

Meeting the needs of Iowans Experiencing Brain Injury

A survey of Iowa's service providers

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IOWA ASSOCIATION OF COMMUNITY PROVIDERS

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INTRODUCTION

Background:

In the fall of 2006, the Iowa Association of Community Providers (IACP), in conjunction with the Iowa Department of Public Health (IDPH), developed a survey regarding brain injury services in the state of Iowa. The purpose of this survey was to assess:

The extent of services currently being provided to individuals diagnosed with brain injury
To identify the level of brain injury training in Iowa

To uncover barriers discouraging providers from offering services to individuals who have experienced brain injury.

In 2010, IACP in partnership with IDPH developed a second survey regarding brain injury services in the state of Iowa. Many of the same themes and questions were utilized and analysis of results was completed including trend measurement.

The 2006 and 2010 survey analysis was utilized as an integral part of the IDPH's State Plan for Brain Injury. This plan was used as a guide for a successful application for a Federal Traumatic Brain Injury grant through the Health Resources and Services Administration (HRSA) in 2014.

Current Survey:

In 2014, a 31-question tool was developed that utilized multiple choice and open-ended questions. The tool was modeled after the instruments utilized in 2006 and 2010 but was revised to reflect recommendations by the Iowa Advisory on Brain Injuries to include questions regarding certification and multi-occurring disorders. Two scholarships to the Brain Injury of Alliance of Iowa's annual conference in March of 2015 were offered to encourage participation in the survey.

METHODOLOGY

Subjects:

The method used for sampling was a subjective method, which identified current disability service providers in the state of Iowa.

Data Collection:

An initial email was sent to Iowa HCBS service providers who previously participated in the IACP Technical Assistance Training. A secondary email was sent approximately 48 hours prior to the closing of the survey to those who had not participated. The survey was conducted electronically utilizing Survey Monkey. The survey was open for approximately one week in December of 2014. Sixty-Five individuals, representing 61 individual agencies, answered the survey. Multiple surveys from single agencies were pulled and analyzed for congruency, when appropriate the responses were represented by one agency response.

Analysis Techniques:

Results were compiled and analyzed by grouping questions into the following four thematic areas:

- I. Participant and Agency Demographics
- II. Barriers to providing services
- III. Services
- IV. Training

