

**It's More Than a Billboard,
"The Faces of Autism"**



Thank You

This is published as our family's thanks for the many cards, prayers and kind memories of positive interactions with my son, Carson Andrew Hagood.

It is our prayer that no other client or resident whom is developmentally disabled and entrusted to the care of others suffer the tragedy of a system that failed in the care of my son.

Carson's only ambition in life was to be a productive citizen. He had a sensitive, kind, forgiving nature inspite of the discrimination, abuse and isolation endured during his most formative years.

Only Christ sustains such a faith, a hope and spirit of determination living in Carson.

We thank you for continuing prayers.

LIFE
IS NOT A PUZZLE,
IT IS A MYSTERY TO BE
LIVED!

(original) quote by:

CARSON Andrew Hagood, 2020
"I know the PLANS I have for you,
says the Lord" Jeremiah 29:11

The family of Carson A. Hagood:

Shawn, Jackie, Delaney

Brittany, Dylan, Aubrey

and Linda

It's More Than a Billboard, "The Faces of Autism"

Each day en route to work I pass a billboard announcing the frequency in minutes of children being diagnosed with Autism. Twenty six years ago my infant son displayed full body tremors as he lay on the exam table at the pediatrician's office during a routine check up. The pediatrician looked at me and asked, "what is that?" Today, when a legal hearing is held in the mental health system to determine commitment, the presiding judge can tell you of full body tremors, "that's a classic symptom of Aspergers (the highest functioning form of Autism Spectrum). Hope has a price in Illinois. We must continue to reach for it. St. Louis, Missouri is home to a premiere provider of services and research in autism: Judevine. However, Judevine Center for Autism does not accept out of state clients unless covered by Individual Care Grants and state approved medical waivers. Few can afford private pay services. These are the goals we need to achieve here in Illinois is health care really is for all, including those having autism. There still remain too many physicians in the mental health field who neither recognize nor know how to approach and treat a patient having autism. This is emphasized when the hearing judge describes classic symptoms to the primary physician.

In our situation, my son's pre-school years were challenging, but nourishing and happier for him. He was a busy, curious child who loved music, books and people. Poverty was a great obstacle. Sitters did not want a child with tremors or communication deficits. My parents attempted to assist us, but were overwhelmed by his needs. I had no options but to attend to my son's care and needs. At three I requested a speech therapist at the local grade school work with him on enunciation and verbalization. Today he still refers to Ameren as CPIS, but everything else is proficiently enunciated. He smiled a lot, laughed a lot and always wanted to give hugs. At age six his head was up and his shoulders were back with a posture of someone happy, expecting and unafraid to go... any where!! The attitude of determination did not change with school years, but the reality of how others perceived and treated him brought the question, "why can't they accept me the way I am?" He started school with tons of love, exuberance and high hopes. He was completely disillusioned and confused by the rejection, isolation, physical, mental and emotional abuse he had endured. By age 15 he had become an excellent swimmer. The manager of the public pool in the town we lived in at that time barred us, stating the full body tremors were disruptive, so I drove my son to a public beach twenty-five miles from our hometown where he learned to swim and play without discrimination from other beach goers. The coach for little league baseball would not allow him to play on the team because he could not quickly follow the coach's calls and was not a coordinated, fast runner. He did not have the hand and eye coordination to tie shoe laces. By third grade I requested an

occupational therapist to teach him the concept and skill of tying laces. Today as an adult he wears slip on shoes and despises lace up shoes. He always demonstrated high levels of reading comprehension, but the fifth grade math teacher forced him to sit in the hallway outside the classroom, stating he was, "demon possessed". In sixth grade, I was called to a parent teacher conference because my son avidly read Stephen King novels and the teacher thought that was, "scary". He also liked jazz, the three tenors and the musical score from Phantom of the Opera. Yes, children and adults diagnosed with autism may have impaired social interactions, problems with verbal and nonverbal communications, unusual repetitive or severely limited activities and interests.

The behaviors can range from mild to severe. When the Sunday School Superintendent telephones your mother to request you never be brought to Sunday School or church it can challenge your Christianity. When cousins at family gatherings refer to you as, "monster", and an uncle yells at you to, "Get Away!" you may have trouble bonding with that cousin, aunt or uncle. Doctors and educators telling your mom that your diagnosis (whatever it is?) makes you a target, may hinder your personal development and prohibit normal stimulations of growing up enjoyed by others in your age group. My son focused on reading and movies. His doctors referred to him as a walking encyclopedia. He can relate the history of the film industry and proficiently use library reference tools. He held the dream of attending film school to become a technician in the film industry. What can be achieved by people having a diagnosis of autism?

