

# Arizona Governor's Council on Spinal and Head Injuries

## 2015 Year in Review Highlights

### What is the Year in Review?

The Year in Review report documents lessons learned by the Council and its partners about the needs and preferences of persons with Traumatic Brain Injury (TBI) and Spinal Cord Injury (SCI) and how we can best enhance their quality of life. Information for this report comes from interactions with persons who have TBI and SCI, their families and caregivers, and those who serve them. Contributors include the Arizona Spinal Cord Injury Association (AzSCIA), the Brain Injury Alliance of Arizona (BIAAZ), the Arizona Department of Economic Security Rehabilitation Services Administration (DES/RSA) Vocational Rehabilitation (VR) and Independent Living Rehabilitation Services (ILRS) Programs, and Council staff and consultants—all of whom have provided services funded by the Council.

### What have we learned about the lives of people who have TBI and/or SCI?

- We learn a lot when we engage with and listen to people with TBI and SCI and their families. It is important to include them in our planning, implementation, and evaluation.
- Each person is different and has different needs, preferences, assets, history, and environment, but they share a need for hope for the future. Connections to peers, the information they need to plan and navigate their future, and ongoing services and supports provide this hope.
- Living with TBI and/or SCI is a private, personal, and every day journey. Unfortunately, many people and their families do not receive the information they need about this journey, either at the time when they are newly injured or when their circumstances change throughout their lifespan.
- Family engagement is critical, particularly for those who have TBI. As one Counselor put it: "Families are as important here as interpreters are for people who are deaf."

### What do people with TBI and/or SCI want and need?

- People who have TBI and/or SCI have the same aspirations as everyone else, but they often need resource facilitation and other supportive services throughout the lifespan to achieve their goals, from the time of injury forward. While Council funding cannot meet every need or satisfy every want, it supports AzSCIA and BIAAZ and they link people to the information and resources that will enhance the quality of their lives.
- People who have TBI and/or SCI want to be as independent as possible. ILRS and VR services can and do help.
- Based on requests for resource facilitation and contacts with VR and ILRS Counselors, the greatest needs are:
  - To be able to live safely and as independently as possible. For all, this means affordable housing that is adapted to their needs. For some, it may mean assistance with activities of daily living, a secure residential setting with behavioral supports, or an age-appropriate environment. For others, it may mean environmental controls and other assistive technology.
  - To be able to get to work and access the community and its resources. For all, this means reliable, affordable transportation.
  - To be able to engage with others in community activities. For all, this means recreational and socialization experiences and opportunities for peer involvement and support.
  - To be able to be understood and served competently in the community. For all, this means access to professionals such as physicians, therapists, and social service providers who really understand TBI and/or SCI. For some, this means access to someone who can help them navigate complex service delivery systems. For many, it means employers who understand the assets that people who have disabilities can bring to their workforce.
  - To be able to manage their lives and futures. For all, there is a need for legal and financial planning. For many, there is a need for life care and special needs planning.

## How has the Council responded?

- Because the number of people with TBI and/or SCI is so large, the Council could never meet all their direct service needs. Alternatively, the approach we have taken is to fund AzSCIA and BIAAZ to impact lives through linkages and support, including resource facilitation, educational classes and conferences, and outreach activities. We need to work together to ensure that everyone knows about AzSCIA and BIAAZ.
- We did not want to lose the momentum that had been built with the military, so we are continuing to partner with the Phoenix VA and Southern Arizona VA (SAVAHCS), as well as the Arizona Coalition for Military Families (ACMF) to address the educational needs of service members and veterans with TBI and SCI, their families, and the professionals who serve them. We have learned and continue to learn about cultural competence with this population. We have established our credibility with this community and are well-positioned to continue to enhance awareness of TBI and its relationship to polytrauma among those agencies and organizations that provide services and supports to them.
- Council funding for the VR TBI Specialists Program and ILRS Program continues to show positive outcomes for people with significant challenges (ILRS serves both those who have TBI and those who have SCI). The most common ILRS services provided for people who have TBI are therapies (occupational, speech and language). The most common services provided for people who have SCI are home and vehicle modifications, which are expensive but essential to independence. For those who have been injured recently, accessibility is the key. Without home modifications, tools, and education, they often cannot get into and out their homes independently. Vehicle modifications are next most important, as transportation is essential to community access and work. Long term employment supports are often needed for people with TBI and/or SCI whose goal is employment. These services are not currently available via VR.
- We continue to offer training and technical assistance for ILRS and VR counselors, but more specialized counselors and more education for general counselors is needed, particularly given the
- rate of turnover among staff.
- Education has been provided to many different professional audiences, thereby enhancing their capacity to identify and appropriately serve persons with TBI and/or SCI in their own systems. There will always be more need than we can meet.
- Primary prevention continues to be a focus of the Council's work with the Injury Prevention Advisory Council (IPAC).
- Prevention of secondary conditions continues to be a focus of all the work the Council, BIAAZ, and AzSCIA do every day.
- In order to help the statewide organizations be successful in carrying out their contracts (and, therefore, continue to enhance the quality of life of people with TBI and/or SCI), technical assistance can be very helpful. As we help them build their capacity, they are better able to serve their target audiences effectively and be good stewards of the Council's resources.
- The work of the statewide organizations is in alignment with the Council's strategic plan and there is ample evidence to indicate that the desired results are being achieved. The new Council plan, *Way Forward*, reflects this and builds on prior successes to extend the reach and impact of the Council.

## **What have we learned about how best to enhance quality of life for people with TBI and/or SCI?**

- People who have TBI and/or SCI and their families want to know that someone is there for them, that they are being heard. They want a long-term relationship with a trusted source of timely, practical, and accurate information—someone that they can count on and come back to when life circumstances change. Particularly among people with TBI and their families, helping them “translate” what they are seeing in reality into clinical terms and vice versa aids communication with professionals and facilitates living with TBI. Resource facilitation addresses these needs.
- Synergy among the services that are funded by the Council extends our reach and benefits everyone, often in unpredictable ways. For example, individual needs identified through the provision of resource facilitation inform the development and delivery of educational classes that reach many people. Individuals who utilize one service (such as a support group) may go on to help deliver another (such as peer mentoring). As the staff at AzSCIA say, “One thing leads to another!”
- Taking a prevention approach can and does positively impact health and well-being. For example, going beyond the request for resource information (for example, for a referral to a urologist) and determining if there is something we can do to help alleviate a problem (such as education about prevention of urinary tract infections) may help a person avoid future medical issues.
- Education we provide/fund for professionals who come into contact with people with TBI and/or SCI enables them to provide better services. For example, the training provided to the educational community via the Council and the Arizona Department of Education benefits both the recipients of the training and their students in the long term.
- Linking people to VR and ILRS counselors and community service providers who understand TBI and SCI helps them to become as independent and productive as possible.
- People who have TBI and/or SCI and their families want ongoing support and mentoring from their peers. They value having a connection to someone who knows what it is like to live with these conditions and can provide individual support and information needed to enhance well-being and quality of life.

