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Traumatic Brain Injury Needs and Resources Assessment for New Jersey

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Traumatic Brain Injury in New Jersey: Needs and Resource Assessment

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Executive Summary

The New Jersey Division of Disability Services (DDS) contracted with the Rutgers Center for State Health Policy (CSHP) to investigate the needs of individuals with traumatic brain injury (TBI) and determine what services are currently available. This information will be used to inform development of new services and supports and create a more coordinated and responsive system. CSHP conducted three surveys: a Survey of Individuals with TBI and Their Families, the State Agency Survey of TBI Services and Support, and the Provider Survey of TBI Services and Support. The three surveys were developed with substantial input from members of the New Jersey Advisory Committee on TBI. The organizational surveys were fielded between January and February 2007, and had a response rate of 34%. The individual survey was fielded between June and August 2008, using mail, web, and telephone options in English and Spanish, and had a response rate of 32.9% (659 individuals).

Participants in the individual survey were predominately ages 18-64; about 72% were non-Hispanic White, 13% were non-Hispanic Black, and nearly 10% were Hispanic. Nearly half of participants described themselves as having a severe brain injury, and about 1/3 described themselves as having a moderate brain injury. More than half of participants were living in a house or condo that was owned by them or a family member or friend; another 26% were living in a rented house, condo, or apartment. A small number lived in a facility such as a rehabilitation center, a nursing home, or a developmental disability center, and most of those and their families indicated that they considered it an inappropriate living arrangement.

Most participants were living with family members and valued the support of their families. However, half worried about where they would live in the future. Nearly 2/3 of those aged 65 and older lived with only an elderly spouse, and 8.2% of those aged 46 to 64 lived with their parent(s). The aging of these caregivers threatens the ability of people with TBI to live in the community as they grow older. In addition, 2/3 of those who said that they needed housing assistance or home modifications did not receive these services.

Over half of participants said that their health coverage was not sufficient for their needs related to their brain injury and did not include needed services such as speech therapy, cognitive therapies, vision therapy, and social skills training. Out-of-pocket costs for services were very expensive, even for those with coverage.

Some services were needed by a majority of individuals who participated, particularly medical and rehabilitative services. These included:

- Pharmaceuticals (75.4%)
- Medical services (66%)
- Cognitive training (64.6%)
- Case management (61.8%)
- Occupational/physical therapy (61.6%)
- Individual counseling (54.5%)
- Psychology/psychiatry (52.5%)
- Dental services (51.1%)

In addition, vision services and transportation were needed by just under half of participants.

Generally, the services listed above also had the highest percentages of individuals receiving them, and participants reported that the services met their needs at least 70% of the time. However, some important gaps in frequently-needed services

were evident; for example, the following services were received by only about half of those who said they needed them:

- Cognitive training
- Individual counseling
- Occupational/physical therapy

In addition, of those who needed them, less than half received:

- Speech therapy
- Alternative therapies
- Behavioral supports
- Family counseling
- Assistive technology

There were large gaps in community support services; 60-85% of those who needed the following services did not receive them: education, employment assistance, respite, or training in money management, social skills or community skills services.

Another service gap was indicated by participants who said that the services they received did not meet their needs. Over 1/3 of those who received the following services said that they did not meet their needs:

- Case management
- Family counseling
- Home care
- Respite
- Assistance getting and/or keeping a job
- Housing assistance/home modifications
- Community skills training

The need for transportation deserves special mention, since it underlies the lack of accessibility of many services which may exist in the state, but are not easily available without reliable and accessible transportation. Transportation was stressed as an area of unmet need by individuals and families as well as by providers; nearly 1/3 of participants said they did not have reliable and accessible transportation, and providers mentioned that transportation problems limit their ability to obtain needed services for consumers. Even when public or specialized transportation is available, it can be difficult and inconvenient to use, while maintaining a car on a limited income or relying on family members for transportation is challenging and often frustrating.

Information from the provider surveys indicate that few providers offered alternative therapies, dental services, vision services specific to TBI, housing assistance, or home modifications. Comments from state agencies and provider organizations highlighted gaps and barriers in receiving many of the same services which were mentioned as unmet needs in the individual surveys. For example, providers commented on the lack of trained professionals with knowledge of brain injury as well as the lack of funding to support cognitive training for sufficient amounts of time to help individuals with TBI. Providers also suggested that there are few sources of funding for alternative therapies. Providers saw a need for more rehabilitation services in parts of New Jersey and/or transportation to allow individuals to get to these services. Even in areas where services were available, professionals often mentioned a lack of knowledge and training about brain injury. Currently, few organizations can identify how many of their clients have a brain injury.

Both professionals and caregivers highlighted the need for more and better trained case managers to assist individuals and families in understanding the continuing needs of people with TBI and navigating the confusing array of available services. About one-third of caregivers said that they needed counseling, respite, and help with advocacy and information about available resources. There is a pervasive need for information about programs and services available to individuals with brain injury, along with hands-on assistance in dealing with complex eligibility requirements and

application forms. In addition, professionals and family members stressed the need for family counseling, education, and support to help families cope with the stresses of supporting someone with brain injury.

The individual survey participants represent those who have had some contact with organizations that serve individuals with brain injury. It is likely that other New Jersey residents who have experienced brain injury have a high need for services, but have less contact with the service community and less connection to sources of potentially helpful information. Service providers stressed the need for outreach to individuals whose native language is not English or who do not have legal status. Individuals, family members, and providers all noted the lack of understanding of brain injury in the professional as well as the general community and the failure to recognize and address symptoms of brain injury.

Traumatic Brain Injury in New Jersey: Needs and Resource Assessment

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Background

According to data from the New Jersey Department of Health and Senior Services Traumatic Brain Injury Surveillance System, each year in New Jersey there are nearly 9,000 traumatic brain injuries (TBI) resulting in hospitalization or death. TBIs are most often caused by a blow or jolt to the head, and can severely disrupt normal brain functions. Approximately 10% of TBIs are fatal. Many more TBIs are treated in emergency departments, outpatient settings, or not at all. Between 1999 and 2005, 65% of TBI inpatients were discharged to home and nearly 20% were sent to other facilities for further acute care or rehabilitation.

TBIs range from mild to severe and can cause impairment of cognitive and physical abilities as well as changes in behavior or emotional functioning. Seemingly mild TBIs can have significant effects that do not immediately appear.

The leading cause of TBI in New Jersey historically has been vehicle crashes (including automobiles, bicycles, and recreational vehicles), followed by falls and assaults. However, in 2003 falls became the leading cause of TBI in New Jersey, responsible for more than 20% more TBIs than vehicle crashes.

The Traumatic Brain Injury Implementation Grant Program of the United States Health Resources and Services Administration provides grant funding to states in order to develop and strengthen the infrastructure of brain injury services. The Division of Disability Services (DDS) has received several of these grants. DDS is the designated

state lead agency for brain injury services, and is responsible for the administration of the both the Traumatic Brain Injury Medicaid Waiver and the Traumatic Brain Injury Fund.

Under such a grant, DDS contracted with the Rutgers Center for State Health Policy (CSHP) to develop surveys which would provide the information to look critically at the system of services and supports for individuals with brain injury, determine what services are currently available, and investigate the needs of individuals with brain injury in New Jersey. This information will be used to inform development of new services and supports and create a more coordinated and responsive system.

CSHP conducted three surveys to gather the information contained in this report:

- 1) the Survey of Individuals with TBI and Their Families, which asked about the living situations, service needs, and services currently received for individuals with brain injury;
- 2) the New Jersey State Agency Survey of TBI Services and Support, which gathered information about services offered and people served by state agencies, as well as opinions regarding barriers and gaps in services; and
- 3) the New Jersey Provider Survey of TBI Services and Support, which gathered similar information from selected community organizations which provide services to individuals with brain injury in New Jersey.

Methodology

The three survey instruments were developed with substantial input from members of the New Jersey Advisory Committee on Traumatic Brain Injury. The starting point for survey content was the Traumatic Brain Injury Needs and Resources

Assessment Tool sponsored by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

The Survey of Individuals with TBI and Their Families

This survey was fielded during June, July, and August 2008 and used a multi-mode approach: a paper questionnaire administered by mail, a web-based option, and a telephone interview option. The mail and web surveys were administered by Abt SRBI, while telephone interviews were conducted by trained CSHP staff. A mailing list of potential respondents was developed from mailing lists obtained from the Traumatic Brain Injury Fund and the Brain Injury Association of New Jersey. After removing duplicates, the resulting list was stratified using information about the racial and ethnic composition of the zip code of residence. A Spanish surname list was also used to identify likely Hispanic/Latino respondents. The sample of 2,000 individuals was then selected using a stratified random approach in an effort to obtain a racially and ethnically balanced response. Flyers were distributed by DDS announcing the survey (see Appendix A), and the surveys were mentioned during community focus groups conducted by DDS. Some individuals from the focus groups requested that their names be added to the mailing list, and these individuals were included in the survey.

Each sampled individual was mailed two cover letters along with a paper questionnaire: one from DDS underscoring the importance of the survey, and another from CSHP with options for completing the survey and contact information (copies are included in Appendix A). Both cover letters were printed in English and Spanish. Individuals who were identified to have a Spanish surname were sent both English and Spanish surveys. Those who did not respond to the initial mailing were mailed two follow-up packets at three-week intervals.

Survey respondents had the option to complete the survey in either English or Spanish on the project website (www.NJ-TBI-Assessment.com) or to request a telephone interview. Telephone interviews were conducted by trained interviewers, who also received an extensive briefing from DDS about the effects of brain injury and

techniques for communicating effectively with people with brain injuries. Completed surveys were edited for errors and entered into an SPSS database by the survey vendor. Additional comments written on surveys or letters included with survey responses were sent to CSHP along with the survey data base. The response rate was 32.9%, or 659 individuals. Responses were received by mail for 83.8% of the survey participants, by the web version for 11.4%, and by telephone for 4.9%.

The New Jersey State Agency Survey of TBI Services and Support and the New Jersey Provider Survey of TBI Services and Support

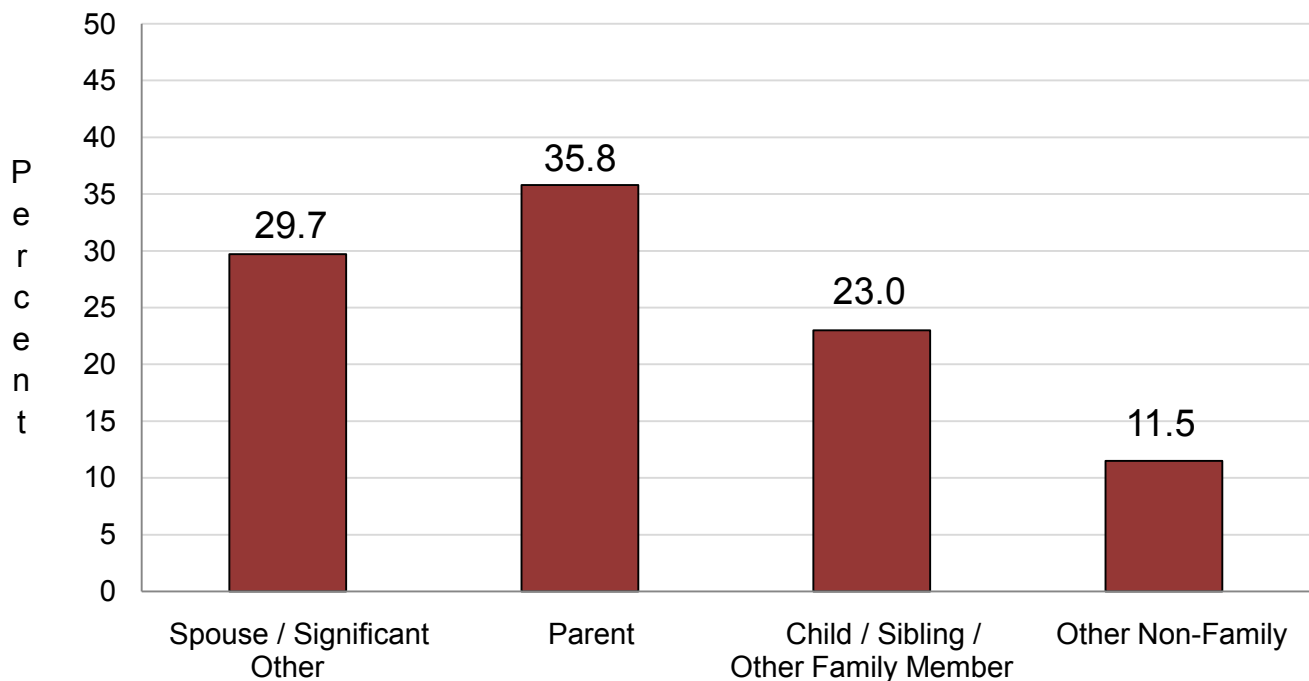
The sample for these surveys was developed by DDS from existing lists of state agencies and community providers who serve individuals with brain injury. The survey instruments were adapted by CSHP staff from those used by other states, in consultation with members of the New Jersey Advisory Committee on TBI. Both surveys were pilot tested in December 2007, and then mailed out with a cover letter to non-state affiliated providers and state agency providers requesting responses by the end of February 2008. Respondents were also given the option to download the survey electronically through the CSHP website. Follow-up letters were sent out in early February of 2008 to improve the response rate. Copies of the letters and survey instruments are included in Appendix B. There were 212 surveys mailed out to community providers; 72 were completed and returned for a response rate of 34%. Some responses reflected more than one location for that organization. There were 25 surveys mailed out to state agency providers, and 8 were completed and returned for a response rate of 32%.

Findings from the Survey of Individuals with TBI and Their Families

Who Responded to the Survey?

Overall, 659 people with brain injury participated in the survey. About 40% (270) of these were people who identified themselves as having a brain injury and completed the survey without any assistance, while the other surveys were completed with assistance from someone else. Over 60% of the people who received assistance got it from a parent, spouse, or significant other. Most of those who did not receive assistance from a family member got it from a friend or roommate. Only a few people received assistance from a therapist or other professional. Of those who received assistance, most got help reading the questions, writing down the answers, and answering the questions. Slightly less than 4% needed help translating the questions into their language.

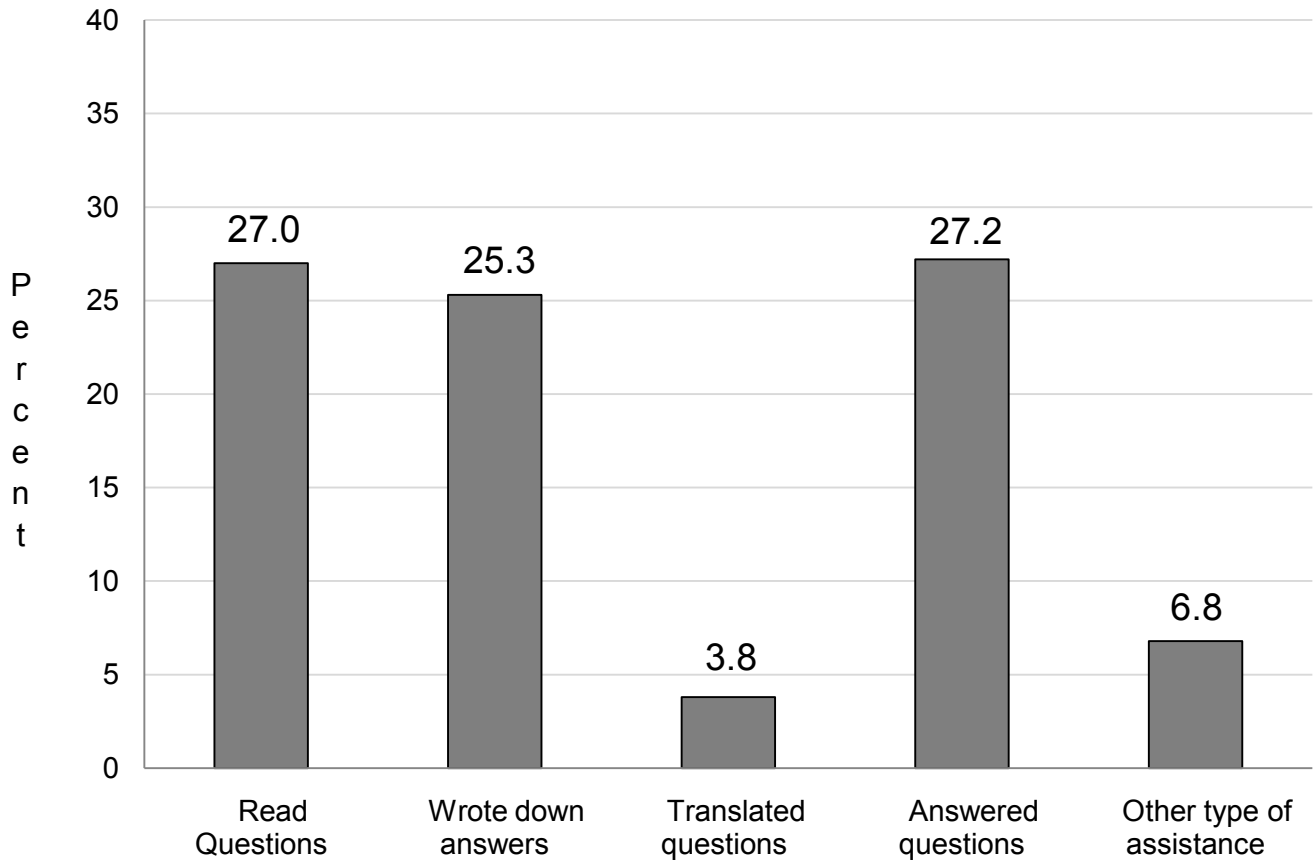
Figure 1: Person Who Assisted Individuals with Brain Injury to Complete Survey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

In this report, we refer to the individuals with brain injury who completed the survey as “participants”, whether or not they received assistance in completing the survey.

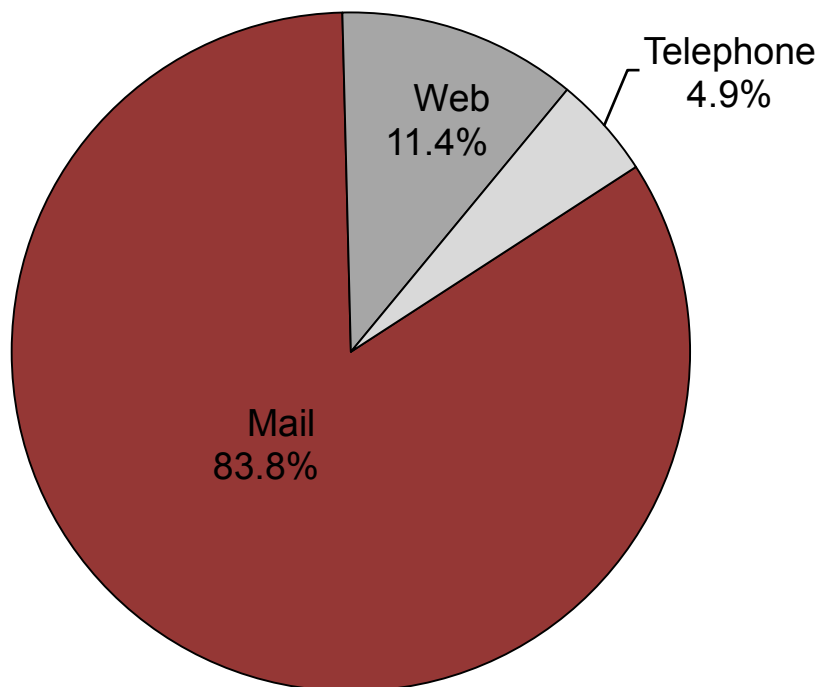
Figure 2: Type of Assistance Received by Individuals with Brain Injury To Complete the Survey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Most people participated in the survey by mail, but 11% responded on the web, and about 5% had a telephone interview.

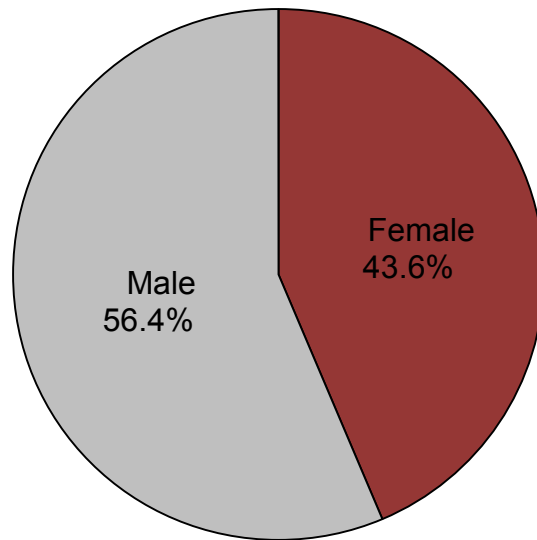
Figure 3: Method of Responding to Survey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

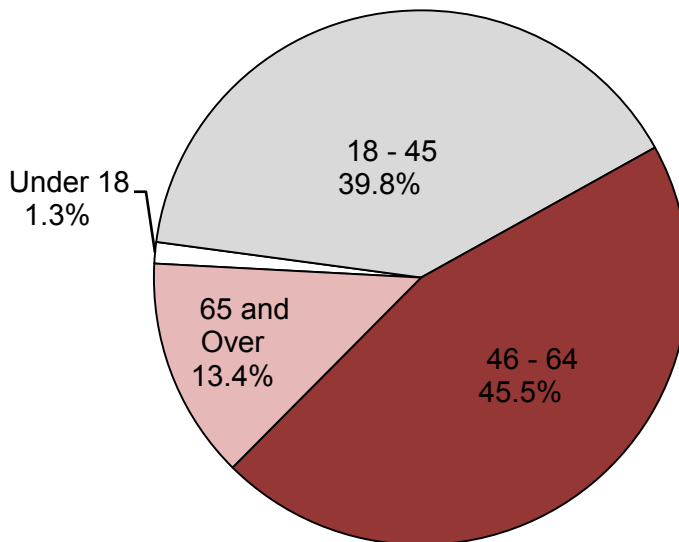
Among the people who participated, more than half (56.4%) were male, and most were between 18 and 64 (86%). Unfortunately, only a small proportion of the participants were under age 18, which limits the amount of detailed information which can be provided on this age group. Nearly 7% of participants did not provide a year of birth, so we were unable to determine their age.

Figure 4: Gender of Individuals with Brain Injury Who Responded to the Survey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

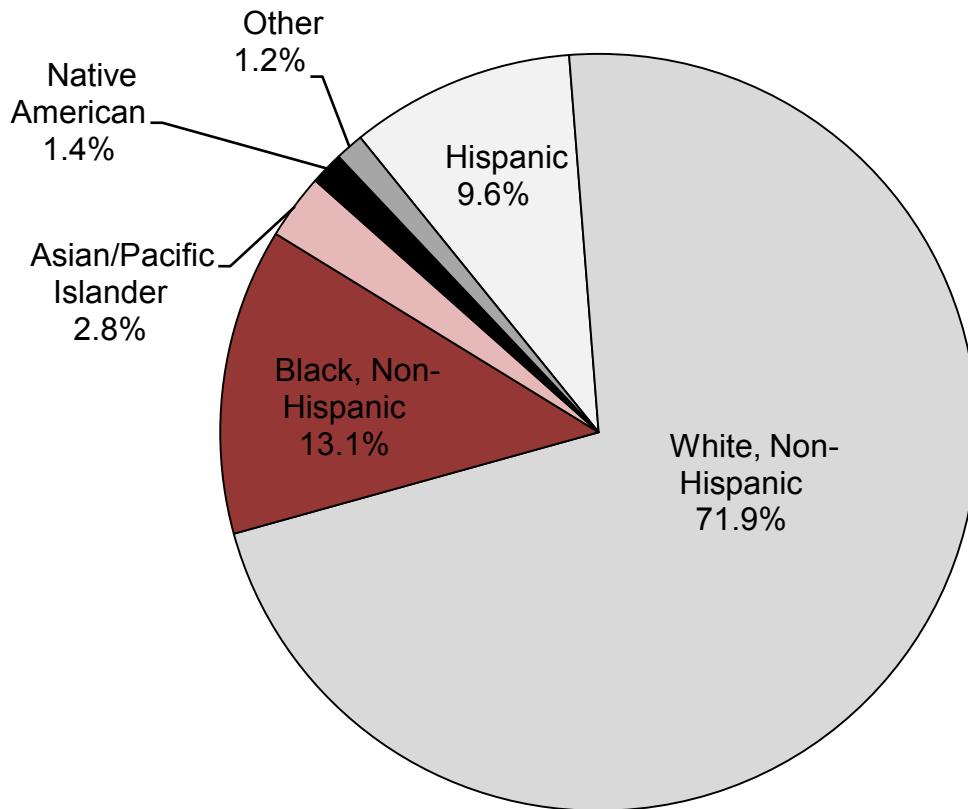
Figure 5: Age of Individuals with Brain Injury Who Responded to the Survey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Almost three-quarters of the participants were non-Hispanic white and most of the remainder were non-Hispanic Black or Hispanic. Among the people identified as Other, most said they were of mixed race. Most people (98.6%) responded in English; the rest responded in Spanish.

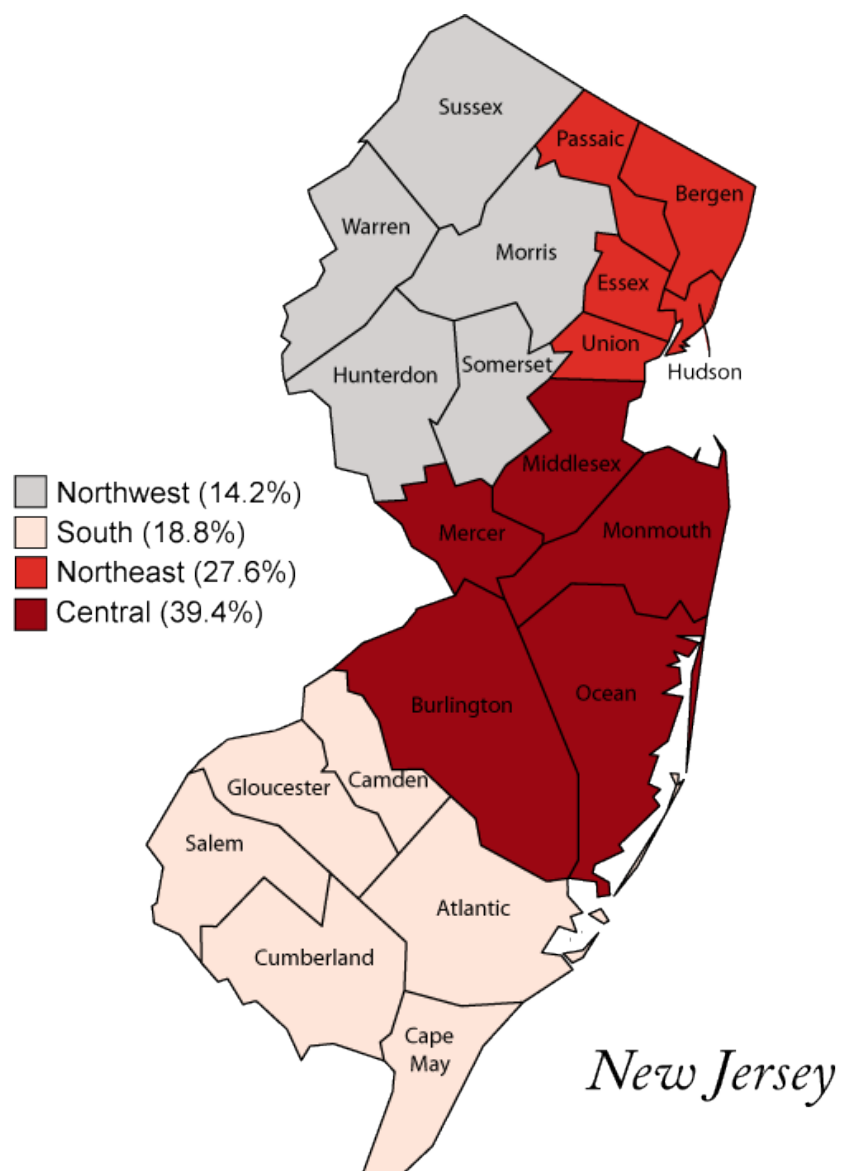
Figure 6: Race/Ethnicity of Individuals with Brain Injury Who Responded to the Survey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Participants lived in all counties in New Jersey; two thirds resided in the central region (including the counties of Atlantic, Burlington, Mercer, Middlesex, Monmouth, and Ocean) or in the northeast region (Sussex, Warren, Morris, Hunterdon, and Somerset). The remainder lived in the northeast region (Hudson, Bergen, Essex, Union, and Passaic) or the southern region (Atlantic, Camden, Cape May, Cumberland, Salem, Gloucester).

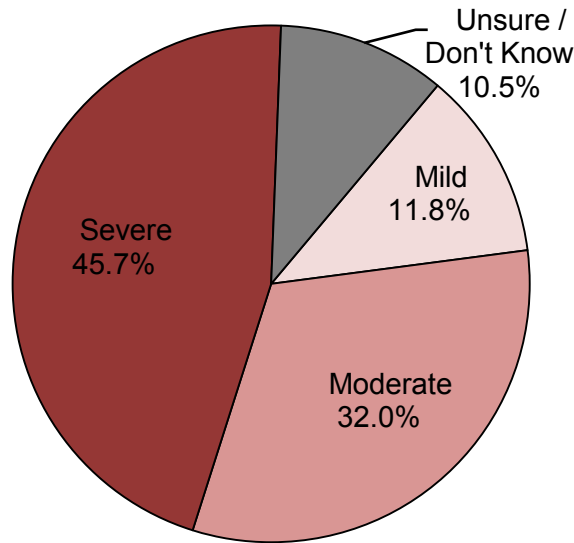
Figure 7: Residence of Survey Participants



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

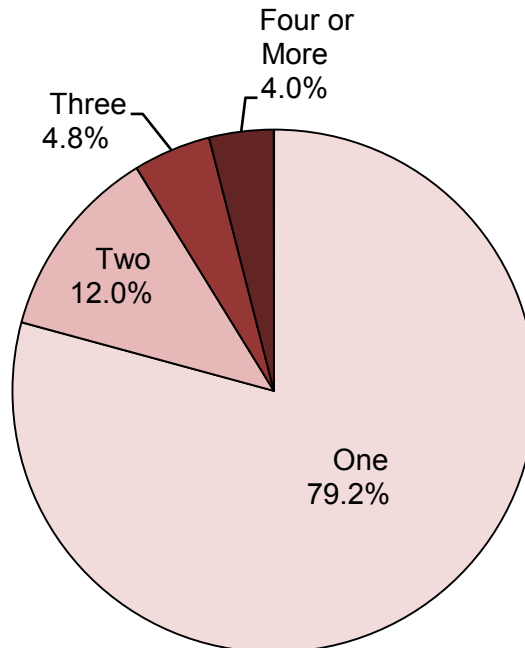
Participants were asked how severe they considered their brain injury. Most survey participants described themselves as having a moderate or severe brain injury. Nearly 80% of participants reported only one brain injury, and another 12% reported two injuries. Only 1% reported that their injury occurred during military service.

Figure 8: Self-Assessed Type of Brain Injury for Survey Participants



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

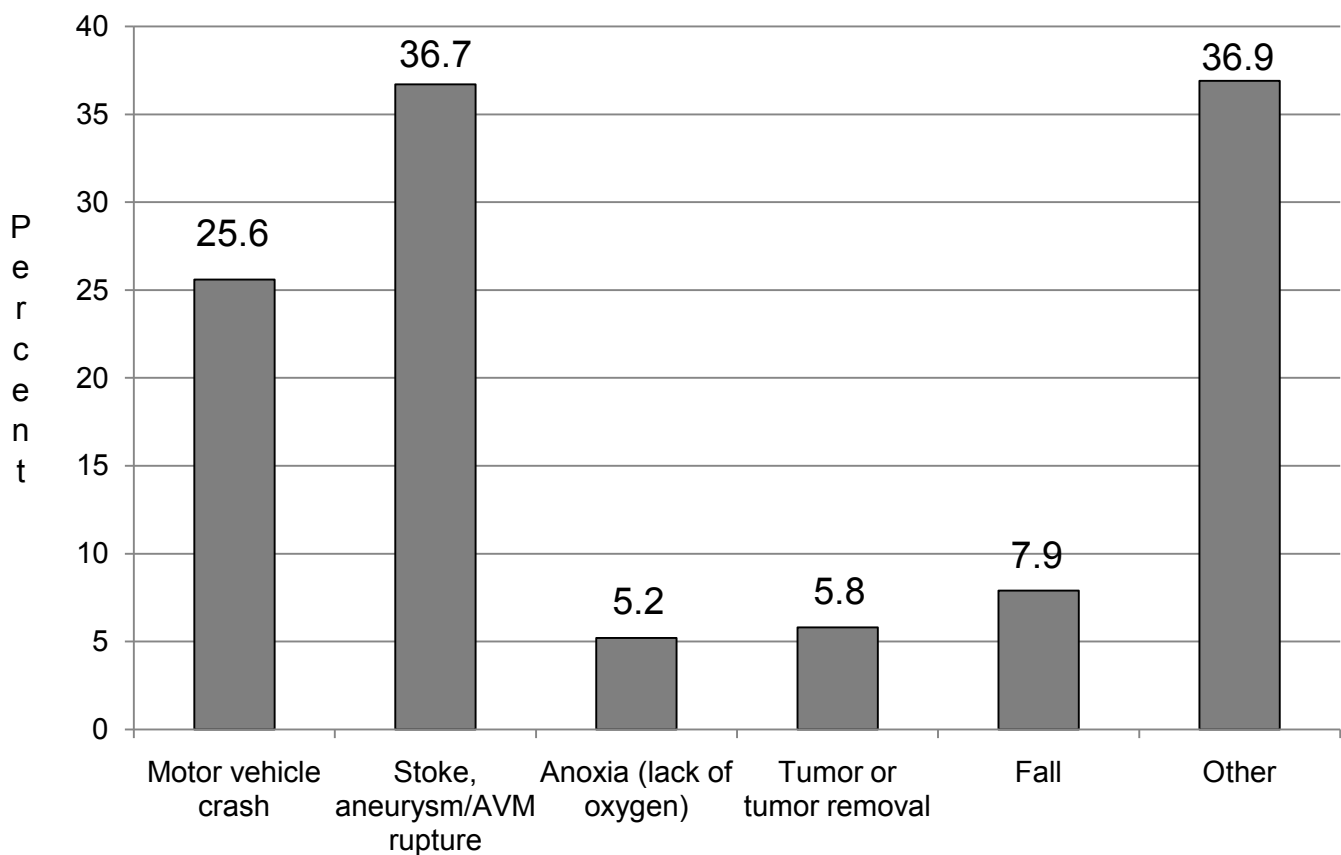
Figure 9: Number of Brain Injuries Reported by Survey Participants



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Overall, slightly less than half of participants (46.4%) reported that their first brain injury was traumatic as defined by the Centers for Disease Control and Prevention (caused by a blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain). Over one third of participants reported that they sustained their injury by stroke or aneurysm/AVM rupture (36.7%), and about a quarter reported motor vehicle crash (25.6%). Other means of sustaining injury reported by more than 5% of participants were falls, anoxia (lack of oxygen), and tumors or tumor removal.

Figure 10: Method of Sustaining Brain Injury Reported by Survey Participants



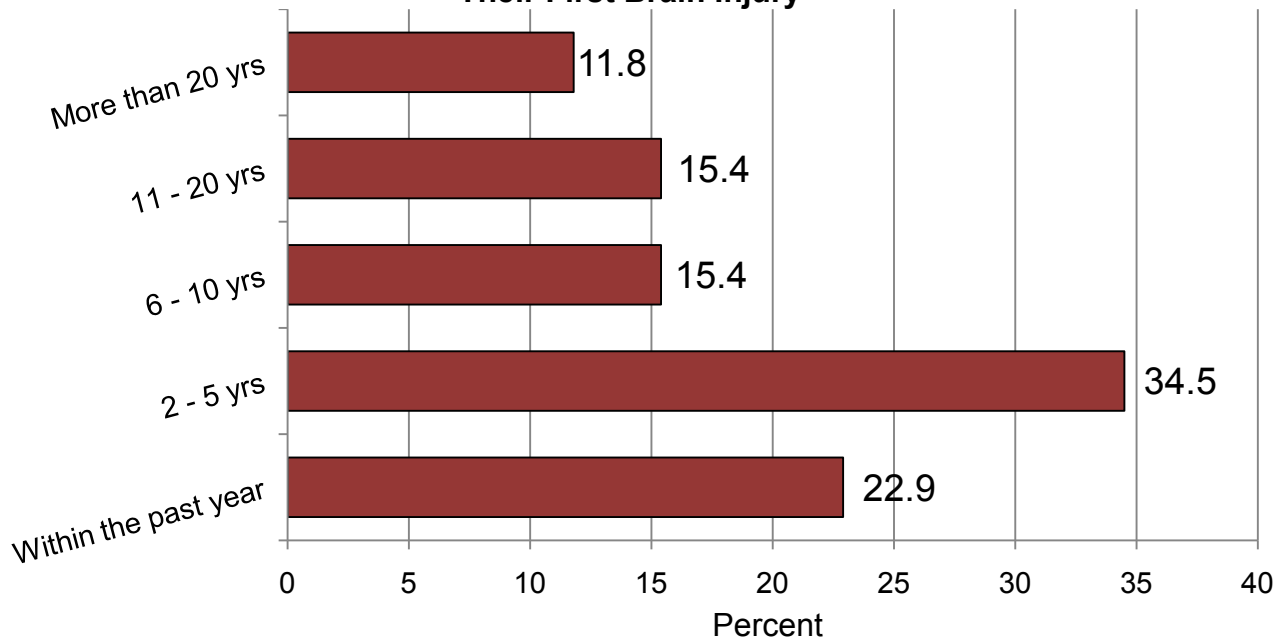
NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

The majority of respondents reported that they went to an emergency room as a result of their injury (86.2%), and/or were admitted to the hospital (87.3%).

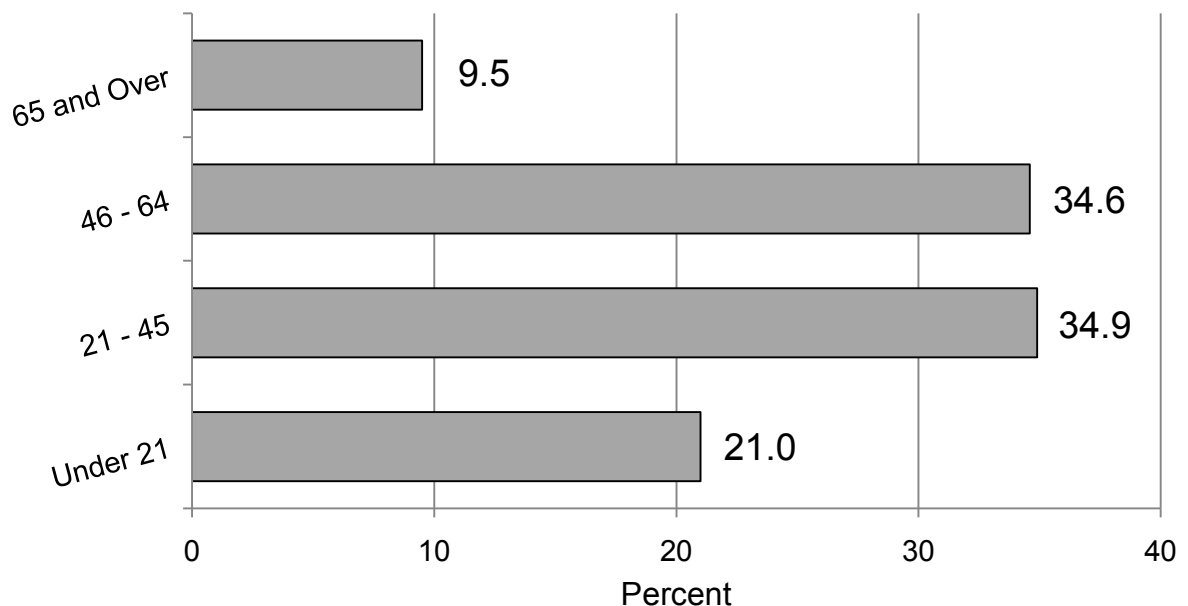
Over half of participants sustained their first brain injury within the past five years, with about a fifth of the reported injuries occurring within the past year. Almost 75% of participants were adults (21-64 years of age) when they sustained their first injury, and 21% were under 21.

Figure 11: Length of Time before Survey that Participants Sustained Their First Brain Injury



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Figure 12: Reported Age at Time of First Brain Injury



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Some participants provided additional information about the effects of their injury beyond the specific questions asked in the survey. A few people reported that they had only minor problems after their initial recovery, but many more people reported problems with short-term memory, difficulty concentrating, and difficulty dealing with emotional issues. Many also said that the effects of their injury would not be apparent to people meeting them, because they appear “normal” after their physical problems have been resolved, but difficulties with perception, cognition, and managing their emotions remained. Participants reported many difficulties resulting from their injuries, including problems speaking, difficulties focusing and staying on track, feeling very angry and/or abandoned, and problems with reading, writing, and filling out forms. These problems interfered with their ability to apply for needed services, advocate for themselves, and perform valued work and leisure activities. A few participants indicated that they had been in jail or in danger of going to jail because of their inability to avoid confrontations and control their responses. Several participants noted that it was very difficult for them to deal with the legal system and going to court, because they were unable to express themselves clearly, and legal staff did not understand the effects of their brain injury.

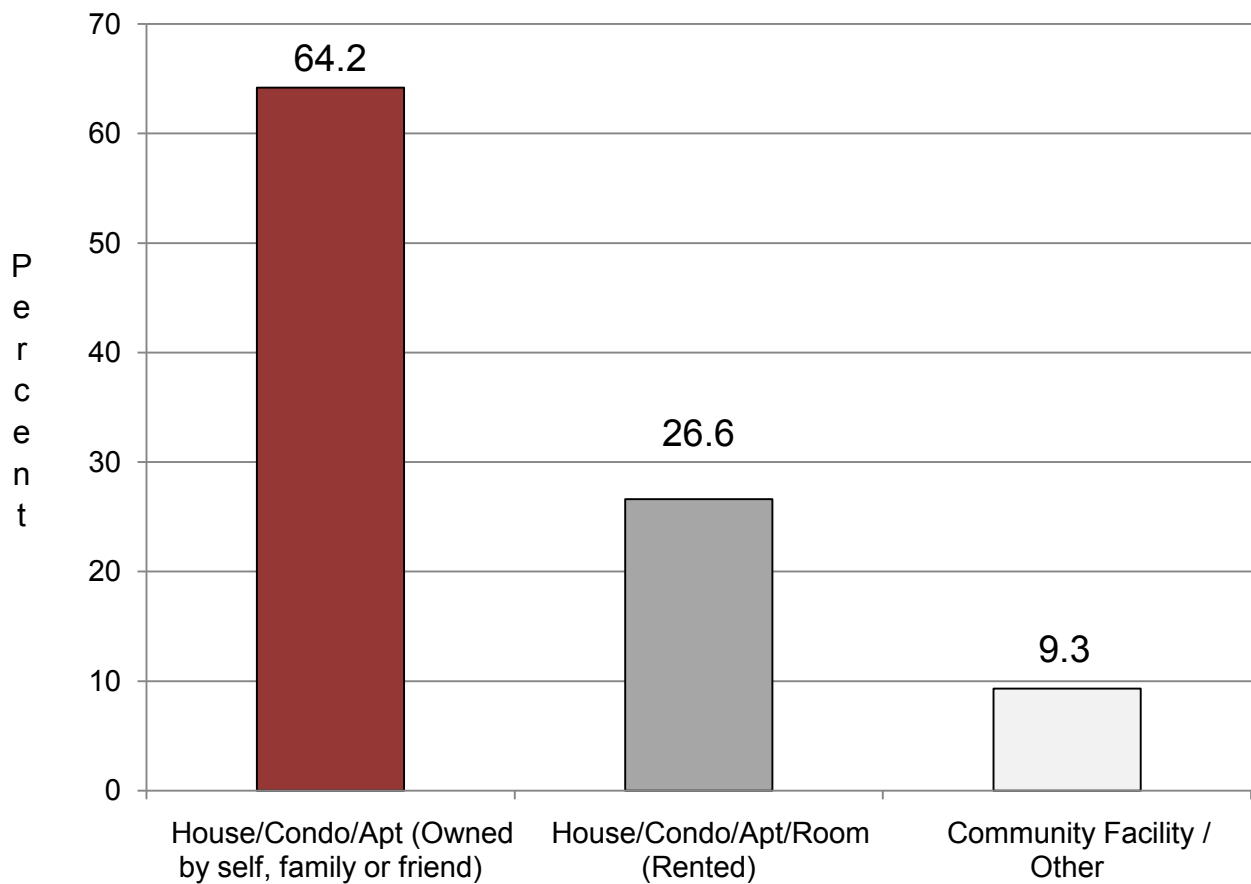
Current Living Situation

More than half (64.2%) of participants were living in a house or condo that was owned by them or a family member or friend; another 26% were living in a rented house, condo, or apartment. A small number lived in a facility such as a rehabilitation facility, a nursing home, a developmental disability center, or a jail, and most of these indicated that they considered it an inappropriate living arrangement, as indicated by comments such as the following:

- Patient is not receiving quality care or therapies to help him regain the use of body if possible. Therapy not provided in nursing home.

