COMMUNITY BRAIN INJURY SERVICES

Providing Innovative services for survivors of brain injury

"Evaluating Brain Injury Clubhouses and their effects on Neurobehavioral Functioning and Participation"

CNI Grant: Final Report
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Executive Summary

Persons with acquired brain injury (ABI) have neurobehavioral impairments in cognition, emotional and social functioning, and behavior. Long-term disability is marked by reduced independence, increased safety risk, poor health, depression, and reduced participation and life quality. Our CNI research project provides a foundational evaluation of the 'Clubhouse Model'—developed and successfully implemented in the mental health population—as a long-term, person-centered, service delivery model to improve the lives of persons with ABI and reduce burden on caregivers and commonwealth healthcare services.

Our CNI research project developed the Brain Injury Clubhouse Profile Questionnaire (CPQ), which provides a standardized tool to identify Clubhouse members, infrastructure, staffing and programming. The Brain Injury CPQ has now been adopted by the International Brain Injury Clubhouse Alliance (IBICA) and could be used for accreditation and quality improvement.

The ABI Clubhouse Model core service delivery includes member participation in meaningful clubhouse operation, maintenance and recreational activities; peer groups; outreach, and wellness and health promotion. Clubhouse help members make healthcare linkages, and access entitlement, housing, family, and substance use supports and services. ABI Clubhouse members have on average 8 chronic health conditions and functional impairments that drive disability; 72% have 5 or more chronic conditions and impairments. There were variations in member characteristics and service utilization within and between Virginia- and non-Virginia based ABI Clubhouses, which reflect the model's emphasis on meeting local needs and leveraging local funding mechanisms.

New ABI Clubhouse members at 6-months post-program start showed substantial reduction in hospitalization risk factors; emergency room visits and acute hospitalizations; and depressive symptoms. Clubhouse members showed improved safety carrying out everyday activities, navigating the community, and following health recommendations. They also showed improved independence in functional abilities, and improved participation in home and community activities. With regard to health-related life quality, clubhouse members reported improved general health and reduced number of days per month in which poor physical or mental health restricted their everyday activities.

As an approved add-on objective, we surveyed 14 IBICA clubhouses in ten states, including all five Virginia ABI Clubhouses, to identify how COVID pandemic has impacted ABI clubhouse services. Thirteen of 14 clubhouses closed their buildings to in-person activities at least once during the COVID pandemic. Almost all clubhouses provided outreach using multiple communication modes and virtual services (typically 1-4 hours per day).

In summary, the ABI Clubhouse Model provides services and supports to those with severe disability and initial evidence shows reduced emergency medical utilization and risk factors, and improved safety, community independence and health-related life quality.

A. INTRODUCTION/RESEARCH TEAM

Our research team is excited to share the results of our ground breaking three-year CNI Grant. This grant was the collective work of ten organizations, encompassing six states. We thank and acknowledge the work of our partners on this foundational research into the impacts of Brain Injury Clubhouse Model programs. Below is a list of our project partners:

- Virginia Commonwealth University: Center for Rehabilitation Science and Engineering (CERSE): Richmond, Virginia
- University of Massachusetts Medical School: Program for Clubhouse Research: Worcester, Massachusetts
- International Brain Injury Clubhouse Alliance
- Community Brain Injury Services: The Mill House and The Denbigh House: Richmond, Virginia and Newport News, Virginia
- Eggleston Services: The Beacon House: Virginia Beach, Virginia
- Brain Injury Services: Adapt Clubhouse: Alexandria, Virginia
- The Bridgeline: Bridgeline Place High Street Clubhouse: Charlottesville, Virginia
- Side by Side Brain Injury Clubhouse: Atlanta Georgia
- Brooks Rehabilitation: The Brooks Clubhouse: Jacksonville, Florida
- Beechwood Neurorehab Clubhouse: Langhorne, Pennsylvania

We present our main findings, grant deliverables, and future direction to improve the lives of adults disabled by brain injury.

B. PRIMARY RESEARCH OBJECTIVES AND RESULTS

Objective One: *Implement a program level data collection system to standardize data concerning the injury and sociodemographic characteristics of people served, the level and duration of services provided, and outcomes generated by Virginia's Acquired Brain Injury (ABI) Clubhouse.*

Results for Objective One: A Brain Injury Clubhouse Profile Questionnaire (CPQ) tool was developed that describes how Clubhouse programs operate organizationally (i.e. services provided, funding structures, staffing patterns), the characteristics of persons served in these programs and how they access services provided. We are excited to report that not only has a Brain Injury-specific CPQ been developed but this tool has already been implemented in one additional Clubhouse beyond the project scope and the International Brain Injury Clubhouse Alliance (IBICA) has committed to utilizing the CPQ on an ongoing basis with its entire Clubhouse membership. IBICA affiliated clubhouses are currently located in ten states within the USA.

The CPQ has given us an understanding of how ABI Clubhouses are structured to best serve this population as well as similarities and differences between Clubhouses serving those living with serious mental illness and with brain injury. An important finding that quickly led to improved quality assurance across all ABI Clubhouses, was that programs reported challenges following specific IBICA and/or Clubhouse International standards. This led to a modification of IBICA standards that, while highlighting a departure from International Standards for mental health clubhouses, provided guidance and clarification for ABI Clubhouses that best supports people

with brain injury. For example, we found that ABI Clubhouse members benefit from a greater focus on family support services and community integration, while educational pursuits and housing supports were less of a need in ABI Clubhouses as compared to mental health clubhouses.

A next step in codifying quality assurance across ABI Clubhouses is now underway utilizing the revised IBICA standards (see Appendix 1). With Clubhouse International's permission, the research team has modified the Clubhouse Self Study which is routinely completed by mental health Clubhouses seeking accreditation by Clubhouse International to reflect the consensus IBICA Clubhouse standards. Clubhouse accreditation is a symbol of quality and a demonstration of a Clubhouse's adherence to the Clubhouse Standards. This new IBICA Clubhouse Self Study has been disseminated to all IBICA Clubhouses to support their efforts toward program development. Two IBICA Clubhouses (one in VA and one in TX) have volunteered to pilot a virtual quality assurance survey in 2021 that will be conducted by a seasoned member of Clubhouse International's Accreditation Faculty who will be paid as a consultant by IBICA. A member of the research team will shadow that survey in an effort to develop a comparable quality assurance faculty team within IBICA.

A comparison between the five Virginia-based ABI Clubhouses and three study sites across the eastern US is discussed in detail in the following section

Objective Two: *Evaluate characteristics of ABI Clubhouses to identify key active ingredients of the ABI Clubhouse Model.*

CPQ data collected from the eight clubhouse partners in the fall of 2019 provides information regarding the ABI Clubhouse characteristics described below. Data includes information from five ABI clubhouses in Virginia, and one in Florida, Georgia, and Pennsylvania.

Results of Objective Two:

Organizational Characteristics of the Brain Injury Clubhouse Programs

Clubhouse Characteristic	**Virginia (n=5)**		**Other States (FL, GA, PA) (n=3)**	
	Mean	Range	Mean	Range
Length of Operation as a Clubhouse (Years)	16.2	11.2 - 20.9	12.3	5.8-19.76
Club has an Independent Board of Directors (Y/N)	0%	0-0%	67.0%	0-100%
Club has an Advisory Board	60%	0-100%	0%	0-0%
Clubhouse has an Auspice (Parent Agency)	100%	100-100%	66.7%	0-100%
CARF Accreditation: Employment Community Services (ECS)	100%	100-100%	67%	0-100%
Attempts to Meet all IBICA Standards	100%	100%-100%	100%	100%-100%

Clubhouse has IBICA Standards that are difficult to comply with	60%	0-100%	33%	0-100%
Annual Budget	$345,733	$199,871-$461,643	$683,078	$325,370-1,081,583
Cost per Year	$9873.62	$5125-$21,983	$12,648	$7,073-$18,026
Cost per Day	$86.43	$33.33-$157.99	$88.83	$30.72-$155.85

Comparison of CPQ data showed that on average ABI Clubhouses in Virginia have been in operation longer than in other states. However, our sample is small and one clubhouse outside of Virginia is much newer. One clubhouse outside of Virginia is also a free-standing entity and is not operated by a parent/auspice agency. Free-standing clubhouses typically have an independent board of directors responsible for program oversight, fundraising, etc. The clubhouses outside of Virginia have an average larger budget but this is due to one clubhouse being significantly larger than the rest of the clubhouses in this sample. The annual budgets often reflect the length of clubhouse operation, number of staff, extent of services offered, and funding systems that vary from state to state. The average costs (daily and annual) are rough calculations based on the annual budgets and the numbers of members served in the average daily attendance and active memberships. Due to the wide variety and discrepancies in state and local funding mechanisms and costs for providing services, these calculations should not be used for rate setting purposes. The average costs per day were similar in and out of Virginia while the cost per member per year was larger outside of Virginia.

Seven out of the eight project's study sites are accredited by the Commission for the Accreditation of Rehabilitation Facilities (CARF), including all 5 of those housed in Virginia. The most common type of CARF accreditation was in the Employment Community Services category with one Clubhouse accredited under Medical Services to coincide with its larger parent agency.

ABI Clubhouses: Funding Sources

Funding Source	**Virginia (n=5)**		**Other States (n=3) (FL, GA, PA)**	
	Mean	Range	Mean	Range
State and Local Government	79.1%	54.7% - 100%	4.77%	0% - 9.3%
Fee for Service- Public (VR and Medicaid Waiver)	1.4%	0% - 6.0%	31.8%	4.4% - 75.0%
Fee for Service- Private (Work Comp, Private Pay, Group Health, other)	1.8%	0% - 5%	21.0%	0.0% - 39.0%
Charitable Gifts, Grants, Donations, Fundraising Events	17.7%	0% - 45.3%	42.43%	1.0% - 86.3%

Funding sources were collapsed into four main categories: funding from state and local governments, fee for service (public), fee for service (private), and from grants, gifts, and fundraising events. There was wide variability in the funding sources for the clubhouses with clubhouses in Virginia receiving the majority of their funding from state and local governments while the major source of funding for clubhouses outside of Virginia was through grants and fundraising, followed by fee for service – public. These differences reflect the funding mechanisms established from state to state. Two project partners outside of Virginia are housed in states employing Home and Community Based Services via Medicaid Waivers and are vendors under these programs. The third is funded largely by its parent agency, a not-for-profit rehabilitation hospital.

Fee for services represents opportunities for Clubhouses to expand funding options. However, the Clubhouses that were most drastically impacted by the current Public Health Emergency (Covid-19) were those funded primarily through fee for services, while those funded by governmental sources could continue to operate and support their members without fear of closing doors. This along with other impacts of the Public Health Emergency are discussed later in this report.

ABI Clubhouses: Staff Characteristics

Staff Characteristic(s)	Virginia		Other States (FL, GA, PA)	
	Mean	Range	Mean	Range
# Full-Time Staff (FTE's)	3.8	3-5	7.7	6-10
# Part-Time Staff	0	0-0	1.7	0-5
% Staff Identifying as Consumers	10%	0-50%	7.7%	0-17%
Active Members to FTE Staff	10.6:1	7:1 - 13:1	7.0: 1	6.0:1 - 8.3:1
# of Volunteers/Students	1.2	0-3	3.7	0-6

Generalist ABI clubhouse staff are most likely to have a bachelor's degree in Human Services or a master's degree in Human Services. ABI Clubhouse Administrators are most likely to have a master's degree in Human Services. Administrators were also more likely to be employed long-term (15-20 year) compared to generalist staff. Most generalist staff in ABI Clubhouses have been employed for less than ten years.

The number of full-time staff is higher in clubhouses located outside of Virginia while the member to staff ratio is higher in clubhouses located in Virginia. This reinforces the observation described in the next section related to the level of self- sufficiency in membership among the Virginia Clubhouses vs those that include more members with Personal Support Assistance. The percent of staff that identified themselves as consumers varied widely.

