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 the 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, and to uncover barriers discouraging providers from offering services to individuals who have experienced brain injury.

The 2006 survey analysis was used as an integral part of the IDPH's State Plan for Brain Injury 2007-2010 and successful application for a Federal Traumatic Brain Injury grant through the Health Resources and Services Administration (HRSA).

Current survey:
In 2010, the IACP in partnership with the IDPH developed a second survey regarding brain injury services in the state of Iowa. Many of the same items and questions were utilized and results of those items will be analyzed for trends. Other items of interest were added and will be analyzed individually.

METHODOLOGY

Subjects:
The method used for sampling was a purposive method which identified current disability service providers in the state of Iowa.

Data Collection:
A 24 question tool was developed that utilized multiple choice and open ended questions. The tool was modeled after the instrument utilized in 2006 but included both minor changes and subject matter changes. Demographic information was collected at the beginning of the survey.

An initial email was sent to over 125 agency members of the IACP, inviting participation. Participation was encouraged by offering three gift certificates ($100, $75, $50) for brain injury related materials from Lash and Associates. 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 January of 2010. Eighty-six individuals, representing 78 individual agencies or 62% of the IACP membership, answered the survey representing an increase of 43% in terms of individual participation and 30% in agency participation from the 2006 survey.

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

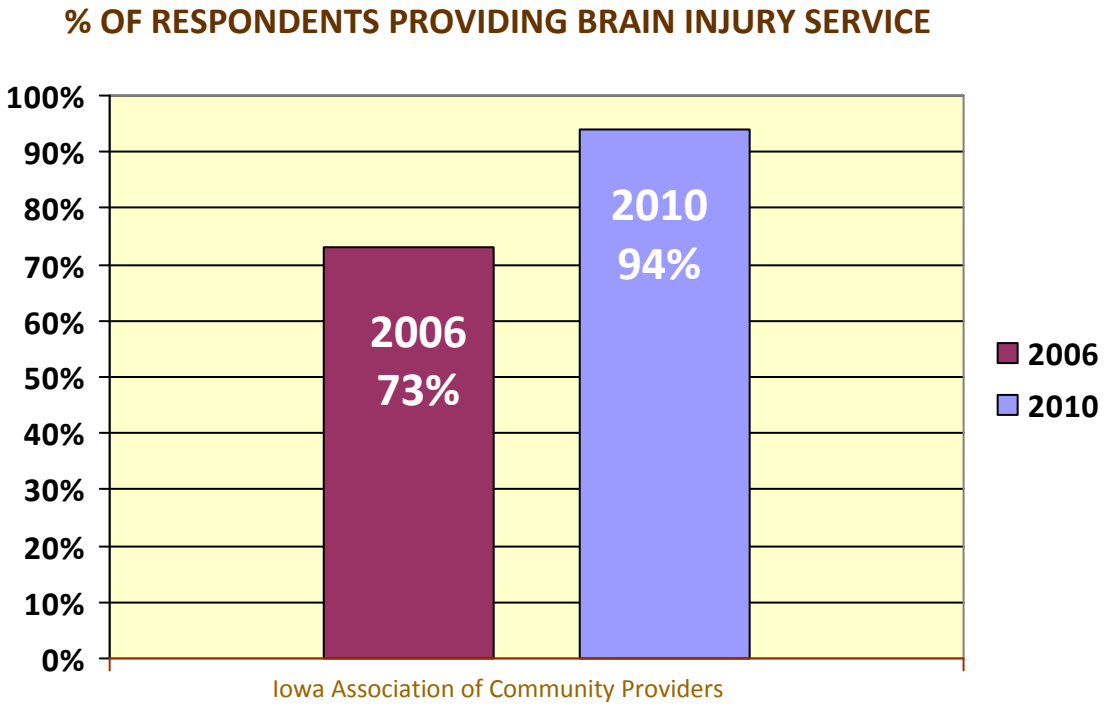
I. Demographics of participants
II. Barriers to providing services
III. Services
IV. Training

