From Loving Arms

Georgia’s Children Living in Nursing Homes and State Hospitals
Special thanks to the individuals and families who told their personal stories for this publication in hopes that in the future no family will have to endure the tragedy and hardships that you have endured.

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“He Thought I Gave Him Up” — Al and Peggy’s Story was written by Vici Decker (staff member at IHDD) as told to her by Al Duval and Peggy Laws.

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In the spring of 2005, the Georgia General Assembly passed House Resolution 633. This legislation urges the Georgia Department of Human Resources, The Department of Community Health, the Department of Education, The Department of Labor, and the Department of Juvenile Justice to work together to provide the General Assembly with a plan (that can be put into effect in the next five years) that will provide home and community-based care for all Georgians with disabilities who have not yet reached the age of 22.

These agencies are being asked to develop this plan with special consideration for the more than 150 children and youth who are currently living in nursing homes and state hospitals and for those who are currently on Georgia’s waiting list for disability services.

The five organizations that proposed HR 633 are part of an effort known as the Children’s Freedom Initiative. This initiative was formed to make sure that children currently placed in nursing homes and institutions live in homes with permanent families and to ensure that in the future no child will live in an institution.

The mission of the Children’s Freedom Initiative reflects the understanding that children belong with loving families – not in facilities. We know that, without the influence of stable and supportive family and community-based supports, children often experience delays in physical, emotional, and social development and are at greater risk for abuse, and neglect.

The stories in this book illustrate the great harm done to children and their families when the service system’s only alternative for support is institutionalization. The common thread in these stories is a state system that perpetuates outmoded and stereotypical views of people with disabilities and the type of support that they and their families need.

When families struggle to meet the needs of their children with disabilities and turn to state agencies for assistance, there must be a plan in place that acknowledges the importance of families. The priority should always be care and assistance that enables the child to grow and thrive in the nurturing arms of a family – either the child’s biological family or with a loving adoptive or foster family. Any other alternative will compromise the child’s development and will perpetuate the idea that children with disabilities are unwanted and not valued.

We hope that everyone who reads these stories will see that the value and the quality of human life are not dependent upon ability but upon the love and the sense of family and community that we all share. The fact that children are living in institutions contradicts the value that we place both upon family and upon the quality of human life.
Most mothers have a common trait that bonds them to motherhood: they want the absolute best life has to offer for their children. At least that’s how Laurie Faulk feels about her son, Don.

Don has been Laurie’s pride and joy since he was born twelve years ago in Albany, Georgia. “He’s my miracle,” Laurie says. “I mean he changed me completely,” she adds.

Laurie knows that she is unable to make Don’s life the best it can be because he is living in a nursing home. Don has lived at Brian Center Nursing Home in Jeffersonville, GA, for the past six years. Six long years that Laurie has wanted him home, living with her, having the opportunity to make every day the best for Don.

The holidays are dark times for Laurie’s family because Don is not able to spend all day celebrating. Her family has to take him back to the nursing home to sleep. Don’s past six birthdays have been heartbreaking because Laurie and Don have had to celebrate in the nursing home where Don is surrounded by people who are six and seven times his young age.

Don spends his days lying in his bed or occasionally in a Geri chair positioned along the wall in the halls of the Brian Center. The social worker at the nursing home says a teacher comes for half an hour, once a week to work with Don.

“He would be so much happier and would learn so much more [at home],” Laurie’s sister, Penny, believes.

Fortunately, Laurie has excellent family support. Her mother, sister, and roommate visit Don frequently and have their own special remedies to keep him comfortable when they are there. Extended family — nieces, nephews, and cousins—also visit with Don and check in with Laurie. Laurie and her family have kept extensive records of all Don’s hospitalizations and incidents. They say they have unsettling photographs documenting neglect of Don and that his doctors have told them to take Don home.

During a recent hospitalization, Don’s physician instructed Laurie to take Don out of the nursing home, as he was severely dehydrated and had complications due to his feeding tube being pushed too far inside his stomach, she says. The physician told Laurie and her family that “no nursing home was good for a child.”

Laurie and her family know methods of keeping Don’s tube area clean and clear and the specific creams to use on his irritated skin, which is caused by him lying in the same place day after day. They believe one hundred percent that Don would be healthier and happier living at home with them. He just doesn’t need to be in a nursing home anymore, Laurie’s mother, Jennifer, says. “It’s pitiful.”

Laurie says her doctors advised her at Don’s birth in 1993 to take him home and take care of him, that he would be a vegetable and would live to be ten years old. Don was born in a comatose state and had brain damage from a traumatic birth.

Laurie brought her baby son home from the hospital and gave him the best care she could: She loved him and spent time with him. She recalls doing therapy with him to strengthen his legs as she changed his diapers. She taught him to say words such as “mom,” “up,” “good,” and “love.”

She was most proud of Don when he said the words “love Mom.”
Don received early intervention services when he was young. Laurie took him from Albany, Georgia, to Columbus for therapy. When Don was four, the family moved to Cochran, Georgia, and a preschool teacher came to their home to work with him. The preschool teacher had Don touch different surfaces to stimulate him and read to him, as did Laurie.

When Laurie and her husband divorced, and she and Don moved to Hawkinsville, Georgia, he was not receiving any services or school support. “I didn’t have money and all to get him places [for therapy],” she says.

I never went anywhere without that baby, Laurie says, “but then I messed up.” Laurie got into legal trouble when Don was six years old and asked her ex-husband to keep Don for awhile. Laurie found out Don had been placed at the Brian Center, “and that’s how I lost him,” Laurie explains.

When Laurie was able to visit Don months later, she discovered that he had been taken from the nursing home to an Intensive Care Unit (ICU) in Macon, GA. Don was being treated for an infection in his stomach. Laurie says Don had been in ICU for a while, but three days after she visited, he was discharged from the hospital and taken back to the Brian Center.

At the nursing home, Don’s room is the most brightly decorated with butterfly mobiles hanging from the ceiling, colorful pictures on the walls, and numerous stuffed animals for Don to cuddle. A fan is constantly blowing wind chimes, which Don loves to hear.

There is a vacant bed in his room that the social worker says belonged to another young boy, who is no longer at the Brian Center. Don has a television and VCR his mother purchased, along with several Disney videos. The sign on his door is covered with teddy bears and says “The Baby’s Room.”

Don rarely spends time outside of his room at the nursing home, the social worker says. Laurie knows Don loves being outside, but does not get the opportunity to go out at the Brian Center. Laurie and her family take walks with Don when he visits them. Don also enjoys baths, Laurie says, but knows the nursing home bathes him in bed.

Country music is his favorite, and he also likes to listen to his Veggie Tales videos. Laurie says Don tries to sing along.

When Don is able to leave the nursing home, they often go to Laurie’s mother’s home in Danville, GA for family reunions and include Don in all the excitement. “He has to be in it [activities] too, everyone else is,” Laurie says.

Her mother, Jennifer, says she’ll have more than fifty family members visiting at one time. Her home is on land that has been in her family for decades, with plenty of room to ride go-carts and shoot fireworks, some favorite family activities. “He’s so excited when he comes home, he won’t even take a nap,” Laurie says.

Don’s cousins entertain him and hug and kiss him when he is at his grandmother’s. His aunt, Penny, believes, “if Don could get around, he’d be a devilish little boy.”

Laurie and her roommate, Julie, drive Don to and from the Brian Center for the occasional visits, but want Don home living with them.
permanently. Julie feels he would improve significantly if he were living at home.

