

TRAUMATIC BRAIN INJURYIT COULD HAPPEN TO ANYONE

In 2007, Jessica¹ was a typical college student. She was a Division I athlete working towards her bachelor's degree, with a steady boyfriend and a close-knit group of friends. Driving back to school after spending the Christmas holidays with her family, she was looking forward to entering her final semester and graduating that spring.

In an instant, everything changed.

Jessica hit a patch of black ice and her car suddenly spun out of control. She swirled into oncoming traffic, where another car hit her square on the driver's side door. When she woke up weeks later, she was in a hospital bed, intubated and with irreversible physical injuries. Doctors initially said it was remarkable she even survived. She couldn't remember anything about the accident nor the weeks that had followed.

Since then, her life has never been the same.

While she was in the hospital, her college friends and boyfriend continued their studies, graduated, and moved on with their lives. She is no longer in contact with most of them. Jessica returned home after her extensive hospital and rehabilitation stays and now lives with her parents. The effects of her injury left her with permanent deficits to her short-term memory and continuing physical disabilities and limitations, which makes employment extremely challenging and living on her own impossible. Today, Jessica looks longingly back at what she had: "I hate to say I had a perfect life, but compared to what it has become, it seemed absolutely perfect."

What she became is a survivor. While she often feels alone and isolated, she is one of the 2% of Americans living with the effects of a brain injury.²

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¹ Name changed to protect her privacy

² www.caregiver.org/resource/traumatic-brain-injury



Two percent of Americans live with the effects of a traumatic brain injury. 130,000 live in

130,000 live in Indiana alone.

In Indiana alone, there are over 130,000 individuals living with a long-term disability due to a traumatic brain injury (TBI).³ While each individual has a unique story, there are many common threads that bind them. For most, their lives changed dramatically after their accident with profound implications for their mental, functional, and emotional well-being. The fact that they also remember life before their accidents adds further emotional distress and creates a longing to regain what they know they have lost.

A TBI may result in mild, moderate, or severe changes in one or more abilities, such as cognition, speech, physical functions, and social behavior.⁴ This affects the overall quality of life for these survivors and often results in great loss – loss of jobs, loss of friendships, loss of self-worth, and loss of community.

Studies of mild to severe brain injury survivors show only 34% are stably employed after three years⁵ and approximately 60% of moderate to severe TBI survivors do not return to work. Of those who do, most are not able to return to their former line of work or are unable to return permanently.⁶

When someone suffers from a TBI, the entire family is dramatically affected. Studies show that caregivers and other family members of people who have suffered a brain injury typically experience feelings of distress, anxiety, anger, and depression.⁷ These family members are often concerned about the future and what will happen when they are gone - namely where can their loved one live semi-independently and with purpose.⁸

³ https://storage.googleapis.com/wzukusers/user-24484025/documents/535693b274764269 a9091aa73401b38a/ACL%20Indiana%20Snapshot%202020.pdf

⁴ www.caregiver.org/resource/traumatic-brain-injury

⁵ www.biausa.org/professionals/research/tbi-model-systems/return-to-work-and-job-stability-after-traumatic-brain-injury

 $^{^6\,}www.pubmed.ncbi.nlm.nih.gov/19484621$

⁷ www.caregiver.org/resource/traumatic-brain-injury

⁸ www.core.ac.uk/download/pdf/60569328.pdf

WHAT TBI SURVIVORS WANT AND NEED

TBI survivors have the same needs as everyone else. In addition to basic needs such as food and shelter, there are higher-level needs to feel safe and secure in the world, to foster meaningful connections and relationships, and to feel productive within the greater society.9

Due to their brain injuries, many of the survivors' relationships are greatly impacted. In families, changes in roles and responsibilities can add stress and increase tension among members. Relationships with friends, coworkers, community members, even family members can become difficult to sustain. 10 This can lead to or exacerbate already existing depression, anxiety, and other mental stressors. 11

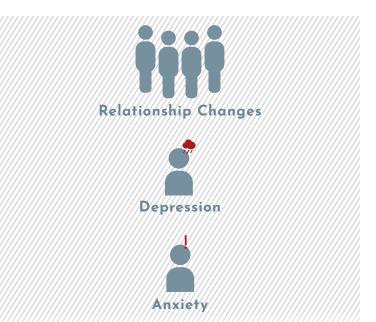
The life of a TBI survivor suffers drastic changes.











TBI survivors often feel isolated and lonely and want more out of life. Their loneliness can be defined as the gap between the social connections they would like to have and those they feel they experience. They feel constrained, however, by their inability to follow conversations, to remember things, and to do physical activities that were once effortless. They feel lonely but reluctant to leave the house, so they withdraw into their own world. The heightened risk of mortality from loneliness exceeds the health risks associated with obesity.¹²

Part of their recovery plan can include getting more involved in activities to reestablish connections within a community, as research has proven this to be beneficial for increased mental health.¹³ However, this can present a challenge when many TBI survivors need help throughout their day to perform even basic tasks and aren't always able to receive it. They often still live at home with their parents who may work or have little time to provide appropriate caregiving, or they live in care facilities that are not designed to meet their unique needs.

