



Did You Know?

Brain Injury is the most misunderstood, misdiagnosed
underfunded public health problem our nation faces*

www.braininjurygeorgia.org

*BIAA Susan Connor

Disclosure Statement

- Jane Jackson, CBIS has disclosed a financial relationship as the Executive Director of Brain Injury Association of Georgia (BIAG) receiving a salary. Jane Jackson, CBIS has disclosed no relevant non-financial relationships



- Waring Jackson, Volunteer, Advocate and Survivor has disclosed a personal relationship with Jane Jackson and does not receive any salary. He has disclosed no relevant non-financial relationships



Our **goal** is to have you leave with knowledge about the role the Brain Injury Association provides; learn about our resources and programs to support the wellbeing and care of the brain injured individuals and their caregiver; educate about a “day in the life of” a survivor and strategies in managing their challenges and behaviors.

Objectives

1. Identify two services provided by BIAG that educates and guides the brain injured and/or their caregiver
2. Describe a program that is therapeutic, promoting socializing and health/wellness for individuals with a brain injury

MISSION

To provide Hope, Help, and Support to the citizens of Georgia who have sustained or have been affected by brain injury.

VISION

BIAG is dedicated to increasing access to quality health care, raising awareness and understanding of brain injury through prevention, education, and advocacy together with its affiliates and support groups throughout the State of Georgia.

Brain Injury Basics

Brain injury is **unpredictable** in its consequences. Brain injury affects who we are and the way we **think, act, and feel**. It can change everything about us in a matter of seconds. The most important things to remember are:

- A person with a brain injury is a **person first**.
- No **two brain injuries are exactly the same**.
- The effects of a brain injury are complex and **vary greatly from person to person**.
- The effects of a brain injury depend on such factors as **cause, location, and severity**.

Introduction to Brain Injury

■ Georgia averages **40,000 +/-** new TBI's a year. With change in ICD10 coding the numbers dropped from **70,000** coded as “non specified”

■ **2.7 million** children and adults sustain a TBI (ED)

■ **795,000** individuals sustain an acquired brain injury (ABI – Strokes) from non-traumatic causes each year

■ **5.3 million** children and adults in the U.S. live with a lifelong disability as a result of TBI and

■ **1.1 million** from a Stroke

■ This makes brain injury the **second** most prevalent injury and disability in the United States.

■ Brain Injury affects the family, friends, jobs and is life changing

Traumatic brain injury (TBI) has been called the

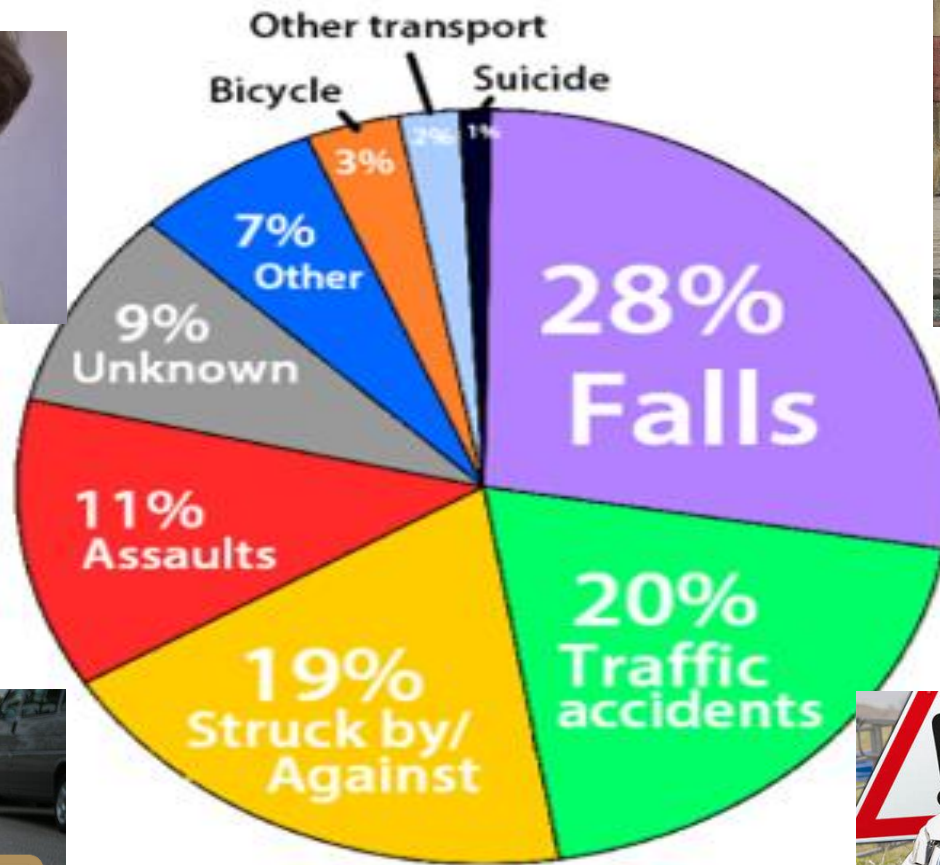
“silent epidemic.”



