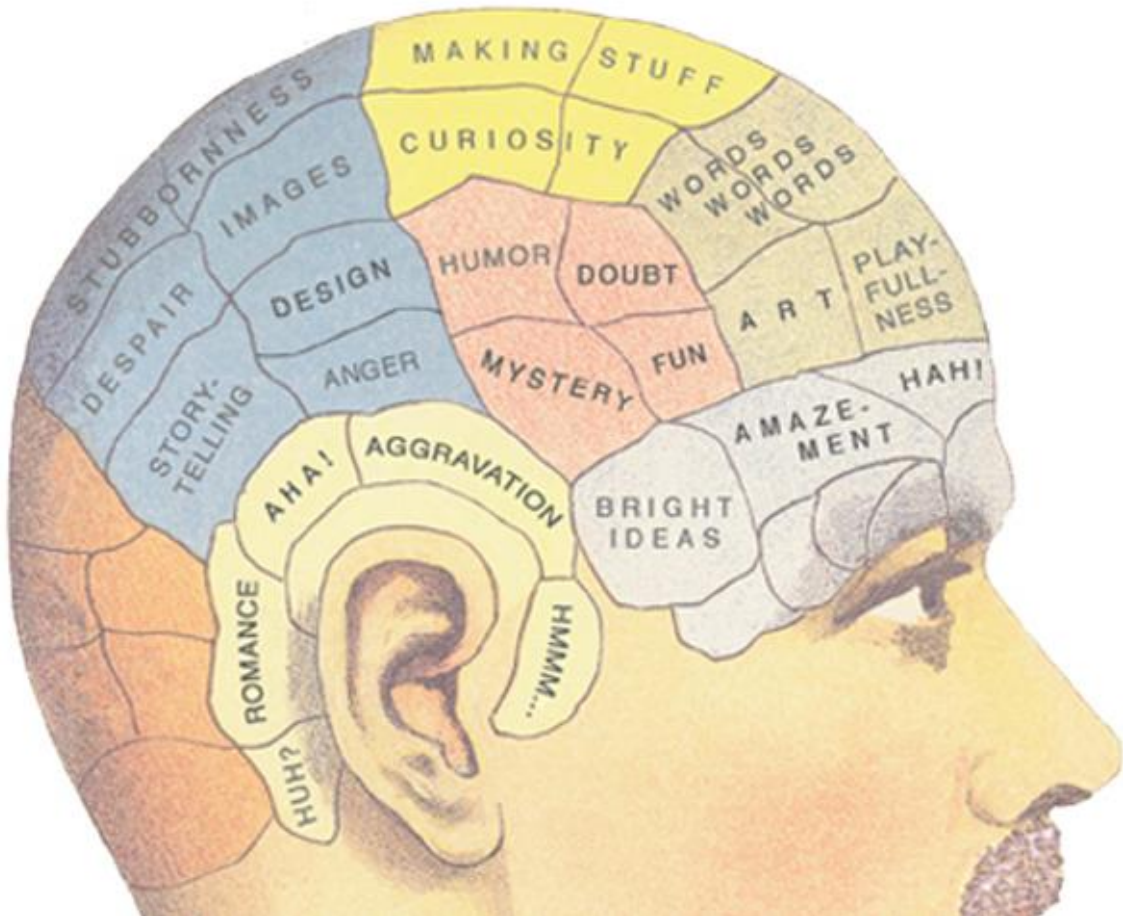


# 2013 Virginia Statewide Brain Injury Services and Needs Assessment

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**Contracted by the Virginia Department for Aging and Rehabilitative Services**  
*Funding: Grant Number 6 H21MC06763-05-02 awarded to the Virginia Department for Aging and Rehabilitative Services by the U.S. Department of Health and Human Services, Health Resources and Services Administration.*

## *Acknowledgement*

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The contract for this statewide needs assessment came from the Virginia Department for Aging and Rehabilitative Services (DARS). The funding came from a grant awarded to DARS by the U.S. Department of Health and Human Services, Health Resources and Services Administration. SERL would like to thank everyone who helped make this assessment successful, especially brain injury survivors and caregivers who shared their stories, the employees at the brain injury clubhouses and support groups throughout Virginia. In addition, we thank those individuals at the Brain Injury Association of Virginia (BIAV) and DARS who provided us guidance and assistance in finding participants for the different assessment activities and in the review of survey materials. Finally, our thanks goes out to all those who served on the ABI steering committee (John Heath, Kelli Williams Gary, Michelle Witt, Mark Salisbury, Patricia Goodall, Kristie Chamberlain , Anne McDonnell, and Sue Marrow) for sharing their insights and views.

# Executive Summary

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The Virginia Department of Aging and Rehabilitative Services (DARS) contracted with SERL to conduct the 2013 Statewide Needs and Resources Assessment, focusing on the needs and resources of brain injury survivors and their caregivers. Funding was provided through Grant Number 6 H21MC06763-05-02, awarded to the Virginia Department for Aging and Rehabilitative Services by the U.S. Department of Health and Human Services, Health Resources and Services Administration. The purpose of this evaluation was to collect information that would inform DARS of the gaps in services for brain injury survivors and their caregivers.

The goals of this comprehensive needs and resources assessment were:

- ✓ To identify service needs of individuals with Acquired Brain Injury (ABI) and their families, such as health, rehabilitative and therapeutic services, housing, employment and other supports.
- ✓ To better understand the existing resources and programs and identify gaps in services for individuals with ABI in each of the regions within Virginia.

To support the assessment, 6 focus groups were held and three surveys were disseminated across Virginia. One survey targeted survivors, one targeted caregivers and families, and one targeted professionals who serve people with ABI. (See full report for methodology and distribution). Together, these surveys paint a picture of the current system of care, including gaps in service, quality of service, and the training needs of professionals.

## Description of Participants

**Focus Groups:** Six focus groups were conducted: Chesterfield County, Fairfax City, Martinsburg, Virginia Beach, Harrisonburg, and York County. A total of 39 ABI survivors and/or their caregivers participated in the 6 focus groups held across the state. In total, 41% of participants characterized themselves as caregivers of an ABI survivor (n=16) and 59% were ABI survivors (n=23). Females outnumbered males in all groups; 3 out of 4 participants were female. With relation to race/ethnicity, 85% of participants were white, 8% were African American, 5% were Native American and 3% were Hispanic. One participant received their injury while in the military. Nearly half characterized their injury (or that of the survivor they cared for) as severe (47%).

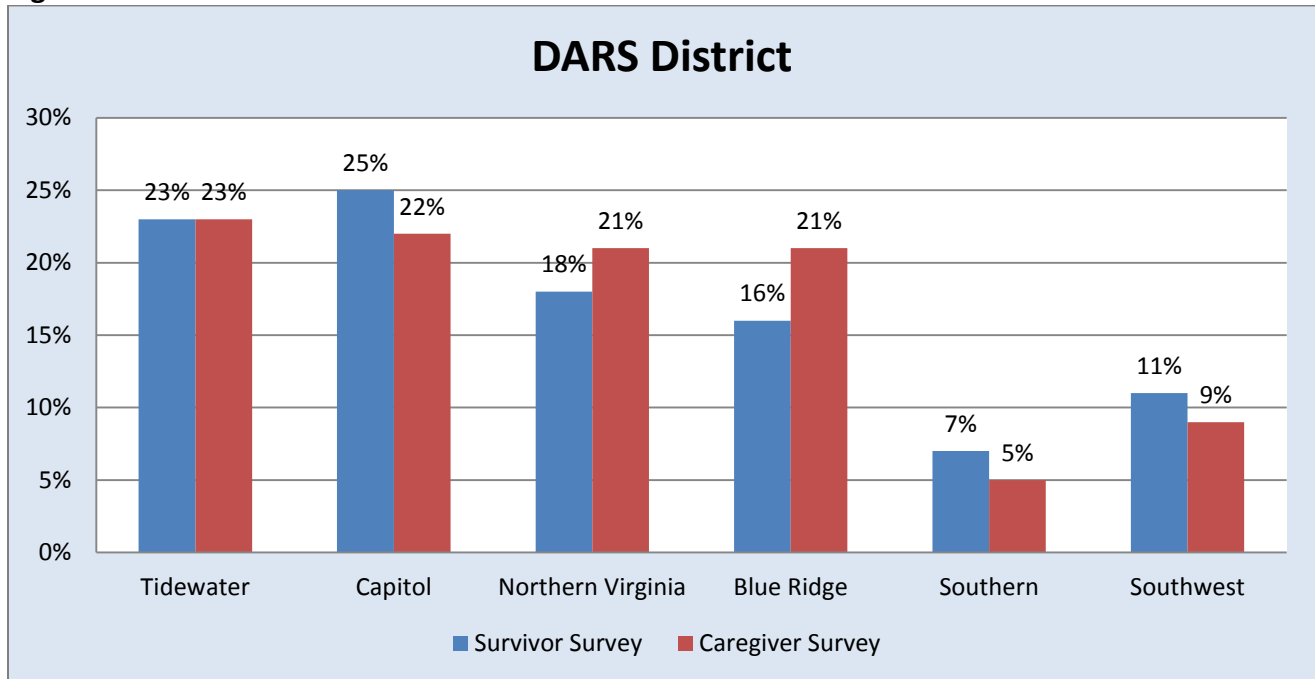
**Survivor Survey:** A total of 213 surveys were received from survivors. Nearly half of respondents to the Survivor Survey live in the Tidewater (23%) or Capitol (25%) districts. The majority of our respondents were aged 40 or older (71%) with a mean of 47 years old. Survivors were evenly split between male (51%) and female (49%), and most were Caucasian (87%). Three out of four respondents (75%) indicated that they had attended at least some college, with 21% reporting that they had earned a graduate degree. In total, the survey was completed by 4 individuals on Active Duty (2% of total sample) and 19 Veterans (9% of total sample). While 65% of respondents were employed full time at

the time of their injury, only 21% reported working full-time now. Nearly 40% were currently unemployed and on full disability.

**Caregiver Survey:** A total of 182 surveys were received from caregivers. Most of the caregivers in the survey were evenly divided between Tidewater (23%), Capitol (22%), Northern Virginia (21%), and Blue Ridge (21%). Nearly three-quarters were aged 50 or older (74%) with a mean of 56 years old, and they were predominantly female (82%). As with the Survivor Survey, most caregivers were Caucasian (87%). Most caregivers (86%) indicated that they had attended at least some college, with 28% reporting that they had earned a graduate degree. In total, the survey was completed by 19 Veterans (10% of total sample). While 67% of caregivers were employed full time at the time of injury, only 53% reported working full-time now. More than half (51%) of the caregivers completing the survey reported that they are the parent of the survivor that they were filling out the survey for. Another quarter (24%) reported that they are the spouse of the survivor.

**Provider Survey:** A total of 60 surveys were received from Service Providers. One participating organization reported that they do not serve individuals with a brain injury or their caregivers, and another 6 providers were out of state. These organizations were removed from the dataset. This left a total of 53 providers for the analysis. More than half (57%) described their organization as private, while the remainder (43%) were public organizations. More than a third (37%) reported that they only serve individuals with a brain injury, while 61% reported that they serve both the person with the brain injury and their family members/caregivers.