Laurie and her family have noticed Don regress during the years that he has been at the nursing home. She says she was most proud of Don when he said the words “love Mom.” She says it was the best feeling, knowing that he loved his mother.

“I’ve always been proud of him,” Laurie says. “He came from a coma to saying words.” Her family talks directly to Don and knows what his facial expressions mean. She says he used to communicate more with his eyes and expressions, but still on good days, he will say the words his mother taught him.

Laurie says she wants Don “to be at home where he belongs.” Jennifer claps her hands, cheering with excitement at the thought of bringing her grandson home to Laurie’s. “He’s one of our angels,” Jennifer says, and explains that he should be living with his mother.

Laurie wants to take Don back to Children’s Healthcare with doctors who work with children. Right now, he is being treated by a doctor at the Brian Center, she says. She wants him to start therapy again, and wants a school teacher to come to her home and work with Don.

Laurie knows she would need supports at home, but knows her roommate and family will help as much as possible in order to get Don out of the nursing home. Jennifer says now that her grandson is older and bigger, she does not believe she would be able to handle him as she did in the past. Laurie interrupts and tells her mother she wouldn’t leave Don with anyone anyway.

Jennifer’s concern is that “they pay all this to these sorry people in nursing homes, why can’t they help Laurie at home?”

Laurie says she can provide the best for Don, and all she wants is for him “to live the rest of his life happy,” she says. She knows how to make him happy. She knows happy means home.
All you need is love

Six-month-old, brown-eyed, dark-haired, Emily (not her real name) was found all alone in a hospital in Macon, Georgia, five years ago. Doctors said that she had “shaken baby syndrome,” which resulted in brain damage, blindness, and seizures. Lorri Fischer, an “ordinary” citizen met Emily after talking with the coordinator of Macon-Bibb Citizen Advocacy. She became Emily’s citizen advocate and started visiting her at the hospital. A citizen advocate is a volunteer involved with a person with a disability who looks out for his/her best interest, Lorri explains.

Before being admitted to the hospital, Emily had been living with her uncles because her mother and grandmother were in jail. She stayed six months at The Medical Center of Central Georgia in Macon. The Department of Family and Children Services (DFCS) gained custody and transferred Emily from the hospital to the Nursing Home Center at Central State Hospital in Milledgeville, GA.

Lorri went through a long process to gain access to visit Emily at Central State and was constantly questioned about her interest in Emily. “They [DFCS representatives, Central State officials] had me jumping through hoops and I jumped through every one of them and they still couldn’t understand why I wanted to see this child,” she says.

Lorri wanted to be able to visit Emily and look after her from outside Central State. Emily was usually in an iron crib and Lorri wanted to give her individual attention and hold her, making her feel loved. She went to visit her every week. Lorri remembers that Emily spent her first birthday, January 28, 2001, inside the nursing home and she knew Emily did not need to be at Central State. She needed a home and family.

Meanwhile in Vienna, Georgia, Marilyn Allen was working as a caregiver at an Easter Seals Group Home. Easter Seals provides support and services to people with disabilities. Easter Seals asked Marilyn about having Emily come live with her, but Marilyn declined because she had just lost her husband in a truck accident.

DFCS was trying to reunite Emily with her mother, Lorri says. Emily’s mother had been visiting Emily at Central State and had almost completed her case plan when she tested positive for drug use. The reunification with the birth family was no longer an option, Lorri recalls.

Lorri had completed the Model Approach to Partnership Parenting (MAPP) training through DFCS, with the hope that Emily might come live with her. But, since Lorri had been informed that Emily was going home to her birth mother, she had already agreed to be a foster parent for another child. Unfortunately, she knew she couldn’t take both children; “Emily comes first,” Lorri said at the time.

Marilyn, in Vienna, kept hearing about the little girl stuck at Central State in a nursing home and finally went to see her. Marilyn had been in contact with DFCS and was discouraged about Emily; she was told that Emily would have a short lifespan, never say ‘I love you,’ and that she was of a different race. While DFCS was trying to discourage Marilyn, Easter Seals was positive that Marilyn could welcome Emily at her home.
Marilyn says the first time she visited Emily in October of 2001, she checked under her clothes to see if the warnings from DFCS were real. “All I saw was a G-tube [feeding tube]. All the things DFCS told me were not true,” she says.

“It was awful. To me it was awful just because of her surroundings,” Marilyn says remembering seeing Emily for the first time. “I know people worked as hard as they could,” she says, but she knew no baby needed to be in a nursing home. “It broke my heart,” she adds.

Marilyn knew from that first visit that she had to bring Emily home. With the help of Easter Seals, Marilyn began the demanding process of getting ready to bring her home.

She continued visiting Emily two times a week to show the nurses at Central State that she knew how to care for her. Marilyn remembers going through a criminal background check, finger printing, a physical, and a psychological evaluation. She had to get statements from her physicians, documenting that her health was good enough to care for Emily, and she had to have her house inspected. She completed the MAPP training through DFCS as well.

“If I wasn’t dedicated, the process would have run me away, but I wanted this little girl,” she says. Finally, on January 14, 2002, after a year of living at Central State, Emily came home with Marilyn.

“And we’ve been here ever since,” Marilyn says, and “without any health problems,” she adds. Nurses came by their home every day, as well as DFCS workers, and Children Medical Services workers. “After the first year, when everybody saw everything was great, they quit coming as much,” Marilyn says.

Their typical day begins between 5 and 7 a.m., when Emily wakes up and has her first feeding, says Marilyn. Then, its fall back to sleep until 10 or 11, and then its bath time to get ready for the day.

Marilyn’s routine for getting Emily dressed and ready involves lying her across her lap on the sofa. “I’m running out of lap,” she says, as Emily is barely able to lie across Marilyn’s lap now because of her height. But she stays there while Marilyn applies lotion, dresses her, and braids her long, dark hair. “We’ve come a long way in three years,” Marilyn says. “She used to be tender-headed,” she adds, while she parts Emily’s hair into four braids.

Every day Emily is dressed in matching outfits, including socks, shoes, and hair bows. “She has a wardrobe out of this world,” Marilyn says, and admits she is always buying clothes and accessories for her. The two of them even coordinate their colors for church service on Sundays.

“When she first came home, you’d touch her and she’d snatch away, draw up,” Marilyn says. Now Emily has found her place in Marilyn’s arms, side by side in the recliner, along with their dog, Chelsea. Marilyn was afraid Chelsea would be jealous of Emily, so in the beginning, she placed Emily on a quilt on the floor and let Chelsea get to know her. Now, Chelsea is protective of Emily and has even nipped therapists who work strenuously with her.

Over the years, Marilyn has maintained a relationship with Emily’s birth mother, against DFCS’s advice. They previously had visitations at the DFCS office, and now Marilyn stays in phone contact with her at least two times a month. “I was kind to her. Thing was, I had...
Emily,” Marilyn says. “Emily was in a safe place. There wasn’t any reason for me to jump on her and beat her down.”

Emily’s biological family lives in a neighboring town, and Marilyn says as long as they respect her relationship with Emily, they are welcome to visit. Emily’s birth mom sends her presents on her birthday and sends Marilyn Mother’s Day cards.

Easter Seals helped obtain court-ordered placement for Emily in Marilyn’s home, which is permanent now. Marilyn is thrilled she doesn’t have to worry about Emily ever leaving. She hasn’t formally adopted her, because she says it would make it harder for both of them. Right now, Marilyn is employed as Emily’s care-taker by Easter Seals; however, if Marilyn adopted Emily, she would have to get a job outside of their home and Emily would require other support.

