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The prevalence of TBI among individuals in the national criminal justice system is as high as 60%. A federal grant (under the Traumatic Brain Injury Act of 1996) is helping Colorado learn more about the prevalence of brain injury in youth and adults in the corrections populations to inform an approach to address it.

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<sup>6</sup> Colorado Department of Education, “Concussion Management Guidelines,” 2012, <http://www.cde.state.co.us/HealthAndWellness/BrainInjury.htm>

## Increased screening efforts in the criminal justice system show high rates of brain injury

The Colorado Brain Injury Program's TBI Implementation Grant's current focus is on screening, identification and referral for people in the criminal justice system and includes a plan to develop a well-informed brain injury workforce across corrections and judicial personnel, streamline the system of support and referrals to appropriate services, and implement and evaluate a comprehensive statewide method of delivering resource facilitation to the corrections population. Through this work, CBIP has learned that of those in the Colorado criminal justice system screened for a lifetime history of brain injury, 42% of individuals were identified to have a history of brain injury and of those, 75% screened positive for gross neuropsychological impairment.<sup>7</sup>

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### PROVIDERS NEED BETTER TRAINING TO IDENTIFY BRAIN INJURY

For providers to be aware of brain injury, there must be additional brain injury training across service systems. Provider training on how to better identify brain injury is the first step towards early intervention and getting people with brain injury connected to appropriate care. Additional training on available resources, best practices, or clinical guidelines may also be necessary depending on the type or provider or location of services.

### Providers agree training and professional development would allow them to provide better services

Providers are interested in participating in additional brain injury education, training, and professional development through a variety of means, to be better equipped to serve individuals with brain injury. Over 60% of provider survey respondents indicated they would like additional funding that would allow staff to attend conferences, trainings and workshops. Another 60% of provider survey respondents indicated they would like coordinated education, training and professional development requirements/career ladder incorporating brain injury across long term services and supports (cross-disability).

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<sup>7</sup> Lifetime History and Neuropsychological Screen Data. Reporting period of June 1, 2016-February 28, 2017

**Figure 12: Provider Identified Education, Training, Technical Assistance or Other Professional Development They Wish Existed to Better Serve People with Brain Injury**



*Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017.*

Efforts to increase training are underway and should be encouraged. BIAC supports professional networking by hosting an annual conference and facilitating Brain Injury Professional Networking (BIPN) in different regions to support enhancement of knowledge and understanding of brain injury by sharing with colleagues and developing a support system for providers, access speakers and trainings, and broadening awareness of brain injury issues and legislation. Additionally, CBIP and BIAC partners to provide training across the state. These training initiatives could be targeted and expanded.

## PEOPLE WITH BRAIN INJURY ARE INVOLVED IN THEIR CARE BUT UNAWARE OF SERVICES AVAILABLE

A large number of survey respondents with brain injury (46%) indicated that they are very involved in their care but (41%) were not aware of services or don't understand the process to get services. Without a clear path to services, and being able to get the support needed to make progress in recovery, treatment is postponed and it becomes very hard to achieve or maintain stable health. This can lead to seeking care in ways which are not ideal, sometimes inappropriate and possibly through over-utilization of more expensive services that don't lead to positive health outcomes. Service systems end up reacting to these outcomes by implementing programs for high utilizers of services.

One of Colorado's responses to this is the Client Overutilization Program (COUP), a post-payment quarterly Medicaid review process that identifies excessive patterns of utilization to rectify practices of clients through designating a primary care physician or pharmacy. An individual can be subject to COUP placement if within a three-month period they: use 16 or more prescriptions; three or more pharmacies; three or more medications in the same therapeutic category; excessive emergency department and physician visits; or through a provider referral to COUP. In addition to COUP, Colorado Springs implemented CARES and CRT to address overutilization

through an integrated health response program with first responders. Lack of awareness of services is not the only cause of overutilization, but awareness of services could reduce the need for programs like COUP, CARES, and CRT.

Increasing awareness among the public, providers, and people with brain injury could go a long way toward preventing brain injury and intervening early with treatment to improve health outcomes. Consistent screening and additional training for providers are key opportunities for improvement.

## ACCESS TO SERVICES: FINDINGS AND DATA

After gaining a better understanding of brain injury and knowing when an individual has experienced one, the next step in the service pathway is for consumers and providers to know where and how they can access services. Some paths to services for people with brain injury in Colorado are not clear and create gaps in services.

### ACCESS TO SERVICES IS PREVENTED BY COST AND HEALTH INSURANCE LIMITATIONS

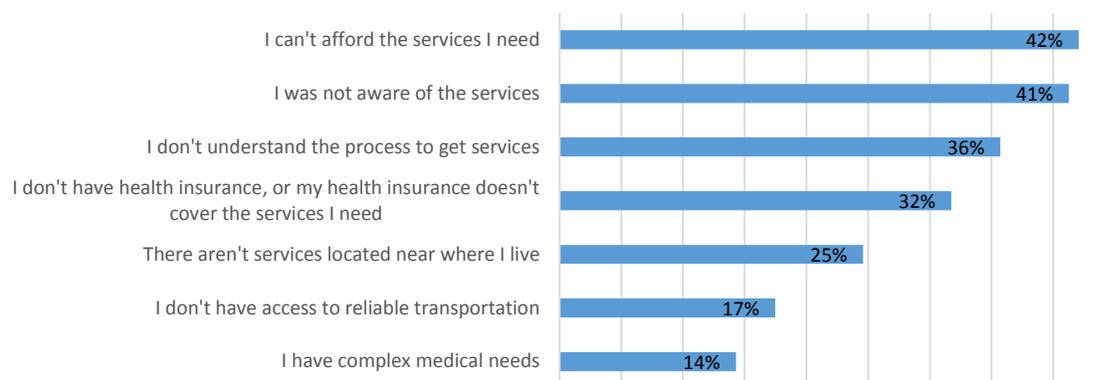
Providers and consumers of services identified cost and health insurance limitations as the biggest barrier to accessing services. Healthcare costs are rising and people with low incomes particularly feel the burden. A combined 73% of people with brain injury surveyed indicated that they have not been able to access services because they could not afford it or they did not have adequate health insurance coverage.

#### People with brain injury identify cost as the biggest barrier to accessing services

People with brain injury identified cost as the biggest barrier to accessing medical and daily living support services while providers ranked cost as the fifth biggest barrier to accessing all services. Some remain uninsured and consumers with health insurance identified out-of-pocket expenses such as co-pays and deductibles as being out of their budget, especially when their injury impacted their ability to work and decreased their income.

“I can’t find a therapist who will take my insurance and is accepting new patients.”

Figure 13: Barriers to Medical or Daily Living Support Services

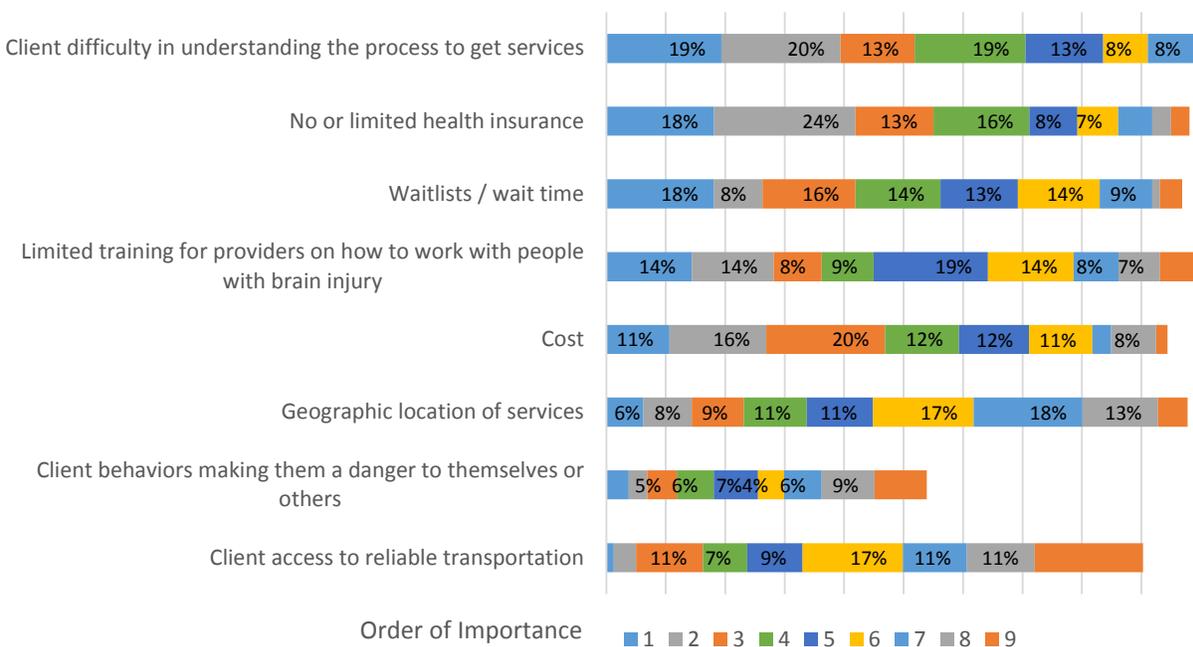


Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017.

Brain injury case management services through BIAAC are free to anyone with a brain injury, regardless of financial situations or severity of injury. Brain injury case management is the service that is the most commonly used among consumer survey respondents, and benefit acquisition is one of the main services provided through case management support. Individuals with brain injury must first become aware of this service to benefit from assistance in acquiring other needed benefits or services.

Providers agree that limited or no health insurance coverage is a barrier to services and ranked it as the second biggest system barrier for people with brain injury to overcome. Limiting service options based on payer source does not allow for patient-centered care and prevents individuals from making choices about what would best help them recover.

**Figure 14: Service Barriers Ranked in Order of Importance by Providers**

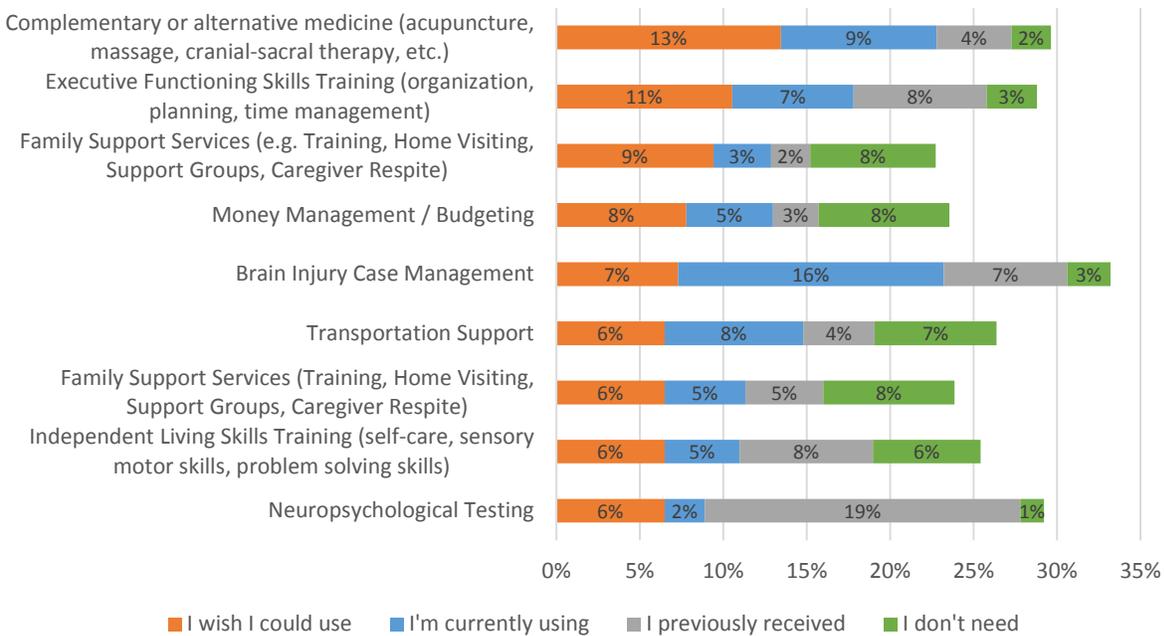


Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017

## COMPLEMENTARY MEDICINE, EXECUTIVE FUNCTIONING SKILLS TRAINING, AND FAMILY SUPPORT SERVICES ARE HIGHEST IN DEMAND

Survey respondents rated complementary / alternative medicine, executive functioning skills training, and family support services as the medical and daily living support services they most “wish I could use”. Requests for accessing more of these services were strongly emphasized during community forums.

**Figure 15: Use of Medical and Daily Living Supports**



*Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017.*

People with brain injury expressed frustration in struggling to access complementary medicine which has growing support in holistically reaching better health outcomes for people with brain injury but is not typically covered by insurance providers.