**Figure E1: DARS Districts**



## History of Acquired Brain Injury

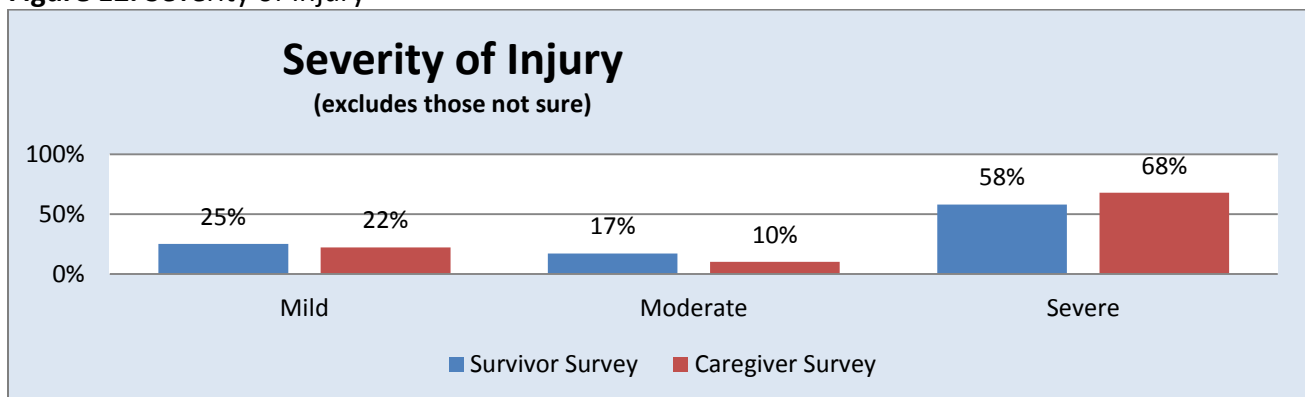
**Survivor Survey:** More than one in four respondents (27%) reported that they had survived more than one brain injury. The average length of time since the most serious brain injury was 12 ½ years, with 71% reporting that their injury took place at least five years ago. Excluding the 17% who were unsure of when they were diagnosed, 48% of the respondents were told they had a brain injury right away and 52% found out eventually, but not right away. Nearly a quarter of respondents (22%) were not sure how long they were unconscious. Of those who knew, 58% reported a serious head injury where they were unconscious for more than 1 day. The three most common causes of brain injury for the survivors in our sample were: motor vehicle accident (38%), stroke/aneurysm/AVM rupture (16%), and fall (12%).

Survivors were asked to describe the problems that they have as a result of their brain injury and they could indicate as many problems as applicable. Nearly all (86%) reported some sort of cognitive disability. Other common problems include behavior or emotional problems (70%), physical disabilities (69%), medical disabilities (66%) and communication disorders (55%).

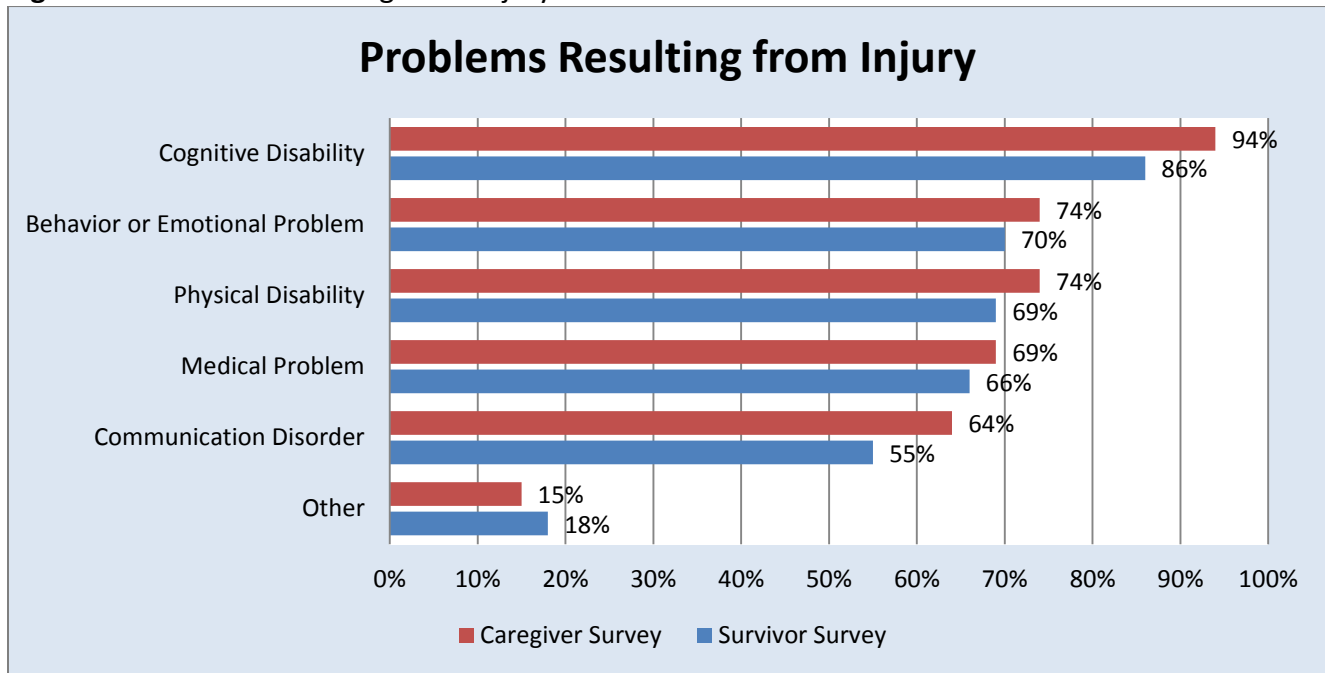
**Caregiver Survey:** Nearly one in four caregivers (24%) reported that the survivor had more than one brain injury. The average length of time since the most serious brain injury was 10 years, with 67% reporting that the injury took place at least five years ago. Excluding the 4% who were unsure of when the survivor was diagnosed, 62% of the respondents were told that the survivor had a brain injury right away and 34% found out eventually, but not right away. Fourteen percent of caregivers reported that they were not sure how long the survivor was unconscious. Of those who knew, 58% reported a serious head injury where the survivor was unconscious for more than 1 day. The three most common causes of brain injury for the survivors in our caregiver sample were: motor vehicle accident (30%), stroke/aneurysm/AVM rupture (18%), and assault/abuse (13%).

Respondents were asked to describe the problems that the survivor has as a result of their brain injury, and they could indicate as many problems as applicable. Nearly all (94%) reported some sort of cognitive disability. Other common problems include behavior or emotional problems (74%), physical disabilities (74%), medical disabilities (69%) and communication disorders (64%).

**Figure E2.** Severity of Injury



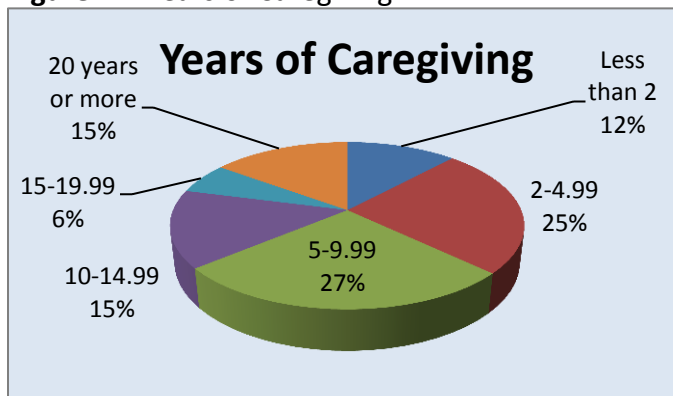
**Figure E3. Problems Resulting From Injury**



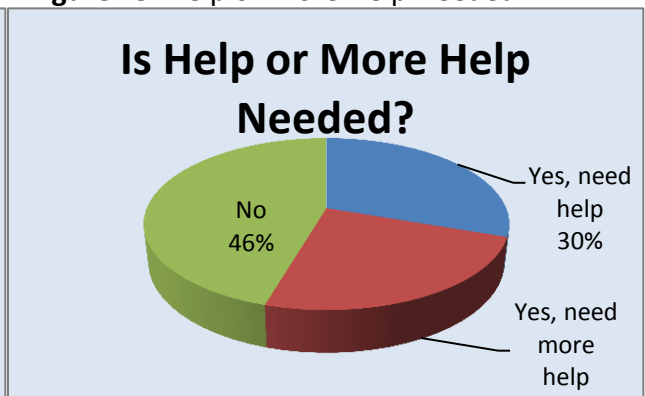
### History of Caregiving

**Caregiver Survey:** Roughly half (52%) of the caregivers have been caring for the survivor between 2 and 10 years. The mean number of years is 9, with the minimum being .25 and the maximum being 31 years. More than 60% of caregivers report that they provide all or most of the care, and over half (54%) indicated that they need help or more help caring for the survivor. Most caregivers said that they could not afford this help (63%), and that there are not enough resources available in their area (56%). Almost half of the caregivers who responded from South West Virginia (44%) and the Capital (46%) districts indicated that they were not getting the level of help needed due to cost/affordability of help in their area. More than half (56%) of the caregivers from Southern Virginia reported that they are not receiving the level of help they need due to lack of resources in their area.

**Figure E4. Years of Caregiving**



**Figure E5. Help or More Help Needed**



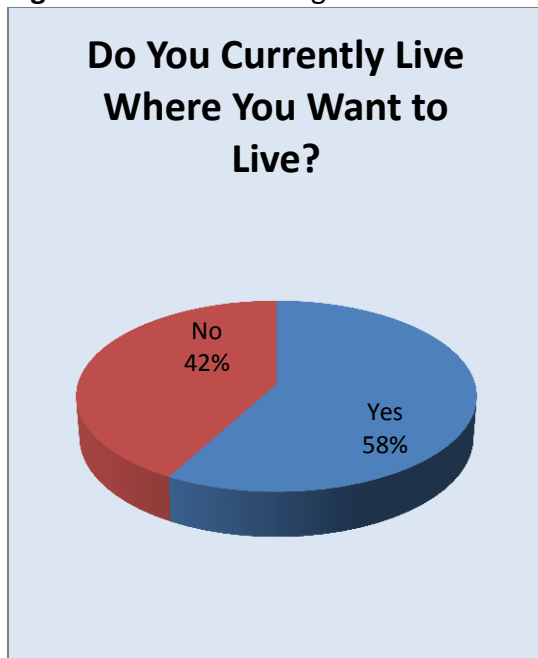
## Living Situation

**Survivor Survey:** At the time of their injury 96% of the participating survivors reported that they lived in a house or an apartment. This figure dropped to 88% currently – or post injury. Most of those who are no longer living in a house or apartment are currently in an assisted living facility (4%), group home (1%), or are homeless (1%). At the time of the injury, most report living alone (19%), with a spouse or significant other (36%) or with their parents and family (33%). This has changed very little; currently most survivors participating in the survey report living alone (26%), with a spouse or significant other (36%), or with their parents and family (29%).