**Above data Does not include our veterans nor those who sought care outside of the ER/Hospital. The number of TBI/ABI who do not seek treatment is unknown. *BIAA, CDC, BSITFC*

What is the number one
cause of a TBI nationwide?

Causes of Traumatic Brain Injury TBI



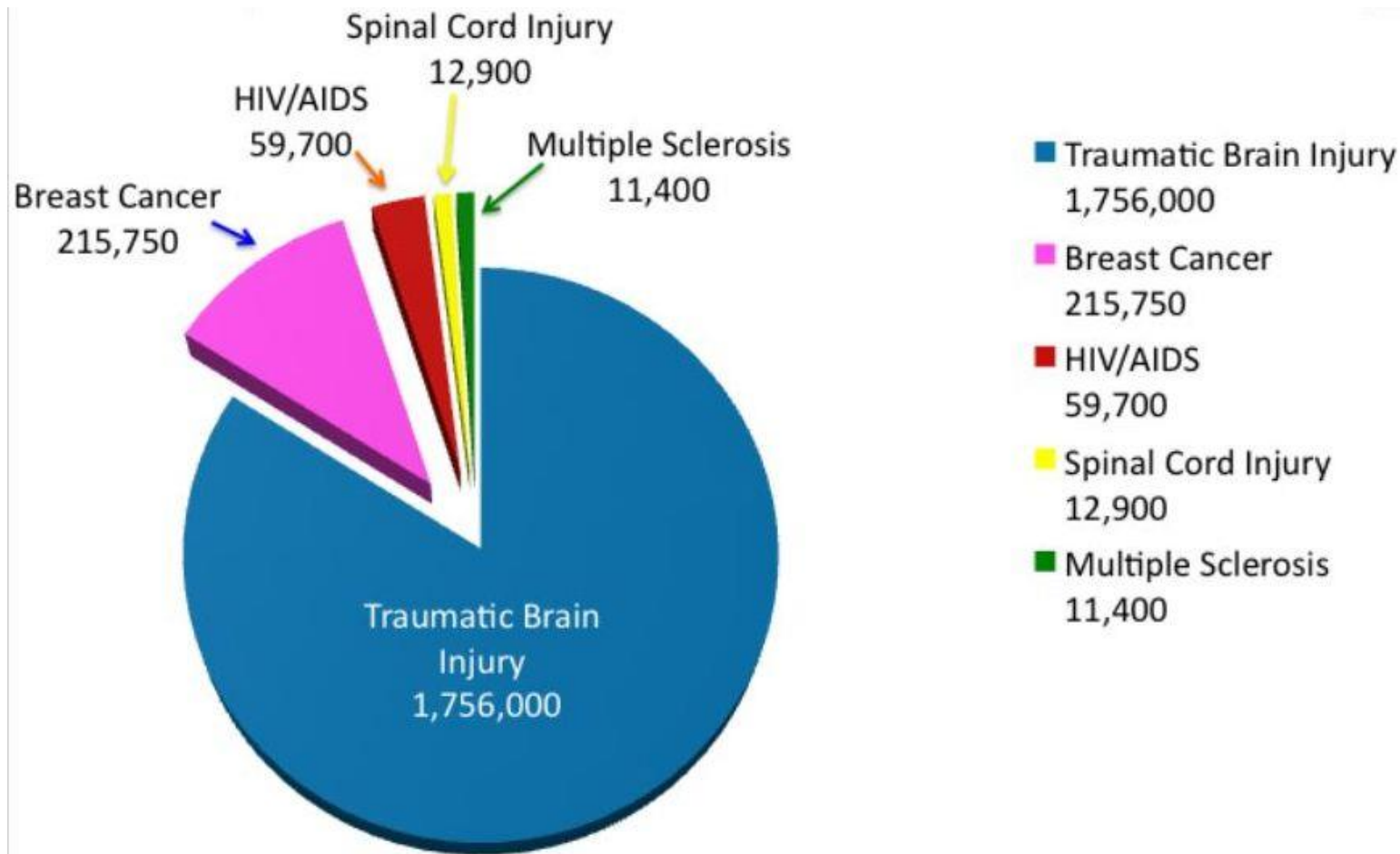
Causes of Acquired Brain Injury ABI

- **Tumor**
- Blood clot
- **Stroke**
- Seizure
- Toxic exposure (e.g., substance abuse, ingestion of lead, inhalation of volatile agents)
- Infections (encephalitis, meningitis)
- Metabolic disorders (insulin shock, diabetic coma, liver and kidney disease)
- Neurotoxic poisoning
- **Lack of *oxygen* to the brain** (Drowning, Suicide, Heart Attack.....)