Membership Characteristics of Brain Injury Clubhouses

Clubhouse Membership Size

Characteristics of ABI Clubhouse Memberships	Virginia		Other States (FL, GA, PA)	
	Mean	Range	Mean	Range
Number of Referrals (Annually)	17.6	10-32	56.0	20-90
% Intake/Tour that become Members	62.0%	20-85%	61.7%	15-90%
Average Daily Attendance	12.8	8-23	23.3	19-29
Evening Weekend Participation	15.2	0-28	6.0	0-18
Active Membership (90 Days)	40.6	21-51	52	46-60
Total Clubhouse Membership (Lifetime)	214.4	50-397	355.7	102-615
# Active Members that bring a Personal Care Assistant (%)	2.60	0-8	16.5*	15-18

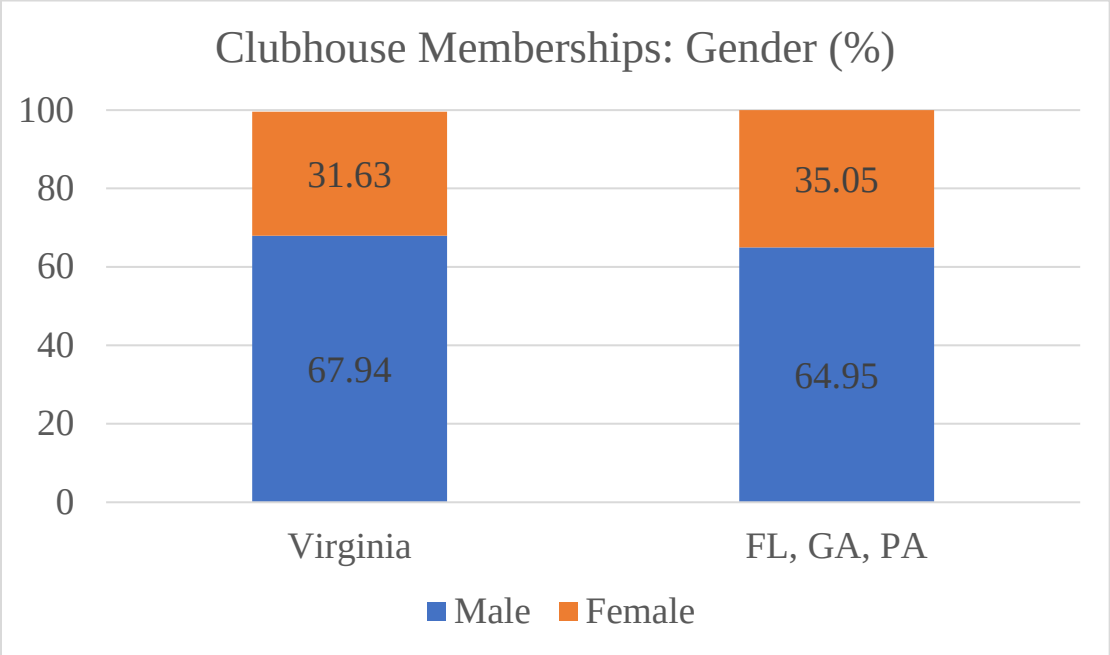
*One clubhouse did not provide this item

The clubhouses in Virginia had smaller memberships – (Average daily attendance and Active memberships). A member is considered active if he/she attends the clubhouse at least once every ninety days. The clubhouses outside of Virginia also had a higher average total membership (lifetime). However, the largest clubhouse in the sample is located outside of Virginia and is much larger than the rest of the clubhouses in our sample. Members were more likely to participate in evening/weekend programming in Virginia. Clubhouses outside of Virginia also had more referrals but this may also be due to one clubhouse being much larger than the rest.

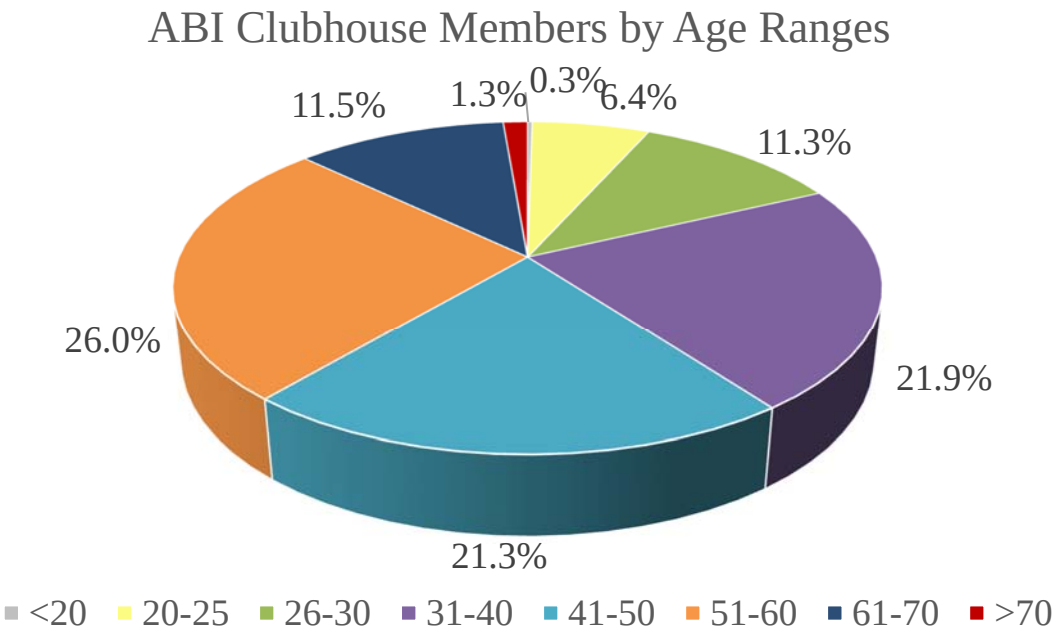
One unique feature of Clubhouses serving people with brain injury vs mental illness is the use of Personal Care Assistants. Since the daily routine of any Clubhouse program is built upon work-type daily tasks, a level of independence is assumed in order to maintain a productive, dynamic milieu with minimal staff intervention. Given the wide range of physical, communication, cognitive, and neurobehavioral challenges inherent in the brain injury community, IBICA Clubhouses have evolved to allow members to bring a Personal Care Assistant if they require 1:1 help for any ADL that arises while participating at the Clubhouse. This allows the limited clubhouse staff to remain available for supporting daily task completion vs providing 1:1 care, which would a) require additional staff and b) redirect the primary focus of programming from activities that maintain the clubhouse's operation and toward personal care – a notable distinction between a Clubhouse program and a traditional Adult Day Care program.

Interestingly, Virginia-based Clubhouses tended to report fewer members with Personal Care Assistants than those in other states. One clubhouse outside of VA reported a higher proportion initially, but toward the project's conclusion, separated the membership into 2 programs to better adhere to IBICA standards related to autonomy and productivity. Another larger Clubhouse that also reports a larger number of referrals, enrolls a higher number of individuals more recently injured, implying a greater need of personal assistance until recovery is further along.

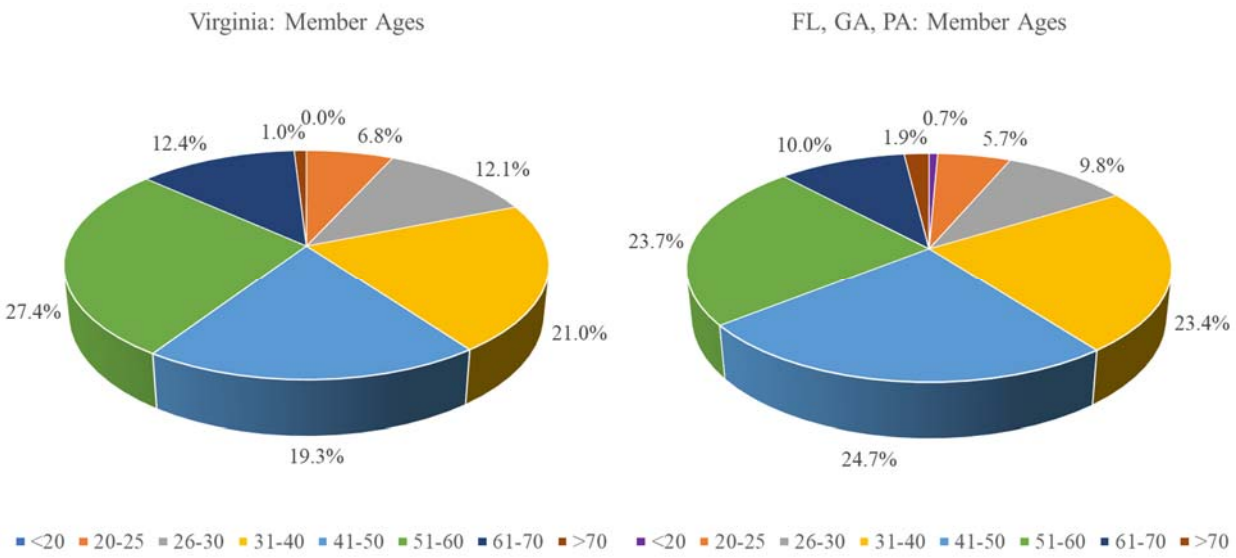
Demographics of Clubhouse Members

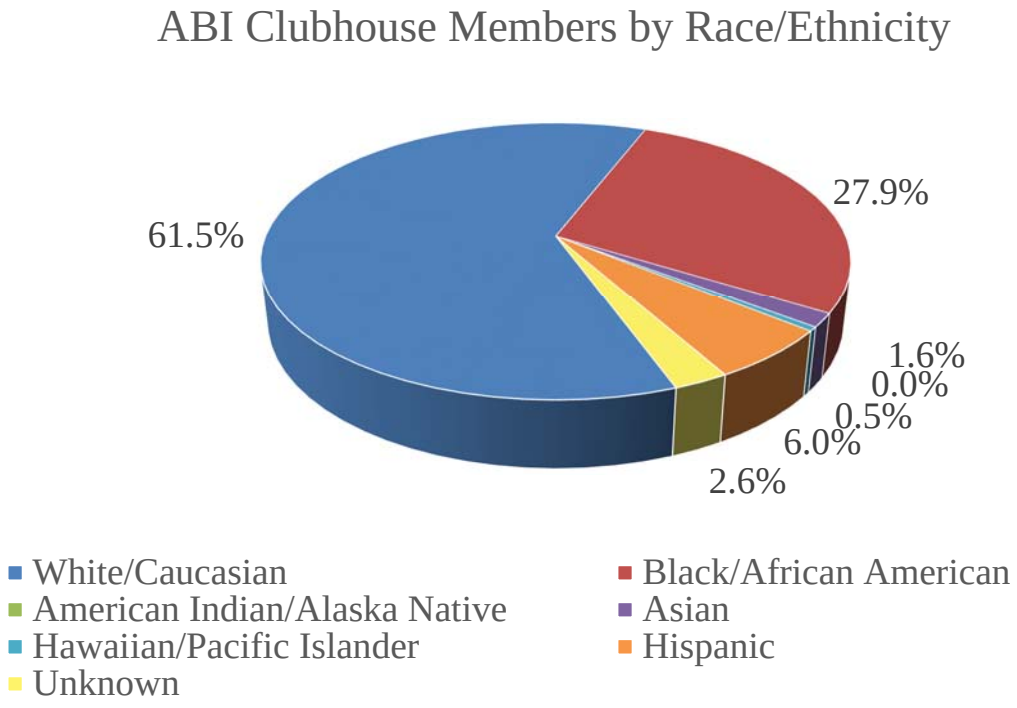


The composition of clubhouse members by gender was similar in both groups with approximately two thirds of clubhouse members being male.