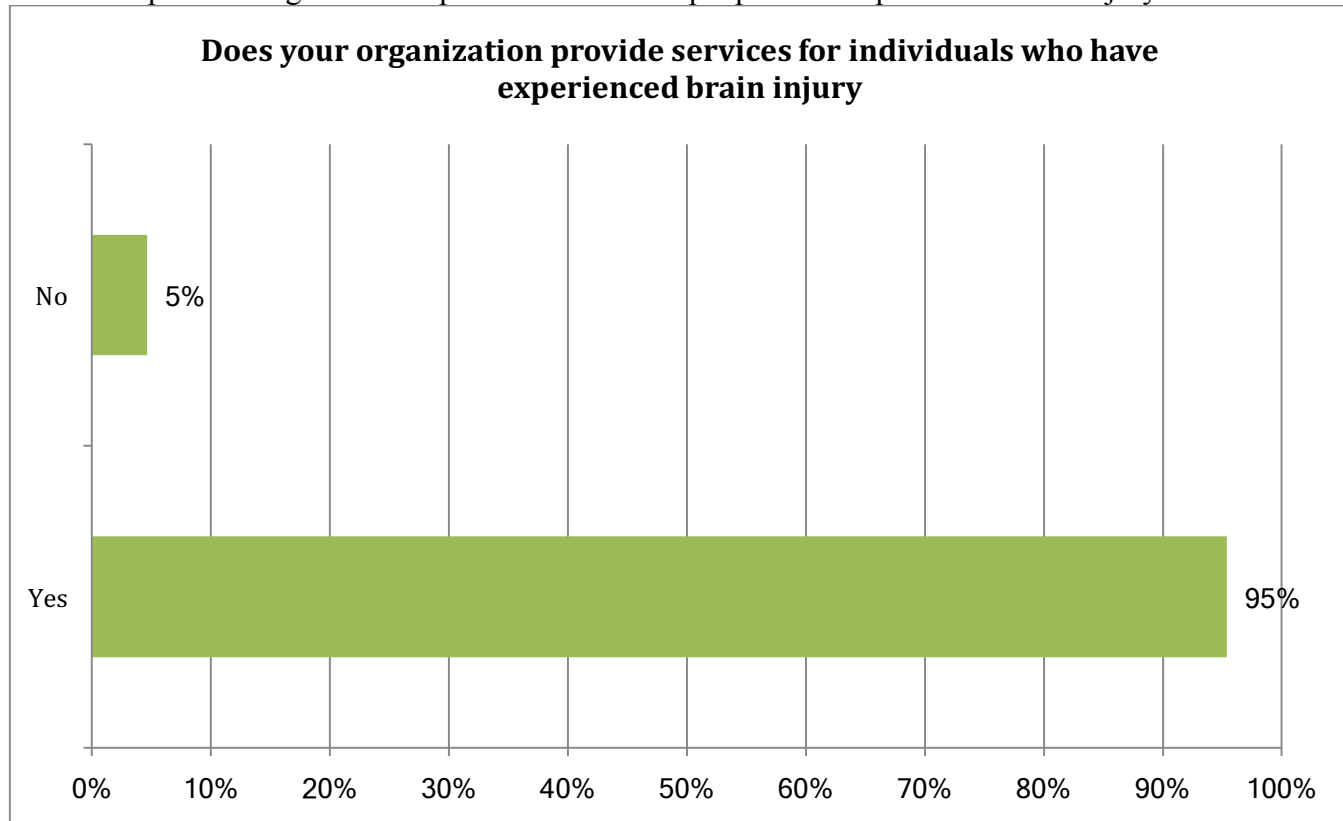
I. Participant and Agency Demographics

The following questions were used for analysis in this area:

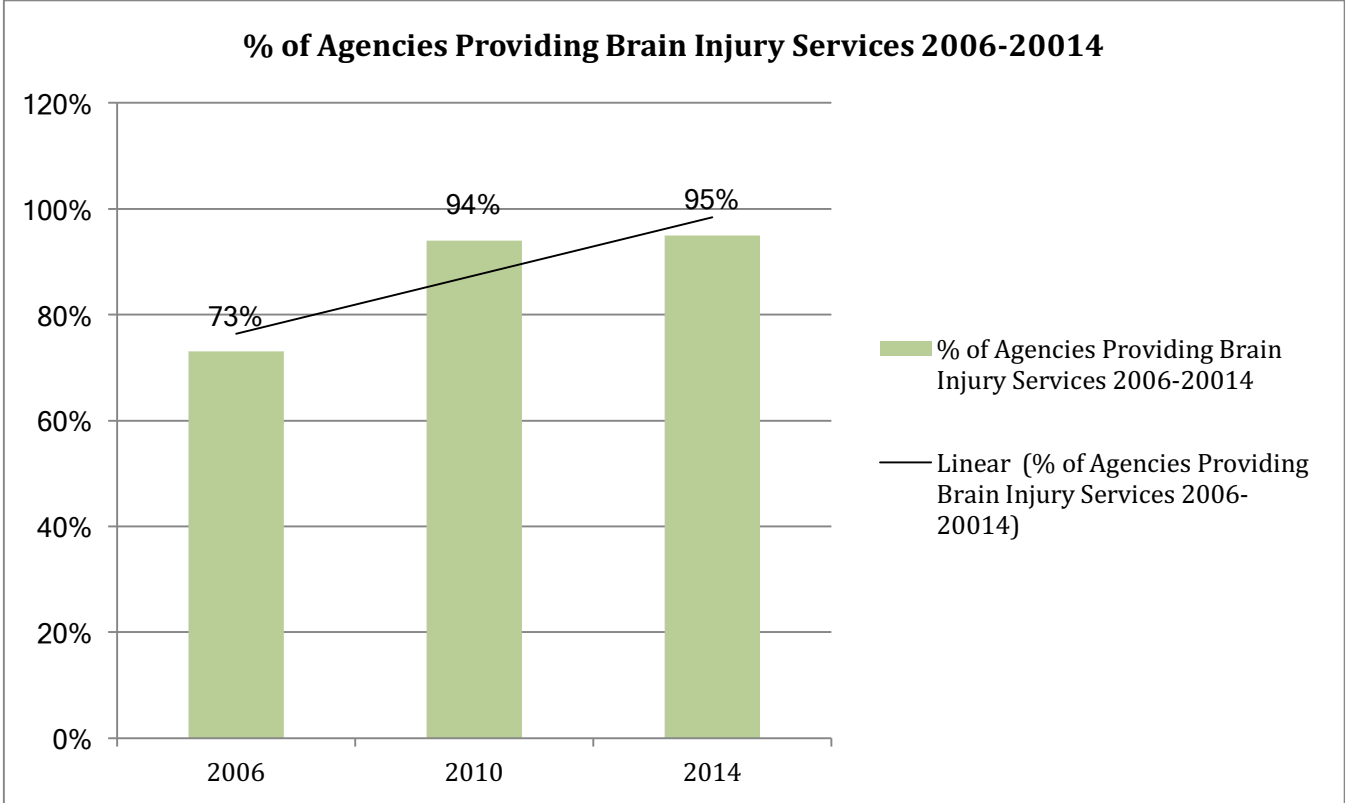
- Does your organization provide services for individuals who have experienced brain injury?
- What funding sources does your agency access to serve individuals experiencing brain injury?
- Through what agency is your organization accredited?
- What was the total number of individuals served by your organization in the last year who had a primary diagnosis of Traumatic Brain Injury?
- Are you or your organization a member of the Brain Injury Alliance of Iowa?
- What services do you currently provide?

