# WV Traumatic Brain Injury Waiver Program

**Open Forum Report** 

June, 2014

In April of 2014 the Bureau for Medical Services and APS Healthcare conducted open forums across the state to solicit feedback and comments from members, families, stakeholders, and providers on specific sections of the current policy manual and services for the Traumatic Brain Injury Waiver Program. This report is a summary of the findings from these forums.

# WV TBI Waiver Program Open Forums - Final Report

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### Acknowledgements

#### Bureau for Medical Services (BMS) Staff

Teresa McDonough Program Manger TBI Waiver Services

#### APS Healthcare of WV (ASO) Traumatic Brain Injury (TBI) Waiver Services Staff

Barbara Recknagel, MSW, LGSW Manager

Melodee Hursey, MSW, LSW, CBIST Provider Educator

Jennifer Logan, MA, CRC, CVE, LPC, CBIS Provider Educator

> Amy Shriver, MA, CRC, CBIS Assessment Coordinator

Bureau for Medical Services and APS Healthcare wishes to thank the following providers for hosting the open forums across the state in April of 2014.

EastRidge Healthcare Systems, Martinsburg Lewis County Senior Citizen Center, Weston Prestera Center for Mental Health Services, Huntington ResCare HomeCare, Beckley

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#### 2014 Open Forums – Executive Summary

The West Virginia Traumatic Brain Injury (TBI) Waiver Program began accepting referrals on February 1, 2012. The program is a Title XIX Home and Community-Based Services Waiver that assists Medicaid beneficiaries to live in the community and avoid institutionalization. The current program has been approved for a three-year period of February 1, 2012 through January 31, 2015 by the Centers for Medicare and Medicaid Services (CMS).

In preparation for the 2015 reapplication to CMS, the Bureau for Medical Services (BMS) and APS Healthcare as the Administrative Service Organization (ASO) conducted eight open forums and one conference call to gather input from members, families, providers, and other stakeholders. These forums were held in April of 2014 across the state and by phone. Input was also submitted to the ASO by email, mail, and fax.

Forums were structured around two surveys that were developed by ASO staff, one for providers and one for members, family, and stakeholders. Provider forums were held in four locations across the state during business hours. Member/Family/Stakeholder forums were held in four locations across the state in the evening hours and on a conference call to allow for members and families to avoid missing work or other activities.

Each survey contained ten (10) items. While there were similar items on each survey, there were also unique items included that were specific to the demographic. The surveys were mailed and/or emailed to all current members, providers, and identified stakeholders such as Center for Excellence in Disabilities, TBI Waiver Quality Assurance and Improvement Advisory Council, WV Advocates, and WV Developmental Disability Council. Seventeen (17) member/family/stakeholder surveys, representing nine (9) counties and eighteen (18) provider surveys, representing twenty-eight (28) counties were completed and returned to the ASO.

A six (6)-point Likert Scale was used for both the Provider and the Member/Family/Stakeholder Survey for the majority of the survey items. There were additional items that required a "yes/no" response or a "check all that apply" response.

L = Strongly Disagree	2 = Disagree	3 = Neutral	4 = Ag	gree	5 = Strongly Agree	6 = Not Applicable	
Me	Member Survey Items			Provider Survey Items			
<ul> <li>my/my family mem</li> <li>I am actively involv</li> <li>My staff are trained</li> <li>The services offerenceds.</li> <li>The age requirement lowered to include</li> <li>The change in polic applicants is a positi</li> <li>The Service Deliver available in the TBI needs.</li> <li>Cognitive Rehabilitite Respondents were asked answer with a request to response was "yes."</li> <li>There are additionatory through the Waiver And, finally respondents</li> <li>Services they were currence 10. Please check all the Respondents were also to the service of the</li></ul>	ed in determining what d and prepared to meet d through the TBI Waive nt for the TBI Waiver pr people under the age o cy that removed the inpa- tive one. y Models (traditional/pu Waiver program meet t ation Therapy is a valual d to respond to one item to provide additional info al services that I would I r. s were asked to identify ently receiving. a services that you are n	services I need. my service needs. er program meet my ogram should be f 22. atient requirement for ersonal options) the member's/my ble service to me. In that required a yes/no ormation if the ike to see offered which TBI Waiver ow receiving. additional comments	to d 2. The men 3. The the 4. The to u 5. The incli 6. The app 7. The in th <i>Respond</i> 8. Are men 9. The <i>And, find</i> <i>they pro</i> 10. Plea prov	develop the s e design of th mbers' need e training req staff to work e policy requi understand. e age criterior ude people u e change in p plicants is a p e service Dell he TBI Waive dents were a with a reque there servic mbers? e policy manu ally responde ovide. ase check all viding. dents were a	e service plan ensures that i s and choices. uirements for personal atte k with the member. rements for provider certific n for the TBI Waiver Program under the age of 22. olicy that removed the inpat	the plan is based on the indant services prepare cation are clear and easy in should be lowered to tient requirement for isonal options) available ber's needs. is that required a yes/no rmation. it would beneficial for rstand? which TBI Waiver Services r agency is currently	