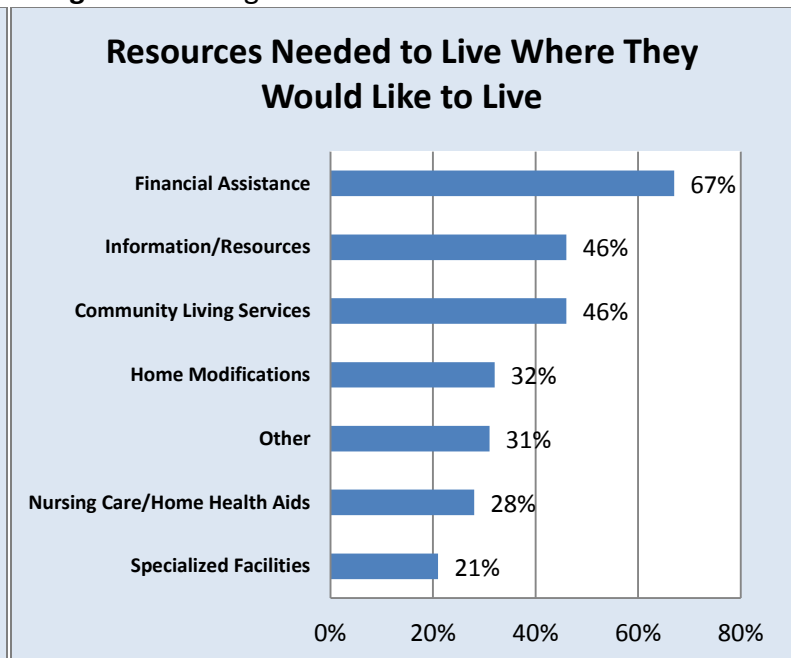
Participants were asked whether they currently live where they want to live. Forty-two percent (42%) reported that they do not. In order to live where they would like, two-thirds (67%) reported that they would require financial assistance, and 46% reported that they would need community living services. Forty-six percent (46%) reported that they would need information and resources.

**Caregiver Survey:** At the time of their injury 94% of the participating caregivers indicated that the survivor lived in a house or an apartment. This figure dropped to 82% currently – or post injury. Most of those who are no longer living in a house or apartment are currently in an assisted living facility (7%), group home (4%), or rehabilitation facility (2%). At the time of the injury, most caregivers report that the survivor was living with a spouse or significant other (35%) or with their parents and family (44%). Currently most survivors in the caregiver sample are less likely to be living with a spouse or significant other (27%), and more likely to be living with their parents and family (49%).

**Figure E6.** Current Living Situation



**Figure E7.** Living Resources



## Treatment History

**Survivor Survey:** Of the 204 people responding to the question, 27% reported that they received their care immediately following their injury *outside* of the state of Virginia. Within the first six months following their injury, most survivors reported receiving emergency room service (81%), inpatient hospital care (67%), inpatient rehabilitation (52%) and outpatient rehabilitation (54%).

Many survivors reported that they were “very satisfied” (34%) or “somewhat satisfied” (25%) with the care they received within the first 6 months after their brain injury. On the negative side, the remaining survivors reported being either “somewhat” (10%) or “very” (21%) *dissatisfied* with the care they received within the first 6 months.

More than half (53%) of the survivors completing the survey reported that they were not provided with information or advised on the services available for person’s with acquired brain injury. Another 22% of survivors were not sure whether they had received information. Of 25% who were provided with information, 59% reported that they received information from a doctor, and 45% received information from caseworkers. Nearly 40% received information from a nurse. A third of respondents reported receiving information about services from family/friends (33%) or the Brain Injury Association of Virginia (33%). The majority of survivors who received advice about services for their injury found the information they were given to be “excellent” (44%) or “good” (38%).

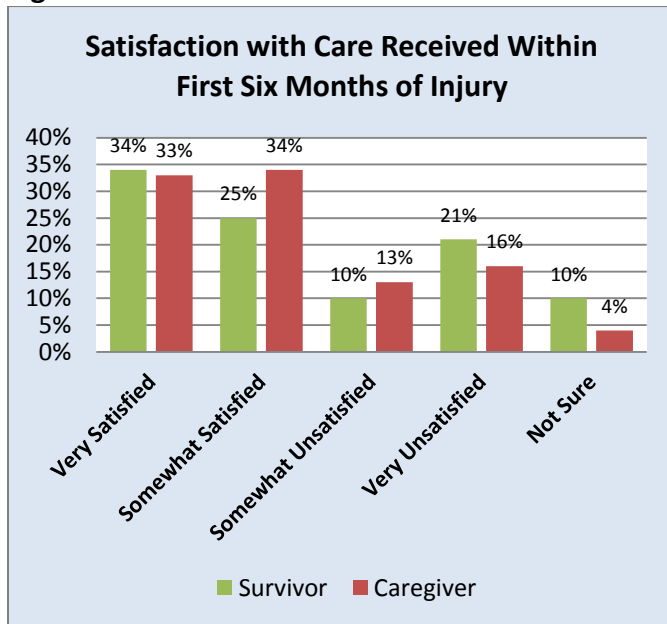
**Caregiver Survey:** Of the 168 people responding to the question, 24% reported that the survivor received their care immediately following their injury *outside* of the state of Virginia. Within the first six months following their injury, most survivors received emergency room service (86%), inpatient hospital care (84%), inpatient rehabilitation (70%) and outpatient rehabilitation (58%).

Many caregivers reported that they were “very satisfied” (33%) or “somewhat satisfied” (34%) with the care the survivor received within the first 6 months after their brain injury. The remaining caregivers reported being either “somewhat” (13%) or “very” (16%) *dissatisfied* with the care the survivor received within the first 6 months.

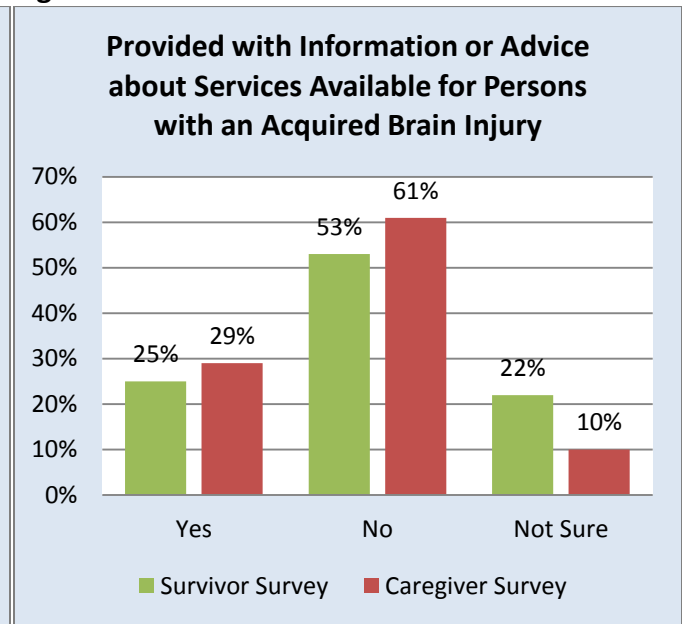
More than half (61%) of the caregivers completing the survey reported that they were not provided with information or advised on the services available for person’s with acquired brain injury. Another 10% of caregivers were not sure whether they had received information. Of those who were provided with information, 54% reported receiving information from a social worker, 42% reported that they received information from a doctor, and 50% received information from case managers. The majority of caregivers who received advice about services for their injury found the information they were given to be “excellent” (42%) or “good” (33%).



**Figure E8. Satisfaction First 6 Months**



**Figure E9. Provided Advice**



A need for better treatment and education at the time of injury has been clearly highlighted by these findings.

## Current Services

**Survivor Survey:** Two-thirds (66%) of survivors report that they are currently receiving medical services related specifically to their ABI. Well over half (64%) report receiving this care within 25 miles from their home, though more than a third (35%) report that they have to travel more than 25 miles from their home for this care. Most respondents reported that they either drive themselves to appointments (41%) or are driven by someone else (40%). More than a quarter (28%) of responding survivors report using more than three different methods to pay for the services they receive. Most commonly used are Medicare (40%), Disability/SSDI (41%), personal funds (37%) and private insurance (33%). Fifty percent of survivors indicated that they felt their health care coverage was sufficient, while 41% said their health care coverage was not sufficient and 9% were unsure.

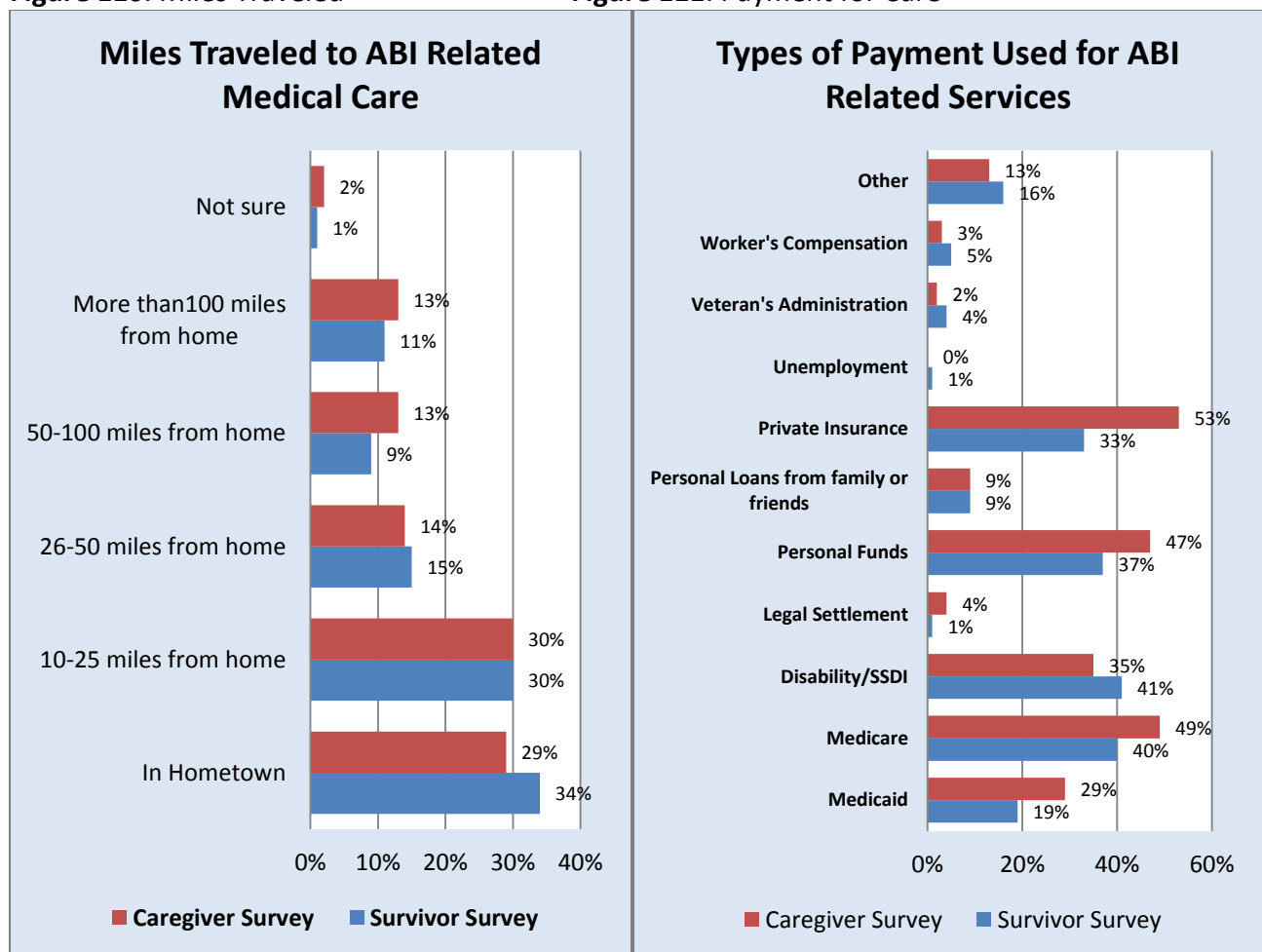
More than a quarter (28%) of survivors indicated that they need physical assistance to help them carry out their daily activities such as bathing, dressing, preparing meals, etc. Of these, 44% reported that they used a paid assistant (PAS) for this purpose. Of those who indicated that they need physical assistance with daily activities and are not currently using PAS, 84% indicated that they would be interested in having a paid helper. Respondents were then asked how many hours a week they would or do use PAS, and the average number of hours reported was 41.03 hours, with a minimum of 4 and a maximum of 168 hours a week.

