



## Appendix V. Traumatic Brain Injury State Partnership Programs

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### ***Administration on Disabilities (AoD) Disability Employment Technical Assistance (TA) Center Landscape Assessment Appendices***

May 2021

As described in the methodology within the main section of the landscape assessment, the Center's project team conducted quantitative and qualitative analysis to identify current Traumatic Brain Injury State Partnership Program (TBI program) initiatives and areas of further development. Appendix V details findings from the quantitative data reviewed as well as the qualitative interviews conducted with TBI program staff and self-advocates.

### **Trends in Provision of Employment and Economic Advancement Supports and Systems Change Efforts**

Federal TBI Partnership Program grants to states have undergone several changes since the TBI Act of 1996 mandated the program. The federal government awarded the most recent state grants in 2018 and required that grant activities increase access to rehabilitation and other services. Specifically, states must address four barriers to needed services by:

- Screening to identify individuals with TBI;
- Building a trained TBI workforce by providing professional training;
- Providing information about TBI to families and referrals to appropriate service providers; and
- Facilitating access to needed services through resource facilitation.

States cannot use State Partnership Grants (SPGs) to support primary injury prevention initiatives, research initiatives, or the provision of direct services. States must use funds to educate the public about the causes, symptoms, and treatment of TBI. Between 1997 and 2018, 48 states, two territories, and the District of Columbia (D.C.) received at least one state agency grant. For the current funding cycle (FY 2018-2021), 27 states received funding for SPGs.

### **Overview of Findings**

Prior to the AoD taking over the TBI State Partnership Grants initiative, the program was housed at the Health Research & Services Administration (HRSA) and there were more parameters placed on grantees in how the funding could be used. When AoD took over the TBI State Partnership Grants program, state teams and external stakeholders advocated for allowing greater flexibility in how the grantees could use their grant funding to include a focus on supporting the provision of



HCBS specific to individuals with TBI. Stakeholders felt this was important because while individuals with TBI generally receive strong medical and clinical support, less attention is focused on helping improve the social determinants of health of individuals with TBI through HCBS provision to support individuals to find a job, secure affordable housing and reliable transportation, and forge strong community and social relationships. Beyond implementing greater flexibility in the TBI State Partnership Grants program, AoD also established the TBI Technical Assistance and Resource Center, whose activities include:



- Providing grantees with individualized technical assistance (TA) to plan and develop effective programs that improve access to health and other services for individuals with TBI and their families;
- Sharing promising practices and lessons learned on implementing project activities and creating and/or incorporating TBI services and funding;
- Communicating TBI-related information and research findings; and
- Offering best practices and tools for grantees to conduct state needs and resource assessments.

AoD has also established nine work groups to focus on addressing some of the social determinants of health (SDOH) challenges that individuals living with TBI continuously encounter, of which one focuses on addressing barriers to employment. While this work group is open to all federally-funded TBI programs, AoD program officers acknowledged that only a small number of TBI programs participate in the workgroup on employment. Interviewees noted that TA resources devoted solely to building the capacity of TBI programs to assume a more active role in employment systems change efforts in coordination with national partners would add value to already existing TA offerings. As such, the AoD Disability Employment TA Center’s project team seeks to closely collaborate with both the TBI TA and Resources Center and the National Association of State Head Injury Administrators (NASHIA) – a strategic partner of the Center – to coordinate and align TA activities to ensure that TBI programs that wish to further concentrate on employment systems change strategies have access to additional TA offerings.

### ***Core Strengths of TBI State Partnership Programs in Effectuating Improved CIE Outcomes and Socioeconomic Advancement of Individuals with Disabilities***

#### ***Strategic Positioning of TBI State Partnership Programs to Promote Employment Systems-Change***

Like the State Councils on Developmental Disabilities (Council), TBI programs have a unique opportunity to promote an increased focus on employment and economic advancement of individuals living with TBI at a systems-level given their position as a state government agency. As state government entities, TBI program leaders can inform state policies, investments, and activities to ensure inclusion and prioritization of the TBI population in state goals related to improving the quality of life of individuals with disabilities. While TBI programs do not work



directly with individuals with TBI, they are able to contribute to building the capacity of publicly-financed service systems to better support individuals living with TBI. For example, state TBI partnership programs can finance trainings and TA initiatives to better prepare providers of system professionals (e.g., education, Medicaid, vocational rehabilitation (VR), workforce investment) to more effectively support the employment goals of individuals with TBI.

TBI programs often collaborate with other state agencies, local Brain Injury Association chapters, self-advocacy and caregiver organizations, other AoD-funded entities (including but not limited to Centers for Independent Living (CIL), Protection and Advocacy (P&A) systems, and Aging & Disability Resource Centers (ADRC)), and the private sector on advancing goals of mutual interest. While TBI programs do not provide direct services or case management to individuals living with TBI, they collaborate with partners at the state and community level to fund initiatives and pilot innovative models for improving the SDOH of individuals with TBI.