I. Demographics

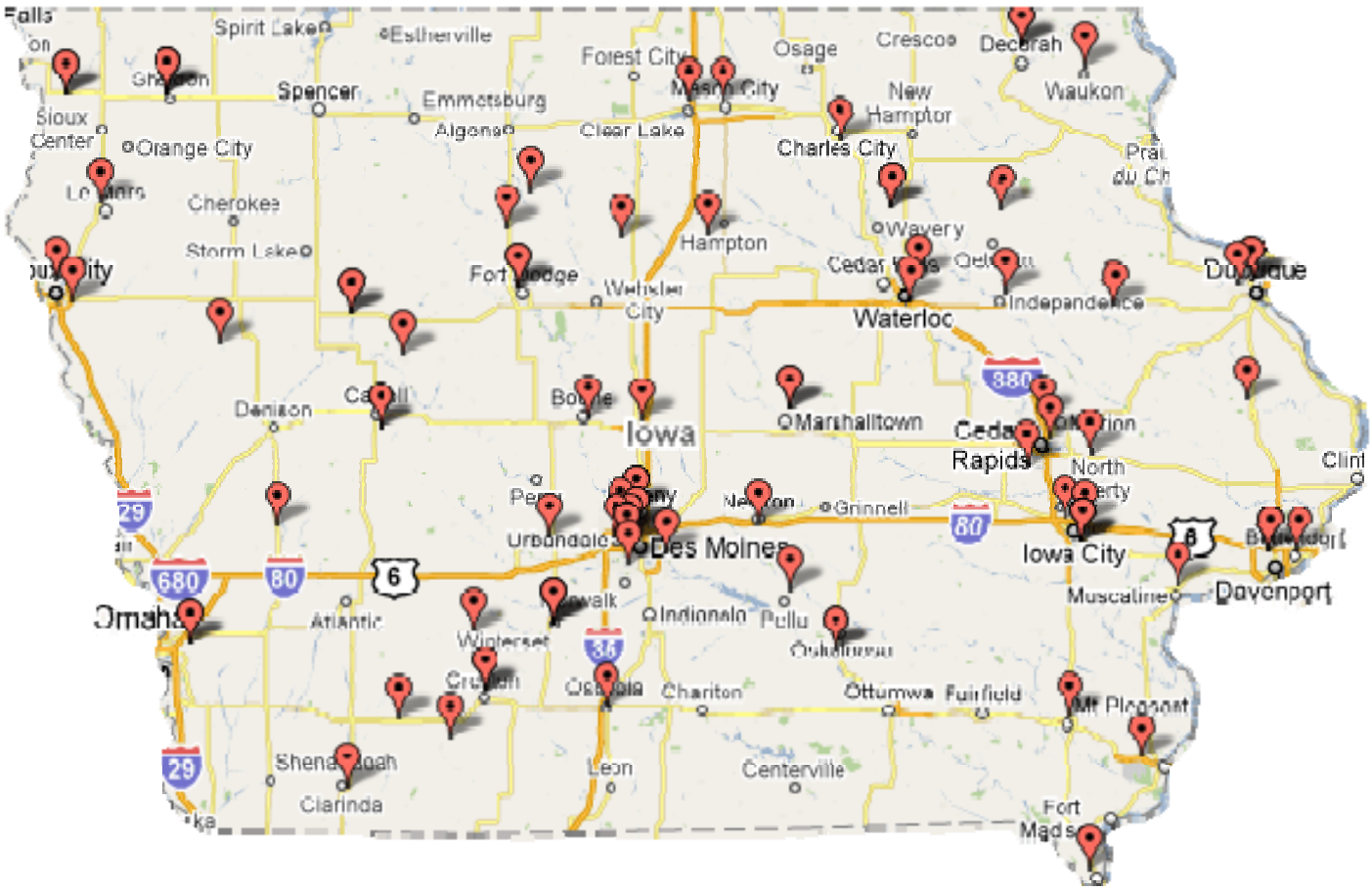
The following questions were used for analysis in this area:

- 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 Iowa Brain Injury Association?
- What services do you currently provide?

A total of 86 individuals from 78 individual agencies responded to the Iowa Association of Community Provider's Brain Injury Provider Survey. Of those respondents 94% responded that their organization provides services to individuals who have experienced brain injury. In the 2006 survey completed by the IACP approximately 73% of respondents provided services to individuals experiencing brain injury. This represents a substantial increase in the amount of the IACP members who are providing services to those experiencing brain injuries.