Others expressed a greater need for support in executive functioning skills training and even support with organizing medical records and benefits paperwork.

Family members and caregivers also voiced frustration in not being able to access enough support or services unless they developed a diagnosis that would then qualify them for services. There is a need for more support groups, individual support, and respite care for families and caregivers to seek an empathic ear and prevent burnout when faced with the challenging needs of their loved ones.

## THERE REMAIN BARRIERS TO ACCESSING COMMUNITY BEHAVIORAL HEALTH SERVICES

More people with brain injury are receiving behavioral health services now than in the past according to OBH, but there remains a need for services. The majority of provider survey respondents (63%) indicated there is an unmet need for mental health case management services for individuals with brain injury. Interviewees discussed challenges for people with brain injury in accessing outpatient mental health services due to questions regarding the covered diagnosis. They suspected high level of needs, challenging behaviors, and service hour limitations as the reasons providers would deny behavioral health services to people with brain injury.

“Mental health providers have been consistently willing to accept me into services if I will accept misdiagnoses that fit into their systems of reimbursement.”

The majority (68%) of behavioral health providers indicate they have not denied services to an individual with brain injury. Of those that have, the biggest reason (8%) for denial was due to funding restrictions. Interviewees discussed medical criteria and necessity as reasons for denying behavioral health care, particularly inpatient care, to individuals with brain injury.

The majority (64%) of consumer survey respondents indicated that they have never been turned away from mental health services. It is important to consider the limitations of the survey which may not have reached the most difficult to serve. Though some respondents (16%) have been turned away more than one time and those that have been turned away indicated they were told that the provider did not treat people with brain injury or that there was not a brain injury specialist available.

**Figure 16: Consumer Report on Denial of Mental Health Services**



*Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017*

The survey questions specific to being turned away from substance use services had a low response rate, however, being told they do not treat people with brain injury received the highest response. Interestingly, there were no differences by severity of brain injury for those being turned away from substance use disorder services or mental health services.

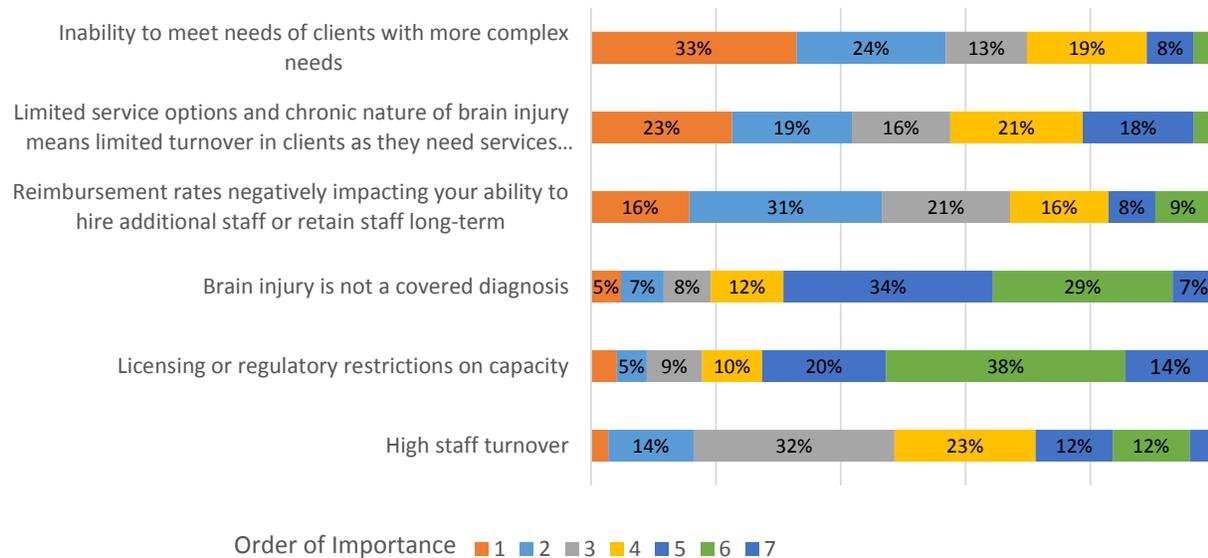
CBIP and BIAC have worked to clarify contracts and Practice Standards with BHOs to assess and treat for covered diagnosis under the capitated Medicaid policy. There remain ongoing education and training needs to clarify practice standards for staff, particularly frontline and intake specialists.

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## PEOPLE WITH MORE COMPLEX NEEDS EXPERIENCE ADDITIONAL LIMITATIONS TO ACCESSING SERVICES

Providers indicate that their biggest constraint to serving more individuals with brain injury is their inability to meet needs of clients with more complex needs. Complex needs have been defined as medical, mental health, and substance use disorder co-occurring with brain injury.

**Figure 17: Provider Ranking of Causes of Waitlists/Constraints on Serving More People with a Brain Injury**



Brain injuries can result in motor, sensory and physical disabilities. These impairments alone can be difficult to overcome, but a person with brain injury may also experience chronic health conditions that further complicate their need for medical care. The severity of brain injury is significantly related to receipt of skilled nursing care, personal assistance, and specialized medical equipment. Those with severe brain injury are likely to use these additional services, and those with mild brain injury are more likely to report they do not need the services.

Based on interviews, individuals with co-occurring complex medical and/or behavioral health needs in addition to brain injury are limited in the services they can access due to the complexity and intensity of their needs and sometimes limited scope of providers. There are reports of individuals lingering in emergency departments, hospitals, post-acute care settings, psychiatric hospitals, and other settings that are not appropriate or therapeutic for the patient.

## PEOPLE WITH BRAIN INJURY STRUGGLE TO ACCESS CRISIS AND STABILIZATION SERVICES

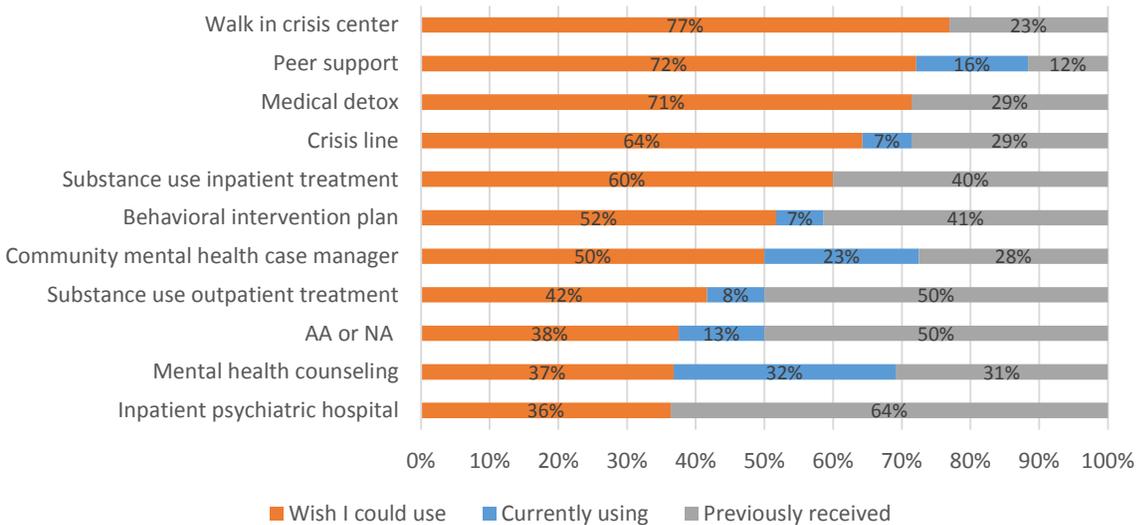
When community resources are not accessible and individuals are not getting the level of supportive services needed, the chances of a crisis and need for institutional care increase.

### People with brain injury include walk-in crisis centers on their wish list of services

Colorado recently launched a statewide mental health crisis line, the Colorado Crisis and Support Line, offering 24/7/365 confidential support over the phone with a trained mental health professional in addition to 11 walk-in crisis centers around the state, mobile care when a mental health professional may need to go into the community, as well as respite services for those needing safe, peer-managed stabilization and support through a one to 14-day voluntary place to stay. Despite the availability of these services, there remain barriers for people with brain injury in accessing them. Seventy-seven percent of consumer survey respondents indicated walk-in crisis center as a

service they “wish I could use” indicating a perception among people with brain injury who believe they cannot use them.

**Figure 18: Use of Behavioral Health Services**



Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017

### Providers indicate there are not enough treatment alternatives to hospitals for crisis stabilization

Provider survey respondents and interviewees indicated that the biggest barrier to services for individuals experiencing co-occurring brain injury and mental illness and/or substance use disorder is that there are not enough treatment options (alternatives to hospitals) for crisis stabilization. The Crisis Stabilization Units are dispersed statewide but still 80 miles away in some parts of the state and they are at capacity and individuals with high or complex needs or aggressive behavior may be screened out. The options for a safe place to stay during a crisis and/or to adjust medications are few and far between. Individuals in crisis end up using emergency responders or in emergency rooms instead, where hospitals attempt to deflect absorbing high costs of care which quickly leads to discharging people back to where they were when they found themselves in crisis, possibly in an unsafe setting or at risk of arrest and incarceration or homelessness.

If an individual with a brain injury presents to an emergency room as dangerous to themselves or others, they may be detained on a 72-hour mental health emergency hold for treatment and evaluation and to determine if they need to be involuntary committed to inpatient psychiatric care. Even under these circumstances providers indicated people with brain injury, complex medical and/or behavioral health needs get caught in discrepancies regarding which diagnosis is causing the behavior and therefore which system is responsible for paying for care.

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### DIVIDED PAYER AND SERVICE STRUCTURE CREATES ACCESS BARRIERS DURING TRANSITIONS

Transitions between stability and crisis is one example of where there are service gaps, especially for those with co-occurring complex medical or behavioral health needs. Interviewees indicated inpatient psychiatric hospitals turn away individuals with complex medical needs based on having a limited scope of medical care capability, while medical units in hospitals decline care due to behaviors they state are beyond their scope of care. Providers may recognize the medical necessity of hospitalization but are left in a bind when systems shift payment responsibilities. If there is space available (which generally there is not) this can result in people with complex needs ending up at one of two state-run mental health hospitals in Colorado – the Colorado Mental Health Institutes in Pueblo and Fort Logan.

One long-term goal heard during interviews, is for Colorado to rebuild both state psychiatric hospitals and develop specialization units at Fort Logan that are designed to treat brain injury and developmental disabilities. They would be considered micro centers of excellence, factoring the environment (natural lighting, sound, line of sight) as well as building a specialty workforce of neuro behaviorist and neuropsychiatrist. Another consideration would be allowing a lengthier rehabilitation with a behavioral approach for smoother transitions back into the community. Other states are also contemplating smaller, regional hospitals that offer specialty care in accordance with behavioral health recovery best practices, and similarly to Colorado, are limited by funding.

An alternative approach at providing specialty care in the community is currently underway in Colorado. The CSCR pilot program for individuals with IDD experiencing a behavioral health crisis is a recent cross-system response in Colorado. It was initiated by legislative action to provide crisis intervention, stabilization, evaluation, treatment, in-home therapeutic respite, site-based therapeutic respite and follow-up services to integrate with the Colorado mental health crisis program. This program will provide lessons learned in approaches to improving crisis services to subpopulations on which brain injury providers can build.

The transition between stability and crisis is only one of several transition periods in people’s lives that leaves room for service gaps. Additionally, there are shifts that occur due to aging in and out of services and changing severity of needs and associated service/program needs that make it difficult to access or stay connected to services across systems.

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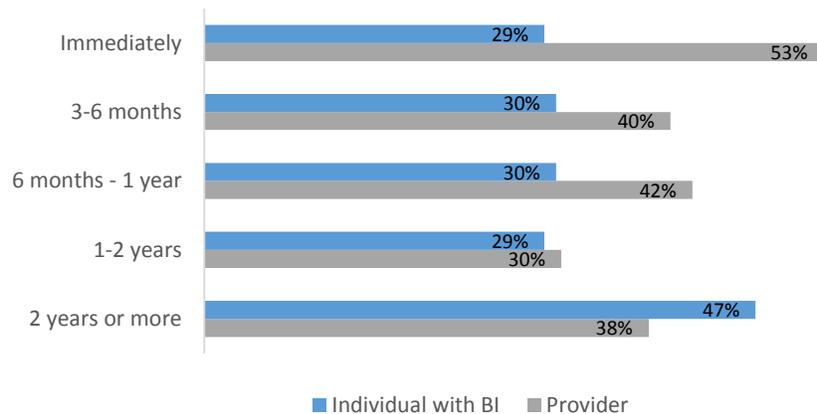
## LONG-TERM SERVICES AND SUPPORTS ARE NEEDED BUT MORE DIFFICULT TO ACCESS

Brain injury is a chronic health condition that requires access to services over the lifespan, however funders and providers are slow to shift from acute care responses to recognizing the need to address long-term management of brain injury symptoms.