- At this point, he would be better at a home environment, but this rehab/nursing home is only providing nursing care, no therapy whatsoever.
- Staff does not check on me twice every eight-hour shift and I have had roommate problems in the past.
- Skilled nursing facilities often do not handle people with brain injuries in a knowledgeable way. They do not know how to redirect people who have problem behaviors. Care is very expensive and the quality is not good.

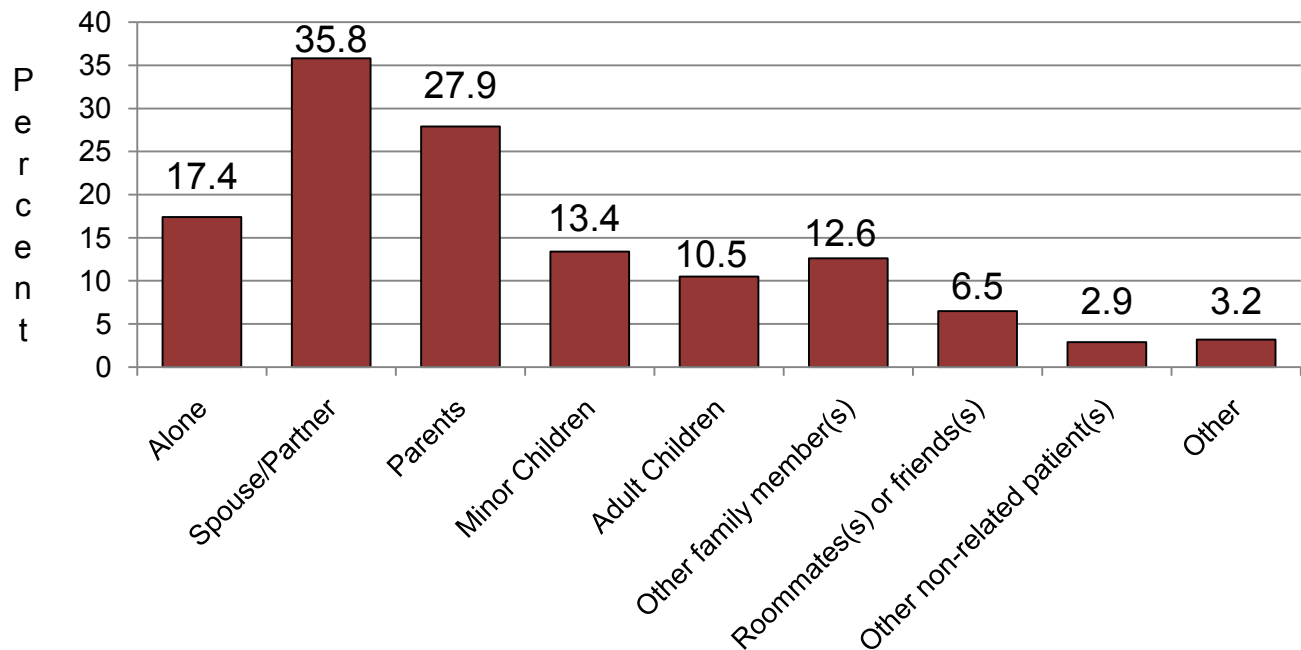
Figure 13: Place Where Survey Participants Lived



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Nearly one-fifth of participants reported living alone; most lived with their spouse or significant other (35.8%) or their parents (27.9%). Of those aged 65 and older, 65.4% lived with only an elderly spouse. Of those aged 46 to 64, 8.2% lived with their parent(s). About 10% lived with a non-family friend, roommate, or caregiver.

Figure 14: Living Arrangement of Survey Participants



NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Nearly three-quarters said that they were happy with their current living arrangements. Most of those who reported that they were happy said they valued living with their families, having their independence, and feeling comfortable and safe. Many participants commented on the love and support they received from their families. Comments about why they were happy included:

- Yes, because my family takes good care of me and I am comfortable.
- Because I'm with family who love me.

- Because I am able to be more independent.
- Because I am living in my own home.
- Because I trust and love my parents. They help me through everything if needed.
- My family provides emotional support and company/companionship, and nobody would understand my troubles like my wife, who has lived thru the whole experience – for 11+ years.
- Because it is comfortable and familiar.
- Because it's my home and I enjoy it and I'm happy living here.
- I can avoid use of additional “energy” and rest when needed, be independent, more relaxed.
- I get up without having to worry about waking others in the house up, I take my time getting ready, I play on the computer...and I go to bed when I want to.
- I like having my own home. I enjoy my wife and daughter. I am still trying to learn how to deal with my emotions, so it may not seem like I like it, but I do.

However, those who were happy also expressed some concerns, particularly regarding the burden on their family, costs, and accessibility. For example:

- For now we can afford it. If I can't return to work, we will have to sell the house and move.
- House needs modifications for safe use.
- Live on second floor – can't get out.
- My mom cannot pay for everything.
- Not completely (happy) – major financial problems and spousal problems.
- Only have SSD check – do not have any rental assistance – can't make ends meet.
- Like it but have a problem keeping up – wish there was affordable alternative that meets my requirements.

The 28% of participants who said that they were not happy with their living arrangement gave reasons such as the following:

- Because I need my own apartment with a place of my own and getting help to pay for it.
- Because is a second floor and we have problems in the bathroom, also to go up and down.
- Because it will never be permanent, nor is it mine.
- There is no privacy or independence.

- Before my accident my mom wanted to sell the house. I feel like I am keeping her here against her will.
- Can't cope – not enough \$. Physical limitations, not able to keep house/grounds up.
- Depend on family. Home needs many improvements that I don't think I will be able to afford in the future.
- House is too much to take care of and pay for.
- Not enough security and accessibility.
- The apartment is unsafe. It is on a second floor which is dangerous for us because we both seizure. Numerous structural, plumbing, and electrical problems.
- Crime – stuck in house.
- Too many things to take care of, feel vulnerable in the city.
- Too many people in one house, so there is no privacy at all.
- Very little social life – everyone else comes and goes and I'm stuck here.

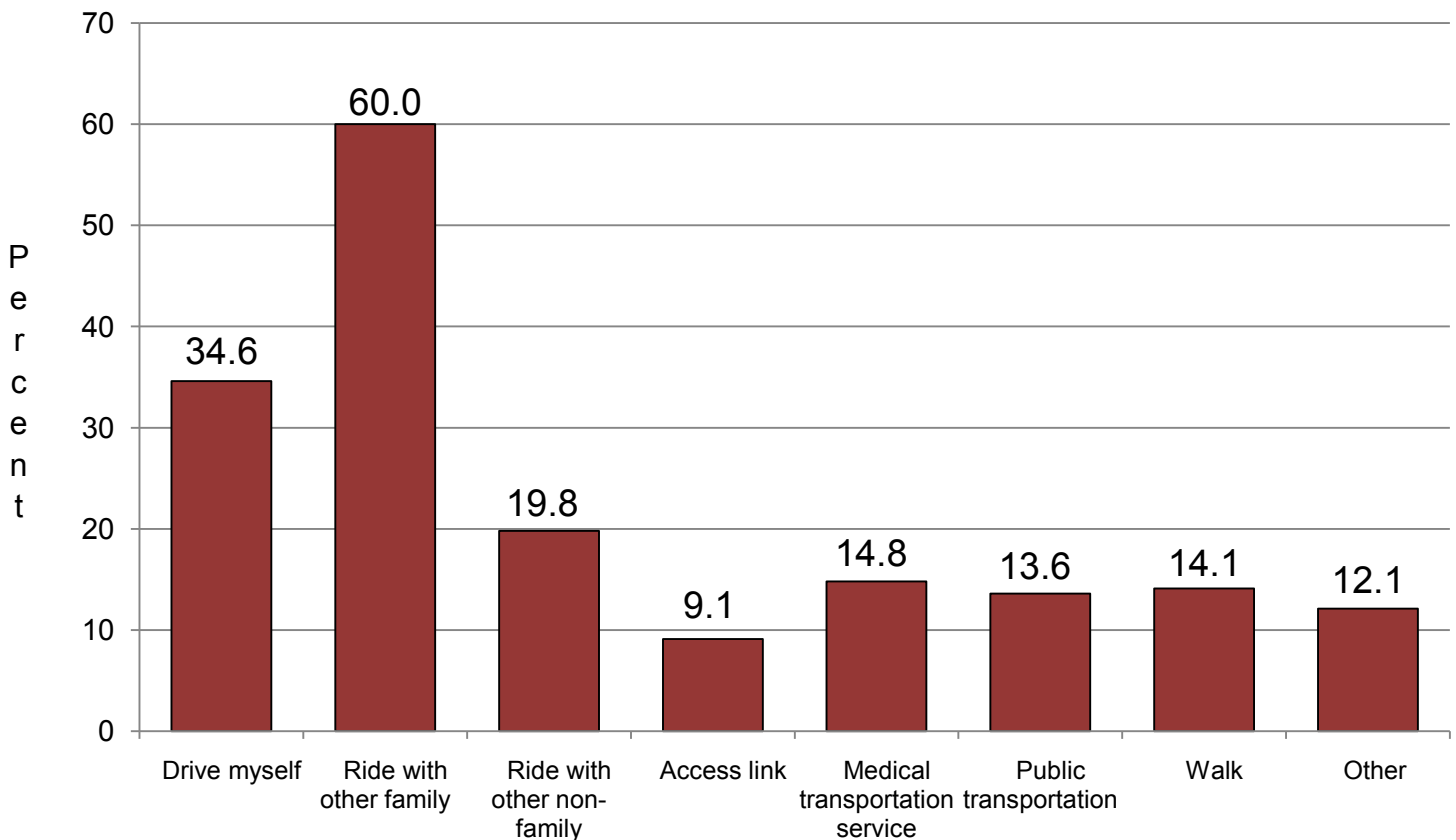
Whether or not they were happy with their current living situation, over half (57.1%) of participants were worried about where they would live in the future because of family or financial reasons. Of these, two-thirds (67.8%) reported that their families were also worried about their future living arrangements. As noted above, many older

adults are living with their elderly parents or an elderly spouse, and are at risk of losing family support. Some sample comments were:

- Spouse and I are 80 years old. We are getting fragile, and we will soon need assisted living.
- Rely on 89 year old parents.
- My 26 year old son is also disabled with multiple TBI – there is no available housing for him and is difficult to manage both of our living expenses, he is receiving TANF – I am on SSDI – my reduced income has placed us in the position of having multiple evictions.
- I cannot get into housing for the disabled -- five year waiting list – section 8 not accepting applications.
- I can't afford to pay my mortgage; I am months behind on my payments.
- Will be losing house soon.

Sixty-nine percent of participants felt that their transportation was both reliable and accessible; however, nearly one-third did not have a reliable and accessible source of transportation. The majority (60%) relied on family members to transport them from place to place, but other popular methods of transportation included driving themselves, rides from non-family, medical transportation services, walking, or public transportation. Most participants used a combination of transportation methods.

Figure 15: Methods of Transportation Used by Survey Participants



NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

For those who did not have reliable and accessible transportation, many mentioned the following problems:

- They have a car but cannot afford payments or repairs.
- They cannot afford a car.
- They need to rely on family members and friends who work and have other obligations.
- Public transport is inconvenient or not available.
- Access Link can be difficult to schedule and use.

The following are typical comments:

- My car is 14 years old and is having lots of repairs.
- It is an old car with over 150,000 miles on it; it needs a transmission and a timing belt; I can only go 15 minutes from my house and I don't have money to fix it.
- Have older vehicle that needs repair and no income of my own.
- Cannot afford a car and cab service is not available.
- I take cabs or my brother takes me places when he can. Taking cabs is expensive.

- My mom is my taxi but she is getting really tired of it. It is hard because she has a job and tries to work around it.
- I have to wait until it is convenient for others to take me wherever.
- Borrowing friends car, van needs to be fixed – can't really afford insurance and gas.
- Bus stops are not close by.
- Cape May County poor public transportation.
- Transportation services provided by NJ Transit are horrible (at least northern Jersey – specifically Essex County).
- Scared to use public transportation because I can't see very well or move very well.
- Poorly trained public transit folks deny accommodations.
- Bus not very flexible – have to call a week in advance.
- Many times access link services have long delays.
- Access ride has often left me at a location. They claim that I was not at pick up location and I was with my home health aide.
- I use access link. I do not live within $\frac{3}{4}$ mile of a bus route so they will not pick me up at my house. I have to get a ride to a nearby library and wait

there for my ride. The ride has a 20 minute window prior to pick up time and after pick up time.

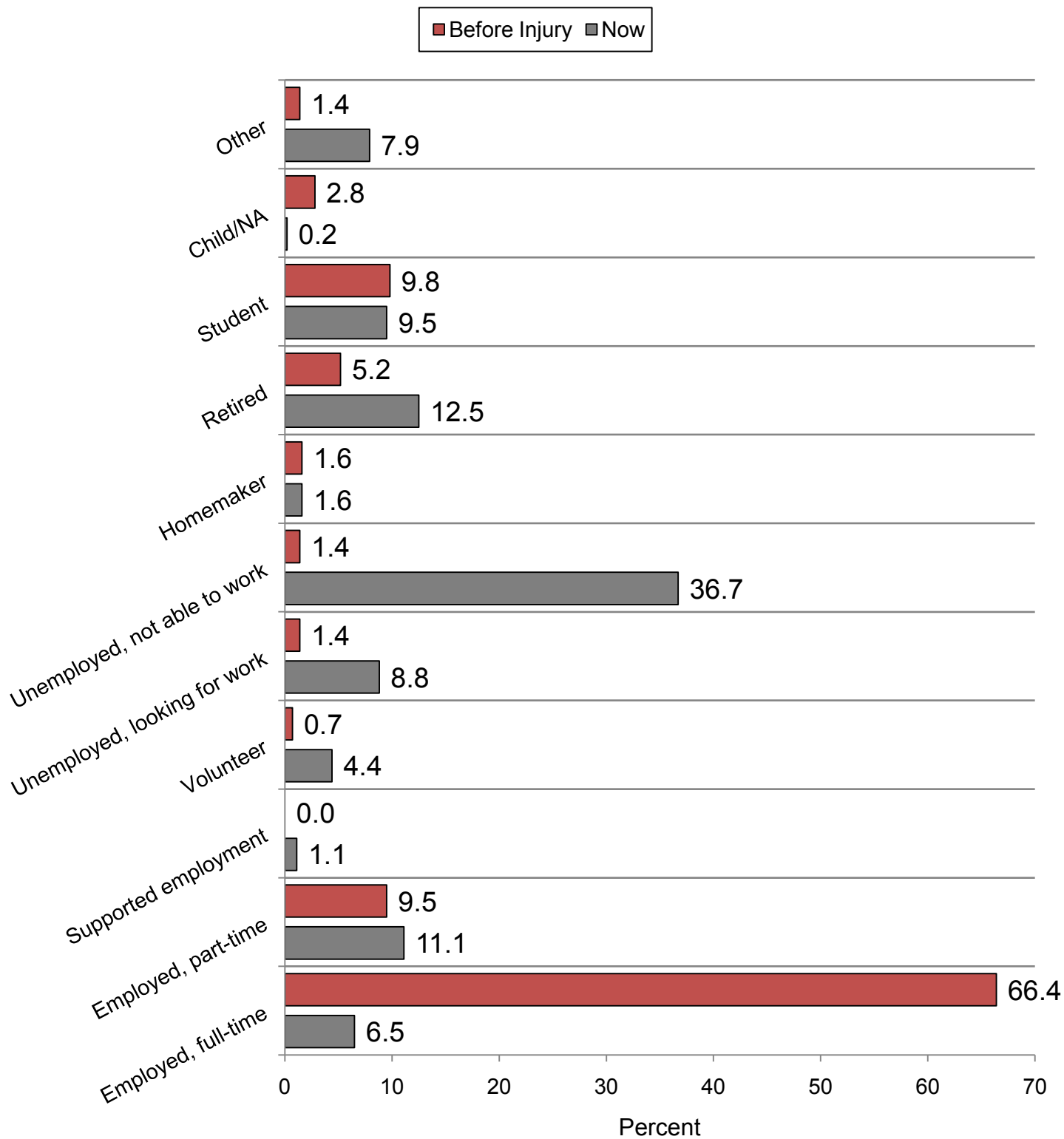
- Need to give 24 hour notice – sometimes appointments just pop up.
- Very hard to get through to make a reservation for a ride.
- Access link is approved for me but I am out of their distance zone, so I can't use it.
- Wheelchair is hard to get in and out.
- Trouble getting my electric wheelchair in my jeep.
- Need medical transport, no one to help me on transport places me at risk of injury/fall.
- I do take paratransit vans which are provided by my county. But the last pick-up times should be later to help people out when doctor's appointments and tests run longer.
- The county transportation does not take me out of the county. I live in Union County – part of my therapies are in Essex County which means I have to pay transportation.
- I have a car but I depend on other people to drive my car.
- Should not rely on same people all the time. No public transportation in area.

- Use train/taxi, and neighbors/friends/wife for transportation. Very difficult coordinating paying people for rides to and from therapies when wife is unavailable due to work.

Employment

Prior to sustaining their injury, two-thirds of participants were employed full-time and nearly 10% were employed part-time. About 10% were students, 5% were retired, and about 3% were children. At the time they were surveyed, only 6.5% held full-time positions. Instead, 36.7% reported that they were unable to work, 12.5% were retired, and 11% were employed part-time. Not surprisingly, 84% of participants reported that their injury had changed their employment situation and over 60% said that they were “very unhappy” or “somewhat unhappy” with their employment situation.

Figure 16: Employment Situation of Survey Participants Before and After Their Brain Injury



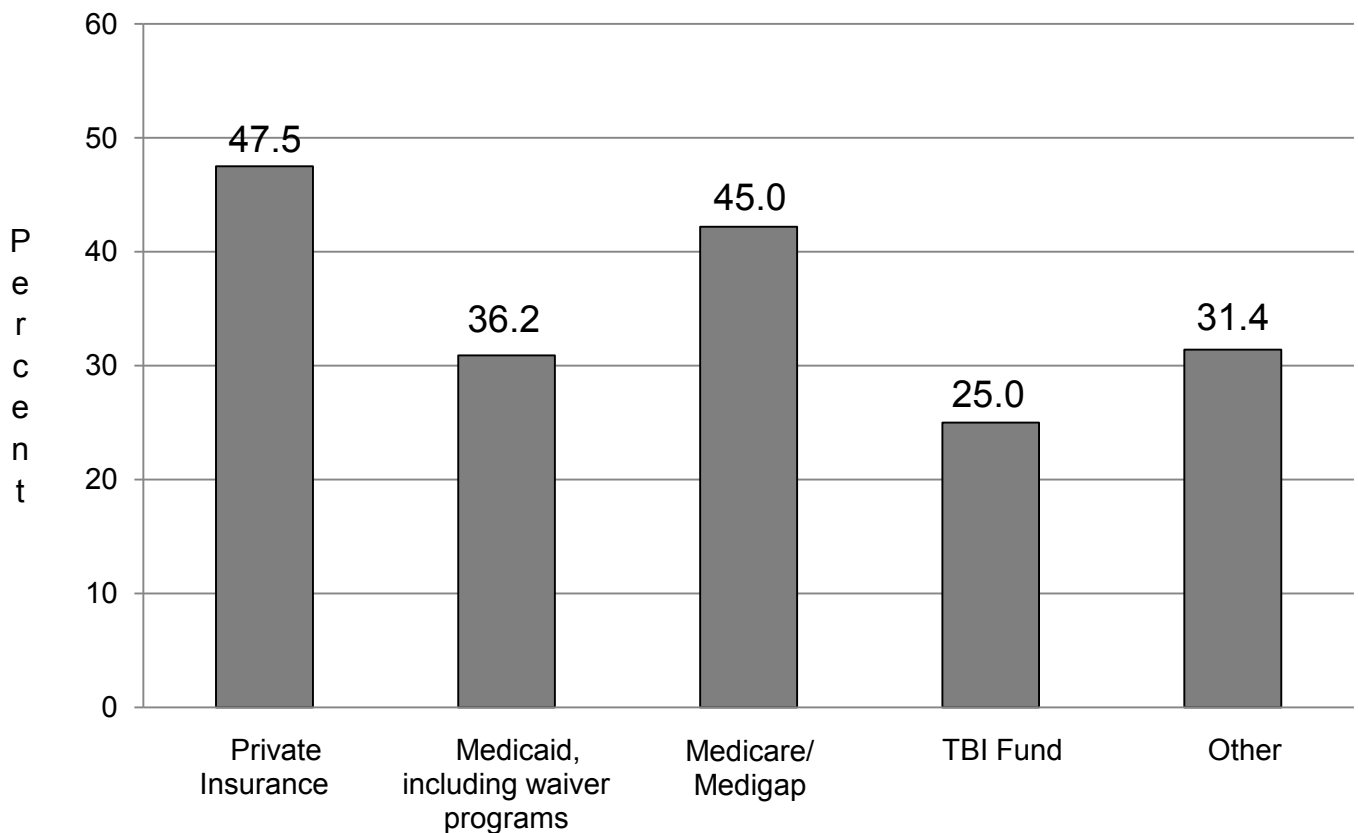
Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

A number of participants expressed frustration with their inability to work, and stated that they wanted to work if they could find employment which would accommodate their disability. Several commented that their difficulties communicating and/or controlling their emotions because of their injury made employment difficult, although they were physically able to work and had worked successfully in the past.

Health Care

Just under half of participants reported that they were paying for their health care costs through private insurance. Other forms of payment included Medicare or Medigap (45%), Medicaid/NJ FamilyCare/other waivers (36.2%) and the Traumatic Brain Injury Fund (25%). Many used multiple forms of payment.

Figure 17: Methods of Paying for Health Care Costs Reported by Survey Participants



NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Only 44% of participants said that their health coverage was sufficient for their needs related to their brain injury. Most of those who did not have sufficient coverage said that their coverage did not include needed services such as speech therapy, cognitive therapies, vision therapy, and social skills training. Out-of-pocket costs for services became very expensive, even for those with coverage. Costs incurred for medications were often very high, and some medications were not covered by insurance. For those not covered by Medicaid, coverage for needed therapies was often not covered or unaffordable; however, Medicaid was not always accepted by all providers for those who had it. In addition, many participants cited the limited number of medical providers with knowledge and experience in brain injury. For children, the availability of services through the school system varied. Some parents told us that they had to be active advocates for their children to receive even services which were available, since school personnel did not understand the effects of brain injury.

Typical comments included the following:

- You only receive state help if your finances are very low. Help should be available to everyone, whether your finances are low enough or not.
- When we had insurance, they would not pay for the full cost of most of the surgeries I had, leaving us to pay the remainder, or the surgeon could write it off.
- With this coverage, there are still outstanding bills that were not covered.
- Some services are very costly but others are free through the school system.
- The school tells us she doesn't need things that she does need. Won't cover speech therapy, social skills training, etc.

- Too few cognitive therapy sessions. Insurance companies unreasonably expect brain injury to heal in 6 months.
- We have to send letters because the insurance company sometimes denies my coverage and most of the time they never answer us.
- Health insurance has denied speech language therapy. Does not cover vision therapy, auditory processing re-evaluations, or any social/community skills training.
- We have large bills (thousands) out of pocket due to long hospital and inpatient rehab stays.
- Very difficult to find neurologist nearby, insurance cancels and requires resubmission of all the records every year.
- Sometimes the hospital uses private doctors which do not accept Medicaid, and oral surgeons are hard to find.
- Some doctors do not accept Medicaid so I have a private insurance to make sure I can see them. Then the insurance co-pay is getting higher. Also, as I get older it is very difficult for me to be part of my parents' insurance coverage.
- Medicaid does not pay for most of the services I need, or specialist such as TBI neurologist does not take Medicaid. I am on antiseizure given by primary care. Side effects have hospitalized me and do not control black outs or strange behavior.

- No insurance. COBRA expired. Cannot afford private insurance at a cost of \$1400 per month. Do not qualify for Medicare until 2/09. All doctor visits and meds paid out of pocket at a cost of roughly \$1200 per month.
- There is limited coverage through Medicare. There is no coverage for home care and many assistive devices are not covered.
- My private insurance doesn't pay any of the costs related to my brain injury. I only have what auto agrees to pay, which is now just neuropsychiatry and medication.
- Medicines—(my child) takes many medications and the copay is approximately \$350/400 per month.
- Donut hole costs for medications are huge for person on fixed income. Co-pays and premiums high, too. Insurance company (not my doctors) deprives me of my medications for weeks. Last year for months they cut my meds against my doctors' instructions.
- Veterans affairs medical centers really didn't have anything to offer me when my accident happened and my care has been hodge podge generally requiring my determination to get what I need.
- The complaints that I have, e.g., very poor memory, pains in my head and neck, are all attributed to my age, rather than to my brain injury.
- There should be money/funds allotted for special services to TBI individuals. Medicaid is not always available for moderately higher-income homes.

- There are not enough medical people with brain injury knowledge and experience.

Applications to the TBI Fund

Nearly two-thirds (63.2%) of participants said that they had applied to the TBI Fund; however, several participants had never heard of the TBI Fund and were given information about it. The survey did not ask specifically about services received from the Fund or satisfaction; however, the following comments were offered about the Fund:

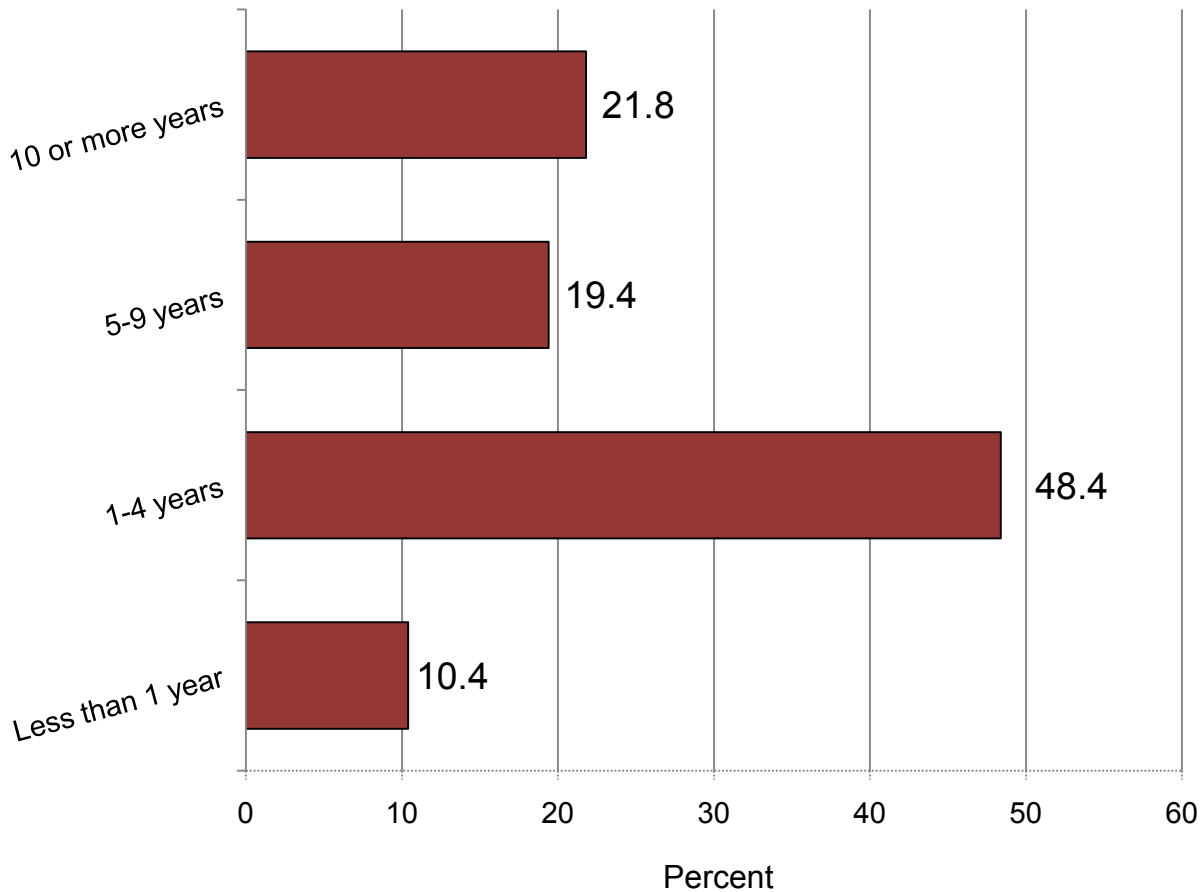
- TBI Fund counselor was helpful.
- I have the paperwork, but it is difficult to fill out.
- I applied several months ago for my husband, but I am still waiting to find out.
- The TBI Fund's housing support services are an utter failure that do not meet the needs of persons affected by TBI trying to live independently.
- I get money from the TBI Fund, but I have to budget it to get drivers to drive me to rehabilitation doctors.
- The TBI Fund helps cover my medical expenses that aren't covered by insurance.
- I need a home health aide at least 20 hours a week. The TBI Fund only provides about 8 months a year of help. After I use that up, I have to pay the rest myself. It's really hard.
- Thank heaven for TBI Fund, or I would have no visual therapy.

- TBI Fund isn't enough to pay medical expenses that insurance won't pay.

Assistance from Family and Friends

The survey asked participants about whether they received help from family members or friends with personal needs or household chores. Close to three-quarters (71.5%) of the participants responded that they received help taking care of personal needs or household chores from a family member or friend. Of these, 91.8% said that they received help at least every week. The length of time people had received help ranged from one month to 48 years. About half of participants said that they had been receiving help for between 1 and 4 years.

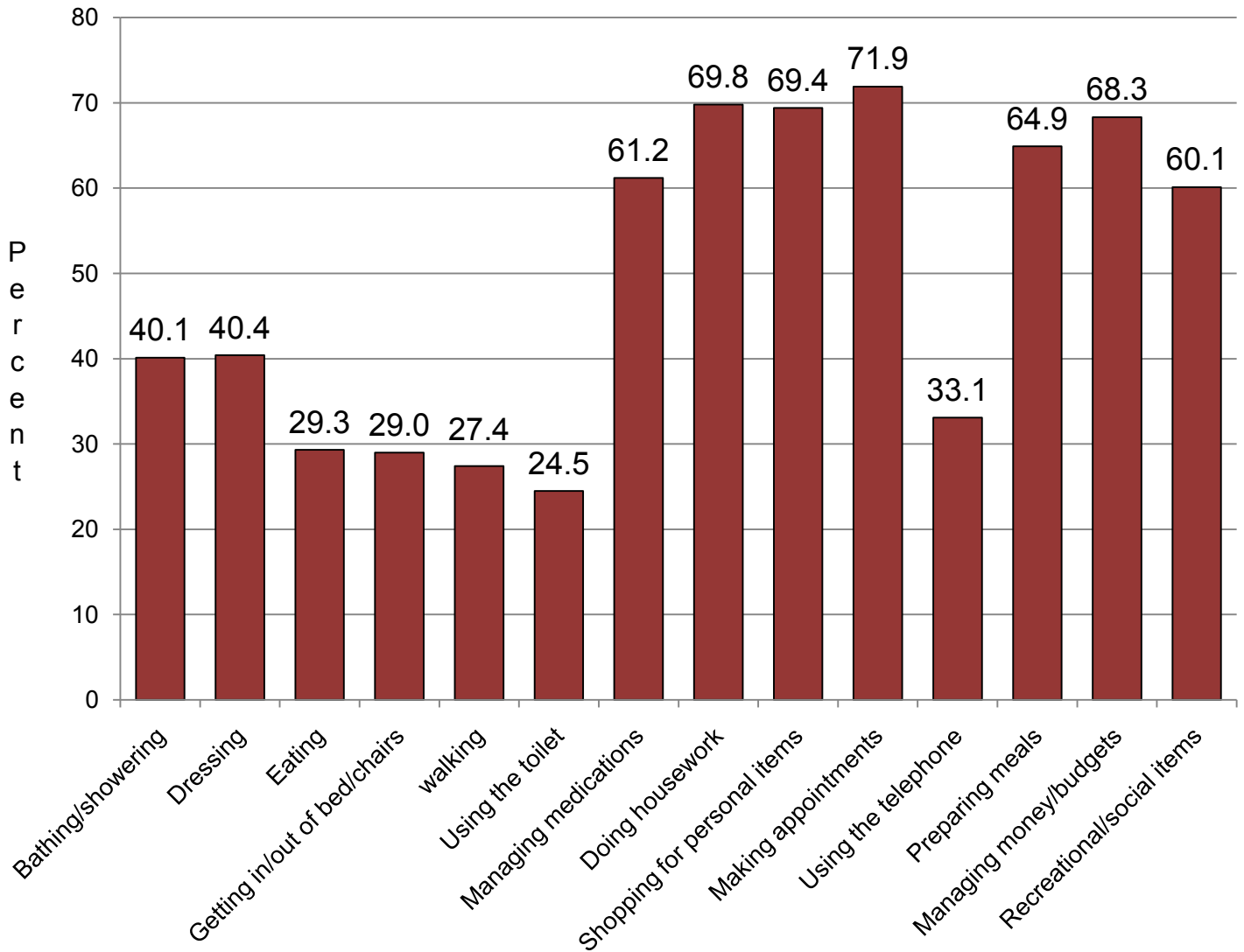
Figure 18: Length of Time Survey Participants Received Help from Family and Friends



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

About two thirds of the participants said that they received help with making appointments, housework, shopping, managing money, and preparing meals. Fewer people received help with such personal activities as eating, walking, getting in and out of chairs or bed, or using the toilet.

Figure 19: Activities for Which Participants Receive Help from Family or Friends



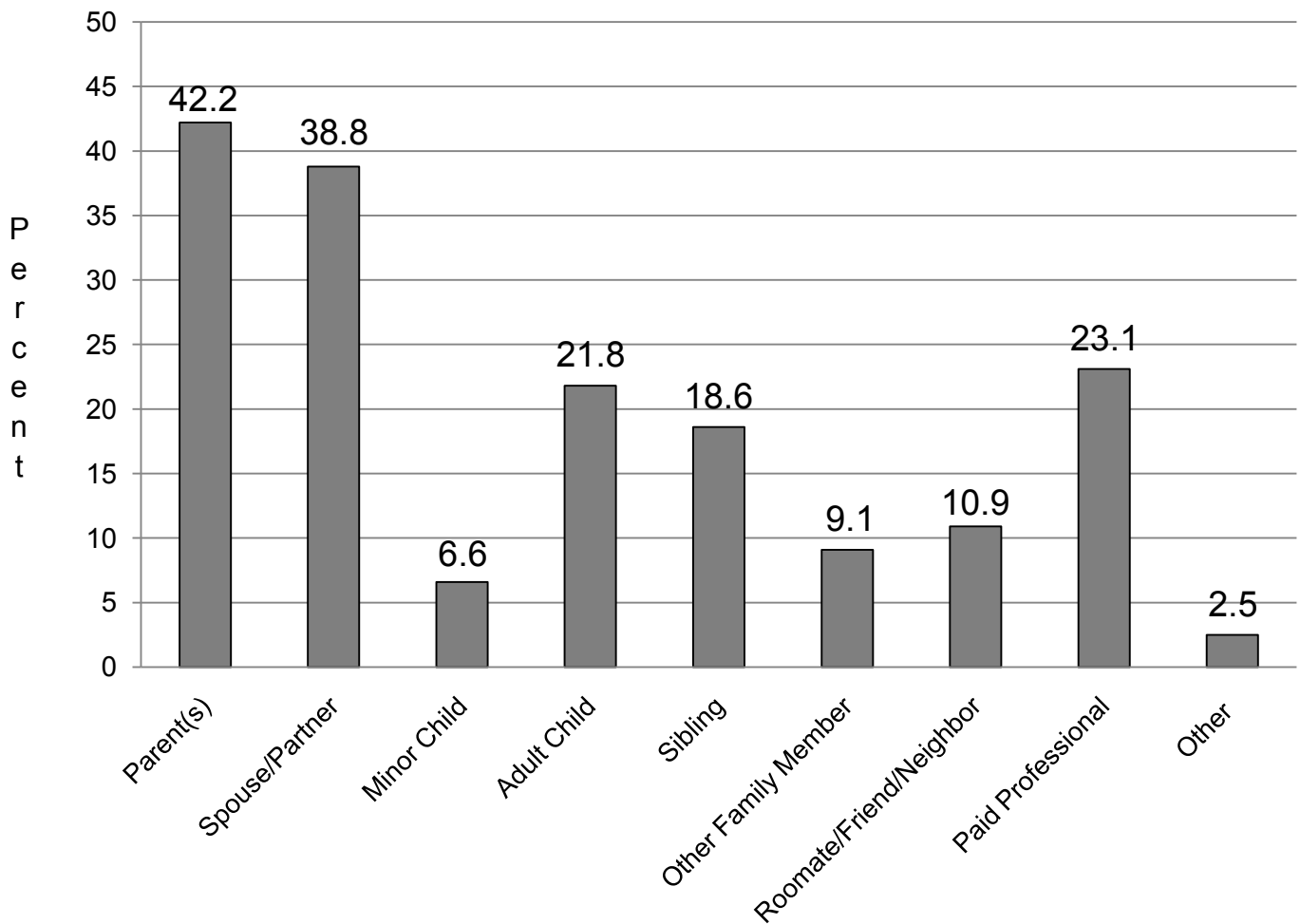
NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

About 60% said that they received help with managing medications, recreational or social activities. About 17% of participants mentioned other types of assistance; the majority said they got help with driving/transportation and cognitive/organizational support (e.g., finding things, staying on task, reminders, explaining things, help finding words/forming thoughts).

Parents and significant others were the individuals that helped most of the time, along with adult children and siblings. Only one in ten received help from roommates, friends, or neighbors. About one-quarter received help from paid professionals.

Figure 20: Individuals Who Provide Assistance to Survey Participants



NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Three-quarters of participants said that they were happy with the help they received. However, those who were not happy said that they worried about the burden on their family and friends or were frustrated about being dependent. Others commented on the difficulty of getting help. Some typical comments were the following:

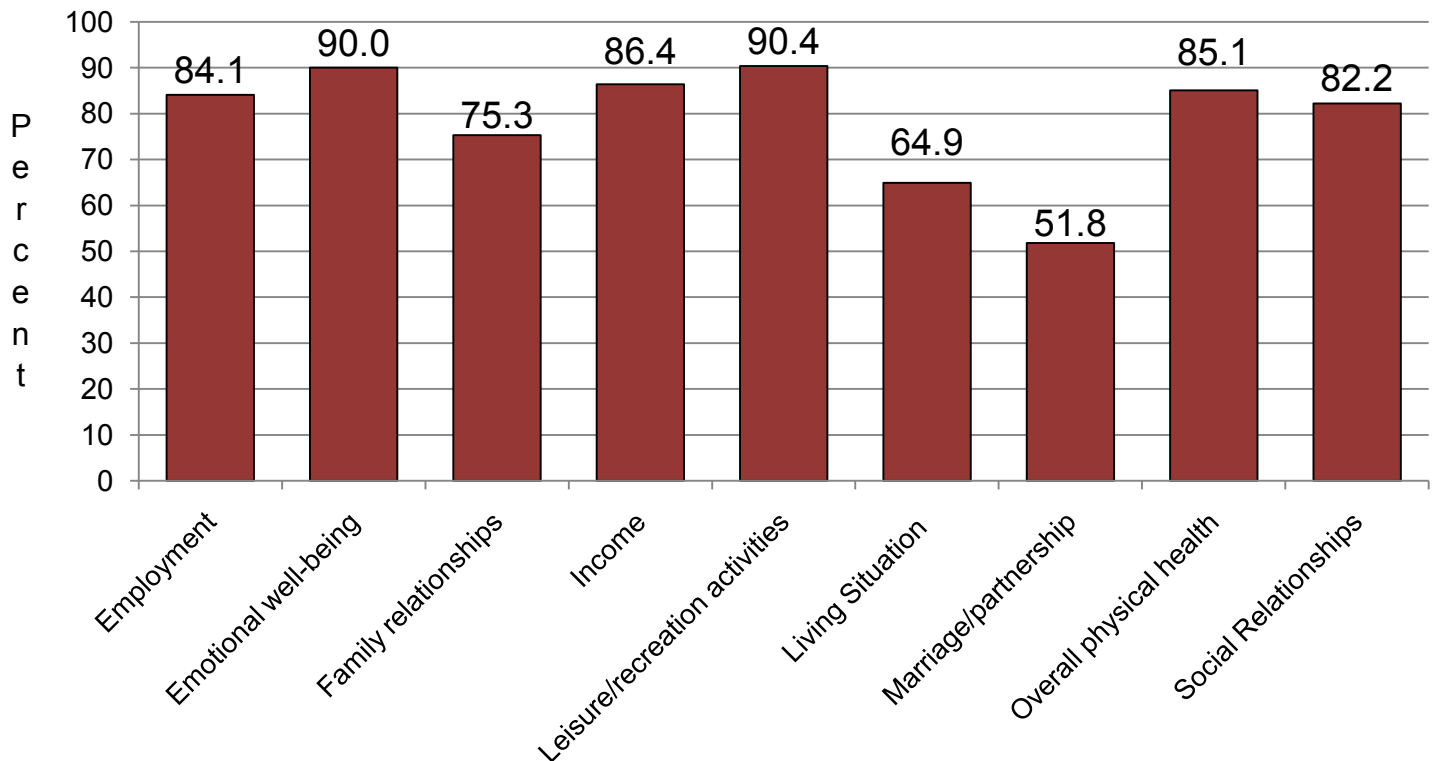
- I'm happy that I have assistance, but I feel guilty that I need it.
- Appreciate help, but resent needing help. Feel inadequate.
- All the pressure is on my spouse – thus our marriage. I want to become independent.
- I feel that I am a burden to my family.
- She feels she is a burden, and as her mom I worry that she is so unhappy.
- Volunteers are loving and kind, but often undependable.
- Aides are hard to come by.
- There were only two agencies in our area and one couldn't do it, so we had to use the other. The aides are fine, but the customer service is terrible. There is a delay of several weeks every time someone quits.
- Everyone is busy, so they help me, but sometimes they don't have time either.
- I know my parents and my friends help me as much as they can, but ideally I'd like to do more out of the house.

- It's hard working around their schedule, as well as cancel around how they feel.
- It would be nice and healthy for my caregiver if she could get a break or even a vacation from all the work she performs in helping me. As it is, the only time off or "vacation" she gets is when I'm in the hospital.

Life Changes as a Result of Brain Injury

Participants were asked to indicate whether their injury changed several areas of their life. The results illustrate the dramatic differences which occurred in people's lives after brain injury. Ninety percent said that their emotional well-being and/or leisure/recreation activities changed, and over 80% said that their employment, income, overall physical health and social relationships changed. Many of the comments in other sections of this report suggest the nature and impact of these changes.

Figure 21: Areas of Life Changed by Survey Participants' Brain Injury

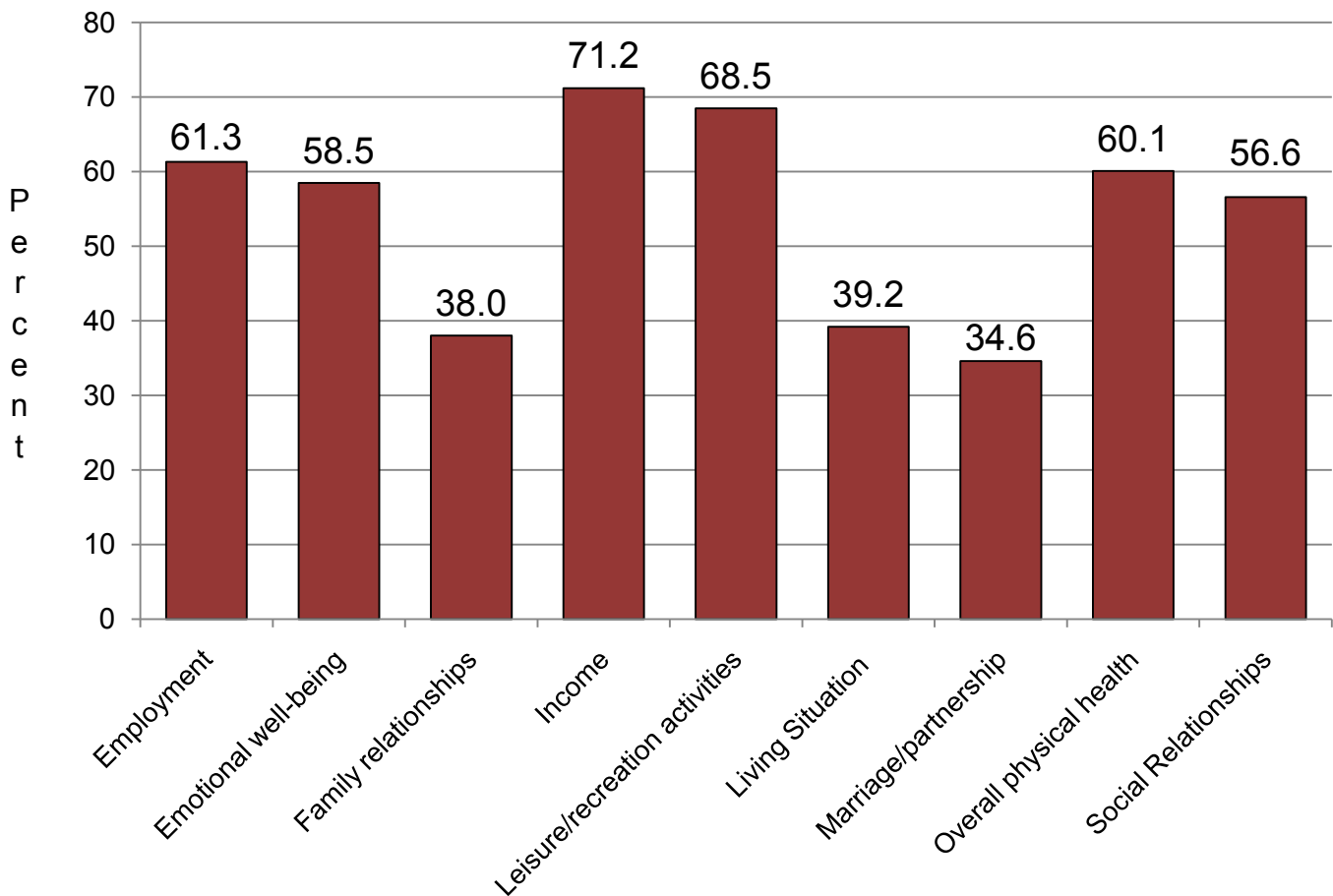


NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Participants were also asked how happy they were with each area of their life. For most areas of their lives, high percentages of participants indicated that they were very or somewhat unhappy. Nearly three-quarters (71.2%) were unhappy with their income and over 60% were unhappy with their employment situation, leisure/recreation activities, and overall physical health. Over half of participants were also unhappy with their social relationships and emotional well-being. Family relationships, marriage/partnership, and living situation were the areas where the lowest percentage of participants said that they were unhappy, but over a third were not happy with these parts of their life.