- **Drug Overdose – opioid epidemic**



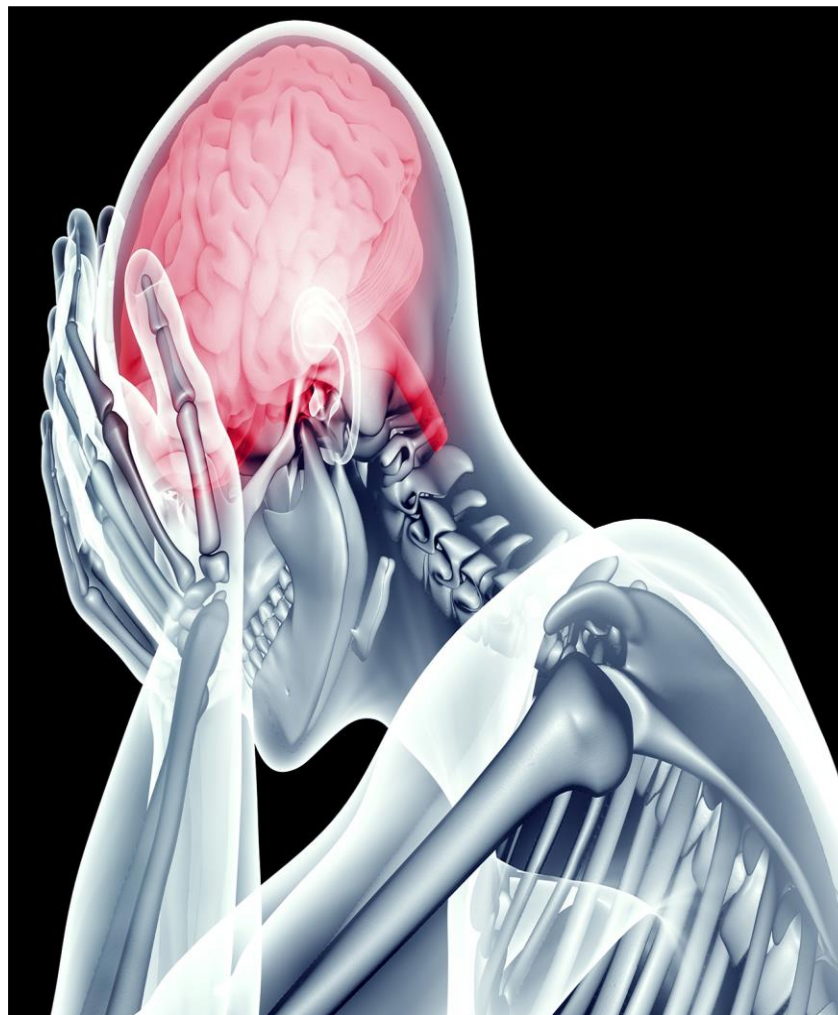
According to the World Health Organization, traumatic brain injury will surpass many diseases as the major cause of death and disability by the year 2020

There are more Brain Injuries than combined breast cancer, HIV/AIDS, SCI, MS (CDC/BIAA)



Problems

- Identity: New Person
- Irritability\Mood swings
- Memory/Forgetfulness
- Aggression/Irritability/Anger
- Depression/Anxiety
- PTSD/suicidality
- Anti-social (you think puberty is hard?)
- Neurocognitive Stall/Missing Milestones
- You're still developing
- Jobs/Employment
- Relationships



