

Virginia
Department of
Rehabilitative
Services
&
Brain Injury
Association
of Virginia



**TOWN
MEETINGS**

Final Report
October, 2005

Virginia Commonwealth University
Rehabilitation Research & Training Center on
Workplace Supports and Job Retention

TOWN MEETINGS



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TOWN MEETINGS



Executive Summary

Purpose of Study is to provide feedback on the identified service areas, and to obtain information that will be critical in the development of a 5-year Brain Injury Action Plan in Virginia (2005 - 2010). This Executive Summary is a synopsis of the overall impressions drawn by the facilitators and recorders for each session from the input given by participants in the Town Meetings.

Process: In order to accomplish the above stated purpose it was vital that a structured process was designed and consistently implemented across each of the town meetings. Staff at Virginia Commonwealth University Rehabilitation Research and Training Center (VCU-RRTC) were contracted with to conduct the facilitation of each town meeting to ensure a neutral process. At the opening of each event representatives from DRS and BIAV provide background and state plan history. Once this information was shared, these representatives left the room and VCU-RRTC personnel proceeded with the meeting facilitation process by setting "ground rules" and explaining the roles of the facilitator and the meeting recorder. An icebreaker question was posed to the group to get participants warmed up and then the facilitator guided the group for approximately 1 hour and 45 minutes through a needs assessment process that would address the three core service areas and ideas for the 5-year state plan.

The five town meetings were held in 5 geographical diverse areas of Virginia to include: Abingdon, Roanoke, Harrisonburg, Virginia Beach, and Alexandria. These five locations were chosen by the Virginia Brain Injury Council in order to acquire a statewide perspective on the State TBI Action Plan.

Audience at Town Meetings: Participants in the town meetings included survivors of head injuries, the parents or family members of survivors (many of whom described themselves as caregivers), service providers, as well as public officials in some localities. The dominant participant input varied across the various meetings. For example, the dominant input at the Abingdon session came from survivors; at the Harrisonburg session, family members, particularly those who described themselves as caregivers, were the most vocal in their input. The Roanoke and Virginia Beach sessions had very balanced input across the various participants. The Northern Virginia session had a very small turnout of eleven participants, most of whom were survivors.

General Summary Impressions Regarding Input on Current Status of Services: The majority of service needs discussed focused on post acute care and long term care services. In a number of the town meetings, it was discussed that initial medical and rehabilitation services are excellent, particularly when an injured person had access to a Level 1 Trauma Center such as University of Virginia (UVA) Hospital in Charlottesville or Medical College of Virginia (MCV) in Richmond. However as a survivor transitioned back to his or her community, little or no assistance was found in locating appropriate services. This input was particularly strong in the more rural, geographically dispersed communities in SW Virginia or along the I-81 corridor between Winchester and Roanoke. Many suggestions were made regarding the need to educate doctors, hospital social workers, and other hospital and rehabilitation personnel on the services needed by survivors of head injuries and their families. There is a need for the medical and rehabilitation staff in home communities to have materials and information to share with survivors and their families.

There are many areas of the state where survivors and their family members describe a sense of isolation in their home communities. This isolation is characterized by needed services not being available; very limited local understanding of the support needs of head injury survivors; limited access to needed information on services; and limited awareness of potentially available services. This sense of isolation was particularly prevalent in the input received from those individuals who live in SW Virginia (west of the Roanoke/New River Valley Area) and those communities along the I-81 corridor (from Winchester to Roanoke) where at present there is very limited case management and regional resource coordination available. In communities such as the Roanoke area or the Tidewater area where more services are available, there was much less of a sense of isolation expressed by participants. In these communities, there is knowledge about the core case management and regional resource services. The discussion in their communities was much more about the need to expand available services, many of which were viewed as being at capacity. People know about existing services; they just need more.

It is also important to note the input on the positioning of services to meet regional and community needs. For example, the participants at the Abingdon session described the access challenge they face when services are not local to their home community. There is not one location in SW Virginia (west of Roanoke), for example, that is viewed as a regional hub locale that would be accessible to the overall region. A similar challenge exists along the I-81 corridor around Harrisonburg. In comparison, core services in Roanoke and in the New River Valley communities were generally viewed as effective service locations for reasonable access. In summary, the perceptions of the current status of services in the state of Virginia among survivors of head injuries and their families are quite

varied. Locales such as the Charlottesville area, parts of Tidewater, and parts of Northern Virginia are viewed as having a variety of core services in place with attention needed on expanding service capacity and opportunities. In other communities, there is a prevailing sense of isolation with very limited services and community support available to survivors and family members.

The Town Meetings focused on three core categories identified in the State TBI Action Plan: case management, regional resource coordination, and clubhouse/day program services. The service most often acknowledged as essential was case management, with four of the five localities placing this service as a number one need and the other location stating that case management is an important secondary service need. Regional resource coordination (RRC) was the next most common service identified as essential; RRC tied for first with case management in two of the localities and was seen as a complement to the case management and day program in the other three locations. Only one of the locations identified the clubhouse or day program as the most important service need. However, it was noted that the day program should have comprehensive services that deal with socialization, independent living, and provide case management and community transportation. Due to differences in geographic location as well as variation in current services available among these localities, each town meeting participant group had a different view of how the services should be implemented and how they would best serve their community.

A very strong impression gained from the Abingdon town meeting was that SW Virginia is viewed as a very large geographic area without a regional hub or a central point for accessing regional services. The participants emphasized repeatedly the importance of locating services in close proximity to where people live because of the substantial transportation and distance issues survivors and their families face in getting to services. The general participant input on needed services centered on the **regional resource coordination/centers and case management services**. Individuals with brain injuries need to be identified; information and referral capacities need to be developed; and a resource for managing service plans needs to be put into place before specific program resources are developed. It is important to reemphasize that according to the participants in the town meeting, this regional resource and case management capacity needs to be put in place in a way in which the services are dispersed throughout the SW Virginia region. Services should not be put into a central location that will require the survivors and their families to travel what would be perceived as long distances to access the services.

The Roanoke town meeting revealed that the core services were available and effective in the Roanoke community, to include Roanoke county and the New River Valley. However, it was noted frequently that the services are currently at capacity. There is a need for an expansion of both the **regional resource coordination and case management service** capacity for the region. Other than the identified need for increasing the above services, there was little consensus on other needed services. However, by the conclusion of the meeting, it seemed that some agreement was found that clubhouses or day programs would be valuable if the program followed a clear emphasis on integration into the community, including a commitment to ongoing support services.

The "Harrisonburg Region" was described as having two general components. The first is the area east of the Blue Ridge Mountains made up of the Charlottesville community. This area is viewed as having a number of services for persons with a head injury, including the Level 1 Trauma Center at the UVA Hospital, acute care services specific to persons with head injuries and a clubhouse program. The second regional area is west of the Blue Ridge Mountains and is defined as running along Interstate 81 from Winchester to Roanoke. This area was generally viewed as having a very limited number of services. Once a person is injured, they are taken immediately to Charlottesville to receive acute medical care and initial rehabilitation treatment. The participants were satisfied with the services during this portion of recovery and were comfortable traveling outside of their home communities for these services. However, once the individual transitioned back to the home community, participants noted services as inadequate. **Case management** that special-izes in brain injury services was identified as the most highly needed service in the community. The participants did not concur on what needs to accompany the case management. Regional resource development, clubhouse, and community living services were the most frequent choices.

The Virginia Beach town meeting included participants from a large geographical area including Virginia Beach/Tidewater, Norfolk, Suffolk, Eastern Shore, Middle Peninsula, Northern Neck, and Isle of White. The current services available varied for each of the communities from no current services in Isle of White, Virginia Beach, Norfolk, and Eastern Shore having limited services available. Other comments with regard to current services were that services were too broad and did not specifically address issues, concerns, and support needs of individuals with brain injury. Also, services were identified as spread too thin over large coverage areas. The majority of participants felt that all three core services, regional resource center/coordinator, case management, and clubhouse/day program, were essential in their community. However, the greatest need identified was for a **clubhouse/day program** because it was seen as an actual service that could have the other two core services grow out of it.

The Alexandria town meeting was very small for the size of the region, and input received may not be a fully accurate reflection of the service needs in this area of the state. The overall impression from participants is that some services are available but that the many services do not specialize in head injury services and do not adequately meet the needs of the community. The audience mentioned a waiting list for most services that were available. Overall, the group felt strongly that **case management** was the most important service needed in the Northern Virginia area. Regional Resource Coordination and two or three additional clubhouses were also seen as needed services in the Northern Virginia area.

Please see the "Facilitator and Recorder Overall Impressions" for further area specific information.



May 10, 2005

Abingdon Town Meeting

Facilitator: Vicki Brooke --- Recorder: Grant Revell

Facilitator and Recorder Overall Impressions

Audience:

The Abingdon participant group contained a vocal majority of brain injury survivors and family members. Service providers appeared to be limited, and two of the most vocal service providers were from the New River Valley area, which appears to be considered more a part of the Roanoke Valley area than the Southwest Virginia region that was the focal point of the Abingdon Town Meeting.