It is an ideal situation, Marilyn says. Through Emily’s Katie Beckett Waiver and Marilyn’s job with Easter Seals, they’ve had everything they’ve needed. And they have family support, too. Marilyn’s three sisters live in the neighborhood, with their families, and everyone looks after Emily. “That little girl really gets around,” Marilyn says.

It’s a world of difference from living in the nursing home at Central State. “I believe if she had stayed there, she would have died,” Marilyn says. “It’s so much different on an individual basis,” she adds.

Marilyn is so proud that Emily beat the odds, she says. When Emily first came home, she was having 25 to 30 seizures a day, Marilyn recalls. “She used to scare me to death,” Marilyn says, but they adjusted her medicines. Now, Emily has one or two quick seizures per day.

Marilyn delightfully remembers the first time Emily ate baby food. “Apricots,” she says, “I’ll never forget that jar of apricots.” And now Emily, who eats two jars of food per day, is even spitting out green vegetables, a sign of improvement, indicating that she knows she doesn’t like green veggies, Marilyn says. “I am just constantly amazed by this little girl,” she says.

But now she’s beginning to worry about her starting school full time in the fall. Emily attended half-day programs for pre-school, but in the fall she will attend school all day at JS Pate Elementary School in Cordele. “I don’t know how I’m going to get through it,” Marilyn says, fearful of her little girl being gone all day. “It’s just been us for three years now, and now they want me to share my baby.”

Emily rode the school bus to her pre-school, so she is accustomed to that, but it’ll be interesting to see for whom the separation is more difficult: Marilyn or Emily. At least Emily is in a home in a community where she is able to ride the bus to school.

Marilyn met with the teachers for Emily’s Individualized Education Plan (IEP) and they set up physical therapy and music appreciation during the school day. Emily loves music, Marilyn says, so she will enjoy that. Marilyn
usually has music playing all the time in their home. Marilyn says she told Emily’s teachers she’ll try to stay away, but “I have to keep an eye on her,” she says. She promised the teachers that she would visit Emily at school only once or twice a week for the first month or two.

When Emily was in pre-school, one of her teachers made Marilyn a Mother’s Day card, which is now framed in their living room. “I just had to let everyone see it,” she says. She carried the card everywhere she went — to the bank, the post office, DFCS office — everywhere, she says. They even made a copy of it at the Easter Seals office. “I’d just break down and cry. That meant so much to me,” she says. She wrote a letter to the editor of the newspaper talking about her Mother’s Day card and how proud she was to receive it.

“It’s funny when you get kids,” Marilyn says. Before having Emily, she was known as Marilyn. Now, she’s known as Emily’s mom. She wouldn’t change it. “We bless each other,” Marilyn says. “It’s not what I do for her. It’s what we do for each other,” she adds.

Another letter Marilyn wrote to the editor reads: “Before I ever saw her, I was told all that she would never be able to do. But my faith led me to her side and as soon as I saw her I was lost. I have had no regrets, because despite her medical and developmental problems, she blesses me because she lives. She reaffirms my faith in God and makes me more than I am.”

Lorri Fischer says of Marilyn: “You can hear the love in her voice when she talks about Emily.” It all worked out, Lorri says. “I don’t have to worry about Emily.” And if Marilyn ever needs us, we will be there for her and Emily in a heartbeat, she says.

Marilyn knows there are over a hundred other children in nursing homes and institutions in Georgia, and she knows that they all need homes and families. To those chosen, special people who are considering bringing children home, Marilyn advises that, “First, you have to be true to yourself. Know what you can handle and know the extent you’re willing to go,” she says. “Second,” she says, “pray a lot for strength, patience and endurance.”

“And third, just have so much love in your heart...overflowing,” Marilyn says. “Don’t think about what you’re going to get. Think about what you’ll give and you’ll get it back.” She’s convinced.

Emily’s real name and identity have been shielded for reasons of confidentiality.
Maurice Walker is 19 years old and he has been institutionalized for more than a third of his young life.

His grandmother, Emma James, is his biggest champion in the outside world. She feels that Maurice is caught in a system that she can’t understand. He is “a forgotten case,” she says. Emma is afraid that Maurice has simply been “let go” by society.

Every week, Emma cooks and packs meals and carries the food across the street from her house in Milledgeville to Central State Hospital, where Maurice lives. It is only a short distance, but it may as well be a country away. That’s how far it feels.

Maurice was taken to Central State Hospital when he was 18. There, he spends part of his day at the Education Work Activity Center. And he dreams the dreams of every 19-year-old: A job, a girlfriend, or girlfriends; his family, especially his grandmother. A life worth living.

He also talks about education, finishing high school so that he is ready for a job. Maurice has not been in a typical public education classroom since he was institutionalized.

Maurice and his brothers and sister were removed from their mother’s home because of abuse and neglect when he was just a year old. Maurice then lived with his maternal grandmother, Emma James, who says that she has always had plenty of room for her grandchildren to live at her house. In her home, there are many photographs of the children growing up, which show how involved she is in her grandchildren’s lives.

When Maurice was five months old, he was left unattended in a vehicle, an experience that Emma feels is to blame for Maurice’s grand mal seizures, as they began approximately one year after the incident. Once Maurice entered public school in Baldwin County, school officials thought he had a behavior problem and sent him to the Medical College in Augusta, where he received medication for the seizures. The medication worked against his behavior, Emma believes, causing the school to place him in behavior and special education classes, where his behavior worsened.

Maurice has been in “the system” since he was seven years old, but his grandmother wants nothing more than for him to live with her permanently. She says she has found it difficult to make others understand that she wants him at home. Maurice lived at a residential treatment center for youth and adolescents who have behavioral and emotional issues, from the age of eleven to fourteen. He was readmitted when he was fifteen. During his stays at Laurel Heights, Maurice did not attend public school, and he only had weekend passes to visit his grandmother’s home.

Since Laurel Heights Hospital serves individuals under eighteen, on his eighteenth birthday, Maurice was discharged and transferred to Georgia Regional Hospital, despite Emma’s request that he come home to live with her. The Department of Family and Children Services (DFCS) and the staff at Laurel Heights were “adamant that he was not coming home,” she says. “It looks like the system doesn’t keep families together, they separate them,” Emma says.

Georgia Regional Hospital was deemed an inappropriate placement for Maurice since he was not in need of mental health services, and he was transferred to Central State Hospital in Milledgeville in October of 2004. The Regional Board intended to place Maurice at Central State Hospital, then discharge him with a Medicaid waiver for a bed in a group home setting that the board believed was available. That plan fell apart when the waiver had already been taken.

Emma was present at Maurice’s admission to Central State Hospital, although neither she nor Maurice was given the opportunity to express their thoughts. Maurice is no longer under the custody of DFCS, but Baldwin County DFCS is attempting to gain adult guardianship, even though Emma wants to be Maurice’s guardian. During the Central State admission, the judge...
mandated that Maurice stay for at least six months to get his anger under control. Emma says she doesn't understand why he is institutionalized.

“Maurice doesn't do anything when he's here [visiting home] except play games and we have family cookouts. He's no threat to the community,” Emma says. Maurice’s social worker at Central State Hospital agrees. If the correct supports were in place, Maurice would be an excellent candidate for community living, his social worker says.

Emma is frustrated that her grandson has not been allowed to visit home during his stay at Central State, especially since her home is across the street from the hospital’s campus. “He's an adult” she says. “He has a right to voice his opinion” about visiting home or making other decisions.

