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The National Institutes of Health (NIH) reported that the number of people living with permanent disability from brain injury grows annually as medical technology has advanced in life saving techniques. However, community-based programs which enable brain injury survivors to live productive lives throughout the entire course of recovery have not grown proportionately to meet this the need. Brain Injury Clubhouses were developed to address the need for coordinated, long-term, community-based supports for brain survivors in a community-based setting. Brain Injury Clubhouses are designed to improve the lives of persons with ABI and reduce strain on caregivers and healthcare services

The information below is designed to provide funders, administrators, policy makers, and other stakeholders with an overview of Brain Injury Clubhouses. The brief also provides outcomes associated with participation in a Brain Injury Clubhouse from a recent research study to provide stakeholders with a better understanding of Brain Injury Clubhouses.



## Brain Injuries

Acquired brain trauma is the second most prevalent disability in the U.S., affecting 13.5 million Americans<sup>1</sup>. Impacts of brain injuries may be short term or affect survivors for the rest of their lives. Chronic health problems and cognitive, physical, emotional, and/or behavioral changes can result from moderate or severe brain injuries<sup>2</sup>. Brain injury sur-

vivors may experience limitations in meaningful activities such as vocational functioning or employment<sup>3</sup> or be at risk for unintentional injury, harm, or victimization<sup>4-5</sup>. A brain injury may impact self-identity, community reintegration, social networks or quality of life<sup>6-8</sup>. These issues can have lasting effects on the individuals experiencing a brain

injury and their families. Thus, there is a need for effective community services that reduce the problems associated with brain injuries. Acquired brain injury (ABI) clubhouses are a long-term, person-centered, service delivery model designed to improve the lives of persons with ABI and reduce burden on caregivers and healthcare services.



## What are Brain Injury Clubhouses?

Brain injury clubhouses originated with the inception of Fountain House in New York City in 1948. The initial goal of the clubhouse was to provide a restorative environment to address social isolation by offering support for people living with mental illness. Today over three hundred mental health clubhouses affiliated with [Clubhouse International](https://clubhouse-intl.org) (<https://clubhouse-intl.org>) are located in thirty countries.

Clubhouse participants are referred to as members rather than patients or clients<sup>9</sup>. Clubhouse membership is voluntary and without time limits. Each member can enter, leave, and re-enter the clubhouse as needed. Members

are wanted, needed and expected and each member's involvement is an important contribution to the clubhouse community.

Mental health clubhouses follow a set of International Clubhouse Standards that serve as a bill of member rights and provide clubhouses with operational guidelines in eight domains:

- 1) Membership,
- 2) Space,
- 3) Relationships,
- 4) the Work-Ordered Day (WOD),
- 5) Employment,
- 6) Education,
- 7) Functions of the House, and
- 8) Funding, Governance and Administration.

The clubhouse provides members with opportunities for meaningful relationships, education, employment, securing housing, and evening, weekend, and holiday activities. These activities occur in a rehabilitative environment known as the Work Ordered Day (WOD)<sup>10</sup>. The WOD parallels a typical business day and provides opportunities for members to work side-by-side with clubhouse staff and other members. to complete all aspects of clubhouse operations including decision-making and governance. Evidence from research supports the efficacy of the Brain Injury Clubhouses in helping members obtain employment or education, reducing hospitalization(s) and improving quality of life<sup>11</sup>.

## Acquired Brain Injury (ABI) Clubhouses

Acquired brain injury (ABI) clubhouses are supportive community centers modeled after mental health clubhouses that offer people living with brain injury opportunities to resume productive lives through partnership, work, and social connections. Brain injury clubhouses serve adults with acquired and traumatic brain injuries. As with mental health clubhouses, each member of a brain injury clubhouse is recognized for their own goals and abilities. Every member is considered a critical part of the ABI clubhouse community.

Clubhouses help members take ownership of their own recovery so they can lead satisfying, productive lives<sup>12</sup>. Clubhouses address many social determinants of health including improving social networks, peer relationships, recreation, unemployment and work, social supports, food security, and transportation. Brain Injury Clubhouses offer a supportive environment where members can regain lost skills, find competitive employment, education, and develop meaningful relationships. Brain injury clubhouses provide a variety of services and supports including but not limited to outreach, family supports, wellness and health promotion activities, linkages to health care, help with entitlements, and social supports or recreational activities.

The first brain injury clubhouse was attempted in the late 1980s<sup>13</sup>. Within several years brain injury clubhouses were operational in three states<sup>13</sup>. Today, there are

**Table 1. Clubhouse Characteristics**

Characteristic	Mean	Range
Length of Operation as a Clubhouse (Years)	16.2	11.2 - 20.9
Clubhouse has an Auspice (Parent Agency)	87.50%	0-100%
CARF Accreditation	87.50%	0 - 100%
Attempts to Meet all IBICA Standards	100%	100% - 100%
Annual Budget	\$472,237	\$199,871 - \$461,643
Cost per Year per Person <sup>1</sup>	\$9,873.62	\$5125 - \$21,983
Cost per Day per Person <sup>1</sup>	\$86.43	\$33 - \$158
# Full-Time Staff (FTE's)	5.25	3 - 10
Ratio of Active Members per FTE Staff	9.3:1	6:1 - 13:1
1. Cost calculations are intended to provide descriptive costs about clubhouses and are not intended for rate setting purposes.		