### People with brain injury indicate difficulty accessing services in the long-term

People with brain injury indicate services are harder to access the longer it has been since they acquired their injury. Conversely, just over 50% of provider survey respondents indicated that immediately following an injury is when services are needed but difficult to access.

Figure 19: Points in Time After Brain Injury Where There is Need for Services but Access is More Difficult



Source: Colorado Brain Injury Hard to Serve Study, Consumer and Provider Survey, 2017

Changing needs and the length of time since injury shifts an individual’s eligibility for services depending on their functional need or their diagnosis depending on the requirements.

One systemic approach to increasing access to long term services and supports (LTSS) is through the No Wrong Door system grant project. Colorado has secured federal funding for No Wrong Door, completed their implementation plan, and selected pilot sites in 2016 with hopes to address the challenges experienced by seniors and people with disabilities by creating a streamlined entry point to the supports and services they need to live in the community, regardless of the funder. It is too soon to determine the full impacts of the No Wrong Door Implementation Grant in Colorado, but further evaluation will be important in determining how well the grant is working.

In addition to more complicated access barriers based on eligibility and funding sources, there remain logistic barriers to accessing services in Colorado.

## PROVIDER LOCATION AND TRANSPORTATION NEEDS REMAIN BARRIERS TO SERVICES

Location of services were indicated to be a barrier to services by interviewees, survey respondents and forum participants. Service locations are more limited in the rural and frontier areas of Colorado. A quarter of survey respondents indicated “these services are not located near where I live” as a barrier to medical and daily living supports (see figure 13). The counties most represented in the consumer survey were urban – El Paso, Boulder, Denver, Jefferson, and Arapahoe but the distribution of the survey did capture responses from rural and frontier counties.

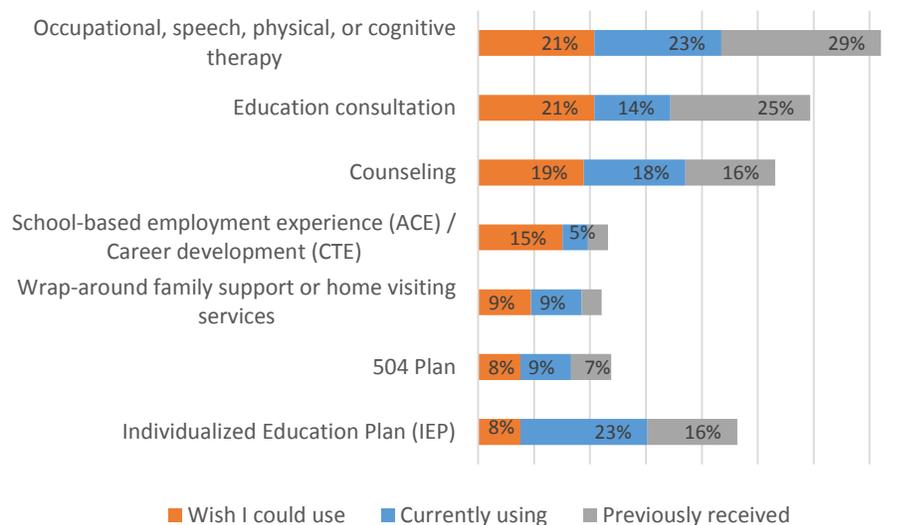
Reliable transportation also came up in surveys as well as community forums. Seventeen percent of survey respondents indicated “I don’t have access to reliable transportation” as a barrier to accessing medical and daily living supports. Public transportation is limited outside of metropolitan areas, which makes transportation needs different in rural and urban areas. However, the non-medical transportation currently available through waivers, more so in metropolitan areas, was also indicated to be unreliable or inaccessible for individuals with brain injury.

## THE SEVERITY OF THE BRAIN INJURY IMPACTS A STUDENT’S ACCESS TO SCHOOL-BASED SERVICES

There is also a gap in services for students with brain injury in school-based services. Most youth with brain injury receive services primarily through school-based services, commonly including individualized education plans (IEPs), occupational, speech, physical, or cognitive therapy, counseling, and educational consultation. Schools often operate independently from other community services and supports. Broader community services and supports are generally used only at the acute phase of the brain injury. Cognitive therapies were perceived as unavailable outside of schools by interviewees. Schools work with limited funding and a broad scope of roles and responsibilities, making it challenging for them to meet the complete needs of youth with disabilities.

### Therapies, IEPs, counseling, and educational consultation are most used and most in-demand educational services

Figure 20: Use of Educational Services by Students with Brain Injury



Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017

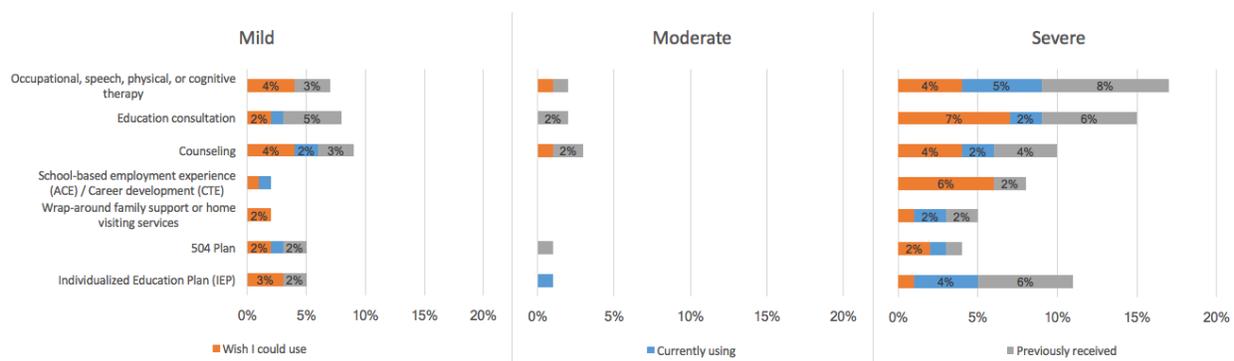
## YOUTH WITH MILD BRAIN INJURY ARE LESS LIKELY TO BE IDENTIFIED AND CONNECTED TO SERVICES

Youth with mild brain injury are less likely to be identified and connected to services. In general, students with more severe injuries have a clearer path to receiving special education services. The table below represents consumer survey respondents, with larger percentages of students with severe injuries receiving or having previously received services. However, the data also show unmet needs also being higher for students with severe brain injury.

More severe injuries have a clearer path, generally because of a medical diagnosis. Students getting injured through non-school events who don't go to doctor/hospital are often not getting identified, and thus go unserved.

## Students with mild brain injury are not accessing accommodations through 504 plans

Figure 21: Use of Educational Services by Students with Brain Injury, by Severity of Injury



Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017

Students with severe brain injury are more often connected to school-based services but those with less severe injuries may be eligible for 504 plans and not accessing accommodations. Schools do not collect data on disability type for 504 plans because students do not have to qualify under specific disability categories or show specific levels of impairment. The school's 504 team needs to determine that a student's disability is severe enough to require an accommodation to support full participation. More students should be served under 504 plan accommodations since its requirements are much lower and more general than special education requirements. However, Colorado, like the nation, has a much smaller percentage of students served on 504 plans compared to IEPs.<sup>8</sup> Schools do not receive extra money to serve students needing 504 accommodations. Brain injury and concussion management teams will be collecting information on the number of students with brain injury receiving 504 services in their database. These data will be available once these teams are functioning statewide.

## MANY INTENSIVE BEHAVIORAL HEALTH SERVICES DO NOT SUPPORT CHILDREN/YOUTH

Like adults, youth with more complex needs requiring a behavioral health intervention reportedly struggle to access behavioral health care. Community mental health centers work with schools and youth-based programs in

<sup>8</sup> 8,560 Colorado students had 504 plans in 2012 compared to 85,133 with IEPs. Nationally, 738,477 students had 504 plans compared to 6,086,426 with IEPs in the same year. Source: U.S. Department of Education, Office for Civil Rights, Civil Rights Data Collection, 2011-12, <http://ocrdata.ed.gov>.

their catchment areas. Some school districts have implemented wraparound supports for youth and families but students with brain injury are receiving behavioral health services at lower numbers than the general student population. Parents report that they are forced to bring their children with brain injury exhibiting aggressive behavior to the emergency room or place them in inpatient settings because there are no viable community-based or crisis stabilization options. A shortage of crisis stabilization unit (CSU) beds exists for adults, and many CSUs reportedly, per interviewees, do not treat youth. In a few cases, youth have been placed in inpatient settings out of state because no in-state facility had the capacity to care for youth with high physical health and co-occurring behavioral health needs.

Colorado is implementing a new phase of its Accountable Care Organization (ACC 2.0), which is joining physical and behavioral health under one accountability organization. Within this transition, the state is implementing high fidelity wraparound services to better serve youth and their families within their community through high intensity interventions.

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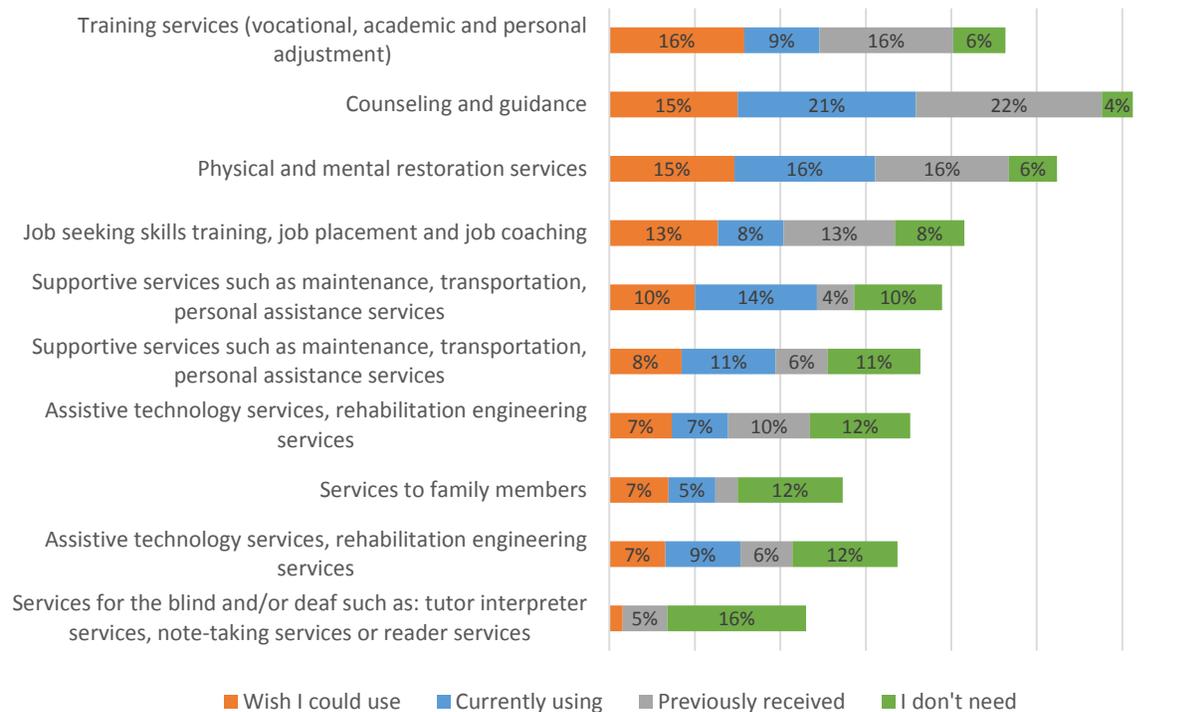
#### PEOPLE WITH BRAIN INJURY HAVE LIMITED ACCESS TO EMPLOYMENT SERVICES

Gaps in services have also been identified for people with brain injury who are looking to employment or mechanisms of productivity or social skill development. People with brain injury generally have a more difficult time identifying a long term, extended service support provider. Without ongoing payer support, it is more challenging for people with brain injury to access supported employment through the Department of Vocational Rehabilitation (DVR). Individuals with brain injury generally have lower rehabilitation rates than the full DVR population.

Consumer survey respondents listed employment support services used currently, used previously, ones they wish they could use, and ones not needed. In general, the desire for services was greater than the use of a service. This was particularly true for people with severe brain injury. The most commonly used employment services, counseling and guidance and physical and mental restoration, were used by less than half to a third of respondents.

## Consumers most likely to receive counseling, restoration, and training vocational services

Figure 22: Consumer Use of Employment Support Services



Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017

When these responses are analyzed by gender, men are more likely than women to receive the two most used employment services – counseling and guidance and physical and mental restoration. Analyzing employment support service use by brain injury severity, people with severe injuries are more likely to use services as well as feel underserved or unserved. People with mild brain injury are also almost as likely to feel underserved or unserved in most employment service categories.