A very strong impression gained from the input of participants is that SW Virginia is viewed as a very large geographic area without a regional hub to serve as a central point for accessing regional services. The participants emphasized repeatedly the importance of locating services in close proximity to where people live because of the substantial transportation and distance issues survivors and their families face in getting to services. No specific distance (e.g., 50 miles of home) was identified as a critical measure of service access; however, the point was made repeatedly that for SW Virginia residents to have needed access to services, these services would have to be dispersed around the region, not centralized in a specific location. It was noted that many survivors had to leave the SW VA area to receive medical and rehabilitation services after their injuries, sometimes out of state. "Thrown to the wolves" and "fed to the sharks" were terms used to describe the feelings of many survivors and their families on return to their home communities after completing acute care. Many audience members characterized what they found as no services, no understanding of their needs, and no way to get information.

Current Status of Services:

A dominant impression is that the survivors and family members as a group in SW Virginia had very limited knowledge about (1) services that might be currently available; and (2) how to access information on available services. Repeatedly when asked about the current availability of services for persons with a brain injury, the response was that no such services exist. Also, there is a sense that the service community in the SW area (such as doctors, Community Services Boards, Social Services) has very limited knowledge and understanding about the impact of brain injuries and how to support and serve this population. People attending the Abingdon Town Meeting feel isolated. "The state of Virginia ends in Roanoke as far as services for people who have brain injuries" was a refrain repeated frequently during the town meeting. There appears to be a dominant need to address this sense of isolation and to build an information and awareness resource/network that will provide a basis for survivors and their families in knowing how to access services.

Needed Services:

The general input on needed services centered on the regional resource coordination/centers and case management services. Consistently, the audience emphasized that there are a lot of brain injury survivors in SW VA who have not been identified. There needs to be a substantial effort to identify these survivors to get a true sense of the real service needs in the region and to bring these individuals and their families into the efforts to address service needs. The example was given that it would be wrong to start with putting together a clubhouse type program instead of regional resource and case management. People need to be identified; information and referral capacities need to be developed; and a resource for managing service plans needs to be put into place before specific program resources are developed. It is important to reemphasize that according to the participants in the town meeting, this regional resource and case management capacity needs to be put into place in a way where the services are dispersed throughout the SW VA region, not put into a central location that will require the survivors and their families to travel what would be perceived as long distances to access the services.

Recorder Script of Participant Comments

I. Introduction

1. **What services are currently available in your community for people with a brain injury?**
 - Nothing in Bristol or Abingdon.
 - Sink or swim on your own.
 - Brain Injury Association of Virginia (BIAV) has monthly support groups in Abingdon and in Johnson City, Tennessee (BIAT).
 - Core group meets in Roanoke.

II. Core Services

Questions 2-4: Discussion of Core Services. Each of the three core services asked for input on the following:

- a. Does identified Core Service fit the needs of people with brain injury in your community?
- b. What do you like about it?
- c. What needs to be changed or added?
- d. How significant is the need for this service in your area?

2. Input on Regional Resource Coordination/Center

- Don't know because never heard of it.
- If you had it, would it be helpful: Yes, if it worked with clubhouse.
- Comment on planned site in Galax.
- 18 or under: falls under MH program.
- RRC would be helpful if there was a single point of coordination across communities.
- Funding would be needed to make information available.
- The Bristol newspaper said it would advertise today's meeting, but it wasn't in there.
- Seems like it would need more than one person because of (9) wide geographic areas and number of services.
- Very critical for Southwest Virginia (but all are critical).
- Heard it a million times, but nothing ever changes.
- Needs an office with a team of people.
- Everyone thinks it is a critical service.

3. Input of Case Management Services

- Meets needs only if you have personal pay capability. If you don't qualify for Medicaid, you fall into a "crack" in services.
- Social Services is of limited help.
- Need to look at income eligibility criteria to open it up.
- Know what needs to be changed when we see it.
- People don't understand brain injury. People need to understand brain injury. Case manager needs to understand.
- Only a survivor will understand how a case manager can help.
- Case manager needs to understand brain injury and also financial needs test.
- Certified brain injury specialists in other parts of the state. In Southwest Virginia – no (nothing west of Roanoke). Roanoke and East of Roanoke – yes.
- Brain injury services of Southwest Virginia – Giles, Floyd, Montgomery, Pulaski, Radford, Roanoke – there are some services in these areas.

- Quality needs assessment done for Southwest area. Need exists for case management.
- Importance of talking with local legislator.
- Current funding is targeted to specific area – restricted to certain identified areas of state – can't bring funds to areas not allowed for in legislation.
- There are programs that might not be brain injury specific but can provide services.
- VERY IMPORTANT.

4. Input on Clubhouse/Day Program Services

- Current clubhouses are not specific to brain injury and don't meet needs.
- Difficulty mixing people with brain injury with people who are depressed.
- Need to change clubhouse model to a place specific to brain injury.
- In Roanoke – have a case manager and R.R.C. – need critical number of people to make the clubhouse work.
- Keep it exclusive to brain injury – need central location for region.
- Single clubhouse won't work in Southwest – too much distance to cover – need multiple locations.
- Need for satellite centers that can assess background causal factors and needed services.
- Community concern #1 for people who are transient (e.g., alcoholics) – frequently brain injury is causal factor.

III. Wrap Up

5. Forced Choice: You have \$150,000 to spend on services for people with brain injury in your community – which of the five categories of services would you purchase? Why? (Note – five services are 3 core services plus Community Living Supports and Residential Services.)

- Assisted living apartments (supported living) Hillsville ex. (Barby) – resource person in apartment to help age 18-40. Social activities.
- Regional resource coordinator – would help expand CSB .
- Combination Case Manager on assessment and coordination of regional resource – assistive community outreach.
- Regional resource coordinators – develop support group as a core, particularly effective with case management.
- TTT Roanoke example – regional resource coordinator and case manager.
- Case manager identifies people and resources.
- Regional resource coordinator develops support groups.
- Advertise needs, resources, and services to help with public awareness.
- Make doctors aware - law says DRS report - regional resource coordinator could help build awareness.
- Regional resource coordinator (2 other people agreed).
- Concerns with isolation and you get drained trying to access widely spread services – need services to be county specific, accessible.
- Move everyone to Richmond.
- Need information readily available.
- Regional resource coordinator.

6. What else? What other services are needed in your community to meet the needs of people with brain injury?

- Public awareness.
- Physicians need to be educated.
- Employment supports that understand head injury and its unique impacts.
- Rehabilitation: cognitive, emotional supports – people have go to Charlotte or Atlanta.
- If service is not available in Southwest Virginia, there are special funds that allow them to do so where services are – a brain injury insurance program.
- Evaluation for insurance help – so many people with brain injury are between 17 and 50 – special needs assessment.

Community Concerns Board

Need for homeless shelters; people with substance abuse issues frequently have a brain injury background. People in flight – need satellite office to assess needs.



Roanoke Town Meeting

May 11, 2005

Facilitator: Vicki Brooke --- Recorder: Grant Revell

Facilitator and Recorder Overall Impressions

Audience:

The audience for the Roanoke Town Meeting appeared to have a balanced mix of survivors, family members, service providers, and public officials (including a delegate to the General Assembly). The Roanoke region was described in terms of two service areas: the general Roanoke City and County area and the New River Valley area. As represented by the audience at the town meeting, there was a sense that service hubs in these two areas could provide a base of services generally accessible to needs of each region. The audience as a group appeared generally informed about the services currently available in the region and very clear in how they described their experiences and what is needed in the region.

Current Status of Services:

The predominant impression is that there is general recognition and support for the current availability in the Roanoke region of regional resource coordination and case management. The audience included individuals providing these services. No differentiation was noted from the input on the availability of these core services in the Roanoke City/County area compared to the New River Valley area. The services exist and are described as being effective. However, it was noted frequently that the services are currently at capacity. There is a need for an expansion of both the regional resource and case management service capacity for the region. People knew about the existing services and described them positively; they just need more.

Needed Services:

Beyond the need for expansion of regional resource coordinator and case management services noted above, the discussion about needed services was quite varied without a clear consensus. Services mentioned included clubhouse/dayprograms, residential services, community living (including employment). There was mention of a need for specialty services. For example, one audience member is working on enrolling in college and felt that there was very limited help for a survivor attempting college/technical programs. The colleges do not know how to support brain injury survivors, and the existing brain injury related resources are not oriented to a person seeking access to a higher level of educational achievement. There was an extended discussion about the fear that a clubhouse type program could lead to segregation from the general community if efforts to integrate participants were not emphasized. By the end of the facilitation process, there appeared to be a developing consensus around the idea that maybe some specialized

programs and residential supports might be needed to help in the initial stages of the survivor returning to the community. However to be effective over time, these programs need to clearly emphasize integration into the community, including an emphasis on competitive employment. The comment was also made a number of times that services at present do not provide the ongoing support over time needed by survivors of brain injuries. There needs to be more attention to the longer term support needs of these individuals.

Recorder Script of Participant Comments

I. Introduction

1. What services are currently available in your community for people with a brain injury?

What exists at present:

- Regional Resource Coordinator.
- Some case management: maxed out.
- Inpatient and outpatient rehabilitation.
- 2 day therapy programs.
- Employment training.
- Support groups.
- Adaptive recreational services – Community recreational program (2 different programs).

II. Core Services

Questions 2-4: Discussion of Core Services. Each of the three core services asked for input on the following:

- a. Does identified Core Service fit the needs of people with brain injury in your community?
- b. What do you like about it?
- c. What needs to be changed or added?
- d. How significant is the need for this service in your area?

