

# The State of Ohio's Needs and Resource Assessment Of Individuals with Brain Injuries and Their Families

March 2006

## Executive Summary

### Introduction

This report contains the results of the 2005 Needs and Resource Assessment of Individuals with Brain Injury (BI) and their Families, conducted by Ohio Legal Rights Service (OLRS) under a grant from the Ohio Brain Injury Advisory Committee. OLRS, an independent state agency, is Ohio's federally and state designated Protection and Advocacy System. The Rehabilitation Services Commission's Brain Injury Advisory Committee and OLRS for the most part funded the project. Additional funding came from the Ohio Department of Health, the Ohio Bureau of Workers' Compensation, the Ohio Department of Mental Health and the Ohio Department of Alcohol and Drug Addiction Services.

The purpose of this report is to provide Ohio policymakers with the information they need – first and foremost, the ideas and experiences of individuals with brain injuries and their families – to plan for and fund an efficient, effective, ability-based, inclusive system of supports and services.

### Background

The Centers for Disease Control estimates that slightly over 2% of the U.S. population or *roughly 227,000 Ohioans currently live with disabilities resulting from traumatic brain injury*. This figure does not take into account children, those living in institutional settings (for example nursing homes, prisons, or psychiatric hospitals), those with "mild" injuries, those with non-traumatic or acquired brain injury (damage due to anoxia or stroke for example) or those whose brain injury has gone undetected.

This Needs and Resource Assessment included a survey completed by 522 Ohioans with brain injuries and their families; a separate survey completed by 143 providers; 3 focus groups with individuals with BI and families; and a survey completed by the 11 state agencies represented on the Ohio Brain Injury Advisory Committee.

Respondents of the Individuals and Family survey were from 68 of Ohio's 88 counties, 57% were from predominantly rural counties. The majority of respondents (61%) were individuals with a brain injury, 24% were parents, and the rest were other family members or people who assisted individuals with BI. Most individuals with a BI lived with families or alone in a home or apartment. Individuals who live in nursing homes and other congregate settings were underrepresented in this survey sample (9%).

## Highlights

Outreach to individuals with brain injuries and families was primarily accomplished through the Brain Injury Association of Ohio. Utilization of this formal support network coupled with the low response rate from residents living in facilities point to the likelihood that the individuals represented in this survey are probably better connected to supports than many people with brain injuries.

Despite that likelihood, the highlights of this Assessment are valid and stark:

- Individuals with brain injury and families have a critical need for dependable and timely information.
- Ohioans with brain injuries and their families face enormous difficulties navigating the existing system of services and supports. Individuals and families often have to look for services across multiple federal, state, local and privately funded systems. Sometimes they find them, sometimes they don't.
- There are significant gaps between the services that are available and the services individuals and their families say they need. Only 38% of individuals with brain injury and family members agreed they had choice among meaningful supports. Just half (50%) agreed they received the supports needed to live where they want to live, and only 53% agreed that supports received reduce their stress.
- People with brain injuries and families want supports that would help them with everyday living. The top ten most needed services identified through this Needs Assessment were cognitive training; recreation and social activities; family counseling; behavioral supports; neuropsychology; individual counseling; social skills training; case management; legal services for injury; and dental services.
- Individuals and families want a continuum of services and housing options, including those for individuals needing long-term care. They want continued access to therapies and counseling services that have only been available in short term rehabilitation just after their injury – if at all.
- Individuals with BI are frequently unemployed or underemployed as a result of their injury. 86% of respondents reported that employment was affected by their injury. Of the 301 adults of typical working ages 22 – 55 who live in a house or apartment, 70% were unemployed – only 9% were employed full-time and 15% part-time.
- Children and adults who sustain brain injuries are not the only persons affected – family members are also in great need of support.
- Services received through traditional service systems (mental health, MR/DD, employment, health) are often neither appropriate nor helpful; people struggle to meet eligibility criteria and obtain supports. Needs and accommodations specific to brain injury often go unaddressed.
- Middle income families are financially squeezed, with significant out of pocket expenses that

are not covered by insurance. 38% of respondents had private health insurance (sometimes in combination with Medicare, Medicaid, or other coverage).