The current gaps in accessing services creates overreliance on more expensive and less beneficial systems such as first responders, hospital emergency departments, and law enforcement. Ineffective intervention among school-aged children with mild brain injury and limiting productivity through lack of supported employment for adults with brain injury leave opportunities for improvement.

### AVAILABILITY OF SERVICES: FINDINGS AND DATA

In addition to an individual finding it difficult to access the existing services they want or need, there are also gaps from services not being available. This leaves missing components and inadequate supply of services that are needed and leads to unmet needs for individuals with brain injury.

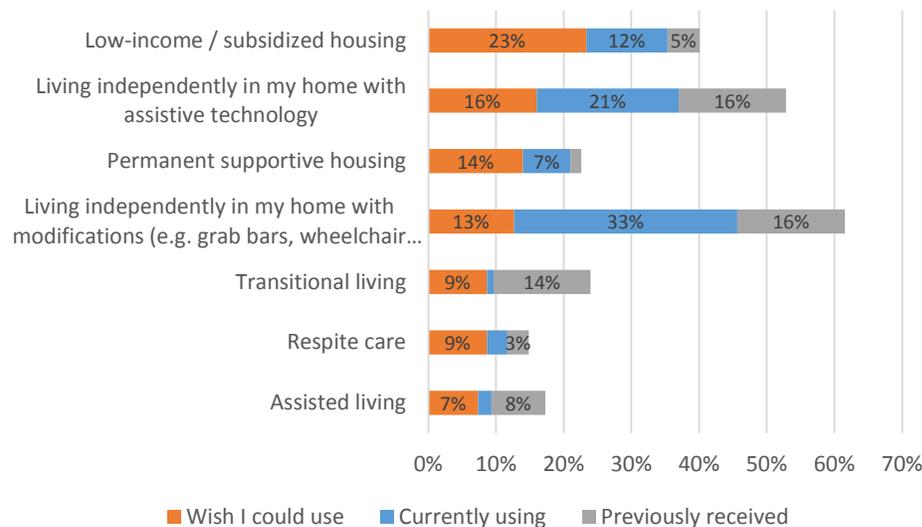
## AFFORDABLE HOUSING AND APPROPRIATE RESIDENTIAL FACILITIES ARE AN UNMET NEED

Lack of affordable housing and appropriate residential placements was of great concern among interviewees, survey respondents, and community forum participants. Rapid growth, particularly in the Denver metropolitan area is increasing housing costs for those living independently in the community. Even those with subsidized housing vouchers are challenged to find affordable rentals.

### Lack of affordable housing is a major barrier for people with brain injury

The cost of housing is a big barrier and the largest percentage of survey respondents ranked low-income or subsidized housing at the top of their wish list.

Figure 23: Use of Housing Services



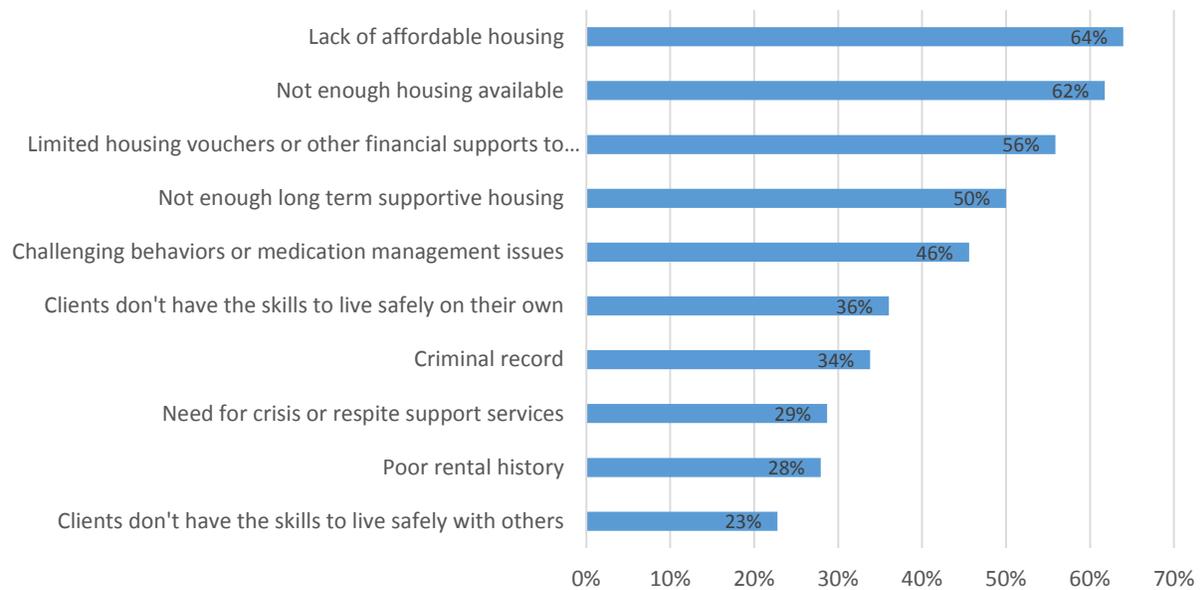
Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017.

Though 60% of survey respondents report living in their own home or apartment, the cost of housing was by far the biggest challenge in finding and keeping a place to live (26%), second to not having a housing voucher/subsidy (15%), and third being that there is not enough housing available (10%). Those that felt successful where they are currently living indicated steady income, strong support network (family and friends), and access to medical/mental health services as the three top reasons for maintaining housing.

Interestingly, there were no significant associations between severity of brain injury and housing status, but this may be due to the small sample size of people with mild, moderate, or severe BI who answered this question.

Providers also indicate lack of affordable housing as the biggest barrier (64%) to gaining/maintaining a safe, stable housing. Housing availability is among the top three barriers preventing people with brain injury from gaining or maintaining a safe place to live. Limited availability of long term supportive housing was also selected by half of the provider respondents, more so than challenging behaviors or not being able to live independently.

**Figure 24: Provider Perspective on Barriers to People with Brain Injury Gaining and/or Maintaining Safe, Stable Housing**

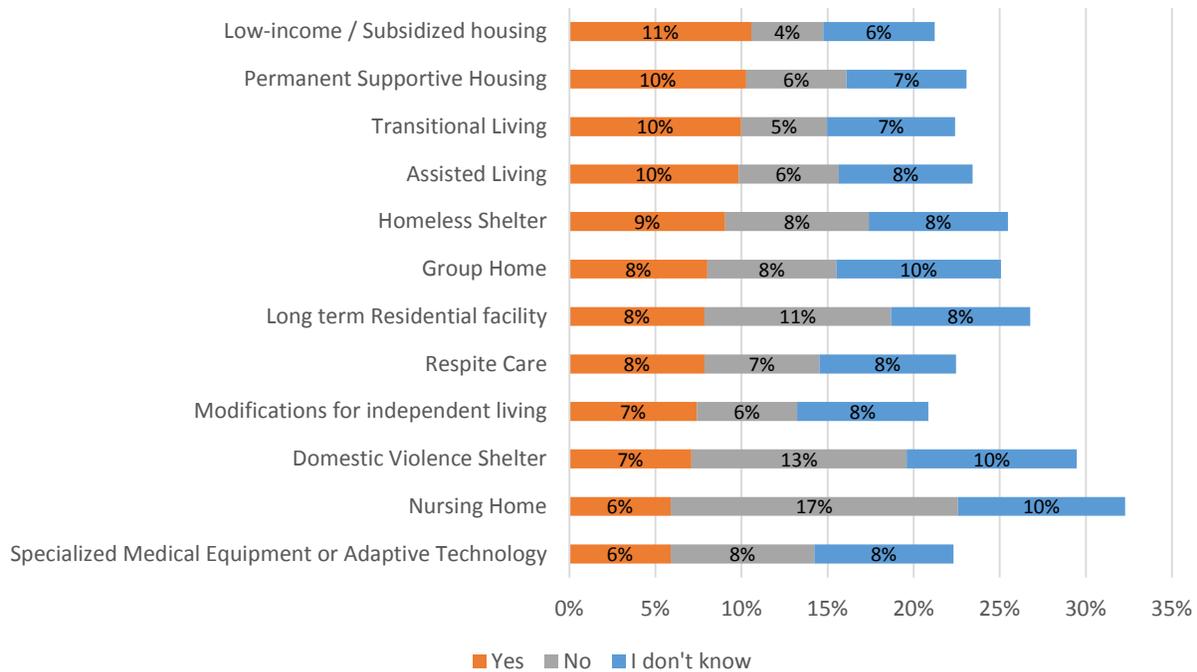


*Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017.*

In addition to low-income housing, providers see an unmet need for permanent supportive housing and transitional living. Many communities nationally are turning to permanent supportive housing with low barriers as options for those with complex medical and behavioral health needs. In this setting, an individual would sign a lease, typically for a studio apartment, but have staff available on site 24 hours a day and a range of supportive services such as meals and medication monitoring. Despite the connection between having a safe place to live and positive health outcomes, there is often a disconnect between homeless/housing and healthcare systems, especially at the state level. Local communities and providers are collaborating with Housing and Urban Development (HUD) for capital “brick and mortar” funding and rent subsidies while states look toward opportunities for Medicaid to fund supportive services in permanent supportive housing settings. In Colorado, HCPF currently works with Department of Housing for the 811 housing they’re funding right now as a growth from the Community Choice Transitions (CCT) partnership under an Interagency Agreement. Most of the expected service funding is through waivers, but it would be good to have better coordination between HCPF and DOH on housing needs beyond CCT.

Housing is an especially big concern for those with complex needs transitioning out of an institution and back into the community, supporting the need for transitional living. Interviewees discussed a need to better support transitions from structured environments to independent living through step-down options with staff support, medication monitoring, and independent skills training. Other individuals with brain injury may need ongoing structure and support to be successful in their living environments.

**Figure 25: Provider Perspective on Which Housing Services are Unmet Needs**



Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017.

## PROVIDERS INDICATE APPROPRIATE RESIDENTIAL FACILITY PLACEMENTS ARE LIMITED

There are two types of residential services offered through the BI Waiver, the Supported Living Program (SLP) and the Transitional Living Program (TLP). These programs provide 24-hour staffing, structure, and supportive services in a facility geared solely for people with brain injury. Interviewees indicate there is a need for increased capacity in these programs.

There are a few additional home and community-based residential options such as alternative care facilities for those that also qualify for the EBD Waiver and Residential Habilitation for those who are also eligible for the DD-Supported Living Services Waiver. Interviewees indicate finding an appropriate residential placement can be very challenging because of waitlists based on capacity and funding.

Complex medical needs sometimes require an individual to go to nursing homes (Skilled Nursing Facilities); however according to interviewees it can be difficult to accept placement, especially for those with complex needs. Skilled Nursing Facilities can deny placement due to aggressive behaviors. These facilities don't usually have the behavioral health services with which to support an individual with brain injury. Colorado Choice Transitions (CCT) can help an individual transition from a skilled nursing facility back into the community, but CCT also struggles to locate appropriate living situations.

## THERE ARE HIGH RATES OF BRAIN INJURY AMONG THE HOMELESS POPULATION, INCLUDING YOUTH

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There are high rates of brain injury among the homeless population, varying between 43-53% depending on the study. The majority of homeless individuals with brain injury sustained their first injury prior to becoming homeless and were at increased risk for additional brain injuries after becoming homeless.

Researchers based out of the University of Colorado College of Nursing examined the impacts of brain injury on homeless youth and found the average age at injury was 15 years old and young people who report a history of TBI became homeless at a younger age and experienced more episodes of homelessness in addition to having lower levels of education and higher rates of behavioral health issues.<sup>9</sup>

Homelessness can range from couch surfing to staying at an emergency shelter to living on the streets, however most permanent supportive housing programs prioritize units to those who are chronically homeless (longer than one year) and staying in shelters or somewhere not meant for human habitation.

### Homeless services don't work well for people with brain injury

When asked about current homeless and housing programs and how well they work for people with brain injury, homeless shelters received an average response from providers between “not well at all” and “slightly well”. This is not surprising given how challenging it is to navigate homeless services without cognitive impairments – remembering to show up at the right time to get a bed. BIAC and CBIP has done outreach to inform homeless shelters of their services, but have not received many referrals.