Interviewees cited a few examples where they provided subcontracts to partners to carry out specific capacity building efforts and to test and validate promising practices related to improving employment outcomes of individuals with disabilities. Other interviewees discussed the strategic positioning of staff specializing in TBI within cross-disability programs to ensure that TBI is adequately represented in cross-disability systems change investments across the state. For example, on program director of a state TBI program shared that their state had provided funding for a part-time staff person at ADRCs in the state, whose focus is to provide TBI-specific information resources, referrals, and service system navigation for individuals with TBI.

Another advantage of the TBI programs is their location within state government ecosystems. Several TBI programs are housed within a state's rehabilitation department and thus have a direct linkage on a regular basis to the state's VR program. Other TBI programs are housed in state departments of health and human services either as part of the state's public health division, or disability-specific program divisions. In these scenarios, TBI programs have an opportunity to inform state strategies for improving the SDOH of individuals with disabilities, as well as advocate for, inform, and provide implementation oversight of Medicaid-funded home and community-based services (HCBS) waiver programs.

### ***Emphasis of TBI State Partnership Programs to Focus on Underserved Populations of Individuals Living with TBI***

Interviewees also noted that TBI programs are required to direct grant funds toward enhancing service options to at least one underserved population of individuals living with TBI. For example, some state programs strategically fund TBI services or specialists in rural, tribal, and frontier communities; low-income communities of color, primarily in urban areas; survivors of domestic or external violence; and homeless individuals. Identifying successful models from TBI programs focused on improving employment outcomes of targeted underserved populations of TBI and help replicate and validate these strategies in other states is a key priority of the Center.



## Key Challenges and Considerations for TBI State Partnership Programs

### Barriers Individuals with TBI Encounter in Securing and Sustaining Employment

Environmental barriers can make re-entering the workforce difficult for an individual after acquiring a TBI in addition to sustaining employment over time. For example, individuals living with TBI experience ongoing cognitive, physical, emotional, or behavioral complications because of their TBI. Interviewees noted that these complications are poorly understood by employers and may interfere with individuals' productivity.<sup>1</sup> Challenges related to cultural and social bias can also negatively impact a job-seeker with TBI in securing competitive, integrated employment (CIE). Interviewees noted that employers and co-workers often lack an understanding of the manifestations of TBI, and as a result, may have preconceived notions, fears, or concerns about employing or working with individuals living with TBI. TBI programs must consider and address these challenges when designing policies and systems change efforts.

“Similar to individuals living with serious mental illness, individuals living with a TBI may experience some initial challenges with getting a job, but the real challenge comes in keeping the job over time.”

-Program Director, State TBI Partnership Program

Additional barriers related to re-entering the workforce and sustaining employment that interviewees noted included:

- Individuals with TBI have significantly higher risks for unemployment than the general population, even when compared to individuals with TBI employed at the time of injury.<sup>2</sup>
- Individuals who suffer mild traumatic brain injuries (mTBI) incur the risk of losing their jobs due to persistent post-concussive symptoms. This is especially true for individuals in their 30's because they often possess less experience in the workforce prior to acquiring their TBI.<sup>3</sup>
- While individuals with low education levels have a 30% higher risk of leaving the labor market following a concussion than individuals without concussion, the same risk is accelerated to 215% for individuals with higher education.<sup>4</sup>
- Previous research has found that only 15% of individuals with moderate or severe TBI were employed three months after their injury. However, 55% were employed after three

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<sup>1</sup> Malec, J. and Scanlan, R. Employment after Traumatic Brain Injury Living with Brain Injury. Brain Injury Association of America. (2015). <https://bianys.org/wp-content/uploads/2015/05/Employment-after-TBI.pdf>

<sup>2</sup> Doctor, J.N., Castro, J., Temkin, N.R., Fraser, R.T., Machamer, J.E., Dikmen, S.S. (2005). Workers' Risk of Unemployment after Traumatic Brain Injury. *Journal of the International Neuropsychological Society*, 11; 747-752.

<sup>3</sup> Graff HJ, Siersma V, Møller A, *et al.* Premorbid risk factors influencing labor market attachment after mild traumatic brain injury: a national register study with long-term follow-up. *BMJ Open* 2019;9:e027297. doi: 10.1136/bmjopen-2018-027297.

<sup>4</sup> Doctor, et. al (2005).



years.<sup>5</sup> Additionally, individuals with impaired cognitive skills and those with psychiatric issues were at highest risk for remaining unemployed long term.

Although returning to the same level of roles and responsibilities in the workforce after acquiring a TBI is difficult, many individuals with TBI do return to their former careers or to new ones that renew their self-confidence and professional fulfillment.

### **Challenges with VR for Individuals Living with TBI**

Interviewees described various challenges that individuals with TBI experience in accessing VR services due to attitudinal barriers, including attaining eligibility and working with VR counselors who do not understand the manifestations of TBI.