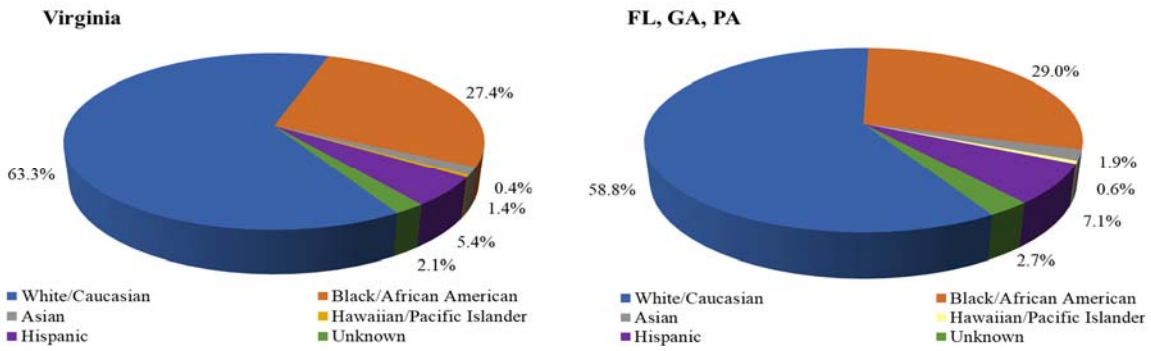
The distribution of active members by age ranges was similar in ABI Clubhouses inside and outside of Virginia. The majority of clubhouse members between the ages of thirty and sixty. This distribution is also similar to that of mental health clubhouses. These results show how ABI Clubhouses serve adults across their lifespan.

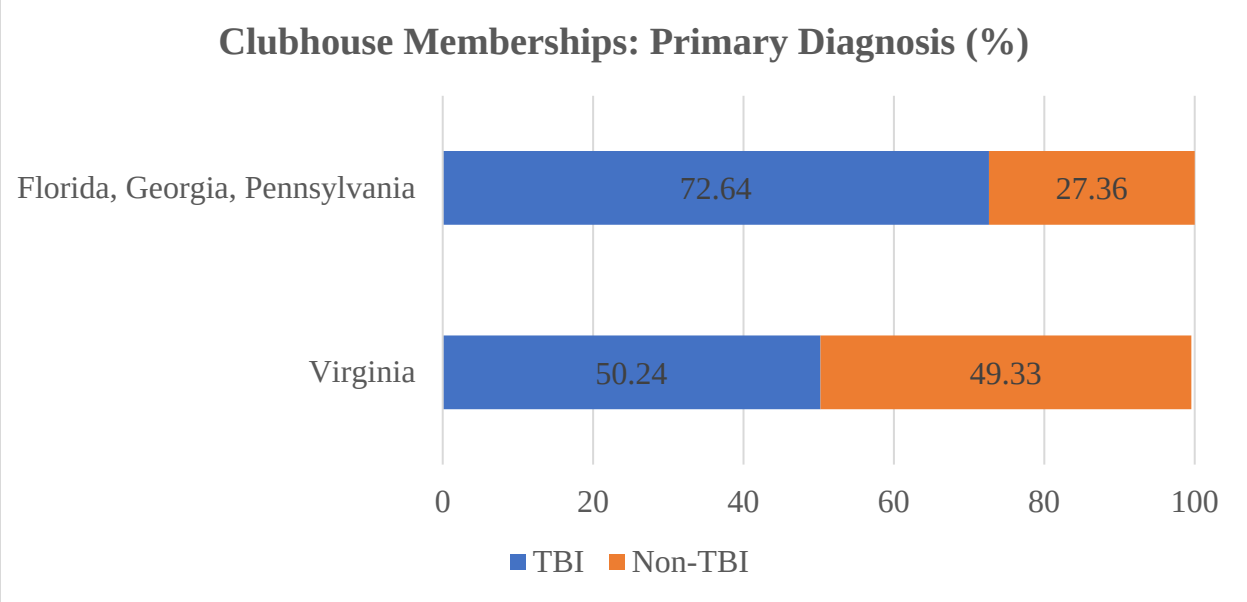




The majority of members served in brain injury Clubhouse are White/Causasian, followed by Black/African American. The small percentage of Hispanic members may be impacted by limited staff and resources along with legal requirements for services. For example, with so few staff per clubhouse there may not be bilingual staff, or potential members may lack adequate documentation to qualify for funded service. Clubhouses could do more outreach to the Hispanic community, including ensuring services are more accessible to Spanish speaking individuals.

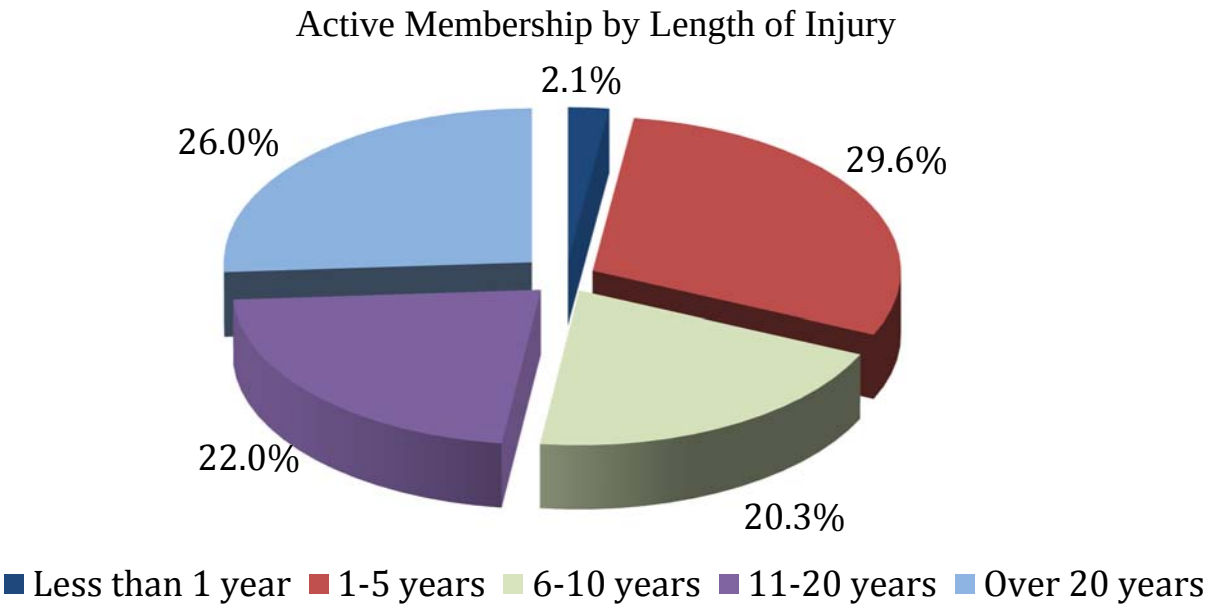
Memberships in Virginia Clubhouses represent very similar proportions of race/ethnicity as those in other states with minor exceptions that could result from local community make-up.

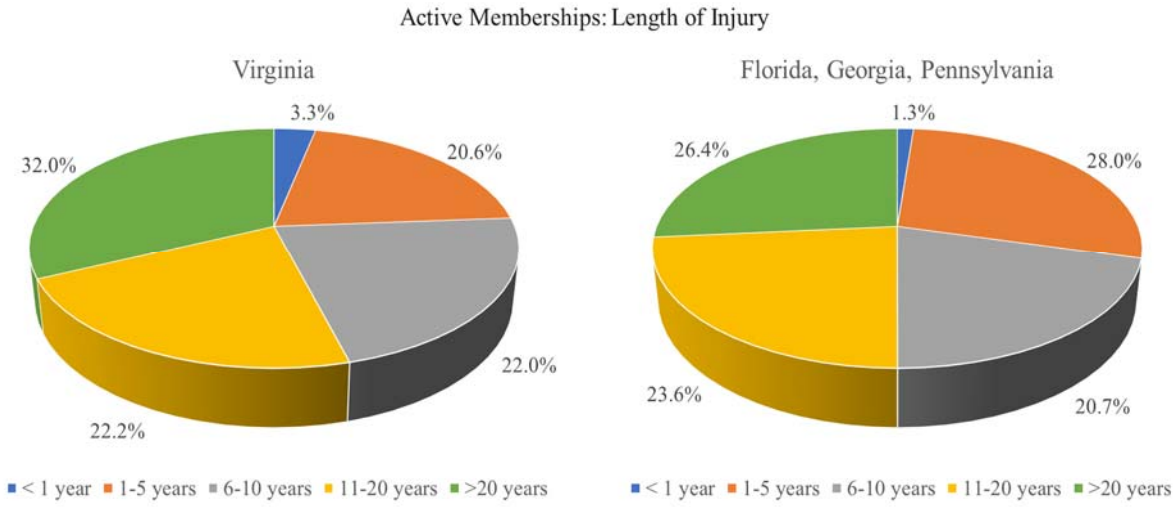




Members outside of Virginia are more likely to have a traumatic brain injury. It is possible that locally defined qualifications for government-sponsored services impact whether people with non-TBI may be served, however, it is apparent that people with both TBI and non-TBI brain injuries request, benefit from, and are welcomed for Clubhouse services.

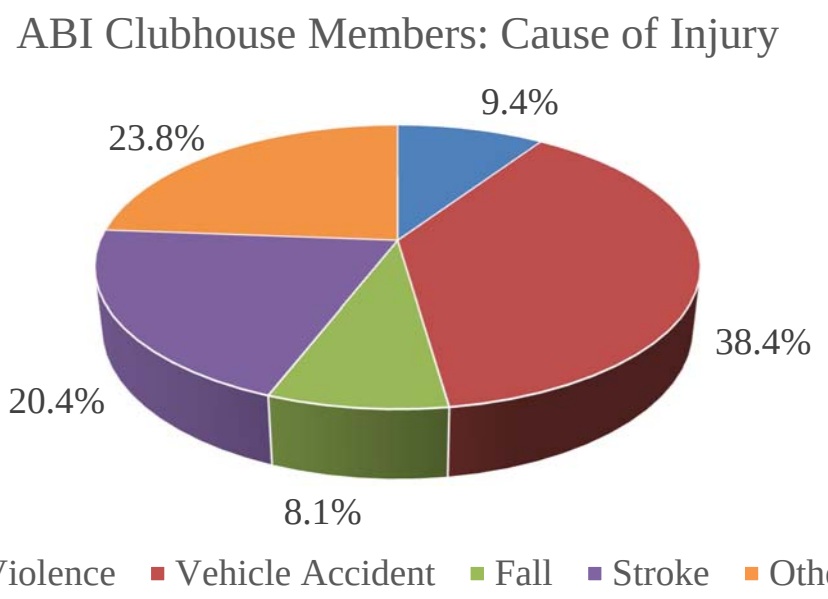
It is notable that over half (54.85%) of active ABI Clubhouse members also have a co-morbid mental health condition.