**Caregiver Survey:** Of the 172 caregivers responding to this item, nearly two-thirds (61%) report that the survivor is currently receiving medical services related specifically to their ABI. Over half (59%)

report receiving this care within 25 miles from their home, though more than a third (40%) report that they have to travel more than 25 miles from their home for this care. Most caregivers reported that they either drive the survivor to their appointments themselves (61%) or that someone else drives the survivor to appointments (16%). Caregivers were asked how services related to the survivor’s brain injury are paid for, and could check all that were applicable. Most commonly used are Private Insurance (53%), Medicare (49%), Personal Funds (47%), and Disability/SSDI (35%). Half of the caregivers (50%) indicated that they felt the survivor’s health care coverage was sufficient for services related to the brain injury, while 50% said their health care coverage was not sufficient. More than half (51%) of caregivers indicated that the survivor needs physical assistance to help them carry out their daily activities such as bathing, dressing, preparing meals, etc. Of these, 58% reported that they used a paid assistant (PAS) for this purpose. Of those who indicated that they need physical assistance with daily activities and are not currently using PAS, 53% indicated that they would be interested in having a paid helper. Respondents were then asked how many hours a week they would or do use PAS, and the average number of hours reported was 45.66 hours, with a minimum of 2 and a maximum of 168 hours a week.

**Figure E10. Miles Traveled**

**Figure E11. Payment for Care**



## Use of Services

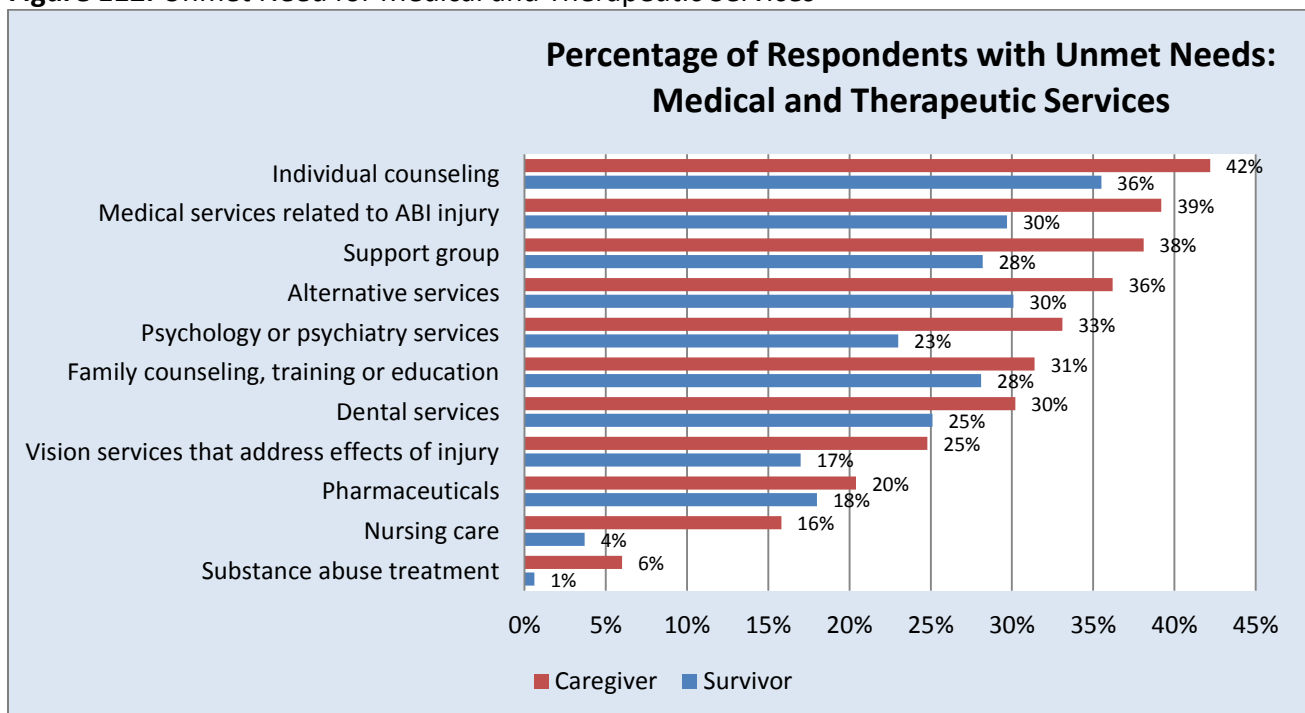
Within this section, respondents of both surveys (survivor and caregiver) were asked about various services that they may or may not need and whether or not they are currently receiving the service if needed. For each service, they were first asked if they had a need for that service. If they indicated that they did, they were asked whether or not they were currently receiving the service. If they answered that they were currently receiving the service then the survey followed up with a question asking whether the service met their needs or not. If they needed the service but were not receiving it they were asked why they were not, and three options were provided: not available, no funding/cannot afford, or some other reason. The section was organized into five broad categories: Medical and Therapeutic Services, Rehabilitation Services, Education/Employment Services, Community Living Support Services, and Residential Services.

A need was defined as unmet if the respondent indicated either (1) that they (or the survivor that they were answering the survey about) needed the service, were receiving it, but that it did not meet their needs, or (2) if they needed the service but were not receiving it for any reason.

### Medical and Therapeutic Services

Of those respondents indicating need for one of the medical and therapeutic services included on the survey, the greatest unmet need was noted for Individual Counseling Services (42% for caregivers and 36% for survivors), Medical Services that address the effects of the ABI (39% for caregivers and 30% for survivors), and Support Groups (38% for caregivers and 28% for survivors). For those participating in the surveys, there was little unmet need for Substance Abuse Treatment. These findings are presented in Figure E12.

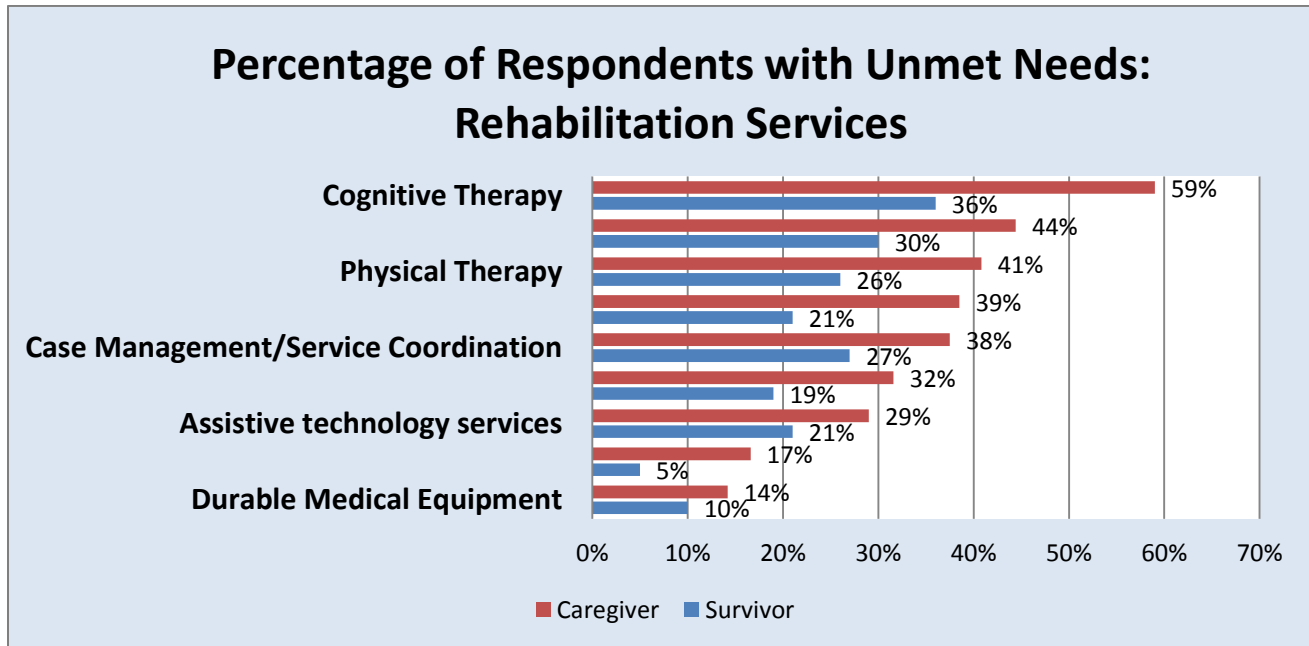
**Figure E12.** Unmet Need for Medical and Therapeutic Services



### Rehabilitation Services

The greatest unmet need for both caregivers and survivors within Rehabilitative Services was Cognitive Therapy (59% for caregivers and 36% for survivors), followed by Behavioral Support (44% for caregivers and 30% for survivors), and Physical Therapy (41% for caregivers and 26% for survivors). These findings are presented in Figure E13.