Figure 22: Participants Who are Very or Somewhat Unhappy with This Area of Their Life



NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

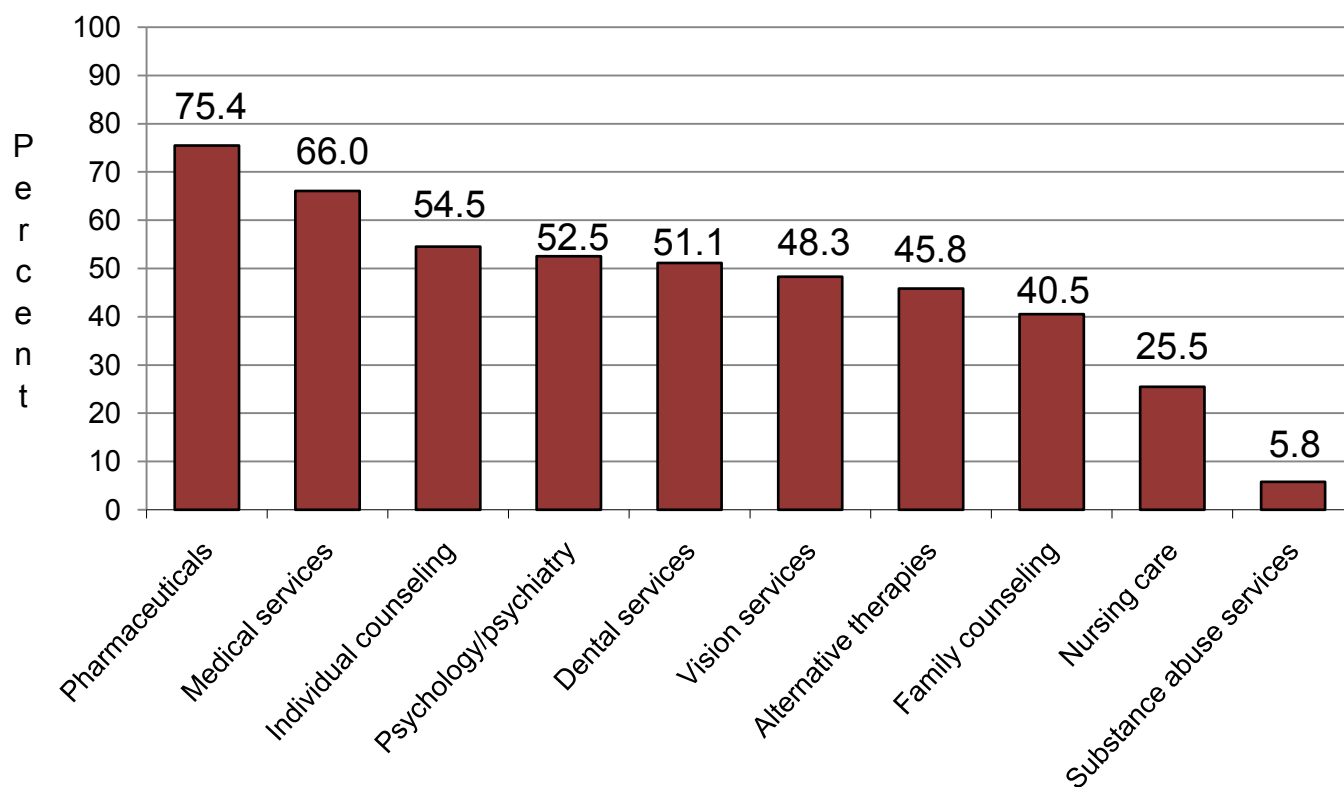
Services Needed by Individuals with Brain Injury

The following section details the responses of survey participants about services they needed, services they received, and barriers to receiving services. The survey asked participants about four general areas: Medical/Therapeutic Services, Rehabilitation Services, Education/Employment Services, and Community Living Support.

Medical/Therapeutic Services

Pharmaceuticals (medications and/or copays, etc.) and medical services to address the effects of brain injury were the most frequently mentioned needs in any area of service. Three quarters of participants indicated that they needed pharmaceuticals, while 66% said they needed medical services. Over half said that they needed individual counseling, psychology or psychiatry services, and dental services, while nearly half needed vision services.

Figure 23: Medical/Therapeutic Services Needed by Participants

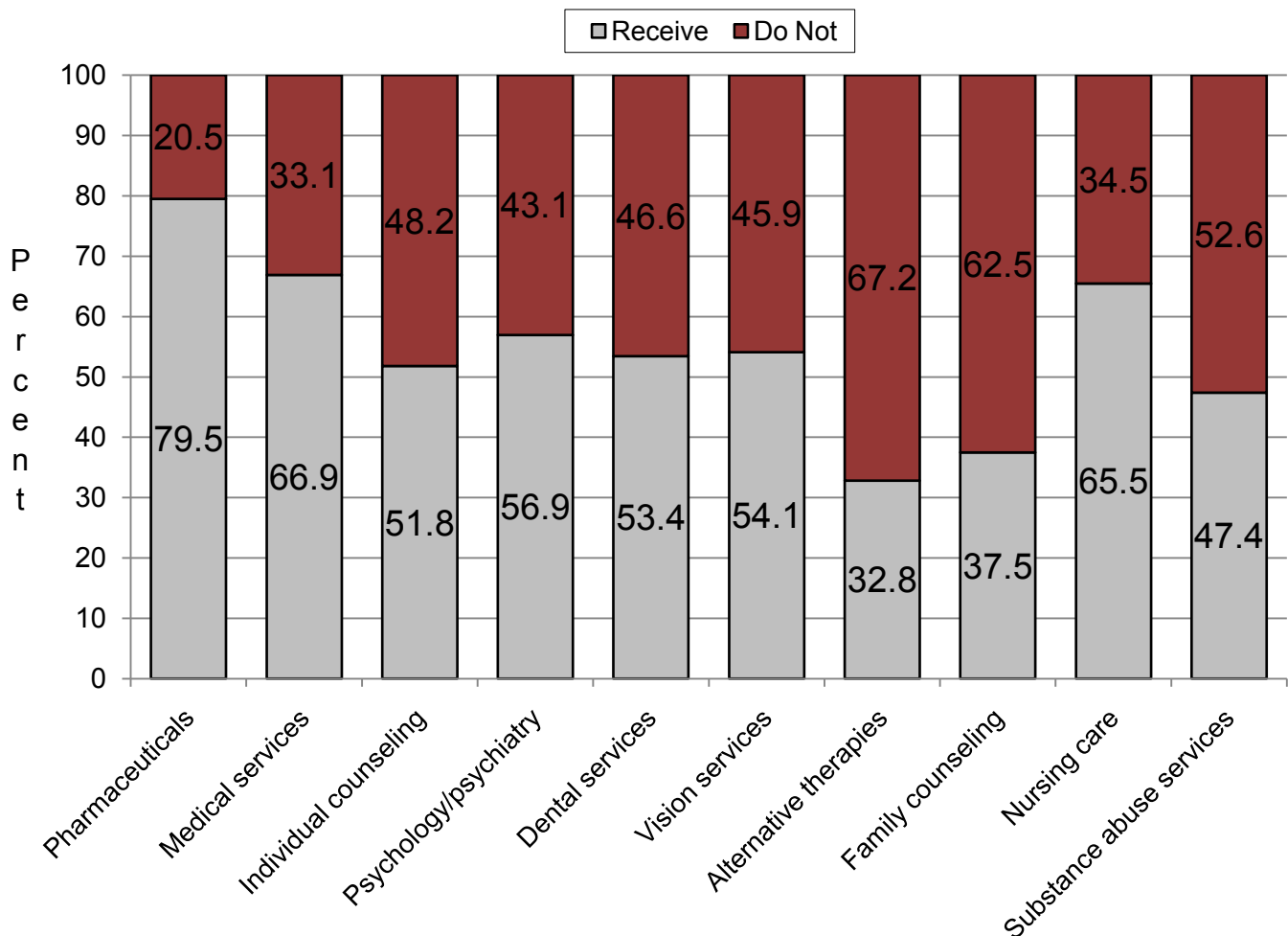


Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

The need for substance abuse services (addiction programs, peer support groups, etc.) was the least often mentioned (5.8%).

While half of participants indicated that they needed individual counseling, psychology or psychiatry services, dental and vision services, only about half of those who needed them received these services. Slightly less than half of those who needed substance abuse services received them, while only around one-third received needed family counseling or alternative therapies. Of those who indicated that they needed the service, 20% indicated that they did not receive pharmaceuticals; one-third did not receive medical services (33.1%) or nursing care (34.5%).

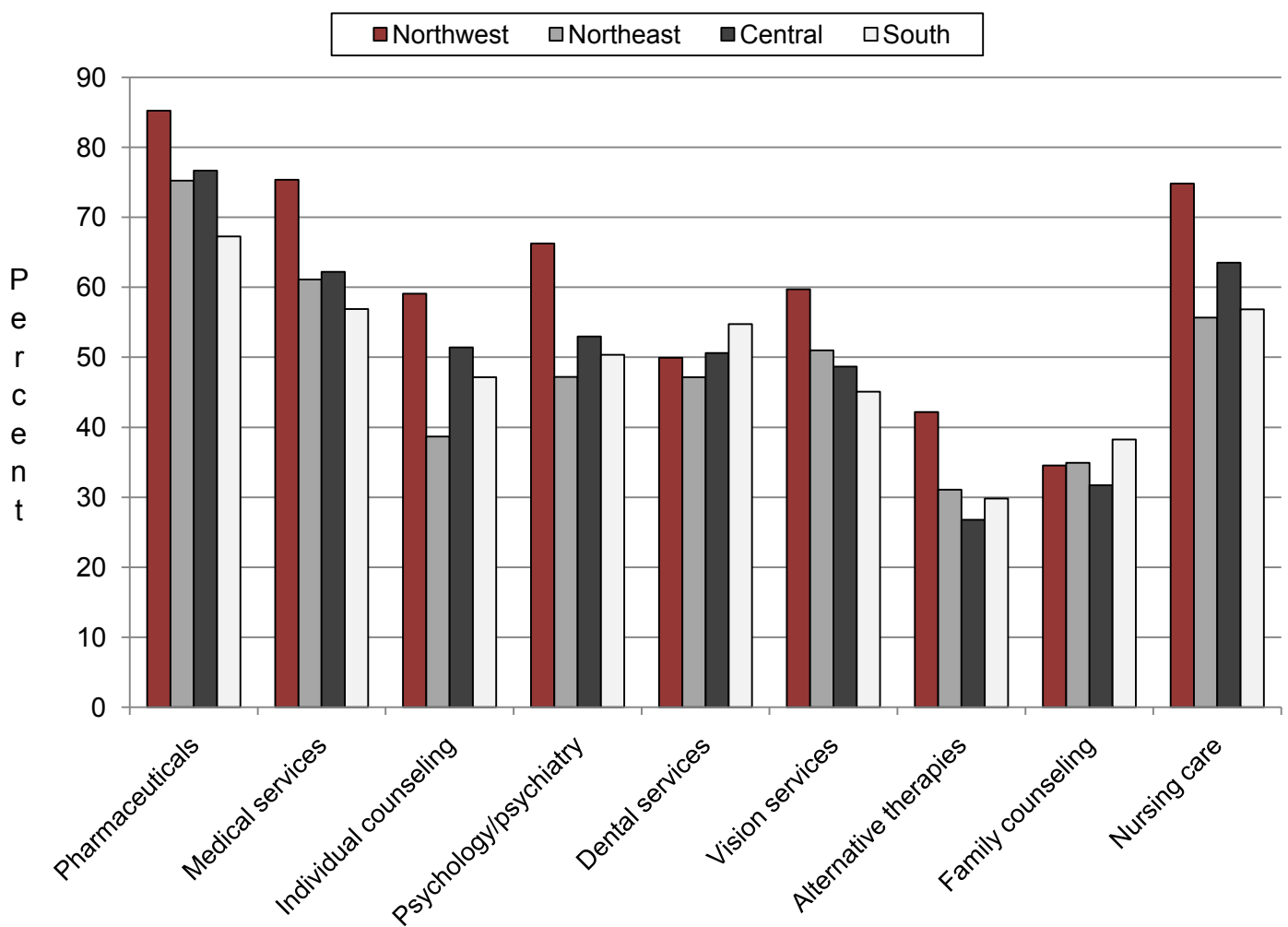
Figure 24: Participants Who Need and Receive Medical/Therapeutic Services



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Figure 25 shows the percentage of participants who indicated that they received needed medical/therapeutic services by region of New Jersey. Of those who needed these services, fewer participants received pharmaceuticals, medical services, nursing care, individual counseling, psychology/psychiatry, vision services, and alternative therapies outside of the northwest region. Participants in the northeast were least likely to receive individual counseling, psychology/psychiatry, and dental services.

Figure 25: Participants Who Need and Receive Medical/Therapeutic Services by Region of New Jersey

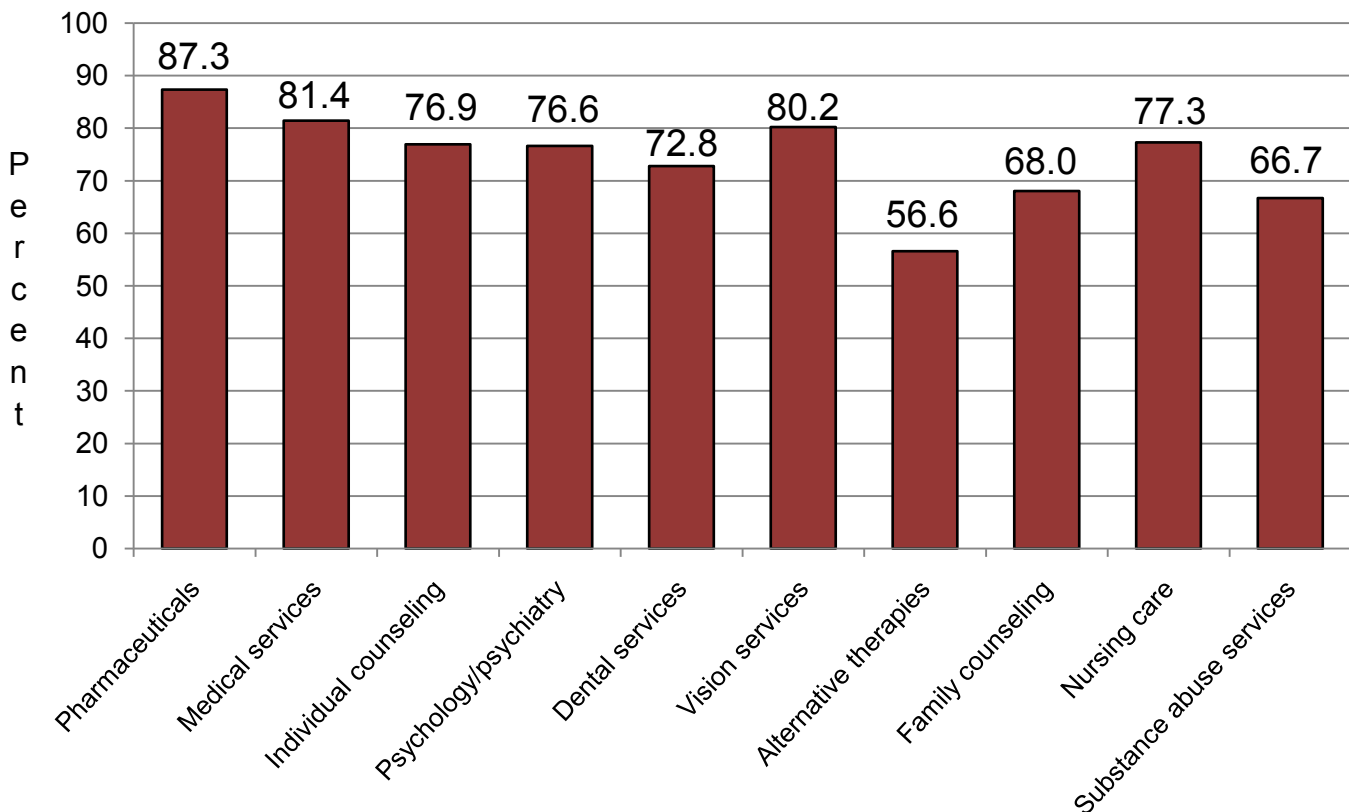


Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Fewer participants in the southern region indicated that they received pharmaceuticals, medical services, or vision services that they needed compared to other regions of the state. While over half of participants reported that they needed individual counseling, psychology/psychiatry, dental and vision services, less than half of those who needed them received services in some parts of New Jersey. Participants in the central region reported the lowest percentages of receiving family counseling and alternative therapies.

Only slightly more than half (56.6%) of participants indicated that their alternative therapies met their needs, while nearly a third of those receiving family counseling or substance abuse services felt that their services met their needs. For about a quarter of participants, their individual counseling, psychology/psychiatry, nursing care, or dental services did not meet their needs.

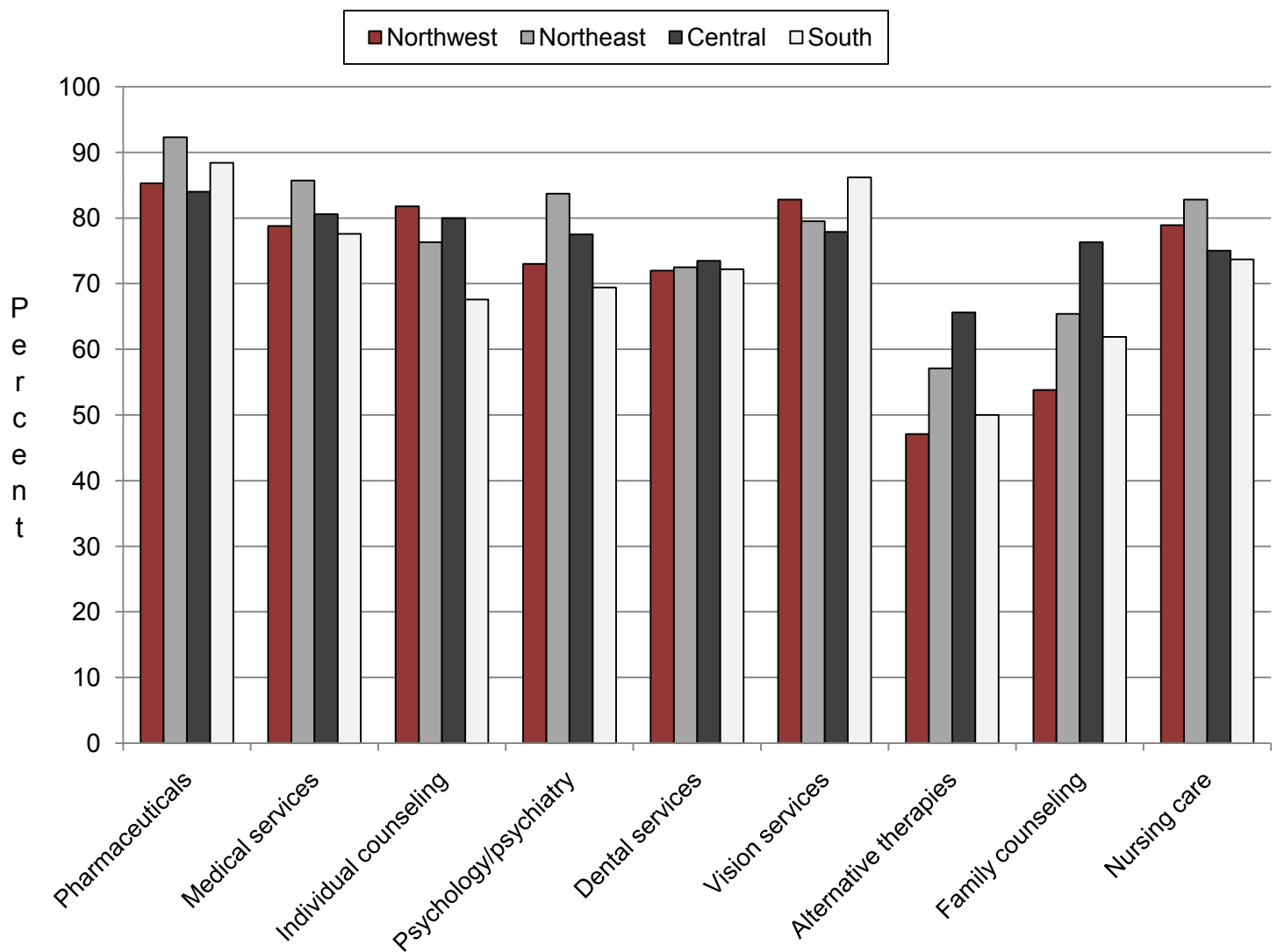
Figure 26: Participants Who Indicate That the Medical/Therapeutic Service They Received Met Their Needs



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Differences between regions in the percentage of participants who indicated that their services meet their needs were not large, except for family counseling and alternative therapies. Participants in the northwest and south were less likely to say that these services met their needs. Participants in the south were also less likely to indicate that their individual counseling or psychology/psychiatry services met their needs.

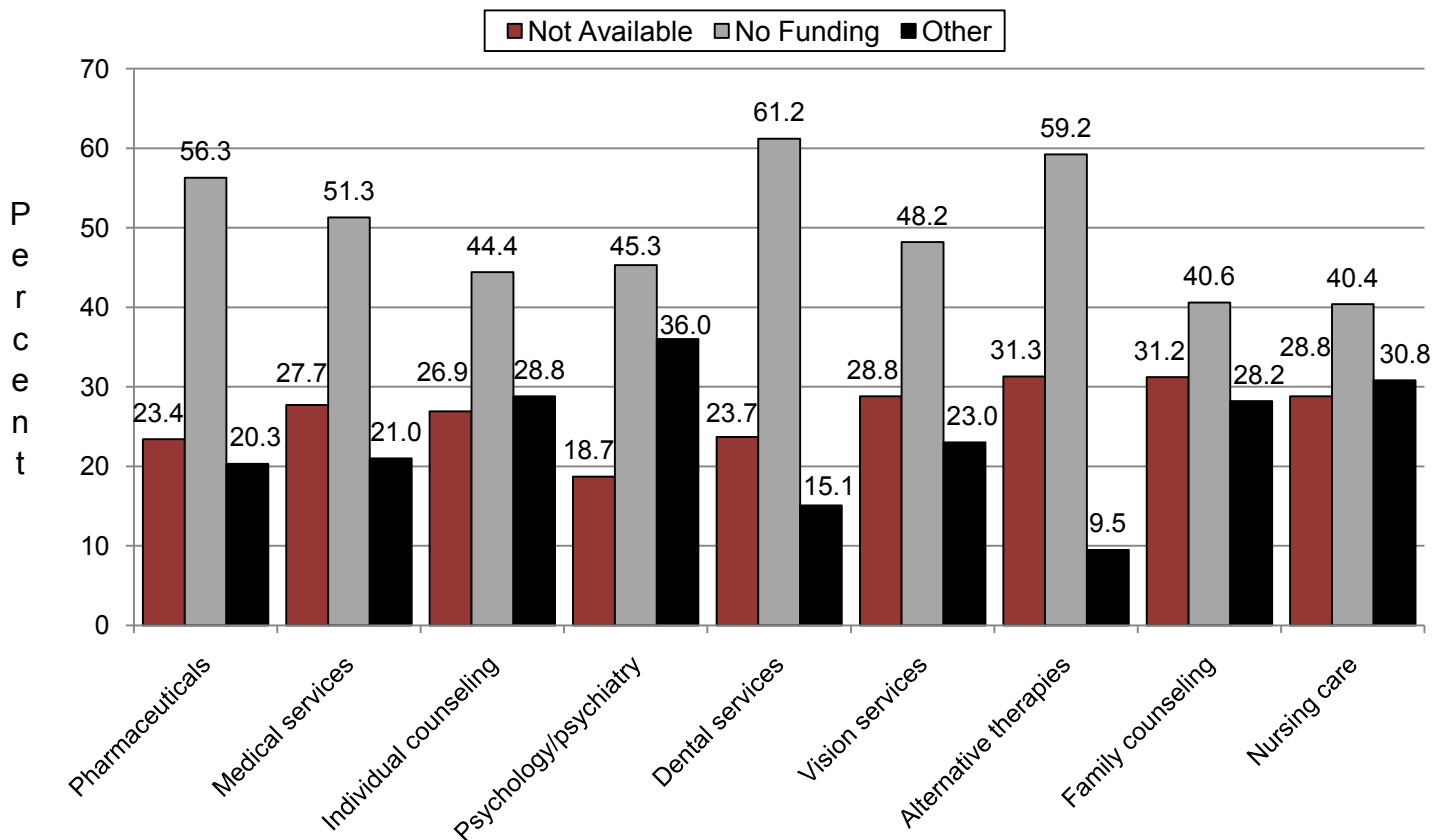
Figure 27: Participants Who Indicate That the Medical/Therapeutic Services They Received Met Their Needs by Region of New Jersey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

The survey asked participants to indicate the reasons they were not receiving needed services: Because it is not available/accessible, because there is no funding/I can't afford it, or some other reason. Overall, lack of funding was the most frequently indicated reason for not receiving needed medical/therapeutic services; this was the reason for more than 40% of the respondents for all services. About 60% of participants who did not receive needed dental services or alternative therapies said that it was because of no funding or they couldn't afford it. About half did not receive needed pharmaceuticals, medical services, or vision services because of financial barriers.

Figure 28: Reasons that Participants Do Not Receive Needed Medical/Therapeutic Services



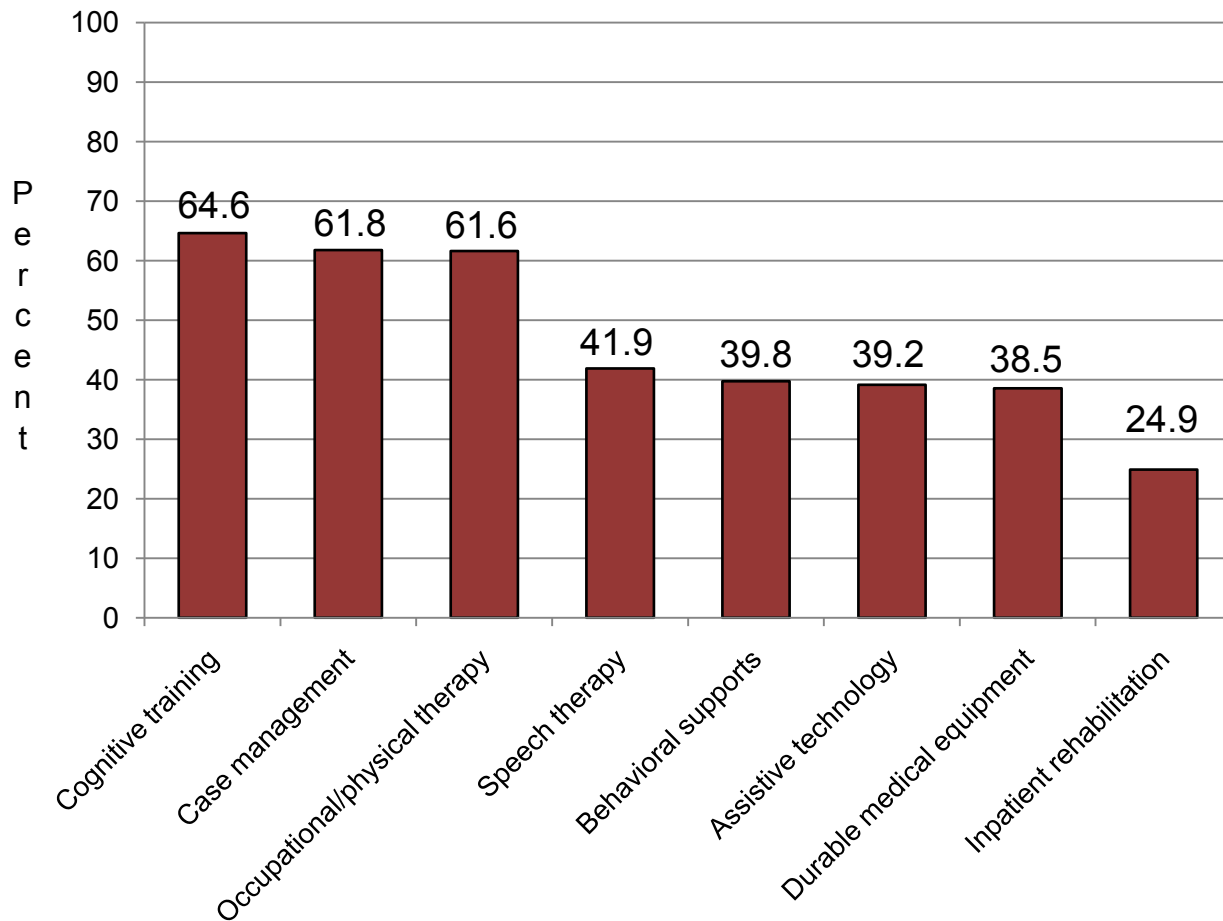
Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

The most frequently given reasons for not receiving services other than lack of availability or lack of funding were the difficulty of applying for services or coverage for services (e.g., Medicaid) and lack of available transportation.

Rehabilitation Services

Nearly two-thirds of participants indicated that they needed cognitive training (i.e., retraining the brain to improve everyday skills), case management/service coordination (i.e., someone who helps to coordinate needed services), and occupational or physical therapy. The least mentioned service need was inpatient rehabilitation, perhaps because most of our respondents lived in the community and had been injured more than a year previously; however, about one quarter of participants indicated that they needed therapies in a hospital.

Figure 29: Rehabilitation Services Needed by Participants

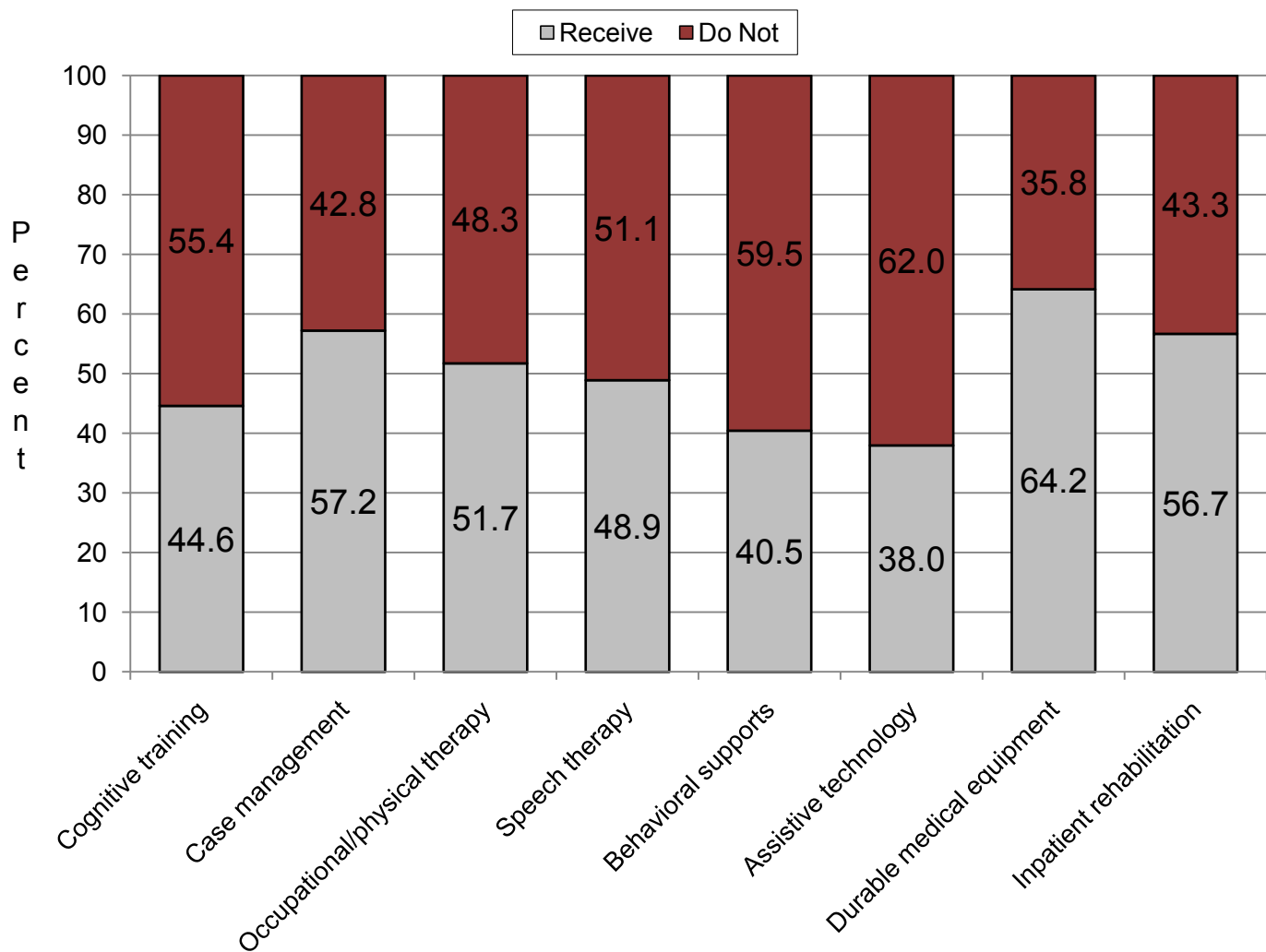


NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Of those indicating a need, over a third reported that they did not receive each type of rehabilitation services. More than 1/3 did not receive durable medical equipment such as a wheelchair, scooter, shower chair, etc. Over 40% did not receive case management, occupational or physical therapy, or inpatient rehabilitation. Fewer than half of participants received other needed rehabilitation services. The greatest gap was for assistive technology, where nearly two-thirds reported that they did not receive the services they needed.

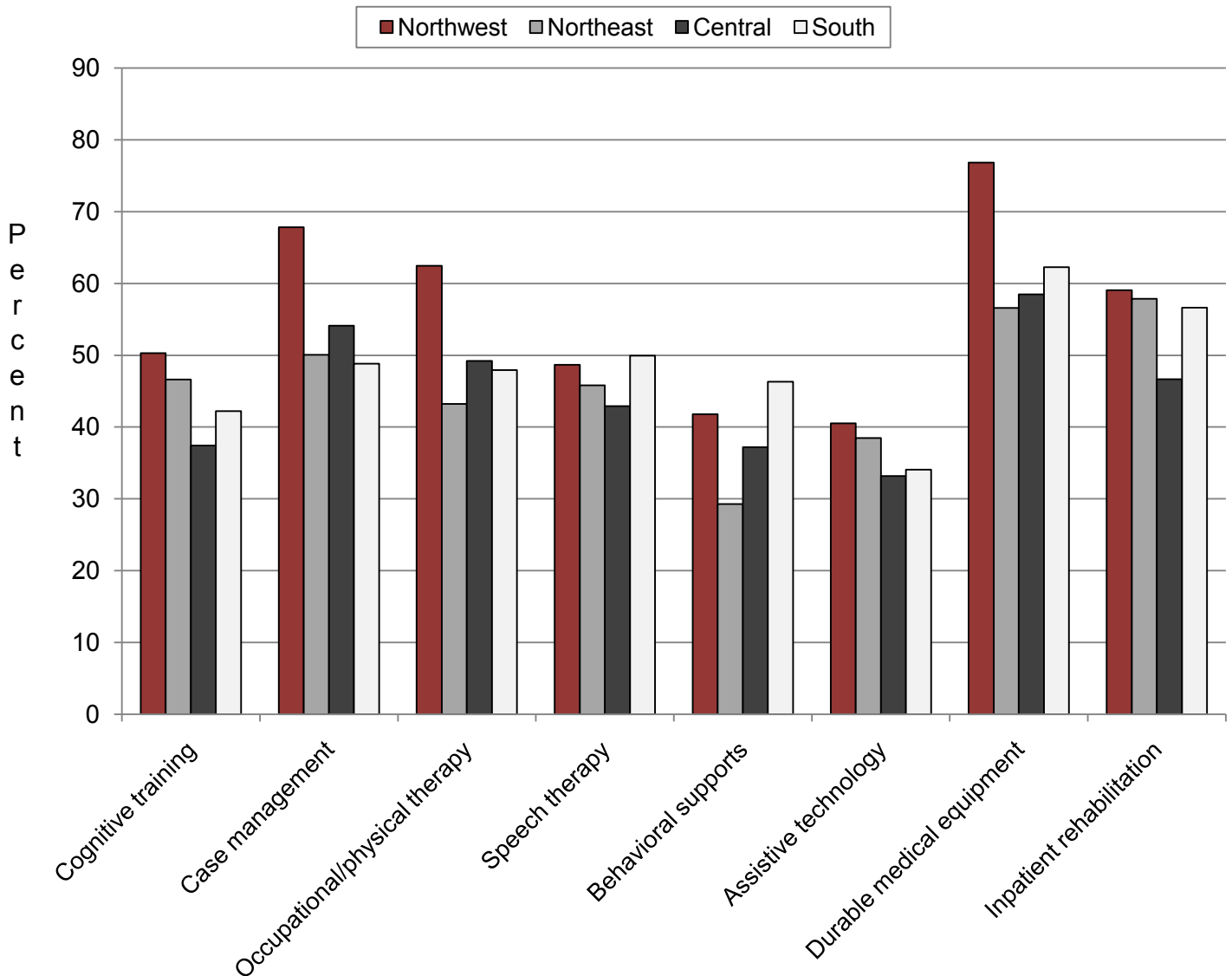
Figure 30: Participants Who Need and Receive Rehabilitation Services



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Overall, participants who lived outside the northwest region were less likely than those in other parts of the state to receive durable medical equipment, case management, or occupational/physical therapy. The northeast region had the greatest gaps in receiving occupational/physical therapy and behavioral supports. The central region had the lowest rates of receiving inpatient rehabilitation and cognitive training.

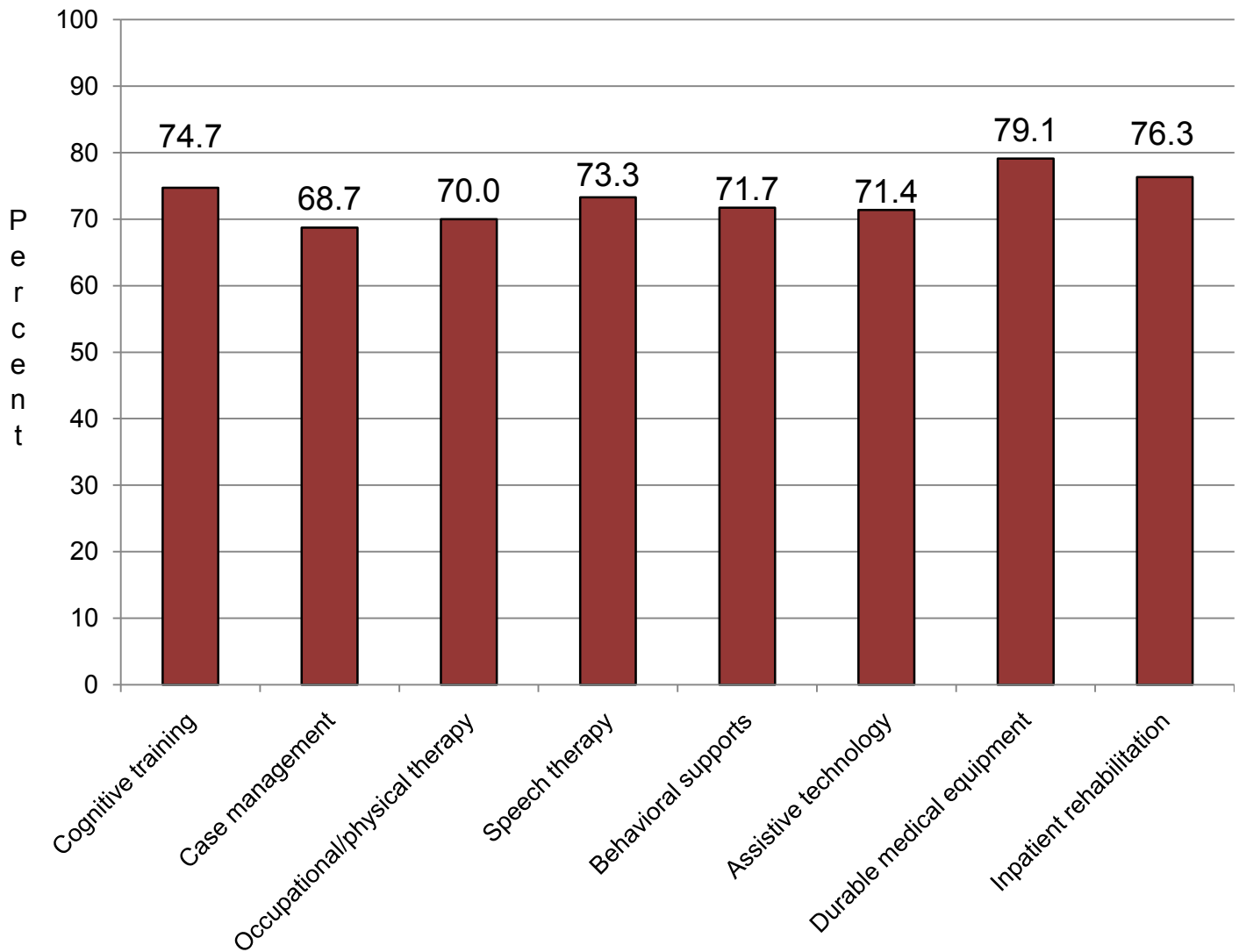
Figure 31: Participants Who Need and Receive Rehabilitation Service by Region of New Jersey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

About 30% of participants reported that the case management, occupational/physical therapy, behavioral supports, and assistive technology they received did not meet their needs. Approximately one-quarter indicated that their durable medical equipment, inpatient rehabilitation, speech therapy, or cognitive training services did not meet their needs.