Maurice says he wants to move back to his grandmother's house, a place he considers ‘home’ after the transfers to and from various hospital settings. He also mentions his father and step-mother who live near his grandmother, as additional support systems, but Emma remains his biggest supporter and advocate. Maurice’s mother (Emma’s daughter) wants what is best for Maurice and agrees that he should live with Emma. Maurice says he would live with his father and step-mother if he could not live with his grandmother, but Emma and the home where he grew up is his first preference.

Maurice realizes that he would need to get a job if he lived in the community.

“Hopefully selling cars,” he says, smiling while thinking about driving and preparing cars for sale. “Fast cars,” he adds, but then changes his thought process and mentions finishing his education first. Upon admission to Central State Hospital, Maurice and his grandmother were told he was not “appropriate for public school.” Maurice says that he wants to go back to regular high school for 12th grade.”

Eventually, Maurice wants his own home, which he knows is feasible with the right supports. He says he would need some help cooking, but does know how to prepare simple meals. Maurice says that he would not need any help cleaning, but that medication management and money management — paying bills and budgeting — are areas in which he would need assistance.

Maurice dreams of getting his driver’s license and driving himself to and from school and a job. He says that if he were living in the community, he would “spend time with his girlfriends, dad, brothers, mom, uncle, and grandmother.” He wants to go shopping, to the movies, and to eat out occasionally. Maurice wants to be able to make his own decisions about whom he shares his time, and he wants free reign over his daily activities.

Emma wants the best for her grandson and knows he would need resources to live in the community. “I would want to see Maurice, since he wants it so bad, to get that high school
Emma says. “Eventually, I want him to have a family of his own,” she adds. She suggests he receive job-training and says that he would need “somewhere to go during the day since I work.”

“You never know what a person can do until he’s given a chance. Maurice is not being given a chance,” Emma says, expressing her frustration. She feels people are not listening to Maurice’s wishes and she says she knows her grandson better than anyone. “It’s sad. Maurice is the one that got thrown away,” Emma adds.

Emma blames Maurice’s transition to several hospitals, instead of into the community, on the lack of preparation by the agencies involved in his case. “They weren’t working on Maurice’s case in advance,” she says, and on his 18th birthday, he had to be discharged from Laurel Heights Hospital immediately. “They didn’t prepare,” Emma says. “Just a forgotten case. He was let go,” she adds.

Emma gave the example of a family preparing to send their child to summer camp, and how the family begins registering the child several months before summer arrives. She believes that his caseworkers should have been planning for Maurice’s discharge since they knew he was going to turn 18 and would be required to leave Laurel Heights.

“I hope everything works out for Maurice. I’m hoping and praying,” Emma says. “I want him out. He shouldn’t have been in in the first place, not out there [Central State Hospital].”

Maurice’s discharge plan on record at Central State indicates that the “treatment team agrees that with the appropriate supports in place, Mr. Walker would be an ideal candidate for community placement,” but that “the supports he needs to live safely in a community setting are not currently available.” His social worker believes Maurice would benefit from a vocational program, a job, and a job coach.

Emma, who describes her grandson as mild-tempered and funny, is concerned that Maurice’s behavior will decline the longer he lives in an institution. But, she says, “It takes a lot to break his spirit.” She pauses for a long minute, and then says, “I’d hate to see his spirit broken.”

Emma is aware that the State pays for Maurice to live in an institution, even though she is willing to provide for him at home. She sums it up with the question that she wrestles with everyday: “They’ll spend $350 a day to keep a family apart. Why can’t they spend a little money to keep us together?”
Meet the Jenkins family: Frank, Cindi, and their two daughters, Jené, 19, and Jayme, 12. They live in Harlem, GA, with their three cats and two dogs.

Frank drives trucks currently, but served in the Army before moving to Georgia in 1995. Cindi works at JC Penney in Augusta. Jené is engaged to be married, while Jayme makes the honor roll at her middle school.

Life seems ordinary for this family; however, a big part is missing, as they will tell you. Cindi will say it's her heart that is missing.

Jason, their first-born and the girls’ older brother, lives thirty minutes away from his family at East Central Regional Hospital on the Gracewood Campus. Jason, who is 23, has lived at Gracewood for the past nine years.

Cindi recalls Jason’s placement as the hardest day of her life. Her daughters, four and ten years old at the time, “cried and asked me why I gave their brother away,” Cindi says, beginning to cry herself. “If we’d been able to get some kind of respite, we’d never have taken him [to Gracewood],” she emphasizes.

Jason, who the family has nicknamed “Bubba,” had a traumatic birth that required an emergency caesarean section. “The cord had prolapsed and Jason was coming breech so he came down on top of the cord with his feet cutting the oxygen off,” Cindi says.

Jason was flown to a hospital two hours from where Frank and Cindi were stationed and stayed for 48 days. He received a gastronomy tube for feeding and underwent numerous tests. “We were told he had severe brain damage and that he would never be anything more than a vegetable. We should consider putting him in an institution,” Cindi remembers. But they didn’t.

Cindi and Frank say caring for Jason was rough at first, but they developed patience and a routine and they worked together. Cindi says that when Frank was at his wit’s end, she would be calm and vice versa. Though Cindi says Jason has always been a “daddy’s boy,” and the rest of the family agrees. When her first daughter was born, Jason would try to keep his sister from getting their Dad’s attention, Cindi says.

Jené doesn’t seem to mind at this point. She says she wants to get her brother out of Gracewood, and promises to take care of him if something happens to their parents.

“Both of my girls have big hearts,” Cindi says, and she believes it comes from having a brother like Jason. Or maybe it comes from having such a loving, supportive family.

Jené remembers having a baby doll when she was younger that had a feeding tube in its stomach. Frank says he had to cut a hole in the doll’s stomach for Jené, so her doll would be like her brother.
The Jenkins moved to Hawaii in 1988 where Frank was stationed for four years. Cindi says Hawaii was the best place for Jason to live. “There the special education was top-notch and we met a dedicated teacher. Between our continuous persistence and hers, Jason began to walk. He was nine years old,” Cindi says.

After Hawaii, the family moved to Oklahoma, and Jason received therapy services there, too. Once Frank left the Army and moved to Georgia, Jason was approaching puberty and life for the family turned upside down.

“When he hit puberty, he all of a sudden got so violent.” Cindi says. “He would fight when I was trying to put him in his wheelchair for school. He started being aggressive towards others. He would pull hair or tear clothing,” she adds.

They needed help and they weren’t getting any. Respite care to support the family was not available, and it was getting harder to keep up with Jason’s supplies. They received $300 to $400 a month from Supplemental Security Income, but were spending $100 a week for his diapers.

Frank’s uncle had told them about Gracewood, located near Augusta, and suggested they put Jason there. “We said never. But that day Jason grabbed me, never came. I was scared that if that had been our youngest child he had grabbed that he would have broken bones in her face. I took Jason to Gracewood. It was the hardest thing I have ever done in my life,” Cindi says. “I cried the whole time I was there and all the way home.”

Jason had become strong enough to overpower his mom. The wake-up call for Cindi and Frank occurred when Cindi was changing Jason and Jason grabbed Cindi’s hair, pulling her on top of him, which frightened Jason. He threw up his knee to protect himself, which connected with his mother’s face and eye, resulting in a large bruise.