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### **Member Survey**

Because the primary attendees at each of the Member/Family/Stakeholder forums were stakeholders, many of the survey items were answered as not applicable (#6). When an answer was provided, the respondents were generally in agreement with the item.

Family and members who responded also scored the items on the positive end of the scale. Few members have used Cognitive Rehabilitation Therapy. While they felt it was a valuable service they had not experienced it firsthand to provide feedback.

Additional services that members/families/stakeholders would like to see offered through the waiver are: Nursing, supported employment, Participant Directed Goods and Services in Traditional Model, respite, supported living, and community day care/interaction.

There was consensus with this group that the state's decision in 2013 to change the admission criteria was a positive change. This policy change removed the requirement that applicants must be inpatient at the time of application.

They also agreed that the age should be lowered below the current requirement of 22 years. However, there was not consensus on what age should be used.

Respondents were generally satisfied with the eligibility determination process, although some respondents did comment on the length of the process.

#### **Provider Survey**

Some surveys received were from providers enrolled but not yet serving members. For this reason there were a high percentage of provider surveys that included qualifying statements such as "The paperwork looks fine, but we have not used it yet, so rated it neutral." Or "I have never completed one of these – brand new to TBI program."

Providers were positive in their responses on all the survey items with the majority scoring each item as agree or strongly agree.

Providers also identified additional services that they felt should be added to the TBI Waiver program. These mirrored the responses received from the members, families, and stakeholders.

Providers felt that generally the manual (Chapter 512) was clear and understandable. However, some felt there were areas that needed more clarification and explanation. For example, providers stated that more information is needed about who can work for a member and what defines legal representative.

As was stated during the member forums, the providers also concurred that removing the inpatient requirement was a positive step. They also supported lowering the age requirement, but there was not consensus on what age it should be. Providers also raised additional questions/concerns regarding their ability to provide services for a younger population since those in attendance were primarily serving adults including elderly persons with disabilities.

Providers who responded to the survey questioned the appropriateness of using the Pre-Admission Screening with a brain injury population. No specific tool was suggested, but respondents felt that a tool that looks at brain injury specific deficits such and memory and cognition would be more suitable.

### Summary/Recommendations

Thirty five (35) surveys' findings were used in completing this report. An additional member survey and two provider surveys were received outside of the reporting timeframe and the findings were considered in this report.

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The purpose of the forums was to seek comment on the current program requirements and services. Any questions or requests that arose during the forums were addressed by BMS and the ASO after the survey items were completed. For example, during one forum a provider agency requested training and technical assistance and the ASO will be providing this.

Overall both groups were positive about the TBI Waiver Program and the changes that were made to the admission criteria. Comments and scoring also reflected an overall positive response to the current forms and processes used to determine eligibility. There were some comments however, that the Pre-Admission Screening and Rancho Los Amigos Levels of Cognitive Functioning Scale may not be the most appropriate tools for this population. A number of respondents expressed a need for evaluation tools that focused more on the specific deficits seen in a traumatic brain injury population, for example, memory and cognition deficits rather than physical deficits.

Both groups identified a number of services that they would like to see included in the Waiver Program. These services should be further explored to determine feasibility of inclusion within the existing budget. The most requested additional services were respite and nursing services. Other services requested included Participant-Directed Goods & Services for members in the Traditional Model, residential, supported living, and day programming.

The age requirement should be further explored and considered for inclusion in the upcoming application. Before inclusion, more information will be needed regarding the impact on current age-based programs, such as Early Childhood Intervention and I/DD Waiver. While many respondents in both groups thought lowering the age requirement was a good idea, no one could speak to the changes that would be required and a number of current providers expressed concerns with their ability to be a service provider for a younger population.

BMS and the ASO will continue to review the comments and recommendations from these surveys and forums as well as other venues to prepare the 2015 reapplication to meet the needs of the TBI Waiver members.