The best physician of our experience was a neuro-psychiatrist. The timing and expertise of the extraordinary and unique physicians placed into my son's life was the intervention of God in our lives in answer to prayer. Not only did my son have a diagnosis of Aspergers, but he had a congenital defect of the pancreas requiring two major surgeries to make the healing correction for the pancreas to drain directing into his small bowel. Divisim of the Pancreas, the particular surgery performed to make this correction, had been practiced only for twenty years. The particular team who researched and resolved my son's surgical needs had never before worked together and were only within the same medical institution for six months before moving out of state. The neuro-psychiatrist had never before accepted a patient who was not an adult. But he accepted my son and nourished him from a 15 year old who had become so damaged and withdrawn he no longer wanted to verbalize, to a twenty-one year old who set personal goals and held down a job.

Autism affects everyone in the immediate family unit. I have two sons. The younger, having the diagnosis of Aspergers has a brother exactly ten years and six days older than he. The older boy always told me he wanted a brother. That all changed when it was obvious little brother had a disability and mom's life was permanently disrupted by it. Lack of money due to my unemployment and constant care needs of the younger child impacted all three of us. His younger brother idolized him, but he was embarrassed by the tremors and outbursts of laughter that would come at times when no one else knew why the child was laughing. It is hard to take your little brother places if he has not the social skills of other children in his age group. Tourettes and Aspergers place persons of that diagnosis four years behind others of that same age group. The analogy: Age 21 is 17 for a person having a diagnosis of Tourettes or Aspergers. So Autism can take on the face of a parent, a brother, a sister or a grandparent. The book of Proverbs states, "a brother is bom for adversity" Proverbs 17:17. You can not separate yourself from a diagnosis that so affects your life and every hope you held for your children. No one can predict the affects or adult repercussions after a growing up through social "conditioning", isolation, abuse, bouts with mental illness brought on by these. There is an account in Matthew 17:15,16&18 that reads like this: "Lord, have mercy on my son: for he is a lunatic, and sore vexed: for oft times he falleth into the fire and oft into the water. I brought him to your disciples and they could not cure him. And Jesus rebuked the devil; and he departed out of him: and the child was cured from that very hour. Some refer to this as the deaf and dumb spirit, some refer to this as Autism. Whether it is a prayer, an announcement on a billboard, a medical waiver from Medicaid or services through Judevine and the Ilinois Center For Autism, we must rebuke the devil of Autism that seeks to plague and isolate our children and our families.

Linda Sue Hagood

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Addenda: Documented medical diagnosis current: HX of Tourette Syndrome Complex, Autism spectrum (Aspergers) OCD, psychotic disorder NOS. Medical symptoms age birth to sixteen (16) that appeared symptomatic of his particular diagnosis: flat footed, poor hand-eye coordination, problems processing initial verbal commands, literal interpretations of all verbalizations or conversations, congenital defect of the pancreas, intrinsic asthma, susceptible to inventigo, limited diet selections.

Wednesday, January 26, 2022 my younger son was involved in a crisis at the group home for the Developmentally Disabled where he has resided. Early that morning I was asked not to contact any source of media regarding the crisis. When I arrived home Wednesday evening, I received from my older son text message showing a sensational by line and negative photo of my younger son aired by WAND TV of Decatur, Illinois. There was also a web site posted which aired comments from the group home staff regarding my younger son. There was no balance, no background, no form of appropriate investigative reporting. No one from WAND had taken the time to speak with me regarding my younger son. I later learned that WSMI had also run this story. No one had questioned: my younger son, since Saturday, January 22 had been verbally communicating his changing mood, thoughts , spitting out his medication, earnestly expressing his fears that he might harm himself or others. No one questioned the response of the staff, the requests from family that this potential for crisis be thwarted by contacting the psychiatrist, a blood draw to test levels and hospitalization. My son, we were advised, was not causing any problems, was interacting appropriately with staff and other residents and that they were administering medications. I visited my younger son on Sunday, January 23. His depressed state of mind and emotion was very obvious. He reiterated his fears of having a breakdown and being sent to a mental institution. Yet, staff was only advised by superiors to "watch" him. I was again reassured he was not being a problem, but in fact one who was always compliant and when workshop was in session, he was the one first up, dressed and ready to go to work without prompts. Sunday evening when I phoned staff I was again assured of this and told Sunday afternoon a house staff had taken him to shop at a nearby Dollar Tree Store. His calls and texts to his brother and myself continued throughout Monday and Tuesday. Now we are faced with tragedy that could have been thwarted and avoided. My son had been leading a successful residency at the group home, all of his home visits had been positive. Now, what future do we face? How many tragedies have to take place before Illinois promotes the proper training, Developmental training, Workshops /trained staffing and community integrated programs essential to our progress and the needs of a growing population with Developmental Disabilities and Mental illness?