Brain Injury Services

95% of respondent organizations provide services to people who experienced brain injury.



In the 2006 survey completed by IACP, approximately 73% of respondents provided services to individuals experiencing brain injury in contrast to 94% of respondents in 2010. This represented a substantial increase in the amount of the IACP members who were providing services to those experiencing brain injuries. In 2014, this number increased to 95% representing a continued commitment to serving people experiencing brain injury.

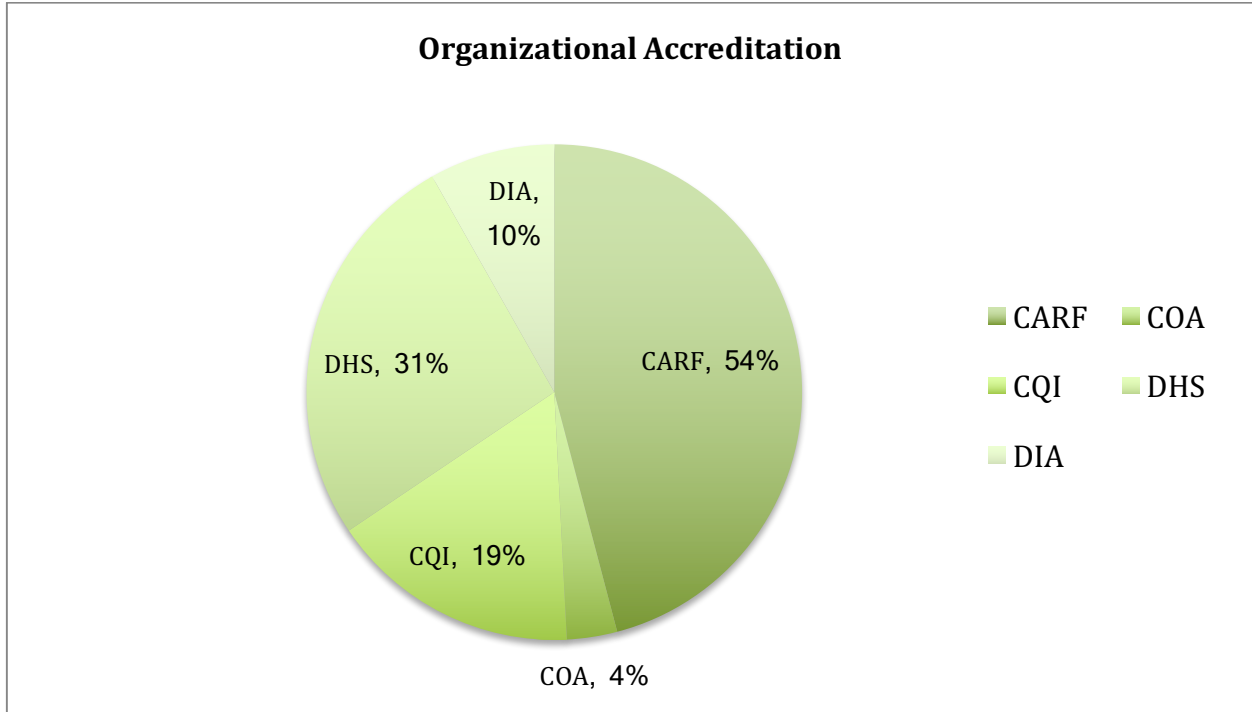


Funding Sources

According to survey results providers of brain injury services access a variety of types of funding to pay for services. Approximately 2/3 of the respondents utilize Iowa Home and Community Services Brain Injury Waiver to pay for the cost of services. The next largest type of funding utilized was county reimbursement. Other types of funding mentioned include: private insurance, workman’s compensation, private pay, Habilitation services, and the Veteran’s Administration.