**Open Forums - Final Report** 

### TBI Waiver Open Forums Survey Findings

The Bureau for Medical Services and APS Healthcare conducted Open Forums (Forums) as an opportunity for members, families, providers and other stakeholders to provide input for the upcoming 2015 application renewal of the WV TBI Waiver Program (Waiver).

WV's TBI Waiver is currently approved for the three-year period of February 1, 2012 through January 31, 2015 by the Centers for Medicare and Medicaid Services. CMS recognizes that the design and operational features of waiver programs will vary depending on the specific needs of the target population, resources available to the state, service delivery system structure, state goals and objectives, and other factors. Because of this, states have latitude to design waiver programs that are cost-effective and employ a variety of service delivery approaches, including participant direction of services.

Eight (8) Forums and one Conference Call were held throughout the state for the convenience of the members, families, providers and other stakeholders. Member forums were typically held in the evening to allow for working members, family members and stakeholders to avoid missing work or other activities. Attendance rates varied depending on locations, and one member/family forum had no attendees. The Forum notices included a survey on the back on which providers/ members/stakeholders could complete and submit back to APS if they were unable to attend a forum. Eleven (11) member surveys were submitted at forums; two (2) were submitted via mail/email. Sixteen (16) provider surveys were submitted at forums; two (2) were submitted via mail/email. One member/stakeholder and two provider surveys were received after the Final Report was completed.

Forums were structured around the survey items to solicit feedback on the TBI Waiver policies, procedures, and covered services. APS staff facilitated each forum to ensure each topic was discussed; attendees had the opportunity to provide verbal feedback and ask questions, as well as documenting feedback on a survey form. Attendees also had the opportunity to bring up topics not on the survey. These were kept track of by APS staff during a "parking lot" discussion, and were addressed at the conclusion of the discussion regarding survey questions. APS Staff who facilitated the forums were Barb Recknagel, TBI Waiver Program Manager; Melodee Hursey, Provider Educator; Jennifer Logan, Provider Educator; and Amy Shriver, Assessment Coordinator. Bureau for Medical Services (BMS) TBI Waiver Program Manager Teresa McDonough attended all of the forums.

Location	Member/Family Provider/Stakeholder	Date	Time	Number Attended
Huntington	Provider	April 8, 2014	2:00 pm – 4:00 pm	3
	Member/Stakeholder	April 8, 2014	6:00 pm – 8:00 pm	0
Beckley	Provider	April 10, 2014	2:00 pm – 4:00 pm	4
	Member/Stakeholder	April 10, 2014	6:00 pm – 8:00 pm	4
Weston	Provider	April 14, 2014	2:00 pm – 4:00 pm	4
	Member/Stakeholder	April 14, 2014	6:00 pm – 8:00 pm	3
Martinsburg	Provider	April 16, 2014	2:00 pm – 4:00 pm	4
	Member/Stakeholder	April 16, 2014	6:00 pm – 8:00 pm	2
Conference Call	Member/Stakeholder	April 24, 2014	1:00 pm – 3:00 pm	2

 Table 1: TBI Waiver Forum Locations and Attendance

# **Open Forums - Final Report**

County	# Member/Family Surveys	# Provider Surveys	County	# Member/Family Surveys	# Provider Surveys
Barbour		1	Mineral		1
Berkeley		5	Mingo		1
Boone			Monongalia	1	1
Braxton		2	Monroe		
Brooke			Morgan		5
Cabell	1	1	Nicholas		2
Calhoun			Ohio		
Clay			Pendleton		
Doddridge		1	Pleasants		
Fayette		4	Pocahontas		
Gilmer		1	Preston		
Grant			Putnam		1
Greenbrier		2	Raleigh	3	4
Hampshire	2	2	Randolph		1
Hancock			Ritchie		
Hardy			Roane		
Harrison		3	Summers		2
Jackson			Taylor		
Jefferson		5	Tucker		
Kanawha	3	1	Tyler		
Lewis	2	4	Upshur	2	3
Lincoln		1	Wayne		1
Logan			Webster		1
Marion		1	Wetzel		
Marshall			Wirt		
Mason			Wood	2	
McDowell			Wyoming		
Mercer		3	Unknown	2	

Table 2: Provider surveys may represent more than one county since many providers serve more than one county

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# Survey Item #1 (Member/Stakeholder)

"I feel that the medical eligibility assessment adequately captured my/my family member's needs" focused on whether the initial medical eligibility assessment tools (the Pre-Admission Screening and the Rancho Los Amigos Levels of Cognitive Function) are effective in determining the needs of TBI Waiver applicants.