Frank and Cindi were afraid Jason might unintentionally hurt their daughters and they were unable to locate any in-home support. “If we would have had any kind of help, we would have never put him in placement [Gracewood]” Cindi says. But, “things were getting so increasingly hard,” she recalls and they were told to put Jason in “temporary and immediate care at Gracewood.”

Temporary turned into weeks and weeks into months, then months into years. Before we knew it, it had been nine years, Cindi says.

The family brings Jason home on the weekends when they can, but it is very exhausting having him at home, they say. “He’s in constant motion when he’s here. We’re worn out after the weekend,” Cindi says.

When they take Jason back to Gracewood at the end of the weekend, he will lock his feet under the dashboard of the car so he will not be able to get out. “He doesn’t want to be there. It’s killing me that I’m the one doing it,” Cindi says. “I think it has a lot to do with him being unhappy in his environment,” Frank adds.

“Going back, looking back…even if I went insane I wouldn’t do it again,” Cindi says, referring to placing Jason at Gracewood.

The family has battled with Gracewood over the years regarding bruises on Jason and the policies used to approach and suppress Jason, which further antagonizes him, Frank says. “It’s frustrating,” he adds. Frank disagrees with Gracewood’s policies for handling clients which, “are set in stone,” he says. “Grabbing Jason in the same spots bruises him,” his dad has noticed over the years.
“We’re so involved in our son and yet they make no attempt to pick our brain for suggestions to deal with him,” Frank says.

The family plays an active role in Jason’s life at Gracewood and want what is best for him. They know that he loves water and advocate that he goes swimming at the facility.

They have a pool at home, and when Jason comes to visit, Jason gets his swimming trunks and suntan lotion, as indication that he wants to be in the pool.

Jason also loves music which is constantly playing in his room at Gracewood. He especially loves country and Christian, his family says, and enjoys watching music videos. The family has a trampoline, and Jason likes lying on it while someone jumps around him to bounce him in the air.

Jayme, Jason’s youngest sister, says Jason loves go-carts, too. They’ve been to Funville and ridden go-carts around the track. “He likes moving,” Jayme says, adding that he loves hammocks and rocking chairs. “He loves to go; he loves speed,” Cindi adds.

Jason has taken a special liking to his mother’s car: a blue Mustang. He will sit in it for hours and roll the windows up and down, change the radio stations, and lock the doors to keep his family from getting him out of the car. He knows what he’s doing. “He’s so much smarter than he wants you to know,” Jené says.

Lights and lava lamps, colorful attractions with movement, interest Jason, too. Wind chimes and ornaments hang from the ceiling of his room, in constant motion from the air conditioner vent.

Currently, Jason’s family is focusing on his interests and what it would take for him to leave Gracewood and live in the community. As much as they would love to have him at home, they know their house is too small and it would not be feasible for Jason and the support that he would require. Frank dreams of building a bigger home with a soundproof room for Jason, so he can watch television in the middle of the night if he wants.

Jason cannot live in a group home setting because he is fed through a tube, which by policy, requires that a nurse administer his feedings. Frank thinks that this is ridiculous, because Jason’s sisters could feed Jason when they were in elementary school, he says. Right now, the family is focusing efforts on developing a Microboard, with the help of Ruthie-Marie Beckworth, from Tennessee (www.tnmicroboards.org). Ruthie is a PATH facilitator, which stands for “Planning Alternative Tomorrows with Hope.” She has helped families in Tennessee develop Microboards and create homes in the community and support for a family member with a disability.

Recently, Jason’s family met with Ruthie and her husband, Mark, as well as with members of their church and community to discuss the possibility of Jason living in the
community. They discussed Jason’s interests and needs and what it would take to get him out of Gracewood. “I’m excited. I’m thrilled,” Frank said at the meeting. “Let’s get started. Jason deserves it.” The group plans to continue meeting until it discovers a solution to help Jason in the community.

Jason’s family knows he needs 24-hour support, and they know that with a Medicaid waiver, it is feasible. Frank says they are very excited about the PATH option. Through the Microboard Ruthie presented, Jason’s family and community supporters would develop a non-profit organization that would run Jason’s support outside of Gracewood. The Microboard would manage Jason’s caregivers, which appeals to them, Frank says.

Cindi wants more than anything to be the one in control of Jason’s care and has felt a loss for the last nine years having to leave him to the care of others. “He’s my kid…God gave us this boy,” she says, her eyes filling with tears. “[It] hurts me that we’re not the ones that get to care for him,” she adds.

She tries to describe the pain she feels knowing that they were not able to care for their son all these years. “It’s horrible that we were unable to get support from the system that would enable us to give that care,” Cindi says.

The family knows they must have support from the State to help Jason live in the community. It’s past time for Jason to leave Gracewood and have a life worth living, surrounded by people that love and support him, his family says. Frank feels that if the state could provide his family with the funds they provide Gracewood, he could give Jason a much better life in a much better home environment. It’s time, they say.
Peggy was only 15 years-old in 1974 when her first baby, Toney Allen Duvall, was born. Her newborn son appeared beautiful and healthy and no one suspected that anything was wrong until they noticed that little Allen didn’t cry when they stuck him with the needles for his blood test. He didn’t seem to notice the pain at all. Still, no one seemed to know just what was wrong. “They didn’t really talk to me about it,” recalls Peggy. She just knows that her son was sent to Grady Hospital in Atlanta for tests and she was not able to take him home until a week later.

At first the baby seemed to do fine, although Peggy noticed that she had to tip his chin up a little so that he would suck on the bottle. But soon, he was eating less and less and after about two weeks Peggy was afraid that he was not getting nearly enough to eat. She took him to the pediatrician again and again and each time the doctor would tell her that her baby was okay, until one day, the doctor looked at Allen and told Peggy that she needed to take him to the hospital “right now.” Then, says Peggy, “once he got to the hospital, they had all those tubes in him and he just went downhill from there on.”

The baby was in the hospital for a month and still no one seemed to know just what was wrong or how to help him. “It was really rough. Allen still couldn’t eat and he would get dehydrated. The doctors told us different things and everywhere we turned nobody seemed to want to help.” Finally, a doctor told Peggy that Al had a birth defect as a result of the Rubella virus that she had contracted when she was pregnant. He told her that she would not be able to care for her baby and that she would need to find a facility that would care for him.

Allen’s parents did not know what to do. Peggy didn’t really understand what was going on; she just knew that Allen needed care. We didn’t have any money, says Peggy, “and no insurance or social security for him or anything, but, they told us that they knew a place that would take Allen anyway. So they sent him there and after he went to that place, they got him a social security check to pay for everything.”

He Thought I Gave Him Up

Allen at 3 months-old

Allen at 3 months-old

Peggy did not know it then, but once they sent Allen to that facility she would never be able to control Allen’s care again. She would always be on the outside looking in.

The staff at the new facility tried their best to physically and emotionally separate Peggy from her young son. Every time that Peggy would go to see her baby, the staff would tell her that he would not live much longer because babies with Allen’s disability did not live very long. “They told me he wouldn’t live to be two-years-old, but he did. And then they told me he wouldn’t live to be three-years-old. They kept telling me he would die until I finally said, ‘don’t tell me that no more!’”

When he was two years old, Allen was moved to the Georgia Retardation Center in Chamblee (the name of the facility was later changed to Brook Run). “In a way,” remembers Peggy, “I was grateful that they were there – but I think he could have been better taken care of.” In fact, Al experienced a number of very serious injuries while he was a child in Brook Run.