People with a TBI differ from those with other developmental and cognitive disorders in that a TBI is an acquired injury. Each TBI survivor was living their life a certain way and now they must live differently due to their injury. This creates a dramatic "before and after" to their lives, and many lament the loss of the life they once had, which now seems unattainable.

⁹ www.masterclass.com/articles/a-guide-to-the-5-levels-of-maslows-hierarchy-of-needs#whatare-the-5-levels-of-maslows-hierarchy-of-needs

¹⁰ www.msktc.org/tbi/factsheets/relationships-after-traumatic-brain-injury

¹¹www.braininjurysupport.org/living-with-a-traumatic-brain-injury/psychological-consequences

¹² www.harvardmagazine.com/2021/01/feature-the-loneliness-pandemic

¹³ www.biausa.org/public-affairs/media/breaking-free-from-loneliness-after-a-brain-injury

THE GREATEST NEED

People need to feel connected to other people who understand their struggles and what they are experiencing. TBI survivors need to be connected to other survivors to share the uniqueness of their situation that others who haven't had a TBI or who have different cognitive issues just cannot understand.

Nic lived an exciting life as a marketing executive for the Indianapolis Motor Speedway. He loved his job, which was a whirlwind of travel, interesting people, and fun corporate events. He resided in the bustle of downtown Indianapolis, had a girlfriend, and many friends – it was a fulfilling and rewarding life.

"They were all at the hospital when they thought he was dying. He lived, and now no one visits or calls."

Returning home on his bicycle after visiting some friends turned into a hit and run that *changed everything in an instant*.

Nic was in a coma for a month. He sustained an open skull fracture, rib fractures, and neck fractures, along with long-term effects that greatly affected his cognition, motor skills, speech, and vision. After a long recovery at home with his parents, Nic decided to move into his own apartment, where he can live semi-independently with the assistance of several support agencies. While he is cared for, he feels incredibly lonely. His mother shared the most heartbreaking part of his new life stating, "None of his friends from high school and college, or his coworkers, call or visit him. They were all at the hospital when they thought he was dying. He lived,

and now no one visits or calls. His father and I provide his social life and try to satisfy his other needs as well."

TBI survivors need their own communities to share life with others who understand and share their daily challenges. Not just a support group to attend once a month, not just the medical or physical therapy staff who help them reach their health goals, and not just their families, who do love them, but may not fully understand.

A DREAM BECOMES A REALITY

It is for this reason, that in February 2018, eight families of adult TBI survivors came together to discuss what the future could look like for their children. In researching long-term living situations, they validated what they suspected, that no organization existed that catered to the unique needs of adults living with a TBI. They were determined to change that – to create a path to help their family members find the support and community that would allow them to thrive.

United in their common goal, these founding families conceived the idea of Villa Licci with a mission "to provide safe and independent housing, fellowship, and dignity in a faith-centered environment for adult survivors of traumatic brain injuries."

"The hope we have for Villa Licci is that it will be a place to find commonality with others," Nic's mother says. "A place to make friends and not be alone. A place to feel safe when going outdoors. A place to call home."

In the future, a national network of residential communities is envisioned that creates the social fabric and fellowship necessary for each survivor to live semi-independent lives filled with hope, self-respect, and purpose.



BEGINNING IN INDIANA

For multiple reasons, Indiana is uniquely poised to create and welcome the first Villa Licci community. Indiana has an extensive infrastructure already in place for TBI survivors — from initial injury to rehab care, to outpatient therapy and other follow-up services. TBI survivors in Indiana have access to several high-quality rehabilitation centers and service providers. Noteworthy in this group is the Rehabilitation Hospital of Indiana (RHI), one of only 16 TBI Model Systems in the country. RHI is the only rehabilitation center in Indiana to be nationally certified in traumatic brain injury. In addition, RHI is one of the premier research facilities in the field of brain injury, ensuring Indiana will be on the cutting edge of understanding, treatment, rehabilitation, and other services for survivors of traumatic brain injuries. ¹⁴

Due to the strength of the existing infrastructure, Indiana was one of only 10 states to receive a mentor grant from the Administration for Community Living to assist other states in designing similar systems of services and supports for all people with TBIs, along with their family and social networks. These funds will be used to teach other states about what is already making a positive difference for TBI survivors. In addition, through this grant, the existing infrastructure in Indiana will be further strengthened and expanded. The infrastructure is a strengthened and expanded.

With Villa Licci being located near these nationally recognized facilities, residents will benefit from their expertise and high level of care. Each resident will maintain their own medical and therapeutic care with their chosen providers through outside organizations. The addition of Villa Licci, however, will address a critical gap

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in this continuum of services, namely providing housing specifically designed for the needs of adult survivors of TBIs. Villa Licci will be a vital next step by providing a home and support community for these individuals.