2. Input on Regional Resource Coordination/Center

- Very important; increased visibility; lots of visibility.
- Fortunate because of skilled person.
- To improve, need more people power – more/expansion.
- Need administrative/clerical support.
- Should this include information that hospitals give to families at discharge?
- Difficulty when people (survivors) thrown out with no transition information. Importance of regional resource coordinator to build awareness.
- Problem when you get services in one community (Richmond for example) and are returned to another area – importance of Regional Resource Coordinator in reaching out to hospitals.
- Nothing offered – information found online.
- Better connection to hospitals.
- Liaison.
- Better statewide coordination across communities.
- Liaison inter-state also move information across state lines
- Single point of contact (not packets of information) at point of time person returns to community.
- Contact in their area (first choice) or a state number to contact (second choice) be specific.
- Follow up from hospital outpatient therapy center. People at exit are overwhelmed. Need proactive follow-up to be sure people are hooked up at community level.
- When you call, get person, not menu of recorded choices. A trained human being.

3. Input of Case Management Services

- Personal experience: so important to have a person providing case management.
- More case management.
- Need funding for individuals who lack funds to pay for services.
- Educate Anthem/Blue Cross on brain injury. Anthem frequently sees problems (speech, for example) as educational, not health issues.
- Need help from government to work with insurance to respond to service needs.
- States, like Texas, have coverage built into insurance to be more responsive. Example, Anthem has \$500 limit on speech therapy.
- Need more case management.
- Need specialized case manager who understands brain injury.

4. Input on Clubhouse/Day Program Services

- Only opportunity for pre-vocational services.
- People feel thrown to the sharks; survivors need a place to go where impact of brain injury is understood.
- Don't like idea of clubhouse – segregates persons with brain injury – expensive resource when there are so many needs. Emphasize integration, even with lots of money, still emphasize integration.
- Marry clubhouses idea and integration, supported living, situation where persons is supported in becoming integrated.
- Example from Texas: TIRR program at university and center with brain injury – worked with clients outside of center – community action team – life skills, pre-vocation in community. Maybe some social therapy at center.
- Right now people try to serve many roles even if they are designated as case management (for example).
- Clubhouse is important but could be better – needs to be more integrated – example: adaptive golf/bowling gives limited opportunity – need program that really encourages community integration.
- There are clubhouses in Richmond and Northern Virginia.
- Example: Clubhouse in Roanoke would not help people in N. River Valley – need approach that is more expansive.

III. Wrap Up

5. Forced Choice: You have \$150,000 to spend on services for people with brain injury in your community – which of the five categories of services would you purchase? Why? (Note – five services are 3 core services plus Community Living Supports and Residential Services.)

- Regional Resource Coordinator, case manager, and residential services
- Clubhouse and community living (enhanced clubhouse).
- Put it all in case managers – there are still people who need to be identified, particularly children.
- Case management and residential (buildings, apartments, housing).
- Regional resource coordinator – first point of contact – get people to services.
- Need residential services – if we had more residential services, it would help case managers – interim step after discharge as people readjust to the community.
- Transition support – regional resource coordinator, case manager, residential (lots of agreement).
- Acknowledge that residential could be expensive but is needed – TBI Family Services in Roanoke has residential.
- Residential – from hospital to a supportive transitional residential option as step to community living – example of people who have to leave community – example of homeless who have brain injury and are un-served.
- Community living assistance.
- Education/awareness – example of a Cancer Association – need to get out and talk to groups – build public awareness – need BIAV to play a larger statewide role.
- Need primary care physicians to be educated on brain injury – physician education – tried physician conferences – physician to physician.
- \$150,000 as good money for lobbying, marketing, to expand resources. Example, breast cancer advocates have changed system. Build similar coalitions.
- Community living (voiced by “aging parent” who wants to know her daughter will have living options).
- Education for Social Services offices/other government support agencies.

6. **What else? What other services are needed in your community to meet the needs of people with brain injury?**
- School systems need better understanding (elementary, post-secondary) of brain injury.
 - Prevention.
 - Virginia does not have neuro-behavioral center. Go to places like those that exist in Florida/Texas.
 - Most services that exist are for people who are at earlier stages of recovery. Need attention to mid to later stages of recovery.
 - Difficult to get insurance coverage once physical symptoms no longer exist. No attention to cognitive needs.
 - Model System in Southwest Virginia like in Richmond (out of Medical College) – 12 in country – needed in Southwest Virginia – bring different resources together.
 - Need attention to community reintegration. Case management type services expanded over long haul – need more long-term services – supported employment.
 - Post secondary – most Virginia colleges don't have a specialized services office that is responsive to persons with brain injury – colleges need to develop this capacity.
 - Personal resources to match needs.
 - Regarding DRS – DRS is not helping people maximize employment potential.
 - Need funds moved from DRS to another neutral entity. There is a conflict of interest in the current system. Current system does not support consumers who need to take action against DRS.
 - Purposeful activity important. Employment gives this purpose.
 - Remember Workforce Development Board--One Stop through VEC provides education, OJT--can get service.

Community Concerns Board

- Anthem is not responsive to rehabilitation needs of persons with brain injury – example, speech therapy limited to \$500. Legislature needs to step in and legislate required coverages.
- All services being discussed really depend on transportation – have to be able to access.

Harrisonburg Town Meeting

May 18, 2005



Facilitator: Jennifer McDonough -- Recorder: Grant Revell

Facilitator and Recorder Overall Impressions

Audience:

The audience in Harrisonburg appeared to be a balanced group of caregivers and providers. Individuals who identified themselves as survivors of a brain injury were fairly limited. Additionally, there was a vocal audience of providers and advocates from the Roanoke area. The Harrisonburg audience asked a number of questions about the core service descriptions (i.e., What is meant by the terms “monitor and evaluate” in the core service definition of case management?). The audience members from outside the Harrisonburg area who had experience with the core services would use their experiences from their own community to help address these questions. It is important to note that the meeting facilitator purposefully would not expand on or interpret the definitions given by Patti and Ann (and on the posters) in the introduction when questions were asked about the core services. This was to prevent bringing new information into the discussion that was not a part of the other Town Meeting. Therefore, the input from audience members giving examples of their experiences with core service was the information source that addressed these questions.

The “Harrisonburg Region” was described by the Town Meeting audience as having two general components. The first is the area east of the Blue Ridge Mountains made up of the Charlottesville community. This area is viewed as having a number of services for persons with a brain injury. These services are anchored by the Level 1 Trauma Center at the UVA Hospital. The Charlottesville area is viewed as having a number of acute care type services specific to persons with brain injuries. The second regional area is West of the Blue Ridge Mountains and is defined as running along Interstate 81 from Winchester to Roanoke. This area was generally viewed as having a very limited number of services. Input from audience members seemed to be highly influenced by whether they were talking about the Charlottesville area or the area West of the mountains I-81 corridor.

Current Status of Services:

The I-81 corridor region was generally described as having minimal services for persons with brain injuries. A reference was made to a vacant Regional Resource Coordinator position and how the advocates and support groups were generally trying very hard to fill the resource identification and coordination gap. No timeline was given as to how long the Regional Resource position had been vacant or current efforts to fill it. The scenario repeated a number of times by caregivers is as follows when a person is injured West of Blue Ridge Mountains: The individual who incurs a brain injury is taken out of the Harrisonburg regional community to Charlottesville and receives treatment at the Level

1 Trauma Center. A rescue squad member in the audience noted his taking an injured person directly from the scene of the accident in the Harrisonburg area to the UVA Hospital. The injured person receives acute medical care and initial rehabilitation treatment in the Charlottesville community. Services up to this point are viewed as being effective. At the time the person comes back over the mountains and returns to his/her community for post-acute care services and continued rehabilitation, the service plan falls apart for a variety of reasons that are listed below:

- Services that specialize in treating persons with a brain injury are very limited (some described it as “non-existent”) in the home community.
- Survivors and their caregivers have very limited information available on services and how to find and access them, and there are very limited resources to help get this information beyond other families, advocates, and support groups.
- There are very few neuropsychologists living and working in our community to provide services to people with brain injury and generally speaking physicians are not well educated on brain injury and the support needs of injured people. Therefore, unless you can find a specialist in neuropsychology, the general medical and treatment community is not that helpful in assisting families in identifying needed services and how to go about getting these services.
- DRS was noted as “offering case management” but not being effective over time in providing needed services.
- There are no day programs or respite type supports to provide an activity center for survivors; care givers are frequently the sole and constant source of support, and this need is personally, financially, and emotionally draining on families.

In summary, caregivers generally view the I-81 corridor of the Harrisonburg region as being devoid of key services. The Charlottesville area is generally viewed as being strong in the acute care and initial post acute care services, including community living and clubhouse.

Needed Services:

The audience’s view on needed services appeared to evolve as the town meeting continued. It is important to note that the opening presentation by Patti and Anne in Harrisonburg differed from the earlier sessions in Roanoke and Abingdon in that the PowerPoint presentation that generally accompanied their presentation was not used in Harrisonburg because of the absence of a screen/wall on which information could be projected. The audience had the handout with the information included on the power point, but the Harrisonburg audience did not have the visual complement from the PowerPoint to the verbal presentation. The observation of the Recorder for this session is that the introductory information on core services was presented more quickly in Harrisonburg, and the audience seemed to have a need to discuss the meaning of the core services before responding to questions on Needed Services. The extent to which this perceived need for more information and discussion was linked directly to the absence of the PowerPoint presentation cannot be determined.