Access to Services

Those most likely to have difficulty accessing services are individuals:

- With *cognitive impairment* but who lack physical disabilities
- Without an effective *advocate*
- With *problematic or unmanageable* behaviors *

* **Without treatment, individuals with problematic or unmanageable behaviors are the most likely to become *homeless, institutionalized in a mental facility, or imprisoned.***

Government Accounting Office (GAO)

Ways to Help Behavioral Issues:

- Don't take it personally!
- Remember that responses are likely part of the brain injury and caused by the neurological disruption associated with TBI
- Remain calm, change subject, do not react.
- Be patient! They may be feeling **overwhelmed, too many choices**



Mental Illness or psychiatric disorder after a TBI

- Psychiatric disorders after traumatic brain injury (TBI) are frequent
- A mental illness may have been present prior to brain injury. A brain injury is also known risk factor for developing a mental illness. One report indicates 42% of people as having a dual diagnosis
- It is not uncommon for people with a dual diagnosis to have challenges accessing support - **mental health services will say they need a brain injury service, but the brain injury services say they should go to a mental health service.** You may like to seek the support of an advocate to resolve this lack of support for dual diagnosis situation
- **At the policy level, no government agency takes responsibility for this group of people.** This plays out at the service level where people with a dual diagnosis are bounced back and forth between the disability, health and homelessness sectors
- There is not a Mental Health Waiver.

[https://synapse.org.au/information-services/mental-health-brain-injury-mental-illness-\(dual-diagnosis\).aspx](https://synapse.org.au/information-services/mental-health-brain-injury-mental-illness-(dual-diagnosis).aspx)

A Day in the Life of Video

The Brain Injury Association of Georgia is helping individuals who have had a brain injury return to as normal of a life as possible. Watch a short 3 minute BIAA video to learn more.

- <https://vimeo.com/304855710>



Brain Injury Association of Georgia (BIAG)

- BIAG is Georgia's a statewide nonprofit organization dedicated to individuals who have survived a brain injury and their families.
- Founded in 1982, the objective of our organization ultimately is to provide resources and support to those affected by a brain injury
- We offer hope, help and support services for all brain injuries from traumatic to acquired
- BIAG support not only the brain injury population, but professionals who work with this population
- BIAG is the state affiliate for the Brain Injury Association of America
- BIAG is the designated service provider for brain injury callers for the state's Aging and Disability Resource Connection ADRC

Education and Awareness

Conferences, Symposiums

Advocacy for Legislation

Centered on collaborative partnerships with family and service providers



Our Core Programs



Advocacy

- *BIAG was a lead agency advocating for the following which supports grants awarded to approved TBI/SCI through the Brain and Spinal Injury Trust Fund:*
 - *Safe Return to Play Act of 2013 for sports concussion and prevention efforts and*
 - *Reckless Driving surcharge 2014.*
 - *Distracted Driving Bill passed in 2018*



Representative
Tanner sponsored
“Reckless Driving
Surcharge”