Organizational Accreditation

The following chart outlines the types of accreditations that participating agencies held, the majority of agencies are CARF (Commission on Accreditation of Rehabilitation Facilities) accredited.



Number of people served

In the last year the agencies that participated in the survey served approximately 827 individuals experiencing brain injury. The largest number served in a single agency was 42 and the smallest number was one. (Eight individual agencies report service to 1) The average number of individuals served experiencing brain injury by the 52 agencies who responded to this question was fifteen. The number of individuals served by respondents to this survey represents over half of the individuals currently on the Iowa Brain Injury Waiver.

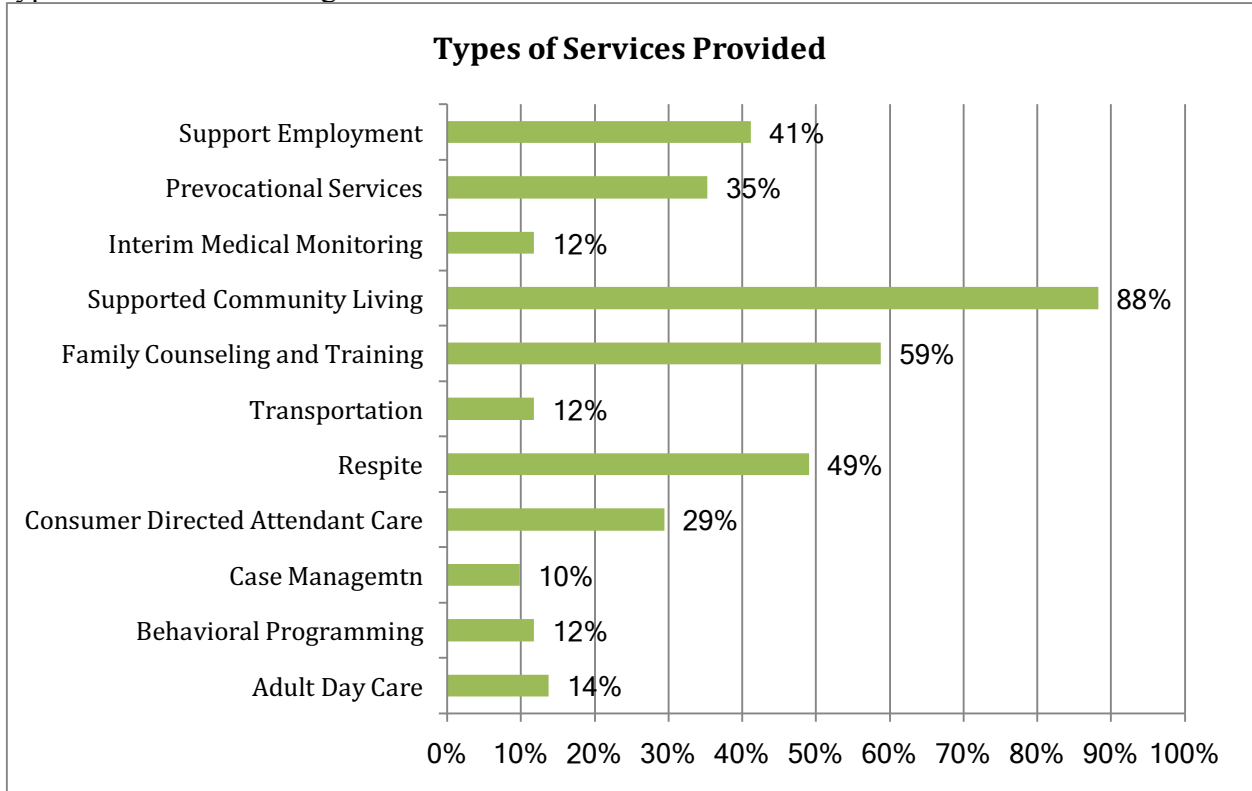
Organizational Membership

Twenty-eight point eight percent of respondents answered that their organization was a member of the Brain Injury Alliance of Iowa. Seventy-one point two percent of respondents reported that their agency was not a member of the Brain Injury Alliance of Iowa.