The discussion on the regional resource coordinator position was characterized by a number of comments questioning the value of the position when so few services exist. One audience member suggested that the position be retitled “regional resource developer”, and from that point on, there seemed to be growing consensus that the regional resource position is needed **if** the responsibilities for that position would include **resource development**. This input reinforces the dominant impression that the audience in Harrisonburg is strongly convinced that there are limited services at present and the key for this area is service development. There is interest in the resource coordinator being a source of information for services outside of the I-81 corridor since there was a degree of resignation in the audience that survivors and caregivers will need to look beyond their home communities to find services. There was also hope that the regional resource position could be an education and outreach force in helping to expand awareness and responsiveness among the doctors, other treatment staff, and the general community about brain injury.

The general consensus is that case management is a highly needed service in the Harrisonburg area. There was a call for multiple case managers. Survivors and caregivers need direct access to people who are specialists in the brain injury case management area. Case management assistance is a priority. There is less consensus on what needs to accompany the case management. As described above, resource development is recognized as being important. However, there was

also a lot of discussion on the immediate need for a day program/ clubhouse (no clear preference was given) type resource that would be a place survivors could go to get assistance in further community reintegration. Caregivers emphasized the need of families to have a program in the community where survivors could go, allowing caregivers an alternative to their direct care responsibilities for the survivors. The community living resource was viewed as being a needed service along this same line of reasoning – an important rehabilitation step in the return to the community and also a needed help to what is now viewed as the total post-injury care responsibility of families.

One final point: Audience members described the Harrisonburg community as a “caring” community that usually responds effectively to the needs of it’s members when they understand what those needs are. There is cautious optimism that an infusion of resources into the I-81 corridor of the Harrisonburg region would be effective in providing needed services for persons with a brain injury.

Recorder Script of Participant Comments

I. Introduction

1. **What services are currently available in your community for people with a brain injury?**
 - Was a regional resource coordinator, but position has been vacated.
 - Support group.
 - Some professionals lack information on brain injury.
 - Charlottesville: residential program is problematic in terms of next step from acute.
 - WWRC.
 - Clubhouse in Charlottesville.
 - Mountain is the dividing line in terms of access to services.
 - Services available in Charlottesville that are not available in Harrisonburg. People go to Charlottesville for services.
 - Example of rescue squad taking injured person to Charlottesville.
 - Central Shenandoah Valley – Winchester to Roanoke – no brain injury support services on this side of mountain from Charlottesville.
 - Need for services in Central Shenandoah Valley – can't depend on Charlottesville for post acute care.
 - Example of evaluation at WWRC, but no services when returned home.

II. Core Services

Questions 2-4: Discussion of Core Services. Each of the three core services asked for input on the following:

- a. Does identified Core Service fit the needs of people with brain injury in your community?
- b. What do you like about it?
- c. What needs to be changed or added?
- d. How significant is the need for this service in your area?

2. **Input on Regional Resource Coordination/Center**

- Would help if there were a person to contact – call for questions – person could feed information on services.
- Example given of regional resource center person in Roanoke and what that person provides.
- Concern that if the services do not exist in the community what is the point of having a Regional Resource Coordinator.
- Person who “primes the pump” if people don't have understanding of what is needed.
- There hasn't always been a Regional Resource Coordinator as the first step in a community (Northern Virginia is an example of case management first).
- Regional resource coordinator is essential starting point – need to know where services are so that people can be referred even if it's outside of region.

- Depends on who regional resource coordinator is; what is that person's knowledge/training – can work with underserved areas, go into community and work with people who are not trained.
- Example of parallels to Alzheimer's group and how support and services are provided.
- Help line; care consultation.
- Public awareness, coming from medical side in community after initial care – help make people aware of what people are experiencing and what is needed. Example: improving maintenance treatment in community for neuropsychological services.
- Giving community – if we increase awareness, community will step forward.
- Change title to regional resource developer.
- Broadened role sounds appealing.
- Will person have support from state to help develop resources? Would need financial commitment from State.
- Resources in Charlottesville because of level of trauma center – need those services in Harrisonburg area.
- Like developer, build grass roots – advocacy with legislators.
- Sure there are people with acquired brain injury who do stay in community – people getting outpatient care – Developer needs to work with caregivers, advocates, and others to build services.
- Lots of people who have no idea services exist – educating DRS to educate patients.

3. Input of Case Management Services

- Regional resource coordinator is the link to the case manager.
- Definitely need case manager.
- People are overwhelmed – want someone to walk them through.
- Overlap between two positions. Both provide some education. Case manager functions independently - step by step assistance is critical.
- Like developer – caregiver was overwhelmed – if someone could have been there to help [we were] not aware (Example: Being turned down for Social Security – need help in knowing where to go next on how to get help from system – high medical insurance costs).
- Case management would be instrumental...needed.
- Question about monitor and evaluate services – addressed by Roanoke example.
- Monitor and evaluate is one part of advocacy; this is working, this isn't. Need advocacy to help work through situations where services aren't working as needed.
- From provider perspective, refer first to case manager – case manager will know community in detail – have a pragmatic understanding of services.
- Big responsibility for one person to know – would need lots of education.
- Can one person do all that?
- Case Manager national certification process described – don't have to be certified in the beginning, but helps in time.
- Roanoke is an example of assistance from a Northern Virginia case management organization to help get service started.
- There is a pretty close group in community that shares information and helps each other.
- DRS will say that they have case managers but weren't helpful. DRS needs information.
- Regional resource coordinator is a resource for multiple case managers. Example: service can't be met, go to regional resource coordinator for help.
- Need Regional Resource Coordinator and multiple case managers.
- If we can, get case managers and network among survivors and support groups.
- Question about paid position for case managers.

4. Input on Clubhouse/Day Program Services

- Seen Richmond clubhouse – it is an immense help for family/caregivers. "X" hours a week persons engaged in lots of positive peer pressure. Day program also helpful, but not as stable. Clubhouse is readily identified and stable.
- Horrendously expensive – comes after case manager and regional resource coordinator.
- Evolutionary process – clubhouse as a goal down the road.
- Case Manager of 35-50 case load; an hour per week.
- Like it, but other needs first. Clubhouse is difficult to run. Case manager now, clubhouse down the road.
- Examples given of clubhouses in Virginia and how they operate in Virginia.
- Described clubhouses as safety net for families.
- Clubhouse more interim, which is what is needed – "step up strategies" – examples from elsewhere in Virginia.

- Generations Crossing is a day program and is willing to grow program and be responsive to person with brain injuries. Would be cost effective.
- Adult day care – diversional – day program/clubhouse – more directed, goal oriented, educational, and return to work. All have a community of people around them.

III. Wrap Up

5. Forced Choice: You have \$150,000 to spend on services for people with brain injury in your community – which of the five categories of services would you purchase? Why? (Note – five services are 3 core services plus Community Living Supports and Residential Services.)

- Pitifully inadequate – why can't we get them here in the valley?
- Caregivers should decide.
- Need regional resource developer and case manager, but key to initial recovery was rehabilitation. Clubhouse really helped during initial readjustment to community and work.
- \$75,000 on case manager. Also need some types of community living services.
- Reinforce mix of Case Management and community living services – services fill gap – community living services including pool of case service funds.
- Case manager and regional resource developer in the Valley – in Charlottesville, more day programs.
- Case manager for \$75,000 and piggyback on direction. Plus for day program – need some place for survivor to go, so caregivers can go to work.
- \$150,000 for case managers, including money for them to do their work, including some grant writers to help build services – “slush fund”.
- Every penny to case management.
- Case management needed, but also source of social stimulation, “reason to live”.
- Case management – they do resource development on a case by case basis.
- Current caregivers want/need case management – day programs, but long-term view is important for regional resource to develop services.
- Volunteers really help as community leaders.
- Change needed for regional resource coordinators to be more involved as developers, and pulling money into the community.

6. What else? What other services are needed in your community to meet the needs of people with brain injury?

- Brain injury program developer.
- Person to coordinate regional resource and case management.
- Mental Health supports for survivors' families.
- Respite care.
- Mental Health System does not understand brain injury...education.
- Education – Community is closed in terms of response to brain injury. Even our local paramedics and police – don't understand brain injury. Example of injured person mistaken for drunk.
- DRS – Disability determination, CIL's, etc. – all need to be educated.

Community Concerns Board

- Concern(s) about just what the Harrisonburg region includes.
- Unclear about practical examples of what services really involve.

Virginia Beach Town Meeting

May 24, 2005



Facilitator: Howard Green --- Recorder: Katie Farmer

Facilitator and Recorder Overall Impressions

Audience:

The participant group for the Virginia Beach town meeting included individuals from a large geographical area including Virginia Beach/Tidewater, Norfolk, Suffolk, Eastern Shore, Middle Peninsula/Northern Neck, and Isle of Wight. The participants were a mixed group of service providers, caregivers, parents, and survivors. The group was very vocal about their needs and concerns and there was good participation from all in attendance. Approximately 60 people were in attendance.

Current Status of Services:

The current services available varied for each of the communities from Isle of Wight having no current services to Virginia Beach, Norfolk, and Eastern Shore having limited services. Some of the services currently available were residential service, DRS SEEK day program (Virginia Beach), No Limits day program (Eastern Shore), Ability Center, Commonwealth Support Services (employment), case management (Virginia Beach), Regional Resource Coordinator (one for the whole Tidewater area), and Medical College of Virginia (MCV) and BIAV (general exchange of information). The participants noted that often the survivor has money allocated for services from Medicaid Waivers and other funding sources but there is a void in programs that provide services to brain injury survivors.