“They said he used to sit in his crib and hit his head on the wall,” Peggy says, ‘because nobody was paying any attention to him – and it didn’t hurt (because Al did not feel pain like other children), so he didn’t stop.” Allen’s face was so damaged by repeated impact with the wall that he would need reconstructive surgery to rebuild his nose.
While Allen was still a small boy, he broke his arm, but again, because he did not feel pain like other children, he didn't react the way other children would. The staff at Brook Run did not realize that his arm was broken for several weeks. By that time a lot of damage had occurred. Allen's arm had to be re-broken and reset and he lost some of his fingers to gangrene.

When Allen was five or six his mother noticed that one of his hands was swollen and blistered when she knew he had been fine only days before. “They told me that he had put his hand in boiling water, and I said, how? He doesn’t even know how to turn on the water!” There was an investigation, but no abuse or neglect on the part of the staff was ever proven. “He used to cry a lot,” Peggy says, “because he just didn’t know what else to do and I know that they used to restrain him by sitting on him.”

In spite of all the dire predictions and the terrible injuries he sustained at Brook Run, Allen survived. When he was old enough to begin to understand what was happening to him, he became a very determined youngster – determined to make other people see him as just a regular kid. “When Allen was nine or ten years-old,” says Peggy, “He was using a wheelchair for little while and I wanted to get a handicapped sticker for the car so it would be easier for him. But Allen wouldn’t hear of it. He said, “No, Mom. We don’t need to park that close, I can walk.”

There are only two things that Allen remembers looking forward to when he lived at Brook Run and those were the two things that would get him away from the institution – going to school and visiting his mother and family every month. Allen went to a number of schools while he lived at Brook Run and when Al was ready for high School, the staff at Brook Run transported him to public school in Gwinnett County every day. Still, he knew that they were underestimating what he could do and he was determined to show them. “I went to a regular school outside of the institution,” says Allen, “and I graduated with my regular class,” (he smiles) “I guess that’s was when the State decided to let me go.”

One day, in 1998, (nineteen years after Allen was placed at Brook Run) he called his mother to tell her that they were closing Brook Run. “We wanted him to come home with us,” said Peggy, “and we asked for that. But they told us that we couldn’t afford to give him the care that he needs. I asked, ‘If you will pay people to take care of him there, why won’t you pay me so I can afford to stay home and take care of him?’ They told me that it was the system. Allen couldn’t come and live at home because that’s not the way the system works. They’ll pay those people but they won’t pay me.”

After Brook Run closed, Allen went to live in a group home. Today, Al (as he is known by his friends) is 35 years old and lives and works in his own community. “I live in a normal setting now,” he says, “I have a regular job.” Al would like everyone to see him as just a regular guy, but his nineteen years at Brook Run left him with a lot of scars and bad memories. Still, he’s a positive person and he tries to think about the good things including his Mom and the rest of his family. Al understands better than anyone how important it is to have a family that cares about you.

“I was lucky enough to know my mother when I was in Brook Run,” says Al, “I wasn’t just left there. I stayed in contact with my family. I was lucky. Not everyone at Brook Run was able to stay connected to their families. I think only about 20% of us were able to do that. A lot of the children that I grew up with went through some terrible times. They were lonely and withdrawn from everyone. They were isolated. Some of them talked to themselves a lot. I think that if more of the children [at Brook Run] had had contact with their families they would have learned to interact with other people more and they wouldn’t have been so unhappy. Lots of them never smiled.”

Al didn’t always have this perspective on what happened to him. “When I was little,” he said, “I didn’t understand why I had to stay in Brook Run. I wondered why me? Where was my normal life?” Peggy says, “Allen thought that I gave him up. And he would ask me why I would do that.”
Later, Peggy tried to explain it all to him. “When I was older,” said Al, “my mother told me that, as a baby, I had trouble eating and sucking from a bottle. I wasn’t getting enough to eat. Doctor’s told my mother that I might die. I did almost die – twice. Mother went to different doctors and hospitals, they didn’t understand what was wrong with me and they didn’t help me. They told my mother that I would probably die. They told my mother that the Georgia GRC (Brook Run) was the only place that could help me, so she had to take me there.”

While Al was able to stay connected to his mother, it was harder for the rest of the family. “My mother came to visit me in Brook Run, says Al, “but my Dad never did. I think he was too scared. He didn’t know what to expect. Maybe Brook Run reminded him of Vietnam because so many bad things happened there and so many people died. Brook Run was like that too. Brook Run was kind of like a prison to me. People got sick and they waited too long to help them and they died. People have flashbacks from being in institutions.”

Al knows about flashbacks. “I get scared sometimes, I have nightmares that I do something wrong and they send me back– but then I remember that Brook Run is closed and they can’t send me back there.” But Al understands that there are other facilities – hospitals and nursing homes – that still incarcerate children and adults and he will not allow Brook Run or any other institution to haunt him without fighting back.

That is why Al is an advocate in the disability rights movement. He speaks at conferences and has worked as a consultant for the Institute on Human Development and Disability at the University of Georgia, speaking to undergraduate and graduate students about his first hand knowledge of institutionalization. Al believes that all institutions should be closed. “I advocate for others so that they can get out and so some people don’t have to go through the same thing I did.”

Al wants everyone to understand the affect that institutionalization has on children and adults. He hopes that talking about his experiences will help him to deal with his own bad memories while it helps to get other children and adults out of institutions. “After I got out of Brook Run, I had to go through a lot of counseling to help me with those bad memories. It helped me a lot but it was painful. Telling my story helps me a lot.”

When I first got out, I didn’t have anybody I could talk to about it and I was still scared. I thought that if I talked about it, people would think that I was lying about what happened to me and other children in Brook Run. But now, I can tell my story and its helps me and it helps other people, because I can tell people how important it is that children have their parents close to them to help them as they progress in life. I love being an advocate.”

Al knows now that his mother never wanted to be separated from him but they both still grieve about the time that they were forced to live apart. A childhood is something that cannot be replaced. Peggy’s advice to parents who are faced with the possibility of institutionalization for their child is: “Find another way - find a way to keep your child at home.”
If I wasn’t Christian’s voice...

Behind a large drum set, complete with a snare, tom-tom, bass, and cymbals, sits Christian Langley. He’s happily pounding away with his drumsticks making thunderous sounds. He hops up to shake hands and then heads toward his computer in the corner of the playroom.

Christian is a nine-year-old boy who captures the attention of everyone who meets him. Despite his young age and the high number of surgeries he’s been through (89), “Christian loves life so much,” his mom, Terry Langley, says.

After Christian has had enough of the computer, he heads toward the living room and hops on his John Deere motorized truck. Christian’s nurse attaches the bag connected to his feeding tube to the back of his truck so he can travel without the wires getting tangled under the moving tires. Maneuvering around his house is not an easy task with the rugs, carpet, furniture, and décor acting as obstacles to the driver; however, Christian knows exactly what to do if he runs into something. He simply puts his truck in reverse, backs up, and heads a different way. He zooms around the living room and into the kitchen, dodging stools, cabinets, and chairs.

Terry says the John Deere truck was his best Christmas present ever and gives him more independence. He loves riding around, inside and outside, and Terry says it has taught him how to problem solve. He knows how to steer and the objective of forward and reverse. He’s even learned to use the truck to express frustration, Terry says, explaining how Christian’s been known to ram it into doorways and furniture.

Christian is constantly on the move during the day. He loves being outside and enjoys swimming in the pool with his floats. He rides the four-wheeler around the neighborhood with his mom and goes camping at Lake Oconee. If Christian could be anywhere, he would be on a boat, Terry says. “He loves to sit behind the wheel of a boat,” she says.