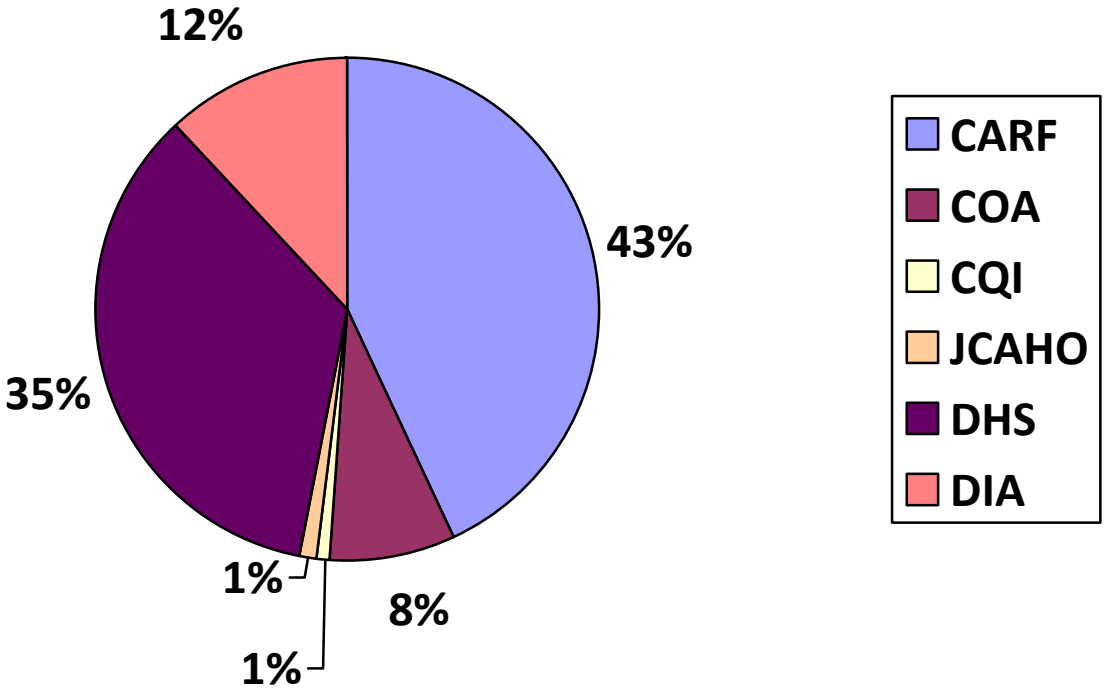
The following graphic represents where each respondent was from:



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.

The following chart outlines the types of accreditations that participating agencies held:

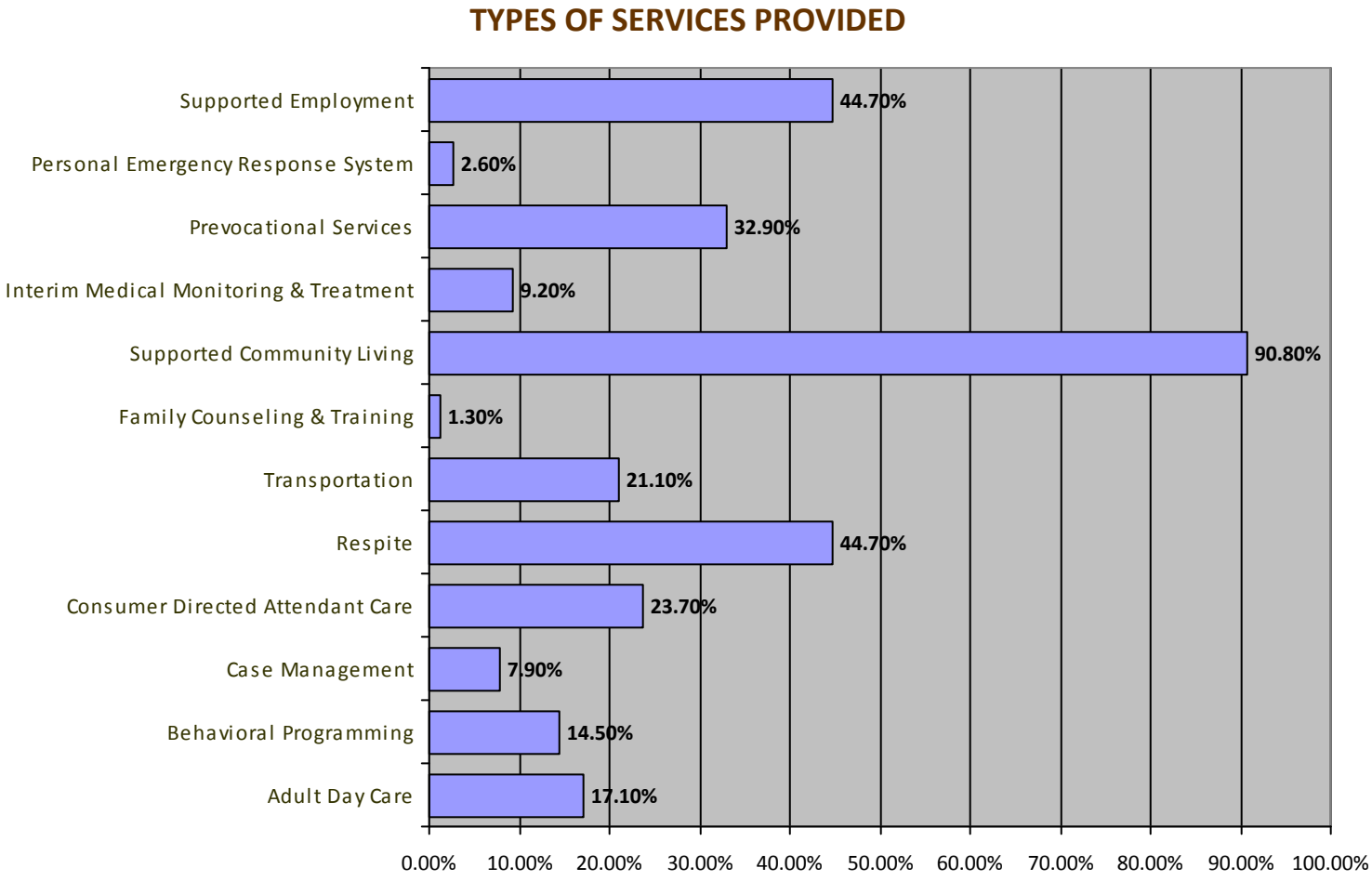
ORGANIZATIONAL ACCREDITATION



In the last year the agencies that participated in the survey served approximately 680 individuals experiencing brain injury. The largest number served in a single agency was 57 and the smallest number was 1. (Eight individual agencies report service to 1) The average number of individuals served experiencing brain injury was 10. The number of individuals served by respondents to this survey represents over half of the individuals currently on the Iowa Brain Injury Waiver.

52.3 % of all respondents answered that their organization was a member of the Brain Injury Association of Iowa. 47.7% of respondents reported that their agency was not a member of the Brain Injury Association of Iowa.

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



II. 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?

Respondents were asked to describe in a narrative format the major barriers they perceived to providing services to people experiencing brain injury. In 52% of all answers funding was mentioned as a barrier to service provision. Within the responses that mentioned funding, the following were also identified as sub-categories of funding barriers:

- Vocational service funding
- Cost of staff training funds
- 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/keeping qualified staff
- Funding for 24 hour support