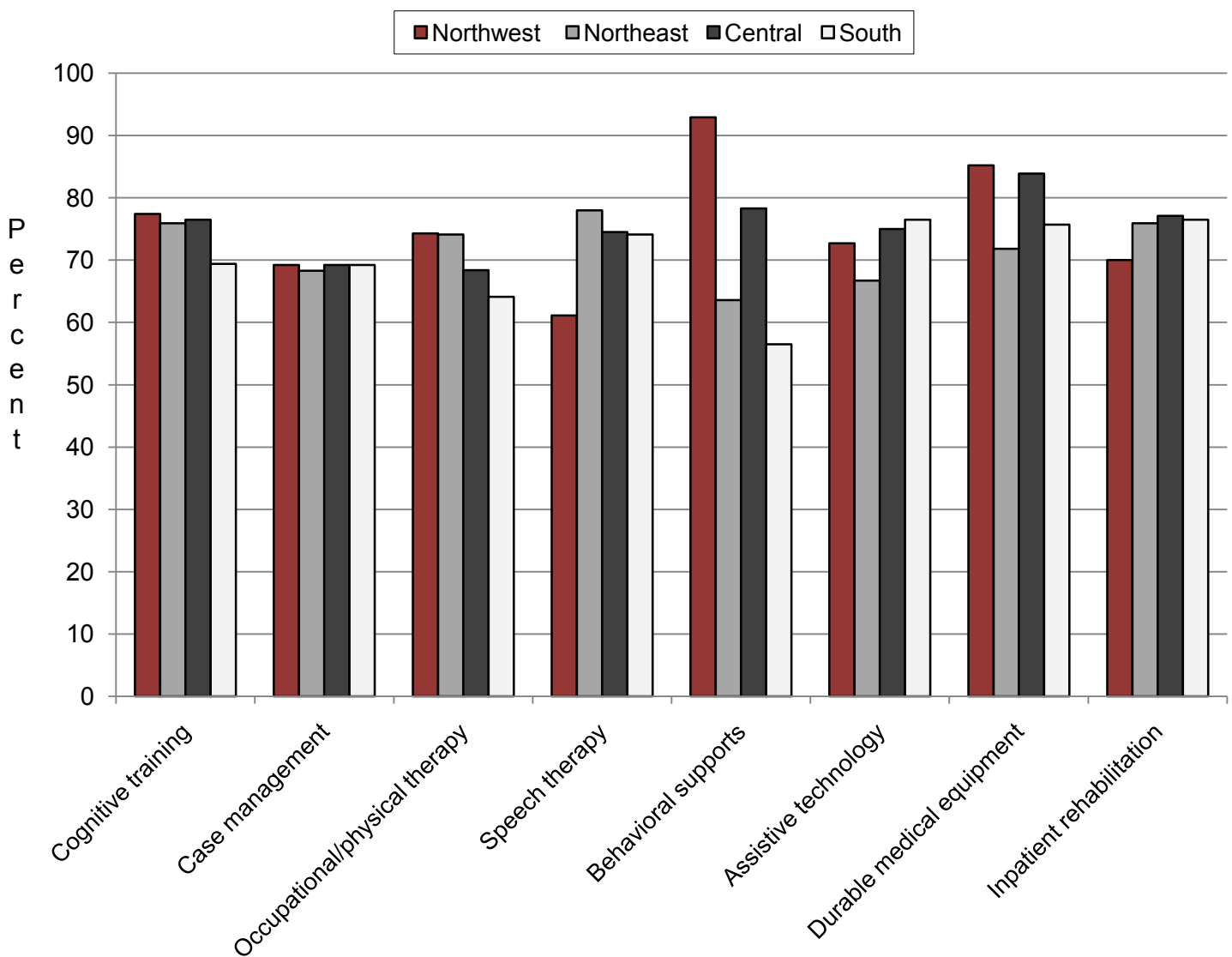
Figure 32: Participants Who Indicate That the Rehabilitation Services They Receive Met Their Needs



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Reports that services met the needs of participants differed more for behavioral supports than for other rehabilitation services, with the highest percentage indicating that their rehabilitative service met their needs in the northwest region and the lowest percentage in the south. While receipt of case management differed between regions, 30% of participants said that this service did not meet their needs in all parts of the state.

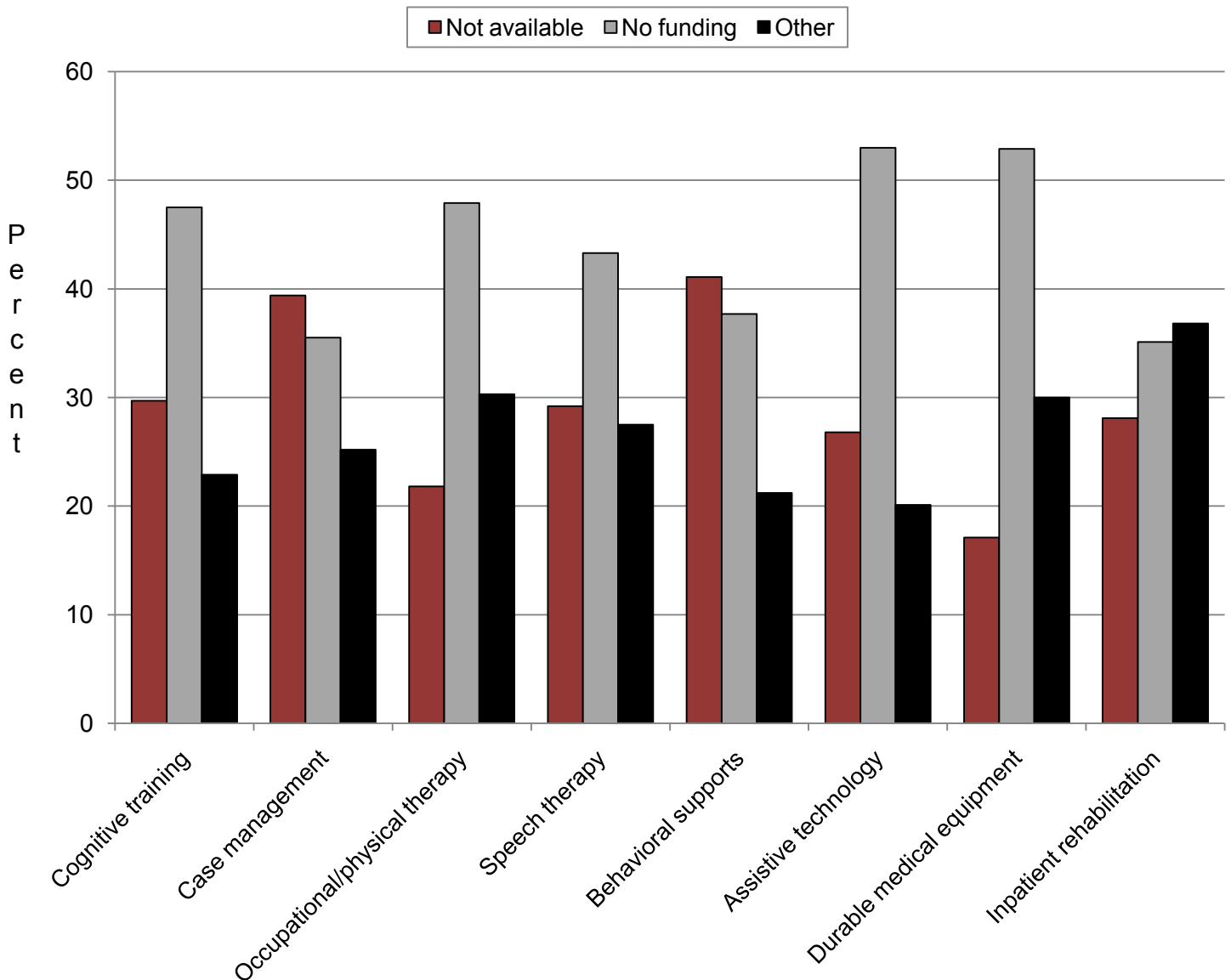
Figure 33: Participants Who Indicate That the Rehabilitation Services They Receive Met Their Needs by Region of New Jersey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

About half of participants reported that lack of funding was the main reason for not receiving durable medical equipment, assistive technology, occupation or physical therapy, speech therapy, or cognitive training. Around 40% of those who needed case management or behavioral supports reported lack of availability of the service.

Figure 34: Reasons for Not Receiving Needed Rehabilitation Services

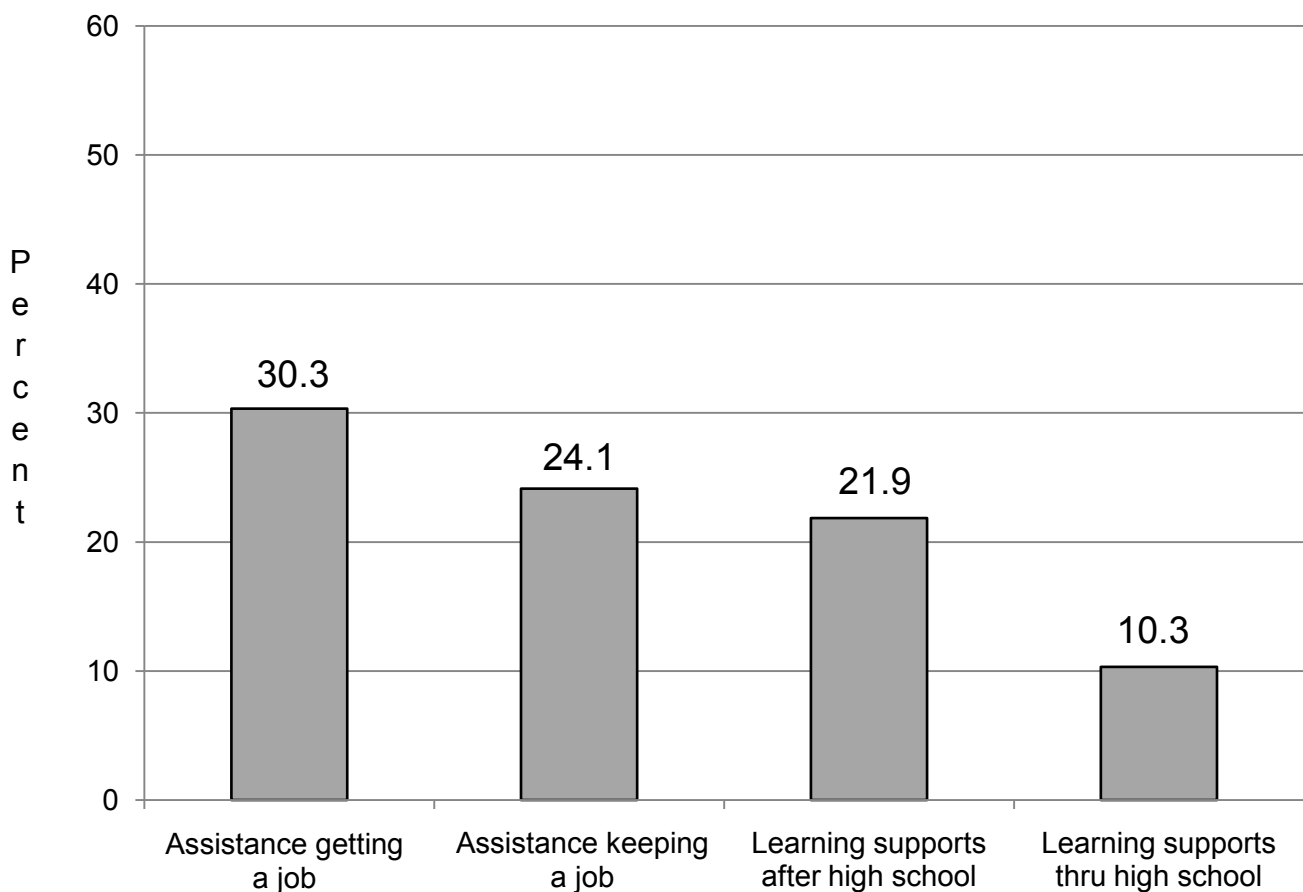


Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Education/Employment Services

About 30% of participants indicated that they needed assistance getting a job, and one quarter indicated that they needed assistance keeping a job. Slightly less reported that they needed learning supports after high school, such as tuition, books and fees, etc. Only 10% indicated that they needed learning support up through high school, but since the survey had relatively few participants under 18, this number may not be representative.

Figure 35: Education/Employment Services Needed by Participants

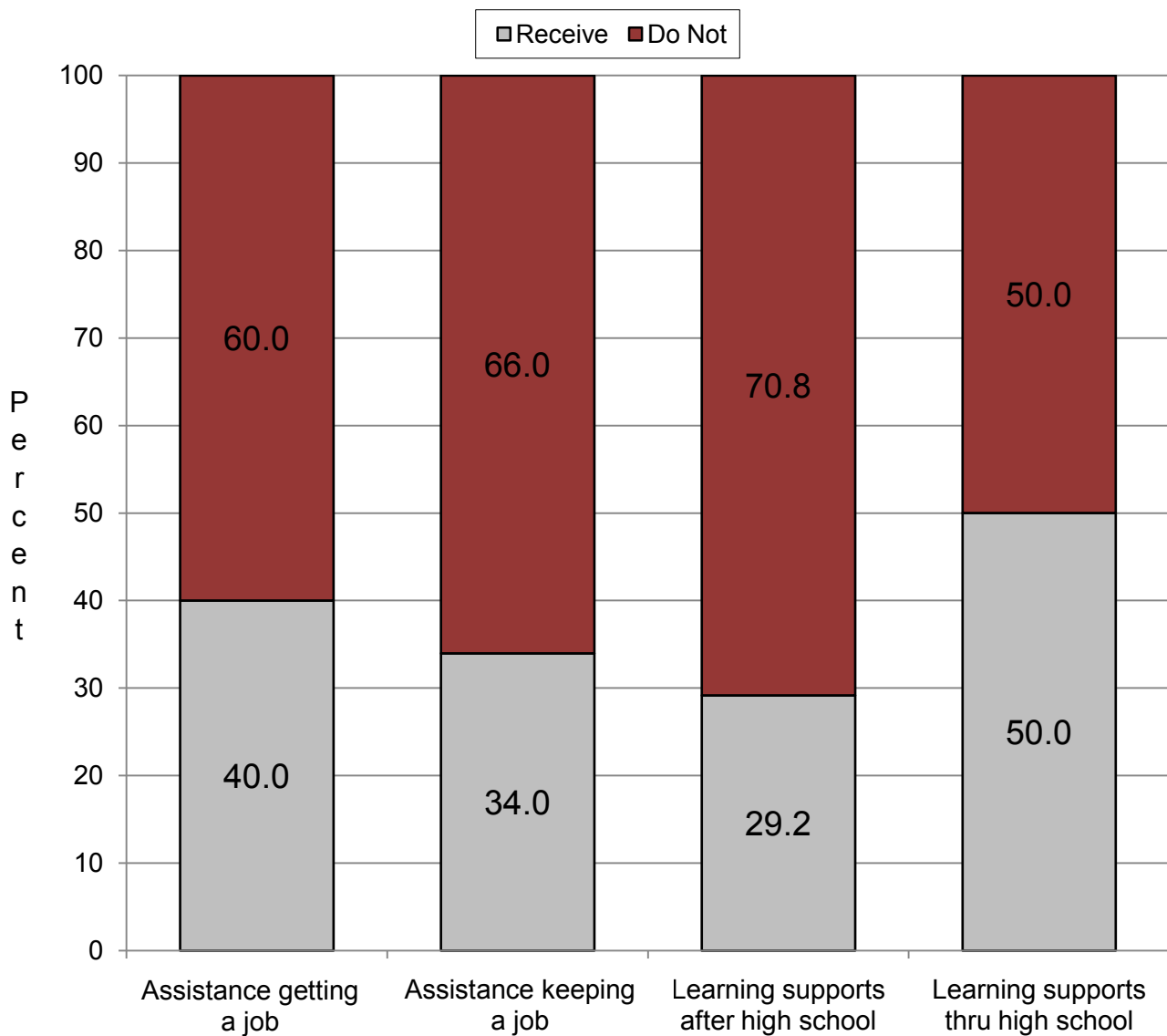


NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

The percentages of participants who reported receiving the education/employment services they needed were lower than most other areas of service. About two-thirds of those who said that they needed assistance getting or keeping a job or learning supports after high school did not receive these services. Only half of those who reported needing assistance with learning up through high school reported receiving those services.

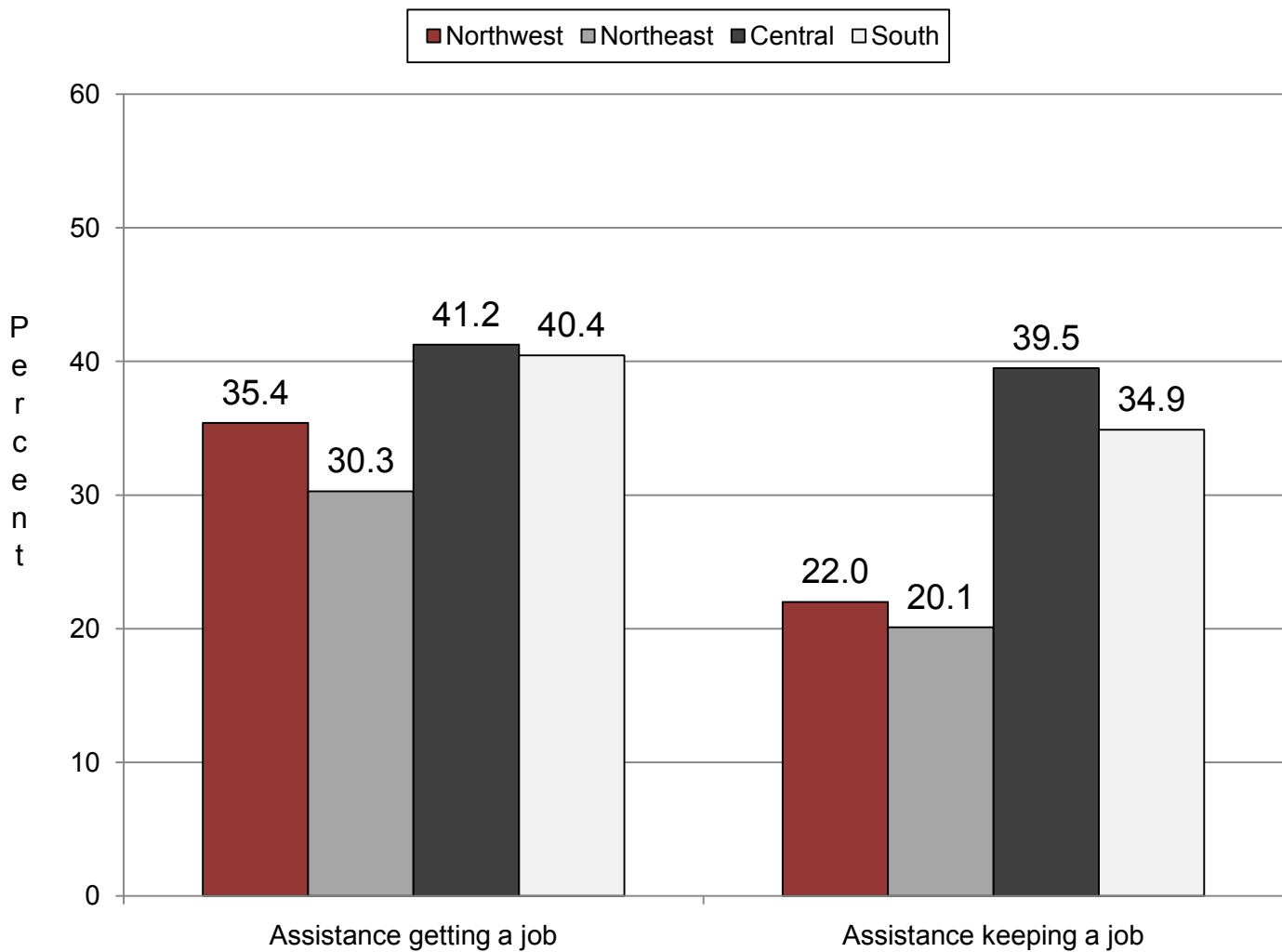
Figure 36: Participants Indicating That They Received Needed Education/Employment Services



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

The northwest and northeast regions of the state had the greatest gaps for employment assistance, with about 2/3 of those who needed assistance getting a job and 80% of those who needed assistance keeping a job failing to receive those services. Too few participants reported receiving learning supports to examine these services by region.

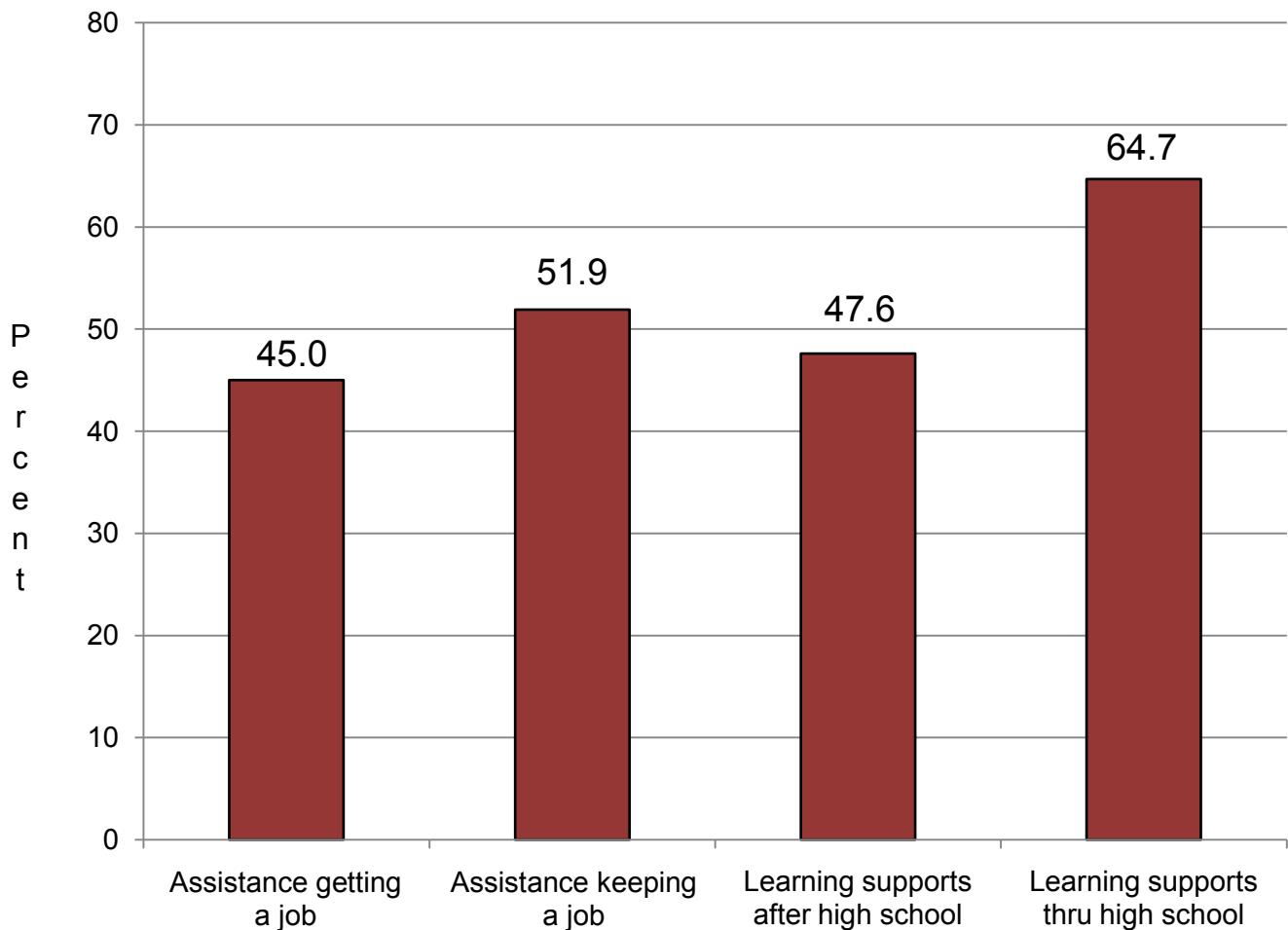
Figure 37: Participants Indicating That They Received Needed Education/Employment Services by Region



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Generally, a lower percentage of participants reported that the education/employment services they received met their needs than other types of services. Over one-third of participants reported that the learning supports they received up through high school did not meet their needs; however, for other services, half or more reported that their services did not meet their needs. There were too few participants reporting receipt of education/employment services to examine whether these services met participants' needs separately by region.

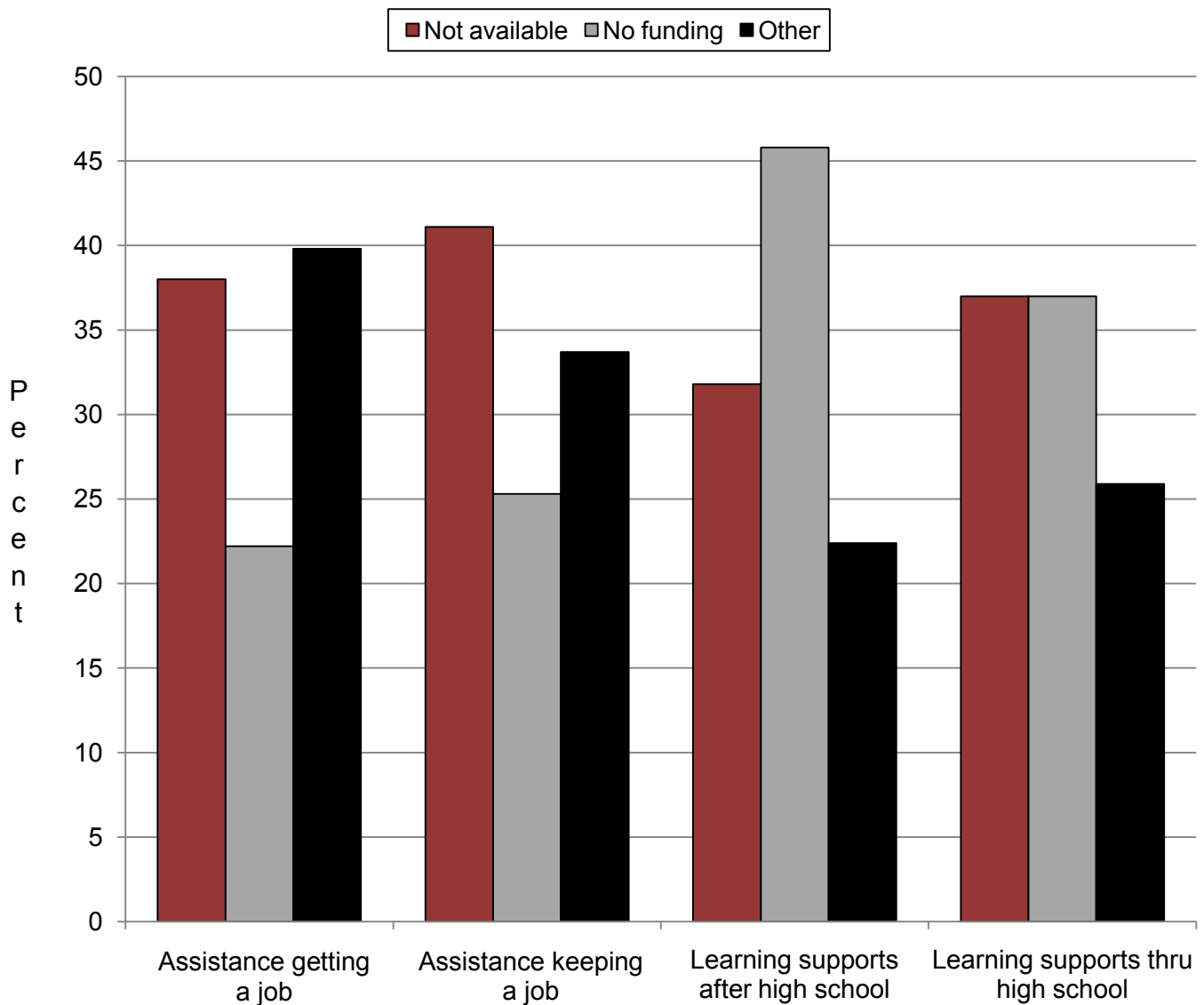
Figure 38: Participants Indicating That the Education/Employment Services They Receive Met Their Needs



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

For those not receiving assistance getting or keeping a job, the main reasons for over 35% of participants were lack of availability or other reasons. Comments suggested that other reasons included transportation difficulties, had tried services and they were not adequate, and limits on ability to earn money and retain benefits. For learning supports, funding was equally or more important than lack of availability.

Figure 39: Reasons for Not Receiving Needed Education/Employment Services

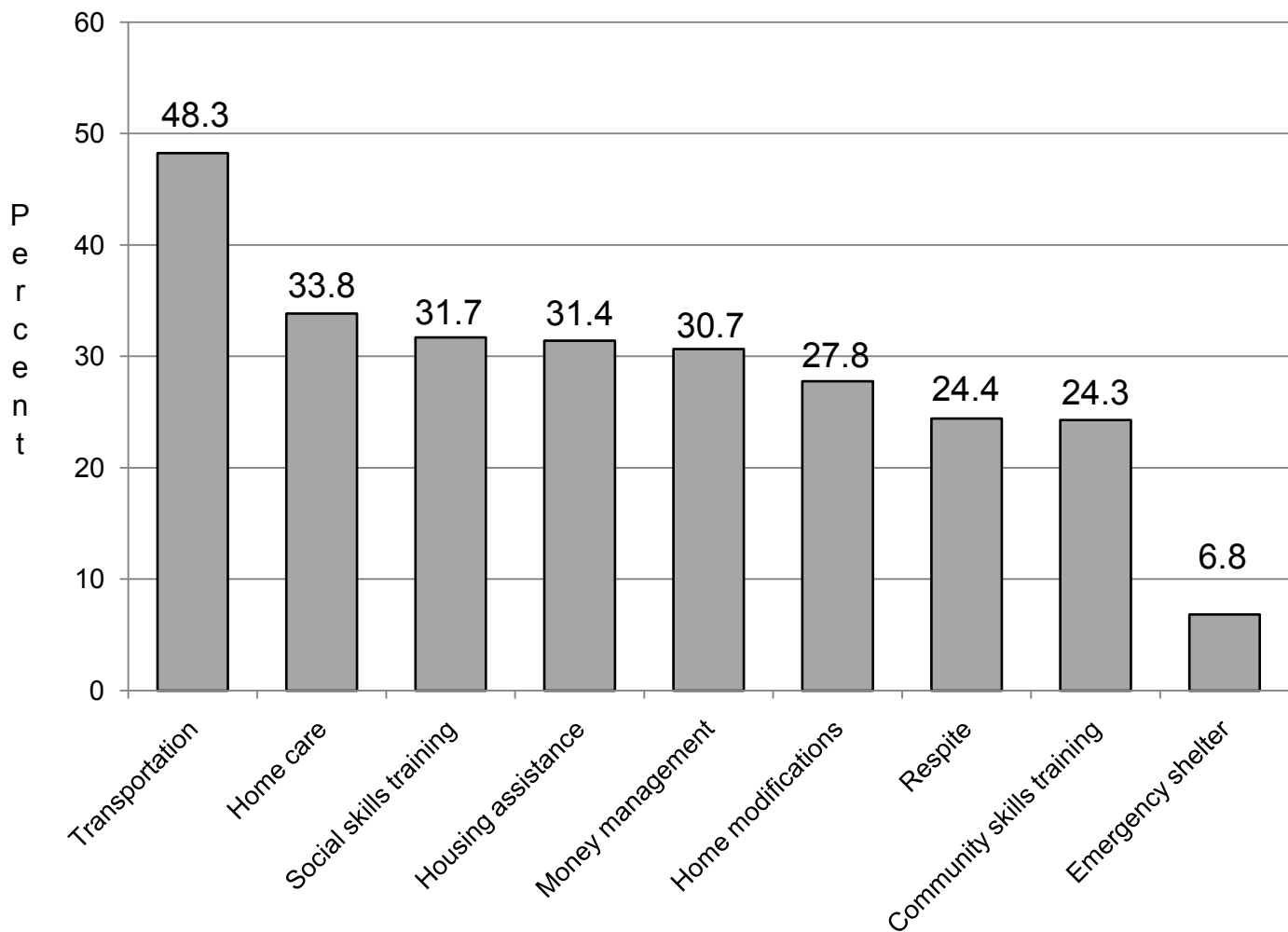


Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Community Living Support Services

Almost half (48.3%) of participants reported that they needed transportation services. About a third reported needing home care support, such as home health care, help with bathing and dressing, and homemaking assistance. Nearly a third indicated that they needed social skills training, housing assistance, or money management services. About 25% reported the need for respite care to give their caregiver a break.

Figure 40: Community Living Support Services Needed by Participants

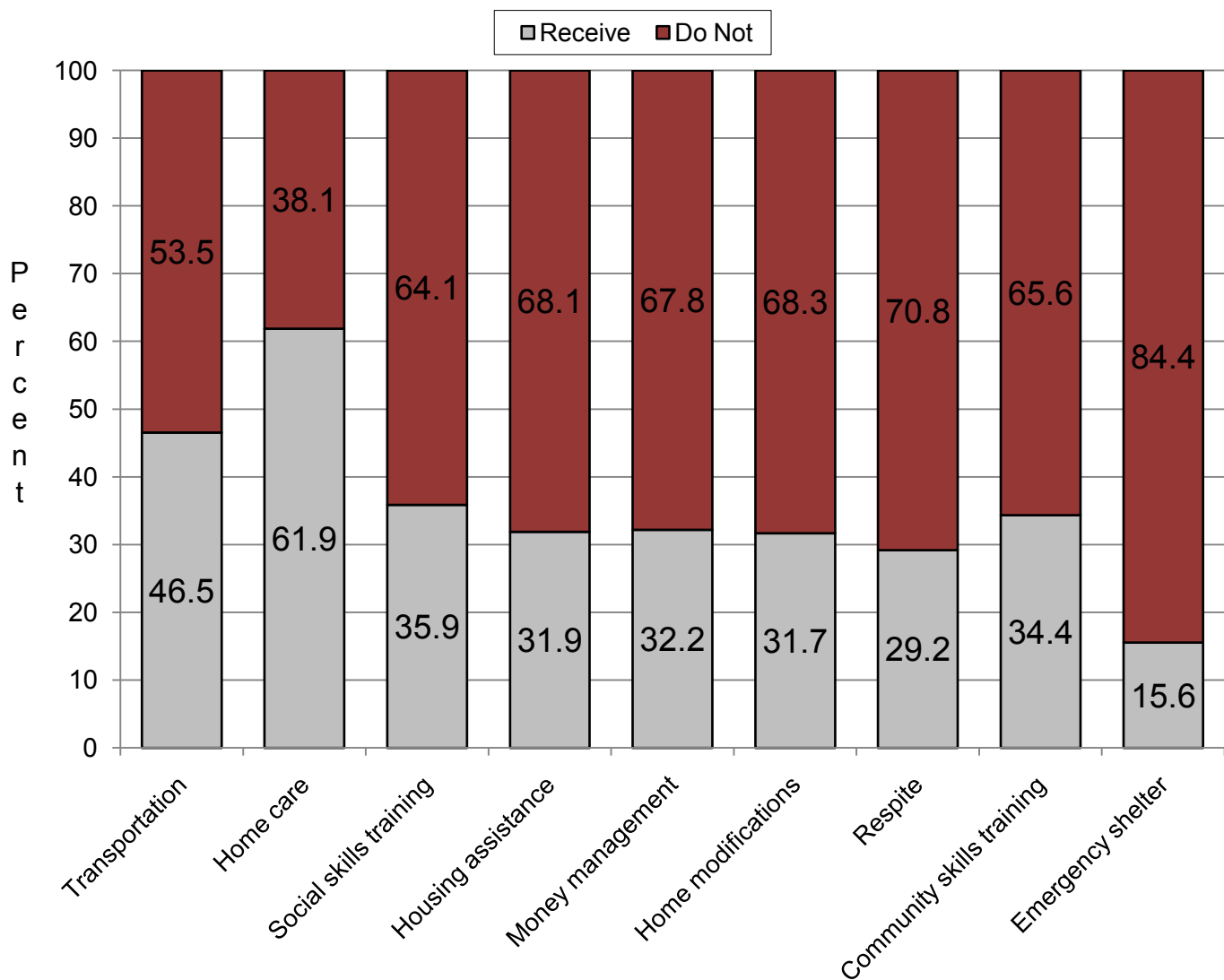


NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Of those who needed it, over half of participants indicated that they did not receive transportation assistance. Even larger gaps existed for other community support services. About 2/3 of participants who needed housing assistance, home modifications, money management, respite, and community skills training did not receive them. Only 15% of participants who said that they needed emergency shelter assistance received it, but the number was very small and may not be representative.

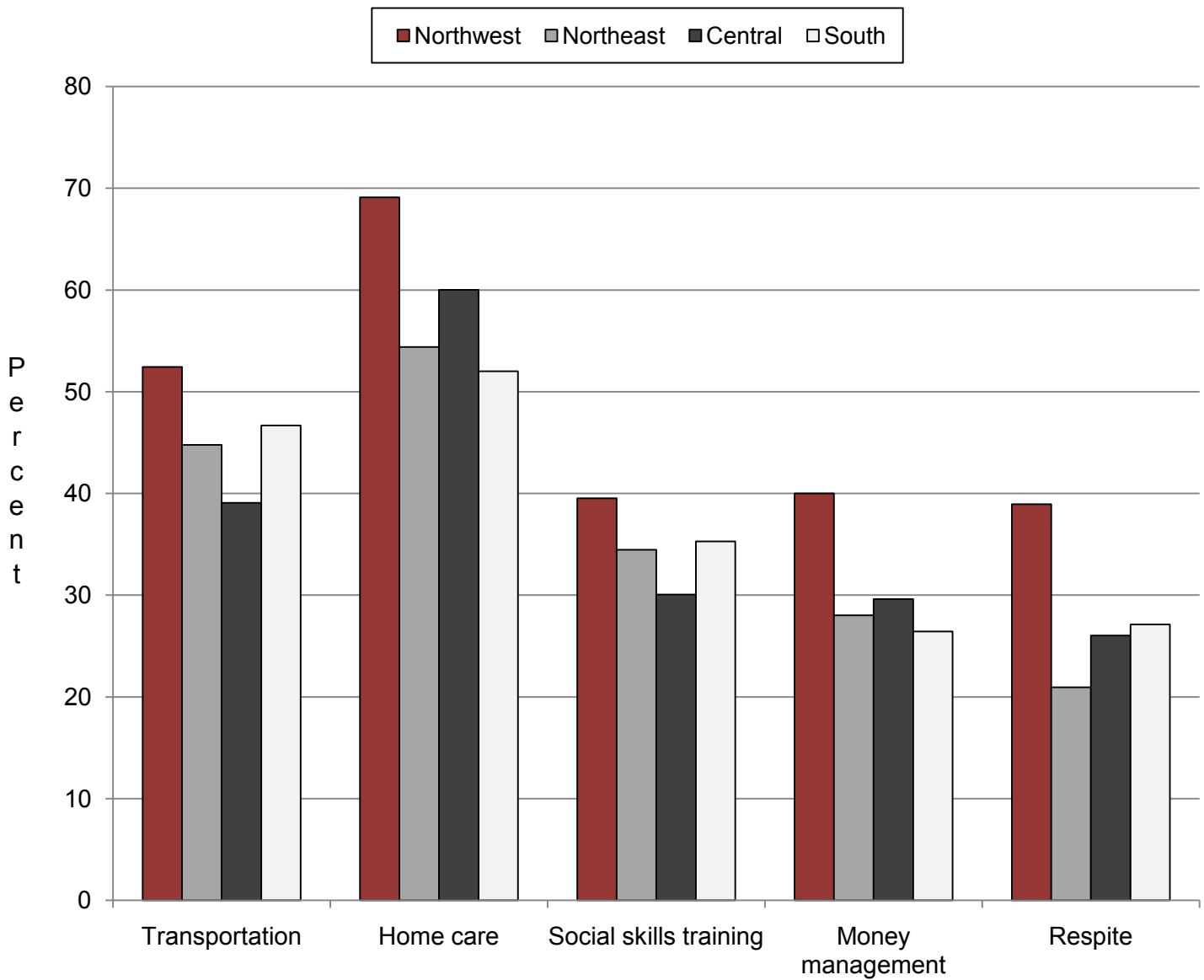
Figure 41: Participants Indicating That They Received Needed Community Living Support Services



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

There were not sufficient numbers to examine all community living supports by region. For those where the data were sufficient, participants who lived in the northwest region of the state were more likely to receive community living support services than those in the rest of New Jersey. Over 70% of those in the northeast, central, and southern regions did not receive money management or respite services.

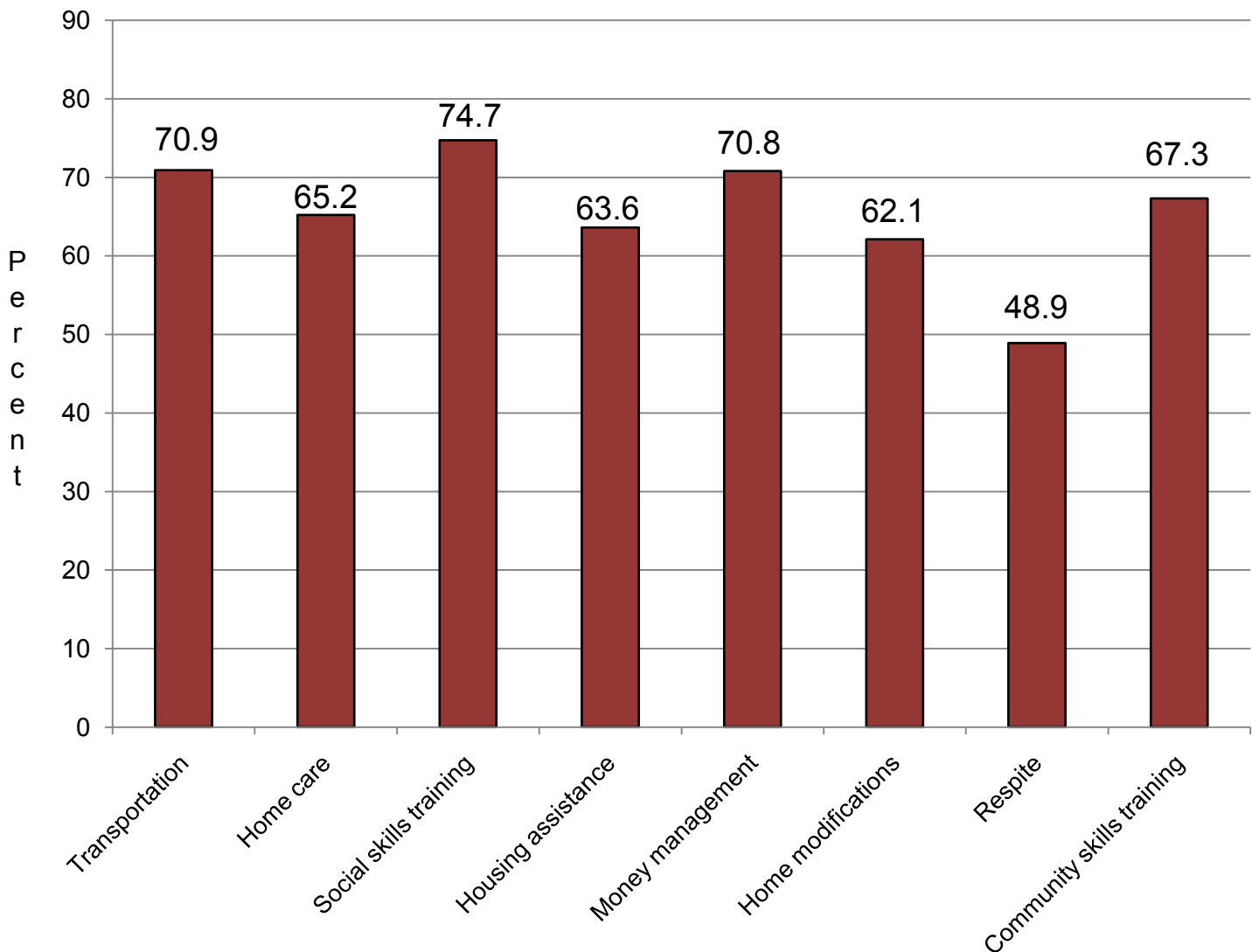
Figure 42: Participants Indicating That They Received Community Living Support Services by Region of New Jersey



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Less than half of participants indicated that respite care services met their needs. At least 1/3 reported that their transportation assistance or money management services did not meet their needs, while ¼ indicated that the social skills training they received met their needs. Over 35% reported that housing assistance or home modifications did not meet their needs.