- Individuals and family members living in poverty face especially desperate situations as they struggle to live with the effects of their injuries. Four in five respondents (86%) reported their income was affected by their injury.
- Regardless of income, individuals with brain injuries and their families face enormous barriers learning about eligibility, applying for, receiving benefits, and subsequent re-determinations of benefits. Significant inequities exist in obtaining services that are based not on need, but on eligibility barriers.
- Opportunities in regular and special education for children with brain injuries can be improved. Identification and appropriate services are essential.
- Often individuals with brain injury and their families are not adequately helped to adjust to the loss of their former lives and to limitations after their injuries. People with brain injuries reported isolation and alienation after their injuries.
- Many Ohioans who know about other disabilities are not familiar with the causes, affects and prevention of brain injuries. Repeatedly, individuals with BI and their families expressed outrage, anger, sadness and resignation about discriminatory treatment and their forgotten status.
- State agencies devote very few resources to meet the needs of individuals with brain injuries and families – in terms of training, staff, or financial resources. Most agencies are not even able to adequately identify those recipients that have a brain injury, a necessary first step to addressing those needs.

### **Recommendations**

The rich quantitative and qualitative information yielded from this Needs Assessment presents Ohio policy makers with a blueprint for configuring a meaningful system of supports and services for children and adults with brain injuries and their families. The results present a clear challenge to make significant changes to improve the quality of life for Ohioans with brain injury and their families. OLRS respectfully makes the following recommendations.

- 1. Create a “home” agency for brain injury that provides accessible information and case management to people with brain injury and develops policy, measures quality, and provides technical assistance and training.** This recommendation also urges that affordable technology solutions should be utilized including a web “home” with information and resources for, and tools to obtain feedback from, individuals with BI and their families.
- 2. Establish a funding source dedicated for brain injury.** Twenty one states have trust funds for individuals with brain injury, and twenty states have home and community based waivers developed specifically for brain injury. Ohio has no dedicated public funding for brain injury services. The lack of funding for services in Ohio has also resulted in limited

availability of providers knowledgeable about brain injury. People with brain injury often must seek services out of state.

3. **Serve all people with brain injury.** This recommendation urges that there should not be barriers to eligibility that currently exist, including type of brain injury, age at injury, income, etc.
4. **Develop a system of services for individuals with brain injury that is based on self-determination.** This recommendation urges that services be developed that people with brain injury identify as needed; that those services are flexible, individualized and provide choice to those who need them. This recommendation also addresses the need for family supports and housing options.
5. **Enhance and develop services and supports that enable individuals with brain injury to be productive and as self sufficient as possible.** This includes recommendations to improve educational services, eliminate barriers to employment, and improve transportation.
6. **Improve existing service systems at both state and local level through state agency leadership.** This recommendation urges state agencies to take immediate steps to improve the services that they provide to those with brain injury. Specifically, state agencies on the BIAC are urged to provide training about brain injury to their staff and providers that they fund; assign and fund staff to work on brain injury issues; develop technical assistance team(s) in collaboration with other agencies; improve data collection that identifies recipients of service who have brain injury; and develop and use screening tools to identify applicants and current recipients who have brain injury.

### **Conclusion**

We encourage individuals with brain injuries, their families, providers and policymakers to read and discuss this report, and work together to implement these recommendations. Implementation will support the inclusion of individuals with brain injuries in neighborhoods, schools, and workplaces, and will markedly improve the day-to-day lives of children and adults, and their families.

While Ohio has a long road ahead of it to create an efficient, cost-effective, coordinated continuum of service that supports flexibility, offers meaningful choice, and promotes ability, the task of implementing these recommendation must be undertaken. As one person wrote,

“Ignoring the problem or saying it’s fixed, won’t make it go away. We are still here - all [us] want is to be dealt with fairly.”

To read the entire report, visit the Ohio Legal Rights Service website, at: <http://olrs.ohio.gov> .