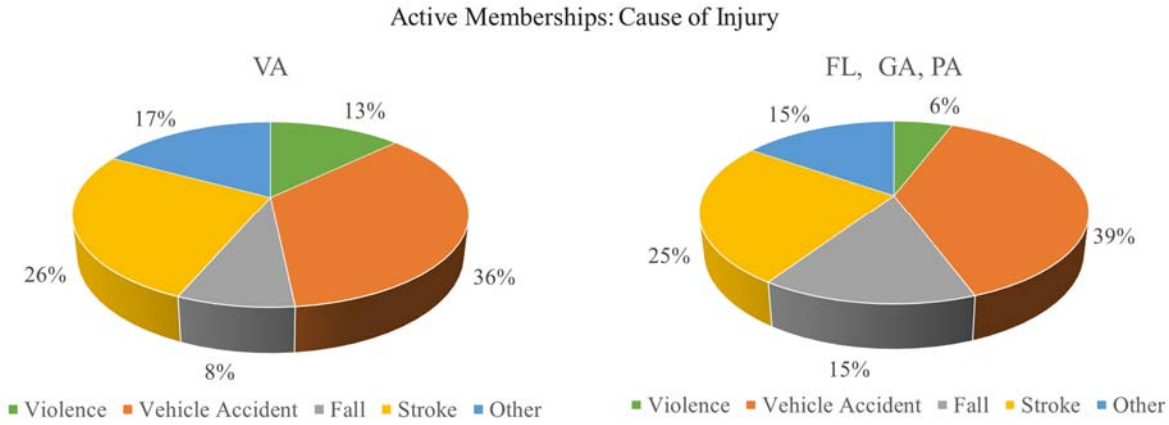


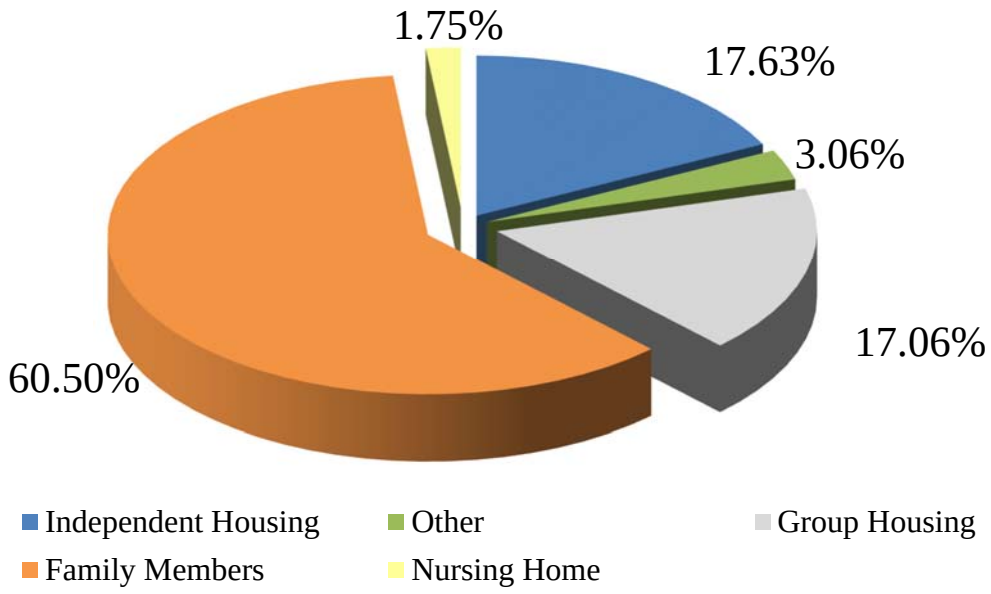
This graph represents the lifelong nature of brain injury-related disability and needed supports. Over 70% of members both inside Virginia and outside sustained a brain injury more than 6 years ago, and over half have lived with disabilities for at least 11 years.

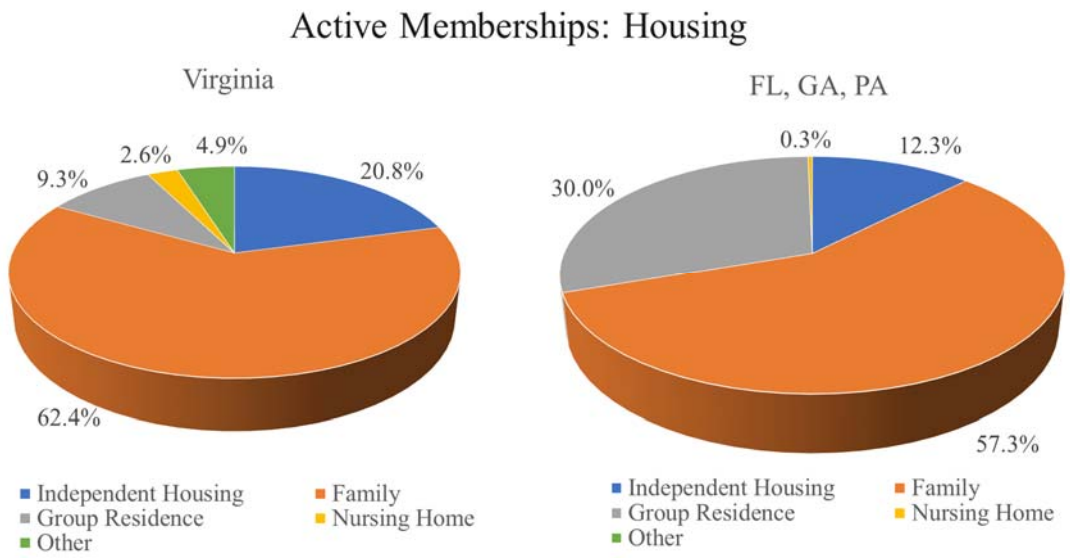
The distribution of active members by length of injury was also similar inside and outside of Virginia. The length of time since injury reflects the clubhouse philosophy of membership being available if a member wants and needs clubhouse services



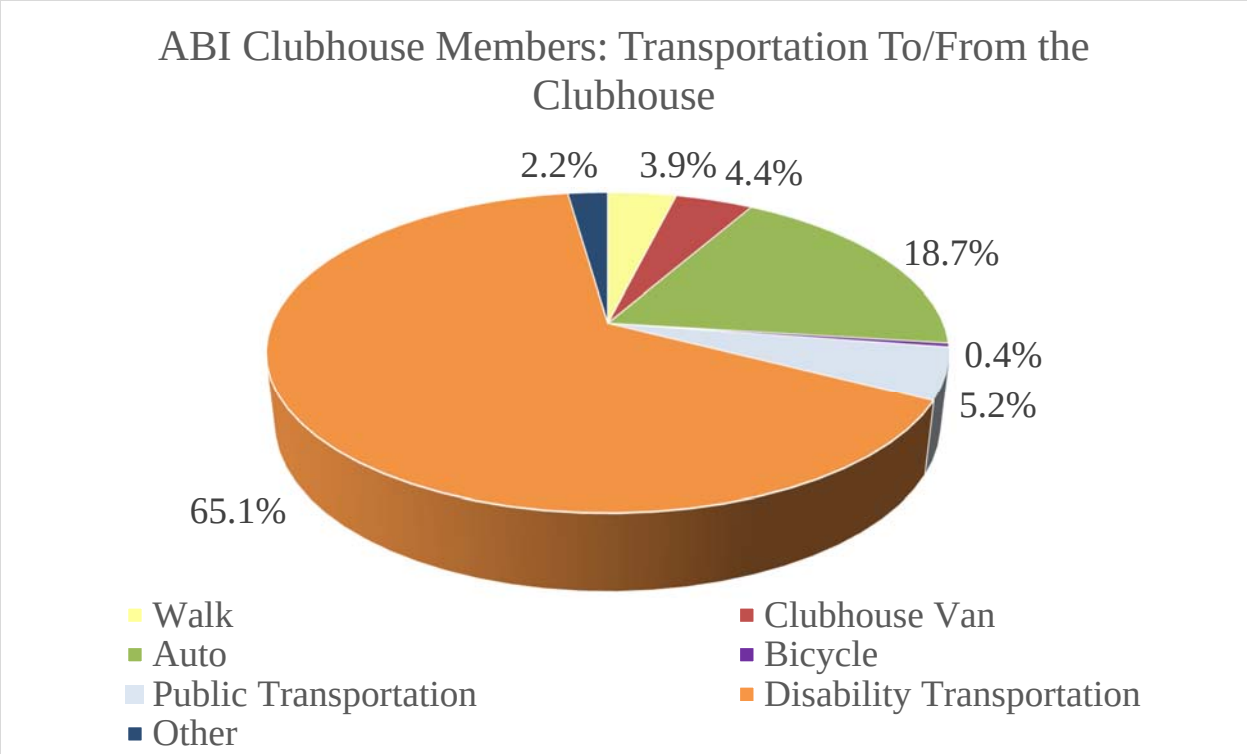
The primary cause of injury is from vehicle accidents, followed by stroke, or from other causes.

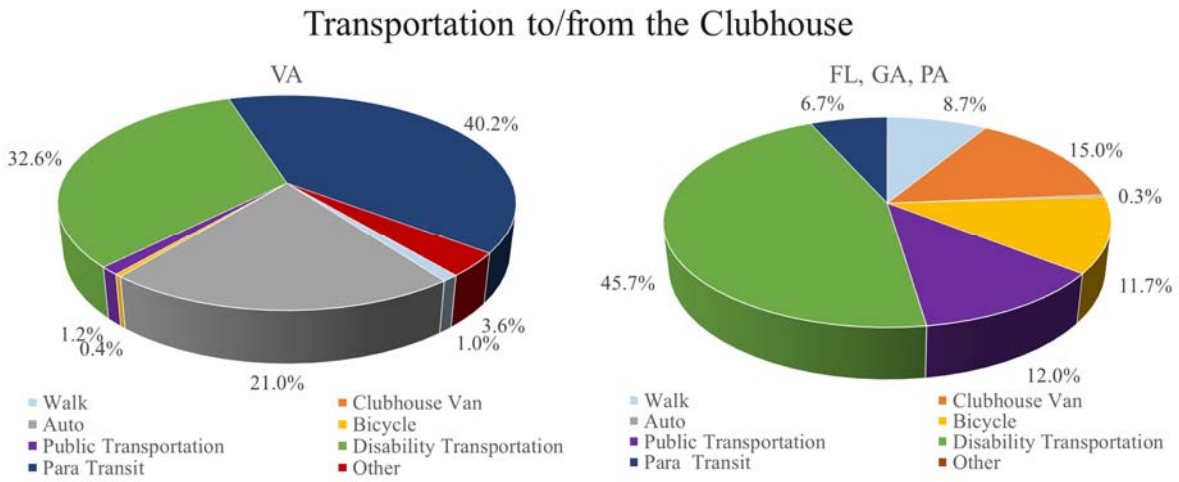






Clubhouse members are most likely to live with family members. The higher number of Clubhouse members outside of VA who live in group residences combined with a lower number living independently, coincides with a more intense need for personal support that is commonly seen in the segment of this population receiving care via Medicaid Waivers.