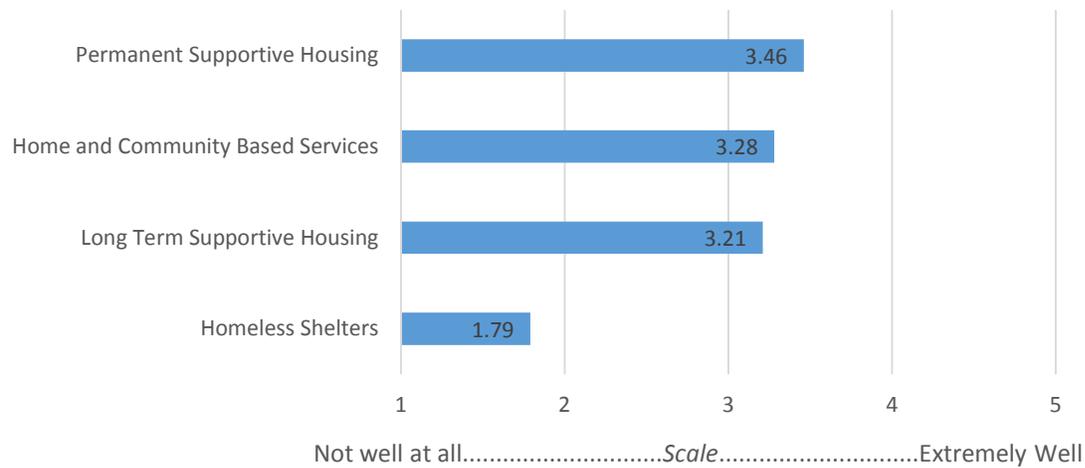


“What keeps me homeless is lack of supports, coordination and care which is both TBI aware and trauma-informed.”

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<sup>9</sup> “Adverse Outcomes Among Homeless Adolescents and Young Adults Who Report a History of Traumatic Brain Injury” Mackelprang, Harpin, Grubenhoff and Rivera. American Journal of Public Health. October 2014.

**Figure 26: Average Provider Perspective on How Well Each Housing Program Works for People with Brain Injury**



*Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017.*

Permanent supportive housing programs received an average response of serving people with brain injury “very well”, with HCBS and long term supportive housing close behind.

The need for housing and appropriate residential placements is only going to continue to grow, which means a need to create more settings for people with brain injury across a wide spectrum of care from living independently with modifications, to permanent supportive housing, to residential facilities. It will take an innovative response to impact housing limitations and collaboration between CDHS, HCPF, and the Colorado Division of Housing to work together toward affordable and accessible housing through all means possible.

## THERE IS LIMITED BRAIN INJURY SPECIALIZATION OR EXPERTISE

People with brain injury indicate there is a limited availability of brain injury specialists both to seek care from directly and for their providers to consult with across service systems (primary health, behavioral health, vocational, and educational). Community forum participants believe every brain injury is unique and this can make it difficult to receive and provide quality care. Additionally, people with brain injury indicated in survey responses that lack of access to a brain injury specialist was a reason they have been turned away from behavioral health services.

Providers also felt it would be beneficial if they were able to consult and receive technical assistance from other providers that have a specialized focus on brain injury care. There is room to enhance training about brain injury in behavioral health, education, and vocational rehabilitation services.

## No formal brain injury specialization caseloads exist within DVR

Unlike for IDD, mental illness, and self-employment, DVR does not have a brain injury specialization. IDD and mental health disability specialists help to package supported employment based on individual client needs and

available work incentives. People with brain injury can have as many needs and employment limitations, but no identified extended payer source to help them stay employed after DVR assistance stops.

DVR training does not generally integrate training on specific disabilities, including brain injury. Attendance at brain injury or any other disability-specific trainings is typically initiated at the local level between a supervisor and counselor. Some counselors take it upon themselves to learn more about brain injury. The extent to which a solid understanding of brain injury impacts on organization, focus, and other employment skill sets exists seems to vary from counselor to counselor.

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#### THERE IS INSUFFICIENT PEER SUPPORT SERVICES AND SUBSTANCE USE DISORDER INPATIENT TREATMENT

Based on survey responses and community forums, peer support services (72%) and substance use disorder inpatient treatment (60%) are in demand but seemingly not available to people with brain injury. (See Figure 18.) Though peer support services are available through behavioral health services, and seen as a valuable resource to recovery services, there are not peer support services specific to brain injury. People with brain injury feel there is a unique need for peer specialists in brain injury services given the unique challenges faced and the ongoing need for daily living support that peer support services could fill.

Limited availability of substance use disorder inpatient treatment was noted in survey responses in addition to community forum participants. Substance use services in general seem to be underused by people with brain injury, but inpatient treatment seems to be limited by both availability and access issues.

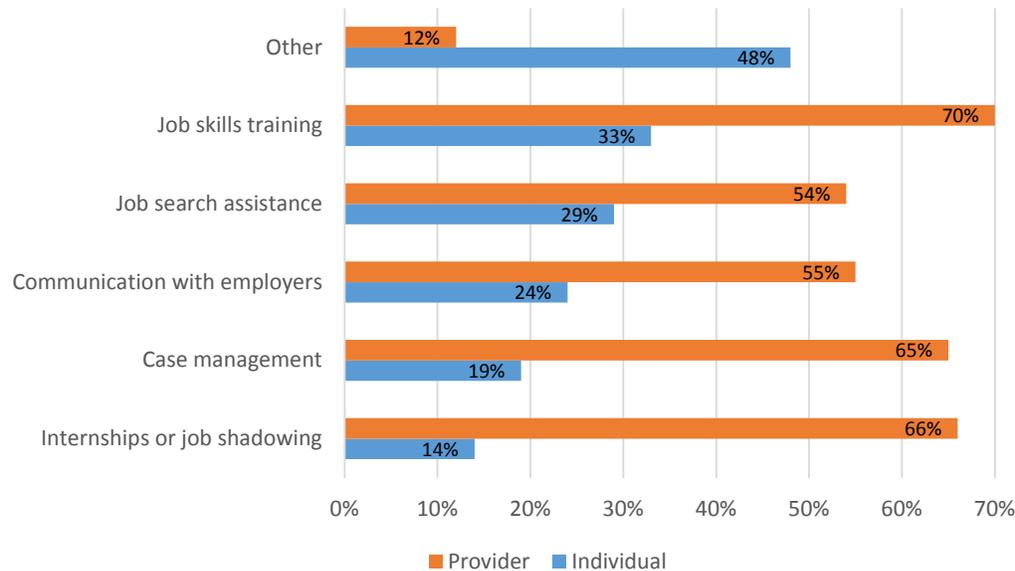
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#### STUDENTS WITH SIGNIFICANT BRAIN INJURIES MAY NOT QUALIFY FOR SWAP

Students receiving special education services must have post-secondary transition plans completed by age 16 or earlier depending on the school district. Youth with more severe brain injuries are more likely to have an IEP (see screening section above), yet DVR youth programming has historically targeted youth with mild to moderate disabilities for one of the organization's more robust youth programs – the School to Work Alliance Program (SWAP). DVR established SWAP in the mid-1990's with a focus on youth with mild to moderate disabilities up to age 25 who could be fast-tracked to employment services. This generally included youth with learning disabilities, and excluded youth with more complex disabilities, such as severe brain injury. SWAP is broadening its focus to work with a broader array of youth with disabilities, however it is not designed to work with individuals with the most severe disabilities who need more ongoing support, such as in a supported employment model. Only a small number of consumer survey respondents replied that they used career supports in an educational setting. More said they wish they could. (See Figure 21.) Only a third or fewer consumer survey respondents cited vocational supports as helpful for transitioning to adulthood. Many of the consumers' "other" responses discussed how they found vocational rehabilitation unhelpful.

## Small percentage of consumers found vocational services helpful in transition to adulthood

Figure 27: Services and Supports Most Helpful for Transition to Adulthood



Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017

Under the Workforce Innovation and Opportunity Act (WIOA), states are required to set aside at least 15% of their federal vocational rehabilitation funding for Pre-Employment and Transition Services (Pre-ETS) for students with disabilities who are eligible or potentially eligible for VR services. This includes students eligible under Part B of the Individuals with Disabilities Education Act (IDEA) or section 504. Pre-ETS is requiring states rethink how they work with youth with disabilities in schools. Colorado DVR is restructuring some SWAP contracts to include Pre-ETS, working with employers to create more onsite workplace experiences, and collaborating with mental health centers to connect youth to supported employment services. Mental health center collaboration with Pre-ETS is only occurring on a small scale, connecting counselors in first episode psychosis units to Pre-ETS funding. Colorado has an opportunity to use Pre-ETS funding to better support youth in transition and system coordination in general.

### SUPPORTED EMPLOYMENT SERVICES ARE LESS AVAILABLE TO PEOPLE WITH BRAIN INJURY

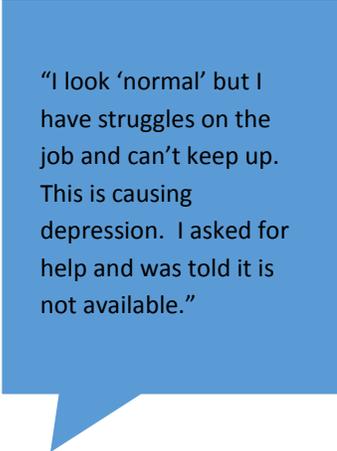
DVR provides three months of comprehensive assessment support for the purpose of vocational goal identification. Successful vocational planning for people with brain injury may take longer because it takes time for people to re-identify who they are after their injury. Per interviewees, the limited assessment timeframe can put people with brain injury at odds with their DVR counselor.

Supported employment services provide longer term support for people with disabilities and their employers to help maintain employment. If a person is assessed as needing supported employment, but an extended services source/payer cannot be identified, DVR counselors may or may not move forward with the provision of supported employment services. If a counselor does elect to move forward with an individual with brain injury needing supported employment, they have to creatively craft and identify alternative sources for extended services. From

the data reviewed, it appears that oftentimes, these sources are not identified, and as a result, low numbers of individuals with brain injuries are served under a supported employment model.

DVR consistently provides supported employment services to two populations – people with intellectual and/or developmental disabilities and people with mental illness. Medicaid pays for extended service providers to meet the supported employment needs of these populations through the adult SLS and DD Medicaid Waivers and Behavioral Health State Plan services. DVR finds the long-term, extended services provider who takes over ongoing employment support after DVR’s responsibilities are complete. Under WIOA, DVR will provide supported employment for youth 24 years and younger when needed, regardless of whether extended employment services are identified through other payer sources.

Supported employment services are not included within the Brain Injury or Elderly, Blind, and Disabled Waivers. A recommendation exists to add supported employment to all waivers, under the assumption that people meeting level of care generally have significant or complex needs, and could benefit from supported employment. People with brain injury not receiving waiver services could arguably also benefit from supported employment services. The extension of supported employment to these Medicaid waivers will leave others with brain injury unserved unless other payer sources for extended services providers can be identified.



“I look ‘normal’ but I have struggles on the job and can’t keep up. This is causing depression. I asked for help and was told it is not available.”

DVR counselors must be creative to uncover supported employment opportunities for people with brain injury. Counselors use Impaired Related Work Expenses (IRWE) or other customized work incentives through the Social Security Administration to pay for extended employment support. Counselors also use post-employment services as a workaround for supported employment. Post-employment services are provided after a person obtains employment, as necessary to assist him or her maintain, regain, or advance in employment. Eligibility does not have to be re-determined to engage in post-employment services. Leveraging post-employment services requires a strong relationship between the counselor or business outreach specialist and employer or individual, so cases can be swiftly reopened and post-employment support can be authorized in a timely way when a situation arises requiring DVR intervention to maintain employment. This allows for intensive services to be reintroduced for a short period of time, covering for the absence of ongoing formal services when appropriate.

## PEOPLE WITH BRAIN INJURY FACE MANY OBSTACLES IN FINDING AND KEEPING EMPLOYMENT THROUGH CURRENT DVR SERVICES

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Colorado has a very low unemployment rate (3.0% in December 2016). People with disabilities are generally employed at much lower rates than the general population. In Colorado in 2014, 28.4% of people with cognitive disabilities (N=125,964) and 39.9% of people with any disability were employed (N=303,115).<sup>10</sup> DVR data indicate lower employment outcomes for people with brain injury compared to the general disabilities population, with a

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<sup>10</sup> State Data: The National Report on Employment Services and Outcomes, 2015, Colorado, <https://www.statedata.info>.

FY2017 rehabilitation rate of 43.8% for people with brain injury compared to 54.5% for the general disabilities population.

Consumer survey respondents before their brain injury were primarily employed full- (60%) or part-time (16%), and/or were full time students (26%). Post-injury, respondents' employment participation declined significantly, with only 18% employed full time and 15% employed part time. "Other" responses for consumers post injury include volunteering, early retirement, and pursuit of artistic endeavors.