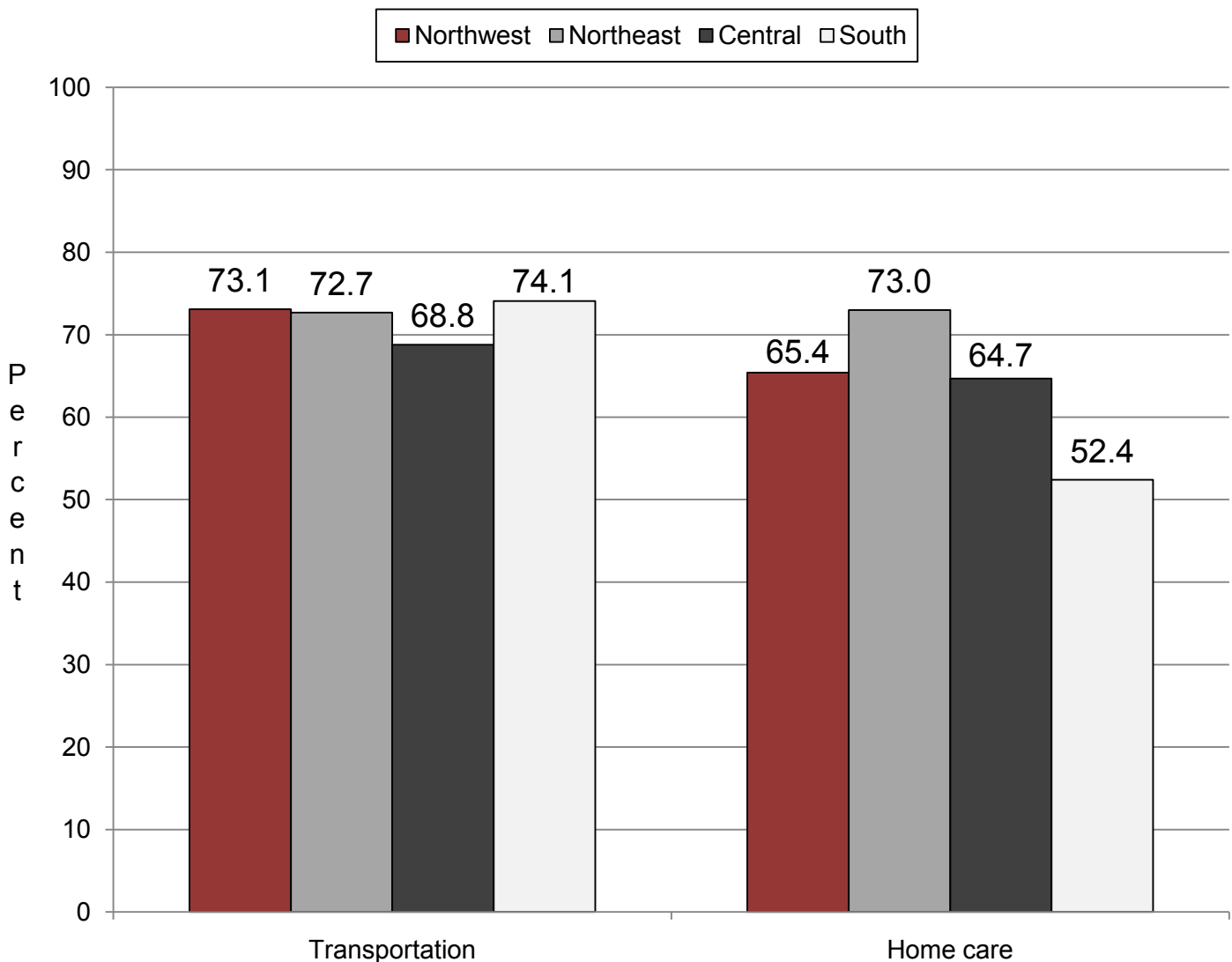
Figure 43: Participants Indicating That Community Living Support Services Met Their Needs



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

There were sufficient numbers to compare regions for transportation assistance and home care support. Similar percentages of participants in all regions reported that the transportation assistance they received met their needs. For home care support, about 30% of participants in the northeast reported that these services did not meet their needs, while the gap in the south was nearly 50%.

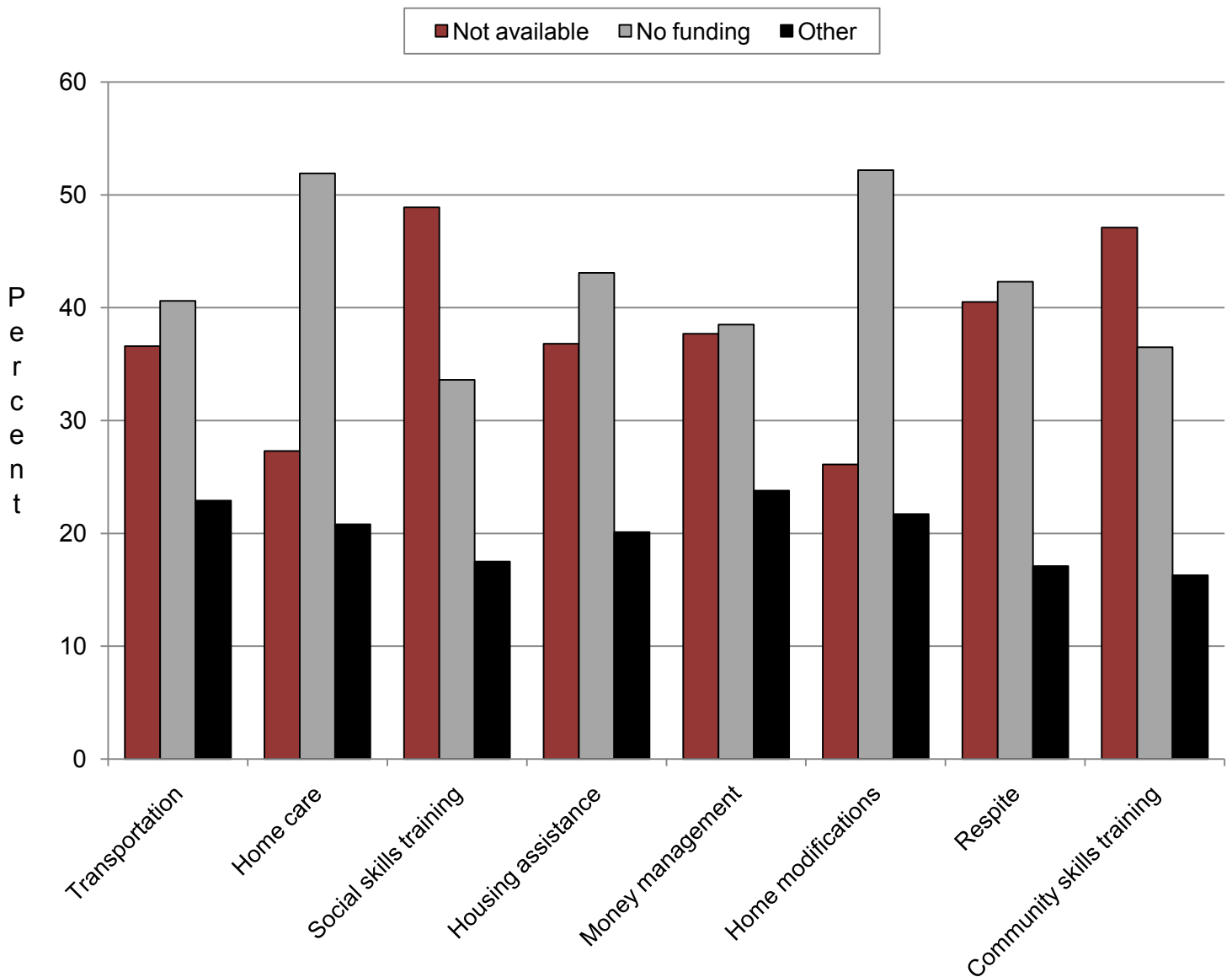
Figure 44: Participants Indicating that Community Living Support Met Their Needs by Region



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Nearly half of participants reported that they did not receive social skills training or community skills training because it was not available. In contrast, more than half of participants indicated that they did not receive home care support or help with home modifications because of a lack of funding, twice as many as said they did not receive these services because they were not available.

Figure 45: Reasons that Participants did not Receive Community Living Support



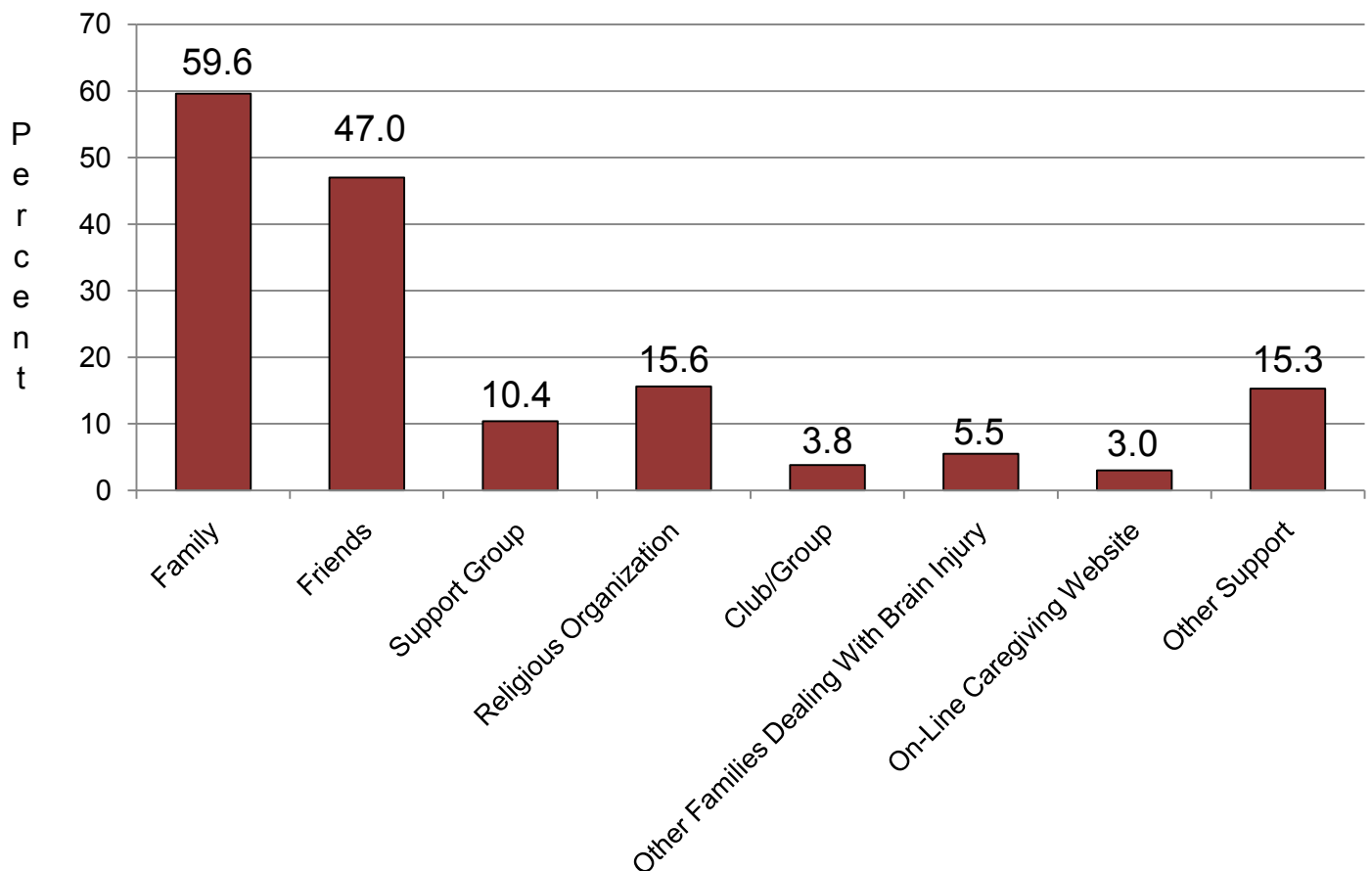
Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Support and Service Needs of Caregivers

At the end of the survey, caregivers who were available at the time the survey was completed were asked to respond to questions about where they went to obtain social/emotional support and what services they needed related to their family member's brain injury. We received responses from 366 caregivers, nearly 80% of the number of participants who said that they received help at least every week.

A small number of caregivers (7%) indicated that they do not need support, and 13.4% responded that they needed support, but were not currently receiving any. Of those who were receiving support, family and friends were by far the most frequent sources of support, with about 60% indicating that they receive support from other family members and about half indicating that they receive support from friends.

Figure 46: Sources of Support Used by Caregivers



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

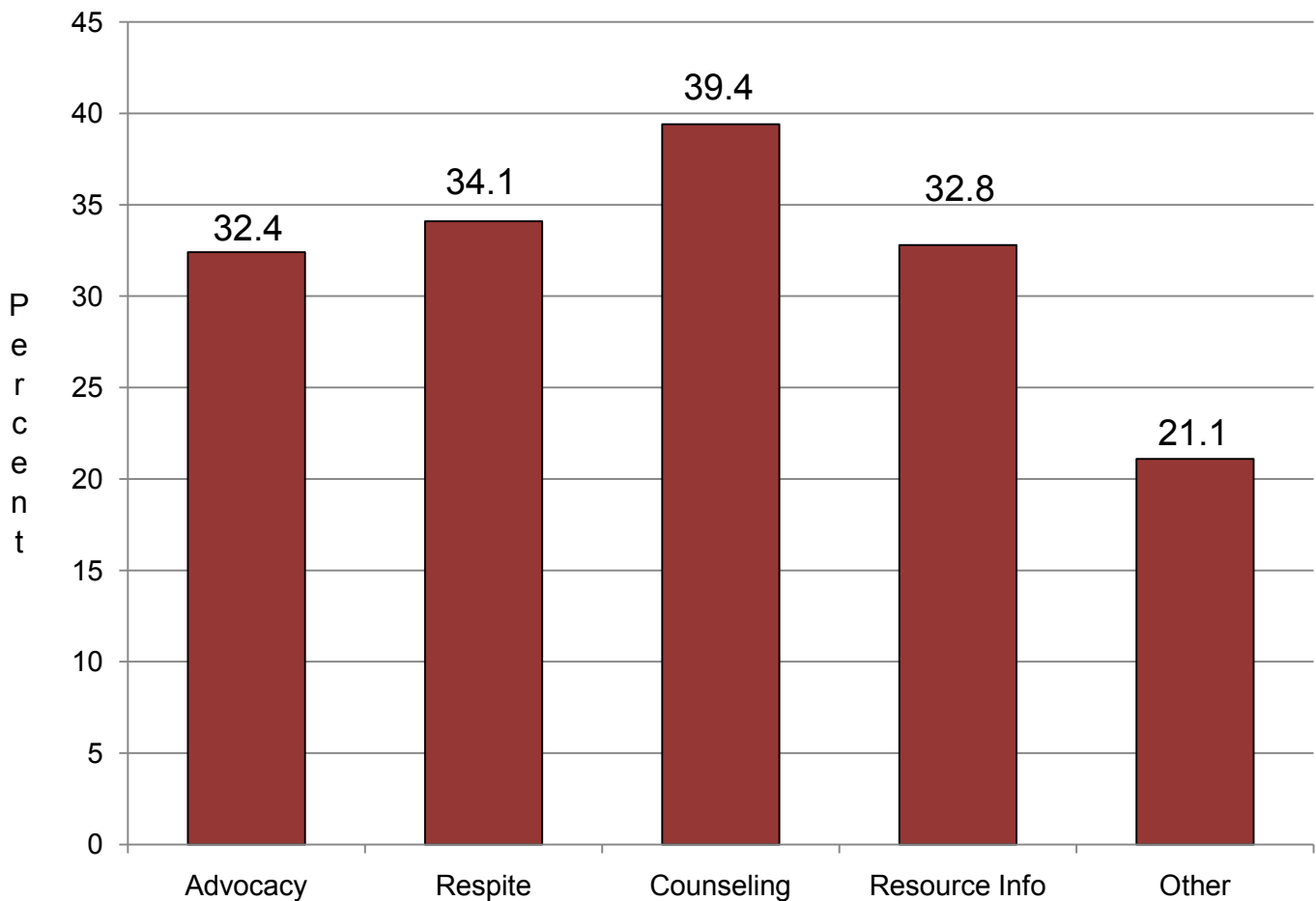
Caregivers who said they used other sources of support most frequently mentioned talking with mental health professionals, reading, meditation, and leisure activities which gave them a break from caregiving. Several noted that, while they had some support, it was not always sufficient.

Those caregivers who said that they needed support but did not have it provided comments suggesting that they were overwhelmed:

- All I do is caregiving and filling out state forms! Who has the energy for anything else?
- Don't feel well enough to go out, I'm exhausted.
- Don't have time nor resources financially.
- Don't want to complain; wouldn't know where to go.
- No one understands. They say she has recovered 90%, so what's the problem?
- Too busy to even think about it. Couldn't leave him to go to support group.

Counseling was the need most frequently identified by caregivers, followed by respite, information about resources, and advocacy. Transportation was the most frequently mentioned other need. Many caregivers echoed concerns of individuals with brain injury about the cost and/or availability of reliable transportation. In addition, assistance completing application forms, help coordinating services, financial help for transportation and medical bills, and long term care management planning were mentioned by several caregivers.

Figure 47: Services Needed by Caregivers



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

A number of caregivers mentioned that it would be helpful to have information about all programs which offer services throughout New Jersey available in one place, e.g., “more information about Medicaid and Medicare—one place for as much information as possible. Types, what each does, requirements, waivers, etc.” A few caregivers mentioned that it would be helpful to raise awareness about brain injury and provide information which would help people know how to behave with someone who is brain injured, so that they could get better support. Finally, several caregivers expressed concern about being able to stay in their homes because of the financial burden of their loved one’s brain injury, particularly if that person had been the principal breadwinner for the family, echoing the concerns of participants about where they would live in the future.

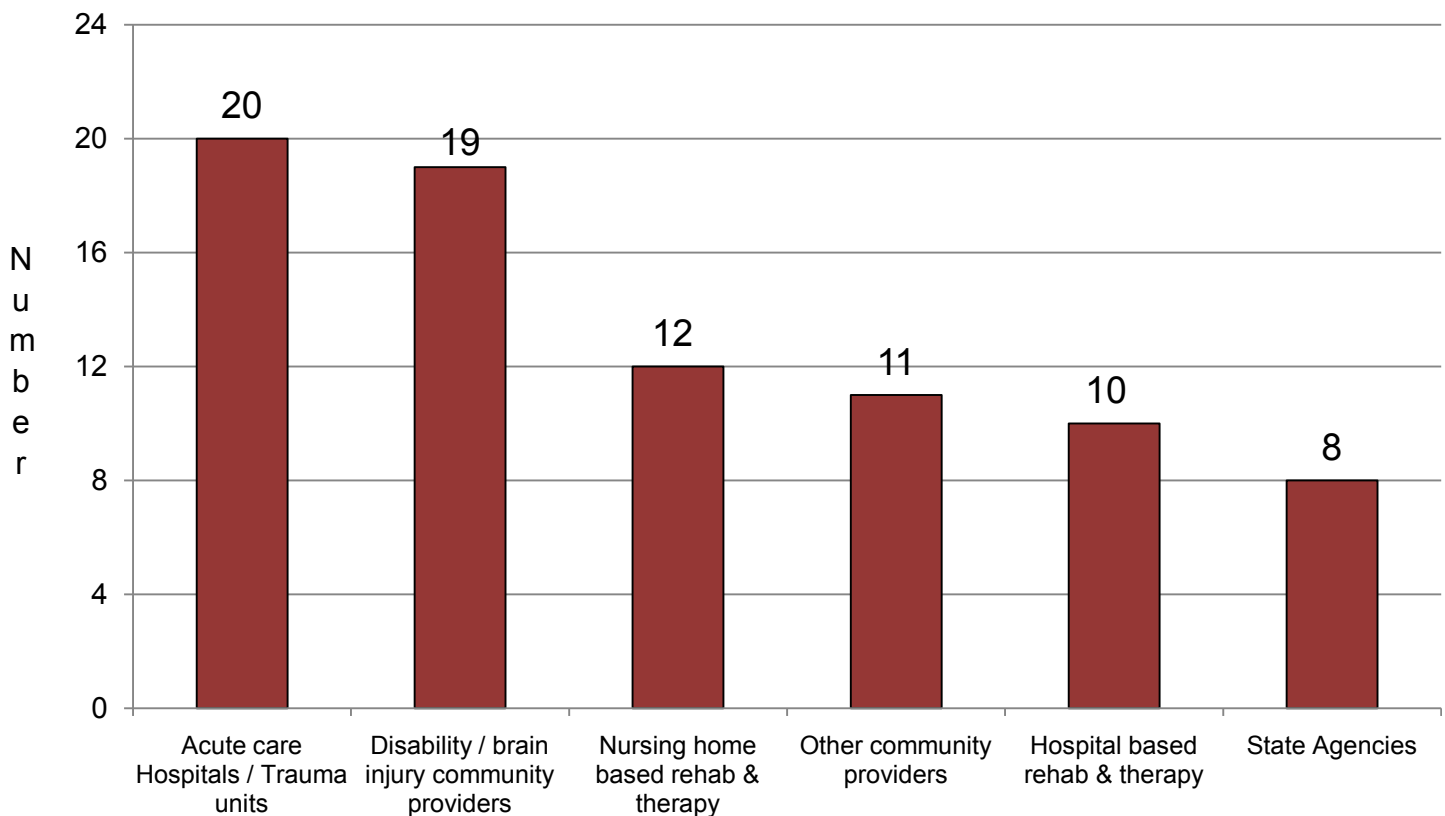
Findings from the Surveys of State Agencies and Provider Organizations

Organizations Which Responded to the Surveys

Eight state agencies completed the New Jersey State Agency Survey of TBI Services and Support, and 72 organizations completed the New Jersey Provider Survey of TBI Services and Support. Many of the provider surveys represented more than one location for that organization.

We received responses from a wide variety of organizations, including hospitals, rehabilitation units, trauma units, providers of brain injury and disability services, and other community providers.

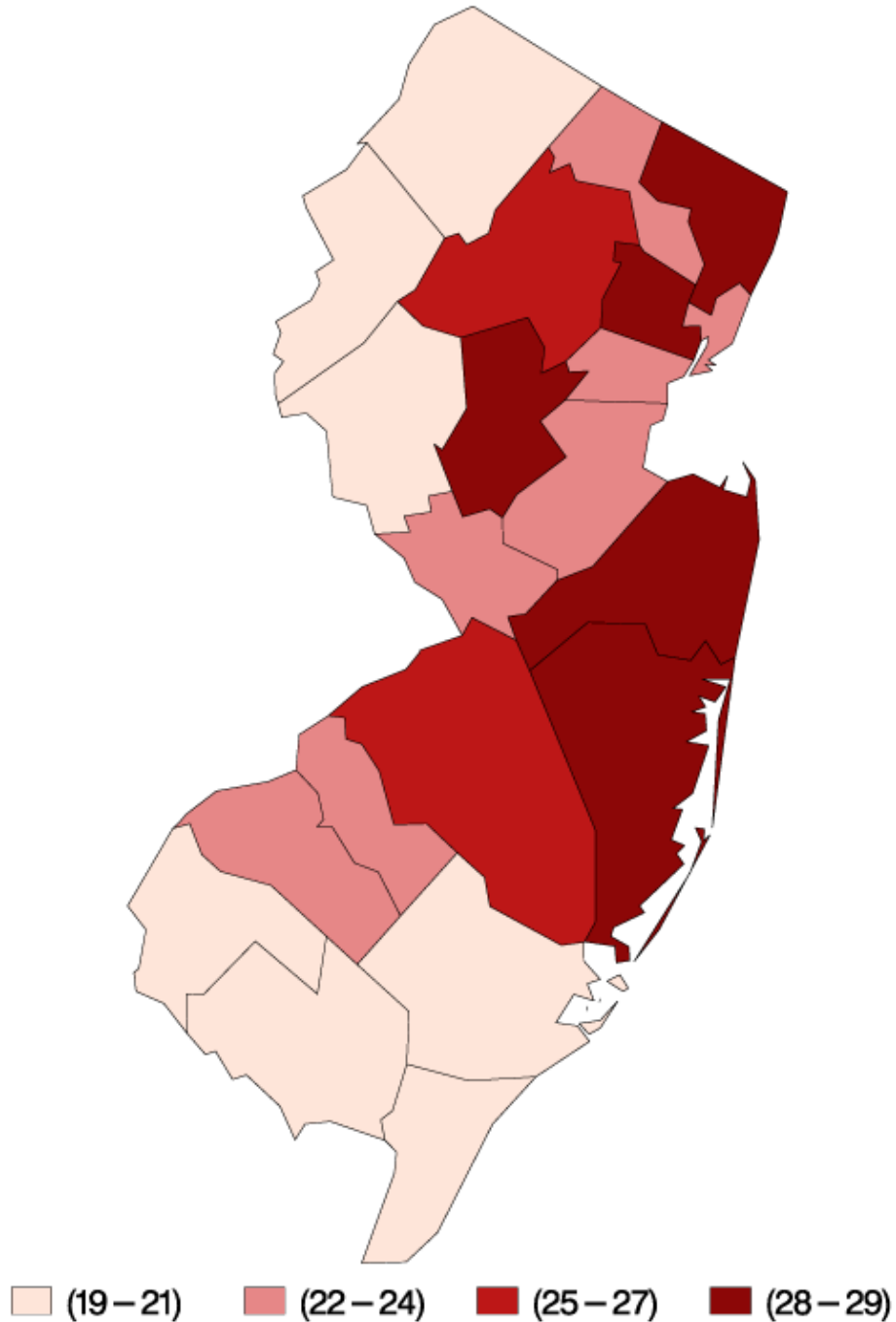
Figure 48: Organizations Responding to New Jersey Provider Survey or State Agency Survey of TBI Services and Support



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Responses came from organizations providing services in all counties throughout New Jersey. We asked each organization to report the counties in which services were offered.

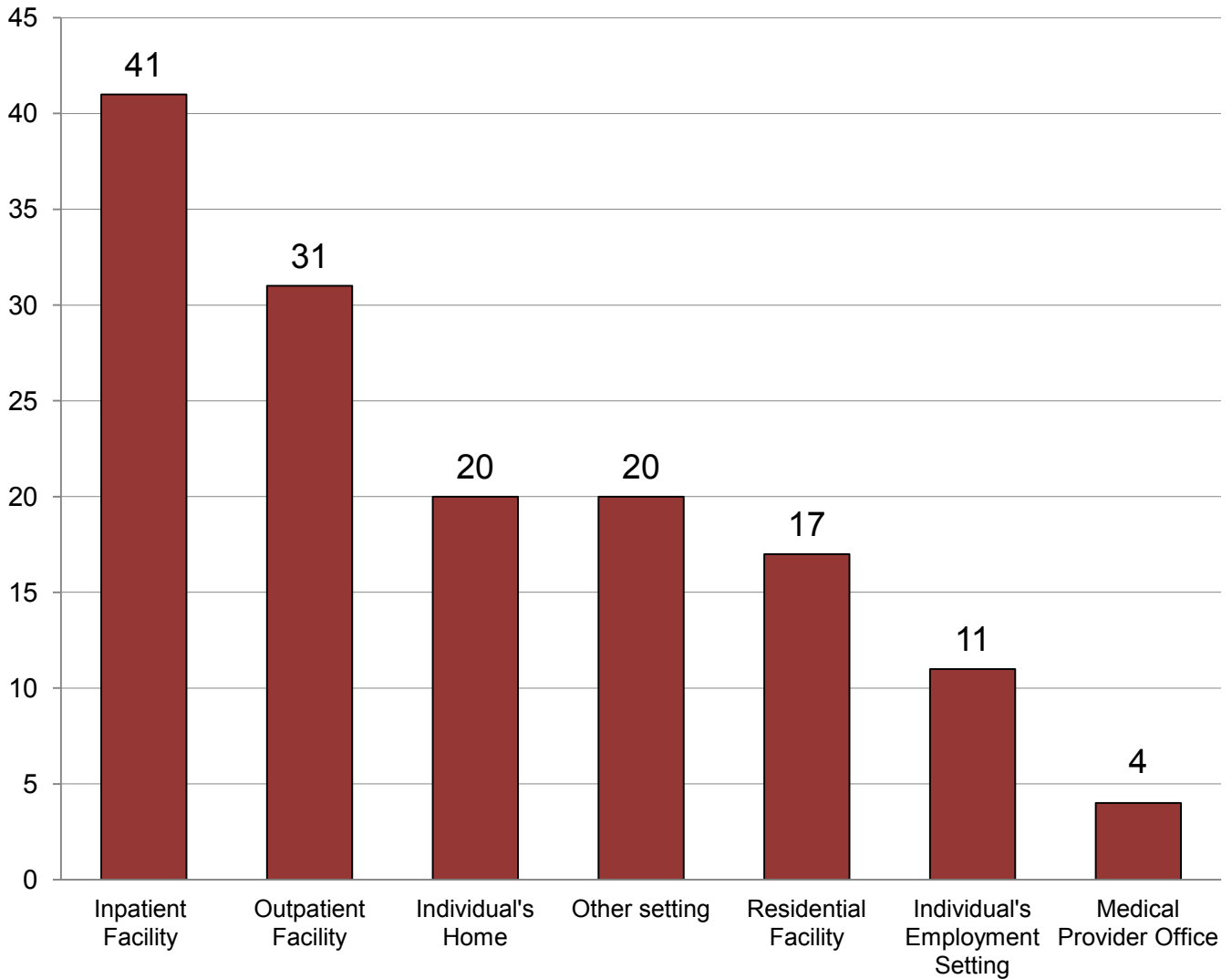
Figure 49: Number of Organizations Providing Service by County



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

The responding organizations provided services in a variety of settings. The largest number of organizations provided services in inpatient and outpatient settings, but one quarter provided services in an individual's home. Many organizations provided services in more than one setting.

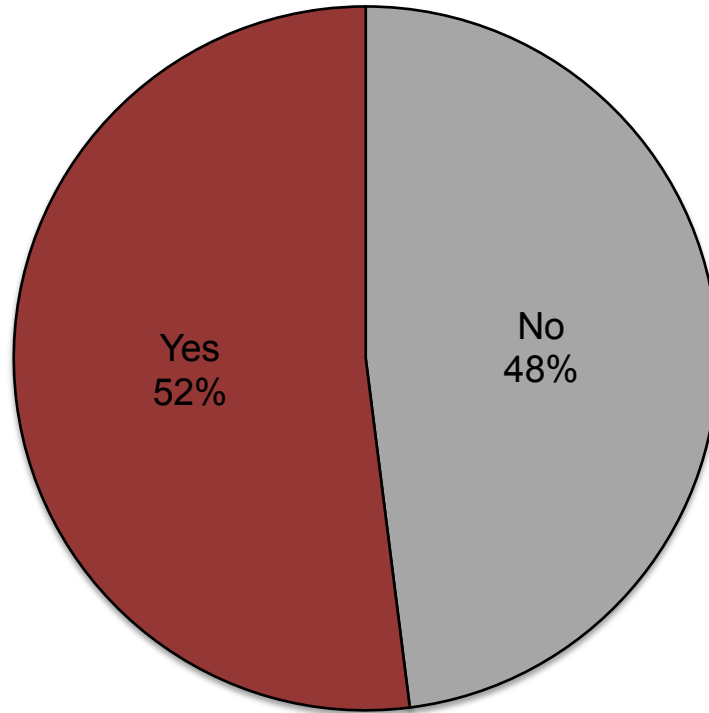
Figure 50: Number of Organizations Providing Services by Setting



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Half of the organizations who responded were able to identify individuals with TBI among their customers. Those organizations reported serving approximately 19,400 individuals with TBI in their most recent fiscal year.

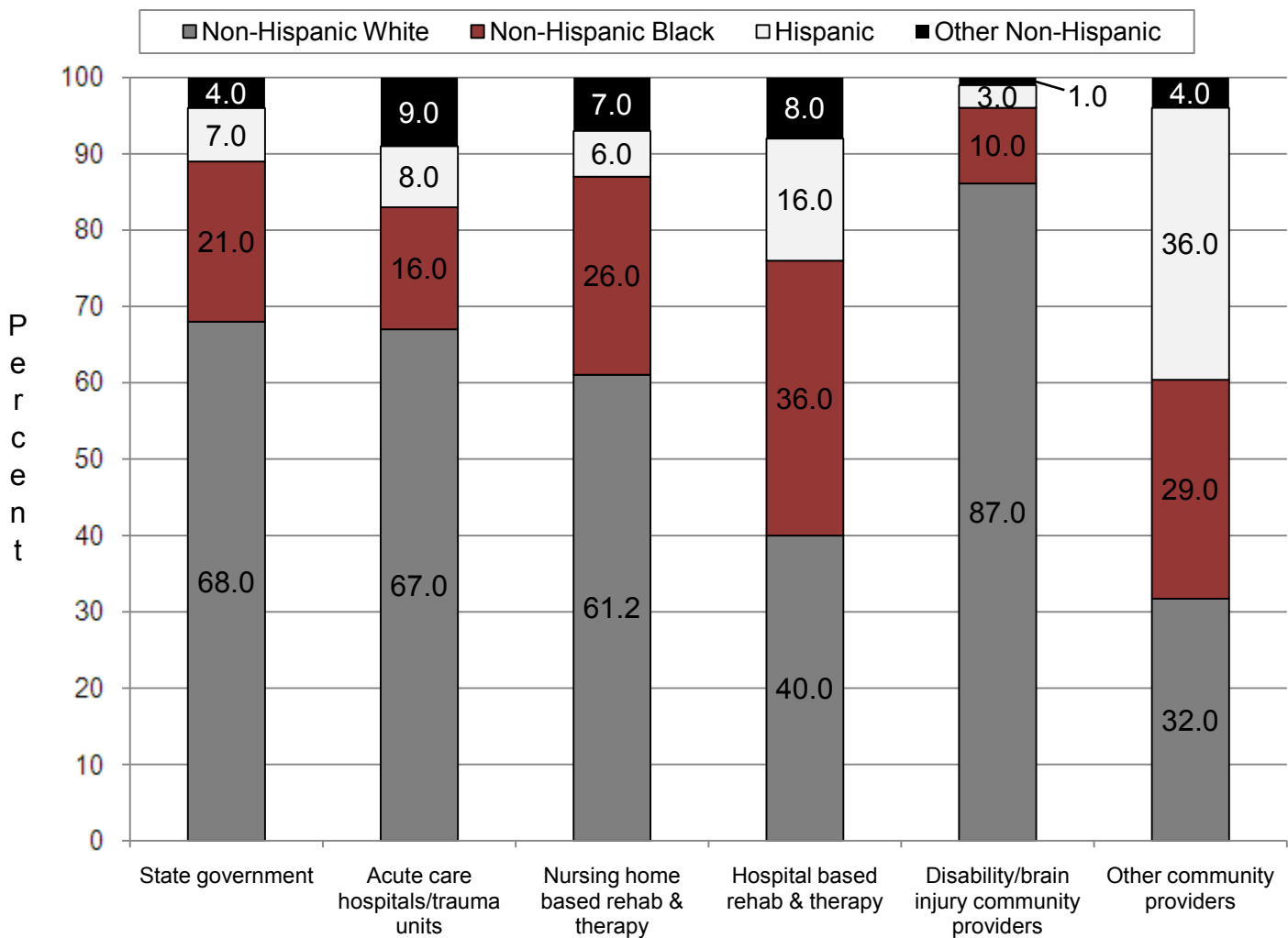
Figure 51: Does the Organization's Data System Identify Whether An Individual Has a TBI?



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

For those organizations who could identify individuals with TBI, all providers reported serving somewhat more males than females. Overall, the individuals with TBI who were most frequently served were non-Hispanic White, followed by non-Hispanic Black. “Other” community providers reported serving the most diverse population with TBI. A small percentage of individuals with TBI were identified as having other non-Hispanic ethnicity. It is important to remember that nearly half of the organizations surveyed were not able to report race/ethnicity for their customers who had a TBI, so these numbers may not be representative of all organizations.

Figure 52: Individuals with TBI Served by Race/Ethnicity

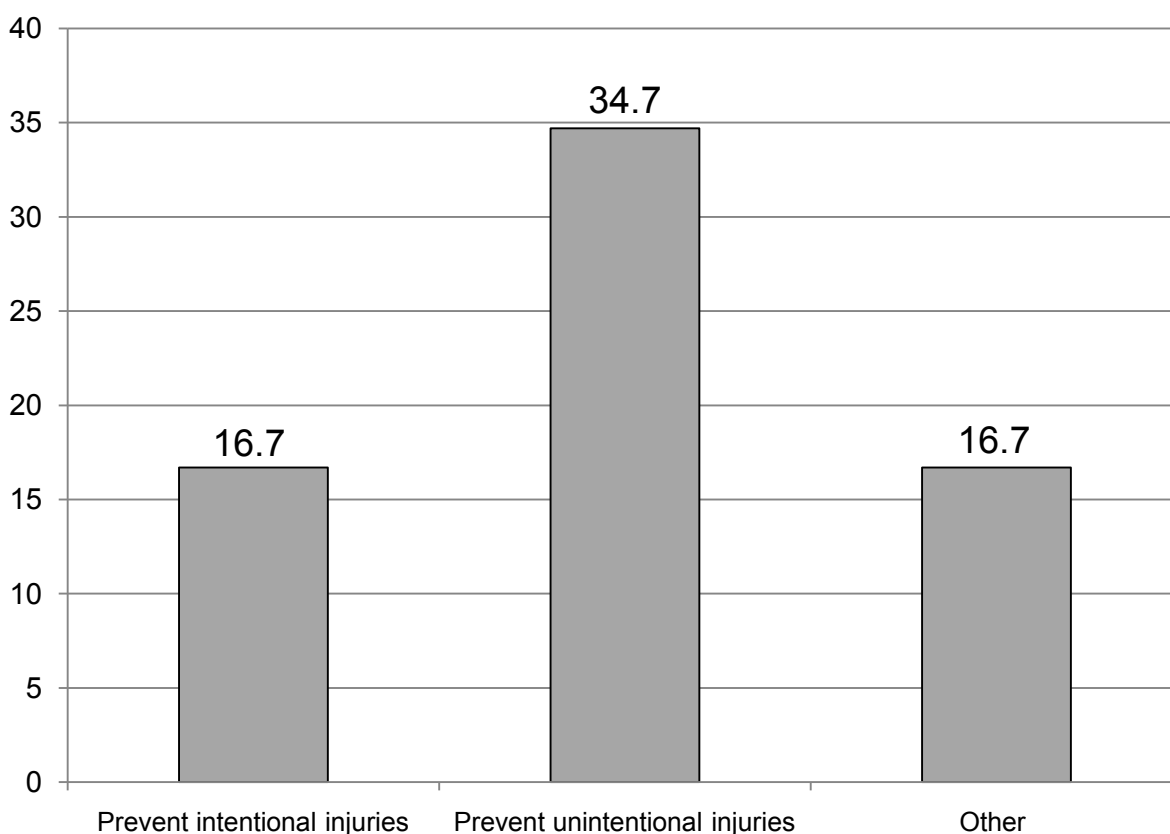


Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Services to Prevent Brain Injury

The majority of prevention services funded or provided were to prevent unintentional injuries. One state agency reported that it funded programs designed to prevent brain injury, both prevention of intentional injuries (shaken baby syndrome, violence, etc.) and prevention of unintentional injuries (falls, motor vehicle accidents, sports injuries, etc.). Two state agencies reported providing services that prevent secondary conditions associated with TBI, such as depression, contractures, cardiopulmonary changes, etc. Of the providers, about half indicated that they provided services designed to prevent brain injury or minimize disability. The other services provided were stroke education and prevention, and home safety assessments.

Figure 53: Percentage of Organizations Providing Prevention Services

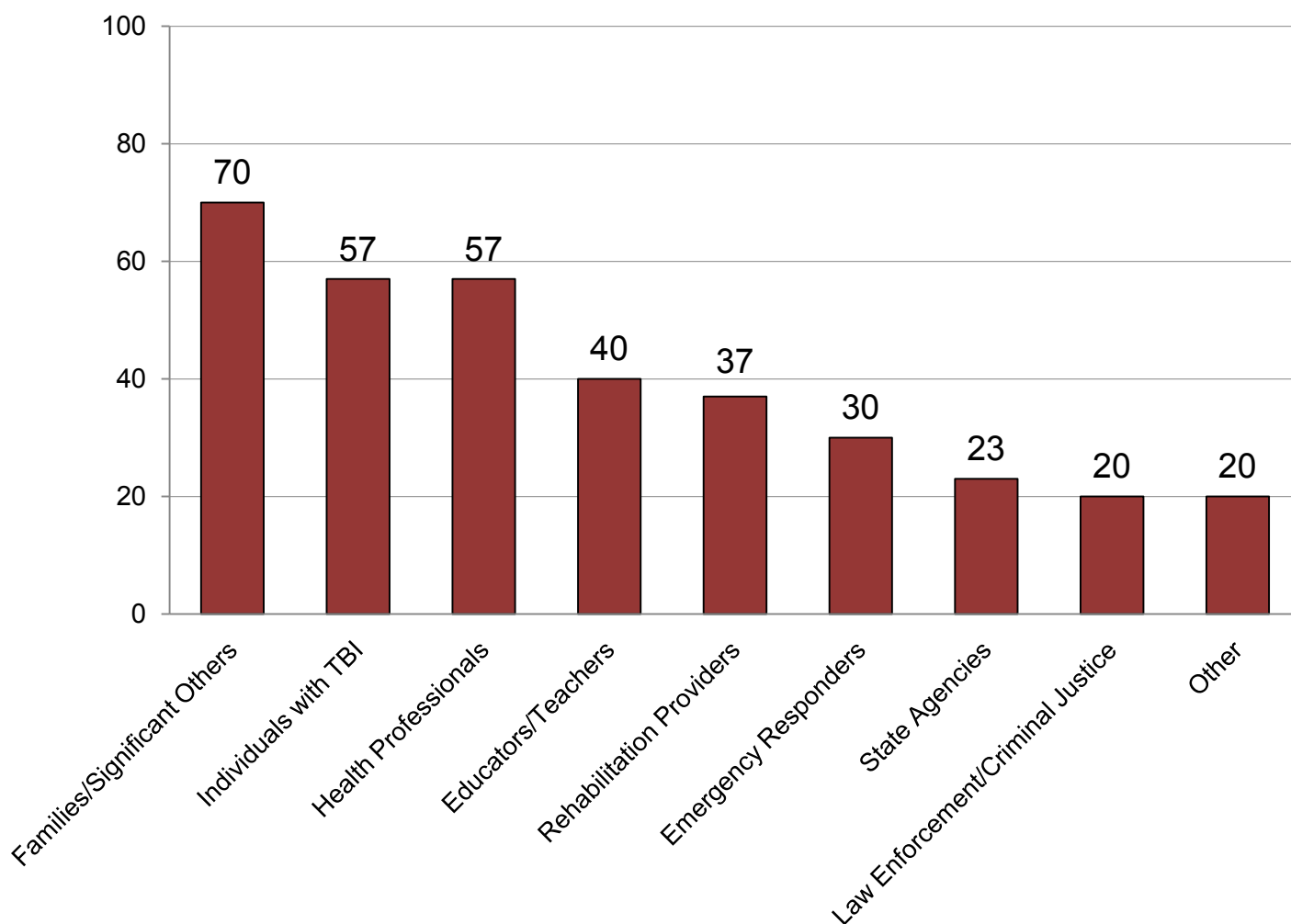


Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Education/Training About Brain Injury

Two-thirds of all organizations reported that they offer education and training about TBI to their own staff and nearly half said that they provided it to external constituencies. Over half of the organizations who offer education and training provide it to individuals with TBI, families and significant others, and health professionals. Three state agencies reported providing education and training about TBI to their own organization and sister state agencies, individuals with TBI, families and significant others, rehabilitation providers, and emergency responders.

Figure 54: Percentage of Providers Who Offer Education and Training About TBI



NOTE: Responses total >100%, since participants could check more than one category.

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Despite the education which is provided, several state agencies and provider organizations commented that there is a lack of understanding about brain injury among individuals, families, agencies, and the general public. The following comments illustrate this concern:

- Not enough understanding in the larger community (schools in particular) about the impact of TBI so children get disciplined instead of supported.
- There is a lack of understanding and recognition of brain injury by referring agencies and organizations.
- We need education for patients and their families on dealing with brain injury.

Services Provided by State Agencies

Only one state agency reported having programs specific to individuals with TBI for both children and adults. The other agencies provide funding and services for individuals with TBI along with other constituencies. The largest number of agencies receive referrals for individuals with TBI from hospitals, but referrals are received from a wide variety of sources.

Figure 55: Source of State Agency Referrals for Services to Individuals with TBI



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Four agencies reported having a case management or service coordination program that serves people with TBI. All four provide this for adults, and three also provide it for children. For the organizations who provided estimated numbers, a total of 1629 adults and 215 children were served. Three agencies provide case management statewide, and all four reported providing case management on a case-by-case basis. Two agencies reported providing case management for longer than three months. The reported caseload size ranged from 5 to 200 individuals per case manager. The need for more coordination of services and case management was mentioned as a gap in services by several state agency respondents.

Three organizations reported that they have programs specifically developed for historically underserved populations (e.g., individuals who are elderly, Native Americans, Hispanics, African Americans, and Asians).

State agencies reported that they funded a wide variety of services. Services were provided to adults more frequently than children under 18, but most services were funded for children by at least one agency. Tables 1 through 4 indicate the number of state agencies providing or funding each general type of service by age, grouped into Medical/Therapeutic Services, Rehabilitation Services, Education/Employment Services, and Community Living Supports. In general, more state agencies funded medical/therapeutic and rehabilitation services, as well as employment services for adults, than community living support services.