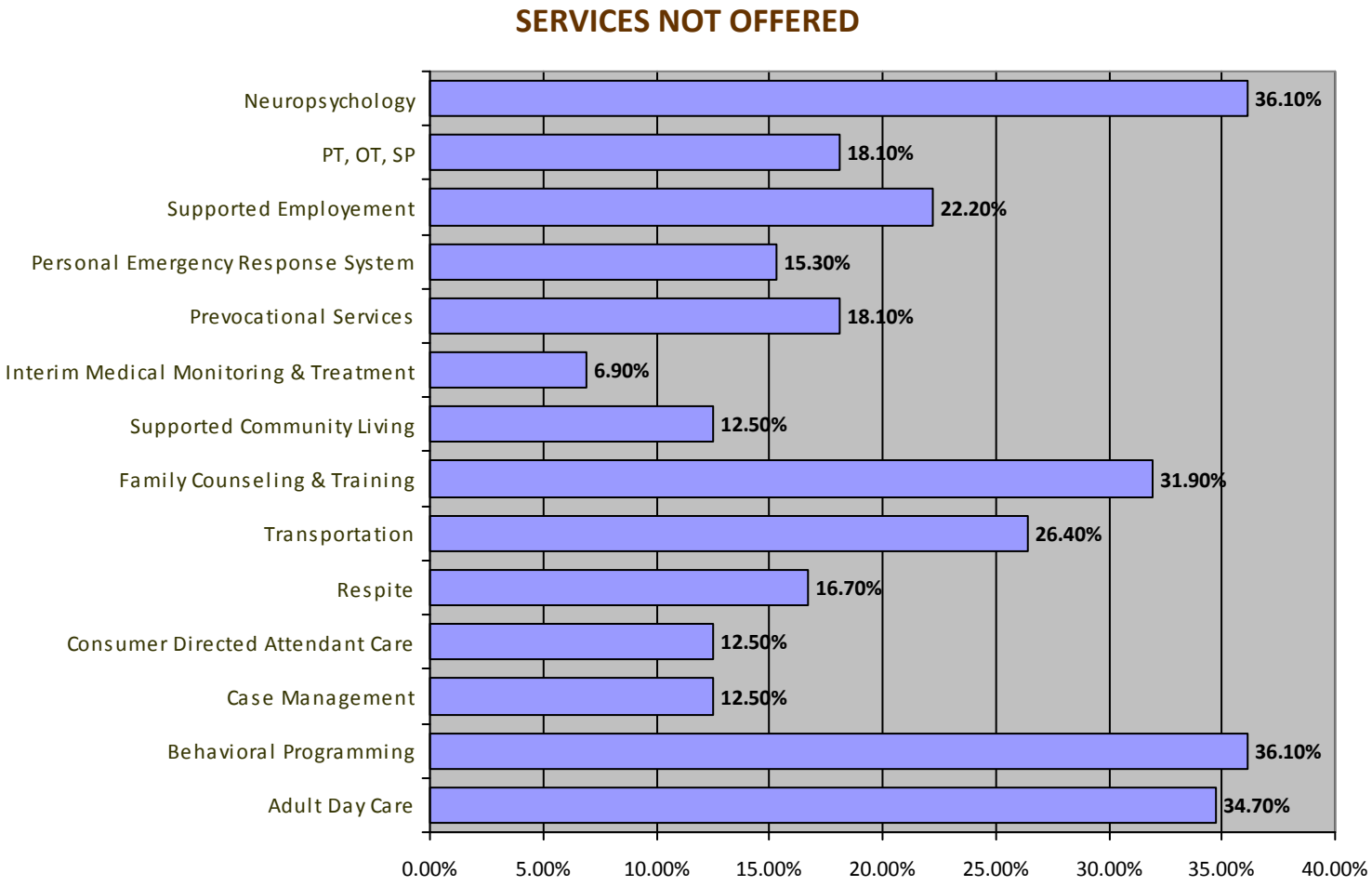
Other perceived barriers to services included:

- 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

In 2006, 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-six 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 puts consumers in need of "daily" services at risk. Another respondent reported that the $2,800 does not cover the scope of services needed by people. In some instances, this lack of funding can lead to a lessening of the quality of services the individual receives.

Respondents were asked to identify services not currently offered and believed would be beneficial to persons experiencing brain injury. The question was multiple-choice with an 'other' option that allowed for narrative feedback.

The responses were as follows:



The last set of questions pertained to cognitive rehabilitation. In the 2008 the Iowa Advisory Council on Brain Injuries sponsored a two day symposium on cognitive rehabilitation. It was discovered that there is limited access to both formal and community based cognitive rehabilitation in the state of Iowa. Approximately 87% of the respondents reported that their agency does not offer cognitive rehabilitation services. When asked 'why', the majority of providers cited a lack of clear funding sources for the service, a lack of knowledge about cognitive rehabilitation as well as how to provide it as barriers. It was consistently mentioned as an area where providers need more information and knowledge to be able to make informed decisions about providing the service. Several recipients also mentioned that training for their staff in this area would be extremely beneficial.

III. Services

The following questions were used for analysis in this area:

- Where does your agency get information about brain injury resources, services, and supports?
- Does your organization have designated staff specifically assigned to work on issues related to TBI?
- 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 traumatic brain injury?
- What type of assessment tool or process does your organization use when beginning services with someone who has experienced TBI?

An overwhelming majority of respondents replied that they get information about brain injury resources, services and supports from the IACP. Respondents also utilize the Brain Injury Association of Iowa, Iowa Medicaid Enterprise and HCBS specialists/trainings for information. Other answers of note include:

- North American Brain Injury Society
- Case Managers
- University of Iowa Lending library
- Websites
- The IDPH
- Magellan
- Polk County Health Services

A 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 34.3% of those agencies reported staff coming to their agency with previous brain injury training and experience. Over 65% of respondents reported staff coming with no previous brain injury training and experience.