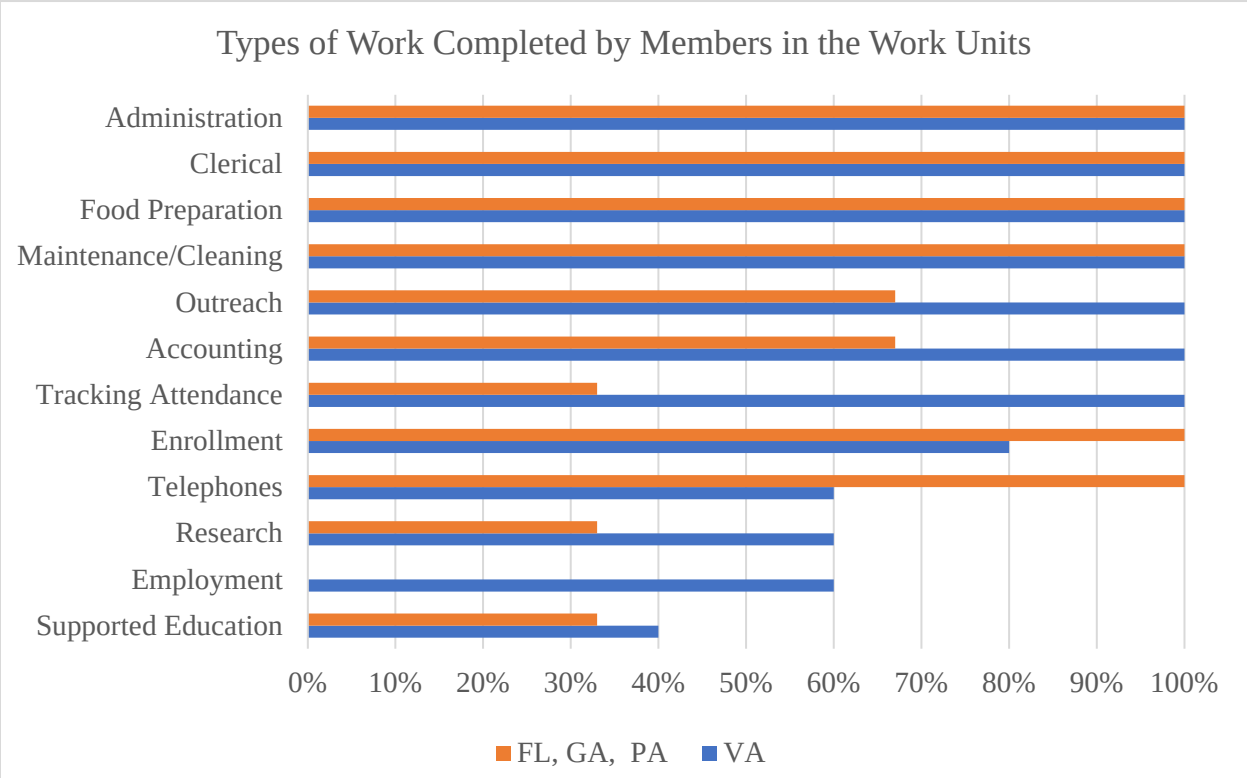




Disability transportation and para transit were primary methods to and from the clubhouse. Members outside of Virginia rarely used an automobile for transportation (.3%) compared to 21% of active members in Virginia ABI Clubhouses. This is another area where we see differences compared with members in mental health clubhouses. Forty-two percent of members in mental health clubhouses use public transportation to get to and from the Clubhouse. Seventeen percent of members in mental health clubhouses are transported by a club van and thirteen percent walk to the Clubhouse. Some mental health clubhouses also receive funding for transportation services.

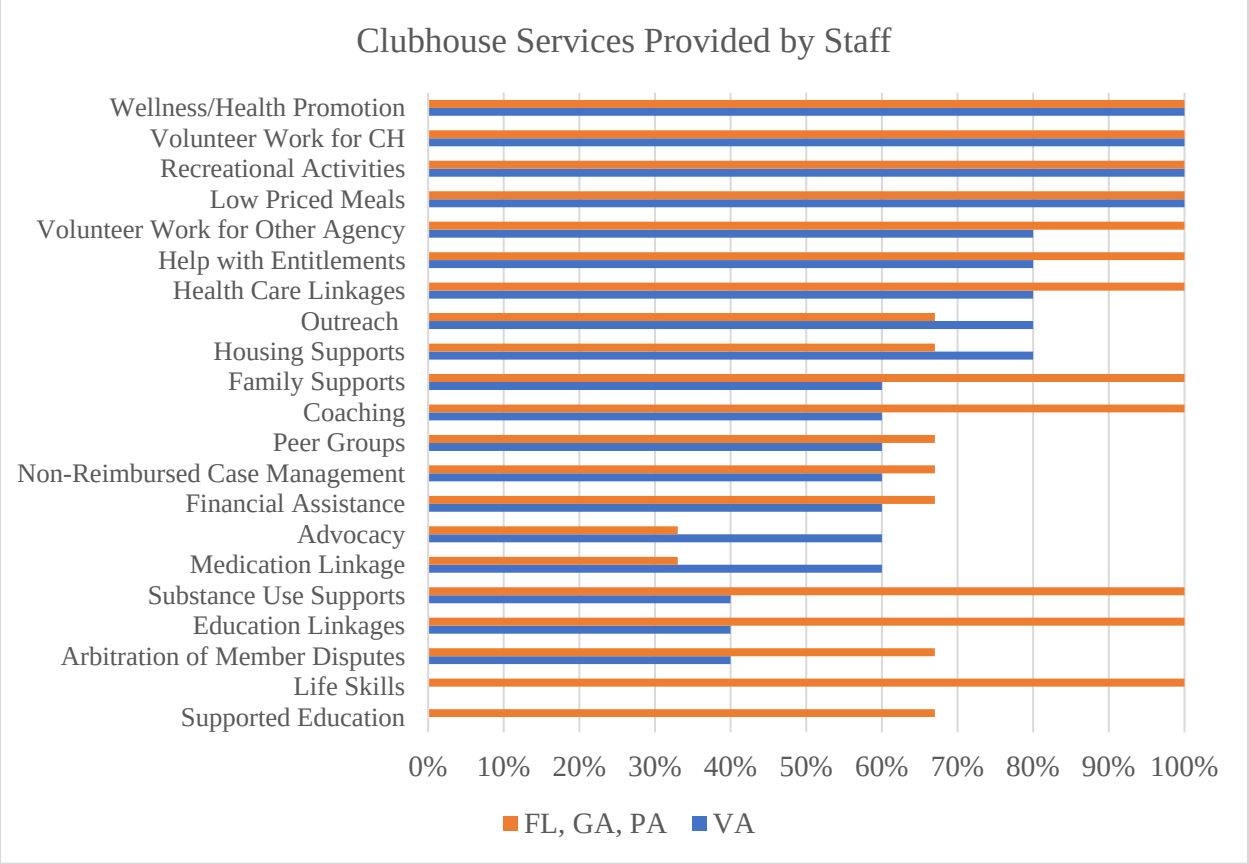
Transportation options are highly dependent on availability of local disability transportation services as most clubhouse members with brain injuries do not drive. Those using 'auto' above may drive themselves, by family, or paid provider. One clubhouse outside of VA that is located on a residential campus represents the walkers, while another in a large urban area represents the larger public transit (non-disabled) riders.

The lack of Medicaid transportation in Virginia limits the catchment reach of its Clubhouses in areas not served by para transit.



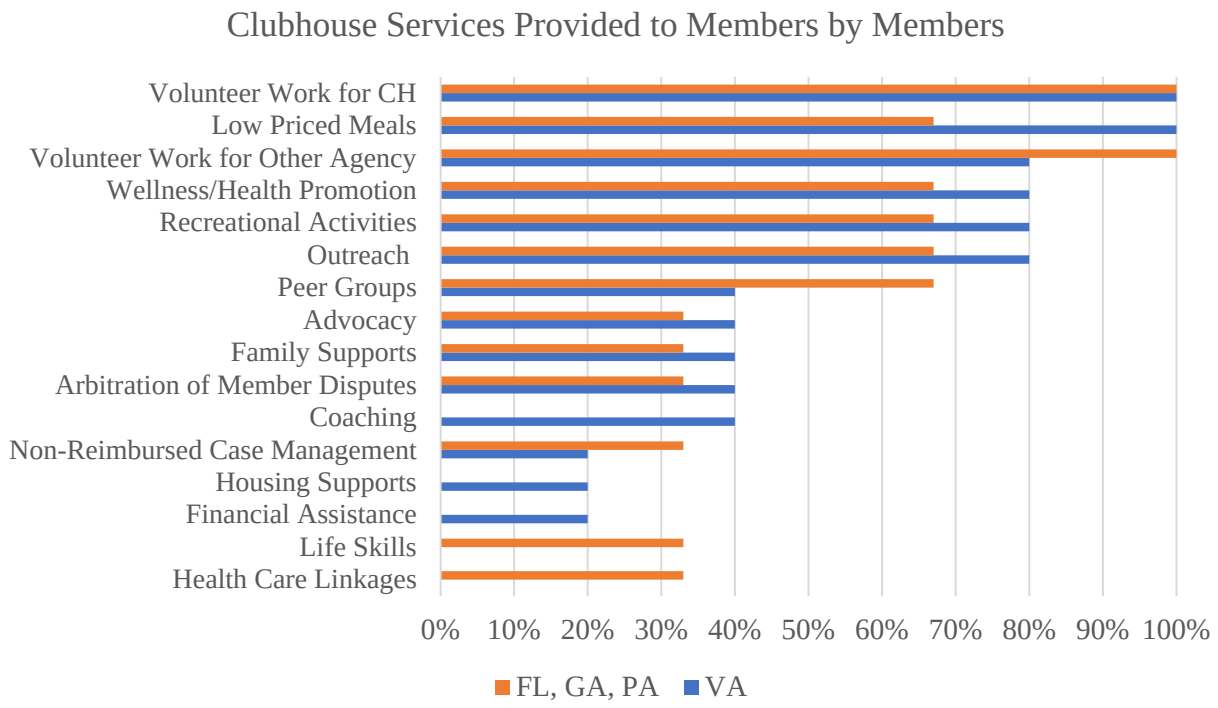
The types of work completed by members in the work units varied from state to state with members participation in administrative activities, clerical work, food preparation, and maintenance/cleaning in all clubhouses. Members were also involved in outreach, accounting activities, and tracking attendance in all Virginia clubhouses. However, members in ABI clubhouses are less likely to be involved with unit work related to employment and education activities. Mental health Clubhouses have 90-100% member involvement in employment and supported education.

Services Provided by Brain Injury Clubhouses*



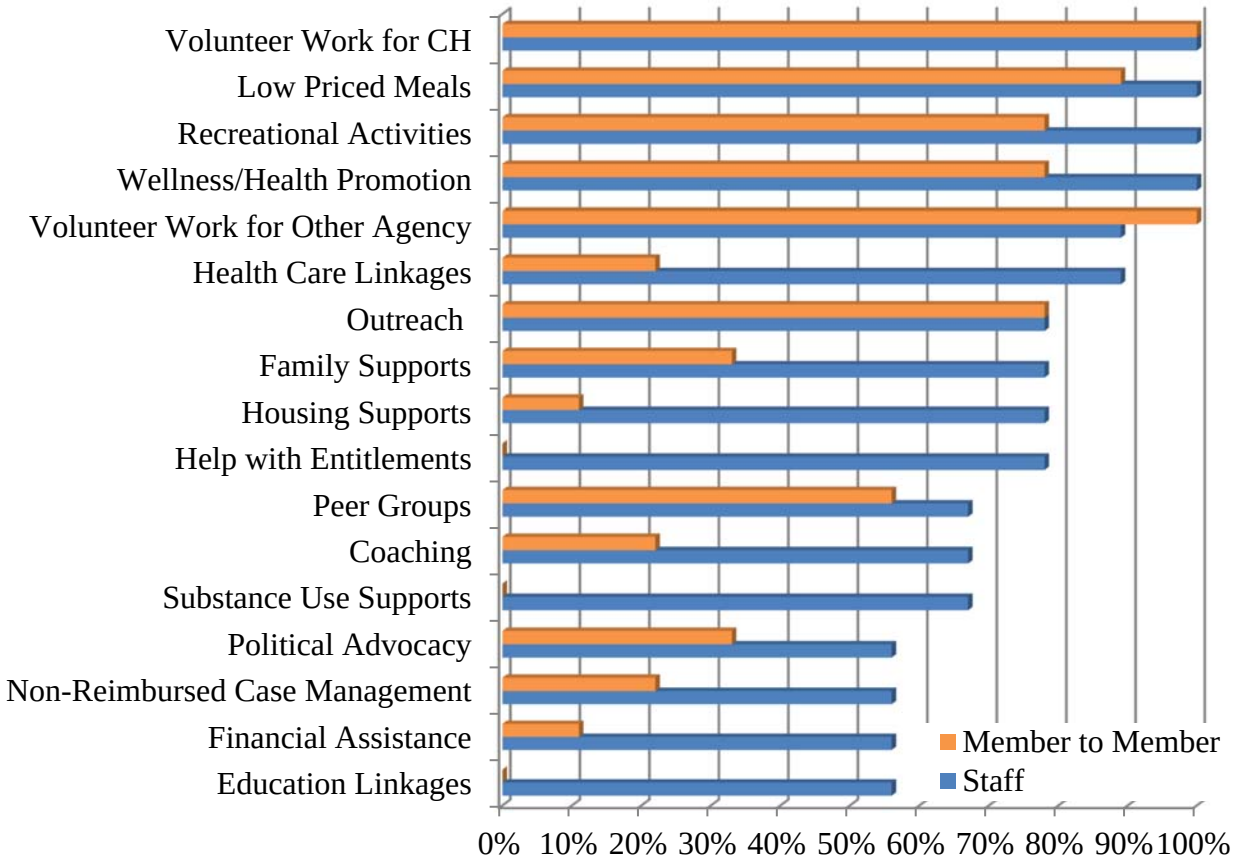
This list of services represents those commonly offered in clubhouses serving people with mental illness and brain injury. Additional services not listed here may be offered in some clubhouses to a lesser extent. For example, Transitional Employment is offered by one clubhouse. Services provided outside of the daily program such as life skills training and family support are more common in Clubhouses outside of Virginia where a coordinated infrastructure of supports is usually not available as it is in Virginia. While all of these services are representative of the clubhouse model philosophy, clubhouses associated with a parent agency often refer members to another area within the agency or a to a local partner for focused supports**.**