### Data Summary

- 42% of respondents strongly agreed or agreed that the medical eligibility assessment adequately captured their needs or their family member's needs.
- 0% had no opinion.
- 5% either strongly disagreed or disagreed.
- 53% had no response.
  - While approximately half of the respondents had no Figure 1: Survey Item #1 Member/Stakeholder response, that group was primarily composed of
    - stakeholders who are not applicants or members of the Waiver, and do not have family members who are applicants or members.

### **Open Forum Comments and Excerpts from Survey Narrative**

- Caregiver mentioned that the ASO staff did a great job with the assessment. Felt our assessment was good. She was impressed with how many questions, and how staff asked the right questions in the right way to help them think about their responses.
- "Everyone we have worked with has been very cordial, professional and competent."
- "PAS is targeted to the elderly which may not be appropriate."
- "Needs more cognitive evaluation."
- "PAS & Rancho are hard to reconcile/use additional sections of PAS IADLs and not just ADLs or add cueing
- A stakeholder mentioned that the process to meet eligibility is too stringent.

### Survey Item #2 (Member/Stakeholder)

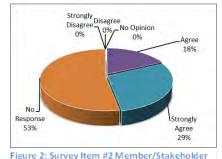
"I am actively involved in determining what services I need" focused on whether members feel they are involved in the process of developing a service plan that reflects their needs.

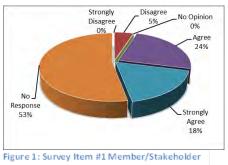
#### Data Summary

- 47% of respondents strongly agreed or agreed that they or their family members are actively involved in determining what services they need.
- 0% had no opinion.
- 0% either strongly disagreed or disagreed.
- 53% had no response.

### **Open Forum Comments and Excerpts from Survey Narrative**

- They felt he was very involved in the process and did a great job with service planning
- "We decide everything together."





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# Survey Item #3 (Member/Stakeholder)

"*My staff are trained and prepared to meet my service needs*" focused on whether staff, which provides services to members of the Waiver, is adequately trained and able to meet the members' needs.

#### Data Summary

- 36% of respondents strongly agreed or agreed that their staff are trained and prepared to meet their service needs.
- 5% had no opinion.
- 0% either strongly disagreed or disagreed.
- 59% had no response.

### **Open Forum Comments and Excerpts from Survey** Narrative

- A stakeholder has heard that additional/more specific training for crisis intervention is needed.
- A caregiver said "I tell him all the time to let me know if I am doing anything wrong or if I should be doing it differently".
- "We always need more training."
- TBI needs are different so more than 8 hours of training is indicated.

### Survey Item #4 (Member/Stakeholder)

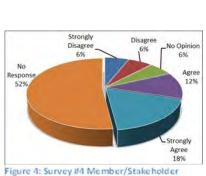
"The services offered through the TBI Waiver program meet my needs" focused on whether the services offered through the Waiver are meeting the needs of members.

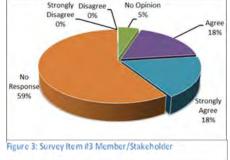
#### **Data Summary**

- 30% of respondents strongly agreed or agreed that the services offered through the TBI Waiver meet their needs.
- 6% had no opinion.
- 12% either strongly disagreed or disagreed.
- 52% had no response.

#### **Open Forum Comments and Excerpts from Survey Narrative**

- A stakeholder feels they do not. She would like to see additional services offered. Specifically, she would like to see services geared toward rehabilitation needs, such as ICF facilities.
- Caregiver feels that they do. She is interested in getting a magnifier so that he can see bank statements, etc. (PDGS).
- A family member said "I am really impressed with the program. It's been an awesome help and blessing to me and my family. If there is anything I can do to help for the reapplication, I would be happy to do so".
- "Nursing services could be very beneficial."
- "I think that the services are inadequate for TBI clearly; strongly disagree that services are enough."





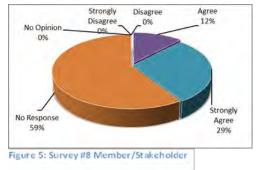
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### Survey Item #8 (Member/Stakeholder)

"Cognitive Rehabilitation Therapy is a valuable service to me" focused on whether Cognitive Rehabilitation Therapy, a covered service under the Waiver, is a valuable service.

#### **Data Summary**

- 41% of respondents strongly agreed or agreed that Cognitive Rehabilitation Therapy is a valuable service offered through the Waiver.
- 0% had no opinion.
- 0% either strongly disagreed or disagreed.
- 59% had no response.