The biggest problem with existing services was identified as not knowing how to find and access these services after exiting the hospital setting. A discussion developed about the need for survivors and their parents to be informed of resources before leaving the hospital. Many participants said that it took them a year or more to finally find support groups and other resources within the community. The group felt that this responsibility should fall on the hospital social workers or discharge personnel. However, other ideas included sending out educational material to the hospitals to give to brain injury survivors or volunteers to visit the hospital to educate families on their options. Some of the town meeting participants indicated an interest in volunteering.

Other comments with regard to current services were that services were too broad and did not specifically address issues, concerns and support needs of individuals with brain injury. Current services, specifically regional resource coordinators and case managers, are spread too thin over large coverage areas, and that some individuals are screened out of receiving services due to age of injury or geographical location.

Needed Services:

The overall consensus among all participants was that regardless of current services available there were many gaps in service and programs in their communities. The majority of participants felt that all three core services, regional resource center/coordinator, case management, and clubhouse/day program, were essential in their community. However, the greatest need identified was for a day program because it was seen as an actual service that could have the other two core services grow out of it. The participants indicated that the day program should have comprehensive services that deal with socialization, independent living, and provide case management and community transportation. They acknowledged that while not all of these services would be immediately available in a day program, the day program would be a facility that would grow these services as time goes on.

Recorder Script of Participant Comments

I. Introduction

1. What services are currently available in your community for people with a brain injury?

- Isle of Wight (Northern Neck/Middle Peninsula) – none (not aware – How do we know where to find these?).
- Living services (residential) – but where – who is monitoring – some before 18 – Hope House (Res.).
- Tidewater has DRS and SEEK – fragmented services because of money.
- Suffolk – none except DRS workers.
- Eastern Shore – No Limits day program.
- Ability Center (provider).
- Commonwealth Support Services (employment).
- MCV and BIAV (general information exchange).
- May have funding, but not services because too far out.
- Day programs for the elderly (45+) – not just brain injury.

II. Core Services

Questions 2-4: Discussion of Core Services. Each of the three core services asked for input on the following:

- a. Does identified Core Service fit the needs of people with brain injury in your community?
- b. What do you like about it?
- c. What needs to be changed or added?
- d. How significant is the need for this service in your area?

2. Input on Regional Resource Coordination/Center

- No – Isle of Wight Co.
- No – York County.
- Not because cannot locate.
- No – Virginia Beach.
- Yes, we need it drastically (Northern Neck).
- CSS/SEEK – Lack of pay for paying coordinators.
- Regional resource needed in every community.
- Currently 1 for whole Tidewater area.
- Dissemination of information/always available.
- Less coverage area.
- Someone to go to.
- Gets information to Richmond/goes into the schools.
- They have laid the groundwork.
- To make sure I have exhausted resources.
- Support groups.
- Helped to have her identified with brain injury – roadmap.
- Make you aware of changes and new services.
- Start immediately (tracking system).
- More coordinators/less coverage for area.
- Get information out that they (RRC) are there!
- They need tools to help reach out/give to volunteers to assist (let people know how to volunteer).
- Target who needs it . . . that are not aware of the services.

- Advertise the services/before they leave hospital – give information to hospital discharge persons and social workers – get to the right person.
- Importance 1-10 = 10 (20) – Resource directory to be distributed.
- Key to continuation for recovery after leaving the hospital.

3. Input of Case Management Services

- Virginia Beach – no . . . too big for 1 person.
- No, on waiting list for 1 year – York.
- They do a good job/need more.
- At a total loss without it (had and lost it).
- Very important.
- Isle of White – no (because they don't have it).
- Eastern Shore – no (because they don't have it).
- 100%
- Varies depending on area.
- Especially related to brain injury.
- Best thing since sliced bread.
- Residential support.
- Someone to talk to.
- Open the door to (doctors, agencies, and other services) – help access the system and jump through hoops!
- They let you know what money there is and how to access money for services.
- Help work on short/long term goals.
- Help get job and get job coaching services.
- Can be neutral vs. family members.
- Smaller caseloads/more money.
- More proactive in identifying individuals who need case management.
- Cannot get it because injury occurred after 18 (Virginia Beach Community Services Board).
- Training specific to caseworkers and more case workers that manage brain injury cases.

4. Input on Clubhouse/Day Program Services

- For a time, day program met our need.
- No, not available in Peninsula/Middle Peninsula.
- SEEK day program in Virginia Beach – Important and beneficial – valuable – don't know how people do without it.
- Provide nice, safe haven while individual is learning to survive.
- Gives independence/socialization.
- Go out/socialize.
- More materials/cognitive related.
- Expand.
- Communication and coordination between facilities/stop reinventing the wheel
- More funding/staffing.
- Access to competitive technology.
- A way for behavior issues to be worked out – involve them in the clubhouse . . . improve behavior modification.
- Transportation in program.
- Extend hours to help caregivers.
- RIC – had one but opened it up to other disability groups and lost focus . . . lost effectiveness.
- Very significant.
- 10+

III. Wrap Up

5. **Forced Choice: You have \$150,000 to spend on services for people with brain injury in your community – which of the five categories of services would you purchase? Why? (Note – five services are 3 core services plus Community Living Supports and Residential Services.)**
- Day program, because it is a resource.
 - Case management/regional resource center/clubhouse (equally)

- Lobbying for services.
- Got to have case management (another person agreed)
- All on salaries for staff.
- Fraction on personal assistance/living and rest in day program.
- Transportation.
- Medical needs.
- Community living and residential with majority in case management.
- 3 CORE and community living.
- You won't need a regional resource coordinator or a case manager if don't have a program to offer to the public . . . and residential and community living as a result.
- Day program helps them start out, but with other services included, for example residential (six other people agreed).
- Depends on audience because people here know about the services and therefore need more services.
- Regional resource coordinator (they help all services).
- Day program (100,000) and case manager (50,000).
- Split equally between all 3 CORE – you cannot do one without the other.

6. **What else? What other services are needed in your community to meet the needs of people with brain injury?**

- Family support (affordable nursing).
- Transportation.
- Community living/residential.
- Respite care.
- Support groups.
- Agency providers who can use DD waiver (Middle Peninsula).
- Get children with brain injuries back into school system.
- Continue family support during recovery that is accessible, affordable, responsive to consumer and continuous.
- Health insurance for cognitive therapy.
- Information/education on brain injury prevention.
- Day Program (49 other people – Middle Peninsula).
- Program for after 18 – Virginia Beach (age appropriate).
- Identification of services early on.
- Networking between services – RRC.
- Behavior/substance abuse modification services.
- Educate general public on brain injury – reduce misconceptions.

Community Concerns Board

- How can I volunteer to assist a RRC?
- Should survivors go to talk to hospitals about importance of RRC after individual leaves there?
- Newsletters/Resource Directory.
- Transportation – Eastern Shore.
- There are case managers on the Eastern Shore, but they are not brain injury specialists.
- Who knows where the money will have the best effect.
- Family Member Testimony- Please see **Appendix A**.

Alexandria Town Meeting

June 7, 2005



Facilitator: Howard Green --- Recorder: Jennifer McDonough

Facilitator and Recorder Overall Impressions

Audience:

The audience in Northern Virginia – Alexandria was remarkably small. There were a total of 11 individuals in attendance. Of these individuals, 7 were survivors of brain injuries, 2 were family members, and 2 were service providers. The group was vocal in their concerns regarding services for individuals with brain injuries.

Due to the small size of the group, the information gathered may not be an accurate reflection of the services provided in this area of the state.

Current Status of Services:

The overall consensus from the group was that there are some services available to individuals with brain injuries, but not nearly enough. While the group mentioned several agencies that work with individuals with a variety of disabilities, there was only one provider mentioned that worked with individuals who had a specific disability of brain injury.

According to the group, there is not a regional resource coordinator. Certain members of the audience mentioned that case management services are available, but not nearly enough and that there is a 2 to 3 year waiting list for these services. The audience said that there is one clubhouse available to individuals and that they would not change anything about the services that the clubhouse provides.

The most important issue that was raised was that the majority of the survivors in the audience did not know of ANY services available to anyone with a disability much less services that are specific to individuals with brain injuries. The majority of information that was provided regarding current services available came from 2 survivors and the 2 service providers that were in attendance.

Needed Services:

The general input on needed services centered on additional funding for case management services in Northern Virginia. Survivors felt that this service needed to start in the hospital setting, immediately following an injury. This would help inform families and survivors about what services are available in the community after discharge from the hospital. This service would also help families support the loved one and help them locate community supports. The majority of survivors and families present did not have any information on what is available following their injury.

Another important service needed was education to individuals with brain injuries and their families about what services are available after sustain-

ing an injury. The participants felt that this education needed to occur for survivors, as well as general public including employers, doctors and the community.

The group felt that a Regional Resource Coordinator would be helpful in the Northern VA area. They discussed that there was a high priority for this service and that it would fit nicely with additional case management and education of the community.

The participants also felt strongly that additional clubhouses/day programs would be beneficial. They thought that 2 or 3 additional clubhouses would be necessary to fit the needs of the large number of survivors in this region.

Overall, the group felt strongly that case management was the most important core service needed in the Northern Virginia area.