Eighty-six point five percent of respondents reported being members of the Iowa Association of Community Providers. Fifteen point five percent reported their agency was not a member of the Iowa Association of Community Providers.

Types of Services

The following chart is offered as a summary of responses to a multiple-choice question about the types of services each organization offered:



Barriers

The following questions were used for analysis in this area:

- What do you perceive as major barriers to providing services to people with TBI?
- Is the current brain injury waiver cap of approximately \$2,800 a barrier to providing services to people experiencing brain injury?
- Are there existing TBI services in your area?
- What services are not offered in your area that you believe would be beneficial to persons with Traumatic Brain Injury?
- Does your agency offer cognitive rehabilitation?
- What would your agency need to consider offering cognitive rehabilitation?

Major Barriers to Services

Respondents were asked to describe in a narrative format the major barriers they perceived to providing services to people experiencing brain injury. Funding was cited as a barrier to service provision in 64% of respondents. Within the responses that cited funding, the following were also identified as sub-categories of funding barriers:

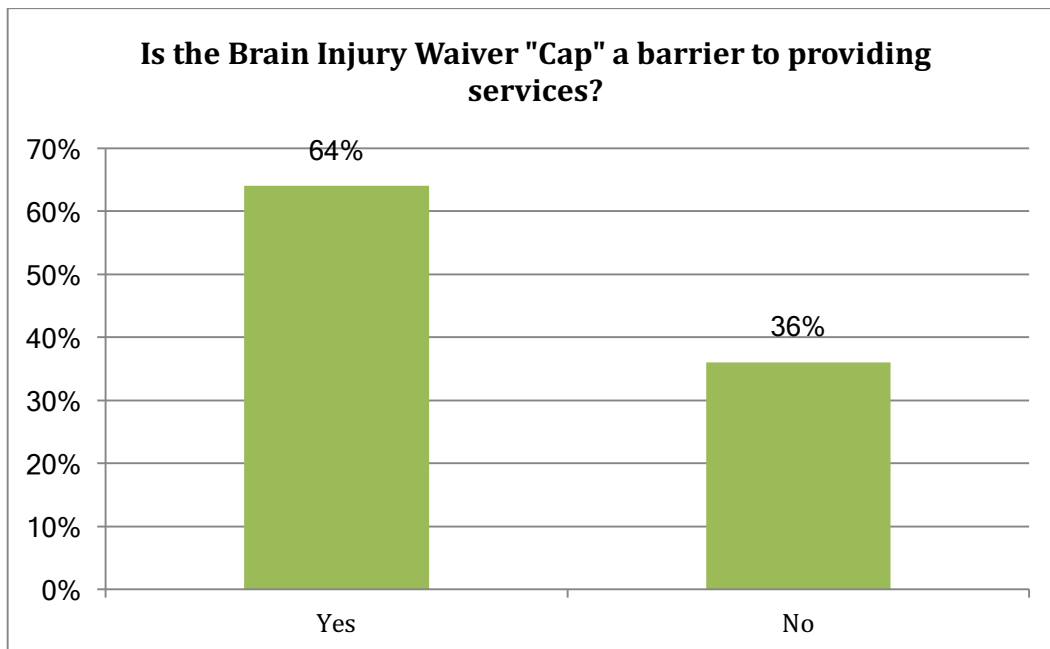
- Vocational service funding
- Cost of staff training
- Funding for adequate services for individuals
- Reimbursement rates
- Lack of reimbursement for behavioral specialists
- Difficulty with rebasing rates
- The funding “cap” on the brain injury waiver
- Recruiting/retaining qualified staff
- Funding for 24-hour support

Other perceived barriers to services included:

- Wages and prevocational services
- Staff serving individuals experiencing different disabilities
- Lack of training for direct care staff
- Lack of education and support for families
- Lack of referrals
- Transportation
- Lack of experience with brain injury
- Appropriate assessment
- Intermittent needs
- Location of clients