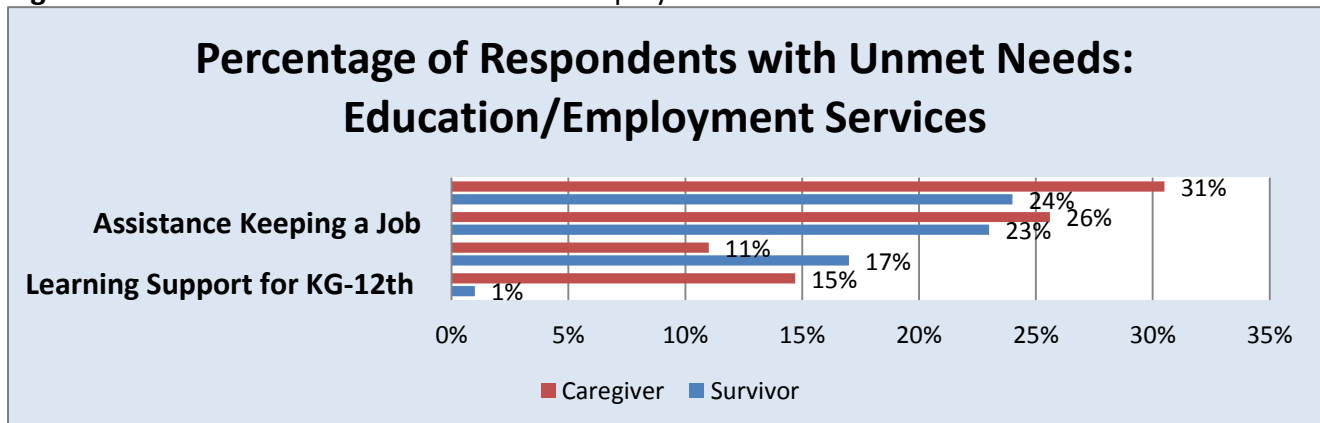
**Figure E13.** Unmet Need for Rehabilitation Services



### Education and Employment Services

The greatest unmet need within Education and Employment Services was Assistance with Getting a Job (31% for caregivers and 24% for survivors) and Assistance with Keeping a Job (26% for caregivers and 23% for survivors). An additional 17% of survivors and 11% of caregivers indicated an unmet need for Learning Supports for Higher Education. These findings are presented in Figure E14. Reasons indicated for the unmet need for this category of Rehabilitation Services are presented for the three services with the greatest unmet need in Figure E14.

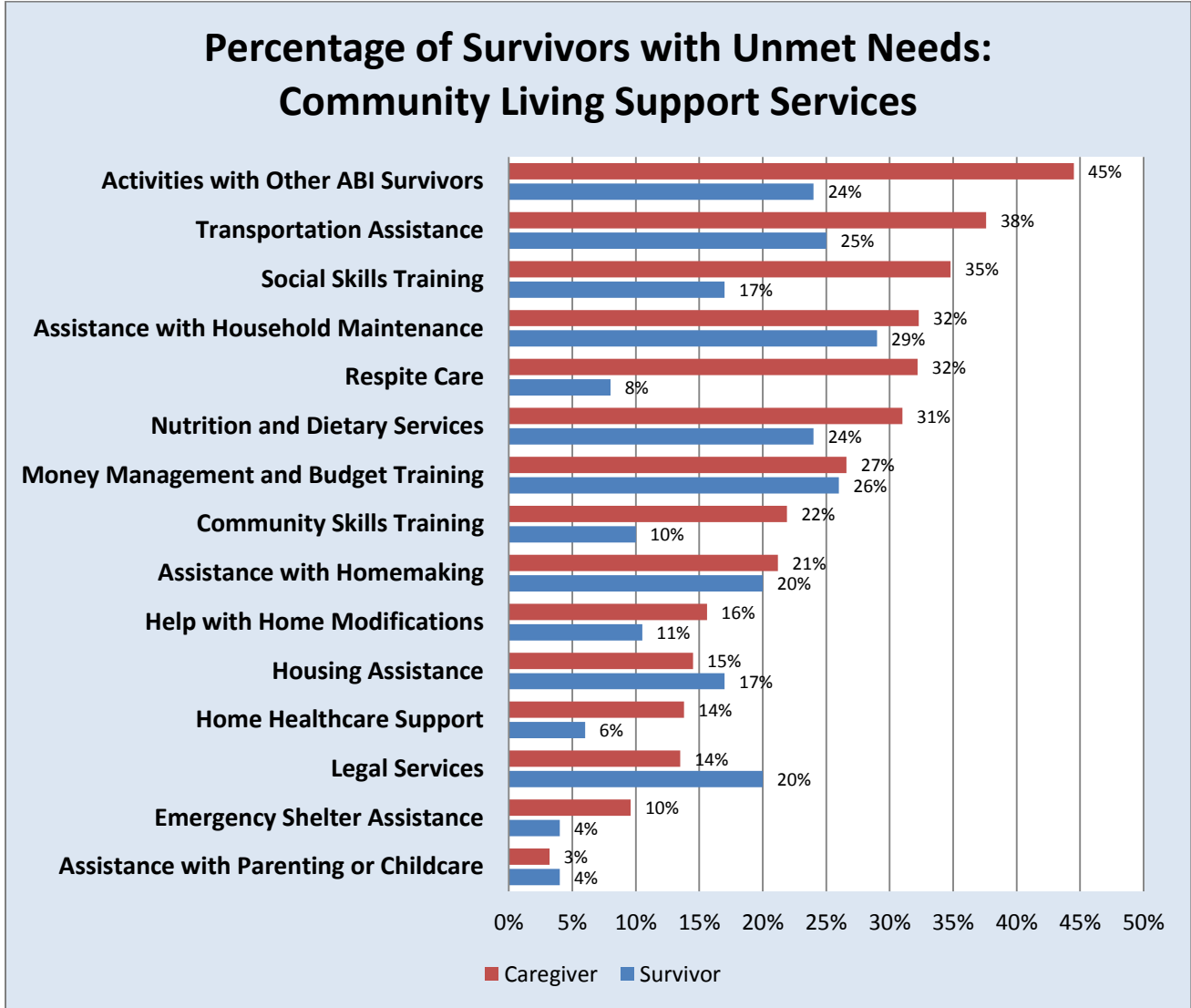
**Figure E14.** Unmet Need for Education and Employment Services



**Community Living Support Services**

The greatest unmet need within Community Living Support Services for caregivers was Activities with Other ABI Survivors (45%), followed by Transportation Assistance (38%). For survivors, the greatest unmet need was Assistance with Household Maintenance (29%), followed by Money Management and Budget Training (26%), and Transportation Assistance (25%). For those participating in the survey, there was little to no unmet need indicated for Emergency Shelter Assistance (4%) or Assistance with Parenting and Childcare (4%). These findings are presented in Figure E15.

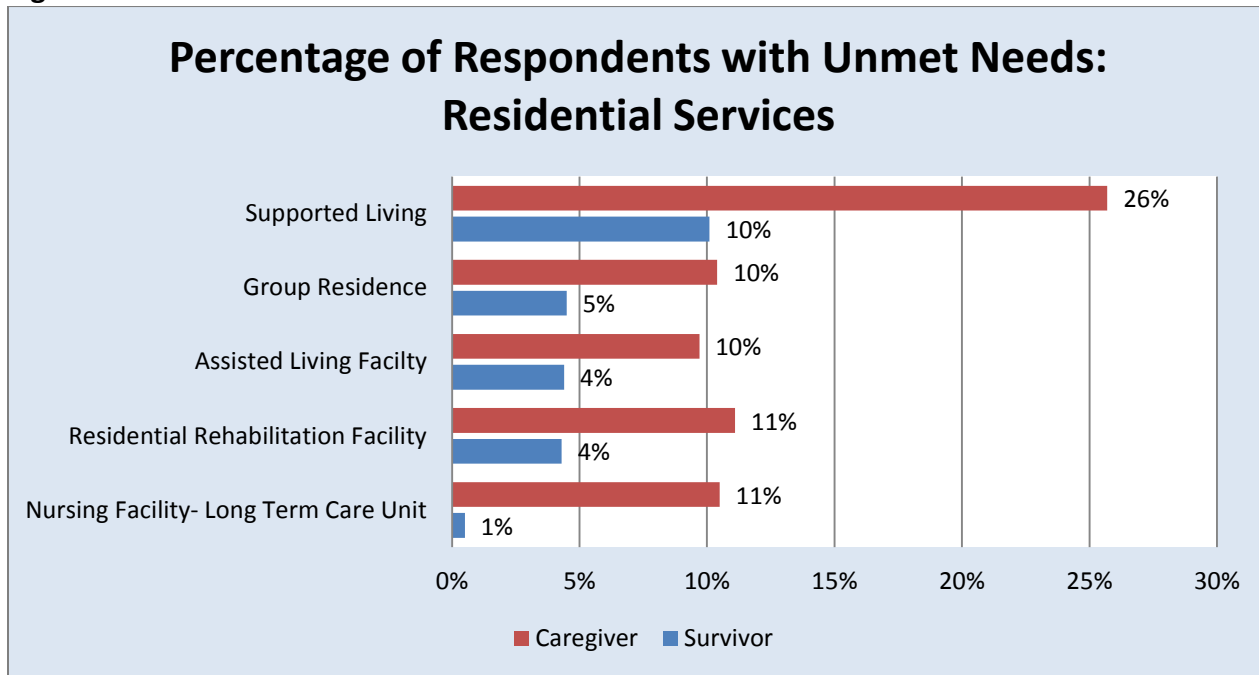
**Figure E15.** Unmet Need for Community Living Support Services



**Residential Services**

This category demonstrated the least unmet need. The greatest unmet need within Residential Services was Supported Living (26% of caregivers and 10% of Survivors). These findings are presented in Figure E16.

**Figure E16.** Unmet Need for Residential Services



It is interesting to compare the greatest needs of the survivors as indicated by the survivors completing the survey to the perceptions of the greatest needs as indicated by the caregivers. The findings for these two groups are somewhat different. Most notably, the caregivers express greater unmet need overall; of the 44 services listed on the surveys, caregivers indicated a greater unmet need than survivors on all but 4 services (Learning supports for higher education, assistance with parenting or childcare, housing assistance, and legal services). However, when reviewing the 4 services with the *greatest unmet need*, cognitive therapy and individual counseling services makes the list for both survivors and their caregivers. In fact, cognitive therapy is at the very top of the list for both groups.