Recorder Script of Participant Comments

I. Introduction

1. What services are currently available in your community for people with a brain injury?

- Brain Injury Services
- Center for Independent Living
- Clubhouse
- National Rehabilitation and Rediscovery Foundation
- Recreation Centers
- Rehabilitation Center
- Section 8 Housing
- Disability Service Board
- DRS
- Support Group

II. Core Services

Questions 2-4: Discussion of Core Services. Each of the three core services asked for input on the following:

- a. Does identified Core Service fit the needs of people with brain injury in your community?
- b. What do you like about it?
- c. What needs to be changed or added?
- d. How significant is the need for this service in your area?

2. Input on Regional Resource Coordination/Center

- Don't have it.
- It's time to establish this.
- They provide information and referral.
- Very significant need for this.
- High priority for this service.
- As a stand alone service, it would be very expensive.

3. Input of Case Management Services

- Not enough.
- Doesn't fit the needs.
- 2-3 year waiting list.
- Some don't know it is available.
- Current case managers are stretched thin.
- Need more.
- Didn't know of organizations until 3 years after injury.
- Did not know case managers were available – needs one.
- Need better educated case managers.
- High turnover in case managers – leads to 6 weeks of no services.
- Emergency case manager services needed.

4. Input on Clubhouse/Day Program Services

- Currently available.
- Wouldn't change anything about it.
- Need more information about it for community.
- 2 more in Fairfax, 1 in Arlington – need more in this area.
- (10) Very necessary.

- Individuals need someone to educate them about everything available after their injury.
- More verbal information.
- More hospital referrals when you leave.
- What's available in Richmond needs to be available here.
- More peer support.

III. Wrap Up

5. **Forced Choice: You have \$150,000 to spend on services for people with brain injury in your community – which of the five categories of services would you purchase? Why? (Note – five services are 3 core services plus Community Living Supports and Residential Services.)**
- Regional resource coordinator
 - Case management (3 votes)
 - Some in case management, some in regional resource
 - Regional resource (if they were connected to individuals in hospital) and case management
 - Clubhouse, case management, and education
 - If you don't have additional services, case management has nowhere to refer
 - Community services (put towards direct services – gives case management more places to refer)
 - BIS, Inc. is fighting for funding indirect services
6. **What else? What other services are needed in your community to meet the needs of people with brain injury?**
- Teaching coordination of services in the community.
 - More education of people on how to work with people with brain injury.
 - No follow through – what you have to do to deal with a brain injury.
 - Educate the public.
 - Prevention.
 - Teach in health classes.
 - Map of services of where to go in community for services.
 - Teaching people about services
 - What therapies are needed,
 - Prioritize what needs to be "fixed" first,
 - Skills training, and
 - Intensive therapy (Medicaid won't pay).
 - Medicaid Waiver is important.
 - Increase funding of Commonwealth Neurotrauma Initiative.
 - 75% of injuries are mild and not seen in hospital – so educate individuals that they may have a brain injury.
 - Educate people that there are many different types of "injuries".
 - Transportation.
 - Educate courts.
 - A lot of these agencies have been helpful.
 - Interesting that a lot of direct services were not mentioned.
 - Asking people to discuss services that they don't know about.

Community Concerns Board

- Consider Brain Injury Services, Inc. placing case managers in this part of Northern Virginia.



APPENDICES

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Virginia Beach Family Member Testimony

Good evening, my name is Evelyn Wolford, and I am the mother of a brain-injured person. I'm going to start out by making this personal, so you can have some understanding of the brain-injured.

My daughter, Christy, became head injured at the age of 14 due to a brain tumor. She was an honor roll student, involved in student government, and her life dream was to become a teacher. Numerous operations, radiation treatments, comas, learning to talk, walk, and physical therapy, she survived when we were told she would not live past 16.

When the doctors at Children's Hospital said she might not make it through her 13th brain surgery, I asked Christy what she wanted. She just raised her hand and gave me a thumbs up, meaning "Go for it". Don't we all wish we had that courage?

Christy survived and now we come to why we are all here tonight!! My daughter survived due to the grace of God, but what next? She has severe short-term memory and other deficits. Finding programs that fit her needs were nowhere to be found.

I contacted the Brain Injury Association of Virginia. Harry Weinstock and Ann McDonald put us in contact with a program in Virginia Beach, and I will always be grateful to them.

Commonwealth Support Systems of Virginia Beach has been our backbone for years, and I can't praise Joanne Mancuso, the staff and SEEK enough. Through these programs the head injured have a support system. They are job trained with the help of job coaches and are overseen so parents can work.

There are 28,000 people today in Virginia alone that have brain injury. It could happen to any one of us here because the numbers are growing. Car accidents and major illnesses are the head injured.

The problem I have come up against, again and again, is that there is not enough funding. Some monies our state and our county council spend on frivolous funding, could be better spent on the people of Virginia Beach. We need your help.

1. They need funding for programs for individual and supported living. There are many clients capable of this to lead a more productive life. Not low income, but safe housing. I would like them to live in my neighborhood, where many people fear them. There are none.
2. Transportation. It's a nightmare. HRT says we live too close to a bus stop which is 6 blocks away on a major highway. My daughter, like many, is unable to walk 6 blocks, much less remember where she is and which bus to take. Help!!
3. More educated staff. God bless the people who work and stay there, because I make more as a housekeeper. Give them paid

(continued)

training and classes, because dealing with the head injured needs education and respect for what they do.

4. Supplies, materials. They have few. I have seen staff pay out of their own pockets just to help.
5. Money for specialized services. Eliminate failing programs, put money towards working programs.
6. Re-evaluate client placements. Through the years I've seen people placed at C.S.S., because there is nowhere else to go.

On a personal perspective, and yes this is all I have to say, for now . . . It's hard enough for these courageous head injured individuals to live day to day, but there are also the mothers, fathers, family and loved ones that this effects daily also. You just can't imagine how hard and frustrating it is.

When you vote for funding, please keep in mind (and I pray it never happens to your loved ones), but it does happen . . . Please fund these important programs. They deserve every penny, but they need thousands.

Thank you for your time.

Alexandria Survivor Testimony

James S. Brown -- 703-933-1896, JSBTBI@AOL.COM
Northern Virginia Brain Injury Association -- Survivor Representative

As many of you know, I attended the steering committee meeting a week ago. It was an astounding meeting. Many on the committee are passionate and persuasive advocates for the disabled in Virginia. On a whole, it was an impressive group. I also noticed some were not as involved. They appeared to be there, doing "damage control" for their agenda, or agency. I am sure that the make up of the Task Force is much the same. I hope those of you that read this are not too bored, or threatened.

The work you are all about is important. It became even more important after the events of 9/11. Freedom, again became the important virtue of the U.S.A., and all rushed to show support for their Nation. The foundation for your Nation is The Constitution. The Supreme Court of your Nation ruled that people should have a choice, in the Olmstead Decision.

The Congress of Nation passed under Title 5, Amendment 14, the ADA. It is a Civil Rights law. The work you are about is making it possible for people, who, now, may now have no choice, to at last, have a choice. Thank you, all.

I have attempted to tackle your draft report. In the business world a "camel is a horse designed by a committee". Many, none brain injured, found the Interim Report to be so confusing that it was almost unreadable. The report your are looking at today should be better. I would have liked to have read it. It was not available, as edits were done, last Monday.

I am usually an advocate for the entire disability community. In these comments, I have focussed on the Brain Injury community, as a Survivor Representative of that community, and am executive officer of the board of directors of NVBIA.

We are a 501c3 corporation that receives no federal, state, or local funding. No one on the board, or that chooses to assist us receives any compensation. It is made up of people that have come to care enough to give their time to serve the brain injured of Northern Virginia, and where possible the entire state. We accomplish some amazing things with our highly limited budget. Please visit our WEB site. www.NVBIA.ORG

I will be using the word survivor, frequently. It is what we have come to call ourselves. Survivors, have survived Acquired Brain Injury (ABI), a brain injury that occurs after birth. This would include people that suffer strokes, brain cancer, Traumatic Brain Injury (TBI), aneurysms, anoxia, and others. Contrary to what some of you may have heard, TBI is a subset of ABI. I include, in my thinking only, at this time, those with genetic and other prenatal brain injuries.

I also talk much of habits. Habits, are how most people live our day. Balance, walking, talking, dressing, and much more, are, for the most part, habits learned when young. Almost no one here can cross a street without looking both ways. You don't have to become aware of the activity you are about to perform, then contemplate what you should do, and then choose to look both ways then decide to do it. Relearning that habit took some time, but less than a month. Buttoning a shirt, tying a tie, took some work also. Re-learning not to spill milk was frustrating, but doable. Re-learning to drive was a nightmare that is now habit. For women keeping a purse, always with you, is a habit. You do not have to think about it. You just keep it with you,

unless you are distracted, and have to concentrate on thinking of something else. All this re-learning, re-habiting, requires a willingness to fail, often, and try again. For this we need support. Lots of “yes, you cans”. I have come to call it cheerleading, or empowerment.

This is something I have always done, and still appear to do well. I lost almost all my life’s habits, post-injury. With much work, living is much easier, now, and will get easier still. Yes, there are some things I will never do as well as I did in the past, and some I will never be able to do again. I am learning to make accommodations that I need to replace them, habits.

By far most of the survivors I have met have the symptoms of Attention Deficit Disorder (ADD). In loose terms, we are readily distracted. If the environment is too confusing. Some minds may just shut down. What parent has not learned that structure is needed in raising a young child. Structure and repetition are needed to learn. Fortunately re-learning, re-habiting, takes much less time.