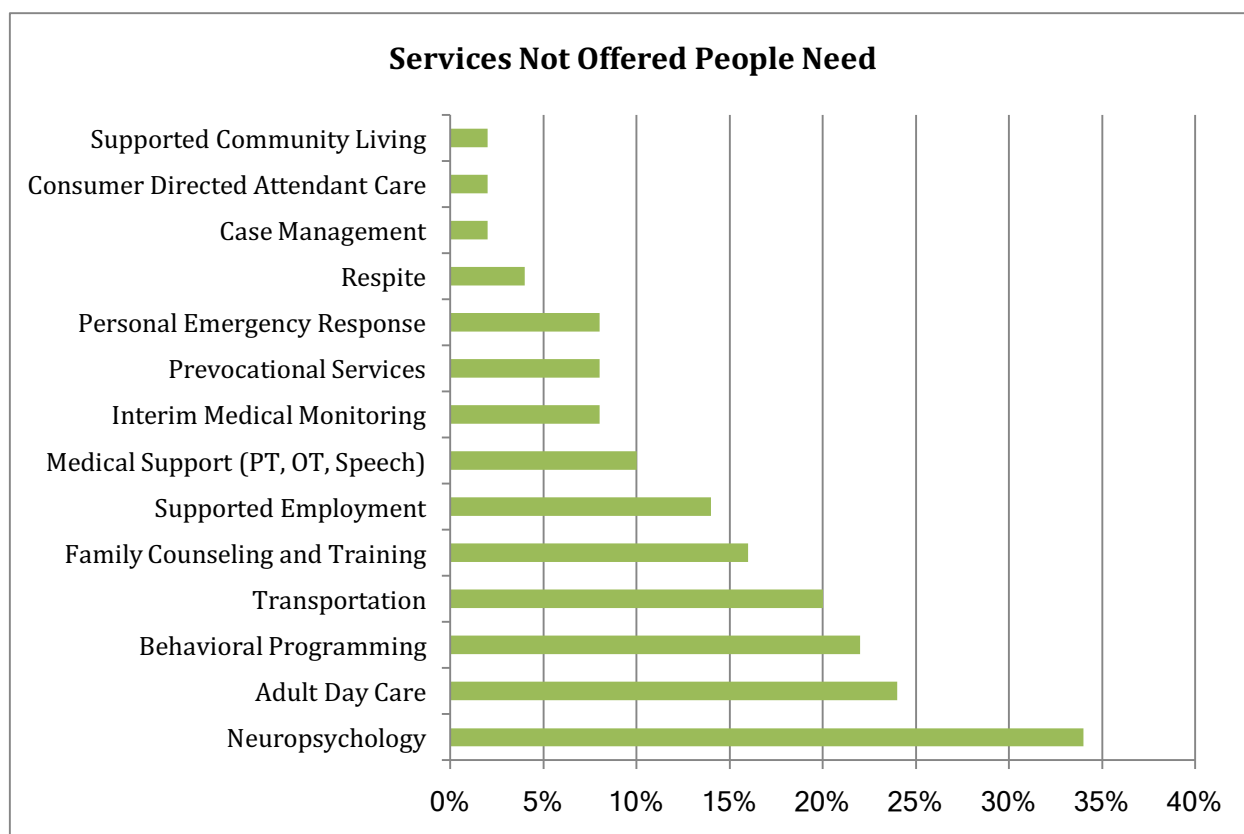
Wavier Barriers

In each year of this survey funding was identified as a major barrier to service provision. Consequently, respondents were specifically asked if the brain injury waiver “cap” of approximately \$2800 was a barrier to service provision. Sixty-four percent of respondents answered that the “cap” was a barrier to providing services to people with brain injury. Many respondents mentioned utilizing exceptions to policy (ETP) as a means for getting the needed funding for services. Some respondents mentioned that ETP’s are not always approved and this was identified anecdotally as a growing trend. If this trend is indeed occurring it puts consumers in need of “daily” services at risk. In some instances, this lack of funding can lead to a lessening of the quality and amount of services a person receives.



Services Not Offered

Respondents were asked to identify services not currently offered but believed to be beneficial to persons experiencing brain injury.



III. Staff and staff training

The following questions were used for analysis in this area:

- Does your organization have designated staff specifically assigned to work on issues related to Brain Injury?
- Did they come to your agency with previous brain injury training?
- What is the total number of staff in your organization who works directly with individuals with Brain Injury?
- Does your agency offer in-service training programs on brain injury?
- What is your estimated number of hours spent per year in continuing education and training specific to Brain Injury by staff that serves individuals? (Conferences, Workshops, Etc.)
- Where does your agency get information about brain injury resources, services, and supports?
- Does any member of your staff regularly attend the Brain Injury Alliance of Iowa's Annual Conference?
- Why don't members of your staff regularly attend the Brain Injury Alliance of Iowa's Annual Conference?