When asked about the total number of staff in their organization who works directly with individuals who experienced brain injury the responses varied greatly. The answers ranged from three organizations reporting over 100 staff working directly with individuals experiencing brain injury, to four organizations reporting no staff working directly with individuals experiencing brain injury. Based on the responses, the average number of staff working directly with individuals experiencing brain injury in any given agency was 16.

Respondents were also asked to describe the type of assessment tool or process utilized when beginning services for someone experiencing brain injury. Many agencies noted that they have developed their own tools while others utilized standardized assessment tools. Respondents also noted utilizing the social history and functional assessment tools completed by case management. No major themes that came out of the answers from respondents.

IV. Training

The following questions were used for analysis in this area:

- What is your estimated number of hours spent per year in continuing education and training specific to TBI by staffs who serve individuals with TBI? (Conferences, Workshops, Etc.)
- Does your agency offer in-service training programs on TBI?
- Does any member of your staff regularly attend the Iowa Brain Injury Association's Annual Conference?
- Why don't members of your staff regularly attend the Iowa Brain Injury Association's Annual Conference?
- How do you currently receive information on educational training programs?
- What training, technical assistance, or information do providers need the most?

Respondents were asked to estimate the time spent by staff engaging in training specific to brain injury in their agency. The responses received varied greatly. Some agencies answered that their staff receiving a minimum of 25 hours of training specific to brain injury, while several answered that their staff receive zero hours of training specific to brain injury annually. A common theme was that staffs receive initial training upon hire, as required by Iowa Administrative Rules, but the level of ongoing training they receive is variable. Another theme mentioned throughout the responses was that one staff, usually in a leadership role, will attend brain injury related training and then present the information to the rest of the staff, including the direct support professionals. This 'train the trainer' model has been incorporated by the Iowa Department of Human Services when providing initial HCBS Brain Injury Waiver Training.

Agencies offer a variety of in-service programs on brain injury and the depth of those topics were variable among respondents. Approximately 53.8% of respondents reported that their agency offers in-service trainings on brain injury. Of that 53.8%, 38% of those agencies only offer a modification of the HCBS Brain Injury Waiver curriculum that is presented by the HCBS specialists throughout the state. One agency noted they offer monthly updates and training opportunities for staff that include case consultation.

Over 98% of respondents reported IACP as their primary source of information for receiving information about available training programs. The Brain Injury Association of Iowa also was mentioned as a source by 57% of respondents.

Respondents were also asked to report if they or any member of their staff attend the Brain Injury Association of Iowa's annual conference. Over 53% respondents reported that they or staffs from their agency have attended this conference at least once. Many respondents noted that they send multiple staff. The largest number noted was eight staff from one agency. When asked why members of their staff don't regularly attend the Brain Injury Association of Iowa's annual conference, 68.8% of

respondents noted that the cost to attend is too expensive. Several respondents also noted that they serve so few individuals experiencing brain injury this is not the best use of limited training dollars.

The final question of the survey asked respondents what types of training; technical assistance and information that service providers need the most. There were three prevalent themes are present in response to this question.

1. The difference between working with individuals experiencing intellectual disability and brain injury,
2. How to work with challenging behavioral issues after brain injury, and
3. How to use assessment tools to plan for services.

Other answers include:

- Training for direct support professionals
- How to utilize services available on the brain injury waiver
- Goal development
- Compensatory strategies
- Crisis intervention
- Accessing funding
- Technical assistance on administrative rules
- Rate setting
- Information on the causes of brain injury and the statistics

DISCUSSION OF FINDINGS

The purpose of this survey was to paint a picture of who provides brain injury services in Iowa, barriers to the provision of those services, the services that are provided and training/consultation needs of service providers in Iowa.

The responses clearly demonstrated that more services and service providers are available for Iowans to choose from in 2010 than in 2006. In the last two years several systemic changes have occurred that may account for this:

1. An increase in the availability of brain injury training in the state of Iowa.
2. Increased availability of training, support, and consultation to brain injury service providers statewide.
3. Increased access to services for individuals experiencing brain injury facilitated by:
    a. The development and successful implementation of a Neuro-Resource Facilitation program.
    b. A substantial increase in the amount of brain injury waiver ‘slots’ (an increase of over 400 since 2006).