Services provided by staff regardless of location included low priced meals, volunteer work for the clubhouse (this may include activities done during the Work-Ordered Day), recreational activities, and wellness or health promotion activities. The array of services provided was slightly greater outside of Virginia. However, this may be due to funding constraints/budget size, and/or staffing available to provide these services. Services and supports related to employment and education may also be provided to members through separate contracts with providers outside of the clubhouse. Mental health clubhouses are also likely to be providing outreach, housing supports, help with entitlements, and education supports in addition to low priced meals, volunteer work for the clubhouse recreational activities, and wellness or health promotion activities.



We also asked clubhouses to indicate where members provided services to other members. These typically included volunteer work for the clubhouse, low priced meals (e.g. daily lunch at the clubhouse), volunteer work for another agency. Member to member support services are less common among Clubhouses serving those with brain injury than mental illness due to the higher levels of cognitive and physical supports needed by those with brain injuries. The volunteer work for another agency is one area where the ABI Clubhouses differ from the mental health clubhouses. This difference is primarily due to the International Clubhouse Standards which indicate that the work of the clubhouse is for the clubhouse and not for other organizations.

Services Offered by at Least 50% of ABI Clubhouses



Clubhouses provide a wide array of services as evidenced in the chart. Volunteer work for the clubhouse (participation in daily clubhouse operations/activities), low priced meals, recreational activities, and wellness and health promotion activities were provided by staff in all of the clubhouses. Volunteer work for the clubhouse and volunteer work for other agencies (but never the parent/auspice agency) were provided by members to members in all of the ABI clubhouses. Volunteer work for other agencies is not common in mental health clubhouses as it conflicts with the International Clubhouse Standards which state that work done in the Clubhouse is exclusively the work generated by the Clubhouse in the operation and enhancement of the Clubhouse community. No work for outside individuals or agencies, whether for pay or not, is acceptable work in the Clubhouse. This standard has been modified (see Appendix 1) to better represent the needs of people with brain injuries who benefit from productive activity in the service of the larger community but often need ongoing support on volunteer or paid work sites which to date, is not reimbursable for this population. Brain Injury clubhouses are in agreement that community service enhances and strengthens the Clubhouse community. It provides an opportunity for rehabilitation of TBI sequela involving executive functioning as it encourages self-awareness and replaces egocentrism commonly associated with frontal lobe injury with repeated opportunities to experience the satisfaction that helping others brings.

Educational Supports offered by ABI Clubhouses

Educational Supports offered by Clubhouses (n=8)	Mean
Clubhouse has an educational component	63%
Clubhouse offers classes led by staff during the Work-Ordered Day (WOD)	75%
Clubhouse offers classes led by non-clubhouse staff during the WOD	50%
Clubhouse offers classes led by members during the Work-Ordered Day	38%
Clubhouse offers classes led by staff outside of Work-Ordered Day (WOD)	0%
Clubhouse offers classes led by non-clubhouse staff outside of WOD	13%
Clubhouse offers classes led by members outside of Work-Ordered Day	0%
Assistance with adult education	63%

The most common types of educational supports were educational classes that were led by staff during the Work-Ordered Day, followed by assistance with adult education, and educational classes lead by non-clubhouse staff during the Work-Ordered Day. While post-secondary education is more common in mental health clubhouses where onset of disability often interrupts traditional education paths, members of brain injury clubhouses are more likely to have completed their formal education prior to injury and have a greater need for repeated education related to their unique and complicated cognitive disabilities.

Vocational Supports offered by ABI Clubhouses

Vocational Support	TE	SE	IE	VOL	CSE	CSE w/o	Other
Advocacy with Employer	13%	38%	38%	38%	38%	25%	25%
Coverage of Employee Absences	13%	0%	25%	13%	0%	13%	0%
Formal Performance Assessments	0%	13%	50%	17%	0%	0%	0%
Help with Job Hunting	0%	63%	50%	38%	38%	38%	38%
Job Skill Assessments	13%	50%	38%	25%	25%	25%	0%
Life Skill Training	13%	63%	50%	38%	38%	38%	50%
Member Job Development	13%	50%	25%	25%	25%	13%	0%
Off-Site Job Training	13%	38%	25%	13%	25%	13%	0%
On-Site Job Training	13%	50%	25%	13%	25%	13%	0%
Peer Support Meetings	0%	0%	38%	38%	25%	13%	13%
Program Sponsored Jobs	0%	13%	0%	0%	13%	0%	0%
Transportation to Interviews	0%	50%	38%	25%	25%	25%	0%
Transportation to Work	13%	25%	0%	13%	13%	0%	13%
Vocational Planning	13%	50%	38%	25%	25%	25%	13%
Work Readiness Assessments	13%	63%	50%	38%	38%	38%	25%

TE=Transitional Employment, SE=Supported Employment, IE=Independent Employment, CSE=Customized Supported Employment, CSW w/o= Customized Supported Employment without

ABI Clubhouses were found to offer a wide range of employment supports for their membership. Many of these supports are provided in a peer to peer capacity, in addition to staff providing them. This is consistent with the peer driven approach of the Clubhouse philosophy.

As compared to clubhouses serving members with mental illness, Transitional Employment (temporary part-time or full-time positions staffed by the Clubhouse and usually lasting 6-9 months) is less common in ABI clubhouses while Customized Employment (i.e. 'job carving') is more common. The higher likelihood of a successful pre-injury career combined with learning and other thinking challenges following brain injury sometimes precludes members with brain injuries from benefitting from temporary, entry-level positions. For these same reasons, Customized Employment which often equates to self-employment with targeted ongoing support may be utilized for those members who may not meet with success via Supported Employment positions at community-based job sites with faded supports.

Objective Three*: Examine impact of ABI Clubhouse on member outcomes including neurobehavioral impacts.*

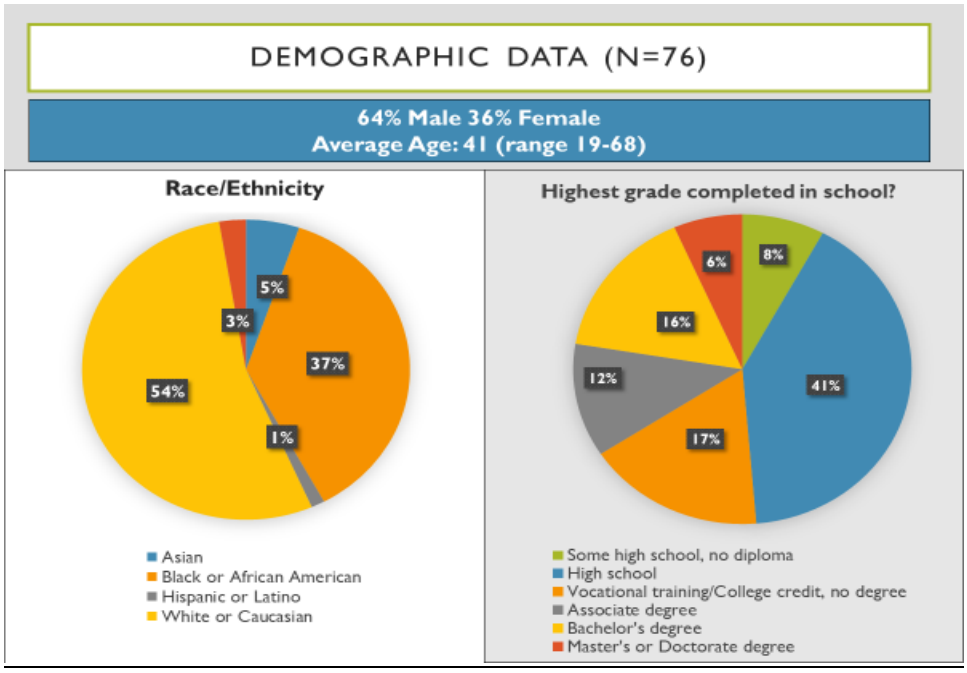
Results of Objective Three: An extensive evaluation tool, comprised of the *Safety Assessment Measure (SAM),* the *Mayo Portland Adaptability Inventory (MPAI-4),* and the *CDC Healthy Days Measure (HRQOL-14)* was administered to incoming Clubhouse members at our 8 Clubhouse test sites during the study. Our hypothesis was: Individuals with brain injury will have improved independence, safety, quality of life/well-being, and skills needed to return to work as the result of participating in an ABI Clubhouse:

Administration of Tool: A total of 76 individuals were administered the survey within one week of clubhouse enrollment with a total of 49 individuals completing the comparative follow-up survey 6-9 months later. Of the 27 who did not complete the follow up, 13 had three or few visits at the Clubhouse and 14 were lost to follow up, most often because they discontinued membership before the follow-up time period.

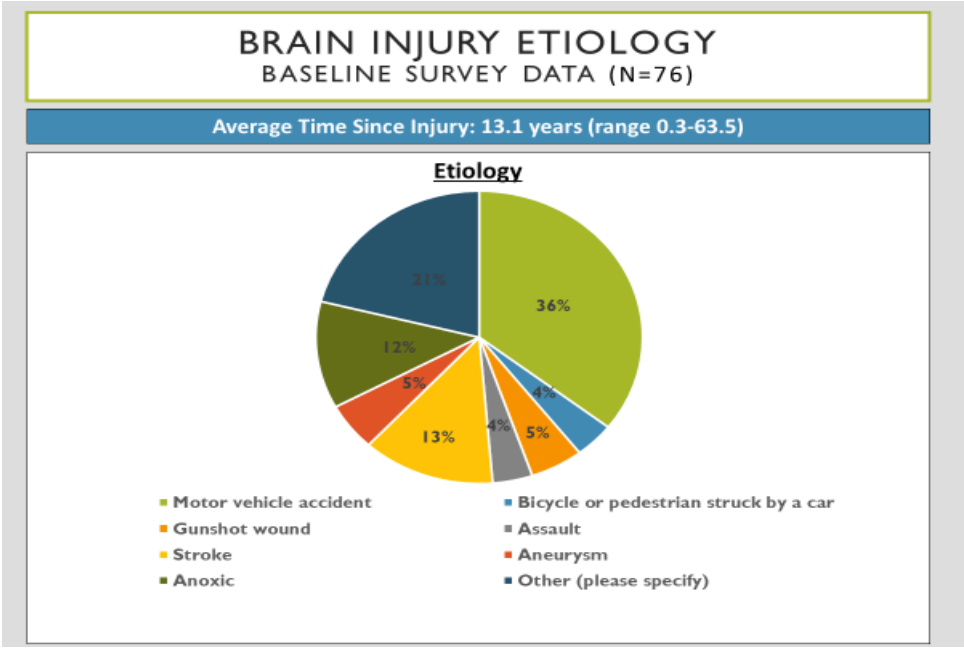
SAM-MPAI-HRQOL-14 Baseline Demographic Data:

It is important to note the demographic data presented for Objective Three below is a subset of the aggregated demographics presented for Objective Two as this data represents only newly admitted clubhouse members during the project period.