Some individuals feel that those who want to work will "pull themselves up by their bootstraps" and get a job. Such individuals fail to appreciate that TBI weakens people's "bootstraps" and that, for the price of relatively inexpensive supported employment services (SES), individuals with TBI can be given the boost they need to get work and contribute to society in ways that more than offset the cost of these services.

**Employment after Traumatic Brain Injury Living with Brain Injury**

Brain Injury Association of America (2015)

## **Emerging Themes and Strategic Opportunities**

### **Building the Capacity of VR Counselors to Successfully Support Individuals living with TBI Secure and Sustain Employment**

After a seminal longitudinal study published in 2003 confirmed that supported employment is not only cost-effective for supporting individuals with TBI but lead to cost decreases over time, state TBI partnership programs have invested in SES and have also validated the dramatic difference SES can make to support individuals with TBI in getting and sustaining employment.<sup>6</sup>

Interviewees who participate in the AoD-created employment work group for TBI programs emphasized that once individuals with TBI qualify for VR services, they are best served by VR counselors who have experience working with job-seekers with TBI. Experienced counselors apply strategies adopted over time that are critical for success in working with individuals with TBI.

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<sup>5</sup> Grauwmeijer E, Heijenbrok-Kal MH, Haitsma IK, Ribbers GM (2012). *Archives of Physical Medicine and Rehabilitation*. Vol. 93(6), pp 993-999.

<sup>6</sup> Wehman P, Kregel J, Keyser-Marcus L, Sherron-Targett P, Campbell L, West M, Cifu DX. Supported employment for persons with traumatic brain injury: a preliminary investigation of long-term follow-up costs and program efficiency. *Archives of Physical Medicine and Rehabilitation* 2003;84:192-6. Data were collected on clients placed into at least one competitive supported employment position from 1985 to 1999. Analyses were performed to examine the costs of supported employment, employment characteristics (e.g., wages, length of employment), and benefit-cost ratios of supported employment for individuals with TBI. The results found that the average length of employment for the current sample was 42.58 months; average gross earnings were \$26,129.74 for individuals during their entire duration of employment; billing charges accrued for employment services averaged \$10,349.37; and individuals with TBI earned an average of \$17,515 more than the costs associated with their supported employment.

[http://www.worksupport.com/documents/se\\_tbi\\_wehman.pdf](http://www.worksupport.com/documents/se_tbi_wehman.pdf)



However, many VR counselors lack experience working directly with individuals with TBI, and thus require additional training and professional development for supporting this specific population of individuals with disabilities.

**Success Story Theme: Systems Change**

**The Rehabilitation Hospital of Indiana and Nebraska VR**

As an Administration for Community Living (ACL) TBI program grantee, the Rehabilitation Hospital of Indiana partners with other TBI grantees to form work groups focused on identifying the array of challenges and the lack of employment opportunities and supports for individuals with TBI. The Indiana TBI team partners with the Nebraska VR TBI team to co-lead the Employment Work Group. The Work Group employs a two-tiered approach where some TBI grantees are Mentor States while others are Partner States. Mentor States have developed core competencies with various professionals, such as VR Counselors, to support individuals with TBI to return to the workplace. The Work Group facilitated a peer review of the competencies in addition to sharing the competencies with the VR agency. As a result, VR Counselors have become more equipped to better serve individuals with TBI who have a desire to obtain employment.

As such, the TBI Work Group led by the Rehabilitation Hospital of Indiana and Nebraska VR focused on developing strategies and implementing tools and resources to support VR programs in counselor capacity-building to better support job-seekers with TBI. Specifically, the workgroup has developed an assessment for VR counselors to ascertain their level of knowledge and experience working with individuals with TBI, as well as a tool for helping VR systems frame training and professional development around core competencies necessary for successful employment outcomes. The TBI programs in Indiana and Nebraska are currently testing the assessment and core competencies, with additional states interested in also piloting this model over time. The Center would like to support the workgroup in publishing its results with respect to the model, sharing it with a national audience, and providing ongoing TA to other TBI programs interested in implementing the assessment and competencies.

***Working with other Partners to Expand Opportunities for SES and CIE Options for Job-seekers with TBI***

In addition to providing TA to the VR system, TBI programs have demonstrated their strength in forging partnerships with state Medicaid HCBS programs, employers, family groups, and other AoD-funded entities. There is growing demand for the establishment or expansion of Medicaid HCBS waiver options focused on supporting individuals with TBI. Additionally, within those waivers, there is demand in including SES and benefits planning as core services. TBI programs can help inform the design and implementation of these waiver services in collaboration with State Medicaid Agencies. TBI programs have also worked to provide informational resources to families who may have misconceptions or fears about their loved ones with TBI returning to the workforce. Additionally, some TBI programs described their efforts to begin developing relationships with companies that have a statewide presence to help them think through strategies for not only hiring more individuals with TBI but supporting them over time to ensure retention of these employees.