**Table 1: Number of State Agencies Providing or Funding
Medical/Therapeutic Services by Age**

| Type of Service | Under 18 | | 18-64 | | 65 and over | |
|--------------------------------------|----------|--------|----------|--------|-------------|--------|
| | Provided | Funded | Provided | Funded | Provided | Funded |
| Alternative Therapies | | 2 | 1 | 1 | | 2 |
| Coma Care | | 2 | 1 | | | 1 |
| Dental Services | | 2 | 3 | 2 | 1 | 2 |
| Durable Medical Equipment | | 2 | 2 | 1 | | 1 |
| Individual Counseling | | 3 | 4 | 3 | 1 | 3 |
| General Medical Services | | 1 | 2 | 1 | 1 | 1 |
| Medical Services Specific to TBI | | 2 | 1 | 2 | | 1 |
| Mental Health Services | | 3 | 3 | 4 | | 3 |
| Neuropsychology | | 3 | 1 | 2 | | 2 |
| Neuropsychiatry | | 3 | 1 | 2 | | 2 |
| Nursing Care | | 2 | 1 | 3 | 1 | 2 |
| Orthodontics/Prosthetics | 1 | 3 | 2 | 3 | 1 | 2 |
| Physical Therapy | | 2 | 2 | 2 | 1 | 1 |
| Psychiatry | | 2 | 3 | 3 | 1 | 3 |
| Psychology | | 2 | 3 | 3 | 1 | 3 |
| Substance Use Evaluation & Treatment | | 2 | 3 | 2 | 1 | 2 |
| General Vision Services | 1 | 3 | 2 | 2 | 1 | 2 |
| Vision Services Specific to TBI | | 2 | | 2 | | 2 |

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Table 2: Number of State Agencies Providing or Funding Rehabilitation Services by Age

| Type of Service | Under 18 | | 18-64 | | 65 and over | |
|--------------------------------------|----------|--------|----------|--------|-------------|--------|
| | Provided | Funded | Provided | Funded | Provided | Funded |
| Acute Rehabilitation | | 2 | 2 | 4 | 2 | 3 |
| Assistive Technology | 1 | 3 | 3 | 3 | 1 | 2 |
| Case Mgt/Service Coordination | 2 | 3 | 3 | 4 | 1 | 2 |
| Cognitive Rehabilitative Therapy | | 2 | 2 | 3 | 1 | 2 |
| Driver Education | | 2 | 1 | 2 | | 1 |
| Family Education/Training/Counseling | 1 | 2 | 2 | 4 | 2 | 3 |
| Independent Life Skills Training | 1 | 3 | 2 | 4 | 2 | 3 |
| Information & Referral | 2 | 2 | 4 | 2 | 2 | 2 |
| Inpatient Rehabilitation | | 2 | 1 | 2 | 1 | 2 |
| Neurobehavioral Treatment | | 2 | 1 | 1 | 1 | 1 |
| Occupational Therapy | | 2 | 2 | 2 | 1 | 1 |
| Pain Management | | 2 | 1 | 2 | 1 | |
| Post Acute Rehabilitation | | 2 | 2 | 2 | 1 | 2 |
| Social Work | 1 | 2 | 2 | 1 | 2 | 2 |
| Speech/Language Therapy | | 2 | 2 | 2 | 1 | 1 |
| Therapeutic Recreation | | 2 | 1 | 2 | 1 | 3 |

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Table 3: Number of State Agencies Providing or Funding Education/Employment Services by Age

| Type of Service | Under 18 | | 18-64 | | 65 and over | |
|----------------------------|----------|--------|----------|--------|-------------|--------|
| | Provided | Funded | Provided | Funded | Provided | Funded |
| Adult Day Program | | 1 | | 2 | | 2 |
| Family Advocacy | 2 | 1 | 3 | 2 | 2 | 2 |
| Self Advocacy | 2 | 2 | 3 | 3 | 2 | 2 |
| Career Counseling/Guidance | 2 | 1 | 3 | 1 | 1 | 1 |
| Higher Education | | 1 | 2 | 3 | | 1 |
| Job Accommodations | 1 | | 3 | 2 | 2 | 1 |
| Job Coaching | | 1 | 3 | 3 | | 2 |
| Job Development | | 1 | 4 | 2 | 2 | 2 |
| Job Placement | | 1 | 3 | 2 | 1 | 1 |
| Job Sampling | | 1 | 2 | 1 | 1 | 1 |
| Learning Supports | | 1 | 3 | 3 | 2 | 2 |
| Prevocational Services | | 1 | 3 | 3 | 2 | 2 |
| Sheltered Workshop | | | 1 | 2 | | 1 |
| Special Skills Training | 1 | 1 | 2 | 2 | 1 | 1 |
| Supported employment | | 1 | 1 | 4 | | 3 |
| Vocational Evaluation | 1 | | 2 | 4 | 1 | 3 |
| Volunteer Placement | | 1 | 1 | 2 | 1 | 1 |
| Work Adjustment | | 1 | 2 | 3 | 1 | 2 |
| Work Support | | 1 | 1 | 2 | | 2 |

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

**Table 4: Number of State Agencies Providing or Funding
Community Living Support Services by Age**

| Type of Service | Under 18 | | 18-64 | | 65 and over | |
|---|----------|--------|----------|--------|-------------|--------|
| | Provided | Funded | Provided | Funded | Provided | Funded |
| Community Advocacy | 1 | 1 | 1 | 1 | 1 | 1 |
| Community Skills Training (relearning skills to use in public places) | 1 | 1 | 1 | 3 | 1 | 2 |
| Companion Services | | 1 | | 1 | | 1 |
| Day program | | 1 | | 2 | | 2 |
| Emergency Shelter Assistance | | 1 | | 2 | | 2 |
| Home Care/Home Support (e.g., home health aide, help with bathing and dressing, etc.) | | 1 | | 1 | | 1 |
| Homemaker Services | | 1 | | 1 | | 1 |
| Housing Assistance (to stay in own home) | | 1 | | 2 | | 2 |
| Environmental Modifications | | 1 | 1 | 2 | | 1 |
| Supervised Housing | | 1 | | 2 | | 2 |
| Income Maintenance | | 1 | | 2 | | 2 |
| Independent Living Services | 1 | 1 | 1 | 3 | 1 | 2 |
| Information/Resources | 2 | 1 | 5 | 2 | 3 | 2 |
| General Legal Services (e.g., divorce, custody, bankruptcy, etc.) | | 1 | | 2 | | 2 |
| Legal Services Specific to TBI | | 1 | | 2 | | 1 |
| Money Management | | | 1 | 2 | 1 | 2 |
| Peer Support | | 1 | 1 | 3 | 1 | 3 |
| Personal Assistance Services | | 1 | | 2 | | 2 |
| Recreation/Social Programs | | 1 | | 2 | | 2 |
| Rental Assistance | | 1 | | 2 | | 2 |
| Respite Care | | 1 | | 1 | 1 | 1 |
| Social Skills Training (how to interact with others) | 1 | 1 | 3 | 3 | 2 | 2 |
| Specialty Care | | 1 | | 1 | | 1 |
| TBI Support Group | | 1 | | 1 | | 1 |
| Transitional Living Services | | 1 | 1 | 2 | 1 | 1 |
| Transportation | | 1 | 1 | 2 | | 2 |
| Utility Assistance | | 1 | | 1 | | 1 |

Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Service Gaps and Barriers Identified by State Agencies

State agencies identified gaps in service, services which needed expansion, and barriers to accessing TBI services in state agencies in general. The following issues were mentioned by state agency respondents:

- A lack of interagency cooperative agreements. No agency in the survey reported having interagency cooperative agreements.
- A lack of knowledge about TBI and its relationship to resulting problems, such as vision loss. Four state agencies reported that they had TBI representation on agency task forces or advisory boards, both from professionals and consumers/families. Two agencies had a representative on the NJ Advisory Council on TBI. However, several agencies commented that they needed to learn more about serving individuals with TBI and understanding the many problems which may result from brain injury.
- Barriers to accessing TBI supports across agency/program boundaries are similar to barriers in accessing health and/or social supports for most individuals with disabilities. There is limited ability to coordinate between agencies and services. There are differences in age, income, residency, and health condition requirements for eligibility for various services, making it difficult to access a full range of services for all individuals who need them. The population served through special child health and early intervention services allows children to access community based services and supports, but these are not always available after age 21 and transition to adult supports can be difficult.
- The use of technical jargon in program applications and educational materials creates a barrier to applications, particularly for individuals with brain injury who do not have someone to advocate and assist them.

- There is a need for more community case managers, especially bi-lingual caseworkers and counselors.
- There is a lack of adequate transportation services for those having a TBI as well as for the general population in New Jersey. Especially in rural areas of New Jersey, public transportation options are few and far between. County para-transit systems are not available everywhere.
- Rehabilitation facilities are not located in close proximity to people in all areas of the state, and transportation to the nearest facility may not be available.
- There is a need for more supported employment vendors specializing in working with TBI consumers. DVRS counselors are in need of more specialized TBI training; some training is provided by the Brain Injury Association of New Jersey, but more is needed.
- The lack of community-based services for individuals with TBI poses challenges for those individuals, and the NJ state agencies that serve them. This leads to increased durations of stay in hospitals and out-of-state placements.
- The cost of rehabilitation services is often unaffordable for people who need it. The person's insurance may not cover all needed rehabilitative services.

Services Offered by Provider Organizations

About 75% of the provider organizations who were surveyed report that they do outreach to inform people about the services they offer. The provider organizations receive payment from a variety of sources, including Medicaid, Medicare, private insurance, Workers' Compensation, automobile insurance, and private individual payments. A few organizations mentioned receiving state, city, or county contracts for services, and foundation or government grants. The hospitals reported receiving some payment from the state funds for uncompensated care. Organizations tended to receive either a large or small portion of their payment from Medicare and/or Medicaid. A third reported receiving 50% or more of their payments from Medicare, while 25% reported receiving 15% or less. One quarter of the organizations received 50% or more of their payment from Medicaid, although half reported receiving less than 10% of their payment from Medicaid. Not surprisingly, organizations providing medical/therapeutic and rehabilitation services received a large percentage of their payments from Medicare, Medicaid, and private insurance. Other organizations reported receiving a smaller amount of payment from private insurance, and half of organizations reported receiving less than 15% of their payments from private insurance.

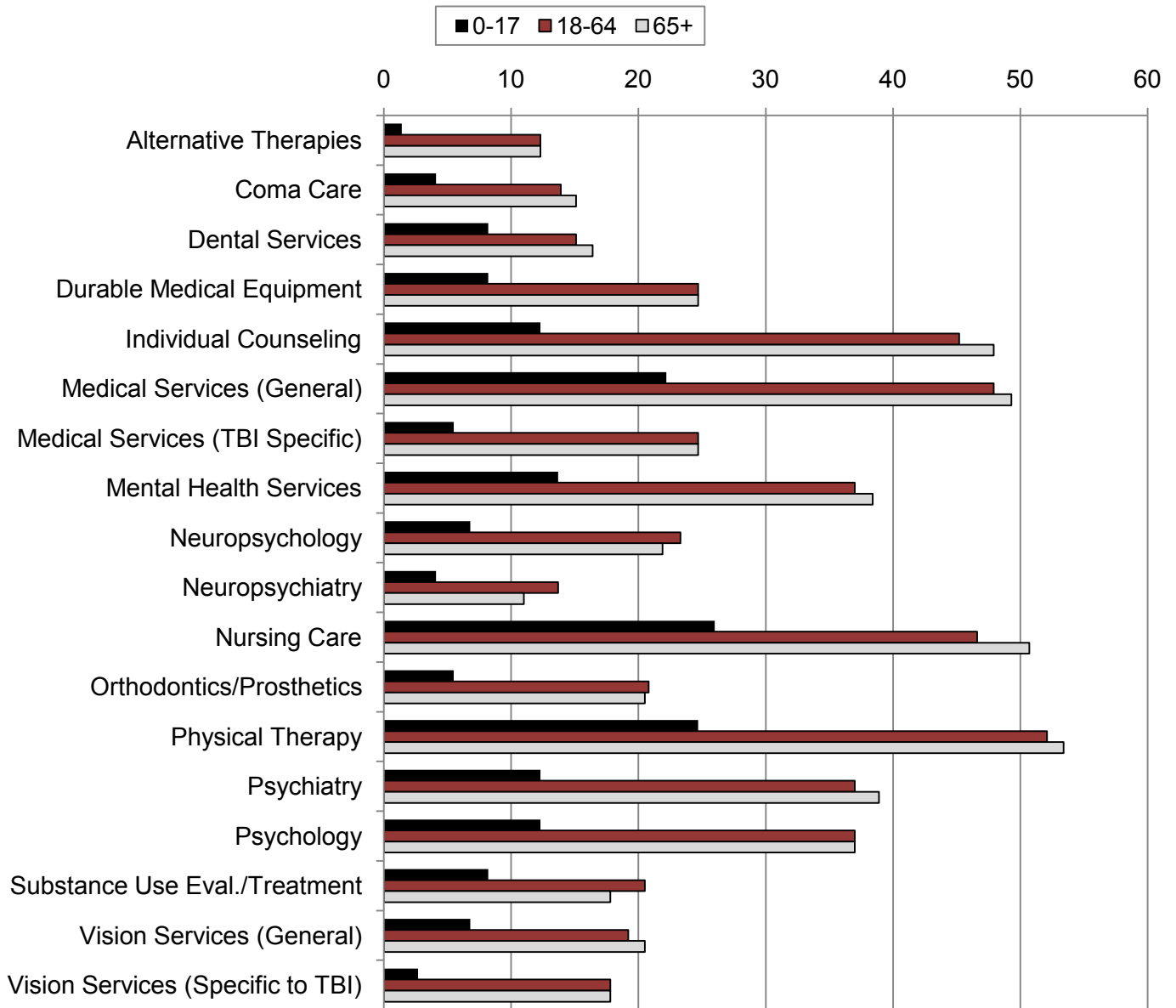
Provider organizations offered a variety of services for children and adults. These services are reported in four broad categories: Medical/Therapeutic Services, Rehabilitative Services, Education/Employment Services, and Community Living Supports.

Medical/Therapeutic Services

All medical/therapeutic services were provided much less often for children than for adults; for all services were provided for children by half as many organizations or fewer, even medical services, nursing care, and physical therapy. Services offered to adults aged 18-64 and those 65 and over were similar, except for substance use evaluation and treatment, neuropsychology, and neuropsychiatry, where services were somewhat more frequently provided for adults under 65.

Vision and dental services, alternative therapies, coma care, and neuropsychiatry were provided less often than most other medical services, especially for children.

Figure 56: Percentage of Organizations Providing Medical/Therapeutic Services by Age



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Detailed figures showing the percentage of organizations providing medical/therapeutic services by region of New Jersey are in Appendix C. For each area of the state, Table 5 shows the specific services which are provided least often compared to the rest of the state. The percentages of organizations providing medical/therapeutic services for adults aged 18-64 and 65 and over were very similar, so all adults are combined.

For children, no organization provided vision services specific to TBI in the northeast and northwest regions; no organization provided alternative therapies in the south. For adults, differences between regions for mental health and dental services were small.

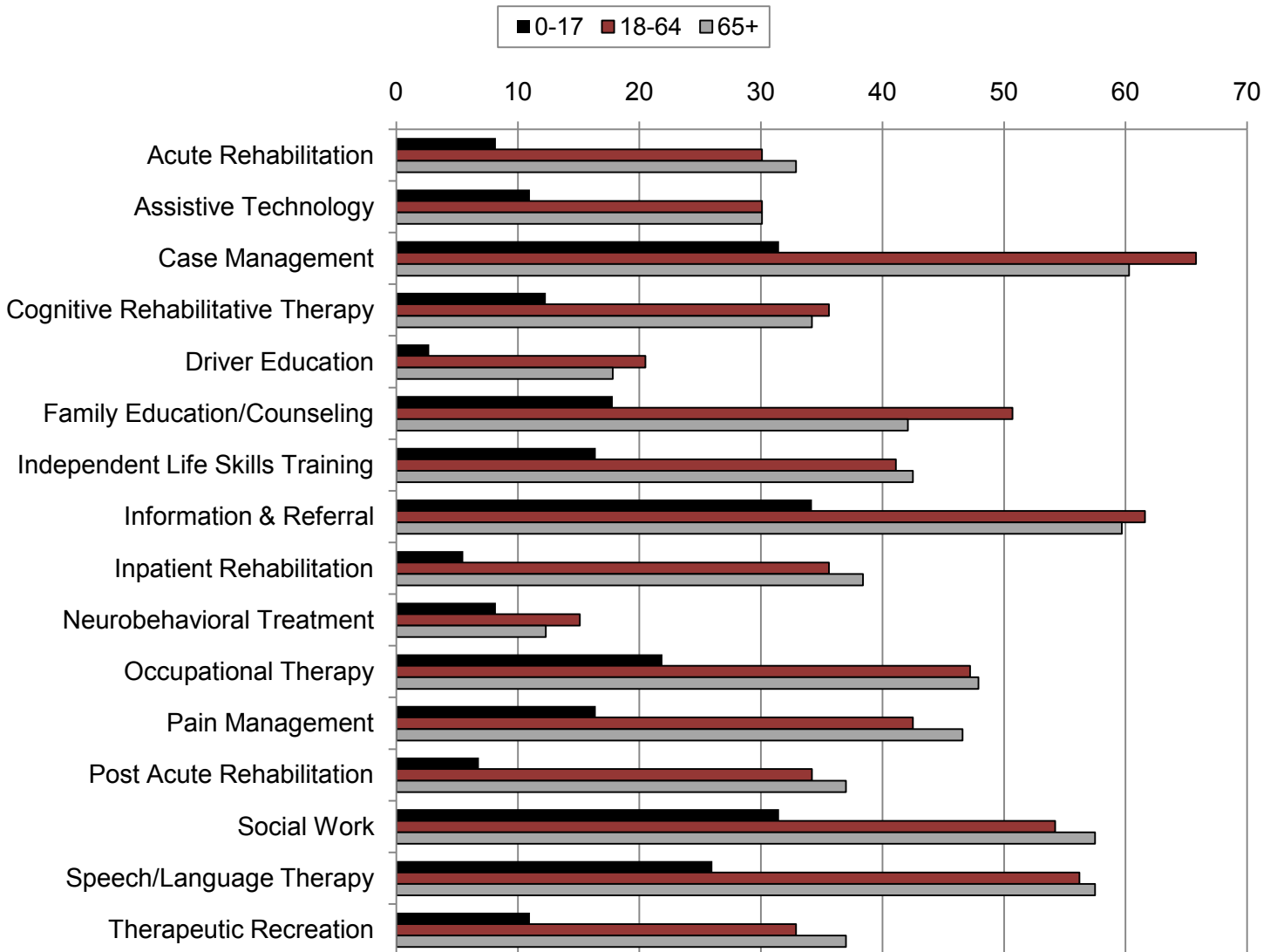
Table 5: Medical/Therapeutic Services Which are Least Often Provided Compared to Other Areas of New Jersey

| Region | Children | Adults |
|---------------|---|--|
| Northwest | Individual counseling, neuropsychology, general vision services, vision services specific to TBI | Dental services, durable medical equipment, general medical services, individual counseling, coma care, neuropsychology, physical therapy, general vision services |
| Northeast | General medical services, medical services specific to TBI, nursing care, physical therapy, psychiatry, vision services specific to TBI | Psychology, nursing care, orthodontics/prosthetics, vision services specific to TBI |
| Central | Alternative therapies, coma care, dental services, neuropsychiatry, substance use evaluation & treatment | Neuropsychiatry |
| South | Alternative therapies | Alternative therapies, coma care, dental services, medical services specific to TBI |

Rehabilitation Services

All rehabilitation services were provided much less often to children than adults. Services provided for all ages by 20% or fewer organizations were driver education and neurobehavioral treatment.

Figure 57: Percentage of Organizations Providing Rehabilitation Services by Age



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Detailed figures showing the percentage of organizations providing rehabilitation services by region of New Jersey are in Appendix C. For each area of the state, Table 6 shows the specific services which are provided least often compared to the rest of the state. The percentages of organizations providing services for adults aged 18-64 and 65 and over were very similar, so all adults are combined.

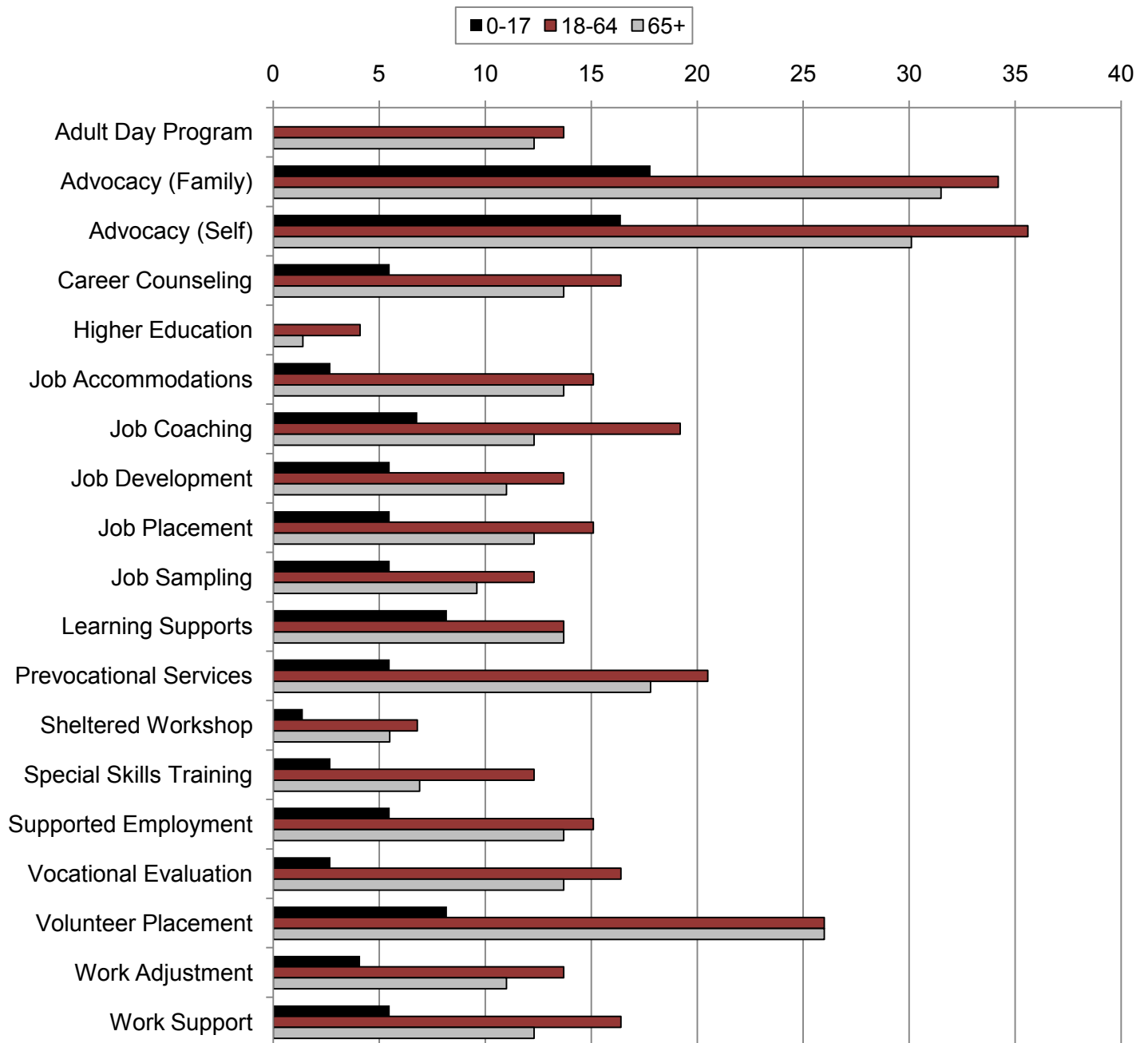
Table 6: Rehabilitation Services Which are Least Often Provided Compared to Other Areas of New Jersey

| Region | Children | Adults |
|---------------|--|--|
| Northwest | Pain management, post-acute rehabilitation | Acute rehabilitation, inpatient rehabilitation, post-acute rehabilitation, pain management, speech/language therapy, occupational therapy, therapeutic recreation, assistive technology, cognitive rehabilitative technology, social work, family education/counseling |
| Northeast | Acute rehabilitation, assistive technology, cognitive rehabilitation therapy, family education/counseling, neurobehavioral treatment, speech/language therapy, social work | Acute rehabilitation, driver education, independent life skills training, neurobehavioral treatment |
| Central | Cognitive rehabilitation therapy, independent life skills training, information & referral, inpatient rehabilitation, therapeutic recreation | |
| South | Case management, pain management | Case management, information & referral, social work, inpatient rehabilitation |

Education/Employment Services

Since employment-related services are most often needed by adults, more organizations provided these services for adults than for children. Advocacy services were most likely to be provided to those under 18 as well as adults.

Figure 58: Percentage of Organizations Providing Education/Employment Services by Age



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

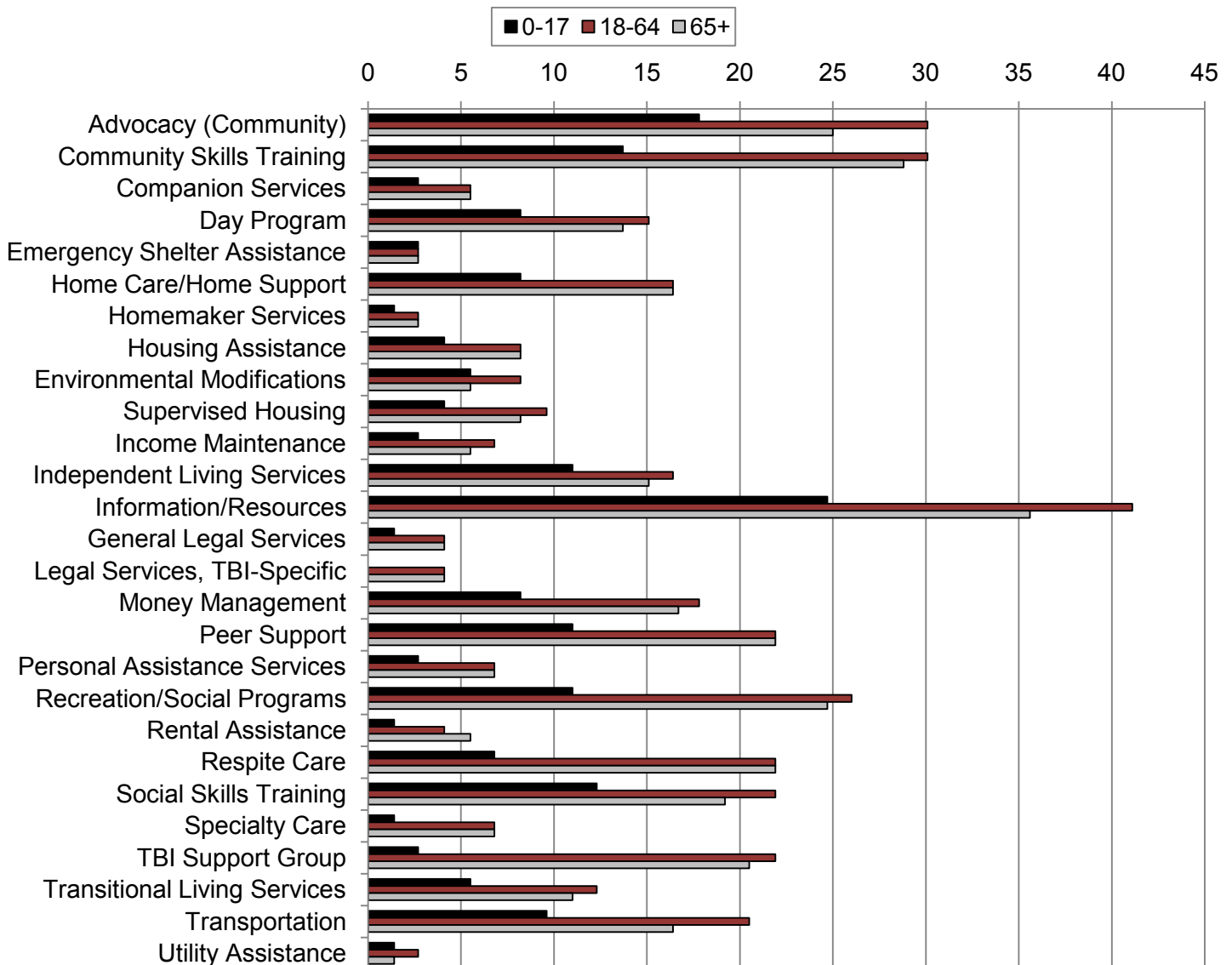
Most employment services were provided less often for adults over 65 than for working-aged adults, but adult day programs, job accommodations, learning supports, sheltered workshops, and volunteer placements were provided to both groups of adults at very similar rates. Very few organizations reported providing higher education services, but we did not survey educational institutions. Other services provided by 15% or fewer of organizations were adult day programs, job development, job sampling, sheltered workshops, special skills training, work adjustment, and learning supports.

There were very few differences in the percentage of organizations offering education/employment services between the four regions of New Jersey, so those results are not shown separately.

Community Support Services

Fewer organizations provided community support services to children than to adults. Emergency shelter assistance, homemaker services, legal services, and utility assistance were provided by fewer than 5% of organizations. Fewer than 10% offered companion services, personal assistance services, or specialty care for adults; the percentages offering housing assistance, environmental modifications, supervised housing, or rental assistance were also less than 10%.

Figure 59. Percentage of Organizations Providing Community Support Services by Age



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Peer support, recreation/social programs, respite care, and TBI support groups were offered to adults by about 20% of organizations.

Detailed figures showing the percentage of organizations providing community support services by region of New Jersey are in Appendix C. For each area of the state, Table 7 shows the specific services which are provided least often compared to the rest of the state. The percentages of organizations providing services for adults aged 18-64 and 65 and over were very similar, so all adults are combined.

No organization reported providing specialty care for either children or adults in the south, and no specialty care for children was reported in the central region. TBI support groups for children were not reported in the central or southern regions.

Table 7: Community Support Services Which are Least Often Provided Compared to Other Areas of New Jersey

| Region | Children | Adults |
|-----------|---|---|
| Northwest | | Emergency shelter assistance, environmental modifications, TBI-specific legal services |
| Northeast | Companion services, day program, home care/home support, personal assistance services, money management | Companion services, emergency shelter assistance, general and TBI-specific legal services, respite care |
| Central | Community advocacy, community skills training, companion services, day program, home care/home support, environmental modifications, supervised housing, personal assistance services, speciality care, TBI support group | Community advocacy, companion services, personal assistance services, day program, home care/home support, homemaker services, supervised housing, rental assistance, information & resources |
| South | Home care/home support, independent living services, peer support, recreational/social programs, speciality care, TBI support group, transitional living services, transportation | Community skills training, independent living services, money management, peer support, transitional living services, specialty care |

Service Gaps and Barriers Identified by Provider Organizations

As with state agency respondents, provider organizations identified a number of service gaps and barriers to receiving TBI services. The principal issues identified were funding, transportation, the need for better referral and information for professionals as well as for individuals with TBI or their families, a lack of case management, a lack of services for non-English speakers, and a lack of understanding of TBI and related problems on the part of professionals.

The following are typical comments:

- It is difficult to be aware of all the sources that are offered to people specifically for TBI. I never knew until last year that people who have had a stroke are also considered as having TBI.
- Consumers need more information on available services and need assistance to work through the logistics of accessing them.
- Case management agencies are not fully aware of the breadth of services needed for communicationally impaired adults re-entering the world; i.e., alternative therapies, YMCAs, churches/synagogues, etc. Sometimes people need comprehensive assessment prior to accessing needed services.
- After 18 years, we still find that the majority of our patients and referral sources have had great difficulty finding us.
- Just knowing where services are and how to access them for a patient.
- There is a lack of coordination of services. Individuals with TBI need to reach out to many services to fill their needs.

- Often it is months or even a year or two before TBI patients are referred for therapy. More follow up needs to be done with patients and their family members to ensure that they know what to do to get necessary services.
- For our agency, transportation is the critical issue, not just to initially access services, but to continue services.
- Location of facilities providing services and lack of funded transportation.
- Transportation to get to services is a problem—just about anywhere in New Jersey.
- Barriers include a lack of resources for community re-entry, including staff and transportation vehicles.
- There is not enough funding for all cases for case management when other services take priority. There is a lack of case management services to assist all of those needing services.
- There is not enough case management starting in the acute care hospital and remaining through transition to the community.
- We need more case managers/social workers with experience in working with brain-injured individuals.
- Case management services, coordination, and family support services need to be expanded.
- Patients that are indigent or have no health coverage are much more difficult to get services for through outside agencies.

- If you review the breakdown of services by race, it is readily apparent that we are not reaching Latinos, African Americans and many other ethnic groups. There may be cultural barriers, but we need to be more proactive in this area.
- Families of children and youth with TBI who are immigrants, especially the undocumented, who speak another language, who are of color and poor, face huge gaps in locating and securing appropriate advocacy and direct services.
- The format of education is not acceptable to diverse communities. I think creative collaboration efforts in immigrant communities could increase awareness of TBI and services.
- Medical insurance coverage is not adequate, particularly for cognitive deficit remediation.
- There is inadequate funding to meet the costs associated with providing services in community settings. Current public funding through Medicaid waiver has no mechanism for cost of living increase.
- The financial situation of our patients is a barrier. Many in our area have little or no insurance coverage.
- A funding source needs to be developed for individuals who are injured before age 21. The Division of Developmental Disabilities is not yet prepared to fund specialized brain injury services, and these persons are not eligible for the Medicare waiver program.
- The most significant gap is for an individual who is uninsured and does not meet requirement for SSI or SSDI. Individuals who do not financially

qualify for rehab, yet still need 24-hour supervision, are a tremendous burden on family members who have full-time jobs.

- There is a lack of understanding and recognition of brain injury by referring agencies and organizations.
- There is not enough information in the larger community (schools in particular) about the impact of TBI.
- Lack of public information on the availability of support groups, both online and community ones.
- Lack of understanding of brain injury in many service systems, such as mental health education, criminal justice, etc.
- There is a greater need for education of the community as a whole, to understand the TBI Fund.

Additional comments highlighted other gaps in services:

- We need to have vocational counselors that can communicate with someone with aphasia and job coaches that could find them meaningful work.
- We need access to affordable accessible housing for consumers, particularly supervised apartment living in the Central and Northern regions.
- Units of housing for individuals with TBI need to be in a wider geographic area. There is a tragic lack of subsidized accessible housing throughout the state.

- There should be more availability of group homes or alternative living arrangements.
- There is not enough housing and not enough caregiving hours in the community settings following inpatient rehabilitation to promote independence.
- Generally speaking, community living is not an option due to the intensity of medical care required or lack of appropriate community care resources.
- The TBI Waiver process has many barriers. The committee to review the application meets only every other month. This holds up the acceptance or rejection for community services. Also the application is difficult for families to complete. We need more TBI Waiver slots.
- We need employment programs—supported employment especially. Day activities for people who do not seek work.
- We need the ability to give outpatient services for extended periods of time. Improve reimbursement sources to continue therapy and ensure transport services.
- There should be more assistance with home care and monitoring of these services.
- Have one regional hospital which can be a center of excellence for brain injury.
- We need more acute rehab centers in New Jersey.

- More neuropsychological services, neuropsychiatric services, and neuro ophthalmology services are needed.
- Patients and their families need education on dealing with brain injury. TBI education and rehab expectations for the TBI patient and significant others and TBI prevention.
- The major area we have observed with TBI clients has been financial management. This includes budgeting, debt management and reduction, controlling impulse spending, etc.
- There are gaps in behavior modification counseling programs, etc. Many clients are unable to stay with parents or in a facility due to behavior problems, and when displaced there is no alternative for them. If a program could be in place to work with them prior to displacement, finding a stable living situation would be easier.
- I would have to say that the problem that is now developing is a reluctance of providers to accept the more challenging cases. It is almost embarrassing to keep reverting to funding, but if you are reimbursed the same amount for everyone, it's tempting to take the easier cases.
- Lack of services to assist families of TBI survivors and the client. In certain areas of the state, there are no services/therapy centers to meet an individual's needs, e.g., Sussex/Warren counties.
- There are few resources to deal with mental health issues, and respite services for families.

- We need support groups for the family, siblings of individuals with TBI. Referral services for families that have individuals with TBI living with them.
- We need more integration of people with TBI into the community.
- The system needs to be user-friendly. Often patients with TBI or other brain injuries get lost trying to access the system.

Conclusions

The individual surveys identified a number of areas where more services are needed, as well as gaps and barriers to receiving needed services. This information can provide the basis for identifying and providing new services and eliminating gaps and barriers. In reviewing this information, it is important to note that the survey did not provide information about the intensity or duration of needed services, nor did we ask participants to set priorities on the services they needed most. While all of these services are important to helping individuals with brain injury lead healthy, safe, and independent 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, but the lack of this service when needed may have grave consequences for an individual's well-being.

The individual and family participants who responded were identified through mailing lists and community forums, so they represent those who have had some contact with organizations who serve individuals with brain injury. It is likely that other New Jersey residents who have experienced brain injury have a high need for services, but have less contact with the service community and less connection to sources of potentially helpful information. Service providers specifically mentioned the need for

outreach to individuals whose native language is not English or who do not have legal status.

Some services were needed by a majority of individuals served, particularly medical and rehabilitative services. These included:

- Pharmaceuticals (75.4%)
- Medical services (66%)
- Cognitive training (64.6%)
- Case management (61.8%)
- Occupational/physical therapy (61.6%)
- Individual counseling (54.5%)
- Psychology/psychiatry (52.5%)
- Dental services (51.1%)

In addition, vision services and transportation were needed by just under half of participants.

Generally, the services listed above also had the highest percentages of individuals receiving them, and participants reported that the services met their needs at least 70% of the time. However, some important gaps in frequently-needed services were evident; for example, cognitive training, individual counseling, and occupational/physical therapy were received by only about half of those who said they needed them. Provider comments reinforced the need for more services, citing the need for more clinicians specializing in brain injury and the need for adequate funding to provide medical and rehabilitation services to all those who need them.

With the exception of transportation, all other education/employment services and community support services were needed by 20-30% of participants, in contrast to the medical/therapeutic and rehabilitation services which were needed by high percentages of participants. However, with a few exceptions (transportation, home care

and learning supports through high school), between 60 and 85% of those who needed education, employment, or community support services did not receive them.

Given the differences in percentage of individuals who need various services and variation in the proportion of individuals who receive the services they need, it is difficult to compare the overall degree of need for various services. To assist in synthesizing the information, we computed an adjusted percentage of those who need but do not receive each service as a proportion of all those who responded to the survey. For example, 64.6% of participants reported that they needed cognitive training, or 426 individuals. Of these, 236 (55.4%) did not receive the service. Another service, alternative therapies, was reported as a need by 45.8% of participants, or 302 individuals. Of these, 203 (67.2%) did not receive the service. When we divide the number of individuals who do not receive each of these services when needed by the total number of survey participants (659), we obtain the percentage of all participants who do not receive needed cognitive training (35.8%) or alternative therapies (30.8%).

It is important to note that this is a very crude measure of unmet need, which does not take into account the intensity or duration of the need, nor the resources required to provide the service. However, it provides a very rough comparison of the proportion of unmet need for each service and can provide a starting point for discussion.

The adjusted percentage of unmet need for each service is shown in Table 8.

**Table 8: Participants Who Do Not Receive a Needed Service
As a Percentage of All Participants**

| Type of Service | N | % |
|-------------------------------------|----------|----------|
| Cognitive training | 236 | 35.8 |
| Alternative therapies | 203 | 30.8 |
| Occupational/physical therapy | 196 | 29.7 |
| Case management | 174 | 26.4 |
| Individual counseling | 173 | 26.3 |
| Transportation | 170 | 25.8 |
| Family counseling | 167 | 25.3 |
| Assistive technology | 160 | 24.3 |
| Dental services | 157 | 23.8 |
| Behavioral supports | 156 | 23.7 |
| Psychology/psychiatry | 149 | 22.6 |
| Vision services | 146 | 22.2 |
| Medical services | 144 | 21.9 |
| Housing assistance | 141 | 21.4 |
| Speech therapy | 141 | 21.4 |
| Money management | 137 | 20.8 |
| Social skills training | 134 | 20.3 |
| Home modifications | 125 | 19.0 |
| Assistance getting a job | 120 | 18.2 |
| Respite | 114 | 17.3 |
| Assistance keeping a job | 105 | 15.9 |
| Community skills training | 105 | 15.9 |
| Pharmaceuticals | 102 | 15.5 |
| Learning supports after high school | 102 | 15.5 |
| Durable medical equipment | 91 | 13.8 |
| Home care | 85 | 12.9 |
| Inpatient rehabilitation | 71 | 10.8 |
| Nursing care | 58 | 8.8 |
| Emergency shelter* | 38 | 5.8 |
| Learning support thru high school* | 34 | 5.2 |
| Substance abuse services* | 20 | 3.0 |

* may not be representative because of small numbers

Information from the provider survey indicates that few providers offered alternative therapies, dental services, vision services specific to TBI, housing assistance, or home modifications. Comments from state agencies and provider organizations highlighted gaps and barriers in receiving many of the same services which appear to have high levels of unmet need in Table 5. For example, providers commented on the lack of trained professionals with knowledge of brain injury as well as the lack of funding to support cognitive training for sufficient amounts of time to help individuals with TBI. Providers also suggested that there are few sources of funding for alternative therapies. Providers saw a need for more rehabilitation services throughout New Jersey and/or transportation to allow individuals to get to these services which are not available statewide.

Even when services were available, professionals often mentioned a lack of knowledge and training about brain injury on the part of both service providers and families. Both professionals and caregivers highlighted the need for more and better trained case managers to assist individuals and families in understanding the continuing needs of people with TBI and navigating the confusing array of available services. In addition, professionals and family members stressed the need for family counseling, education, and support to help families cope with the stresses of supporting someone with brain injury.

The need for transportation deserves special mention, since it underlies the lack of availability of many services which may exist within the state, but are not easily available without reliable and accessible transportation. Comments from individuals with brain injury show that 'accessibility' is a complex issue. Even when public or specialized transportation is available, it can be difficult and inconvenient to use, and individuals who need assistance or extra time may not feel welcome or receive competent service. Maintaining a car on a limited income or relying on family members for transportation is challenging and often frustrating. It is impossible to know how much service utilization would be improved by better transportation, but lack of

transportation is a serious barrier to receipt of services as well as to participating in many other community activities.

Individuals who reported that they received a service but it did not meet their needs represent another gap in services. For example, many participants indicated that they would like to work, but about half of participants who received assistance getting a job, assistance keeping a job, learning supports after high school, or respite reported that those services did not meet their needs. We were not able to get detailed information about why each service did not meet a participant's needs, but comments from participants and providers suggest that job assistance and learning supports could be improved by better training about the needs of those who have brain injury and by more opportunities for supported employment for those individuals who want that alternative.

Over half of those who receive respite services report that those services do not meet their needs. Comments indicate that effective provision of respite services is hampered by a lack of providers and reliable, trained caregivers. About 40% of those who received alternative therapies said those services did not meet their needs. Comments suggested that it is difficult to get those services in sufficient quantities, especially over time, because of the need to pay out-of-pocket.

As noted previously, many community support services did not meet the needs of between a quarter and a third of the individuals who received them. Comments suggested that the lack of easy availability and/or funding to obtain sufficient amounts of service, along with a lack of understanding and specialized training about brain injury, are factors which contributed to the inadequacy of services. Over a third of participants who received home modifications and housing assistance said that these services did not meet their needs. These services may be critical to allow individuals to remain safely in their homes, a concern for both the present and the future voiced by individuals with TBI as well as their families.

The need for case management has already been mentioned. A general theme of the comments from both individuals and providers was the pervasive need for information about programs and services available to individuals with brain injury, along with hands-on assistance in dealing with complex eligibility requirements and application forms. One-third of caregivers needed assistance with information about resources and advocacy.

Providers and individuals both said that they needed more information about the Traumatic Brain Injury Fund and the Traumatic Brain Injury Waiver. Both also suggested the need for more funding for these services, which provide help for individuals who would not otherwise receive it. However, the need to simplify applications was noted for these and other services.

Finally, individuals with brain injury, their families, 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 their neighbors. The difficulties in reading, speaking, comprehending, and interacting experienced by many individuals with brain injury are poorly understood and can lead to exclusion, ridicule, or other types of discrimination. Isolation and the inability to participate fully in valued activities in the community compound the already significant difficulties faced by many individuals with brain injury.

Appendix A

If you or someone you know have been affected by a brain injury, such as:

stroke, traumatic brain injury (TBI) due to motor vehicle accident, fall or assault, brain tumor or other permanent brain damage,
you can make a difference.

The New Jersey Division of Disability Services is conducting open forums and community surveys regarding the experiences of people with brain injuries and their families.

Your input may help to shape new programs and improve the quality of life for all New Jersey residents who live with brain injury.

If you are interested in making a difference and would like to learn more about this program, please contact:

Amy Taklif, TBI Specialist
Division of Disability Services
1-888-285-3036 (toll-free- press 2)
or 1-609-633-1297



State of New Jersey

DEPARTMENT OF HUMAN SERVICES

PO Box 700

TRENTON, NJ 08625-0700

JON S. CORZINE
Governor

DIVISION OF DISABILITY SERVICES

JENNIFER VELEZ
Commissioner

WILLIAM A. B. DITTO
Director
609-292-7800

June 2008

The New Jersey Division of Disability Services (DDS) has contracted with the Center for State Health Policy (CSHP) at Rutgers to conduct a survey of individuals who have experienced brain injury, and their families, in order to learn more about their needs and the services they have received. The information we collect will help us to plan services and supports for people with brain injury and their families, and will help us develop a new State Action Plan for people with brain injury. This means that your response will help to shape new programs and services for the brain injury community in New Jersey.

Enclosed please find a questionnaire for your review and response, as well as a letter from Rutgers University detailing all of your options for completing this survey. **This survey is important, but it is purely voluntary.** If you decide not to answer the questions, this will not affect your health benefits or any other services you get.

Thank you in advance for your cooperation. Your input is essential to improving brain injury services for survivors and their families. Should you have any questions, please contact Dorothy Gaboda at the Rutgers University Center for State Health Policy at 732-932-4678 or via email at dgaboda@ifh.rutgers.edu.

