

FOCUS ON CAREGIVERS 2010-2011 NEEDS ASSESSMENT

In 2010, Brain Injury Association of Florida commissioned WellFlorida Council (WFC) to conduct a needs assessment of caregivers of persons with a traumatic brain injury (TBI). This needs assessment is part of BIAF’s ongoing work to define the magnitude and pervasiveness of TBI throughout Florida, and to augment, improve, refine and, where possible, create the services to enhance the quality of life for survivors of TBI, their families and caregivers. At this point in time, the first stage of the assessment is complete and the second stage is underway.

In the first stage, focus groups (and structured interviews where necessary) were conducted to gain meaningful qualitative insights into major care giving issues. Caregiver participants represented a diverse cross-section of TBI caregivers. The loved ones of some caregivers had been injured as recently as 3 months prior to the focus groups up to nearly three decades prior. Mechanisms of injury included vehicle crashes, firearms, and physical assault. Nearly all of the injuries to loved ones reported by caregivers were initially serious enough that immediate survivability was an issue. In the vast majority of instances, caregivers were either the parent or spouse of an individual with TBI.

A total of five focus groups were conducted and the 32 participants in this process provided observations and identified potential directions and opportunities for services geared toward strengthening and supporting

caregivers in their roles. Discussions followed three thematic areas:

Most Difficult Caregiving Stages and Issues

Through discussion, most members acknowledged that every stage brings its own difficult and challenging issues and that the perception of “most difficult” is often driven by the current stage or challenges being faced. Critical stages identified and discussed in depth are identified in the following chart:

| TBI Caregiving Process | |
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| Stage | Challenge(s) |
| Golden Hour/ Initial Injury | Survival of loved one; quality care |
| Inpatient Hospitalization | Poor doctor communication; new vocabulary |
| Discharge/ Settling Into Home | Impact on lifestyle; strategies for patience |
| Re-Integrating Into Regular Activities | Expectations of loved ones; family dynamics |
| Surviving Long-Term | Respite; End-of-life planning |

Essential Caregiver Resources, Services and Attributes

The groups explored resources and services that were deemed critical for successful caregiving. Some already existed and some might not exist but were seen to be needed and advocated. Thirteen separate areas were identified including maintaining support groups, training on managing behavioral problems, building opportunities for ongoing interactions with other TBI families, and having someone who can help them access community services.

Caregiver Personal Needs

Most caregivers indicated that the needs of their loved one with TBI and other family members came first no matter what. Discussions indicated a disconnect between the recognition of the need for respite services

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versus, as one person put it “feeling the permission” to use them. Many indicated that adequate respite services were not available to them anyway. Participants also said maintaining a sense of hope and building patience skills were vitally important but extremely difficult in the face of exhaustion and isolation.

Generally speaking, upon discussion with the caregiver focus group participants, there seems to be three categories of caregivers when it comes to acceptance

of brain injury as long-term. The first group are those who immediately during that first day understood that if their loved one survived, TBI would be a long haul. Another group of individuals came to this realization later, usually after some sort of milestone event, like getting to rehabilitation and seeing the other people in rehabilitation, triggered this realization. Still others indicated that, as a coping mechanism, they choose not to acknowledge the long-term nature of their loved one’s injury as they are constantly looking for improvement, even incremental as it may be, in their loved one’s condition.

These differing levels and timing of acceptance of TBI as a long-term issue must be acknowledged if programs and training are being developed to assist caregivers of those with TBI.

The final phase of this needs assessment will be conducted in May and June 2011. The responses from the focus groups have been used to develop questions for a survey instrument which will be distributed to all caregivers whose loved ones participate in BIAF’s Resource Facilitation Program. This survey will be administered initially in 2011, with the intent of being administered annually thereafter. This ongoing process will monitor the perception among caregivers of their critical support needs and how these needs are being met. Survey results would then inform both tactical and strategic service delivery and planning.

Final conclusions, recommendations and next steps will be published in the next edition of BrainWaves. To see the TBI Caregiver Focus Groups Final Report, visit www.byyourside.org and search for Caregiver Focus Groups.