As in 2006, survey respondents came from every geographic area of the state and the majority of them utilize the Iowa Brain Injury Waiver to bill for services that they provide. Predictably, over 78% of all respondents were either accredited by the Iowa DHS or CARF (which allows a provider deemed status with Iowa DHS).

Supported community living, respite care and supported employment were the most commonly provided services. Of respondents, 14.5% reported offering behavioral programming but according to Iowa DHS data behavioral programming has not been billed for since the origination of the waiver in 1996. This would suggest that agencies are providing the service as part of their operational activities and are not billing or providing it as a separate service. The results were similar to the results found in 2006.

Much of the barriers listed related to funding and issues of not being able to provide services at current reimbursement rates or within the current rule structure. This theme was much more pronounced than in 2006 where most answers focused on a lack of demand. Over 66% of respondents reported the brain injury waiver 'cap' of approximately $2,800 was a barrier to service provision. This aligns with anecdotal data from families who say agencies are unwilling to serve their family member due to a lack of funding. This leaves many individuals who have either high medical needs or challenging behavioral issues shut out of much needed "daily" services. Also, respondents continue to rate a lack of quality training and qualified staff as a major barrier to service provision.

Respondents replied that the most needed but unavailable services in the state of Iowa were: neuropsychology, family counseling and training, behavioral programming, adult day services, and transportation. These answers were consistent with the answers from respondents in 2006 in which the same answers were identified.

In 2010, agencies are 17% more likely to have staff members assigned specifically to work with individuals experiencing brain injury in comparison to the 2006 data. Furthermore, a greater number of those staff members who are coming to agencies have previous training, this number rose by 13%. Both indicators would suggest that there is more opportunity to work with individuals experiencing brain injury and that the quality of the workforce is growing.

Overall the rate of agencies offering in-service training specific to brain injury rose by approximately 18% in comparison to the data from 2006. The amount of time spent on training on an annual basis continues to be variable based upon agency. Agencies offer training initially as required in Iowa Administrative Code but that initial training varies in length and curriculum. Many agencies offer the entire curriculum presented by the Home and Community Based Services Specialists, while others offer a modified version of the curriculum utilizing videos, articles and outlines of presentations.
The IACP continued to be recognized as the agency where respondents received pertinent information on available training and workshops. The BIA-IA was also mentioned by 57% of respondents and there

was a sharp increase in the number of respondents who reported attending their annual conference. In 2006, 14% replied that they regularly attended the BIA-IA annual conference, while in 2010 over 68% reported regularly attending. This increase could be attributed to increase collaboration between the IACP and BIA-IA and scholarships offered by the IACP to the BIA-IA annual conference.

Respondents reported a need for high quality, brain injury specific training in the state of Iowa. Although a variety of answers were given, three major themes were revealed in the current survey: the difference between working with individuals experiencing intellectual disability and brain injury, how to work with challenging behavioral issues after brain injury, and how to use assessment tools to plan for services. These themes are more advanced than the responses offered in 2006 in terms of the technical content which providers are requesting.

RECOMMENDATIONS

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

1. Giving providers opportunities at the local, state, and national level to expand their knowledge regarding brain injury service provision has proven to be an efficient and effective way to expand capacity. The Iowa Association of Community Providers recommends expanding these opportunities through the development of a Brain Injury Externship program. This program would involve an intensive study period of approximately one year through a variety of types of experiences including: classroom learning, online discussion and blogging, project-based learning, and an immersion experience. It is anticipated that this group would be comprised of 12-15 learners and could be facilitated by the existing brain injury training position within the IACP.
2. Development of secondary and intermediate trainings in the following areas:
    a. Working with individual experiencing brain injury in traditional service delivery systems;
    b. How to work effectively with individuals experiencing challenging behavior;
    c. Effective assessment strategies for individuals experiencing brain injury.
3. Continued collaboration between the IACP, BIA-IA, IDPH and IDHS to develop a consistent online training curriculum for use with all staff prior to providing services to people experiencing brain injury.
4. Further development of a consultative model for individuals experiencing brain injury, including linkage into existing resources such as I-PART, the state run mental health centers and community mental health centers.
5. Development of a definition and related skills training for community based service providers on the provision of community-based cognitive rehabilitation. This would be a parallel effort utilized to complement the existing efforts of the Iowa Advisory Council on Brain Injuries.
6. Continued support of current training opportunities, individual agency trainings and consultation as provided through the IACP.