- Age, race/ethnicity and educational backgrounds were reported as follows:



- The average time since injury was 13.1 years and the cause of the brain injury was broken down per the chart below:

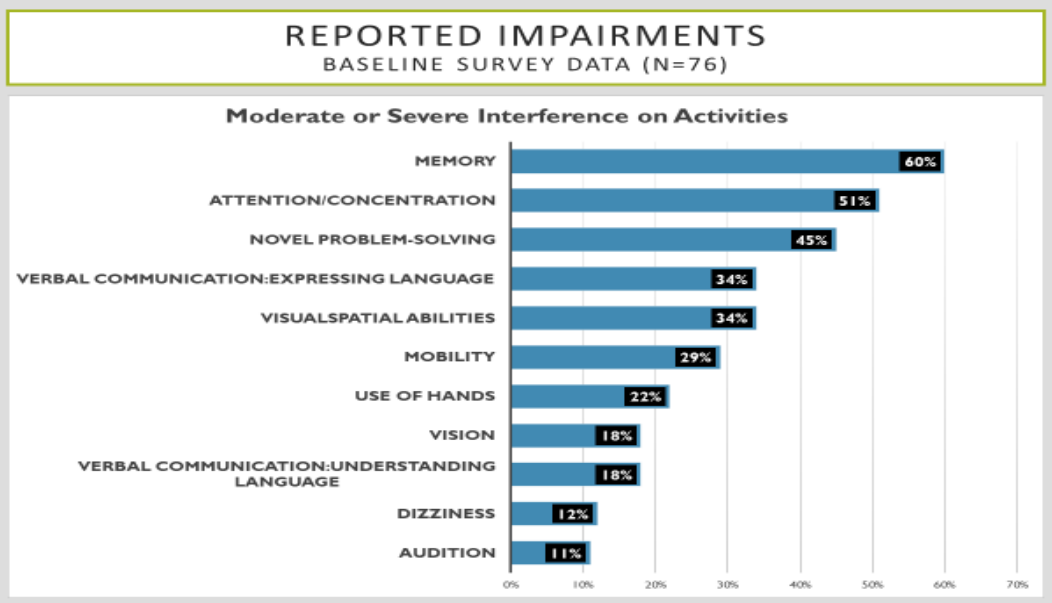


- Participants showed a wide array of co-occurring medical conditions in addition to their brain injury.

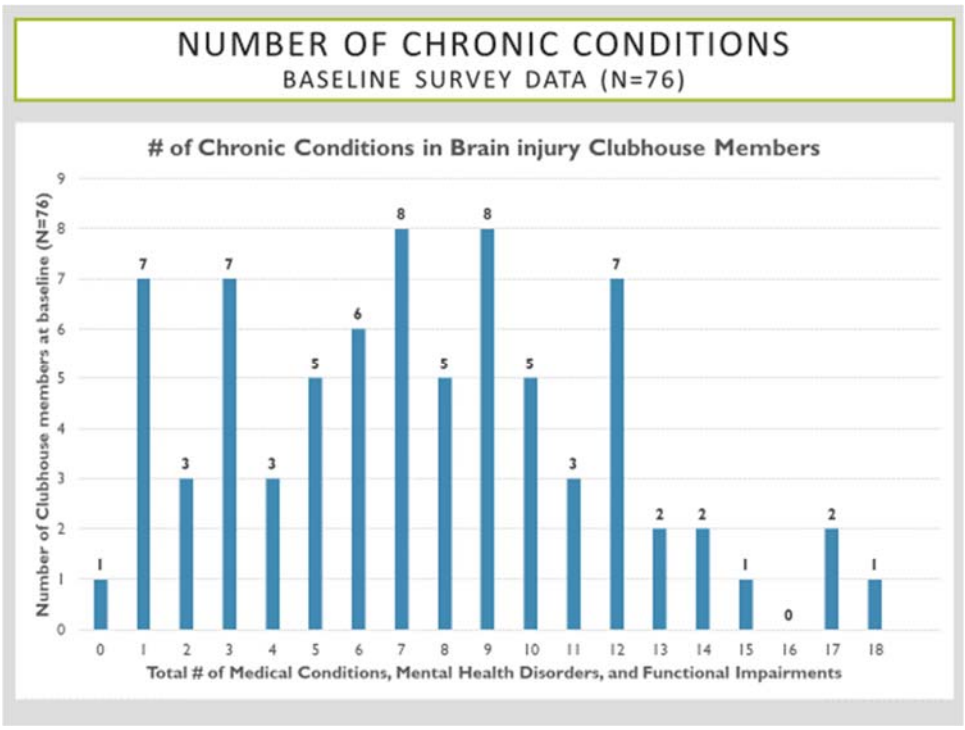
MEDICAL CONDITIONS
BASELINE SURVEY DATA (N=76)

Conditions	%	n
Depression	45%	34
Seizure disorder	29%	22
Sleep-wake disorder (sleep apnea, insomnia, other)	18%	14
Tone/spasticity	18%	14
High cholesterol	13%	10
Chronic pain	12%	9
Intellectual disability	11%	8
Arthritis	11%	8
Diabetes	9%	7
PTSD	7%	5
Bipolar disorder	7%	5
Swallowing disorder	5%	4
Heart disease	5%	4
Autism Spectrum	4%	3
Pulmonary (lung disease)	4%	3
Schizophrenia	3%	2
Chronic kidney disease	1%	1
NONE	13%	10
Other (please specify)	33%	25

- Participants showed a wide variety of brain injury related disability impairments that impacted their ability to conduct daily activities.



- Participants had a mean of 8 other chronic medical conditions in addition to their brain injury diagnosis.



In summary, baseline data showed that persons accessing ABI Clubhouse services exhibit impacts of severe and lifelong disability as well as a significant number of co-occurring health conditions impacting both their physical and mental well-being and their ability to carry out daily activities.

SAM-MPAI-HRQOL-14 Data Analysis.

A series of analyses was performed comparing brain injury clubhouse members outcomes between their clubhouse start date and 6-month follow-up assessment. Clubhouse members were assessed on five primary domains of daily functioning: safety in everyday activities, medical events, depression, functional ability and independence, and health-related quality of life.

- Clubhouse members showed improved safety-related behavior/reduced safety risk related to:
    - carrying out everyday activities, e.g., cooking, managing meds, household chores;
    - judgment, e.g., navigating the community, interacting with strangers, using dangerous tools; and
    - following recommendations, e.g., following health recommendations, avoiding dangerous activities, using safety-related aids
    - a 6- to 7- point average reduction in safety risk scores would indicate that members' safety risks were decreased in four activities, e.g., moving from somewhat likely risk to somewhat unlikely risk

SAFETY RISK OUTCOMES
(N=49)

Safety Assessment Measure-Carrying Out Activities (t-test, bootstrap)

	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	32.2	20.7	6.67	-1.56, 15.14	.128
6-month	25.6	22.6			

Safety Assessment Measure-Judgment (t-test, bootstrap)

	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	28.7	23.0	7.15	-1.61, 15.4	.114
6-month	21.6	21.7			

Safety Assessment Measure-Follows Recommendations

	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	19.4	19.0	5.85	-1.50, 12.83	.107
6-month	13.6	16.9			

- Clubhouse members showed substantial reduction in hospitalization risk factors, e.g., falls, unmanaged medical conditions, number of medications, etc. On average, members reduced their risk factors from about 2 to about 1.25.

HOSPITALIZATION RISK OUTCOMES
(N=49)

# of hospitalization risk factors last 3 months
ED visit, hospital-medical/inj., hospital-psychiatric, falls (2+), functional decline, difficulty following medical instructions, taking 5+ meds, exhaustion prevents daily activities

	0	1	2	3	4	5	6
Baseline	14	8	10	8	4	2	3
6-month	20	13	5	8	1	2	0

# of hospitalization risk factors last 3 months (paired t-test, bootstrap)

	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	1.96	1.79	.71	.25, 1.20	.009
6-month	1.24	1.41			

- Clubhouse members showed a substantial reduction in emergency room visits and acute hospitalizations, with less than 1 in 5 having a medical event requiring hospital care versus over 3 in 5 prior to clubhouse membership
- Clubhouse members had lower depression screening scores following 6-month participation.

DEPRESSIVE SYMPTOMS OUTCOMES
(N=49)

Mayo-Portland Adaptability Inventory (MPAI) Depression
sad, blue, hopeless, poor appetite, poor sleep, worry, self-criticism

	Normal involvement	Mild, no interference	5-24% interference	25-49% interference	50-74% interference	75+% interference
Baseline	13	10	8	10	6	2
6-month	15	7	17	5	3	2

PHQ-2 Depression Score
sad, blue, loss of interests

	0	1	2	3	4	5	6
Baseline	13	14	7	4	8	0	3
6-month	21	11	8	3	6	0	0

PHQ-2 Depression Score (paired t-test, bootstrap)

	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	1.84	1.76	0.61	0.16, 1.08	.016
6-month	1.22	1.39			

- Clubhouse members showed improved independence in functional abilities and participation in home and community activities. On average a four-point improvement on each measure represents improving 25% on each of four abilities AND four everyday living activities.

MPAI PARTICIPATION OUTCOMES
(N=49)

Initiation
problems getting started on activities without prompting

	Normal involvement	Mild, no interference	5-24% interference	25-49% interference	50-74% interference	75+% interference
Baseline	13	5	5	8	11	7
6-month	19	5	8	8	9	0

Independent Living and Homemaking

	Independent, no concerns	Independent, others concerned	5-24% assistance, supervision	25-49% assistance, supervision	50-75% assistance, supervision	>75% assistance, supervision
Baseline	5	4	12	8	9	11
6-month	9	5	8	10	4	13

Transportation
All modes of transportation including driving

	Independent, no concerns	Independent, others concerned	5-24% assist/supv cannot drive	25-49% assist/supv cannot drive	50-75% assist/supv cannot drive	>75% assist/supv cannot drive
Baseline	3	2	9	4	6	25
6-month	8	1	9	1	6	24

- With regard to health-related life quality, clubhouse members reported improvement in their overall general health

CDC – HEALTHY DAYS LIFE QUALITY OUTCOMES
(N=49)

Over the past month, would you say that in general your health is...					
	Excellent	Very good	Good	Fair	Poor
Baseline	5	9	22	11	2
6-month	9	15	16	8	1

General health last 30 days (paired t-test, bootstrap)					
	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	2.92	1.00	0.39	.08, .71	.018
6-month	2.53	1.04			

- While no significant changes were observed in Clubhouse members reported number of days with either poor physical or mental health in our study, Clubhouse members reported a large reduction in the number of days that poor physical or mental health restricted their everyday activities. On average, Clubhouse members had 4 less days per month in which poor health restricted their activities.