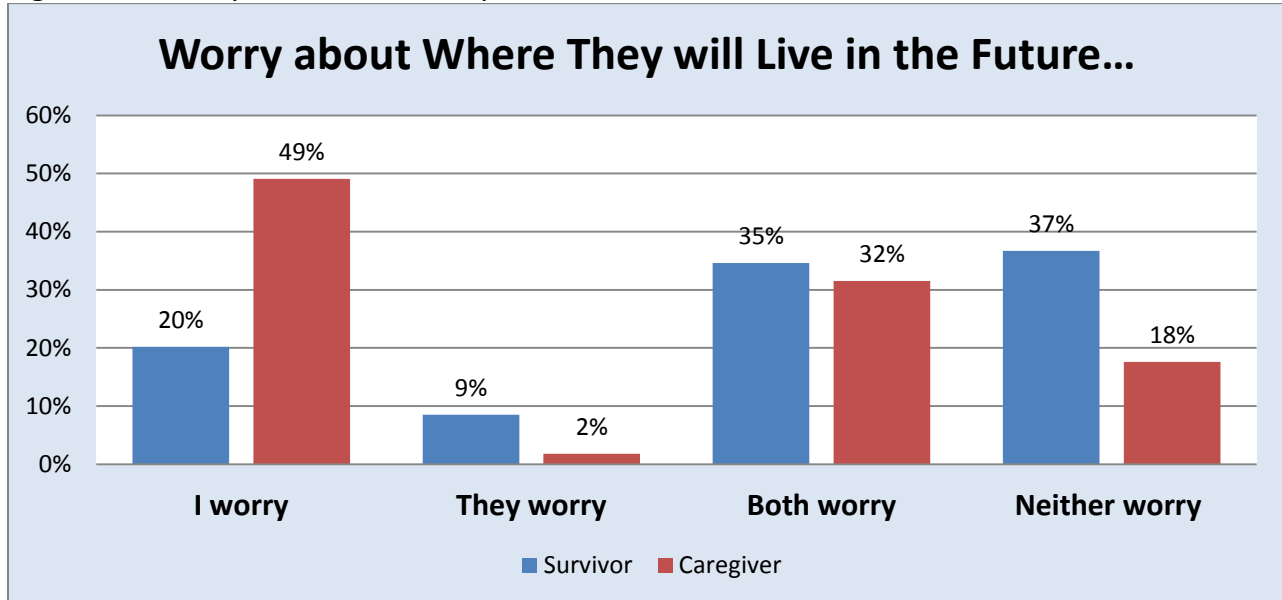
**Table E1.** Comparing the Perceptions of the Greatest Unmet Need of Survivors and Caregivers

	Survivor Survey	Caregiver Survey
1	Cognitive therapy (36%)	Cognitive therapy (59%)
2	Individual counseling (36%)	Activities with other ABI survivors/ recreational activities (45%)
3	Alternative services (acupuncture, massage therapies, etc.) (30%)	Behavioral supports (44%)
4	Medical services that address the effects of ABI injury (30%)	Individual counseling services (42%)

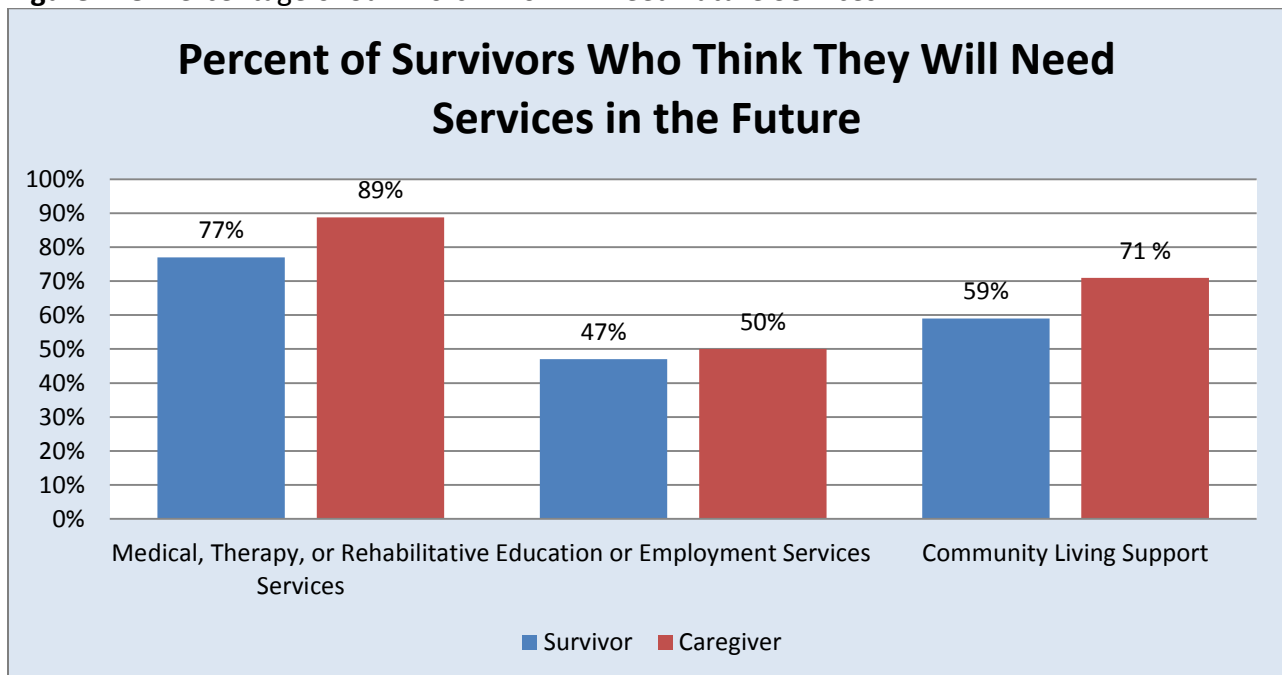
### Future Needs

When asked whether they (or their family/survivor) worry about where they will live in the future, only 18% of caregivers and 37% of survivors indicated that no one worries. In addition, 89% of caregivers and 77% of respondents reported that their survivor/they will need Medical, Therapy, or Rehabilitative Services in the future. Fewer respondents felt that they would need Education or Employment Services or Community Living Support in the future. These findings can be found in Figure E18.

**Figure E17.** Worry about Where They Will Live in Future



**Figure E18.** Percentage of Survivors Who Will Need Future Services



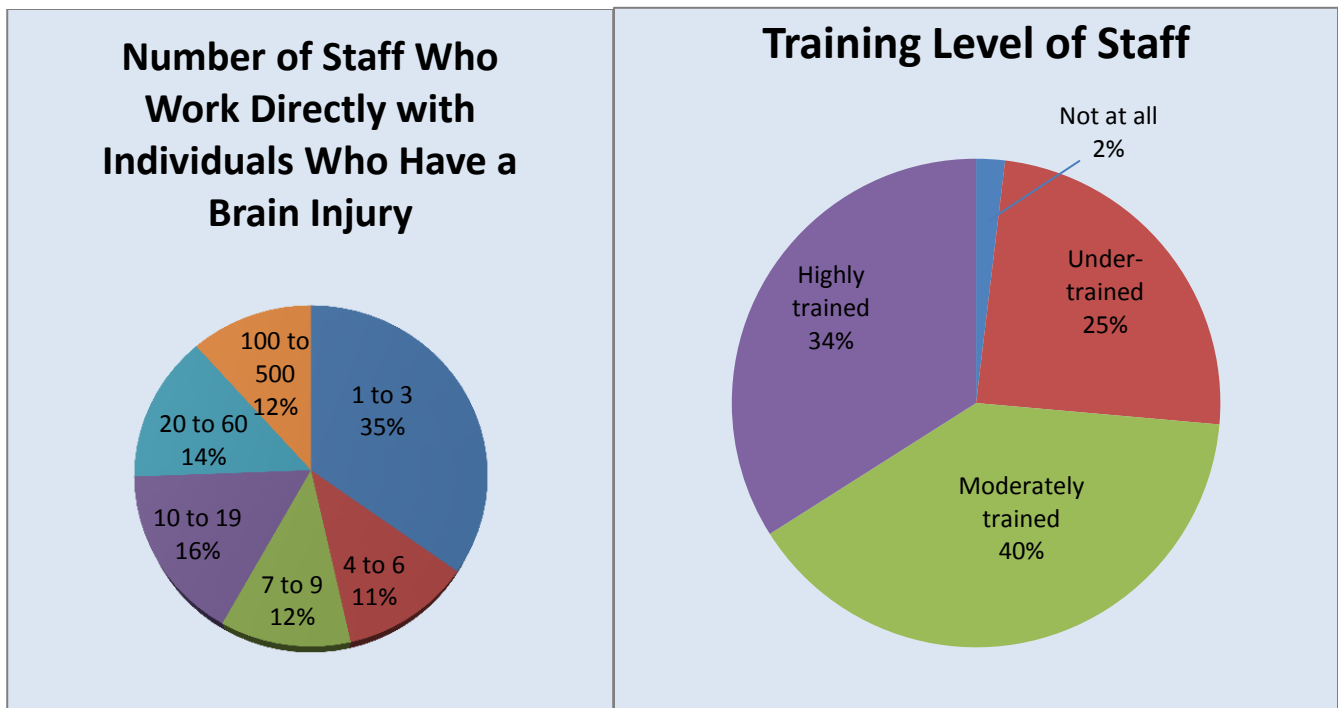
## Provider Survey

The participating provider organizations were asked how their agency receives referrals for brain injury services. The survey presented them with a list and they could check all that were applicable. Most receive self-referrals (81%), referrals from hospitals or rehabilitation facilities (75%), and referrals from private providers (65%). Most all providers provide services to those with a mild brain injury (98.1%) or moderate brain injury (94.2%). Nearly 70% report that they serve survivors with a severe brain injury. Providers were also asked about the population that they serve. Slightly more than a third serve infants and toddlers (35.8%), and roughly half serve older youth aged 3-11 (50.9%). Most served young adults aged 18-29 (88.7%), adults aged 30-49 (88.7%), adults aged 50-64 (85%), and those 65 and over (81%). Roughly 4 in 10 organizations serve families and caregivers (44%).

More than a third of those organizations participating in our survey reported that they have between 1 and 3 staff who work directly with individuals who have a brain injury (34.9%). The median number of staff who work directly with individuals with a brain injury is 8, with a range from 1 - 500. These findings are presented in Figure E19. Most organizations reported that they provide education or training about brain injury to staff members (75.5%). A quarter of organizations reported that they believed their staff is either under-trained or not at all trained to serve persons with brain injuries. Nearly 40% report that staff is moderately trained, and 34% report that staff is highly trained (See Figure E20 below). Most report that they are interested in receiving education or training about brain injury for their staff (82.7%).