VILLA LICCI TIMELINE



¹⁴ www.rhirehab.com/

 $^{^{15}}$ https://storage.googleapis.com/wzukusers/user-24484025/documents/535693b27476426 9a9091aa73401b38a/ACL%20Indiana%20Snapshot%202020.pdf

 $^{^{16}}$ https://acl.gov/grants/traumatic-brain-injury-state-partnership-program-mentor-state-funding-opportunity-0



VILLA LICCI DEVELOPMENT PHASES

At the center of all the challenges that TBI survivors face, finding an understanding community and building lasting relationships are among the toughest, but the most important. These survivors, who are already managing various other disabilities, don't need the added burden and consequence of loneliness. Villa Licci will be a pioneer in providing these survivors with just such a place to find and build these critical relationships.

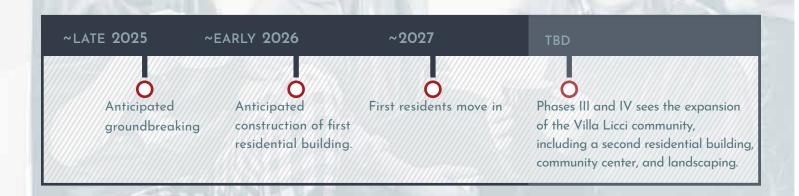
The family-like environment at Villa Licci will be designed to include shared common spaces and provide planned social opportunities to nurture friendships which contribute to an overall sense of belonging and well-being for all residents.

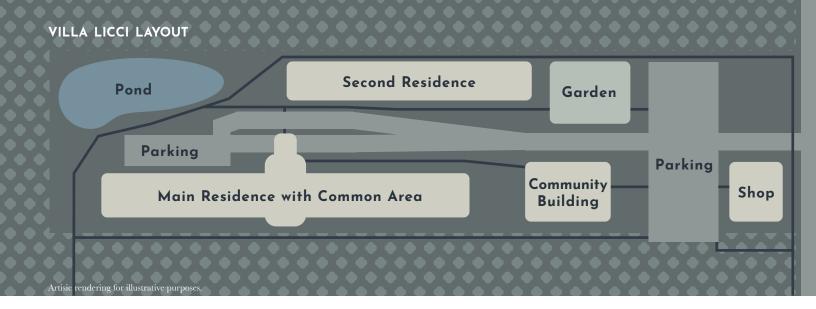
Phase I of this project was to identify and acquire property that would meet the planned development needs. In April 2021, a 13-acre property located in central Indiana was purchased, funded by a group of parents of TBI survivors, thus completing Phase I of this project.

Phase II of this project begins with the selection of the site development partners for architecture, engineering, and construction and concludes with the completion of the initial community, which will feature the first residential building that contains one- and two-bedroom apartments, a gathering room, common space, and a chapel. Around the community, there will be walking paths, gardens, recreation spaces, and a pond, encouraging residents to partake in outdoor and physical activities. Apartments are intended to be equipped with various private living features such as a kitchen, laundry facilities, a living room, and an outdoor space. Because of the vast spectrum of TBI-related disabilities, each unit will be outfitted to best suit both the abilities of the survivors and the challenges they face, such as wheelchair accessible rooms and easily maneuverable spaces. We have identified site development partners and are currently in the planning stages of this phase.

Phases III and IV will consist of expanding the community by erecting a second residential building, adding a community center, and enhancing the landscaping for the residents to enjoy. The timeline for these phases is to be determined.

Over the next five years, Villa Licci will continue its capital campaign, break ground, and begin construction on its first residence, with a target move-in date for the first residents of 2027.





Villa Licci will secure funding to build the core structure through fundraising, partnerships and contributions from local corporations, gifts from philanthropic organizations and individuals, and grants. The goal of Villa Licci is to secure sufficient contributions, gifts, and grants to pay for the structure outright before residents are welcomed.

Utilities, maintenance, and upkeep for the structure will be funded through the rental payments from the residents, subsidies from families, and annual fundraising. Residents will be charged rent based on their ability to pay.

The caregiving costs will be subsidized through the Traumatic Brain Injury Waiver, Community Integration and Habitation Waiver, families, and private pay. Villa Licci will partner with a provider to secure a qualified and committed caregiving staff.

SUMMARY OF ANTICPATED PHASE I & II PROJECT COSTS	
Land Acquisition	\$ 700,000
Site Development	\$ 610,000
Professional Fees (architectural and survey fees)	\$ 600,000
Construction	\$ 9,500,000
Equipment, Fixtures, and Furnishings	\$ 500,000
Contingency/Financing/Other	\$ 1,750,000
Campaign Costs	\$ 840,000
ESTIMATED TOTAL	\$ 14,500,000

Note: The campaign costs, which include educational materials, communications, accounting, and fundraising staff, is approximately six cents for every dollar raised. According to fundraising best practices, this return on investment is exceptional.

For more information, contact Richard Sontag, Executive Director rsontag@villalicci.org or (317) 439-8028