**Table 2. Funding Source(s)**

Funding Type	Mean	Range
State and Local Government	69.5%	6.6% - 100%
Fee for Service- Public (VR and Medicaid Waiver)	11.0%	0% - 48.1%
Fee for Service- Private (Work Comp, Private Pay, Group Health, other)	1.8%	0% - 5%
Charitable Gifts, Grants, Donations, Fundraising Events	17.7%	0% - 45.3%

brain injury clubhouses in at least ten states. Seventeen brain injury clubhouses throughout the United States and Canada network through the [International Brain Injury Clubhouse Alliance](http://International Brain Injury Clubhouse Alliance) ([braininjuryclubhouses.net/](http://braininjuryclubhouses.net/)).

IBICA was founded in 2005 to support the development, training, quality, and stability of brain injury clubhouses. IBICA developed a set of consensus ABI Clubhouse Standards for ABI clubhouses<sup>14</sup> that parallel the International Clubhouse Standards for mental health clubhouses. Most brain injury clubhouses are accredited by CARF International, an independent, non-profit, and an international accreditor

of health and human services.

## Research on Brain Injury Clubhouses

Findings from a multi-site longitudinal study of brain injury clubhouses provides additional information including key ingredients of these programs and outcomes associated with participation in them. Eight brain injury clubhouses affiliated with IBICA in four states completed an electronic survey—the Brain Injury Clubhouse Profile Questionnaire (CPQ) in 2019 as part of the larger research project. The CPQ gathers program-level information concerning practices, characteristics, concerns, and performance outcomes of club-

house programs. CPQ data below provides information about the brain injury Clubhouses including members served, infrastructure, staffing, programming, and other organizational characteristics.

### Organizational Characteristics of Brain Injury Clubhouses (n=8)

Funding mechanisms for brain injury clubhouses vary from state to state. The five clubhouses in Virginia receive most of their funding from the state. Less than ten percent of funding for these clubhouses is through Medicaid. TBI waivers in Georgia and Pennsylvania allow Medicaid funds to be used for community-based programs like brain injury clubhouses. Yet, funding mechanisms like a national brain injury waiver for participation in ABI clubhouses have not been established. The variations in number of individuals served, number of staff, the extent of services offered, and hours of operation may be reflected by differences in funding across states.

### ABI Clubhouse Memberships

- » Most ABI clubhouse members (69%) are between the ages of thirty and sixty.
- » Approximately sixty-seven percent of ABI clubhouse members are male.
- » Most members are Caucasian (61.5%) or African American (28%).
- » Member's primary diagnosis is a TBI (59%) or a non-TBI (41%).
- » Primary causes of injury include a vehicle accident (38.4%), or a stroke (20.4%).
- » Less than three percent of active members in brain injury

**Table 3. Membership and Member Participation**

Characteristics	Mean	Range
Number of Referrals Annually	32	10 - 90
Average Daily Attendance	16.8	8 - 29
Evening Weekend Participation	11.8	0 - 28
Active Membership	44.9	21 - 60
Total Clubhouse Membership (Lifetime of Clubhouse)	267.4	50 - 615

**Table 4. Health Impacts for Persons with ABI Participating in ABI Clubhouses**

Health Impact(s)	Change	Significance
Number of hospitalization risk factors	Reduced	<.01
Depressive symptoms	Reduced	<.05
General health	Improved	<.05
Impact of poor health on daily activities	Reduced	<.01
Abilities (attention, memory)	Improved	<.01
Participation (initiation, activities, social)	Improved	<.01

clubhouses experienced the brain injury within the past year.

- » The length of time post injury is 1-5 years (23.4%), 6-10 years (21.5%), 11-20 years (22.7%) or more than twenty years (29.9%).
- » Many members also have co-morbid mental health conditions (54.9%).

### ABI Clubhouse Impacts

Data from the longitudinal study also examined health impacts for persons with ABI (n=49) who participated in brain injury clubhouses. Results showed statistically significant positive impacts including neurobehavioral, safety, physical and mental health, and functional ability. Many of these individuals also had a variety of co-morbid health conditions including but not limited to depression (45%), seizure disorder(s) (29%), sleep-wake disorders (sleep apnea, insomnia, oth-

er) (18%), tone/spasticity (18%), or other disorders (33%).

ABI clubhouse members showed improved safety-related behavior and reduced safety risk on twelve behaviors/activities after participating in the clubhouse for six months. Improvements that were found in carrying out everyday activities, judgment and following recommendations may lead to real changes such as reduced injuries, need for healthcare services, and professional or family caregiver supervision.

ABI clubhouse members had reductions in:

- » The number of days that poor health restricted their activities
- » Hospitalization risk factors
- » Actual emergency room visits
- » Acute hospitalizations

These reductions represent savings in hospitalization costs and follow-up care. While these



positive impacts were not seen in every person in our study, the benefits of clubhouse participation on daily life and functional abilities of a person living with a brain injury cannot be understated.

Additional research is needed that identifies and describes the full impact of the array of services available within brain injury clubhouses. Studies are needed that examine the cost-effectiveness of brain injury clubhouses and/or the impact of:

- » Specific clubhouse services and supports on outcomes
- » Clubhouse participation on family caregiver burden
- » Clubhouse quality assurance efforts
- » Clubhouse participation on member health and participation including return to work

Findings from these studies would be beneficial to funders, administrators, service providers, researchers, and other stakeholders, particularly in an era of limited funding.

### **Conclusion**

ABI clubhouses can provide an option to address the rising impact of brain injuries and the lack of community-based services to address them. The ABI clubhouses in this study reported offering a wide array of services and supports to assist members. The ABI Clubhouses 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.

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