**Figure E19.** Number of Staff Who Work with ABI

**Figure E20.** ABI Training Level of Staff

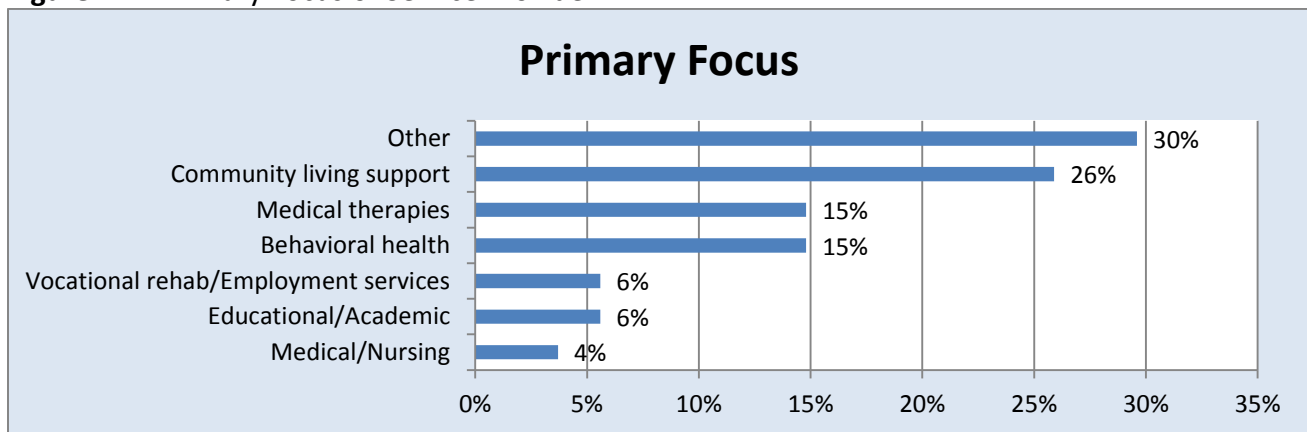




## Services Provided

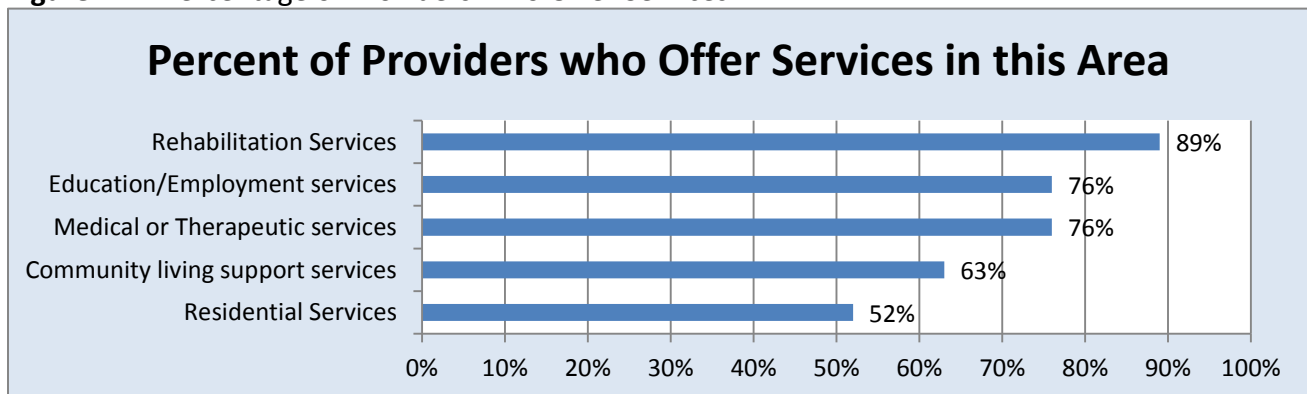
In this section providers were asked the primary focus of their organization, how they get paid for services provided, and what other funds support delivery of their services. Of those responding, nearly 30% stated that their primary focus lay outside of the categories provided on the survey. Some of these responses included: pre-screenings for services, case coordination/management, in-center cognitive training, adult day health care services, acute care, neuro-feedback and OT services, and psychiatric hospital. Another 26% of respondents said that their primary focus was community living support, which includes things such as case management, clubhouse programs, social and recreational activities, transportation, etc. All responses are presented in Figure E21.

**Figure E21.** Primary Focus of Service Provider



More than half (52%) of the responding organizations provide residential services, with larger numbers providing these services for the adult population than for children. Most providers (76%) offer medical or therapeutic services. While they are more likely to provide these services to adults, 39% provide these services to children. Nearly 90% of providers offer rehabilitation services of some sort. While they are less likely to serve children, over half do (52%). Three out of four providers offer some sort of education or employment services. Community living support services are provided by 63% of our respondents. Again, they are more likely to provide this service to adults, though 35% report serving children. All responses are presented in Figure E22.

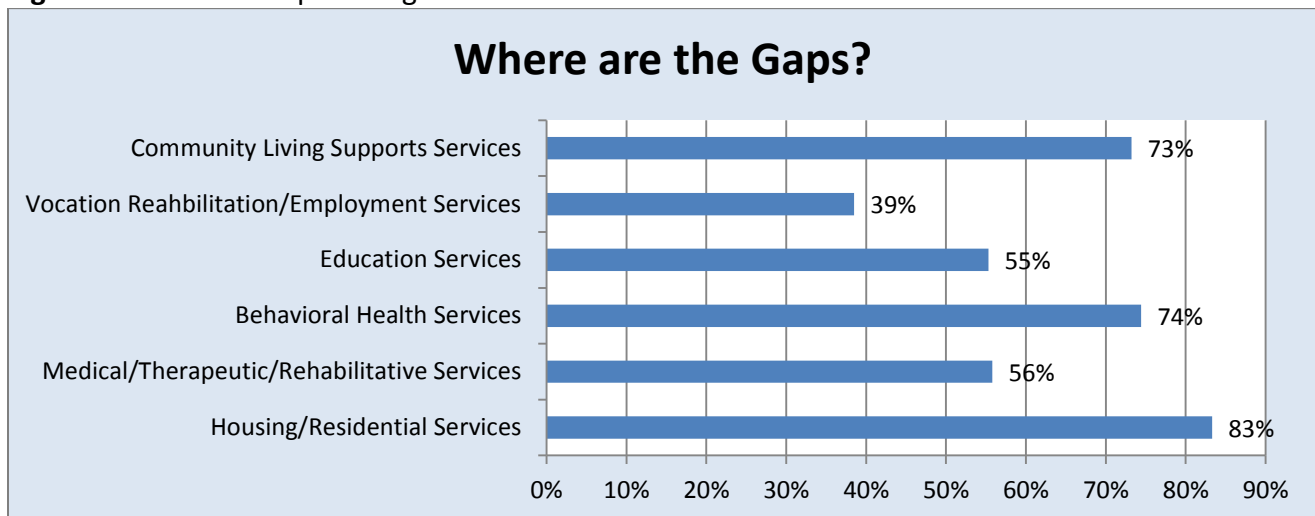
**Figure E22.** Percentage of Providers Who Offer Services



## Service Gaps

In this section of the survey, providers were asked their perspective on service needs or gaps, both in Virginia, and in their area of the state in particular. Six broad categories were provided (Housing/Residential, Medical/Therapeutic/Rehabilitative Services, Behavioral Health, Education, Vocation Rehabilitation/Employment, and Community Living Supports) and if the respondent indicated that there was a gap in this broad category they were asked which services in particular were needed in their area. Additionally, providers were asked how well services for people with a brain injury are coordinated among agencies in their area, whether there were service providers in their area that they would recommend for people with a brain injury, and whether they would be interested in having their name and contact information included on a list of brain injury service providers that will be made available to individuals throughout Virginia. A full 83% of providers believe that there are gaps in residential services. Nearly three-quarters believe there are behavioral health service gaps (74%) and community living support services gaps (73%). All responses are provided in Figure E23 below.

**Figure E23.** Service Gaps in Virginia



When looking at specific services, overall, the largest gaps were perceived for Behavioral Therapy (52%), Supported Living (48%), and Group Residence (46%). Four of the top six gaps fell in the area of Housing and Residential Services, suggesting the greatest needs may fall to a need for more alternatives for living arrangements. From our survivor survey we learned that 42% of survivors do not live where they would like to live. Please see findings for the largest gaps in service as perceived by providers in Table E24.

**Table E24.** Greatest Gaps in Service

Provider Survey	
1	Behavioral Therapy (52%)
2	Supported Living (48%)
3	Group Residence (46%)
4	Residential Rehabilitation Facility (39%)
5	Assisted Living Facility (39%)
6	Life Skills Training (39%)

## Conclusions

Focus group participants and survey respondents across Virginia related the strengths and weaknesses that they see in brain injury services. They would like to see a greater level of awareness, training and competency for professionals who work with persons with brain injury and their families. They would like brain injuries to be diagnosed more quickly. They would like more information about resources available to them and to be better educated themselves about what they can expect from this new life with a brain injury.

The three surveys and focus groups identified a number of areas where more or better services are needed, as well as gaps in necessary services. This information can provide the basis for identifying and providing new services, improving existing services, and closing gaps in crucial services that will help brain injury survivors become more integrated into their communities and as independent as possible. When reviewing the information presented in this report, one should note that the survey did not provide information about the intensity or duration of needed services, nor did the surveys ask participants to prioritize the services that they most needed. Each of the services listed on the surveys are important to helping brain injury survivors to live safe, healthy, and self-sufficient lives. The consequences of failing to receive a service differ depending on which service is needed. For example, a very small number of participants reported needing emergency shelter or substance abuse treatment, but the lack of these services when needed may have more serious consequences than others.

The individual and caregiver or family participants who responded were identified through professionals within the ABI community. These professional organizations posted information about the surveys and focus groups on their websites, with e-mail notifications, etc. Therefore the participants represent those who have had some contact with organizations who serve individuals with brain injury. It is likely that other Virginia residents who have experienced a brain injury also have a need for services, but have less contact with this community and less connection to sources of potentially helpful information. For this reason it would be helpful to have a system in Virginia to track the incidence and prevalence of ABI among both children and adults, and particularly for mild and moderate injury survivors.

Given the differences in the number of survivors who need various services and variability in the proportion of individuals who receive the services they need, it is difficult to compare the overall need for various services. In order to synthesize this information, we computed the unmet need for each service that includes those who need but do not receive each service or who are receiving the service but find that the service does not meet their needs, as a proportion of all those who responded to the survey. It is important to note that this is a simple measure of unmet need, which does not take into account the intensity or duration of the need, nor the resources that may be necessary to provide the service. It does, however, provide a rough comparison of the proportion of unmet need for each service and gives us a starting point for discussion.

Some services demonstrated an unmet need by a larger proportion of survivors, as indicated by the survivor themselves or their caregiver. These are presented in the table below.

	Survivor Survey	Caregiver Survey
1	Cognitive therapy (36%)	Cognitive therapy (59%)
2	Individual counseling (36%)	Activities with other ABI survivors/ recreational activities (45%)
3	Alternative services (acupuncture, massage therapies, etc.) (30%)	Behavioral supports (44%)
4	Medical services that address the effects of ABI injury (30%)	Individual counseling services (42%)

Service providers were asked their perspective on service needs or gaps. Six broad categories were provided (Housing/Residential, Medical/Therapeutic/Rehabilitative Services, Behavioral Health, Education, Vocation Rehabilitation/Employment, and Community Living Supports) and if the respondent indicated that there was a gap in this broad category they were asked which services in particular were needed in their area. Overall, the largest gaps were perceived for Behavioral Therapy (52%), Supported Living (48%), and Group Residence (46%). Four of the top six gaps fell in the area of Housing and Residential Services, suggesting the greatest needs may fall to a need for more alternatives for living arrangements. This finding is supported by the survivor survey, where we learned that 42% of survivors do not live where they would like to live. The largest gaps in service as perceived by providers are presented in the table below.