## People with brain injury employed at lower rates post-injury

Figure 28: Consumer Survey Respondent Employment Status Pre-and Post-Brain Injury

	Pre-Injury %	Post-Injury %	Change %
<b>Full time work</b>	60.0%	18.0%	-42.0%
<b>Part time work</b>	16.4%	14.8%	-1.6%
<b>Underemployed and looking for more work</b>	0.7%	8.6%	+7.9%
<b>Working inside the home (e.g. caregiver, parent)</b>	2.1%	2.3%	-0.2%
<b>Unemployed and looking for work</b>	3.6%	16.4%	+12.8%
<b>Full time student</b>	26.4%	10.2%	-16.2%
<b>Part time student</b>	2.1%	1.6%	-0.5%
<b>Military service</b>	2.1%	0.0%	-2.1%
<b>I am not looking for work</b>	-	22.7%	+22.7%
<b>Other</b>	10.0%	21.9%	+11.9%

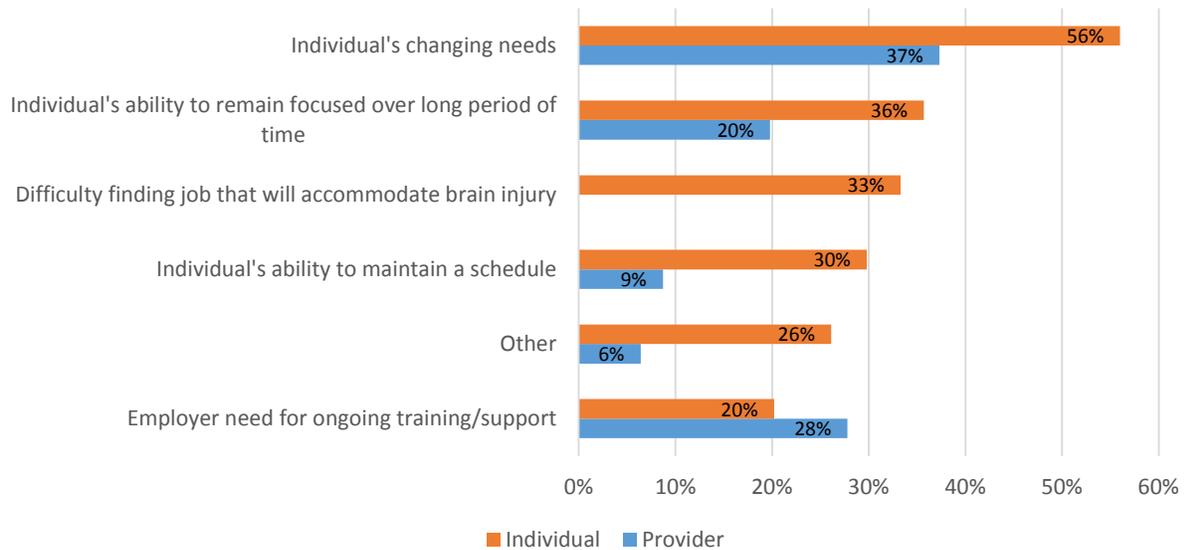
Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017.

Adults with brain injury receiving behavioral health services are less likely to be employed than the general population receiving substance use disorder (14.7% individuals with brain injury and substance use disorder employed full and part time versus 36.7% of the general substance use disorder population) or behavioral health services (14.7% individuals with brain injury and mental health employed full and part time versus 20.2% of the general behavioral health population). People with brain injury and behavioral health issues are employed at lower rates than the general behavioral health population.

The majority of consumers and over a third of provider survey respondents cited changing needs associated with brain injury as the primary employment obstacle. Changing needs may include fluctuating skills, abilities, and limitations. Consumers ranked challenges with remaining focus and ability maintain a schedule as significant barriers. Both consumers and providers expressed a need for additional employer capacity building. Consumers saw this more so through the lens of struggling to find a job, and providers recognized it as a need for more employer training and support. Consumer "other" responses include pain, fatigue, memory issues, difficulty being in public, and co-occurring disabilities.

## Changing needs of people with brain injury make it hard to find and keep work

Figure 29: Challenges to Gaining and Maintaining Employment for People with Brain Injury

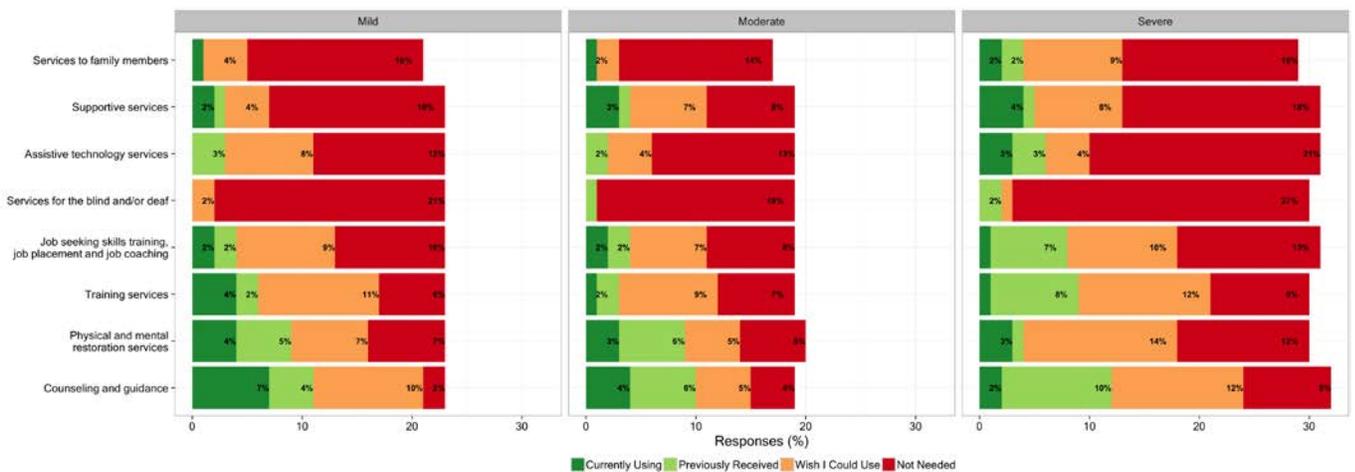


Source: Colorado Brain Injury Hard to Serve Study, Consumer and Provider Survey, 2017

Analyzing employment support service use by brain injury severity, people with severe injuries are slightly more likely to use services as well as feel underserved or unserved. People with mild brain injury are also almost as likely to feel underserved or unserved in most employment service categories.

## People with severe brain injury most likely to be under or un-served

Figure 30: Consumer Use of Employment Support Services, by Brain Injury Severity

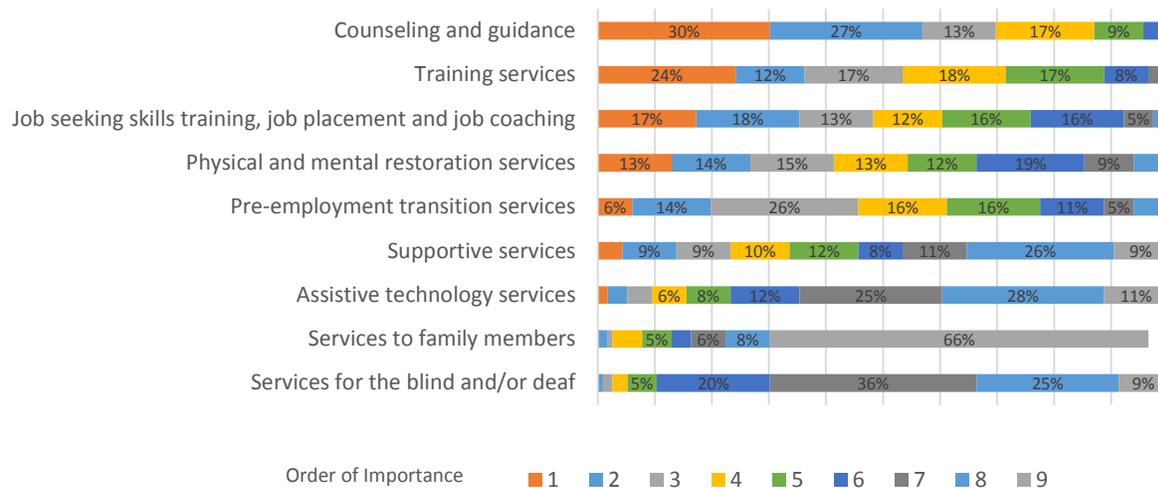


Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017

The provider perception of valuable employment-related services largely mirrors the services provided by DVR, with counseling and guidance, training services, job skills development, job placement, and job coaching, and physical and mental restoration services ranked as most important. However, people with brain injury are struggling to acquire, maintain, and advance at work with the current service system structure compared to the overall, general DVR population.

### Providers perceive counseling and guidance as most important service/support to gain job

Figure 31: Services and Supports Most Successful in Helping Adults Gain Employment, Ranked Responses



Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017

Insufficient availability of services leaves individuals with brain injury in need of care. Missing service components that are required to provide holistic services meets the definition of being a gap in services. Colorado has an opportunity to increase capacity of certain in-demand services.

## SYSTEM COORDINATION: FINDINGS AND DATA

In general, health and human service systems are innately complicated and coordination between siloed systems is a well-known challenge. Brain injury is unique in that it impacts people of all ages to varying degrees, presenting changes in symptoms and evolving needs over a lifetime that cross over into the multiple service systems. Due to the challenging nature of brain injury, it is no surprise that coordination of these services across systems is one of the main concerns to emerge.

Colorado has placed much emphasis on cross system responses through recent initiatives, such as integrating primary care and behavioral health care to create health homes and implement Accountable Care Collaborative Phase 2 (ACC 2.0), the No Wrong Door Grant, and creating a pilot program for adults with IDD in a behavioral health crisis (CSCR Pilot). Despite this progress, additional resources and responses are needed to address system coordination challenges.

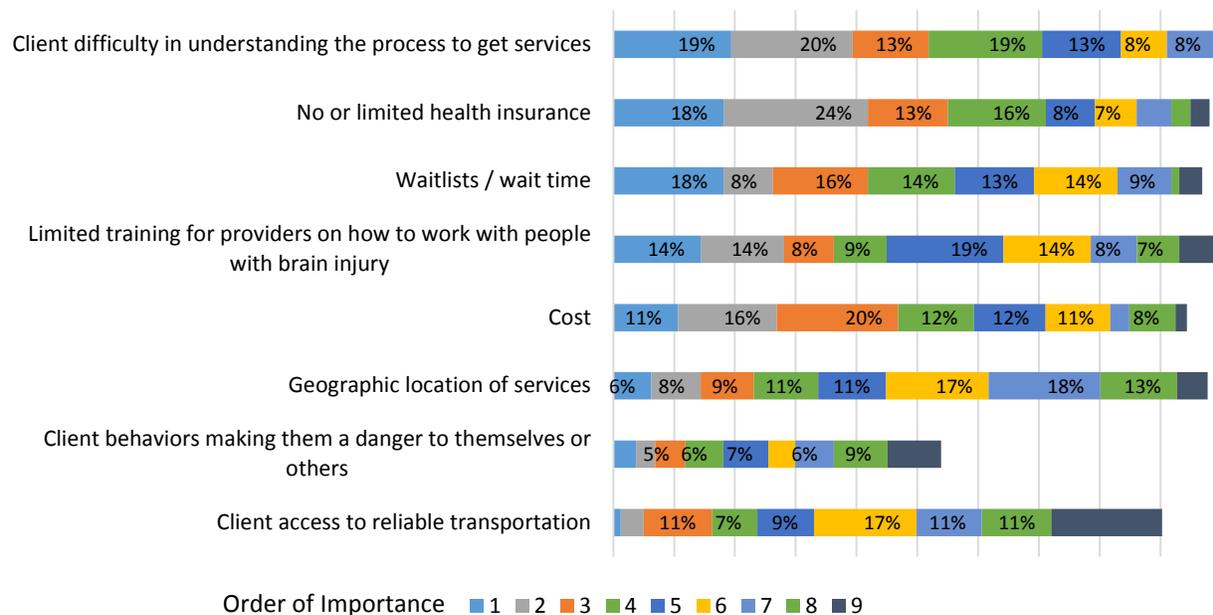
## DISPARATE SYSTEMS ARE DIFFICULT FOR INDIVIDUALS AND PROVIDERS TO NAVIGATE

In addition to needing more choice in services, individuals with brain injury also need support in navigating disparate service systems. It is a common challenge and one that the healthcare industry has responded to by creating a new field for patient navigation.

### Providers rank difficulty of navigating systems as the biggest barrier for individuals to accessing services

Service systems are siloed with different points of entry into each system. A consumer of services must first be aware of the service, determine if they qualify to use them, and then know how to go about accessing them. This is a big undertaking, especially after enduring an injury that can impact both physical and cognitive functioning and make it difficult to accomplish activities of daily living, let alone finding the right path through a maze of services.