SafeKids America event
Sports and helmet safety



Gov. Deal signing
“Safe Return to Play Act “

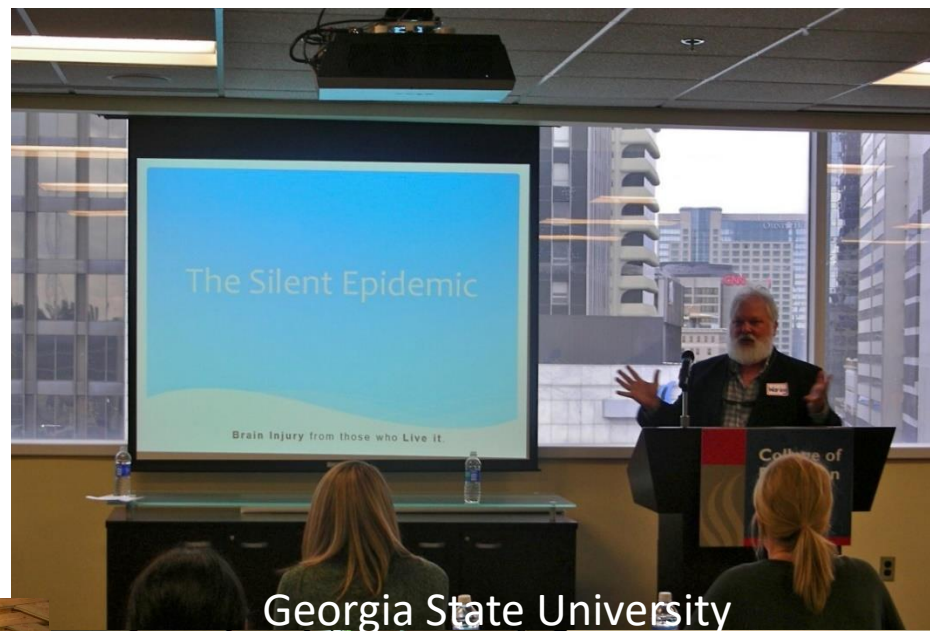
Community Outreach & Education

- Strengthening the VOICE of BIAG
- Expanding Marketing & Communication Efforts
- Educational Opportunities for Survivors and Families and Professionals
- Support Group Leadership Summit
- Workshops, Mini Conferences
- Awareness



Community Outreach & Education

Brain Injury training and education conducted at colleges, housing, staff workshops and foster parenting including concussion (mTBI) safety for our youth



Information Resource Program IRP

A Certified Brain Injury Specialist (CBIS) offers a “HELPING HAND” to individuals and families impacted by a brain injury.



An individual or family member is given an opportunity discuss their specific needs and situation one-on-one with someone who is familiar with the challenges they face. CBIS also works with service providers and professionals who serve the brain injured ABI/TBI

Resource Rooms Serviced by IRP

**Emory Center for Rehab and
Wellstar Atlanta Medical Center.**

Our Resource Room provides packets of brain injury information, education and a place to meet in private to discuss their situation or needs



Information Resource Program CBIS provides

Consultation...Education ... Guidance ... Support ... Resources



Hope, Help, Support - Not Alone Anymore!

- **1:1 Consultation services**
- **Application processing through Medicaid to Food Stamps**
- **Medicaid Waiver Assessment**
- **Caregiver Support**
- **Connect to a Support Group**
- **Guidance for “next steps”**
- **Education about brain injury**
- **Peer Facilitator**
- **Referrals to Health Care Professionals and service providers**
- **Resources – community**
- **Strategies & understanding in dealing with challenges**
 - **Cognitive, Emotional, Memory....and more**
- **Visitations - hospitals, homes**

Assist with application for benefits. Help ensure a smooth transition from hospital to home!

Where is our Value

- **We offer people the ability to understand their brain injury.**
- **Patient education is a significant factor in recovery**, along with a support system
- People who understand their injury better tend to have **better outcomes**.
- **Assistance understanding:**
 - terminology, concepts
 - systems (healthcare, disability, state programs, etc.).

Our expertise is required in both these areas to **help navigate through these systems with some level of confidence.**


- **It's the application of the knowledge specific to that person** that makes the service valuable to that person...and having 1:1 consultation.

“They call for one reason, or do not know the help needed.....by the time we are done they have a plan, they have resources and they have hope.”

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Key Resources (or lack of)

- Financial – Brain and Spinal Trust Fund (limited to TBI/SCI)
 - Housing – HUD.... Affordable, accessible and available; Group Homes for TBI (will not accept Medicare/Medicaid) or if they have behaviors
 - Transportation – Medicaid, Marta Mobility, Uber, Lyft, or walk/bicycle.
 - Home or personal care – Must accept Medicare/Medicaid/Waiver ICWP, Source or CCSP
 - Medicine – Help paying: Ga Cares, Patient Assistant Foundation, Georgia Gateway, Healthwell Foundation, Pharmaceutical Assistant; talk to your pharmacist)
 - Medical treatment (Modest Needs Foundation; Patient Advocate Program; Refugee Medical Assistant Program; Georgia Clinics)
 - Someone to hand hold them – they go into overload and become overwhelmed
- To the brain injured, counseling is as important as a wheelchair is to a spinal cord individual
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Support Groups - Statewide

East



North



- **Safe and supportive environment**
- **Socialization**
- **Survivors & Caregivers** support for
- **Continued Healing** – sharing of mutual experiences
- **Positive Recovery Experience**

West



South



An additional
28 Support
groups from
Stroke to
Aphasia to
Tumor

Support Group Social Activities



Support Groups participated in a **Global Picnic worldwide**, held on the same day, to raise awareness



Seminole Spirit hosted a **Swim For Brain Injury**



Gwinnett Support Group hosted **Unmasking Brain Injury**. Masks will be shown in a traveling exhibition nationwide.