Sincerely,

William A. B. Ditto
Director

WABD:AT:kw
Enclosure

June 10, 2008

Dear ,

The Center for State Health Policy at Rutgers is conducting a survey to learn about Traumatic Brain Injury needs and services in New Jersey. You have been chosen as part of a random sample of people who have experienced a traumatic brain injury or are caring for an individual with traumatic brain injury. To get accurate information, we need answers from all the people we ask to take part in this survey, even if you do not currently need services. Most people find that it takes only a short time to complete the questionnaire.

In addition to the enclosed mail questionnaire, we are also offering you the option of completing the same survey via the internet. If you prefer to use this internet option, the following is the information that you will need:

- Website: <http://www.NJ-TBI-Assessment.com>
- PIN #: **315947** (you will need to enter this # upon starting the survey)

If you prefer to take the survey over the telephone, please call Jose Nova at 732-932-4682 to make an appointment with an interviewer.

Your responses will be kept confidential. Confidential means that the research records will include some information about you, such as your age, your gender, the zip code where you live, and when you were injured. I will keep this information confidential by limiting individual access to the research data and keeping it in a secure location. The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published or the results are presented at a professional conference, only group results will be stated. All study data will be kept for seven years.

You may choose to fill out this survey or not. If you decide not to answer the questions, this will not affect the health benefits or any other services you get.

If you have any questions about this survey, please contact Dorothy Gaboda at the Center for State Health Policy at Rutgers University, 55 Commercial Avenue, New Brunswick, NJ, 08901-1340, or by telephone at 732-932-4678. If you have any questions about your rights as a research subject, you may contact the IRB Administrator at Rutgers University at: Rutgers University, the State University of New Jersey, Institutional Review Board for the Protection of Human Subjects, Office of Research and Sponsored Programs, 3 Rutgers Plaza, New Brunswick, NJ 08901-8559, Tel: 732-932-0150, ext. 2104, Email: humansubjects@orsp.rutgers.edu.

Sincerely,



Dorothy Gaboda, MSW, Ph.D.
Associate Director

New Jersey Survey of Individuals with Traumatic Brain Injury and Their Families

Please select your language preference:

- English
 Spanish

If you should need to stop the survey at any point in order to finish it at another time, or if you should lose your internet connection in the middle of the survey, you will still be able to continue at the exact point where you left off by simply returning to the survey's Home Page (i.e. – www.NJ-TBI-Assessment.com) and re-entering your PIN #.

1. Is this survey being completed by the person who has sustained a brain injury without any assistance from another person?

No, another person is providing assistance

Yes

Now go to question #4

2. Who is assisting with this survey?

- Spouse
 Sibling
 Parent
 Child
 Significant other
 Other family member
 Other non-family (Specify): _____

3. What type of assistance are you providing?
Check all that apply

- Read questions
 Wrote down answers
 Translated questions into person's language
 Answered questions
 Other type of assistance (Specify): _____

NOTE: If you are providing assistance with completing this survey, please answer the questions from the viewpoint of the individual with a traumatic brain injury whom you are assisting.

Section A. This section asks for information about your injury or injuries.

4. How many brain injuries have you sustained?

- One Two Three Four More than four

5. Did your brain injury (or ANY of your brain injuries) occur during Military Service?

- Yes No

6. Please indicate the month and year that your brain injury occurred. If you sustained more than 1 brain injury, please answer about your FIRST brain injury.

Month:

- 1 – January
2 – February
3 – March
4 – April
5 – May
6 – June
7 – July
8 – August
9 – September
10 – October
11 – November
12 – December
99 – Don't Know

Year:

2008
- through -
1900

Don't Know - 9999

6a. Did you go to the Emergency Room as a result of this injury?

- Yes No

6b. Were you admitted to the hospital as a result of this injury?

- Yes No

7. How did you sustain your brain injury (or injuries)? Check all that apply

- | | |
|---|--|
| <input type="checkbox"/> Motor vehicle crash | <input type="checkbox"/> Near drowning |
| <input type="checkbox"/> Motorcycle crash | <input type="checkbox"/> Fall |
| <input type="checkbox"/> Bicycle crash | <input type="checkbox"/> Assault/Abuse |
| <input type="checkbox"/> Pedestrian accident | <input type="checkbox"/> Firearms/Gunshot |
| <input type="checkbox"/> Stroke, aneurysm/AVM rupture | <input type="checkbox"/> Sports injury |
| <input type="checkbox"/> Anoxia (lack of oxygen) | <input type="checkbox"/> Suicide attempt |
| <input type="checkbox"/> Tumor or tumor removal | <input type="checkbox"/> Poisoning, overdose |
| <input type="checkbox"/> Disease (meningitis, Lyme, encephalitis, etc.) | |
| <input type="checkbox"/> Other (Specify): _____ | |

8. Do you consider yourself to have a mild, moderate, or severe brain injury?

- Mild
 Moderate
 Severe
 Unsure/Don't know

Section B. This section is about various services that you may or may not be receiving in your current situation.

| 9a. Do you need this service? | | | 9b. If you need this service...are you currently receiving it? | | | | |
|--|--------------------------|--------------------------|--|----------------------------------|---|--|----------------------------|
| | <u>No</u> | <u>Yes</u> | <u>Yes,...(check only 1)</u> | | <u>No, because...(check all that apply)</u> | | |
| | | | ...and it meets my needs | ...but it does NOT meet my needs | ...it is NOT available / accessible | ...there is no funding / I can't afford it | ...of some other reason(s) |
| <u>Medical/Therapeutic Services</u> | | | | | | | |
| a. Nursing care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Individual counseling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Family counseling, training or education | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Psychology or psychiatry services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Alternative therapies (acupuncture, massage therapies, aqua-therapy, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Vision services that address the effects of your injury | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Medical services that address the effects of your injury | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Pharmaceuticals (medications and/or co-pays, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Dental services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Substance abuse (addiction programs, peer support groups, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <u>Rehabilitation Services</u> | | | | | | | |
| k. Inpatient rehabilitation (i.e. therapies you receive while staying in a hospital) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. Speech therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. Cognitive training (i.e. retraining your brain to improve everyday skills) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n. Occupational or physical therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o. Case management/service coordination (i.e. someone works with you to coordinate the services you need) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| p. Behavioral supports (i.e. learning ways to reduce or avoid unwanted behavior) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| q. Assistive technology services (a device that helps you speak, tape recorder for memory, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| r. Durable medical equipment (wheelchair, scooter, shower chair, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| 9a. Do you need this service? | | | 9b. If you need this service...are you currently receiving it? | | | | |
|---|--------------------------|--------------------------|--|----------------------------------|--|--|----------------------------|
| | <u>No</u> | <u>Yes</u> | <u>Yes...</u> (check only 1) | | <u>No, because...</u> (check all that apply) | | |
| | | | ...and it meets my needs | ...but it does NOT meet my needs | ...it is NOT available / accessible | ...there is no funding / I can't afford it | ...of some other reason(s) |
| <u>Education/Employment Services</u> | | | | | | | |
| s. Learning supports (for students through high school) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| t. Learning supports (for students after high school: tuition, related books and fees, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| u. Assistance getting a job | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| v. Assistance keeping a job (job coach, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <u>Community Living Support</u> | | | | | | | |
| w. Home care support (home health care, help with bathing and dressing, homemaking assistance, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| x. Housing assistance (security deposit, moving fees, rental assistance, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| y. Help with home modifications (ramps, bathroom accessibility modifications, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| z. Emergency shelter assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| aa. Respite care (e.g. temporary care to give caregiver a break) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| bb. Community skills training (i.e. relearning skills to use public places) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| cc. Social skills training (i.e. how to act with others) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| dd. Money management and budget training | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ee. Transportation assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

The purpose of the Traumatic Brain Injury (TBI) Fund is to allow New Jersey residents who have survived an acquired brain injury to obtain the supports they need to live in the community.

10. Have you ever applied to the TBI Fund? Yes No

Section C. This section asks questions about you.

11. In which county do you live?

- | | | | | | |
|-------------------------------------|-------------------------------------|------------------------------------|-----------------------------------|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Atlantic | <input type="checkbox"/> Cape May | <input type="checkbox"/> Hudson | <input type="checkbox"/> Monmouth | <input type="checkbox"/> Salem | <input type="checkbox"/> Warren |
| <input type="checkbox"/> Bergen | <input type="checkbox"/> Cumberland | <input type="checkbox"/> Hunterdon | <input type="checkbox"/> Morris | <input type="checkbox"/> Somerset | |
| <input type="checkbox"/> Burlington | <input type="checkbox"/> Essex | <input type="checkbox"/> Mercer | <input type="checkbox"/> Ocean | <input type="checkbox"/> Sussex | |
| <input type="checkbox"/> Camden | <input type="checkbox"/> Gloucester | <input type="checkbox"/> Middlesex | <input type="checkbox"/> Passaic | <input type="checkbox"/> Union | |

12. Which of the following **best** describes your current living situation? Check only 1 response

- House/condominium (owned by you or a family member)
- House or Apartment (rented)
- Hotel/motel
- Supervised Apartment
- Transitional Living Program (prep for independent living)
- Boarding House
- Group Home
- Rehabilitation Facility
- Hospital
- Assisted Living
- Nursing Home
- Another Place (Specify) : _____

13. With whom do you currently live? Check all that apply

- Alone (if selected, no multi-record)
- Spouse/Partner
- Parents
- Minor children
- Adult children
- Brother/sister
- Friend
- Other family member(s)
- Other non-related roommate(s)
- Other non-related patient(s)
- Other (Specify): _____

14. Are you happy with your living arrangement?

- Yes No

15. Why do you feel this way? _____

16. Do you worry about where you will live in the future?

- Yes No

17. Does your family worry about where you will live in the future?

- Yes No Not Sure

18. Overall, is your transportation reliable and accessible?

Yes No. Why not? _____

19. How do you travel from place-to-place on a daily basis for medical or non-medical reasons? Check all that apply

- | | |
|---|---|
| <input type="checkbox"/> Drive myself | <input type="checkbox"/> Public transportation |
| <input type="checkbox"/> Ride with other family | <input type="checkbox"/> Taxi |
| <input type="checkbox"/> Ride with other non-family | <input type="checkbox"/> Walk |
| <input type="checkbox"/> Access Link | <input type="checkbox"/> Bike |
| <input type="checkbox"/> Medical transportation service | <input type="checkbox"/> Other (Specify): _____ |

20. What is your gender?

Male Female

21. What is your date of birth?

| | | | | | | | | | | | | | | | | | | | | | | | | | |
|--|--|-------------|--------------|-----------|-----------|---------|----------|----------|------------|---------------|--------------|---------------|---------------|-----------------|------|--|---|-----------|----|--|-------|---|------|-----------|------|
| Month: | <table border="1"><tr><td>1 – January</td></tr><tr><td>2 – February</td></tr><tr><td>3 – March</td></tr><tr><td>4 – April</td></tr><tr><td>5 – May</td></tr><tr><td>6 – June</td></tr><tr><td>7 – July</td></tr><tr><td>8 – August</td></tr><tr><td>9 – September</td></tr><tr><td>10 – October</td></tr><tr><td>11 – November</td></tr><tr><td>12 – December</td></tr><tr><td>99 – Don't Know</td></tr></table> | 1 – January | 2 – February | 3 – March | 4 – April | 5 – May | 6 – June | 7 – July | 8 – August | 9 – September | 10 – October | 11 – November | 12 – December | 99 – Don't Know | Day: | <table border="1"><tr><td>1</td></tr><tr><td>-through-</td></tr><tr><td>31</td></tr><tr><td><i>(# of days should correspond to "Month" selected)</i></td></tr></table> | 1 | -through- | 31 | <i>(# of days should correspond to "Month" selected)</i> | Year: | <table border="1"><tr><td>1992</td></tr><tr><td>-through-</td></tr><tr><td>1900</td></tr></table> | 1992 | -through- | 1900 |
| 1 – January | | | | | | | | | | | | | | | | | | | | | | | | | |
| 2 – February | | | | | | | | | | | | | | | | | | | | | | | | | |
| 3 – March | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 – April | | | | | | | | | | | | | | | | | | | | | | | | | |
| 5 – May | | | | | | | | | | | | | | | | | | | | | | | | | |
| 6 – June | | | | | | | | | | | | | | | | | | | | | | | | | |
| 7 – July | | | | | | | | | | | | | | | | | | | | | | | | | |
| 8 – August | | | | | | | | | | | | | | | | | | | | | | | | | |
| 9 – September | | | | | | | | | | | | | | | | | | | | | | | | | |
| 10 – October | | | | | | | | | | | | | | | | | | | | | | | | | |
| 11 – November | | | | | | | | | | | | | | | | | | | | | | | | | |
| 12 – December | | | | | | | | | | | | | | | | | | | | | | | | | |
| 99 – Don't Know | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | | | | | | | | | | | | | | | | | | | | | | | | | |
| -through- | | | | | | | | | | | | | | | | | | | | | | | | | |
| 31 | | | | | | | | | | | | | | | | | | | | | | | | | |
| <i>(# of days should correspond to "Month" selected)</i> | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1992 | | | | | | | | | | | | | | | | | | | | | | | | | |
| -through- | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1900 | | | | | | | | | | | | | | | | | | | | | | | | | |

22. Which ethnic category best describes you?

- | | |
|--|---|
| <input type="checkbox"/> Hispanic | <input type="checkbox"/> Asian/Pacific Islander |
| <input type="checkbox"/> White, Non-Hispanic | <input type="checkbox"/> Native American |
| <input type="checkbox"/> Black, Non-Hispanic | <input type="checkbox"/> Other (Specify): _____ |

23. How are your health care costs paid? Check all that apply

- | | |
|--|---|
| <input type="checkbox"/> Private Insurance | <input type="checkbox"/> TBI Fund |
| <input type="checkbox"/> Medicaid, including waiver programs | <input type="checkbox"/> Personal Injury Protection (i.e. automobile insurance) |
| <input type="checkbox"/> Medicare | <input type="checkbox"/> Charity Care |
| <input type="checkbox"/> NJ FamilyCare | <input type="radio"/> No coverage <i>(if selected, no multi-record)</i> |
| <input type="checkbox"/> Medigap | <input type="checkbox"/> Other (Specify): _____ |

24. Is your health coverage sufficient for those needs related to your brain injury?

Yes No. Why not? _____

25. Please describe your employment situation, both now and before your injury. Check only 1 response per column.

| | <u>Now</u> | <u>Before Injury</u> |
|------------------------------|--------------------------|--------------------------|
| Employed full-time | <input type="checkbox"/> | <input type="checkbox"/> |
| Employed part-time | <input type="checkbox"/> | <input type="checkbox"/> |
| Supported employment | <input type="checkbox"/> | <input type="checkbox"/> |
| Volunteer | <input type="checkbox"/> | <input type="checkbox"/> |
| Unemployed, looking for work | <input type="checkbox"/> | <input type="checkbox"/> |
| Unemployed, not able to work | <input type="checkbox"/> | <input type="checkbox"/> |
| Homemaker | <input type="checkbox"/> | <input type="checkbox"/> |
| Retired | <input type="checkbox"/> | <input type="checkbox"/> |
| Student | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (Specify): _____ | <input type="checkbox"/> | |
| Other (Specify): _____ | | <input type="checkbox"/> |

26. Please indicate if your injury has changed the following areas of your life?

27. How happy are you with this area of your life? For each item, please select the answer that best applies.

| | <u>Yes</u> | <u>No</u> | <u>Very Unhappy</u> | <u>Somewhat Unhappy</u> | <u>Neither Happy nor Unhappy</u> | <u>Somewhat Happy</u> | <u>Very Happy</u> | <u>Not Applicable</u> |
|-----------------------------------|--------------------------|--------------------------|-----------------------|-------------------------|----------------------------------|-----------------------|-----------------------|-----------------------|
| a. Employment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |
| b. Emotional well-being? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |
| c. Family relationships? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |
| d. Income? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |
| e. Leisure/recreation activities? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |

| | | | | | | | | |
|-----------------------------|--------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|----|
| f. Living situation? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |
| g. Marriage/partnership? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |
| h. Overall physical health? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |
| i. Social relationships? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |
| j. Other? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | NA |

Section D. These questions ask about help that you may be receiving from other people.

28. Do you receive help from a family member or friend to take care of your personal needs or household chores? This person does NOT need to live with you.

Yes

No

Survey is now Complete; Do NOT answer remaining questions

29. With which of the following activities do you receive help from a family member or friend? Check all that apply

Bathing/showering

Shopping for personal items

Dressing

Making appointments

Eating

Using the telephone

Getting in or out of bed or chairs

Preparing for meals

Walking

Managing money

Using the toilet

Recreational/social activities

Managing medications

Other (Specify): _____

Doing housework

30. Who helps you most of the time with this activity or these activities? Check all that apply

Parent(s)

Other family member(s)

Spouse/Partner

Roommate(s)/Friend(s)

Minor child(ren)

Paid professional(s)

Adult child(ren)

Volunteer(s)

Brother(s)/Sister(s)

Other (Specify): _____

31. For how long have you been receiving help with any of these activities? Your best estimate is fine.

(Please answer in weeks, months, and/or years)

| | | | |
|--------|--------------------------------|---------|---------------------------------|
| Weeks: | <input type="text" value="0"/> | Months: | <input type="text" value="0"/> |
| | <input type="text" value="1"/> | | <input type="text" value="1"/> |
| | <input type="text" value="2"/> | | <input type="text" value="2"/> |
| | <input type="text" value="3"/> | | <input type="text" value="3"/> |
| | | | <input type="text" value="4"/> |
| | | | <input type="text" value="5"/> |
| | | | <input type="text" value="6"/> |
| | | | <input type="text" value="7"/> |
| | | | <input type="text" value="8"/> |
| | | | <input type="text" value="9"/> |
| | | | <input type="text" value="10"/> |
| | | | <input type="text" value="11"/> |

Years:

(Show error message if 1 or more NOT answered, or if ALL are answered as "0")

32. Do you receive help from a family member or friend at least every week for any of these activities?

Yes No

33. Are you happy with the help that you receive?

Yes

No. Why Not? _____

33a. If you have a brain injury, then do NOT complete the next section.

This next section is only to be completed by the family member or friend that you previously indicated provides you with help.

If that person is available now, please have them complete this next section. If that person is NOT available, or you do NOT have someone who helps you, then please select the appropriate answer below.

- 1 = Yes, that person IS available
- 2 = No, that person is NOT available / I do NOT receive help

(If Q33a=1, ask Q34 and Q35. Else skip to Closing)

34. Where do you go for social/emotional support? Check all that apply

- Family
- Friends
- Support group
- Religious organization
- Organized club/group
- Other person(s) who have a family member with a brain injury
- Online care-giving website
- Other (Specify): _____

I do NOT need support (if selected, no multi-record)

I need support, but NOT currently receiving any. Why not? (if selected, no multi-record) _____

35. What services do you need related to your family member's brain injury? Check all that apply

- Advocacy
 - Respite
 - Counseling
 - Information about resources
 - Other (Specify): _____
- I do NOT need any services *(if selected, no multi-record)*

Closing 1

The survey is now complete. If you need to go back to review or change any or your answers, you may do so by using the "<<" button below. Otherwise, please click the ">>" button to continue.

Closing 2

Thank you very much for your time. Your participation will help to shape new programs and services for the brain injury community in New Jersey.

After clicking OK you will be redirected back to the survey home page. You may close your browser at that point.

Encuesta de New Jersey de Personas con Lesión Cerebral Traumática y sus Familias

Please select your language preference:

- English
 Spanish

Si usted necesita parar la encuesta en cualquier momento para terminarla alguna otra vez o pierde la conexión de internet puede empezarla de Nuevo donde paro, simplemente regresando a la pagina de internet (i.e. - www.NJ-TBI-Assessment.com) y entrando su numero de pin de nuevo.

1. ¿Está llenando esta encuesta sin ayuda la persona que ha sufrido una lesión cerebral?

No, otra persona está proporcionando ayuda

Sí

Ahora vaya a la pregunta 4

2. ¿Quién está ayudando con esta encuesta?

- Cónyuge
 Hermano/hermana
 Padres
 Hijo/Hija
 Pareja
 Otro familiar
 Otra persona no familiar (Especifique): _____

3. ¿Qué tipo de ayuda está proporcionando?
Marque todos los aplicables

- Leyó preguntas
 Anotó respuestas
 Tradujo preguntas al idioma de la persona
 Contestó preguntas
 Otro tipo de ayuda (Especifique): _____

NOTA: Si usted está proporcionando ayuda para llenar esta encuesta, sírvase contestar las preguntas desde el punto de vista de la persona con lesión cerebral traumática a la cual usted está ayudando.

Sección A. Esta sección pide información acerca de su lesión o lesiones.

4. ¿Cuántas lesiones cerebrales ha sufrido?

- Una Dos Tres Cuatro Más de cuatro

5. ¿Ocurrió su lesión cerebral (o CUALQUIERA de sus lesiones cerebrales) durante el servicio militar?

- Sí No

6. Sírvase indicar el mes y año en el cual ocurrió su lesión cerebral. Si sufrió más de 1 lesión cerebral, conteste acerca de su PRIMERA lesión cerebral.

Mes:

- 1 – Enero
2 – Febrero
3 – Marzo
4 – Abril
5 – Mayo
6 – Junio
7 – Julio
8 – Agosto
9 – Septiembre
10 – Octubre
11 – Noviembre
12 – Diciembre
99 – No está seguro

Año:

- 2008
- through -
1900

No está seguro - 9999

6a. ¿Fue a la Sala de Emergencias como resultado de esta lesión?

- Sí No

6b. ¿Ingresó en el hospital como resultado de esta lesión?

- Sí No

7. ¿Cómo sufrió su lesión (o lesiones) cerebrales? Marque todos los aplicables

- | | |
|---|---|
| <input type="checkbox"/> Choque de automóvil | <input type="checkbox"/> Casi ahogado |
| <input type="checkbox"/> Choque de motocicleta | <input type="checkbox"/> Caída |
| <input type="checkbox"/> Choque de bicicleta | <input type="checkbox"/> Asalto/abuso |
| <input type="checkbox"/> Accidente de peatón | <input type="checkbox"/> Armas de fuego/tiro de arma de fuego |
| <input type="checkbox"/> Apoplejía, aneurisma/ruptura AVM | <input type="checkbox"/> Lesión deportiva |
| <input type="checkbox"/> Anoxia (falta de oxígeno) | <input type="checkbox"/> Intento de suicidio |
| <input type="checkbox"/> Tumor o remoción de tumor | <input type="checkbox"/> Envenenamiento, sobredosis |
| <input type="checkbox"/> Enfermedad (meningitis, Lyme, encefalitis, etc.) | |
| <input type="checkbox"/> Otro (Especifique): _____ | |

8. ¿Considera que tiene una lesión cerebral ligero, moderada o severa?

- Ligero
 Moderada
 Severa
 No está seguro/no sabe

Sección B. Esta sección trata de los distintos servicios que usted puede o no estar recibiendo en su situación actual.

| 9a. ¿Necesita este servicio? | | | 9b. Si necesita este servicio ... ¿lo está recibiendo actualmente? | | | | |
|--|--------------------------|--------------------------|--|--------------------------------------|---|---|-----------------------------|
| | <u>No</u> | <u>Sí</u> | <u>Sí,...(marque 1 solamente)</u> | | <u>No, porque...(Marque todos los aplicables)</u> | | |
| | | | ...y satisface mis necesidades | ...pero NO satisface mis necesidades | ...NO está disponible/accesible | ...no hay financiación / no puedo costéarmelo | ...debido otro(s) motivo(s) |
| <u>Servicios Médicos/Terapéuticos</u> | | | | | | | |
| a. Cuidado de enfermería | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Consejería individual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Consejería familiar, capacitación o educación | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Psicología o servicios de psiquiatría | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Terapias alternativas (acupuntura, terapias de masajes, terapia acuática, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Servicios de la visión que abordan los efectos de su lesión | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Servicios médicos que abordan los efectos de su lesión | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Agentes farmacéuticos (medicamentos y/o copagos, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Servicios Dentales | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Abuso de sustancias (programas de adicción, grupos de apoyo de iguales, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <u>Servicios de Rehabilitación</u> | | | | | | | |
| k. Rehabilitación de paciente ingresado (es decir, terapias que recibe mientras permanece en un hospital) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. Terapia del habla | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. Capacitación cognitiva (es decir, capacitación de su cerebro para mejorar las destrezas de la vida diaria) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n. Terapia ocupacional o fisioterapia | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o. Administración de caso/coordinación de servicios (es decir, alguien trabaja con usted para coordinar los servicios que necesita) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| p. Servicios de apoyo del comportamiento (es decir, aprender maneras de reducir o evitar comportamientos indeseados) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| q. Servicios tecnológicos coadyuvantes (un dispositivo que le ayuda a hablar, grabador para la memoria, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| r. Equipos médicos duraderos (silla de ruedas, escúter, silla de ducha, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| 9a. ¿Necesita este servicio? | | | 9b. Si necesita este servicio...¿lo está recibiendo actualmente? | | | | |
|--|--------------------------|--------------------------|--|--------------------------------------|---|---|-------------------------------|
| | <u>No</u> | <u>Sí</u> | <u>Sí,...(marque 1 solamente)</u> | | <u>No, porque...(Marque todos los aplicables)</u> | | |
| | | | ...y satisface mis necesidades | ...pero NO satisface mis necesidades | ...NO está disponible/ accesible | ...no hay financiación / no puedo costearlo | ...debido a otro(s) motivo(s) |
| <u>Servicios de Educación/Empleo</u> | | | | | | | |
| s. Apoyos de aprendizaje (para estudiantes hasta terminar secundaria) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| t. Apoyos de aprendizaje (para estudiantes después de secundaria, costos de enseñanza, libros relacionados y cargos, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| u. Ayuda para obtener un empleo | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| v. Ayuda para conservar un empleo (instructor de trabajo, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <u>Apoyo de la Vida Comunitaria</u> | | | | | | | |
| w. Apoyo de cuidado en el hogar (cuidado de la salud en el hogar, ayuda para bañarse y vestirse, ayuda con quehaceres domésticas, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| x. Ayuda de vivienda (depósito de garantía, costos de mudanza, ayuda de alquiler, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| y. Ayuda con modificaciones en el hogar (rampas, modificaciones de accesibilidad de cuarto de baño, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| z. Ayuda de albergue de emergencia | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| aa. Cuidado de descanso de cuidador (p. ej., cuidado temporal para que descanse el cuidador) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| bb. Capacitación de destrezas comunitarias (es decir, aprender de nuevo destrezas para usar en lugares públicos) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| cc. Capacitación de destrezas sociales (es decir, cómo desenvolverse con otras personas) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| dd. Capacitación de administración del dinero y presupuestos | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| ee. Ayuda de transporte | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

El Fondo de Lesiones Cerebrales Traumáticas (sigla en inglés, TBI) tiene por finalidad permitir a los residentes de New Jersey que han sobrevivido una lesión cerebral adquirida a obtener la ayuda que necesitan para vivir en la comunidad.

10. ¿Ha sometido alguna vez una solicitud al Fondo TBI? Sí No

Sección C. Esta sección plantea preguntas acerca de usted.

11. ¿En qué condado reside?

- | | | | | | |
|-------------------------------------|-------------------------------------|------------------------------------|-----------------------------------|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Atlantic | <input type="checkbox"/> Cape May | <input type="checkbox"/> Hudson | <input type="checkbox"/> Monmouth | <input type="checkbox"/> Salem | <input type="checkbox"/> Warren |
| <input type="checkbox"/> Bergen | <input type="checkbox"/> Cumberland | <input type="checkbox"/> Hunterdon | <input type="checkbox"/> Morris | <input type="checkbox"/> Somerset | |
| <input type="checkbox"/> Burlington | <input type="checkbox"/> Essex | <input type="checkbox"/> Mercer | <input type="checkbox"/> Ocean | <input type="checkbox"/> Sussex | |
| <input type="checkbox"/> Camden | <input type="checkbox"/> Gloucester | <input type="checkbox"/> Middlesex | <input type="checkbox"/> Passaic | <input type="checkbox"/> Union | |

12. ¿Cuál de los siguientes **mejor** describe su situación de vivienda actual? Marque 1 sola respuesta

- Casa/condominio (propiedad suya o de un familiar)
- Casa o apartamento (alquilado)
- Hotel/motel
- Apartamento supervisado
- Programa de Vivienda Transicional (preparación para vida independiente)
- Pensión
- Residencia colectiva
- Centro de rehabilitación
- Hospital
- Residencia con Servicios de Ayuda
- Sanatorio especializado
- Otro lugar (Especifique): _____

13. ¿Con quién vive actualmente? Marque todos los aplicables

- Solo *(if selected, no multi-record)*
- Cónyuge/pareja
- Padres
- Hijos menores
- Hijos mayores
- Hermano/Hermana
- Amistad
- Otro(s) familiar(es)
- Otro(s) compañero(s) de vivienda sin parentesco
- Otro(s) paciente(s) sin parentesco
- Otro (Especifique): _____

14. ¿Está satisfecho con su situación de vivienda?

- Sí No

15. ¿Por qué se siente así? _____

16. ¿Se preocupa acerca de dónde vivirá en el futuro?

- Sí No

17. ¿Se preocupa su familia acerca de dónde vivirá en el futuro?

- Sí No No está seguro

18. En general, ¿es su transporte confiable y accesible?

- Sí No. ¿Por qué no? _____

19. ¿Cómo viaja de un lugar a otro diariamente por motivos médicos y no médicos? Marque todos los aplicables

- | | |
|--|--|
| <input type="checkbox"/> Manejo yo mismo | <input type="checkbox"/> Transporte público |
| <input type="checkbox"/> Viajo con otro familiar | <input type="checkbox"/> Taxi |
| <input type="checkbox"/> Viajo con una persona no familiar | <input type="checkbox"/> Caminando |
| <input type="checkbox"/> Access Link | <input type="checkbox"/> Bicicleta |
| <input type="checkbox"/> Servicio de transporte médico | <input type="checkbox"/> Otro (Especifique): _____ |

20. ¿De qué sexo es usted?

- Hombre Mujer

21. ¿Cuál es su fecha de nacimiento?

| | | | | | | | | | | | | | | | | | | | | | | | | | |
|--|---|-----------|-------------|-----------|-----------|----------|-----------|-----------|------------|----------------|--------------|----------------|----------------|---------------------|------|--|---|-----------|----|--|------|---|------|-----------|------|
| Mes: | <table border="1"><tr><td>1 – Enero</td></tr><tr><td>2 – Febrero</td></tr><tr><td>3 – Marzo</td></tr><tr><td>4 – Abril</td></tr><tr><td>5 – Mayo</td></tr><tr><td>6 – Junio</td></tr><tr><td>7 – Julio</td></tr><tr><td>8 – Agosto</td></tr><tr><td>9 – Septiembre</td></tr><tr><td>10 – Octubre</td></tr><tr><td>11 – Noviembre</td></tr><tr><td>12 – Diciembre</td></tr><tr><td>99 – No está seguro</td></tr></table> | 1 – Enero | 2 – Febrero | 3 – Marzo | 4 – Abril | 5 – Mayo | 6 – Junio | 7 – Julio | 8 – Agosto | 9 – Septiembre | 10 – Octubre | 11 – Noviembre | 12 – Diciembre | 99 – No está seguro | Día: | <table border="1"><tr><td>1</td></tr><tr><td>-through-</td></tr><tr><td>31</td></tr><tr><td><i>(# of days should correspond to "Month" selected)</i></td></tr></table> | 1 | -through- | 31 | <i>(# of days should correspond to "Month" selected)</i> | Año: | <table border="1"><tr><td>1992</td></tr><tr><td>-through-</td></tr><tr><td>1900</td></tr></table> | 1992 | -through- | 1900 |
| 1 – Enero | | | | | | | | | | | | | | | | | | | | | | | | | |
| 2 – Febrero | | | | | | | | | | | | | | | | | | | | | | | | | |
| 3 – Marzo | | | | | | | | | | | | | | | | | | | | | | | | | |
| 4 – Abril | | | | | | | | | | | | | | | | | | | | | | | | | |
| 5 – Mayo | | | | | | | | | | | | | | | | | | | | | | | | | |
| 6 – Junio | | | | | | | | | | | | | | | | | | | | | | | | | |
| 7 – Julio | | | | | | | | | | | | | | | | | | | | | | | | | |
| 8 – Agosto | | | | | | | | | | | | | | | | | | | | | | | | | |
| 9 – Septiembre | | | | | | | | | | | | | | | | | | | | | | | | | |
| 10 – Octubre | | | | | | | | | | | | | | | | | | | | | | | | | |
| 11 – Noviembre | | | | | | | | | | | | | | | | | | | | | | | | | |
| 12 – Diciembre | | | | | | | | | | | | | | | | | | | | | | | | | |
| 99 – No está seguro | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | | | | | | | | | | | | | | | | | | | | | | | | | |
| -through- | | | | | | | | | | | | | | | | | | | | | | | | | |
| 31 | | | | | | | | | | | | | | | | | | | | | | | | | |
| <i>(# of days should correspond to "Month" selected)</i> | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1992 | | | | | | | | | | | | | | | | | | | | | | | | | |
| -through- | | | | | | | | | | | | | | | | | | | | | | | | | |
| 1900 | | | | | | | | | | | | | | | | | | | | | | | | | |

22. ¿Cuál categoría étnica mejor le describe?

- | | |
|---|---|
| <input type="checkbox"/> Hispano | <input type="checkbox"/> Asiático/Isleño del Pacífico |
| <input type="checkbox"/> Blanco, no hispano | <input type="checkbox"/> Americano nativo |
| <input type="checkbox"/> Negro, no hispano | <input type="checkbox"/> Otro (Especifique): _____ |

23. ¿Cómo se pagan sus costos de atención médica? Marque todos los aplicables

- | | |
|--|--|
| <input type="checkbox"/> Seguro privado | <input type="checkbox"/> Fondo TBI |
| <input type="checkbox"/> Medicaid, inclusive programas de exención | <input type="checkbox"/> Protección de Lesión Personal (es decir, seguro de automóvil) |
| <input type="checkbox"/> Medicare | <input type="checkbox"/> Cuidado de caridad |
| <input type="checkbox"/> NJ FamilyCare | <input type="radio"/> Sin cobertura <i>(if selected, no multi-record)</i> |
| <input type="checkbox"/> Medigap | <input type="checkbox"/> Otro (Especifique): _____ |

24. ¿Es su cobertura médica suficiente para aquellas necesidades relacionadas con su lesión cerebral?

Sí No. ¿Por qué no? _____

25. Sírvase describir su situación de empleo, tanto ahora como antes de su lesión. Marque 1 sola respuesta por columna

| | <u>Ahora</u> | <u>Antes de la lesión</u> |
|--------------------------------|--------------------------|-------------------------------|
| Empleado a tiempo completo | <input type="checkbox"/> | <input type="checkbox"/> |
| Empleado a tiempo parcial | <input type="checkbox"/> | <input type="checkbox"/> |
| Empleo con apoyo | <input type="checkbox"/> | <input type="checkbox"/> |
| Voluntario | <input type="checkbox"/> | <input type="checkbox"/> |
| Desempleado, busca trabajo | <input type="checkbox"/> | <input type="checkbox"/> |
| Desempleado, no puede trabajar | <input type="checkbox"/> | <input type="checkbox"/> |
| Ama de casa | <input type="checkbox"/> | <input type="checkbox"/> |
| Jubilado | <input type="checkbox"/> | <input type="checkbox"/> |
| Estudiante | <input type="checkbox"/> | <input type="checkbox"/> |
| Otro (Especifique): _____ | <input type="checkbox"/> | |
| Otro (Especifique): _____ | | <input type="checkbox"/> |

| 26. Sírvase indicar si su lesión ha cambiado los siguientes aspectos de su vida? | | | 27. ¿En qué medida está contento con este aspecto de su vida? Para <u>cada</u> renglón, por favor, seleccione la respuesta que <u>mejor se aplique</u> . | | | | | |
|--|--------------------------|--------------------------|--|-----------------------|----------------------------------|-----------------------|-----------------------|-----------------------|
| | Sí | No | Muy descontento | Algo descontento | Ni contento ni descontento | Algo contento | Muy contento | No aplica |
| a. ¿Empleo? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. ¿Bienestar emocional? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. ¿Relaciones familiares? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. ¿Ingresos? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. ¿Actividades de esparcimiento / recreación? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. ¿Situación de vivienda? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. ¿Matrimonio/relación? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h. ¿Estado de salud físico general ? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| i. ¿Relaciones sociales? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| j. ¿Otro? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Sección D. Estas preguntas piden información acerca de la ayuda que podrá estar recibiendo de otras personas.

28. ¿Recibe ayuda de un familiar o amistad para atender a sus necesidades personales o quehaceres domésticos. Esta persona NO tiene que vivir con usted.

Sí

No

La encuesta está completa hora; NO conteste las demás preguntas

29. ¿Con cuáles de las siguientes actividades recibe ayuda de un familiar o amistad? Marque todos los aplicables

Bañarse/ ducharse

Compras de artículos personales

Vestirse

Hacer citas

Comer

Usar el teléfono

Subirse o levantarse de la cama o de sillas

Preparar comidas

Caminar

Administrar dinero

Usar el inodoro

Actividades recreacionales/sociales

Manejar los medicamentos

Otro (Especifique): _____

Quehaceres domésticos

30. ¿Quién le ayuda la mayor parte del tiempo con esta actividad o estas actividades? Marque todos los aplicables

- | | |
|--|---|
| <input type="checkbox"/> Padres | <input type="checkbox"/> Otro(s) familiar(es) |
| <input type="checkbox"/> Cónyuge/Pareja | <input type="checkbox"/> Compañero(s) de vivienda/Amistad(es) |
| <input type="checkbox"/> Hijo(s) menor(es) | <input type="checkbox"/> Profesional(es) pagado(s) |
| <input type="checkbox"/> Hijo(s) adulto(s) | <input type="checkbox"/> Voluntario(s) |
| <input type="checkbox"/> Hermano(s)/Hermana(s) | <input type="checkbox"/> Otro (Especifique): _____ |

31. ¿Desde hace cuánto tiempo ha estado recibiendo ayuda con cualquiera de estas actividades? Su mejor estimado será suficiente.

(Sírvase contestar en semanas, meses y/o años)

| | | | |
|--------|--|---------|--|
| Weeks: | <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> | Months: | <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> <input type="text" value="11"/> |
| Years: | <input type="text" value="0"/> -through- <input type="text" value="99"/> | | |

(Show error message if 1 or more NOT answered, or if ALL are answered as "0")

32. ¿Recibe ayuda de un familiar o amistad por lo menos cada semana para cualquiera de estas actividades?

- Sí No

33. ¿Está contento con la ayuda que recibe?

- Sí
- No. ¿Por qué no? _____

33a. Su usted sufre de una lesión cerebral, pues NO complete la próxima sección.

Esta próxima sección debería completarse por parte del familiar o amigo que usted previamente indicó que le ayuda.

Si esa persona está disponible en este momento, por favor, haga que le completen esta sección . Si esa persona NO está disponible, o usted NO tiene a alguien que le ayuda, pues, sírvase seleccionar la respuesta correspondiente abajo.

1 = Sí, esa persona ESTÁ disponible

2 = No, esa persona NO ESTÁ disponible / NO recibo ayuda

(If Q33a=1, ask Q34 and Q35. Else skip to Closing)

34. ¿A dónde acude usted para apoyo social/emocional? Marque todos los aplicables

- Familia
 - Amistades
 - Grupo de apoyo
 - Organización religiosa
 - Club/grupo organizado
 - Otra(s) persona(s) que tienen un familiar con una lesión cerebral
 - Sitio de Internet de cuidado en línea
 - Otro (Especifique): _____
- NO necesito apoyo *(if selected, no multi-record)*
- Necesito apoyo pero NO lo estoy recibiendo actualmente. ¿Por qué no? *(if selected, no multi-record)*
- _____

35. ¿Cuáles servicios necesita relacionados con la lesión cerebral de su familiar? Marque todos los aplicables

- Representación
 - Descanso
 - Consejería
 - Información acerca de recursos
 - Otro (Especifique): _____
- NO necesito ningún servicio *(if selected, no multi-record)*

Closing 1

La encuesta ha terminado. Si necesita cambiar o ver sus respuestas de nuevo, puede hacerlo simplemente usando el boton "<<" que se encuentra abajo o simplemente usando el ">>" boton para continuar.

Closing 2

Muchas gracias por su tiempo. Su participación nos ayudará a configurar a programas y servicios nuevos para la comunidad que sufre de lesiones cerebrales en Nueva Jersey.

Despuès de que èntres OK va reqresar à là paina donde emperó la encuesta. Puede cerrar esa pagina.

Appendix B



State of New Jersey

DEPARTMENT OF HUMAN SERVICES
PO Box 700
TRENTON, NJ 08625-0700

JON S. CORZINE
Governor

DIVISION OF DISABILITY SERVICES

JENNIFER VELEZ
Commissioner

WILLIAM A. B. DITTO
Director
609-292-7800

December 2007

Dear Colleague:

The Division of Disability Services (DDS) has received a multi-year Traumatic Brain Injury (TBI) Grant from the federal Health Resources and Services Administration (HRSA) in order to develop and strengthen the infrastructure of brain injury services. DDS is the designated lead agency in New Jersey for brain injury services and is responsible for administration of the TBI Medicaid Waiver and the TBI Fund.

The objective of the TBI Grant program is to create a coordinated and responsive system of services and supports. As part of this project, DDS will be conducting focus groups and consulting with experts to assess gaps in supports and services available to people with brain injury. In addition, DDS has contracted with the Rutgers Center for State Health Policy to conduct surveys of state agencies, service providers and individuals with TBI and their families. This information will allow us to look critically at the State's TBI system, in order to analyze what services are currently available and what the unmet needs are of individuals with TBI in New Jersey.

As part of this project, we are asking your organization to complete the attached survey. It is critical that we gather complete and accurate information about each organization in order to identify services and supports available to people with brain injury. Your organization's responses will be used to assess the overall system of supports and services in New Jersey, but information in our report will be summarized across all organizations and your information will not be identified individually.

If you prefer to use an electronic copy of the survey, please go to www.cshp.rutgers.edu/tbi. If you have questions about this survey, please feel free to contact me at (609) 292-7800.

If you have any questions about your rights as a research subject, you may contact the Sponsored Programs Administrator at Rutgers University at (732) 932-0150 ext. 2104 or by email at humansubjects@orsp.rutgers.edu.

We thank you in advance for your participation in this important survey. **To allow us to complete our assessment promptly, please return the survey no later than Friday, January 25, 2008.**

Sincerely,

William A. B. Ditto
Director

WABD:kw
Enclosure



Rutgers Center for State Health Policy

The Institute for Health, Health Care Policy and Aging Research

February 11, 2008

Dear Colleague,

A few weeks ago you were mailed a Traumatic Brain Injury Survey seeking information about your organization in order to identify services and supports available to people with brain injury in New Jersey. Rutgers Center for State Health Policy is conducting surveys of state agencies, services providers and individuals with TBI and their families. This information will allow us to look critically at the State's TBI system, in order to analyze what services are currently available and what the unmet needs are of individuals with TBI in New Jersey.

As of yet we have not received a response from your organization. To ensure that this study accurately attains information of the State's TBI system, it is important that your organization completes and returns the TBI Survey. No specific information will be disclosed about any organization in our report.

If you have already completed and returned the survey, please accept our sincere thanks. If not, please use the enclosed survey to do so at your earliest convenience. You can also access an electronic version of the survey online at <http://www.cshp.rutgers.edu/tbi> Thank you for your cooperation.

Sincerely,

Dorothy Gaboda, MSW, Ph.D.
Associate Director for Data Analysis

Enclosures

Rutgers, The State University of New Jersey
55 Commercial Avenue, 3rd Floor
New Brunswick, New Jersey 08901-1340
T. 732.932.3105
732.932.0069
www.cshp.rutgers.edu

New Jersey State Agency Survey of TBI Services and Support

Traumatic brain injury means an acquired injury to the brain. It may include injuries due to trauma, aneurysm rupture, stroke, tumor or tumor removal, infection or anoxic brain injury. This term does not include brain dysfunction caused by congenital (e.g., cerebral palsy) or degenerative disorders (e.g., multiple sclerosis, Alzheimer's) or injuries due to birth trauma.

NOTE: If you have questions, please contact Dorothy Gaboda at dgaboda@ifh.rutgers.edu or 732-932-4678.