So much of our early post injury life is spent in the now. What to do? How do I do it? Should I do it? Am I doing it right? Am I forgetting something? What have I forgotten? This goes to the simplest of life’s activities. Believe me, this level of decision making and concentration can be exhausting, and defeating. Once a habit forms that activity becomes automatic and requires less, or no thought, walking, for example.

It is often said that, “ignorance is bliss”. I am sorry if what I share with you invades your misconceptions. I have found this to be the case, too often. It can be scary. Rest assured the odds are with you, sort of. The high risk groups for TBI are the group between fifteen and twenty five, and over seventy five. Both these groups seem to be of equally high risk. If you are a male, your risk goes up. If you have had prior injuries, your risks go up.

I have had the opportunity to meet hundreds of survivors, and family members. However certain you are, that you will **never** need what I am presenting to you, let me assure you it is a false belief. The odds are on the belief’s side. I have met many, from all walks of life. professionals, executives, managers, police men, repair men, mechanics, athletes, etc. I have heard just as many stories. It can happen at any time to anyone, unless they stay in bed, never go outside, drive a car, ride a bike, walk in the city, use stairs, have a stroke, at any age, have an aneurysm, develop a tumor, or cyst, suffer anoxia, and so many others that I will not bore you with it any longer.

The brain injury does not just happen to the survivor. It “happens” to, and effects the entire family. They are as often as confused as the survivor is. No one looks after the survivor’s loved ones, as they do not seek it out. They are not the one in a coma, and returns, almost a different person. A person they do not recognize, **a stranger**, with a different personality, different abilities, memories, wants and needs, comes home. They go looking for help. They look for the person that they knew and can not, and will not find him. They need help, and cannot find it.

This is one area where the support groups, that NVBIA offers, can work. It is inspiring to sit among so many that were given little, or not hope. More than one of my friends were given last rites, a number of times. They laugh about it now. To a person, the survivors, I know, are fighters, with amazing courage. They are my family, now.

So many other survivors have been lost by a system that appeared to want to lock them up in an institution, or lose them, because the system does not know what to do, or what is possible.

As I mentioned, the structure of the draft I reviewed was confusing to this poor survivor. I am will attempt to address my “Public Comments” to the teams that appeared to be concerned with issues that concern the brain injured. The draft you will be reviewing later today may be much improved.

ACCOUNTABILITY TEAM

I find myself representing a relatively new community to the physical disability population. Little is understood and/or known by state systems, about the best practices in serving this community. There are cracks in the systems that often place many of us in untenable positions. I have “fallen through most of them, in another state, and in Virginia, but all the same cracks are here.

There are services in Virginia that, in my experience best serve this community. To start with, Brain Injury Services, Inc. serves many Virginians, more than 500, and has a much clearer understanding of the needs of this community. I was very disappointed when I did not see a representative from that state-funded, non-profit, organization on the task force list. B.I.S. is a case management, and advocacy organization, that has one-to-one contacts with this group. They also have many interactions with institutions, and services that serve the Brain Injured needs. They

have a developed a clear idea of what works, and what does not work. Each consumer is unique, with a unique set of needs. Unfortunately, the funding is limited, and there are over two year waiting lists. This is totally unacceptable, as you will see if you read on.

Waiting lists are defeating to the already defeated. The first two years, post injury, of services are the most important. The sooner the better, if the objective is to have the individual return, as a contributing member of society. Many habits will be learned in these two years, services or not. Unlearning them is incredibly more difficult than re-learning ones lost.

I have to hold the organizers of this Task Force accountable for not having them represented. In this, they have failed as much as 10% of the disability community in Virginia. The disability, that is now growing most rapidly. It would also have been appropriate to have a survivor that is living day in, day out, with the disability.

The Virginia Independent Living Council also serves the Brain Injured community well, and the centers are much needed. Recovery to independent functioning can take quite a while, and may never happen. It often depends on services and attitudes. I am still in the process. Having met many survivors of Brain Injury residing in institutions I have found that some institutions have wonderful programs, most do not. I ask that if one is going to measure accountability then one should ask those that know and understand the problems. Also, those that may deal with them, daily.

It is always possible that close family, or friend may need services at any time.

EDUCATING THE PUBLIC, CONSUMERS, AND FAMILIES TEAM

I heartily support all the recommendations. I would like to add one. As a Survivor Representative, I have become very busy in these functions. How many Task Force members would know what to do, where to go, what is available, and where to get the services needed, should they suddenly find themselves in need of such information? Would they approve of those services? There are others like me in the state. Unfortunately too few. This is one reason why the support groups works so well, and we need the Virginia Independent Living Council

We, the Brain Injured, are on a journey, I call it an adventure. Each day we get closer to our goals. Much may have been lost, and the recovery of functions takes time, and support. In my journey, and that of others, I have found that too many agencies think of themselves as "one-stop-shops". Given the complexity and uniqueness of brain injuries, **none** can make that concept a practice. Planning, or executive functioning are usually not our forte. Survivors often do not know what they want, or need until after they **need** it. Often, it is then too late. "Oops ... another one fell through the cracks." Some just quit, and are lost to society. Some take another option.

Gloucester, Virginia -- Mini Town Meeting July 7, 2005

1. The number one priority expressed at this meeting was to preserve funding for the Regional Resource Coordinator (RRC). Comments: The Regional Resource Coordinator (RRC) is good for a dispersed community like ours. We are here right now at this meeting through the efforts of the RRC! Our RRC worked on getting a satellite Center for Independent Living (CIL) in the area; helped put on a Disability Fair; links people to services. Having the RRC is like "planting a seed" to begin developing services in the area. Without the Regional Resource Coordinator, there is nothing!

Another concept that received a lot of support was to have a "place" like a clubhouse or day program where the Regional Resource Coordinator could be housed and also where case management services could be provided. However, the RRC was stated as the priority, with the clubhouse/day program as second priority. (Since the case manager position will be filled, the idea here was that the clubhouse/day program could be a "home base" for both RRC and case manager, as well as a place to provide clubhouse / day program services. Since these communities are so dispersed, a single day program would not be accessible for everyone; multiple programs are needed to fill the need.)

2. The second priority expressed by members of the group was to fill / maintain the state-funded case manager position which serves their area (DRS Community Rehabilitation Case Management Program position). The case manager who was in that position resigned and someone will be hired to fill the position.

Other comments (not listed in order of priority, as these were expressed by various members separately):

Over past 30 years, there has been little to no awareness of resources for survivors and caregivers. Need more public awareness / education about available brain injury services and resources.

Better diagnosis and medical treatment, preferably through Level I and Level II hospitals (e.g., where a neurosurgeon is available 24 hours a day or on-call); coordinated medical services and therapies

Work with wellness centers that provide physical and mental health wellness services through hospitals;

Supported living services (for 21 year old son)

Separate services for survivors and caregivers.

- for survivors: help communicating; assistive technology; a Partners in Policymaking advocacy academy to learn how to "help ourselves"
- for caregivers: better information and support while person is still in hospital and after; local support groups (especially in Williamsburg!)

Fundraising! We can't expect the state to always "gimme."

Endepence Center in Norfolk, Virginia Mini Town Meeting -- July 20, 2005

- 11 people attended: 9 survivors, 1 family member, 1 staff person (group facilitator, Tarra Davis)
- Would like to have more community services available in Chesapeake (a support group would be nice!), Virginia Beach (need more staff for the day program there!), Portsmouth, and Norfolk. Individuals would like more opportunities to do things in the community. Since many live in nursing facilities, even if activities were available, they would need specialized transportation to attend / participate. There is specialized transportation available, but not in the evenings.
- Specific services mentioned:
 - ◆ Funding
 - ◆ Community Services
 - ◆ Transportation
 - ◆ Residential
 - ◆ Clubhouse / Day Program – could start out as a part-time program that is open two or three times per week
- Many of the support group participants live in a nursing facility and would love to have more activities in the evening. It was stated several times that “there is nothing to do except sit around and look at each other.”

VCU-RRTC Facilitation Script

Agenda: (Total Time: 120 Minutes)

| Allotted Time | Meeting Activity | Meeting Leader |
|--------------------|--|----------------------------|
| 15 minutes | Overview of State Plan History | BIAV or DRS Representative |
| 10 minutes | Ice Breaker Question | VCU-RRTC |
| 25 minutes | Building Block 1: Regional Resource Center | VCU-RRTC |
| 25 minutes | Building Block 2: Clubhouse or Day Program | VCU-RRTC |
| 25 minutes | Building Block 3: Case Management | VCU-RRTC |
| 7 minutes | Wrap-up Question 1 | VCU-RRTC |
| 7 minutes | Wrap-up Question 2 | VCU-RRTC |
| 6 minutes | Closing Thank You and Final Remarks | VCU-RRTC |
| after meeting ends | Questions | BIAV or DRS Representative |

Rules of Facilitation

Good evening, my name is Valerie Brooke and this is Grant Revell, we will be serving as the meeting facilitator and recorder. Grant and I are from Virginia Commonwealth University (VCU) in Richmond, Virginia and as you just heard, we have been asked by VA DRS and the Brain Injury Association of Virginia to conduct a series of town meetings that will not only provide feedback on the identified service areas but will also update the current brain injury state plan.