### **Open Forum Comments and Excerpts from Survey** Narrative

- A stakeholder indicated that more information is needed about the service, and education is needed for applicants/members about where/how to access these services.
  - A stakeholder called it imperative. Stakeholder 2 said he heard there were problems locating CRT providers because the requirements were so strict. Stakeholder 2 asked "Are there any incentives for agencies to provide CRT, and why are there not more providers"? Also questioned was the reimbursement rate.
- "Do not have a person able to come. Why not a case worker?
- "Just signed up for these services."
- "Valuable service for individuals with a TBI."
- "Is imperative to treating a TBI."

### Survey Item #1 (Provider)

"The template for member assessment provides enough information to develop the service plan" focused on whether the member assessment template is thorough enough to develop an effective service plan.

#### **Data Summary**

- 78% of respondents agreed or strongly agreed that the template for member assessment provides enough information to develop the service plan.
- 17% had no opinion.
- 0% either strongly disagreed or disagreed.
- 5% had no response

#### **Open Forum Comments and Excerpts from Survey Narrative**

- "We have one member and the paperwork is good."
- A Provider said "Yes, it's very thorough; takes forever to do one."
- A Provider feels like the service plan is very person centered and the member assessment is pretty lengthy and thorough.

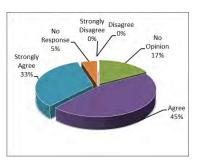


Figure 6: Survey Item #1 Provider

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• "Covers all areas to provide proper service for Activities of Daily Living coverage."

### Survey Item #2 (Provider)

"The design of the service plan ensures that the plan is based on the members' needs and choices" focused on confirming that the service plan is person-centered, and sufficiently focused on the needs and choices of TBI Waiver members.

#### **Data Summary**

- 78% of respondents strongly agreed or agreed that the service plan design ensures that the plan is based on the members' needs and choices.
- 16% had no opinion.
- 0% either strongly disagreed or disagreed.
- 6% had no response.

#### **Open Forum Comments and Excerpts from Survey Narrative**

- A Provider felt that the design was person-centered and reflected peoples' differences.
- "Ensures person-centered service plan."
- "Members' choices are highly stressed."
- "Not enough space on ADL section."

#### Survey Item #3 (Provider)

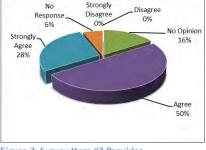
"The training requirements for personal attendant services prepare the staff to work with the member" focused on whether waiver staff is adequately prepared to work with members, given the current training they receive.

#### **Data Summary**

- 39% of respondents strongly agreed or agreed that the training requirements for personal attendant services prepare the staff to work with the member.
- 33% had no opinion.
- 0% either strongly disagreed or disagreed.
- 28% had no response

#### **Open Forum Comments and Excerpts from Survey Narrative**

- A Provider feels the crisis intervention training is somewhat vague, and her agency could use resource material.
- "What type of certification is required for providing crisis training?
- A provider said "We have had members who have behavioral issues. We have researched in order to be able to provide additional training specific to the member's needs.
- "Need more resources to train crisis intervention vs. emergency response."
- "May need supplemental for special needs."





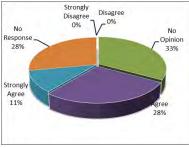


Figure 8: Survey Item #3 Provider

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### Survey Item #4 (Provider)

"The policy requirements for provider certification are clear and easy to understand" focused on the clarity of the policy requirements for provider certification.

#### **Data Summary**

- 67% of respondents strongly agree or agree that the policy • requirements for provider certification are clear and easy to understand.
- 28% had no opinion.
- 0% either strongly disagreed or disagreed.
- 5% had no response

#### **Open Forum Comments and Excerpts from Survey Narrative**

- A Provider felt that it was very easy to understand with help provided by the ASO staff.
- Some Providers had questions about the quality management plan within the provider certification. One Provider requested additional training and/ or technical assistance from APS.

### Survey Item #9 (Provider)

"The policy manual is clear and easy to understand?" focused on whether the policy manual is user-friendly.

#### **Data Summary**

- 78% of respondents said yes.
- 11% said no.
- 11% had no response.

#### **Open Forum Comments and Excerpts from Survey Narrative**

- "So far, yes", said A Provider. "The language is easy to interpret, but Figure 10: Survey Item #9 Provider there are a few things that need interpretation."
- A Provider feels some areas could be enhanced, including the area of legal representation.