Blue Ridge Support Group sponsored a table at a local **health fair**



No. Fulton Group hosted a **Burgers & Brain Picnic** for local group members

Support Group Educational Activities

Riverdale “Miracles Happen” Support Group Hosted “HOPE Matters” Symposium



- Education and training for support group leaders
- Add new groups or support group options in underserved markets
- Encourage existing groups to grow engagement



- Focuses on providing unique recreational therapy to adult brain injuries survivors (18+).
- Promotes socialization, health and wellness
- Staffed with health care professionals, counselors & volunteers
- A one-of-a-kind camp serving Georgia survivors and caregivers



Camp BIAG

Builds Self-Confidence, socialization, life skills



Various Arts and Craft Activities are utilized to improve basic cognitive functions of attention, orientation, memory. Karaoke improves breathing-good for many parts of your brain



lowers their stress and depression

Caregiver Respite Camp

- Caregivers may enjoy needed respite time
- Led by a Clinical Licensed Social Worker who is highly experienced in brain injury



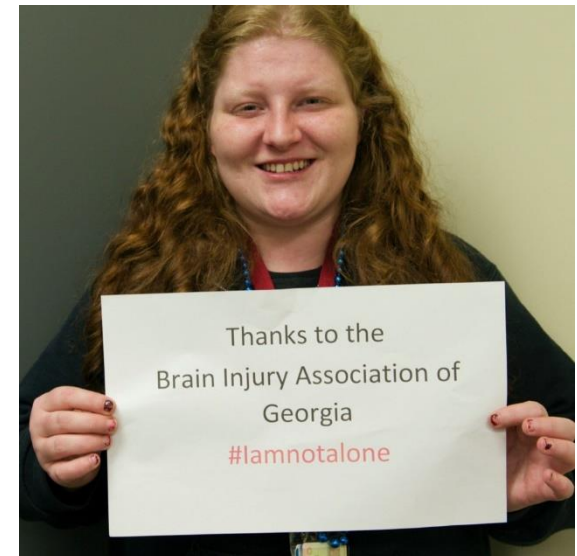
Caregiver and Family

- A brain injury happens to the family...not just the individual.
- Don't forget to take time out for yourself
- If someone offers to help – accept it
- Accept imperfection - you cannot control everything or your loved one
- Accept your loved one may have dramatically changed.
- Recognize PTSD – get help
- Seek counseling, support groups, church For you and the family
- Know that resource are out there – contact BLAG

The greater the role of the Caregiver, the greater the impact on his or her own physical, emotional and mental health.

Faces of Brain Injury

#NotAloneinBrainInjury



A Care and Support Plan, sometimes called a thoughtful “Letter of Intent”, to help family or guardian describe the person’s history, current status and that they hope for their loved one in the future.

No one else knows your child or loved one as well as you do, and no one ever could. You are a walking encyclopedia of your loved one’s history, experiences, habits, and wishes. If your loved one has special needs, the family’s history adds a helpful chapter to your loved one or child’s book, one detailing their unique medical, behavioral and educational requirements.

- Appoint a legal guardian/ Prepare a letter of intent to with a difficult transition when you are no longer there. It is not a formal legal document and the minimum should address the following topics:
- **Family History** – stories about family, their birth, memories, list relatives
- **General Overview** of their life to date and your general thoughts and hopes about their future
- **Daily Schedule** – list their routine, favorite activities, loves or hates. List what chores they like and what frustrate them
- **Food** – diet, favorite foods, how it should be prepared or served. List allergies or foods they dislike
- **Medical Care** - detail their disability, medical history, allergies, list of doctors, appointments, current medications
- **Education** – when applicable. Include educational experiences, school, classes, extra activities, preferred voc rehab
- **Benefits** – list gov’t benefits include SSI/SSDI, SNAP, Housing; include agency contact info and important dates
- **Residential Environment** – describe living arrangements
- **Social Environment** – types of social activities, can they handle spending money
- **Religious Environment** - Specify religion if any, local clergy
- **Behavior Management** – described behavior management program – positive ones and unsuccessful ones in the past
- **Final Arrangement** – List their final arrangements, funeral planning, who is to officiate
- **Other Information** that is unique or will help the person assuming care to understand or need to know
- **Sign and date the letter**

Hope, Help & Support



Song written at Camp BIAG by survivors (Song starts at 110)

Camp Videos: <https://youtu.be/6C6-OcWrVls>



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