Figure 32: Providers Ranking of Service Barriers



Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017

### The referral process leaves room for streamlining

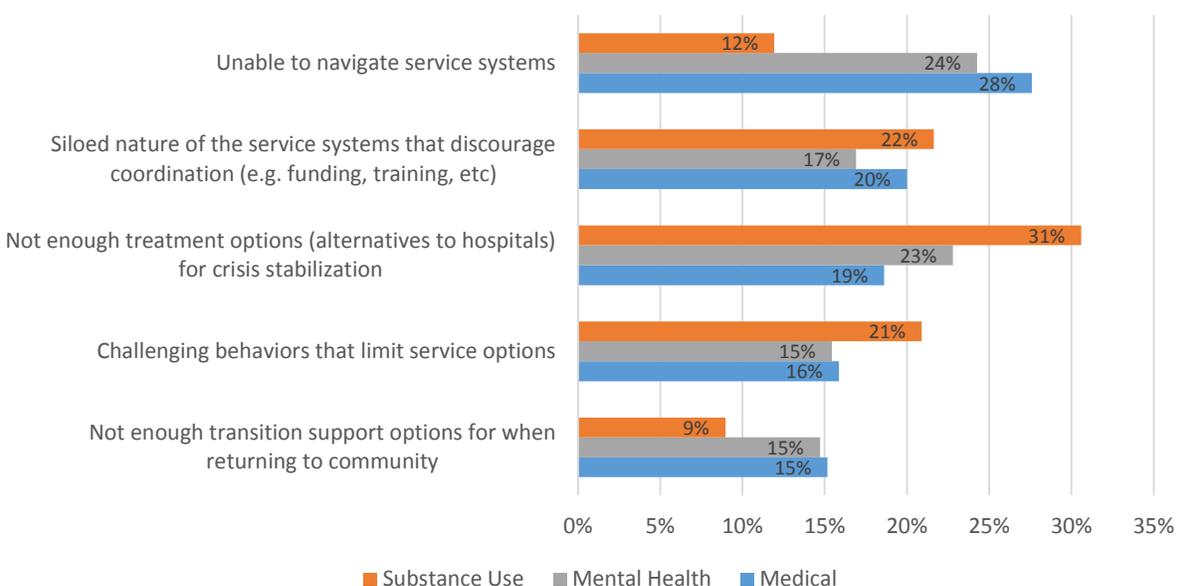
Sixty-four percent of provider survey respondents indicate that the services they provide are only accessible through referral. Depending on the referral process, this leaves room for wait times, missed connections and potential gaps in service acquisition. Interviewees and forum participants indicated it can sometimes take weeks or months after a referral before they see a provider, missing care through an important time during their recovery.

BIAAC has made outreach efforts and streamlined their referral process through electronic submission. There is room for improvement among providers as well as system-wide on streamlining referral processes using existing resources such as the Crisis and Support Line and electronic health records.

## INDIVIDUALS WITH CO-OCCURRING CONDITIONS ESPECIALLY CHALLENGED TO NAVIGATE SERVICES

Provider survey respondents indicated that the biggest barrier to services for individuals experiencing co-occurring brain injury and complex medical issues or brain injury and mental health issues is that they are unable to navigate service systems. Complex systems are even more complicated for people with complex needs. Fifty-two percent of survey respondents wish they had a behavioral intervention plan and 50% indicate they wish they could work with a mental health case manager. Seventy-one percent wish they could go to medical detox and 60% wish they could go to substance use inpatient treatment.

**Figure 33: Provider Perspectives on Barriers to Services for Individual with Brain Injury and Co-occurring Complex Medical or Behavioral Health Needs**



*Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017*

Colorado is attempting to address system coordination across healthcare service domains through integrating primary care and behavioral health care through ACC 2.0. This will allow for an individual with co-occurring disorders to access services with fewer barriers.

Colorado Springs has developed an integrated health response program to address over-utilization called Community Assistance, Referral, and Education Services (CARES) through the Fire Department to identify and redirect high utilizers of the emergency medical system to more appropriate care that leads to better patient outcomes. Additionally, Colorado Springs responded to community mental health needs through a Community

Response Team (CRT) that can perform psychiatric evaluations in the community and medically clear patients for admittance to behavioral health treatment facilities.

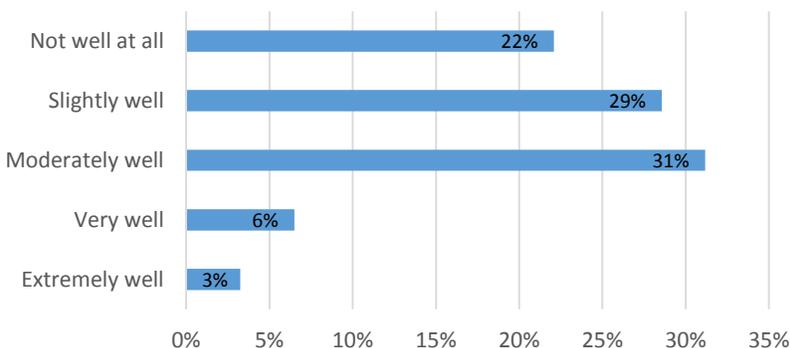
## COMMUNICATION AND INFORMATION SHARING BETWEEN PROVIDERS COULD BE IMPROVED

A big part of service coordination is communication and information sharing between providers. Ninety percent of survey respondents indicated they have between one and three case managers, though it is likely that they have far more service providers. Fifty-one percent of provider survey respondents are case managers / care coordinators, probation / corrections officer, or vocational / employment support staff. Additionally, there were responses from rehabilitation providers (speech, occupational, physical therapists), health care professionals, mental health and substance use providers, school staff (teachers, nurses, psychologists), residential service providers, advocates, independent living skills trainers, life skills coaches, neuropsychologists, alternative/complementary care practitioners, hospital social workers, and mobile crisis workers. One individual with a brain injury could theoretically interact with all these providers at some point during their lifespan.

### Nine percent of providers indicate brain injury services and supports are well coordinated

Just over half of provider survey respondents indicated that brain injury services and supports are coordinated not well at all or slightly well. An additional 31% thought care coordination ranked moderately well. A small minority ranked coordination highly.

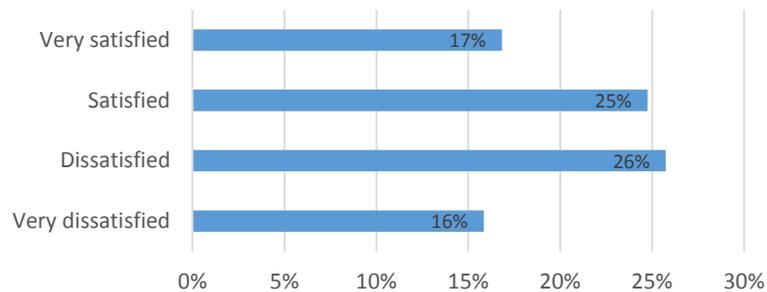
Figure 34: Provider Perspective on How Well Brain Injury Services are Coordinated



Source: Colorado Brain Injury Hard to Serve Study, Provider Survey, 2017.

Interviewees and forum participants expressed challenges with provider collaboration, though interestingly, consumer survey respondents were split between satisfied and dissatisfied with the how well their service providers communicate with each other. This response indicates that there may be some providers who are doing a better job communicating than others.

Figure 35: Consumer satisfaction with provider communication



Source: Colorado Brain Injury Hard to Serve Study, Consumer Survey, 2017

Interviewees reported workforce challenges as a potential contributor to poor service coordination as staff turnover affects engagement with clients as well as relationships between providers that allow for smoother transitions and warm “hand offs”. Higher turnover rates typically occur among frontline staff and strong agency partnerships can negate the impact of turnover. It is worth noting that 44% of provider survey respondents have worked in their field for 11 years or longer.

Forum attendees reported challenges around sharing information between providers, particularly obtaining and providing medical records. Documentation of a brain injury is not consistently entered into health records in the same way, sometimes being entered as a case note (52% of survey respondents) and other times as a diagnostic code (42%) which can create challenges in pulling reports based on diagnosis and compiling data on prevalence.

The mixed responses around communication and information sharing among providers indicate room for improvement in this area. Providing ongoing support, connection, and continuity between service providers is an important aspect of service coordination.

One option for improving coordination between providers is by having one case manager work across programs, or to assign the case manager who is trained in that specialty to take the lead in service coordination. More states are coordinating patient-centered care in accordance with the Affordable Care Act and there are lessons to be learned from that. Brain injury case managers could play the role of cross-system care coordinator with additional training, capacity, and clarified roles and responsibilities.

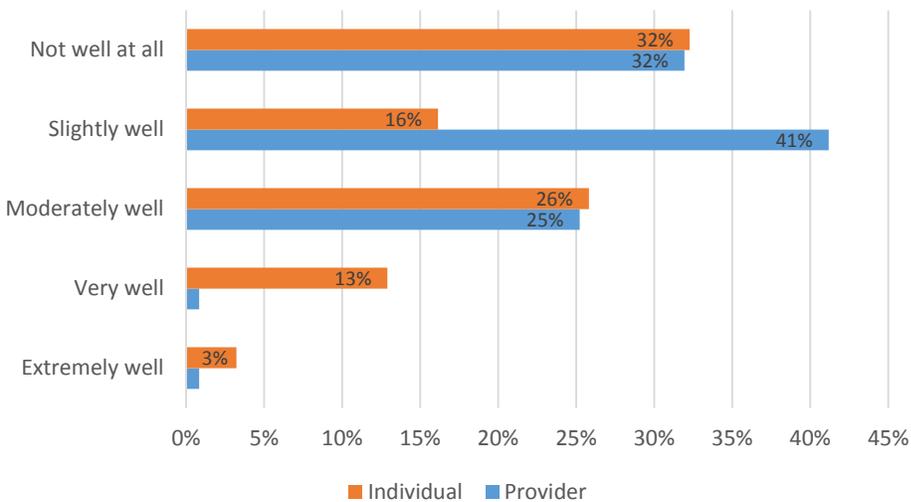
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## TRANSITIONS IN SCHOOLS ARE NOT SEEN AS SUCCESSFUL

Transitions happen for youth with brain injury from grade to grade, school building to school building, teacher to teacher, as well as the transition to adulthood. The school system is responsible for youth up to their 21<sup>st</sup> birthday. Schools generally focus on education, employment, and vocational skills to prepare youth to be contributing members of society. Approximately half of youth and more than 70% of provider survey respondents felt that schools prepare youth for transition poorly (not well at all) or fairly (slightly well).

## Providers and consumers believe schools can improve in supporting transition to adulthood

Figure 36: How Well Do Schools Prepare Youth with Brain Injury for Their Transition to Adulthood



Source: Colorado Brain Injury Hard to Serve Study, Consumer and Provider Survey, 2017

Supporting transitions is a central part of the BrainSTEPS team role. BrainSTEPS teams ensure follow up with the student, knowledge transfer with educators, and services are adjusted as needed. This data point will be one to track as BrainSTEPS becomes more broadly used and integrated within school culture.

BrainSTEPS teams are encouraged to help families enroll students in BIAC case management services at any age, but especially at transition to adulthood. The decision to engage with BIAC is parent driven and not systematic. BrainSTEPS is beginning to collaborate with DVR at the state level. Local collaboration between BrainSTEPS and SWAP staff likely varies by district.

Youth with non-traumatic brain injury have fewer service and support options available once they are adults. This is particularly true for youth with congenital brain injuries such as fetal alcohol spectrum disorder. These youths are served through special education and need the same types of interventions in school as other youth with brain injury, but adult brain injury services are not available to them.

Youth receiving HCP services begin transition work at age 10 to prepare families and individuals to move from the pediatric (ability-focused) to adult (disability-focused) healthcare system. Adolescents are a vulnerable population in terms of public health risk factors, and these risks may be higher when a teenager has a brain injury because of associated issues like impact on executive functioning and impulse control. There may be a need to work on transitions earlier for all youth impacted by brain injury or other disabilities.

## EMPLOYMENT SERVICES DO NOT HAVE SHARED PERSON-CENTERED PLAN OR CARE COORDINATION

DVR counselors do not always work with their consumers in collaboration with other community-based, brain-injury services and supports. There is no common, person-centered plan shared between medical, behavioral, housing, child care, food assistance, and employment support providers. Interviewees felt that people with brain injury who have the most success with DVR services have strong teams. Generally, those with the strongest teams are referred from Craig Hospital, which has a formal referral process with DVR. Peer support is not a systematic part of the brain injury system in Colorado, meaning peers are not a resource to support people with brain injury in a person-centered planning process.

It is not clear how BIAC case managers collaborate with DVR counselors throughout the state. There are no clear roles and responsibilities to support effective collaboration, or transition processes to support a warm handoff between the entities.

Challenges in coordination between systems leaves services gaps for people with brain injury.