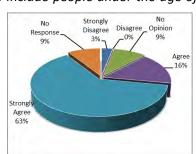
### Survey Item #5 (Provider & Member/Stakeholder)

"The age criterion/requirement for the TBI Waiver program should be lowered to include people under the age of

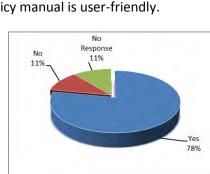
22" focused on whether the minimum age of 22 should be lowered or eliminated, so that individuals under 22 can receive services through the Waiver.

#### Data Summary

- 79% of respondents strongly agreed or agreed that the age requirement should be lowered from 22.
- 9% had no opinion.
- 3% either strongly disagreed or disagreed.
- 9% had no response.







No

Response

Strongly

50%

Figure 9: Survey Item #4 Provider

Agre 17% Strongly

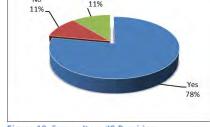
Disagree

0%

Disagree

No Opinior

0%



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• Overwhelmingly, respondents felt that the age requirement for the Waiver should be lowered.

#### **Open Forum Comments and Excerpts from Survey Narrative**

- A Provider asked whether there are other resources available for that age demographic. She said "my agency's outings consist of Wal-Mart and would not be age appropriate. They are geared towards the senior population".
- A Provider is passionate about this. She believes the thinking was that people under 22 could be covered on IDD, but their wait list is over 1000. She has seen a lot of families struggling, and the wait time for IDD is approximately three (3) years. Statistically, the highest number of brain injuries occurs in males age 15-24. An agency received a lot of calls about a younger male with a TBI. His family had to move because of the lack of resources for children locally. BMS asked "do the agencies have any issues about opening up to people under 22?" "There would need to be additional training for homemakers who are used to working with adult members. It's hard to get IDD providers to switch gears and provide services to individuals with TBI. Additional education, training and involvement with the school system would be needed".
- A Provider said "definitely for teens and up. Maybe not for pediatric patients, as services we provide are not geared to that demographic".
- A Provider asked "Why was age 22 the original age requirement"? The Provider feels that it would be good to have a younger age requirement for TBI Waiver. There are a lot of MVA and ATV accidents that occur with teenagers.
- A Provider said "the statistics say that males 18-24 are the biggest group not represented and left to their own devices. They run into mental health and legal issues due to cognitive issues". Provider 2 said "I agree that services are needed for people under age 22. Fifteen and sixteen-year olds are driving and are at increased risk for TBI. A Provider said "the program had to start somewhere and needed to cover services for those who were without services for years".
- The DD Council would like to see the age lowered.
- "Positive."
- "Some individuals may qualify as having DD but not meet IDD diagnosis required for IDD Waiver."
- "Yes absolutely!"
- "To teen & adolescent age, pediatric resources are not in this geographical area."
- This could leave a gap of uncovered time for some individuals (before 21, a DD Disability)."

### Survey Item #6 (Provider & Member/Stakeholder)

"The change in policy that removed the inpatient requirement for applicants is a positive one" focused on the policy change that allowed people living in the community to be referred for the Waiver

#### **Data Summary**

- 86% of respondents strongly agreed or agreed that this policy was a positive change.
- 8% had no opinion.
- 3% either strongly disagreed or disagreed.
- 3% had no response.

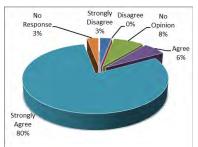


Figure 12: Survey Item #6 All Responses

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#### **Open Forum Comments and Excerpts from Survey Narrative**

- A Provider said "It's been proven that patients heal better in their own homes, so it's a positive change".
- A Provider said "Some people in nursing homes need more care than is available through the waiver, since it doesn't cover 24 hour care. I feel it was good to open up to the community. It is a better fit for people who need less intensive care".
- A stakeholder said "That was a phenomenal change". "In WV, a lot of people take family members home and try to provide care on their own, so this change was a positive one."
- A stakeholder feels that any change which makes the program more inclusive is a positive one.
- A Provider said "It has been a blessing. My daughter was inpatient, and after she was discharged, we found out about the program. She would not have qualified under the old criteria"

#### Survey Item #7 (Provider & Member/Stakeholder)

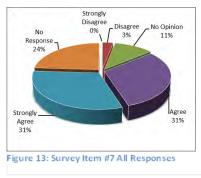
"The Service Delivery Models (traditional/personal options) available in the TBI Waiver program meet the member's/my needs" focused on whether the two available service delivery models are sufficient to meet the needs of Waiver members.