“I don’t want to downplay how medically fragile he is,” Terry says, but “he’s not tied down to an area. We allow him flexibility, choices.”

Christian receives breathing treatments every four hours, and his mom or nurse will set up the treatment wherever Christian is at the time. They do treatments outside or in the car when traveling. “I believe the reason Christian is so well is because I give him a normal life,” Terry explains.

Christian requires a ventilator at night, and his mom says he associates the ventilator with being in bed. If he’s sick, he knows to rest and stay on the vent in bed. “We’re fortunate enough,” Terry says. “He has strength enough during the day that he doesn’t need the vent, only at night.” Most people who use ventilators use them constantly and give into the support, but Terry says she has never treated Christian as fragile and has given him normalcy. “Because of that, I really believe Christian’s will defies statistics,” she says.

Christian is constantly on the move!
When Christian was born, his neck was broken at delivery, and Terry says the doctors gave her a long list of what was wrong with her baby. Terry, a nurse, says she could not see herself quitting her job, and she did not have family nearby to help her with the new baby. She was presented with the option of giving her son up for institutionalized care.

“I probably would have let the system take over if I’d never laid eyes on him,” Terry says. But she did. Prepared with the doctors’ warnings of how different he looked, she held her new son. “Yes, he was different,” she says, “but he was my different child. To me, he was beautiful; he was so sweet. The minute I held him, we bonded.”

Terry gets teary-eyed remembering how she could have opted to give her son away. She is so thankful that she didn’t. And now she can’t picture living any other way. “I couldn’t imagine living without the impact of what he’s taught me…to have compassion for others,” she says.

“He is the most precious, brightest ray of sunshine, who gives meaning to life,” Terry says. “You look in his eyes and if he can get up and give you a smile after all he’s been through, who am I to complain?”

Terry had to leave Christian at the hospital for 17 days after he was born. When he was released, the doctors told her he would be a Sudden Infant Death Syndrome (SIDS) baby, “but because I’m a nurse, I knew the things [machines, medicines] to ask for,” Terry says. “You look in his eyes and if he can get up and give you a smile after all he’s been through, who am I to complain?”

Terry has researched her son’s rare condition, OPITZFG Syndrome, and taken him to the doctor in Salt Lake City who identified the syndrome. To be diagnosed with OPTIZFG, a person has to have six or more characteristics, and Christian has 72, Terry says. She has also found other specialists and has driven Christian to various parts of the country for treatment.

Terry says that she knew her rights as a parent and Christian’s rights as a child with disabilities. When she first came home from the hospital, she had a Babies Can’t Wait referral from the hospital and received Katie Beckett funding. (The Katie Beckett waiver serves children with serious disabilities whose families keep them at home, disregarding the parents’ income and resources).

At one point though, a provider “dropped” Christian before he went into the hospital for a scheduled surgery, and Terry knew not to sign a waiver that would send him to an institution for care. She says she held a press conference at the hospital and refused to take him home without supports.

“I chose to keep him in the hospital for two weeks to demand services because if I’d brought him home, I’d never get services at home,” Terry explains. She knew the hospital could not discharge a patient labeled “medically fragile” without correct supports and resources. “I knew if anything happened, the hospital was liable,” she says. She also knew if she signed the waiver, Christian would have been sent to an institution.

Terry feels that he would not be alive if she had placed him in an institution. “I can’t fathom how much we’ve identified that keeps him alive and gives him a better quality of life…he would have died in an institution,” she says.

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Terry knew the numbers, too: It cost Medicaid $2,645 per day to keep Christian in the hospital because he has to be in an Intensive Care Unit. It would cost $552 per day for a nurse at home.

Finally, after what she described as an awful two weeks of leaving her son in the hospital, Terry brought Christian home with supports in place. The Department of
Community Health implemented a Pilot Program called SOURCE (Service Options Using Resources in a Community Environment), which allows people with disabilities to receive home- and community-based care so that they can stay at home; which is what Christian so desperately deserved and needed. The Model Waiver Christian receives now serves children who use oxygen and ventilators by providing a nurse in the home.

“I don’t ask for anything other than what Christian needs,” Terry says. Currently, she is appealing to Medicaid for the cost of Christian’s supplies. Terry is paying $1,200 a month out of pocket for supplies that Medicaid should cover. She’s been told that “if he’s so needy, put him away,” she recalls. “Over my dead body, I’ll institutionalize him,” she says.

Through the Model Waiver, Christian is allotted 84 hours of nursing support per week at home. Based on prior crises that the family abstained, Christian is not able to utilize the complete 84 hours as Terry wishes. They like having some weekends free of outside interference which increases Christian’s independence, family time and privacy. However, Terry continues to advocate with nursing agencies to be able to fulfill his nursing needs, she says.

At night however, Christian requires medications and respiratory treatments as often as every four hours, which a nurse must administer so Terry can get a full night’s rest and be ready to attend to Christian the next day. On weekend nights, Terry sleeps in her son’s room to administer the treatments herself. Christian sleeps right through the treatments every four hours.

Now, Terry is a part of Georgia ARCH (Advocates for Rights to Children’s Healthcare), a parent advocate group, because, “parents really do know,” she says. She learned from other parents of children with disabilities and learned to advocate and network. She says she knew that, “If I wasn’t Christian’s voice, nobody was.”

“The parents are not asking for the moon and all that,” Terry explains, “just the resources our children need. We know how to take care of our kids best,” she says.

“With the right resources, he can do anything. In an institution, he wouldn’t even be outside,” Terry says.

He would miss out on the constants in his life too, like his mom, Terry says. It’s hard to develop lasting relationships in institutions where shifts change and employees come and go.

“The joys of seeing him get up when he wants to and play are wonderful,” Terry says. “I wouldn’t be able to experience it if he were in an institution,” she adds. “He wouldn’t be as happy. I’m not convinced he’d be alive. He’s so medically fragile.”

At home, Christian receives physical, occupational, and speech therapy every week. He also receives augmentative communication support where he learns to communicate through a computer that the school purchased for him. Christian communicates with pictures and understands some sign language.

Christian attended public school with a nurse when he was younger, but has been home schooled for the past three years because of his
illnesses and number of surgeries. His teacher comes to their home two days a week and Christian loves it, Terry says. “He loves people.” The teacher works with him on fine motor skills, attending to tasks, identifying objects, and using picture boards. He is also learning to tolerate different textures in his mouth.

Looking toward the future, Terry hopes that her son never has to compromise his independence. “Should anything happen to me … that Christian is able to maintain the independence I’ve given him,” she explains. She wants to eventually build a home that has separate living quarters for Christian, she says. “It will be his home. I want him to have his own, with support,” she adds. Terry believes Christian knows how strong his mother is and hopes that she will be an example for him.

Terry says, “life is good” often, especially with the support from the model waiver, but there is sadness in her life as well. Terry’s daughter, Destiny, was ten years old when Christian was born. She says her children loved each other and there are numerous photographs around her home of her children playing together. When Destiny was 17, though, Terry says she ran away from home.

Destiny felt Terry gave more attention to her younger brother, Terry explains. When Destiny was in high school, Terry says she was lenient with her and she believes Destiny became involved with the wrong crowd. Before she left home, Destiny was an honor roll student and a cheerleader.