My younger son originated this quote during 2021:

"LIFE IS NOT A PUZZLE, IT IS A MYSTERY TO BE LIVED"

What is the mystery of Mental Health that Illinois and the media neither
realize nor reckon with?

Linda Hagood

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Carson Andrew Hagood is the son of George Eugene Culley and Linda Sue Hagood and the sibling of Shawn Corman Perkins. Carson has a diagnosis of Autism accompanied by multiple neuro-psychiatric and physical diagnosis which is not uncommon for those on the Autism Spectrum. Carson was born at a time when little if anything was understood about Autism.

Carson met a lifetime of challenge having to endure abuse, neglect, isolation and discrimination. Carson exhibited a determined and tolerant will in spite of the most cruel and unjustified circumstances during his life. Carson's immediate family enjoyed seeing him smile and his stoic expression

when he made all of us laugh with his very literal interpretation of family situations. Carson adored his older brother, Shawn and was beloved by his namesake, Carson McNurlin Hagood, his maternal grandfather. The happiest times of Carson's life were when he was allowed to participate in work, education, sport, church or social function as others without discrimination.

Unfortunately, this was not the case for Carson during most of his life. Carson's family request that any expression of empathy themselves or for Carson's circumstances and others coping with the challenges of Autism be made in monetary donations to the Montgomery County Autism Support Group. It remains our prayer that these individuals and their families will have access to the fullness of life so many before them were denied due to the lack of understanding of Autism.

Carson is sick again. He appears to be beyond the reach of his brother and me. Carson's medical diagnosis has always been multiple. In addition to being Developmentally Disabled, Carson was what his neuro-psychiatrist termed, "a conditioned response" to the repeated abuse, neglect, rejection and discrimination Carson endured during his formative years. Whether by extended family members, school experiences, church or society in general, by the time Carson was 16 years of age he was so withdrawn the neuro-psychiatrist determined that Carson had been so traumatized and damaged that if doctor could not reach him, Carson would be "lost". I was advised if the doctor was able to reach Carson, the trust between Carson and the neuro-psychiatrist could not and would not be violated, even by me. That doctor did reach Carson and he began a long journey back to health and moving ahead in life.

My dad, who is Carson's name sake, once told me Carson was the most determined person he had ever met. He made this comment after driving Carson to grade school. When Carson started walking up to the school, some other children began kicking Carson; but Carson kept going and did not turn back to ask his grampa for help. Carson NEVER refused to go to school regardless how badly he was treated by teachers or students. Carson never understood why he was treated differently than others. Carson never wanted to take medications, do mental health programs, though when he did he excelled and became a model patient or client. I have documents to prove that.

Carson endured a lot of hospitalizations and surgeries. During Christmas break of 1999 Carson asked to accept Christ as his Savior and demonstrated a marked difference in his behavior both with his immediate family and at the residential school where he was in treatment at that time. Again, I received phone calls from his teachers and doctor to verify this. Carson gave no rest until he persuaded a country Baptist preacher to baptize him and then hounded his older brother Shawn to attend his baptism. Carson and I were alone during his hospitalizations and surgeries except for those psychiatric, medical and surgical professionals whom attended Carson during those times. We prayed a lot and Carson came to say, "Jesus, help me!" when he was in pain or discouraged. Now we have come to the time in our lives when there appears to be nothing more to be done to intervene in Carson's life beyond the Christ who answered his cry, "Jesus, please help me..."