#### **Data Summary**

- 62% of respondents strongly agreed or agreed that the Service delivery models available in the Waiver program meet their or their family members' needs.
- 11% had no opinion.
- 3% either strongly disagreed or disagreed.
- 24% had no response

#### **Open Forum Comments and Excerpts from Survey Narrative**

- A stakeholder said "It's good to have the options".
- A member agreed.
- A stakeholder said "I think it's positive that we have both delivery models".
- "Good that those families/members have options."
- "Different options allow for more person-centered."
- "Meets some but not all needs, but no model answers all needs. More choices are good.



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# Survey Item #9 (Member/Stakeholder) and Survey Item #8 (Provider)

"There are additional services that I would like to see offered through the Waiver" focused on whether members/ stakeholders had specific services they would like to see offered through the Waiver, which are currently not offered.

"Are there services not currently offered that would be beneficial for members?" focused on whether there are additional services that are not currently offered through the Waiver that would benefit members.

#### Data Summary

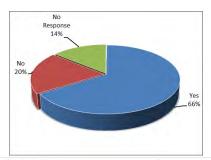
- 66% of respondents said yes.
- 20% said no.
- 14% had no response.

### **Open Forum Comments and Excerpts from Survey Narrative**

• The following services were mentioned by survey respondents/forum attendees

Service/# of respondents who recommended		
Nursing – 10	Psychological Services/Behavioral Therapy – 3	
Respite – 10	Supported Employment – 2	
Residential – 3	24 hour in home services – 2	
ICF – 2	Participant Directed Goods & Services – Traditional – 3	
Supported Living – 3	Step Down Residential – 1	
Day Programs – 3	Vocational Rehabilitation – 1	

- A stakeholder said "some place for people to go". Many of the people the stakeholder talks to have no interaction other than with mom or other family members.
- ICF some type of residential placement for individuals to receive services through the day and to be safe at night. WV does not offer step down rehabilitation or long-term residential treatment.
- A stakeholder mentioned "In Kentucky, you can get 24 hour care in the TBI Waiver". The stakeholder would like to see an interdisciplinary approach where all services are provided and the providers are communicating. This way, treatment could be more tailored to the person's needs.
- "Yes. As a service provider to individuals with Brain Injury, I have noticed survivors experiencing transportation issues at every community-based support services."
- "Yes. More community interaction."
- "Spouses should be able to be caretakers."
- A Provider feels respite is most important. Families sometimes don't realize until they get their loved one home how much care they will need.
- A Provider said "Medical administration, if someone has a tracheostomy or other skilled nursing needs". Another Provider said "PA's aren't allowed to use Band-Aids or address any medical need". The initial Provider said "Family can be trained to do some things, like ROM activities, but need education".
- "Yes, Participant Directed Goods and Services for traditional model, and more cognitive rehabilitation therapists.



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Figure 14: Item #9 Member/Stakeholder & Item # 8 Provider – All Reponses
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### Survey Item #10 (Member/Stakeholder)

"Please check all the services that you are now receiving."

#### **Data Summary**

- 25% receive Personal Attendant Services Traditional Model.
- 19% receive Personal Attendant Services Personal Options.
- 38% receive Case Management.
- 12% receive Cognitive Rehabilitation Therapy.
- 6% receive Dual Services (Personal Care services and TBI Waiver services).

#### **Open Forum Comments and Excerpts from Survey Narrative**

- Survey circled Cognitive Rehabilitation Therapy and stated they would like to receive, if someone able to provide.
- Survey stated member just signed up for Cognitive Rehabilitation Therapy.
- "In the process of being approved."

### Survey Item #10 (Provider)

"Please check all the TBI Waiver services your agency is currently providing."

#### **Data Summary**

- 35% provide Personal Attendant Services Traditional Model.
- 19% provide Personal Attendant Services Personal Options.
- 42% provide Case Management.
- 4% provide Cognitive Rehabilitation Therapy

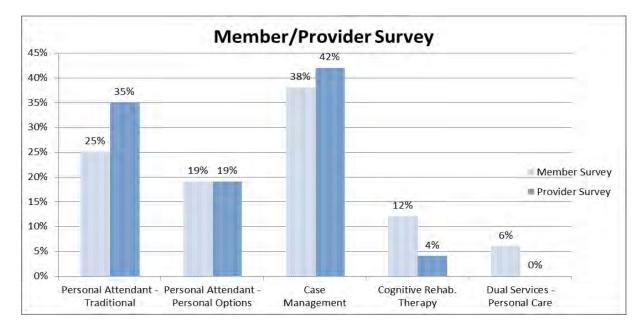


Figure 15: Item #10 Members & Item # 10 Provider - All Reponses

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#### **Open Forum Comments and Excerpts from Survey Narrative**