Terry says she did not have enough support to care for a medically fragile child and attend to her daughter. She wishes that she had spoken with the medical team voicing Christian’s needs so that more nursing hours could have been utilized when Destiny was at home so that hopefully the family could have remained in tact, Terry says. Readjusting Christian’s nursing hours would have allowed Terry to spend more one on one time with her daughter as she would have been able to leave Christian with the nurse.

“I wouldn’t change anything,” Terry says, except she would advocate for more one-on-one time for siblings. Supports are not only for the child, but for the whole family. Terry says she was unaware that the 84 hours of nursing per week did not have to be split into 12-hour days, but that she could have used a 24-hour day or 36-hour shift and spent time with Destiny while the nurses were with Christian.

Terry does not know where Destiny is now or how she is doing. She only hopes Destiny will “realize the roots that I instilled in her and never give up,” Terry says, “because I could have thrown her brother away to society.” Terry says she knows Destiny needs her own time, her own space, and her own identity. She says Destiny was known as “Christian’s sister” which hindered her in making a name for herself.

“I have no regrets other than not using nursing hours to be with my daughter,” Terry says. And “Christian loved his sister,” she adds, glancing over the photographs of the two of them together.

Terry says she considered seeking temporary placement for Christian after Destiny left home, but she’s glad she didn’t go through with it. “Christian is my therapy,” she says. “It would break my heart to know other families are out there not enjoying what I have with Christian,” she adds.

Terry advises other families to keep trying for their children. “You can’t be faulted for trying,” she says. “Always ask questions and insist for answers,” she adds.

“Christian is here for a reason,” Terry says. She and the other parents with Georgia ARCH share the same belief that their children are here to make a difference. “Until you get active, things don’t change,” she says.

“Don’t give up,” she advises. “I don’t care what you have to do and what you have to go through. You are their voice and their vehicle!”
“I figured by now, since 1995, since River’s Crossing closed and Brook Run closed — I thought surely that everybody, at least in Georgia, lived at home,” says Lori Bagnell. In 1995, Lori’s son, Chase, was the first child in Georgia to leave an institution (River’s Crossing in Athens, Georgia) and move into his own home in the community with the assistance of 24-hour caregivers.

Lori is surprised that today, ten years after Georgia’s first child left an institution for life in the community, still more than 150 children live in nursing homes and institutions throughout Georgia.

“I hope to be able to help other children like Chase,” Lori says, “and we cannot have any of them in institutions or nursing homes.”

Lori knows what institutional life is like for a child through personal experience. “I was one of those parents who said I would never put my child away — in an institution or even away from home,” she says. “I was so wrong.”

Lori tried everything imaginable to obtain assistance that would allow Chase to remain in the family home. Chase, who was seven in 1993, had become more difficult and extremely hard to handle Lori says. “I began to seek some kind of help and found out real quick there was not any out there,” she says.

Chase’s teachers were unable to control him and constantly called Lori to pick him up from school. Lori thought that of all people, teachers trained to work with kids with disabilities should be able to work with Chase. She felt she had no where to turn. “Everybody was putting him off on everyone else,” she says.

The school recommended Cobb County Mental Health, but she was sent from there to Cobb County Mental Retardation Center. The doctor there said Chase was “uncontrollable and needed 24-hour supervision.” The doctor issued a 10-13 (an order to admit a person to a psychiatric hospital), and Chase was sent to a hospital.

From there, Chase was transferred to Brook Run, an institution for people with mental retardation. At Brook Run, Lori was told they had neither a place nor a program for a child and could not guarantee his safety.

The first time Chase was sent to Brook Run, Lori did not leave him. The second time, she says she left him for the 48 hours the 10-13 required. At the end of the 48 hours, a man from Brook Run called Lori and told her to come get Chase.

The Brook Run representative said he would call the Department of Family and Children’s Services (DFCS) if Lori did not come for Chase.

Again, Lori felt that she was at a dead end where no one would help since DFCS had instructed her to take Chase to Brook Run.

“People didn’t want to take time or initiative to try and help him,” Lori says. In February of 1993, Chase was transferred to River’s Crossing, 93 miles away from his home and family.

“Everyone was so nice at River’s Crossing, but it was an institution... a lot like a jail,” Lori says. “I couldn’t stand going upstairs. The long hard floors, the cement walls; there was nothing homey about it...a very sad place,” she adds.

Lori drove to Athens to visit Chase at least every weekend. But they avoided spending time in Chase’s room. “The rooms were empty, except for the bed and maybe a dresser,” Lori says. She brought Chase toys, but they always disappeared.

Lori remembers the joy in Chase’s eyes when she arrived for visits. She also remembers the
look on his face when she left, and that she cried as she drove away from River’s Crossing. She could never dismiss the feeling that she had abandoned her son. She carried guilt with her every day and prayed that Chase did not feel unloved and abandoned.

Inside River’s Crossing, Chase’s potty training stopped. He lived on an all-girl floor (“because he was smaller”, Lori says). This was not what Lori and her family wanted for Chase’s childhood, but it was the only support they could get from the state. Chase stayed at River’s Crossing, and Lori continued advocating for a better way.

Lori learned of community-living practices in some northern states. She researched, wrote letters, talked to the press, and made numerous phone calls. Lori went to New Hampshire with employees of the Department of Community Health to examine community placements from a recently closed facility. Lori knew a similar placement could work for Chase. She just had to find the support outside of the institution.

Lori wanted the money that was going to River’s Crossing for Chase to follow him into the community. The numbers were in Lori’s favor. She knew it would cost $75 less per day for Chase to live in the community than in River’s Crossing — a difference of $27,000 a year.

At the time, in 1995, it was not possible for Chase to live with his family and receive support from the state. Determined not to give up, Lori decided that if the state would not provide support to Chase in their home, they’d just do the next best thing, and get Chase his own home in the community.

That’s just what they did. Chase left River’s Crossing on November 15, 1995, and moved into his own home located 17 miles from his family.

“The staff from River’s Crossing was very helpful in making the transition,” she says. Chase visited his new place several times before moving, and his new staff was educated on his likes, dislikes, and treatments.

Chase’s home was located at the end of a quiet street with a fenced-in backyard. The house was modified to fit Chase’s needs. He received full time support and began interacting with others in the community.

His family was close enough to visit often, and Lori usually tucked Chase in bed at night. She says she lay down with him in his bed, until he nudged her, indicating that he was ready for her to leave. Chase was comfortable and happy in his home.

Chase’s behavior and health improved, after his family and provider found caregivers to whom Chase could relate. Chase began going on outings and traveled with his family and caregivers.

On July 15, 2001, when Chase was 15 years old, he died in a car accident. The loss was very hard on his family and his community. Lori says she is grateful that Chase had the opportunity to develop a life outside of the institution for the last six years of his life.

Chase was nine years old when he moved out of River’s Crossing. He had spent almost three years there. While his mother knows the staff did their best, she wishes he had never lived in an institution.

She hopes there are better options for families now. “I tried everything and saw that he was falling through the cracks, and I would not let that happen,” she says.

Her advice to other parents: “I would tell them not to give up. There is something or somebody out there they can get help from.” When somebody says no, advises Lori, go above that person. That was how she helped Chase leave the institution.

As for the 150 children still living in institutions and nursing homes, Lori believes that they should have the opportunity, as Chase did, to live in a home in the community. “One hundred and fifty is not that many when it comes to getting them out,” Lori says. “One hundred and fifty waivers doesn’t seem ridiculous.”

Not to this courageous mother who found a way out.

Dedicated to the memory of
Chase Barrett, April 1986 – July 2001