## RECOMMENDATIONS

Interviewees, survey respondents, and community forum attendees universally wanted to see improved coordination of service and support access and delivery for individuals with brain injury in Colorado. The following recommendations stem from community forums and best practices utilized in other states.

### INCREASE AWARENESS

Awareness, screening, training, and support are central to progress being made across all the findings and opportunities included in this report. Broader understanding creates a culture supportive of and inclusive of people with brain injury.

1. **Increase use of IDD waiver and other Medicaid services for eligible youth with brain injury.** Medicaid, particularly waiver services may help meet medical, behavioral, rehabilitative, caregiver, and other needs for students with brain injury and their families beyond what school districts are able to provide. Local control of schools makes outreach and education work needed to support this service coordination more challenging. (Low level of difficulty)
2. **Support providers and educators by offering more training across systems.** Make information and resources available to everyone and increase information sharing across provider types. Develop additional online training modules on brain injury evidence based practices or disseminate trainings from existing resources. Increase training for providers to recognize and treat brain injury appropriately. (Low level of difficulty)
3. **Incorporate brain injury awareness and support in employer-focused work.** DVR can work to improve employment outcomes for people with brain injury through work with employers. This may be an extension of a brain injury specialization or a special project done in conjunction with CBIP. (Low level of difficulty)

4. **Continue improving awareness for youth through BrainSTEPS, Concussion Management Teams, and BIAC**, especially for student populations who do not participate in organized sports but may be injured outside of the school realm (e.g. skiing or mountain biking) and fall into service gaps. (Low level of difficulty)
5. **Develop, implement, evaluate, and disseminate a best practice protocol for screening, identification, and assessment of brain injury statewide.** Routine screenings for lifetime history of brain injury should be prioritized in agencies and organizations that serve high risk populations such as co-occurring behavioral health, homeless, domestic violence, etc. Incorporate lessons learned from the criminal justice system implementation grant being implemented by the CO Brain Injury Program at CDHS. Schools should implement a consistent screening process to identify youth with brain injury in needing special education or accommodations to maximize intervention effectiveness. DVR should integrate robust brain injury screening into eligibility processes to improve the outcomes of people with brain injury looking for employment through connecting clients with more effective interventions, and allow DVR and other brain injury stakeholders to use the data to analyze the impact of interventions. Incorporate lessons learned from the Cross-System Behavioral Health Crises Response Pilot Program (CSCR Pilot) for persons with intellectual or developmental disabilities (IDD) around the importance of using assessments to connect symptoms and behaviors with the appropriate co-occurring condition to prevent diagnostic overshadowing in which brain injury is misidentified and left unsupported, and/or in which behavioral health conditions are untreated. Resolving confusion around diagnosis allows for use of best practices. (Low to moderate level of difficulty)
6. **Build a more robust referral system.** This can be achieved through using existing resources like the crisis line to connect individuals to services and electronic health records to enhance information sharing between providers. (Moderate level of difficulty)
7. **Continue information gathering / surveillance and education through Craig Hospital.** Building on what is already known about Coloradans with brain injury will allow for ongoing outreach and education to inform the public and providers. (Moderate to high level of difficulty)
8. **Increase public education and awareness about brain injury.** Broader understanding will help to increase acceptance and community integration of people with brain injury and decrease stigma. Increased awareness will support prevention of brain injury. Educating the public about brain injury will help people self-identify, particularly in cases where the injury was misdiagnosed or overlooked, which supports early and more effective intervention. (High level of difficulty)

## IMPROVE ACCESS TO SERVICES

1. **Remove remaining barriers to accessing behavioral health services.** Continue to offer trainings on best practices treating the behavioral health needs of individuals with brain injury. Conduct outreach and strengthen relationships between brain injury and behavioral health providers. Disseminate best practices in treating co-occurring brain injury and behavioral health to support consistency in treatment

and identify lessons learned from the CSCR pilot program. Implement performance measures to track progress in this area. (Low level of difficulty)

2. **Expand efforts toward waiver simplification.** Find ways to integrate brain injury services across waivers as people with brain injury receive services outside of dedicated waivers. Broadening screening for brain injury across all Medicaid services and supporting brain injury specialists/expertise in the workforce throughout systems will strengthen these efforts. (Low level of difficulty)
3. **Increase students with brain injury's use of vocational rehabilitation services.** DVR, CDE, CBIP, and BIAC should analyze how to strategically use Pre-ETS funds to better support youth with brain injury across severity levels. Pre-ETS could create a natural continuation of services from school to DVR and it could also create an avenue to connect more youth with brain injury to community mental health centers/behavioral health services before leaving school. (Low level of difficulty)
4. **Increase efforts to coordinate care over time and across an individual's continuum of needs.** Coordinated care should be streamlined and incorporate a holistic look at person's life, including housing, transportation, employment, physical health, behavioral health, social supports, and other factors impacting overall well-being. The problems faced by people with brain injury are lasting and require long-term, lifelong disease management approaches. People need more dynamic care teams to make connections between physical and behavioral health. Consider service coordinators across systems, including how to extend brain injury case management into this more holistic role. CBIP should be represented at No Wrong Door Implementation Grant to help coordinate pilot sites. Increase BIAC capacity to provide in depth care coordination for a larger number of people and consider increasing intermittent follow up over a longer period of time for anyone suspected of brain injury. (Moderate level of Difficulty)
5. **Increase access to crisis stabilization services, specifically crisis stabilization units.** Increase public awareness of existing crisis services and expand capabilities to serve people with complex needs in crisis stabilization units or create a Center for Excellence for intensive management of individuals with complex needs. Use an existing resource to offer specialized brain injury care throughout crisis services. Conduct research to improve treatment and support future policy development. (Moderate level of difficulty)
6. **Look for funding opportunities to expand access to complementary / alternative medicine, as well as support services for families and caregivers such as support groups and respite care.** (Moderate to high level of difficulty)
7. **Ease transitions between institutions and the community.** Look for solutions to diagnosis barriers that prevent access to services based on payer source when providers dispute which diagnosis is causing the symptoms in need of services. This is especially true for those with complex medical and/or behavioral health needs. (Moderate to high level of difficulty)

## INCREASE AVAILABILITY OF NEEDED SERVICES

- 1. Support the providers and educators by increasing the availability of brain injury specialists with whom to consult and train across systems.** Identify local disability-competent providers and support professional development to support specialists in the field. Use telemedicine to increase access to existing brain injury specialists or consultation. Telemedicine can be especially helpful for those who live in the rural or frontier areas of Colorado with limited services and/or reliable transportation. It also offers a more affordable way to access medical professionals and specialists in the field such as neurologists and neuropsychologists. (Low to moderate level of difficulty)
- 2. Integrate peer support across the brain injury systems.** Enhance peer support options for people with brain injury. Peer support is a best practice in person-centered recovery – people who know the most are the people who have experienced it. Peers can help people with brain injury navigate the re-identification process associated with navigating changed career and personal goals. Increased self-advocacy skills could also help people with brain injury more effectively lead their person-centered planning process. Peer support should be available through CBIP case management, Medicaid, and DVR to ensure broad accessibility. (Low to moderate level of difficulty)
- 3. Develop brain injury expertise/specialization within DVR.** DVR, CBIP, and BIAC should determine what the best option is in terms of curriculum for direct care staff and professionals working with people with brain injury, which could be integrated with DVR training to expand brain injury expertise. The Academy of Certified Brain Injury Specialists offers a voluntary national certification program, which could be an option. Brain injury expertise could be concentrated in a few lead counselors who provide technical assistance and support to other counselors, or who manage a brain injury caseload. Brain injury awareness and training could also benefit the full DVR counselor population. (Low to moderate level of difficulty)
- 4. Expand supported employment for people with brain injury.** The Brain Injury and Elderly, Blind, and Disabled Waivers should include extended services and long term supports in collaboration with DVR for employment. Additionally, DVR providers, BIAC case managers, and other providers should work to better connect people with brain injury to existing supports that could help stabilize people so they are better able to find and maintain employment and/or serve as extended employment support. This may include Medicaid State Plan services, Social Security benefits or, for current beneficiaries, SSA employment supports/work incentives, and natural supports. A coordinated service delivery system should be developed to ensure a continuum of care that includes employment. (Moderate to high level of difficulty)
- 5. Prioritize need for additional affordable housing and appropriate residential facilities.** There is a need for a wide spectrum of housing from an increase in Supported Living Program to permanent supportive housing programs set aside for individuals with disabilities. Consider an interagency agreement with the Colorado Division of Housing to coordinate efforts through all means possible and look toward efforts to use Medicaid funding to pay for supportive services in permanent supportive housing programs. (Moderate to high level of difficulty)

## IMPROVE SYSTEM COORDINATION

Most providers (67%) believe service coordination could be most improved by having more options for brain injury services and supports. Increasing access allows for providers to meet individualized care needs. Individuals with brain injuries emphasized the importance of shifting healthcare decision making power away from payer sources and toward the patient to meet their care needs.

- 1. Improve system coordination for children or youth with brain injury as they transition through school and into adulthood by building on the BrainSTEPS initiative.** Educators and providers need to continue to follow up with children who had brain injury at younger ages so behavioral changes or other challenges related to executive functioning can be linked to the earlier injury. BrainSTEPS should define common metrics for use at district and statewide levels to determine impact of work in terms of system change and student outcomes. BrainSTEPS and concussion management teams can support this work by ensuring accurate data capture, and comparing Colorado's identification and service outcomes to national data. (Moderate level of difficulty)
- 2. Look for opportunities to partner beyond DVR and BIAC to provide socialization, career development, and cognitive retraining supports.** New partners may include post-secondary schools and nonprofits. People with brain injury need to develop skills beyond speech, physical, occupational, and cognitive therapy. This could be integrated with DVR work. (Moderate level of difficulty)
- 3. Continue advancements toward person-centered, patient driven care.** Increasing access and choice improves patient health outcomes as well as system coordination. Individuals should be able to self-direct their care based on their needs rather than funding. Consider using a common person-centered plan across services (physical health, behavioral health, vocational, etc.). (Moderate to high level of difficulty)
- 4. Sustain and expand collaboration between CBIP and criminal justice system as well as other high risk populations such as homeless and domestic violence shelters.** Increasing awareness, screening, appropriate interventions, and transition support for people with brain injury in the criminal justice system is an important effort that should be expanded and continued among other high risk populations. (Moderate to high level of difficulty)
- 5. Continue efforts toward integrated care to assure individuals with complex needs are getting services.** Establish all-inclusive health care through integrating behavioral health and physical health care funding and service delivery models. Look to results from CSCR pilot program, which has been successfully catching people with less severe cognitive disabilities who had previously fallen through the cracks, to see ways to better integrate brain injury and behavioral health. Data show that individuals with brain injury are more likely to suffer from behavioral health concerns, but are less likely to receive treatment. Aligning physical and behavioral health care delivery from the consumer's perspective under the Accountable Care Collaborative Phase 2 (ACC 2.0) should help, although funding streams will not be aligned. Diagnoses constraints limiting individuals with brain injury's access to behavioral health services extend to students. Within the transition to ACC 2.0, behavioral health organizations (BHOs) should analyze their work with school districts and youth/families to see how they can better serve youth with

brain injury. The inclusion of high fidelity wraparound services within ACC 2.0 should incorporate youth with brain injury. Services should be available at a reduced cost for those that fall through the financial cracks. The state should consider setting performance targets for associated performance measures to track progress in this area. (High level of difficulty)

## CONCLUSION

Brain injury is complex because there is no standalone brain injury system of services and supports. Brain injury is a chronic condition impacting all aspects of life, which can occur at any age. Because of this, brain injury needs to be a lens used across systems, so people with brain injury can be integrated into broader services and support structures, at work, and in their communities.

This analysis provides insight into service gaps experienced by people with brain injury, particularly individuals with complex medical needs or co-occurring behavioral health conditions, youth/students, and individuals seeking employment. Data show systemic gaps around awareness, screening, transitions for youth and adults, placement/residential options, and care coordination.

Beyond urban/rural geographic disparities impacting availability of services, data indicate disparities exist to a certain extent based on the severity of brain injury. Employment services are generally more accessible for individuals with less severe brain injury in youth and adulthood. This contrasts with Medicaid services, which are primarily available only for those with the most severe injuries. Medicaid service access inequity is also impacted by waiver choice. Differing service definitions/requirements and service menus restrict access to some services, such as independent living skills training and supported employment.

The state is making progress in addressing gaps related to service system access and coordination through a wide variety of initiatives including the CSCR Pilot program, Olmstead-related initiatives including CLAG and the Employment First Advisory Partnership, WIOA, BrainSTEPS, and ACC 2.0. Colorado has shown a great interest in continuing to bend the curve to improve outcomes for people with brain injury through improved awareness, access, service availability, and system coordination.