	Provider Survey	Percent of Providers who Perceive a Gap
1	Behavioral Therapy	52%
2	Supported Living	48%
3	Group Residence	46%
4	Residential Rehabilitation Facility	39%
5	Assisted Living Facility	39%
6	Life Skills Training	39%

Additionally, more than half of the providers in the survey (58.1%) believed that coordination of services for people with brain injury is acceptable, with room for improvement, among agencies in their area. Nearly a third (32.6%) felt that service coordination is poor in their area. Only 7% of respondents felt that this coordination was very good to excellent. Survivors and caregivers seemed to agree that this could be better. A general theme from the focus groups and from the comments from both survivors and caregivers was the need for information about programs and services available to individuals with brain injury. More than half (61%) of the caregivers completing the survey reported that they were not provided with information or advised on the services available, while 10% were not sure whether they received information or not. More than half (53%) of the survivors completing the survey reported that they were not provided with information or advised on the services available for person's with acquired brain injury. Another 22% of survivors were not sure whether they had received information.

As a final point, individuals with a brain injury, their families, caregivers, and professionals all noted the lack of understanding of brain injury in the general community and the many barriers to allowing individuals with brain injury to participate fully in social, recreational, employment, and civic activities along with others in their community. The difficulties in reading, speaking, comprehending, and interacting experienced by many individuals with brain injury are poorly understood and can lead to exclusion, isolation, discrimination, and job loss. Isolation and the inability to participate fully in activities in the community compound the already significant difficulties faced by many individuals with brain injury.

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## Recommendations

Recommendations for future efforts to improve services emerged in three broad areas: (1) Education, (2) Improvement in Diagnosis, and (3) Supports.

### *Education*

Through focus group and survey findings, specific groups were identified as in need of more education about acquired brain injury. Those in need of education include the general public, namely in understanding the outcomes associated with brain injuries and how these outcomes can affect an individual. The public also needs to be encouraged to seek treatment after experiencing any type of blow or injury to the head.

Findings also suggest a need to educate caregivers, family members and survivors concerning the possible outcomes of the brain injury, future services that should be explored, and resources available to them in their area. There was a recurring theme in both the focus groups and surveys of survivors and caregivers being discharged after initial stays in the hospital with little or no information about their brain injury.

Another group of individuals who may benefit from further brain injury specific education are professionals who will be interacting with individuals who have brain injuries, such as teachers and employers. Comments suggest that these individuals need to be made aware of the changes that can occur in an individual who has a brain injury and how to deal with those changes in a proactive and constructive manner.

The final group of individuals who were identified as needing additional education relative to brain injury is health care providers. Both survivors and caregivers feel that health care providers lack the level of understanding needed to provide the brain injury survivors the appropriate services or to refer them for the correct services that they need. The following recommendations are being made concerning education:

### **Educational PSAs concerning brain injuries**

*"...where again physically they look fine, and their injuries are invisible and the world doesn't understand it and there's the caregiver, and as a patient myself at the same time with issues, it's very frustrating because you look fine..."* quote from survivor who attended a focus group.

There is a need for the general public to be educated, specifically about the fact that brain injuries are not immediately visible. While an ABI survivor may look the same to an employer, for example, there are residual effects from the injury that may not recede and that need to be taken into account. Therefore, it is suggested that Public Service Announcements (PSAs) be created to educate the general public. The message of these PSAs should not only be about when someone should see a health care professional for a possible brain injury, but also what type of health care provider to visit and what to expect from the visit. PSAs could also describe the different ways in which a brain injury may manifest itself. The outcome of these PSAs should be providing education that will lead to the empowerment of individuals to be a positive advocate for themselves or for or someone within their family or community.

### **Immediate Education for Survivors and Caregivers**

*"...Having no frame of reference for what to do next, having no educational assistance, no case worker, ... to follow what are we doing... next with this very severe injury"* quote from Caregiver who attended a Focus Group

It is suggested that caregivers and family members and survivors receive education in the form of counseling immediately following the injury. This is supported by more than half (53%) of the survivors completing the survey who reported that they were not provided with information or advised on the services available or person's with acquired brain injury. A statewide policy should be mandated that outlines the educational procedures to follow when an individual presents with a brain injury. It is suggested that counseling occur with family members/caregivers and the survivor prior to the release of the survivor from medical care. Additionally, this should be accompanied by an information packet outlining questions they need to ask, possible future services, possible outcomes of brain injury, and a list of resources by type of service and location.

### **Creation of Certificate and Continuing Education (CEU, CME) Opportunities**

*"...And giving you a book or a brochure to read is not enough. Your primary care doctor needs to be able to talk to you about what it means, and he needs to send you to somebody like a*



*speech and language pathologist, or some other person to help you work with memory, emotion, communication, cognitive problems* “quote from Survivor who attended a Focus Group

Education opportunities need to be created for individuals within the healthcare field, as well as educators and which focus on increasing knowledge about the ABI population. These opportunities can be offered for health care providers and educators through CEU, CME, and Certificate Program opportunities. Additionally, it is suggested that a training be created that can be administered through human resources departments to employers within Virginia.

Provider survey findings indicate a quarter of organizations believe their staff is either under-trained or not at all trained to serve persons with brain injuries. In addition, most providers report they are interested in receiving education or training about brain injury for their staff (82.7%). In addition, almost a third of survivors report they were either “somewhat” (10%) or “very” (21%) dissatisfied with the care they received within the first 6 months due to both the knowledge of the health care professional and their understanding of the injury.

It is greatly recommended that these training opportunities be created for to those who offer services identified by both survivor and caregiver as being most needed. These would be individuals providing cognitive therapy, individual counseling, alternative services, behavioral supports, and medical services to acquired brain injury survivors.

### ***Diagnosis Recommendations***

Findings suggest a considerable amount of frustration amongst survivors and caregivers/family members when it comes to the initial diagnosis or treatment associated with acquired brain injuries. Therefore it is recommended that Virginia review the current practices and policies of health care providers in the diagnosis, assessment, and treatment of acquired brain injuries. One of many possible ways to decrease the frustration felt surrounding diagnosis, assessment, and treatment of brain injuries is to create a decision chart as described below.

### **Diagnostic Decision Chart**

*“...would have liked a correct diagnosis by a fair doctor who knew very much about brain injury”* quote by Caregiver who attended a Focus Group

*“In 2009 I was totally misdiagnosed. They – they said I was psychotic and they put me on the wrong medication and that entire year that I was on that wrong medication I was a totally different person.”* quote by Survivor who attended a Focus Group

It is recommended that Virginia create and adopt a diagnostic decision chart to be used by all health professionals in the position of diagnosing and/or assigning treatment for brain injury patients. This chart should be based on work conducted by U.S. Navy cardiologist Lee Goldman and the successful implementation of Goldman’s work by Brendan Rielly associated with Cook

County Hospital in Chicago. Though this particular decision tree was created to diagnosis heart attacks, it does show that adapting a decision tree can lead to a significant increase in the percentage of successful diagnoses and treatment. The idea of a medical decision tree is to allow health care professionals to quickly evaluate possible brain injuries leading to more efficient decision making concerning treatment needed. Though there are several computer systems that can be used to diagnose brain injuries, such as The Traumatic Brain Injury Model Systems, we are suggesting a more simple decision tree to be used in situations where brain injuries are initially being diagnosed and treatment decided upon. Additionally, there exist various decision trees developed specifically for brain injury diagnosis and treatment that should be considered for review (i.e. VA/DoD Clinical Guidelines for Management of Concussion/Mild Traumatic Brain Injury). Examples can be found in Appendix D.

### ***Support Recommendations***

The amount of support survivors and caregivers indicate they need spans a variety of areas.

### **Acquired Brain Injury Caseworkers**

*“...but I think what was lacking was case coordination or a patient advocate--- someone who could really know all the things that needed to be done”* quote from a Caregiver who attended a Focus Group

*“...this world is so, so into money-- everything is so cost effective we don't have someone that is really standing up with a strong advocacy, a really strong advocacy for the brain injury association. ... on the legal aspect can we afford it? We can't afford to pay our bills and this, that and the other. How can we afford an attorney that's worth taking?”* quote from a Caregiver who attended a Focus Group

*“You'd like to know that there's somebody who can help traverse through the minefields that are out there”* quote from a Survivor who attended a Focus Group

It is suggested that a certificate program be created to train Acquired Brain Injury Caseworkers. Survivors and their caregivers again and again indicated the need for an advocate to assist them with navigating the ABI services network. This community needs assistance in identifying, securing, and keeping track of the services they need or will need. This help needs to come from professionals who are knowledgeable about all services available for Virginians with an Acquired Brain Injury. A caseworker would be a tremendous help in creating an action plan for caregivers and survivors concerning their needs relative to health care services, residential services and social support. A caseworker could also assist survivors and their caregivers in obtaining financial support. Ultimately these individuals would also be the education leaders for survivors and caregivers/family members.

## Caregiver Support/Respite Care

*"...And so we have to watch him twenty-four/seven, and it is the two of us and that's it – part of it is, my mother's unwilling to take some help that has been offered but it, it is exhausting, it's completely time-consuming..."* comment from Caregiver who attended a Focus Group

It is recommended that a closer evaluation be conducted on caregiver respite services that are available for ABI caregivers and family members. It was expressed that there exists a need for services that will support and strengthen a caregiver's ability to provide care. This is supported by the caregiver survey, where more than half of the caregivers indicated that they needed help or more help to care for the survivor (54%). When examining this need more closely it is important to take cost into consideration, since 63% of caregivers indicated that they weren't receiving help because it was cost prohibitive.

## Telephone Support Program

*"..so that was my biggest need, my biggest need was really for – conversation"* quote from a Survivor who attended a Focus Group .

Another support recommendation is to implement a Survivor and Caregiver Telephone Support Program modeled after the evidence based program created by Dr. Gendron and colleagues within the Department of Gerontology at Virginia Commonwealth University. Faced with the need for a support program for elder caregivers and little money, Dr. Gendron and her colleagues reviewed relevant research and came up with the Caregiver Telephone Support Program. This program successfully provided needed support to caregivers through weekly phone calls conducted by graduate students. Through active listening skills, these phone calls were found to reduce feelings of burden and stress in caregivers, as well as connect caregivers to needed resources. We feel this could be equally successful with survivors who are living independently.

## Survivor Social Outlets:

*"If there had been more support groups, this is when I went to the [???]... even though it was an hour away I went there because it was the nearest one I could find.... support groups are really important to tell you that you're okay, to tell you that other people have the same problem, hear what other people are doing to cope with this"* quote from a Survivor who attended a Focus Group

Finally, it is recommended that a closer evaluation be conducted on the social based support groups that currently exist throughout Virginia for caregivers and survivors and to make sure that they are available in all areas of the state.

Individuals with brain injury aspire to become as fully integrated into their communities and as independent as possible. It is our responsibility to make these goals a reality.