- Are you familiar with the Certified Brain Injury Specialist Certification?
- How many employees within your organization are Certified Brain Injury Specialists?
- What are barriers to staff becoming Certified Brain Injury Specialists?
- What training, technical assistance, or information do providers need most to serve people with brain injury effectively?

Designated Staff

A small majority of respondents do not have staff specifically designated to work with individuals experiencing brain injury. Approximately 49% of respondents do have staff that work specifically on issues related to brain injury. Of the respondents that do have staff who work specifically on issues related to brain injury, only 20% of those agencies reported staff coming to their agency with previous brain injury training and experience. Over 80% of respondents reported staff coming with no previous brain injury training or experience. This number would suggest that many staff working with people who have experienced brain injury are new to working in brain injury service provision.

Staff Training

Approximately 90% of respondents reported their agency offered in-services training programs on brain injury. Types of training reported by responded comments varied widely including:

- A video
- Training specific to individuals and their needs
- ACBIS training
- Online training through CDS (mentioned 7x)
- Iowa Medicaid’s Online Brain Injury Training (mentioned 9x)
- Training provided on-site by IACP

The estimated number of hours spent in brain injury specific training varied with a range from 0 hours to over 100 hours annually. Of those respondents (33) who answered with a numeric value the average number of hours of training was nine hours of training per year. If you remove both the high and the low numbers reported the average is 6.5 hours of annual training specific to brain injury per year.

Information Sources

An overwhelming majority of respondents (90%) replied that they get information about brain injury resources, services and supports from the IACP. Respondents also utilize the Brain Injury Alliance of Iowa (45%), the regional service delivery system for information (20%), direct mailing (7.5%) and Iowa Medicaid Enterprise (2.5%). Other answers of note include:

North American Brain Injury Society
Case Managers

The IDPH
Magellan

Conference Attendance

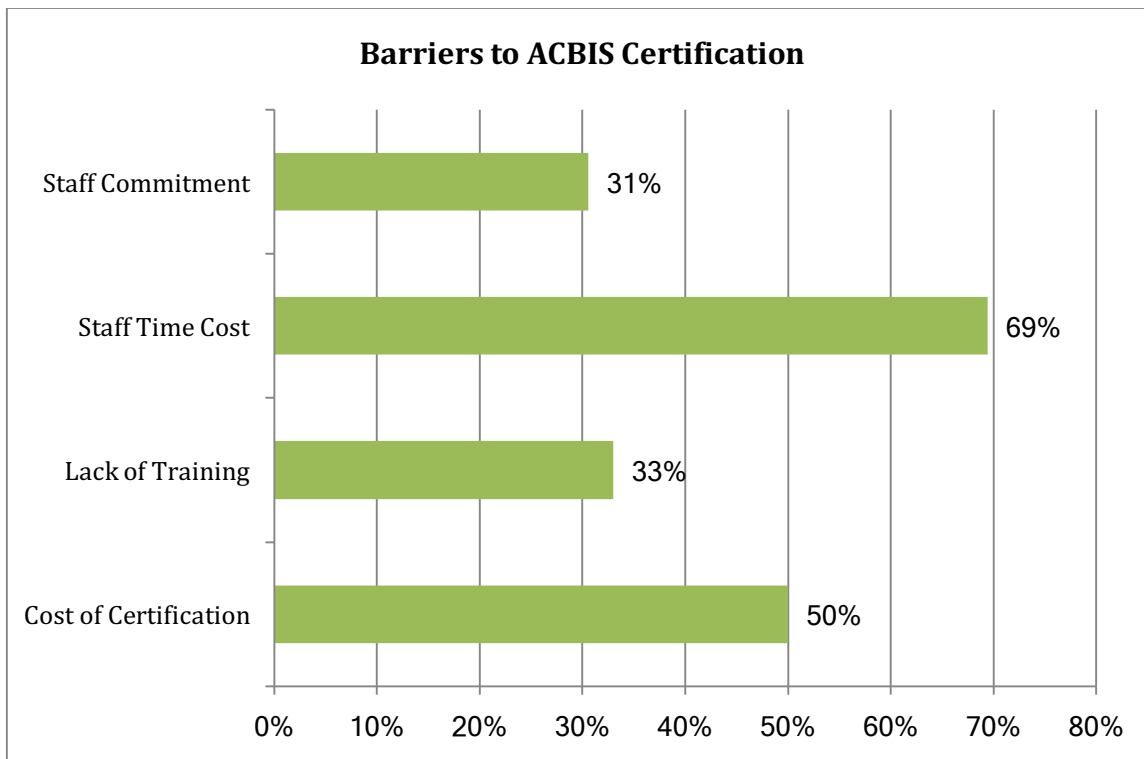
Twenty-eight percent of respondents reported attending the Brain Injury Alliance of Iowa’s annual conference. This is the largest brain injury specific conference held in Iowa and is supported by IDPH and IACP as partners in the Iowa Brain Injury Services Program. Respondents reported the cost as the primary barrier to attending the conference. This is consistent with information gathered by IACP regarding their annual convention where attendees reported cost as a major factor in deciding to attend or not attend.