In order for us to assist in accomplishing this goal – as the meeting facilitator it is important that I set a few ground rules to help ensure that we have a successful and productive meeting. The ground rules will include:

- One individual will speak at a time.
- All participants will be encouraged to share ideas.
- Questions may be asked to clarify ideas.
- No one may criticize another.
- Feelings may be expressed. They are not to be disregarded or denied.
- Discussions are about positions, not personalities

The meeting recorder will create a visual memory of our group discussions. At times it may be necessary for the recorder to stop the meeting and check that he has accurately captured a participant's response. If at any time the recorder makes an error recording a response than the participant may seek further clarification. From time to time throughout the evening the Recorder will check for accuracy.

It is important for you all to know that we are neutral in this process. We will be respectful of your time and look forward to an exciting exchange of ideas as we begin to discuss services for individuals with brain injury in your community.

There are a total of 12 questions that we need to address during our 1 hour and 45 minute town meeting. We anticipate that during the course of our discussion here tonight many important issues and ideas will be shared. If these issues are not part of tonight's agenda we will record them over here under the **Community Concerns Board**. These notes will then be included as part of the official transcript of the town meeting. VCU will develop a final report from the town meetings that reflects the expressed ideas from each community and this report will then be submitted to DRS and the BIAV for consideration and planning purposes.

Facilitation Questions

- **Ice Breaker Question:** What services are currently available in your community for individuals with Brian Injury?
- **Building Block 1: Regional Resource Center**
 - **Question 1:** Does Regional Resource Coordination fit the needs of people with brain injury in your community?
 - **Question 2:** What do you like about it?
 - **Question 3:** What needs to be changed or added?
 - **Question 4:** How significant is the need for this service in your area?
- **Building Block 2: Case Management**
 - **Question 1:** Does Case Management fit the needs of people with brain injury in your community?
 - **Question 2:** What do you like about it?
 - **Question 3:** What needs to be changed or added?
 - **Question 4:** How significant is the need for this service in your area?
- **Building Block 3: Clubhouse/Day Program**
 - **Question 1:** Do Clubhouse / Day Programs fit the needs of people with brain injury in your community?
 - **Question 2:** What do you like about it?
 - **Question 3:** What needs to be changed or added?
 - **Question 4:** How significant is the need for this service in your area?
- **Wrap-up Question 1:** Forced Choice! You have \$150,000 to spend on services for people with brain injury in your community - which of the five categories of services would you purchase? Why?
- **Wrap-up Question 2:** What else? What other services are needed in your community to meet the needs of people with brain injury?

Closing Remarks

Thank you so much, we have identified the services that are currently available in your community, discussed each of the three primary building blocks identified in the 2004 survey, and identified additional areas of interest. We will take this rich information back to DRS and BIAV for their study in updating the State Action plan that will best meet the needs of your community. Now I would like to turn the meeting over to BIAV for some closing remarks.

Facilitator Responsibilities After Meetings are Completed

- Collect and bring all notes taken at the meeting back to VCU-RRTC to be used for the write-up of the facilitation.
- Collect and bring back all supplies (markers, extra-easel pad sheets, easel stand, and UTAC) and display boards to VCU-RRTC.

Introduction

- Update Virginia's Brain Injury Action Plan
- Define brain injury service options, terms
- Solicit feedback on “core” services
- Identify local service needs
- Discuss development of services



Brain Injury Association of Virginia

History of TBI Action Plan

- 1998: federal TBI Act Grant awarded to Department of Rehabilitative Services (DRS), in partnership with Brain Injury Association of Virginia (BIAV) and Virginia Commonwealth University (VCU)
- Purpose of federal grant was to develop “action plan” in brain injury for Virginia
- 2000: to assess needs of Virginians with brain injury, BIAV held 19 **town meetings** and VCU mailed 10,000 **written surveys**
- 2000 *Traumatic Brain Injury Action Plan in Virginia* based on town meetings, surveys
- Available at: <http://www.vadrs.org/publications.htm>



Brain Injury Association of Virginia

2000 TBI Action Plan

- #1 need identified was education and public awareness
- Other needs: information & referral, support, advocacy
- Service needs: case management, residential treatment program, community living services, employment, transportation, day programs/services, social/recreational opportunities



Brain Injury Association of Virginia

Accomplishments Linked to 2000 TBI Action Plan

- Established 5 Regional Brain Injury Resource Centers
- Expanded case management and support groups
- Created clubhouses / day programs
- Conducted over 150 training sessions for a variety of groups
- Facilitated over 50 broadcast / print media features
- Provided training / assistance to over 25 school districts
- Developed informational materials; enhanced websites
- Obtained the largest single appropriation of funds specifically for brain injury services in Virginia's history:

2005: **\$825,000**

2006: **\$1,075,000**



Brain Injury Association of Virginia

Services Identified in 2000 TBI Action Plan

Created seven (7) categories of services for discussion at 2005 Town Meetings:

Case Management
Clubhouse / Day Program
Regional Resource Coordination
Community Living Supports
Residential
Employment
Transportation



Brain Injury Association of Virginia

“Core” Services

- 2004-2005 advocacy efforts involved local communities and organizations
- Legislators asked for a “core” of services to be used as building blocks for developing services
- Three “core” services identified by advocates and legislators: **Case Management, Clubhouse / Day Program, and Regional Resource Coordination**
- **Success!** General Assembly appropriated ongoing state funding for FY '05 / FY '06
- Funded a “core” service in several communities



Brain Injury Association of Virginia

2005 Town Meetings

- Solicit feedback on the three “core” services, as well as on **Community Living Supports** and **Residential Services**
- To update Virginia’s BI Action Plan, DRS wants to know:
 - Do “core” services meet needs in most local communities?
 - Do “core” services PLUS Community Living and Residential meet needs in most local communities?
 - If not, what else is needed?
- Will not focus on **Employment** or **Transportation**:
 - Important issues for people with all disabilities (not just BI) Being addressed in other ways (e.g., advocacy for more supported employment funds; statewide study group on transportation)



Brain Injury Association of Virginia

Regional Resource Coordination

What is Regional Resource Coordination?

Services provided by one staff person in unserved and underserved areas to:

- Identify resources and build coalitions to address local needs
- Provide public awareness, information & referral, education, outreach, and advocacy



What are the unique features?

- Focuses on needs of local community
- In-depth knowledge of local community services and supports
- Provides some help to individuals without access to case management or clubhouse/day programs to find and use local resources
- Creates momentum for development of services

Cost: \$75,000/year

Numbers served: entire community

Case Management Services

What is Case Management?

Services provided by one staff person to:

- Identify an individual's needs, then find resources to meet those needs
- Monitor and evaluate services



What are the unique features?

- Individualized approach to determine person's needs / desires; develop a plan with personal goals
- Creation of "support team" for each person
- In-depth knowledge of local community services and supports
- Service to person is long-term
- With additional funding, could purchase limited services for individual

Cost: \$75,000 minimum/year
Numbers served: 35 - 50

Clubhouse / Day Program

What is a Clubhouse? A Day Program?

- Several staff provide services in a community setting to more than one person
- Supportive environment aids physical, cognitive, and emotional recovery; improves social skills
- Clubhouse "members" operate a work-oriented program with staff assistance. Day program participants choose vocational, educational, or social activities.



What are the unique features?

- Individualized approach to determine person's needs / desires; develop a plan with personal goals
- Limited case management may be provided
- In-depth knowledge of local community services and supports
- Services are long-term
- With additional funding, could serve as "hub" for other services (e.g. employment, regional resource coordination, expanded case management)

Cost: Clubhouse - \$150,000/year;
Day Program - \$125,000/year
Numbers served: 35/program

Community Living Supports

What are Community Living Supports?

- Services from a variety of providers that enable persons with brain injury to live safely and successfully in community settings of their choice
- Purchase and coordination of services can be “managed” by one person
- Focus is on supporting people to live in Services may include personal assistance, life skills training, volunteer activities, social / recreational activities



What are the unique features?

- Services are consumer controlled
- Services are provided in integrated settings (e.g. home, community, work)
- Services are individual-focused, not program-focused, and allow for more flexibility

Cost: depends on number of individuals served, types of services provided

Numbers served: depends on funding

Residential Services

What are Residential Services?

- Services provided by several staff to more than one person; varies in terms of location and in the type and amount of assistance
- Individual or group settings (apartments, homes)
- Can be short or long-term housing

What are the unique features?

- **Short term:**
 - *Transitional Living:* from rehabilitation to home
 - *Neurobehavioral treatment:* structured program for people with challenging behaviors
- **Long term:**
 - *Supported living:* ranges from “on call” (as needed) to weekly support to 24-hour assistance
 - *Secure therapeutic environment:* for people with serious, persistent behavioral / psychological issues



Cost: \$170,000/year for supported living with weekly assistance

Numbers served: 20

Town Meeting Discussion

1. Does Case Management fit the needs of people with brain injury in your community?

What do you like about it? What needs to be changed or added?
How significant is the need for this service in your area?

2. Do Clubhouse / Day Programs fit the needs of people with brain injury in your community?

What do you like about it? What needs to be changed or added?
How significant is the need for this service in your area?

3. Does Regional Resource Coordination fit the needs of people with brain injury in your community?

What do you like about it? What needs to be changed or added?
How significant is the need for this service in your area?

Town Meeting Discussion

4. Forced Choice! You have \$150,000 to spend on services for people with brain injury in your community - which of the five categories of services would you purchase? Why?

5. What else? What other services are needed in your community to meet the needs of people with brain injury?



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