Date _____

Name of Agency _____

Division/Department/Program _____

Contact Person _____

Title _____

Mailing Address _____

City _____ State _____ Zip Code _____

Phone _____ Fax _____

E-mail _____

Home page _____

Section A. We would like to begin by asking some background questions about your State agency and the clients you serve. Please indicate your answer by placing a check or number in the space provided.

| | |
|---|---|
| <p>1. What was the total number of individuals served (or services funded for) by your State agency from July 1, 2006 through June 30, 2007?</p> <p>NOTE: If you use a different fiscal or reporting year for questions 1, 2a-c, and 5a, please note the dates for which you are reporting.</p> | <p style="text-align: center;">(fill in number)</p> <p style="text-align: center;">Is this value: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> <p>Dates for which information is reported: to _____ .</p> |
| <p>2. Does your data system include a field that identifies whether an individual has a TBI?</p> | <p><input type="checkbox"/> No. <input type="checkbox"/> Yes.</p> |
| <p>2a. If so, what was the total number of individuals served by your organization from July 1, 2006 through June 30, 2007 who had a diagnosis of traumatic brain injury?</p> | <p style="text-align: center;">(fill in number)</p> <p style="text-align: center;">Is this value: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> |
| <p>2b. Indicate the total number of individuals with TBI served by your organization from July 1, 2006 through June 30, 2007 for each racial/ethnic category.</p> | <p>Asian</p> <p>Black, Non Hispanic</p> <p>Hispanic</p> <p>Native American</p> <p>White, Non-Hispanic</p> <p>Unknown</p> <p>Other (please specify): _____</p> <p>Are these values: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> |
| <p>2c. Indicate the total number of individuals with TBI served by your organization from July 1, 2006 through June 30, 2007 for each gender category.</p> | <p>Female</p> <p>Male</p> <p>Are these values: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> |

Section B. The following section asks questions about the services that your State agency funds/provides. Please indicate your answer by placing a check in the appropriate box.

| | |
|---|---|
| <p>3. How are referrals for TBI services received by your organization? (Check all that apply)</p> | <input type="checkbox"/> Area Agencies on Aging <input type="checkbox"/> Brain Injury Association of New Jersey (BIANJ) or other non-profit organization <input type="checkbox"/> County Offices on Disability <input type="checkbox"/> County Social Services <input type="checkbox"/> Division of Disability Services (DDS) <input type="checkbox"/> Division of Vocational Rehabilitation (DVR) <input type="checkbox"/> Division of Children and Families (formerly DYFS) <input type="checkbox"/> Education System <input type="checkbox"/> Hospitals <input type="checkbox"/> Person with TBI or family/caregiver <input type="checkbox"/> Professionals (physicians, counselors, etc.) <input type="checkbox"/> Protection & Advocacy <input type="checkbox"/> Rehabilitation facilities <input type="checkbox"/> Special Child Health Services <input type="checkbox"/> State agencies (other than DVR) <input type="checkbox"/> Other. Please specify: <input type="checkbox"/> Don't know |
| <p>4. Does your organization have programs specific to individuals with TBI?</p> | <input type="checkbox"/> No <input type="checkbox"/> Yes, for adults (18 years of age and older) <input type="checkbox"/> Yes, for both children and adults |
| <p>5. Does your State agency have a case management or service coordination program that serves people with TBI?</p> | <input type="checkbox"/> No. <input type="checkbox"/> Yes, for adults (18 years of age and older) <input type="checkbox"/> Yes, for both children and adults |
| <p>5a. If so, what was the total number of adults and children that received case management or service coordination from your organization from July 1, 2006 through June 30, 2007 who had a diagnosis of traumatic brain injury?</p> | <p>Adults (18 years of age and older): (fill in number) Is this value: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> <p>Children (under the age of 18): (fill in number) Is this value: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> |
| <p>5b. If so, what types of case management or service coordination services are offered? (Check all that apply)</p> | <p>Please check all services that are offered.</p> <input type="checkbox"/> Short term (0-3months) <input type="checkbox"/> Long term: 3mos to (fill in the blank) <input type="checkbox"/> Provided Statewide <input type="checkbox"/> Regional Basis <input type="checkbox"/> Case by case <input type="checkbox"/> Other (please specify) |
| <p>5c. If so, please indicate the approximate number of clients per case manager:</p> | |
| <p>6. Does your organization have programs specifically developed for historically underserved populations (e.g., individuals who are elderly, Native Americans, Hispanics, African Americans, and Asians)?</p> | <input type="checkbox"/> No <input type="checkbox"/> Yes |

| | | | |
|---|--|--------------------------|---|
| 7. Does your organization provide or fund programs for individuals designed to prevent brain injury? | Please check all services that are provided/funded. | | |
| | Provided | Funded | |
| | <input type="checkbox"/> | <input type="checkbox"/> | Prevention of intentional injuries (shaken baby syndrome, violence, etc.) |
| | <input type="checkbox"/> | <input type="checkbox"/> | Prevention of unintentional injuries (falls, motor vehicle accidents, sports injuries, etc.) |
| | <input type="checkbox"/> | <input type="checkbox"/> | Other (please specify) |
| 8. Does your organization provide or fund services that prevent secondary conditions associated with TBI, such as depression, contractures, cardiopulmonary changes, etc.? | <input type="checkbox"/> No <input type="checkbox"/> Yes, we provide this service <input type="checkbox"/> Yes, we fund this service | | |

| Please check all services that your organization provides for children and adults. | | Children (under 18) | | Adults (18-64) | | Adults (65 and over) | |
|--|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | | Provided | Funded | Provided | Funded | Provided | Funded |
| 9. Medical/Therapeutic Services | Alternative Therapies | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Coma Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Dental Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Durable Medical Equipment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Individual Counseling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Medical Services (General) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Medical Services (Specific to TBI) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Mental Health Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Neuropsychology | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Neuropsychiatry | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Nursing Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Orthodontics/Prosthetics | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Physical Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Psychiatry | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Psychology | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Substance Use Evaluation & Treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vision Services (General) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| Vision Services (Specific to TBI) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 10. Rehabilitation Services | Acute Rehabilitation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Assistive Technology | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Case Management or Service Coordination | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Cognitive Rehabilitative Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Driver Education | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Family Education/Training/Counseling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Independent Life Skills Training | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Information & Referral | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Inpatient Rehabilitation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Neurobehavioral Treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Occupational Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Pain Management | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Post Acute Rehabilitation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Social Work | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Speech/Language Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Therapeutic Recreation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |

| Please check all services that your organization provides for children and adults. | | Children (under 18) | | Adults (18-64) | | Adults (65 and over) | |
|--|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | | Provided | Funded | Provided | Funded | Provided | Funded |
| 11. Education or Employment Services | Adult Day Program | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Advocacy (<i>Family</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Advocacy (<i>Self</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Career Counseling/Guidance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Higher Education | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Accommodations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Coaching | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Development | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Placement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Sampling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Learning Supports | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Prevocational Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Sheltered Workshop | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Special Skills Training (<i>Computer, Data Processing, etc.</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Supported Employment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Vocational Evaluation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Volunteer Placement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Work Adjustment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Work Support | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 12. Community Living Support | Advocacy (<i>Community</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Community Skills Training (<i>relearning skills to use in public places</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Companion Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Day Program | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Emergency Shelter Assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Home Care/Home Support (<i>e.g. home health aide, help with bathing and dressing, etc.</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Homemaker Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Housing Assistance (<i>to stay in own home</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Environmental Modifications | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Housing (<i>Supervised</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Income Maintenance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Independent Living Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Information/Resources | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Legal Services in General (<i>e.g., divorce, custody, bankruptcy, etc.</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Legal Services Specific to TBI | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Money Management | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Peer Support | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Personal Assistance Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Recreation/Social Programs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Rental Assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Respite Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Social Skills Training (<i>how to interact with others</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Specialty Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | TBI Support Group | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Transitional Living Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Transportation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Utility Assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| Other, please specify: | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |

| | |
|---|--|
| 13. Does your agency offer educational and/or training programs <u>about</u> traumatic brain injury? | <input type="checkbox"/> No |
| | <input type="checkbox"/> Yes. Please check all groups served. |
| | <input type="checkbox"/> Individuals with TBI |
| | <input type="checkbox"/> Families/Significant Others |
| | <input type="checkbox"/> Own Agency |
| | <input type="checkbox"/> Sister State Agencies |
| | <input type="checkbox"/> Educators/Teachers |
| | <input type="checkbox"/> Health Professionals |
| | <input type="checkbox"/> Hospital Personnel |
| | <input type="checkbox"/> Rehabilitation Providers |
| | <input type="checkbox"/> Law Enforcement |
| | <input type="checkbox"/> Criminal Justice Personnel |
| | <input type="checkbox"/> Emergency Responders (e.g. EMT, Police, Firefighters) |
| <input type="checkbox"/> Other <i>(please specify)</i> | |

Section C. We would like to ask you some questions concerning inter-agency participation among State agencies that provide services related to TBI. Please indicate your answer by placing a check in the appropriate box.

| | |
|--|---|
| 14. Does your State agency have any interagency agreements with other agencies to coordinate or co-fund TBI services? | <input type="checkbox"/> No <input type="checkbox"/> Yes. With which agencies? |
| 15. Does a representative from your State agency participate on the NJ Advisory Council on TBI? | <input type="checkbox"/> No <input type="checkbox"/> Yes. Who is that individual? |
| 16. Is there TBI representation on any of your State agency's task forces or advisory boards? | <input type="checkbox"/> No <input type="checkbox"/> Yes. Please indicate the type of representative(s). <input type="checkbox"/> Consumer <input type="checkbox"/> Family member <input type="checkbox"/> Professional <input type="checkbox"/> Not Applicable <i>(our agency does not have task forces/advisory boards)</i> |

Section D. The following questions ask about needs or gaps in services as they relate to TBI. Remember, your responses will remain completely confidential. Feel free to attach additional sheets if you need more space to respond.

17. In your opinion, what are the gaps in services for individuals with TBI in state agencies?
18. In your opinion, what are the barriers to accessing TBI services either in your agency or other agencies?
19. In your opinion, what TBI services need to be expanded in your agency or other agencies?
20. In your opinion, what are the other significant gaps in TBI services in the State (due to location, ethnicity, severity of injury, etc.)?

THANK YOU FOR YOUR PARTICIPATION.

PLEASE RETURN THE COMPLETED SURVEY BY MAIL OR EMAIL BY January 25, 2008 TO:

**Jose Nova
Rutgers Center for State Health Policy
55 Commercial Avenue, Third Floor
New Brunswick, NJ 08901-1340
Email: jnova@ifh.rutgers.edu
Fax: 732/932-0069**

New Jersey Provider Survey of TBI Services and Support

Traumatic brain injury means an acquired injury to the brain. It may include injuries due to trauma, aneurysm rupture, stroke, tumor or tumor removal, infection, or anoxic brain injury. This term does not include brain dysfunction caused by congenital (e.g., cerebral palsy) or degenerative disorders (e.g., multiple sclerosis, Alzheimer's) or injuries due to birth trauma.

NOTE: If you have questions about this survey, please contact Dorothy Gaboda at 732-932-4678 or dgaboda@ifh.rutgers.edu.

Date _____

Name of Provider _____

Contact Person _____

Title _____

Mailing Address _____

City _____ State _____ Zip Code _____

Phone _____ Fax _____

E-mail _____

Home page _____

Section A. We would like to begin by asking you some background questions about your organization and the clients you serve. Please indicate your answer by placing a check or number in the space provided.

| | |
|--|--|
| <p>1. Please describe your organization. <i>(Check all that apply.)</i></p> | <p><input type="checkbox"/> Acute-care hospital</p> <p><input type="checkbox"/> Brain Injury or Disability Provider Organization</p> <p><input type="checkbox"/> Community Provider Agency</p> <p><input type="checkbox"/> County or Municipal Government Agency</p> <p><input type="checkbox"/> Nursing Home-Long Term Care Unit</p> <p><input type="checkbox"/> Nursing Home-Rehabilitation Unit</p> <p><input type="checkbox"/> Outpatient Therapy</p> <p><input type="checkbox"/> Rehabilitation Hospital</p> <p><input type="checkbox"/> Special Care Hospital</p> <p><input type="checkbox"/> Trauma Unit</p> <p><input type="checkbox"/> Other public agency (please specify): _____</p> <p><input type="checkbox"/> Other private agency (please specify): _____</p> |
| <p>2. Please list the county or counties where you provide services</p> | |
| <p>3. In what settings are services provided? <i>(Please check all that apply.)</i></p> | <p><input type="checkbox"/> Individual's Employment Setting</p> <p><input type="checkbox"/> Inpatient Facility</p> <p><input type="checkbox"/> Medical Provider Office</p> <p><input type="checkbox"/> Outpatient Facility</p> <p><input type="checkbox"/> Individual's Home</p> <p><input type="checkbox"/> Residential Facility</p> <p><input type="checkbox"/> Other setting (please specify): _____</p> |

New Jersey Provider Survey of TBI Services and Support

| | | | | | | | | | | | | | | | |
|---|--|----------|---|----------|---|-------------------|---|------------------|---|----------------------|---|----------------------|---|-------|---|
| <p>4. What was the total number of individuals served by your organization between July 1, 2006 through June 30, 2007?</p> <p>NOTE: If you use a different fiscal or reporting year for questions 4 and 5, please note the dates for which you are reporting.</p> | <p style="text-align: right;">(fill in number)</p> <p>Is this value: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> <p>Dates for which information is reported: _____ to _____</p> | | | | | | | | | | | | | | |
| <p>5. Does your data system include a field that identifies whether an individual has a TBI?</p> | <p><input type="checkbox"/> No. <input type="checkbox"/> Yes.</p> | | | | | | | | | | | | | | |
| <p>5a. If so, what was the total number of individuals with TBI served by your organization between July 1, 2006 and June 30, 2007?</p> | <p style="text-align: right;">(fill in number)</p> <p>Is this value: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> | | | | | | | | | | | | | | |
| <p>5b. Indicate the total number of individuals with TBI served by your organization from July 1, 2006 through June 30, 2007 for each racial/ethnic category.</p> | <p>Asian Black, Non Hispanic Hispanic Native American White, Non-Hispanic Other (please specify): _____</p> <p>Are these values: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> | | | | | | | | | | | | | | |
| <p>5c. Indicate the total number of individuals with TBI served by your organization from July 1, 2006 through June 30, 2007 for each gender category.</p> | <p>Female Male</p> <p>Are these values: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> | | | | | | | | | | | | | | |
| <p>6. What percentage of your payment comes from each of the following sources?</p> | <table style="width: 100%; border-collapse: collapse;"> <tr><td style="width: 80%;">Medicaid</td><td style="text-align: right;">%</td></tr> <tr><td>Medicare</td><td style="text-align: right;">%</td></tr> <tr><td>Private Insurance</td><td style="text-align: right;">%</td></tr> <tr><td>Private Payments</td><td style="text-align: right;">%</td></tr> <tr><td>Workers Compensation</td><td style="text-align: right;">%</td></tr> <tr><td>Automobile Insurance</td><td style="text-align: right;">%</td></tr> <tr><td>Other</td><td style="text-align: right;">%</td></tr> </table> <p><i>Please specify other sources:</i></p> <p><input type="checkbox"/> None, do not accept payment</p> <p>**Remember: Percentages should total 100%**</p> | Medicaid | % | Medicare | % | Private Insurance | % | Private Payments | % | Workers Compensation | % | Automobile Insurance | % | Other | % |
| Medicaid | % | | | | | | | | | | | | | | |
| Medicare | % | | | | | | | | | | | | | | |
| Private Insurance | % | | | | | | | | | | | | | | |
| Private Payments | % | | | | | | | | | | | | | | |
| Workers Compensation | % | | | | | | | | | | | | | | |
| Automobile Insurance | % | | | | | | | | | | | | | | |
| Other | % | | | | | | | | | | | | | | |
| <p>7. Does your organization conduct outreach efforts?</p> | <p><input type="checkbox"/> No. <input type="checkbox"/> Yes.</p> <p>If Yes, please specify: _____</p> | | | | | | | | | | | | | | |
| <p>8. If your organization has specific eligibility requirements that people must meet, in addition to traumatic brain injury. (Please check all that apply.)</p> | <p><input type="checkbox"/> Age Limitations, Please Specify: _____</p> <p><input type="checkbox"/> Homelessness</p> <p style="padding-left: 20px;"><input type="checkbox"/> Income, Please Specify: _____</p> <p style="padding-left: 20px;"><input type="checkbox"/> Assets, Please Specify: _____</p> <p><input type="checkbox"/> Trauma or Assault</p> <p><input type="checkbox"/> Inpatient status</p> <p><input type="checkbox"/> Medicaid eligibility</p> <p><input type="checkbox"/> Mental illness diagnosis</p> <p><input type="checkbox"/> Substance abuse diagnosis</p> <p><input type="checkbox"/> Other, Please Specify: _____</p> | | | | | | | | | | | | | | |

New Jersey Provider Survey of TBI Services and Support

| | |
|--|--|
| <p>9. How many staff in your organization provide direct services?</p> <p>9a. Of the staff that provides direct services, how many staff work more than half time with individuals with TBI?</p> | <p style="text-align: center;">(fill in number)</p> <p style="text-align: center;">Is this value: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> <p style="text-align: center;">(fill in number)</p> <p style="text-align: center;">Is this value: <input type="checkbox"/> Estimated <input type="checkbox"/> Actual</p> |
| <p>10. Does your organization offer periodic education and training about TBI to staff members?</p> | <p><input type="checkbox"/> No. <input type="checkbox"/> Yes.</p> |
| <p>11. Does your organization offer education and training programs about TBI to people outside your organization?</p> | <p><input type="checkbox"/> No. <input type="checkbox"/> Yes.</p> <p>If yes, please check all services that are provided.</p> <p><input type="checkbox"/> Individuals with TBI</p> <p><input type="checkbox"/> Families/Significant Others</p> <p><input type="checkbox"/> State Agencies</p> <p><input type="checkbox"/> Educators/Teachers</p> <p><input type="checkbox"/> Health Professionals</p> <p><input type="checkbox"/> Rehabilitation Providers</p> <p><input type="checkbox"/> Law Enforcement/Criminal Justice</p> <p><input type="checkbox"/> Emergency Responders</p> <p><input type="checkbox"/> Other <i>(please specify)</i></p> |
| <p>12. Is your organization looking for education and training resources specific to TBI for your staff or outside education purposes?</p> | <p><input type="checkbox"/> No. <input type="checkbox"/> Yes.</p> <p>If yes, please specify what services your agency is looking for:</p> |
| <p>13. Does your organization provide services designed to prevent brain injury or minimize disability?</p> | <p><input type="checkbox"/> No. <input type="checkbox"/> Yes.</p> <p>If yes, please check all services that are provided.</p> <p><input type="checkbox"/> Prevention of intentional injuries (<i>shaken baby syndrome, violence, etc.</i>)</p> <p><input type="checkbox"/> Prevention of unintentional injuries (<i>falls, occupant protection, etc.</i>)</p> <p><input type="checkbox"/> Other <i>(please specify)</i></p> |
| <p>14. Does your organization provide or fund services that prevent secondary conditions associated with TBI, such as depression, contractures, cardiopulmonary changes, etc.?</p> | <p><input type="checkbox"/> No. <input type="checkbox"/> Yes.</p> |

Section B. The following questions ask about the services your organization provides. Please indicate your answer by placing a check or number in the space provided.

| Please check all services that your organization provides for children and adults. | | Children (under 18) | Adults (18 to 64) | Adults (65 and older) |
|--|---|--------------------------|--------------------------|--------------------------|
| 15. Medical/ Therapeutic Services | Alternative Therapies | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Coma Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Dental Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Durable Medical Equipment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Individual Counseling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Medical Services (<i>General</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Medical Services (<i>Specific to TBI</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Mental Health Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Neuropsychology | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Neuropsychiatry | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Nursing Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Orthodontics/Prosthetics | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Physical Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Psychiatry | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Psychology | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Substance Use Evaluation & Treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Vision Services (<i>General</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vision Services (<i>Specific to TBI</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 16. Rehabilitation Services | Acute Rehabilitation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Assistive Technology | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Case Management or Service Coordination | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Cognitive Rehabilitative Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Driver Education | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Family Education/Training/Counseling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Independent Life Skills Training | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Information & Referral | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Inpatient Rehabilitation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Neurobehavioral Treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Occupational Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Pain Management | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Post Acute Rehabilitation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Social Work | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Speech/Language Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Therapeutic Recreation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |

| Please check all services that your organization provides for children and adults. | | Children (under 18) | Adults (18 to 64) | Adults (65 and over) |
|--|---|--------------------------|--------------------------|--------------------------|
| 17. Education or Employment Services | Adult Day Program | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Advocacy (<i>Family</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Advocacy (<i>Self</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Career Counseling/Guidance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Higher Education | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Accommodations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Coaching | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Development | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Placement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Job Sampling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Learning Supports | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Prevocational Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Sheltered Workshop | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Special Skills Training (<i>Computer, Data Processing, etc.</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Supported Employment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Vocational Evaluation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Volunteer Placement | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Work Adjustment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Work Support | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| 18. Community Living Support | Advocacy (<i>Community</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Community Skills Training (<i>relearning skills to use in public places</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Companion Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Day Program | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Emergency Shelter Assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Home Care/Home Support (<i>e.g. home health aide, help with bathing and dressing, etc.</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Homemaker Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Housing Assistance (<i>to stay in own home</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Environmental Modifications | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Housing (<i>Supervised</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Income Maintenance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Independent Living Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Information/Resources | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Legal Services in General (<i>e.g., divorce, custody, bankruptcy, etc.</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Legal Services Specific to TBI | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Money Management | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Peer Support | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Personal Assistance Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Recreation/Social Programs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Rental Assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Respite Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Social Skills Training (<i>how to interact with others</i>) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |

| Please check all services that your organization provides for children and adults. | | Children (under 18) | Adults (18 to 64) | Adults (65 and over) |
|---|------------------------------|-------------------------------|-----------------------------|--------------------------------|
| | Specialty Care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | TBI Support Group | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Transitional Living Services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Transportation | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Utility Assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| | Other, please specify: | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Section C. The following questions ask about needs or gaps in services as they relate to TBI. **Remember, your responses will remain completely confidential.** Feel free to attach additional sheets if you need more space to respond.

19. In your opinion, what are the barriers to accessing TBI services either in your agency or other agencies?
20. In your opinion, what TBI services need to be expanded in your agency or other agencies?
21. In your opinion, what are other significant gaps in services for individuals with TBI in New Jersey (due to location, ethnicity, severity of injury, etc.)?

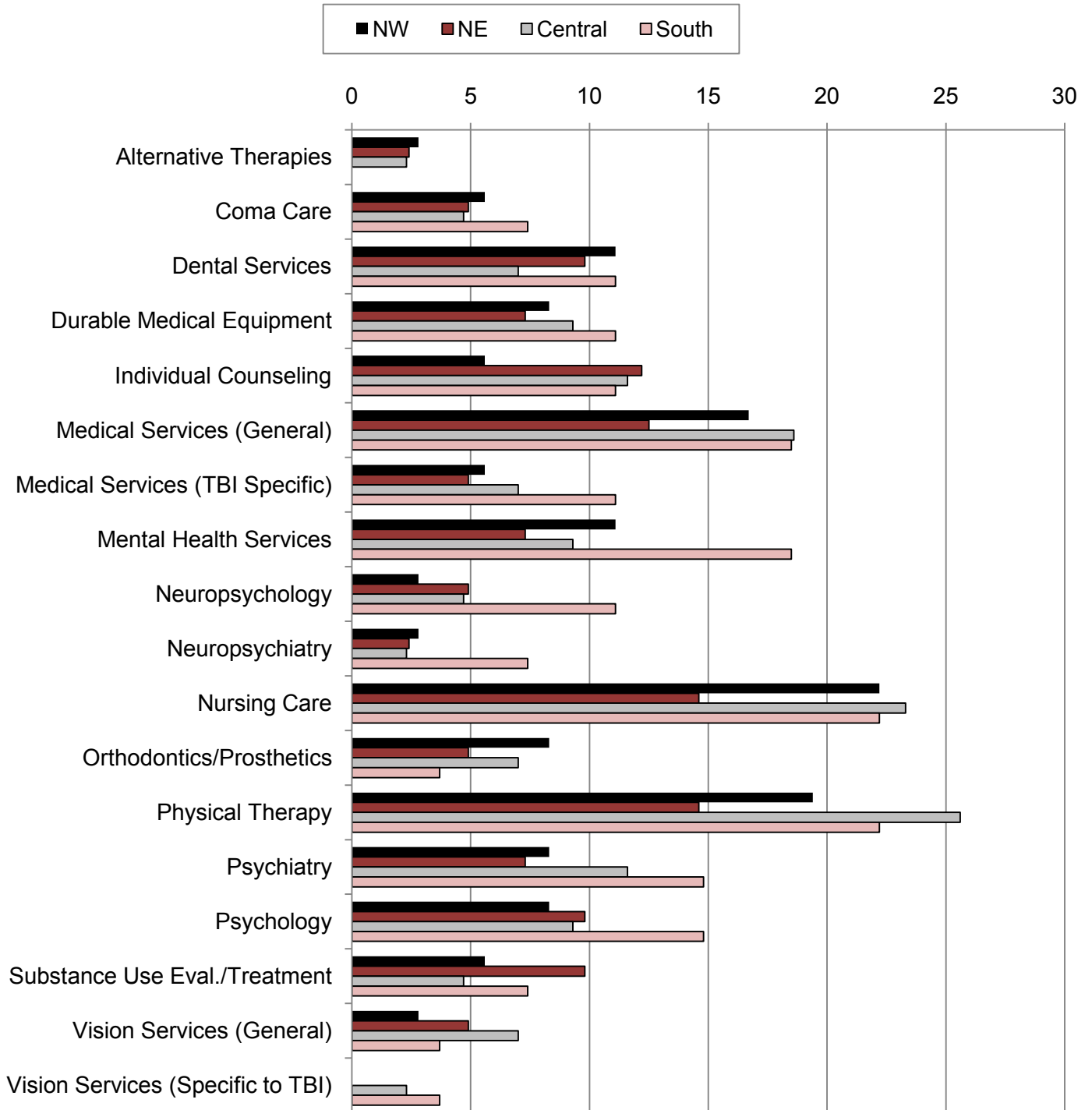
THANK YOU FOR YOUR PARTICIPATION.

PLEASE RETURN THE COMPLETED SURVEY BY MAIL OR EMAIL BY January 25, 2008 TO:

**Jose Nova
Rutgers Center for State Health Policy
55 Commercial Avenue, Third Floor
New Brunswick, NJ 08901-1340
Email: jnova@ifh.rutgers.edu**

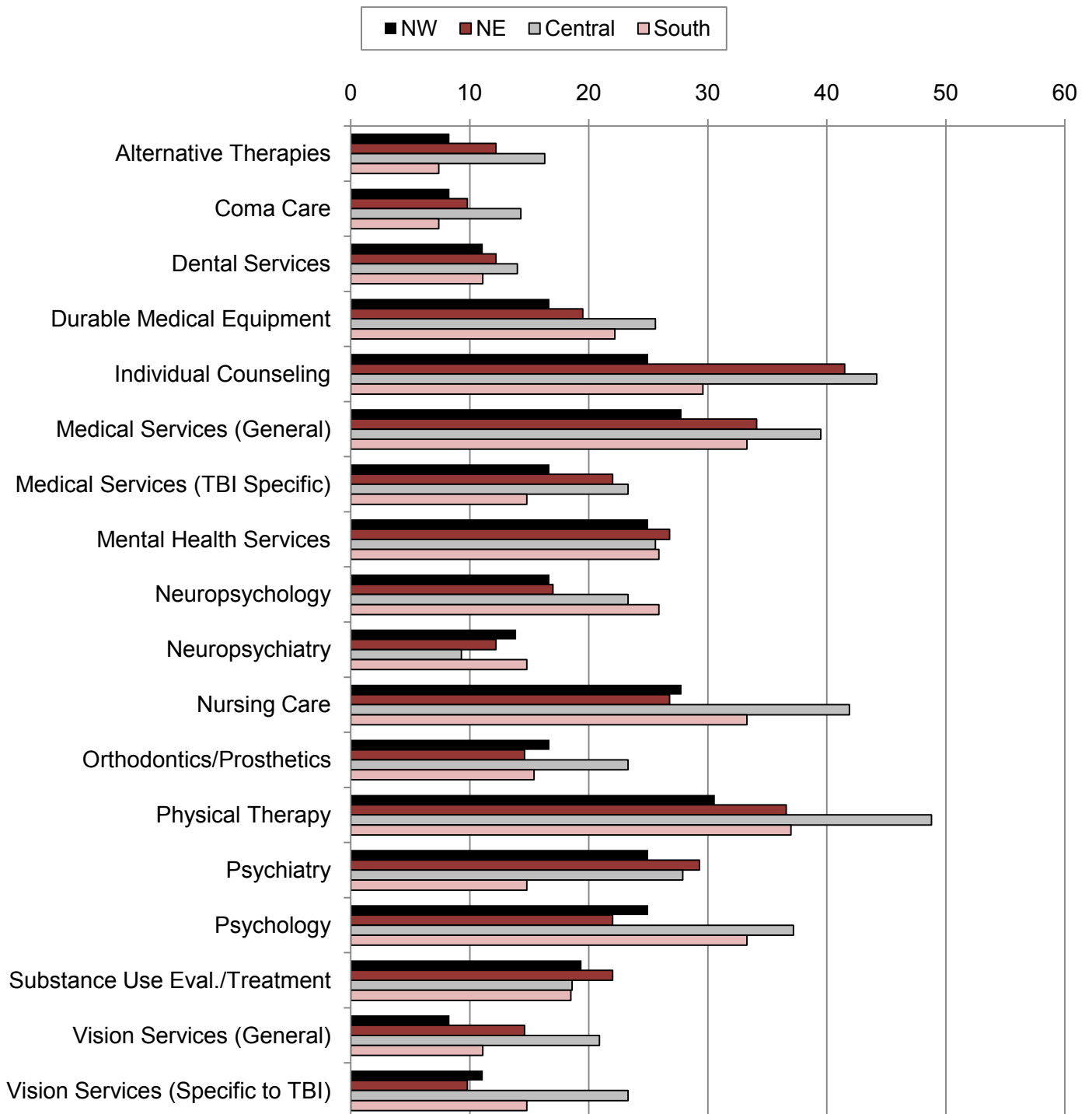
Appendix C

Figure C-1: Percentage of Organizations Providing Medical/Therapeutic Services for Children by Region of New Jersey



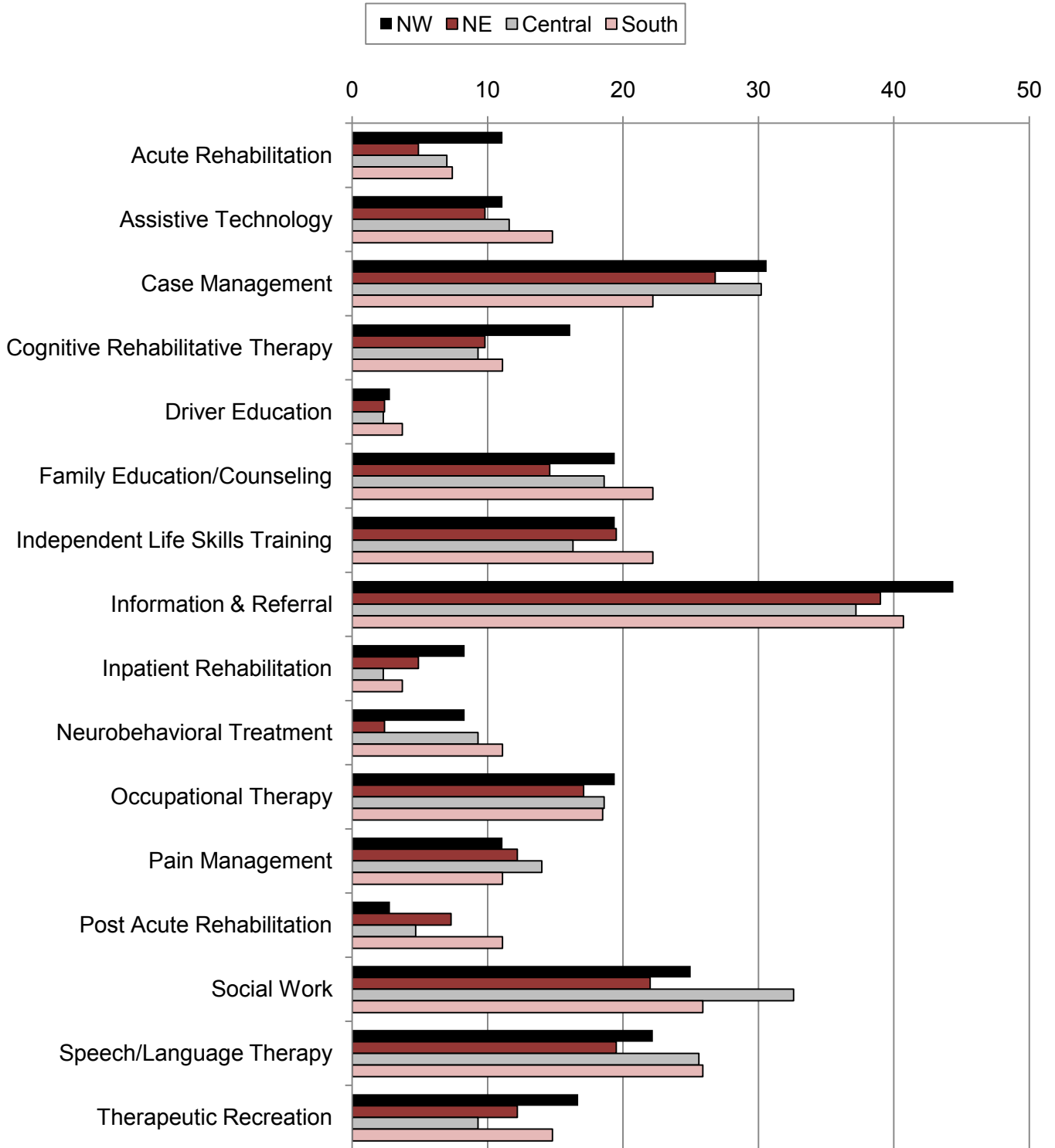
Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Figure C-2: Percentage of Organizations Providing Medical/Therapeutic Services for Adults by Region of New Jersey



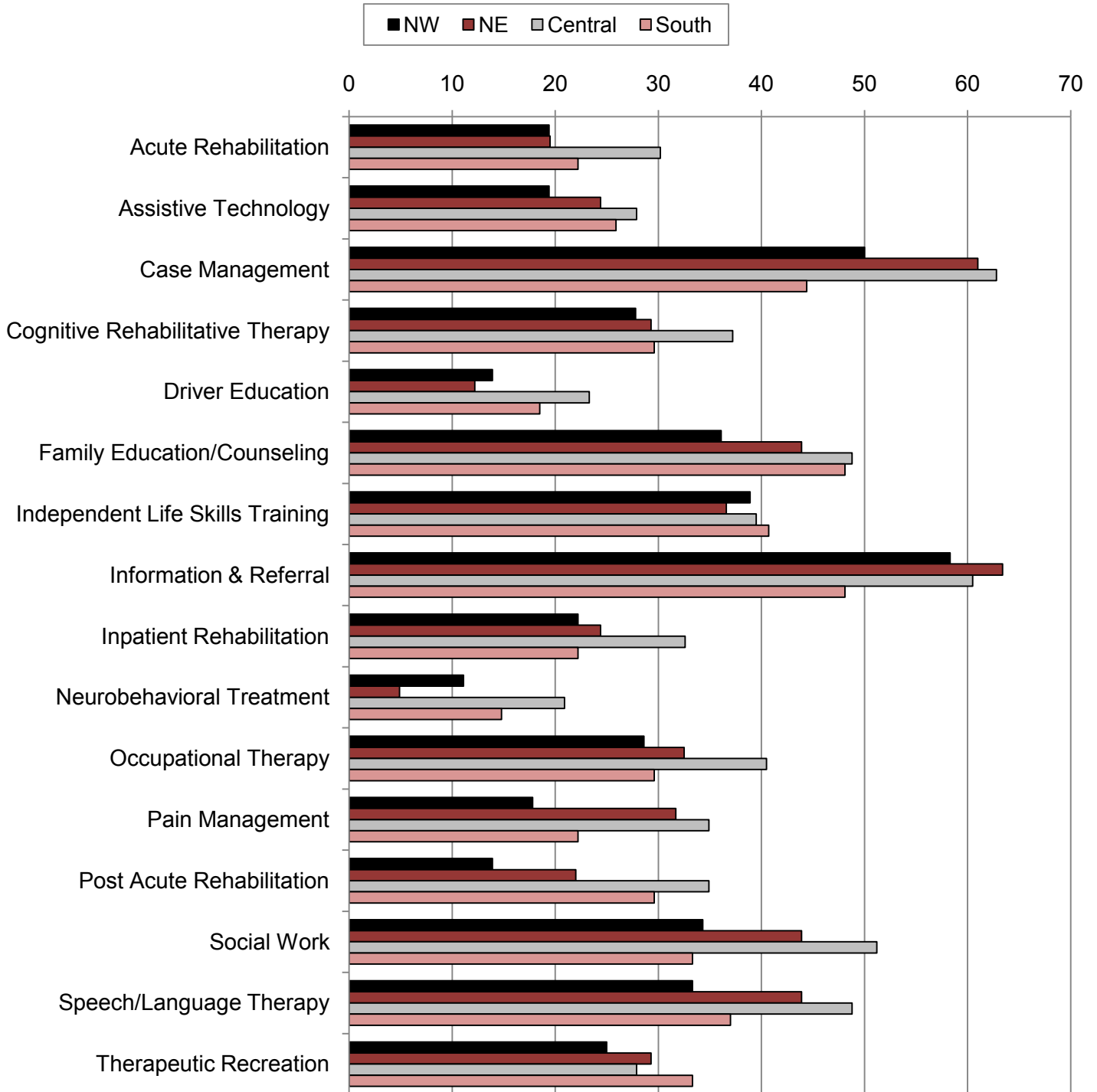
Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Figure C-3: Percentage of Organizations Providing Rehabilitation Services to Children by Region of New Jersey



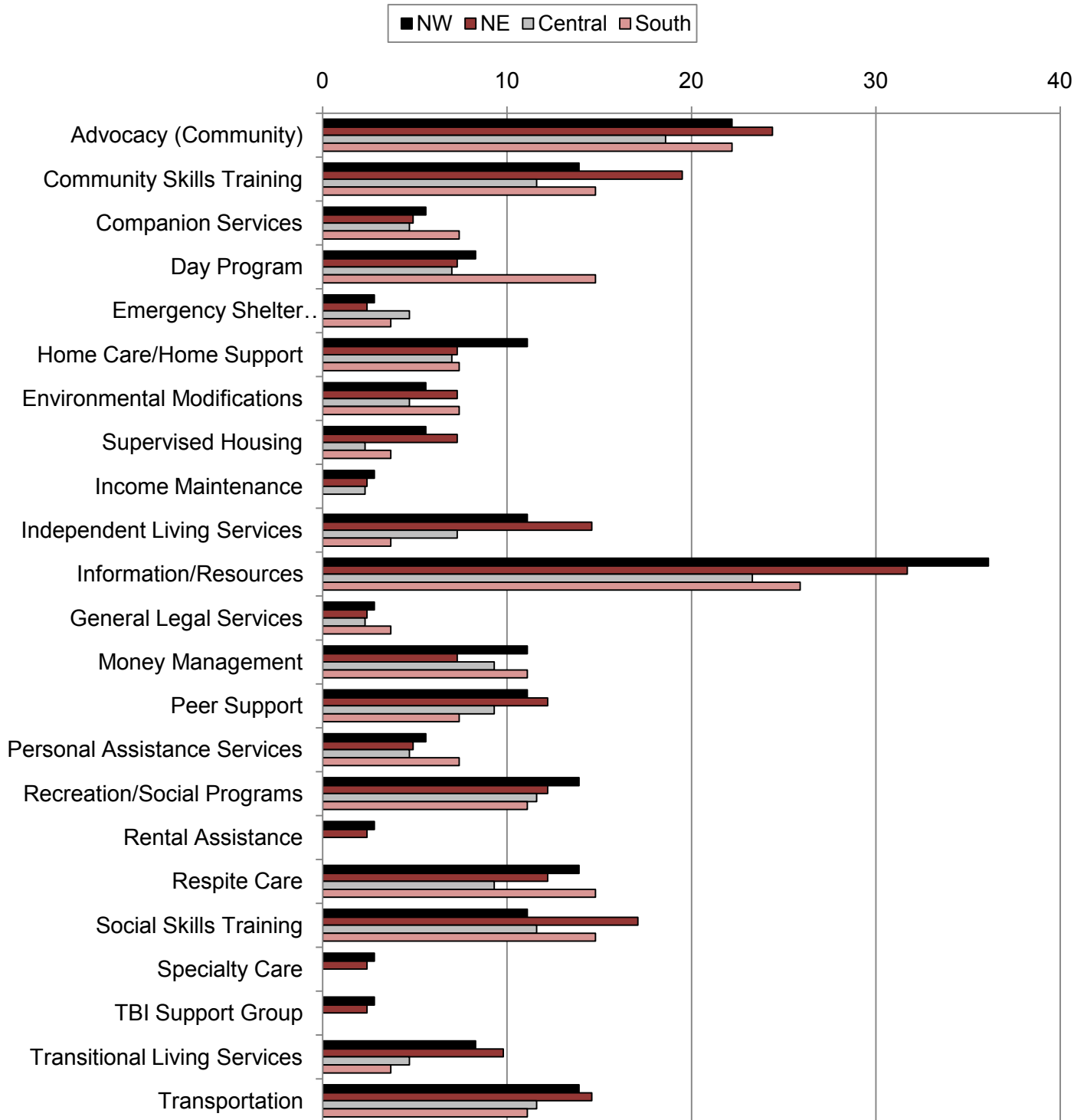
Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Figure C-4: Percentage of Organizations Providing Rehabilitation Services to Adults by Region of New Jersey



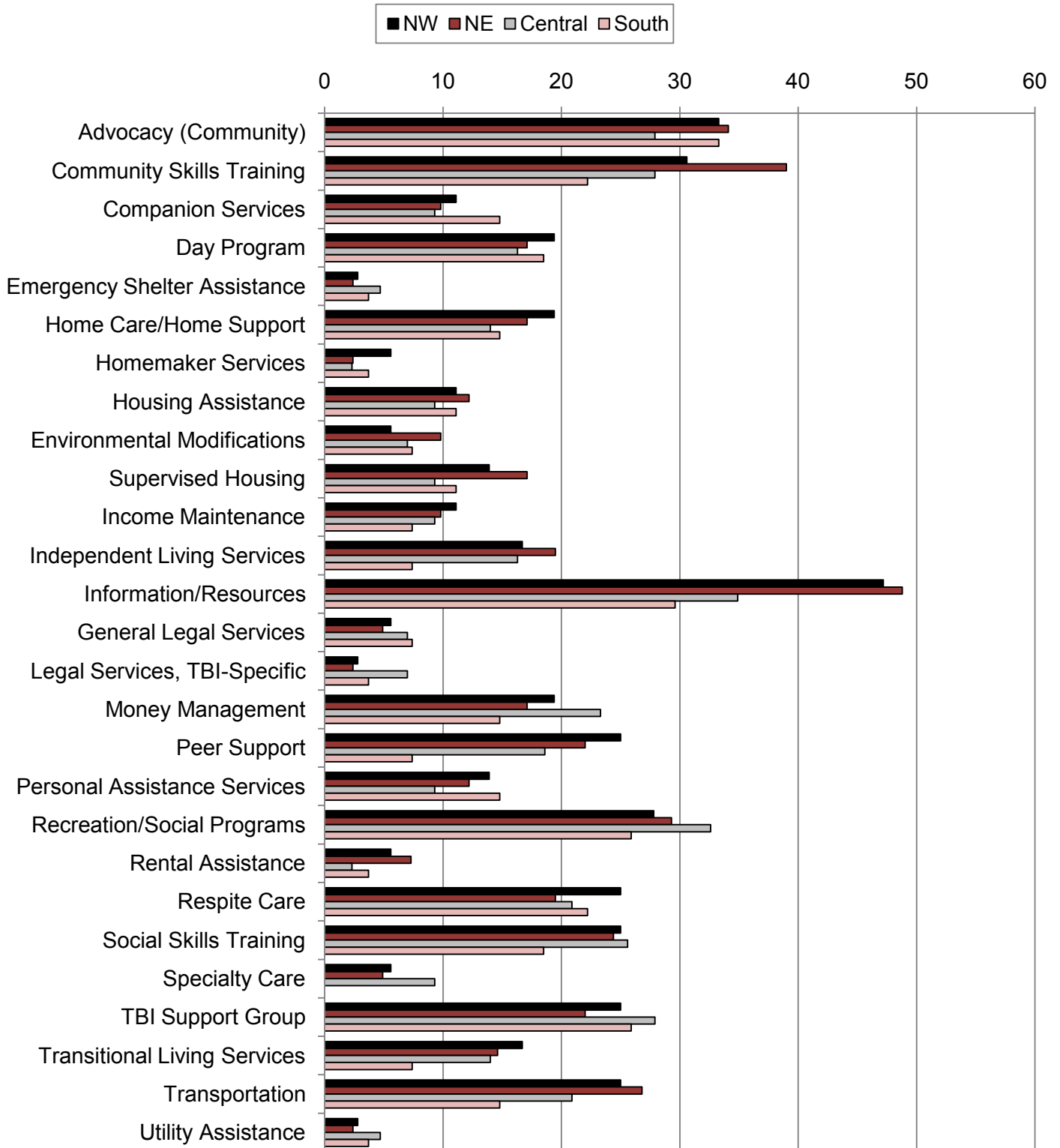
Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Figure C-5: Percentage of Organizations Providing Community Support Services to Children by Region



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment

Figure C-6: Percentage of Organizations Providing Community Support to Adults by Region



Source: New Jersey Traumatic Brain Injury Needs and Resource Assessment