Certified Brain Injury Specialist Certification

The next set of questions pertained to the Certified Brain Injury Specialist (CBIS) Certification offered by the Academy of Certified Brain Injury Specialists (ACBIS). This certification was created, and is supported, by the Brain Injury Association of America and is currently the only certification available to professionals working in brain injury service delivery.

55% of respondents were familiar with the CBIS certification. Of the 14 respondents who reported CBIS certified staff, the highest number of certified staff per agency was 50 and the lowest number was one. The average number of staff certified in these 14 agencies is 11.

Respondents reported the following barriers to ACBIS Certification:



Technical Assistance Needs

The last question in the survey asked respondents what training, technical assistance or information do providers need to serve people with brain injury effectively. Themes included:

- The cognitive impacts of brain injury and how to work with them
- Behavioral training/de-escalation
- How to assist people in meeting their desired outcomes/service planning
- Dual diagnosis and brain injury
- Skill building

Discussion of findings

In December of 2014, the Iowa Association of Community Providers in conjunction with the Iowa Department of Public Health and the Advisory Council on Brain Injuries developed and implemented a 31-question survey to assess the needs of brain injury service providers in the state of Iowa. The survey completed in December of 2014. Sixty-Five individuals, representing 61 individual agencies, answered the survey. The results of the 2014 survey are consistent with previous surveys that have been completed in 2006 and 2010.

The numbers of service providers providing brain injury services in the state of Iowa increased from 94% to 95% of all respondents in 2014. Although this increase is modest at best it does represent the gains that have been made in terms of service availability have been maintained. Supported Community Living Services Continue to be the mostly widely available services. Services least available are behavioral programming, adult day care, and interim medical monitoring. The service that respondents noted as the most needed and not available in the state of Iowa was Neuropsychological services.

Funding, as consistent with the two previous surveys, is a major barrier to service provision. Both the monthly monetary cap of the Home and Community Based Services Brain Injury Waiver and low service reimbursement rates impact the availability of services for people experiencing brain injury in Iowa.

Staff providing services often do not have prior experiencing working with people experiencing brain injury. And of those staff only 49% work specifically with people experiencing brain injury, while the remaining 51% work with multiple populations. The training that staff receives varies widely from the training required by state administrative code to over 100 hours annually.

An area specifically looked at in this survey for the first time was Certified Brain Injury Specialist Certification. The Advisory Council on Brain Injuries specifically requested that this topic be included. Respondents were asked if staff commitment, time cost, lack of training or cost was a barrier to certification. The cost of staff time and the cost of certification were the primary barriers reported by respondents.

Recommendations

Based on the survey and the discussion the following recommendations are made:

1. Continued access by Iowa's service providers to brain injury training and individual case consultation for challenging cases.

2. Continued offering of opportunities for Iowa service provider staff to become certified by the Academy for the Certification of Brain Injury Specialists.
3. Development of alternative training curriculum and certification structure that will be:
 - a. Accessible
 - b. Cost effective
 - c. Outcome driven
 - d. Portable
 - e. Voluntary
4. Development of curriculum for mid-level managers who supervise direct support professionals within above-mentioned curriculum.
5. Development of curriculum for serving people with multi occurring disorders.
6. Develop learning opportunities for Iowa's service providers to address increasing capacity for serving individuals experiencing multi-occurring disorders and/or challenging behaviors.
7. Continued support and coordination with the Brain Injury Alliance of Iowa including offering collaborative training opportunities.