CDC – HEALTHY DAYS LIFE QUALITY OUTCOMES
(N=49)

Physical health not good last 30 days (paired t-test, bootstrap)					
	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	3.63	6.44	0.65	-2.20, 3.29	.628
6-month	2.98	7.23			

Mental health not good last 30 days (paired t-test, bootstrap)					
	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	8.24	10.02	1.06	-2.51, 4.20	.535
6-month	7.18	9.66			

Poor health restricted activities last 30 days (paired t-test, bootstrap)					
	Mean	SD	Mean Diff.	95% C.I.	Sig.
Baseline	6.65	9.06	3.90	1.55, 6.43	.007
6-month	2.76	4.23			

ADDITIONAL EFFORTS: CLUBHOUSE COVID SURVEY

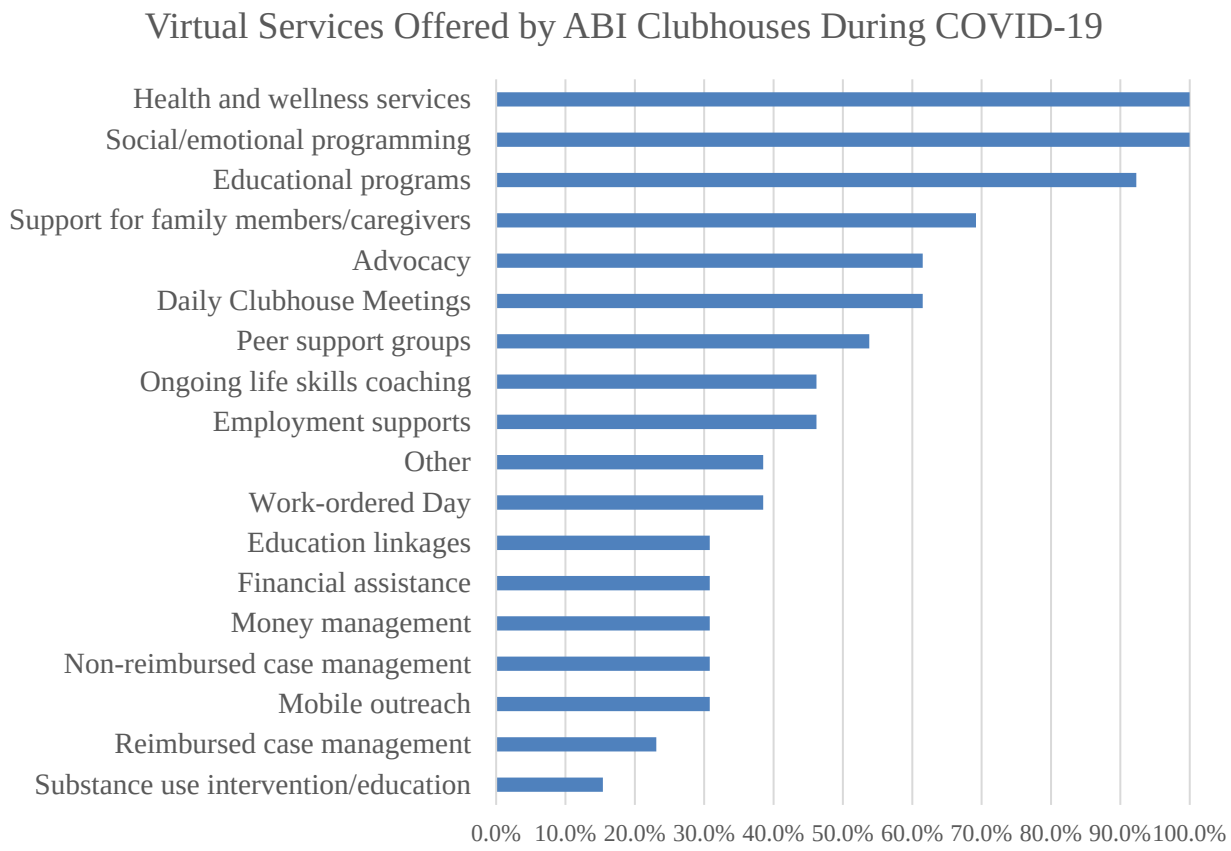
The research team utilized some additional unexpended funding from our original grant request to examine the impact of COVID on the Brain Injury Clubhouse system; the findings below represent the results of that research. The research team also conducted a survey of all IBICA Clubhouses during the Public Health Emergency (PHE) to better understand how Covid-19 has impacted ABI Clubhouses and service delivery. Fourteen IBICA clubhouses in ten states responded to the survey. Five respondents were from ABI Clubhouses in Virginia. Approximately ninety-three percent of the clubhouses responding to the survey reported having to close their buildings during the COVID pandemic. One clubhouse had to close more than once. These closures were the result of local or state government public health mandates (33.3%), positive cases in the community (22.2%), or both (44.4%). The majority of clubhouses (78.6%) also indicated that referrals to the clubhouse were impacted by the pandemic. Most clubhouses (90.9%) reported a decrease in referrals.

Funding constraints may have impacted any services or supports that were offered virtually. Over seventy percent (71.4%) of ABI Clubhouses that had to close their buildings reported providing enhanced outreach to 75-100% of their active memberships during the PHE. Many clubhouses (78.6%) also reported providing outreach to members that were not active. This is similar to reports by mental health clubhouses. Clubhouses serving both populations have been successful in engaging non-active members during the pandemic. It will be interesting to see how virtual service offerings may impact program design after the PHE given the higher level of engagement among some member subsets.

Methods of communication for outreach included telephone calls (100%), emailing (92.9%), Zoom (92.9%), Facebook or Facebook Messenger (85.7%), texting (71.4%), FaceTime (28.6%) or Instagram/Instagram Live (21.4%), Twitter (14.3%), Google Hangout (14.3%), or WhatsApp (7.1%). The extent of the methods used to maintain contact with members (e.g. Zoom or Google Hangout) increased as did the number of clubhouses using them (e.g. Zoom, FaceTime, Google Hangout, GoToMeeting). Most clubhouses (84.6%) were able to connect with members that were not active.

All but one clubhouse was able to offer virtual services during the building closure(s). The extent and range of services varied among clubhouses. Over half (53.8%) of the ABI Clubhouses responding to the survey offered 1-4 hours of virtual services daily, four clubhouses (30.8%) offered more than four hours of virtual services per day, and two clubhouses (15.4%) offered virtual services less than daily but more than once a week. Approximately half of the average daily attendance in these clubhouses participated in virtual services.

Two clubhouses (14.3%) reported that staff stopped working during the pandemic and one indicated that staff were furloughed. Three clubhouses indicated that staff had tested positive for COVID-19.



Seventy-one percent of ABI clubhouses reported members had tested positive for COVID-19. Three clubhouses had members who were hospitalized for COVID and nine (64.3%) clubhouses had members who were hospitalized for other health reasons during the pandemic.

Over seventy percent (71.4%) of ABI Clubhouses reported a loss of funding. Four indicated that they lost 6-12% of their funding, two lost 20-25% of their funding, one lost 60%, and one lost 80%. The remainder did not indicate how much of their funding was lost. The types of funding lost included funding from donations or other private sources (60% of respondents), or private pay (60%). Half of the clubhouses reported losing foundation/grant funding, forty percent indicated they lost funding from income generating activities, thirty percent lost funding from vocational rehabilitation, or state government(s), two clubhouses lost local government funding, and/or workers compensation insurance, and/or other private sources. One clubhouse also reported losing funding from public insurance programs. Two clubhouses reported that their clubhouse is in danger of closing permanently due to lost funding. Over half of the ABI Clubhouses said there were no other community-based services available for members in their local community if their clubhouse closed permanently.

Fifty-seven percent of clubhouses applied for funding during COVID-19. All of these clubhouses indicated that they received funding. Types of funding obtained included PPP loans, payroll funds, emergency grants or Medicaid waivers.

C: DISCUSSION AND PROGRAM RECOMMENDATIONS

The results of this research show statistically significant positive impacts from participation in a brain injury clubhouse across a variety of areas, including neurobehavioral, safety, physical and mental health, and functional ability.

SUMMARY ABI CLUBHOUSE OUTCOMES
(N=49)

Outcome	Change	Sig.
# of hospitalization risk factors (falls, unmanaged medical conditions, # of medications, etc.)	**reduced**	**<.01**
# of ER visits and acute hospitalizations	**reduced**	**<.01**
Safety risk (everyday activities, judgment in home and community, adherence)	reduced	<.12
depressive symptoms	**reduced**	**<.05**
general health	**improved**	**<.05**
physical health	**equal**	NA
mental health	**equal**	NA
impact of poor health on daily activities	**reduced**	**<.01**
abilities (attention, memory)	**improved**	**<.01**
participation (initiation, activities, social)	**improved**	**<.01**

- Clubhouse members improved safety-related behavior and reduced safety risk on 12 behaviors/activities across carrying out everyday activities, judgment and following recommendations may lead to very real changes such as reduced injuries, need for healthcare services, and professional or family caregiver supervision.
- Clubhouse members experienced substantial reduction in hospitalization risk factors and actual emergency room visits and acute hospitalizations. While we do not have benefit-cost data as part of this study, reduced risk factors for hospitalizations and actual reduced ER and unplanned acute admissions represent real healthcare system savings in hospital costs, event-associated follow-up care, and the potential for long-term costs associated with increased disability level.
- Reduced risk of depression is also associated with reduced risk for developing medical conditions and improved management of conditions.
- Improving 25% on independence in each of four abilities AND four everyday living activities has potential impactful reduction on the need for professional or family caregiver supervision.
- We note that clubhouse services do not target walking ability, so no improvement was expected. Further, the baseline range of poor self-control was already low as clubhouses do not accept membership from individuals with significant neurobehavioral issues.

- Clubhouse members reducing the number of days that poor health restricted their activities from about 7 days to less than 3 represents real world improvements in societal productivity and reduced need for professional or family caregiver health-related service provision and/or supervision.

While not all of these positive impacts were seen in every person in our study, the collective impact on Clubhouse participation in a person living with brain injury daily life and functional abilities cannot be understated. It should also be noted that the population being served within brain injury Clubhouse is a population with severe disability, co-occurring health conditions, and lifelong impairment resulting from their brain injury. This is a population that traditionally has been woefully underserved in community settings and has often resulted in high lifelong medical costs. Payers and funders of all types should view participation in a brain injury Clubhouse as a potentially cost-effective supports and services program with the ability to further reduce long term health costs.

D. NEXT STEPS AND FUTURE RESEARCH OPPORTUNITIES

Our research team is in the process of submitting manuscripts for journal publication. We have submitted a manuscript entitled "Organizational Characteristics of Brain Injury Clubhouse Model Programs" to the Brain Injury journal. We are preparing a second manuscript entitled, "Brain Injury Clubhouse Participation and Effects on Members' Healthcare Utilization, Safety, Independence and Life Quality" to the Journal of Head Trauma Rehabilitation.

Our research findings were presented at several national conferences including:

- International Brain Injury Association: I 2020: NABIS Conference on Brain Injury
- Brain Injury Association of Virginia 2020 Making Headway Conference
- International Brain Injury Clubhouse Alliance 2019 and 2020 Annual Conferences
- National Association of State Head Injury Administrators (NASHIA) conference: We were selected to present at the 2020 conference prior to COVID forcing the conference to go to a virtual format. We plan on resubmitting for their 2021 conference.

Ongoing dialogue continues with the leadership of both IBICA and Clubhouse International to develop training and quality assurance mechanisms for ABI Clubhouses. This dialogue has resulted in the development of self-study and piloting an accreditation survey process utilizing faculty from Clubhouse International to conduct two consultations with ABI Clubhouses in 2021, including one of the Virginia Clubhouses.

Lastly, this project has produced a Public Policy Tip Sheet highlighting the main findings of our research that will help funders and payers better understand the benefits and impacts of ABI Clubhouses.

Future research opportunities exist to help identify and describe the full impacts of the array of services available within ABI Clubhouses. Below are several areas, this research teams feels are relevant future research opportunities on this important and growing service model for persons with brain injury.

- Evaluating the “dose and duration” of specific clubhouse services and supports on specific outcomes
- Identifying discrete case mix groups that benefit from specific services and supports measured with specific empirical outcomes
- Cost-effectiveness studies relative to a population not receiving clubhouse services
- Positive impact of clubhouse on family caregiver burden, health and participation including return to work
- Impact of clubhouse quality assurance efforts