- A Provider asked "Have people been resistant to having strangers come into the home to provide services?" Discussion was held regarding personal options vs. traditional, and that it is member specific as far as how people react to having someone from outside come in.
- "Since I'm not the one doing the recertification, how do I know what we are certified to provide? And is it something we have to recertify for every year? What would happen to existing members if an agency did not recertify?" There is a policy in place for transfers of members whose agencies opt to not continue to provide services. There is also provisional certification for agencies that miss deadline.
- "Our guy uses Case Management, Personal AS through PPL, so ERS only does Case Management."

#### Additional "Parking Lot" Comments Outside of Survey Items

- A Provider said that they are seeing people who are meeting eligibility the first time they are assessed, and then not meeting eligibility on re-evaluation.
- Reliance of the PAS on physical vs. cognitive deficits was raised as a concern. A provider said that TBI
  members need more cueing than physical assistance. Deficits are more cognitive than physical. Another
  provider said it's difficult to use a PAS which doesn't address cognitive deficits to develop a service plan to
  address cognitive deficits, and asked whether there is another tool that could be used in place of PAS, or
  an add-on to correlate the Rancho scores with the PAS.
- A provider works with a family who could benefit from several hours of respite so that they can attend activities outside the home.
- A provider asked if a CNA is working as a PA, is he able to perform skilled nursing activities. The ASO responded was that he cannot bill for those services because it's not a covered service under the waiver.
- A Provider works with a member whose wife had to leave her job to care for her husband, and is upset that she can't be paid as a caregiver.
- A Provider asked if there is any plan to add services for people with Acquired Brain Injury. BMS said this will be taken into consideration.
- A provider indicated that she likes the Pre-Hearing Conference process.
- A family member asked "Where do you get help to determine overall big picture brain injury needs in general"? APS staff replied that the case management agency is instrumental in providing assistance with determining needs and developing service plan which addresses those needs. The family member asked who has the expertise to decide what the needs are. The ASO staff mentioned CED. The family member has worked with them but is looking for someone who can help streamline the process. BMS mentioned support groups.
- A stakeholder mentioned developing a list of providers who specialize in TBI. He also felt that a list of how many visits to different specialists under Medicaid would be a helpful resource.
- A stakeholder asked about reimbursement rate for CRT. He feels that is too low for most professionals who would provide those services.
- A stakeholder stated that without federally mandated funds for the Waiver, you can't provide all services. The Provider mentioned adult day care for TBI- which doesn't exist in WV.
- Caregiver noted that any time she has a question or problem and calls the office she gets a prompt return call/answer.
- A caregiver asked about Veterans being served. ASO staff indicated that veterans are served if they meet the medical and financial eligibility.

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#### Summary, Conclusions, and Recommendations

Thirty five (35) surveys' findings were used in completing this report. An additional member survey and two provider surveys were received outside of the reporting timeframe and the findings were considered in this report.

The purpose of the forums was to seek comment on the current program requirements and services. Any questions or requests that arose during the forums were addressed by BMS and the ASO after the survey items were completed. For example, during one forum a provider agency requested training and technical assistance and the ASO have since followed up with this provider.

Overall both groups were positive about the TBI Waiver Program and the changes that were made to the admission criteria. Comments and scoring also reflected an overall positive response to the current forms and processes used to determine eligibility. There were some comments that the current Pre-Admission Screening tool and Rancho Los Amigos Levels of Cognitive Functioning Scale may not be the most appropriate tools for this population. A number of respondents expressed a need for evaluation tools that focused more on the specific deficits seen in a traumatic brain injury population, for example, memory and cognition deficits rather than physical deficits.

Both groups identified a number of services that they would like to see included in the Waiver Program. These services should be further explored to determine feasibility of inclusion within the existing budget. The most requested additional services were respite and nursing services. Other services requested included Participant-Directed Goods & Services for members in the Traditional Model, residential, supported living, and day programming.

While many respondents in both groups thought lowering the age requirement was a good idea, a specific age was not agreed upon. A number of current providers expressed concerns with their ability to serve a younger population. The age requirement should be further explored and considered for inclusion in the upcoming application. Before inclusion, more information will be needed regarding the impact on Early Childhood Intervention programs and other home and community based services.

BMS and the ASO will continue to review the comments and recommendations from these surveys and forums as well as other venues to prepare the 2015 reapplication to meet the needs of the TBI Waiver members.