Building New Lives In The Community

Hopes, Fears and Dreams... one year later

by Dottie Adams, Jo Ann Cox, Gillian Grable, Patsy Sailors, Judy Salmon

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INTRODUCTION

Rivers Crossing locked its doors on June 30, 1996, and became the first Georgia institution to close. It was an historic event. This booklet tracks what has happened to nine of the young people who previously lived at Rivers Crossing. Their stories were selected because they represent families who were both supportive and opposed to community placement, people who are medically fragile, people who have significant behavioral challenges, and people who have widely varying levels of family involvement.

The stories tell the good news as well as the struggles. The facts and quotes included came from direct interviews with the family members, the person with a disability, and the service providers. All the perspectives were important to document.

We acknowledge the willingness of the participants to share their thoughts and their stories in an effort for us to examine the lessons that have been learned over the past year. Their courage and pioneering spirit serve as inspiration to those who dream to have a life outside the institution and those families who are afraid of the change to community life.

The Program on Human Development and Disability staff designed the interview process with the following quality measures and values in mind:

- Dignity and Respect
- Relationships
- Choice
- Control
- Dreaming
- Contribution and Community
- Changing Role of Professionals

The stories are an illustration of the determination, hope and dignity of people who have expanded their horizons and ours by becoming our neighbors, co-workers, friends, and fellow citizens. We hope to follow their lives as they unfold in the various Georgia communities where they have chosen to call home.
"Fear" is the word which comes to mind when Carla's mother recalls how she felt as plans for the closure of Rivers Crossing were announced. She was not sure what she wanted Carla to do, but she was very uneasy at the idea of Carla living in the community. Carla had left her parents' home when she was 6 years old, just after her younger sister was born. Donna, Carla's mother, remembers that their home was in turmoil at that time. Carla was not sleeping at night and neither was her mother. Life was so stressful that Carla's family came to believe that the only solution was for Carla to live in an institution. As hard as it was for them to take this step, it seemed even harder for them to believe that the safety and security they believed to exist in the institution could be provided in a home setting. So many questions went through Donna's mind as she heard about ways for persons with severe disabilities to be supported in typical homes and neighborhoods. She feared the possibility of abuse, feared that there would not be enough staff in the home to watch over and care for Carla, wondered about who would have access to Carla's home, and worried about who would make sure Carla took her medicines. "Safety" was a primary concern for Carla's family and they were definitely against the "community placement" idea. These were the feelings of Carla's family before her move to her home in Augusta. Now almost a year later, Carla's mother sits peacefully rocking in the den of Carla's comfortable and attractive home, and smiles as she says she is "extremely" satisfied with the way Carla's life is going. When asked if she would change or improve anything about Carla's situation, she thought for a minute, and then said that she really could not think of anything she would change.

After living at Rivers Crossing for 16 years, at the age of 22, Carla had a chance to return to living at home—not in the home of her parents, because of the support she still needs and because of her status as a young adult, ready to live away from her family; but, closer to her family—about 35 miles from her mom, instead of the previous 65 miles to Rivers Crossing. Carla and her 3 housemates live in a neatly kept and quiet suburb. The thing Carla's mother says she likes most is the

"I'm extremely satisfied with the way Carla's life is going."
Donna
Carla's mom
Carla moves about at her own pace, enjoying her home in a very relaxed way. On a recent Saturday afternoon when she arrived, Donna said she found Carla taking an afternoon nap on the couch in the den. Donna said it makes her happy to see how comfortable and "at home" she seems to feel in her new situation. Carla seems to enjoy being able to walk into the fenced-in back yard to enjoy the spring weather, coming back in when she is ready. Carla has her own room, attractively decorated and set up just for her, and seems to enjoy her spacious home. At Thanksgiving, Carla and her housemates invited their families over for a delicious meal.

One of the things Donna has noticed and really appreciates is the kindness and caring manner of the staff. She also notes that Carla really has more staff time and attention in her home than she had at Rivers Crossing--2 staff for 4 persons living in the home, during most of the non-sleep-time hours. Carla's life is very full. She attends a service center during days, and is out and about with housemates and staff during the afternoon, evenings and weekends. Carla and her friends gave a Valentine's Party at their home and invited guests. Carla is working on learning to help with household chores. Photographs of Carla performing various household tasks are used to communicate to Carla that it is time to help with a certain chore. She has begun to participate a little bit in these tasks, and staff in the home are very supportive and encouraging to her when she tries. Carla is living in her home doing the things that a normal flow of life brings to her, and she has the support she needs.

"My advice to parents who find themselves facing a similar situation: Go for it; try it. Your biggest fear is fear itself. Go ahead and take the plunge!"

    Donna
    Carla's mom

Carla's mother would be the first to say that providing the right supports to Carla is not something which comes easily and without effort and expertise. Carla is a 22 year old young woman whose life has been complicated by more than just her diagnosis of profound mental retardation. She also has a complex mental illness which brings about troubling and distressing mood swings, self-injury, and physical aggression towards others. Carla's affectionate and loving nature has often been hidden by the cloud of depression and withdrawal associated with her mental illness. All of these support needs are understood by the Augusta Area Community Support Services staff who serve Carla through the funding of the Mental Retardation Medicaid Waiver Program. A year ago, Carla's mother felt fear and uncertainty as she faced the idea of Rivers Crossing's closure, but today she feels that Carla's quality of life has been significantly improved by moving from the institution to a home in the community.
Gladys, Edgar, and I are sitting in the lovely living room of Will’s home chatting and looking out the long, wide windows awaiting the arrival of the school bus. Soon, Edgar bounds up with a “there it is” as he exits the door to meet Will and his housemate who are returning from the local public high school. Will’s home is located in a fairly new, neighborhood in Winder, Georgia, within five miles of his parents, Carol and Bill.

Will was rolled through the door with a big smile on his face and a twinkle in his eyes. He has always had an expressive face from which one can read many emotions.

Gladys welcomes the ‘guys’ and Edgar enters the kitchen where a homemade milkshake, just prepared, is waiting for after school snack. He sits with Will and talks as the milkshake quickly disappears. There is also orange juice from cold, fresh squeezed oranges. Both of these are daily treats readily available as are his care providers with their smiles and loving greetings.

Will is a 19 year old with severe physical disabilities that render him essentially unable to walk, talk or to care for himself. He is totally dependent upon others to meet all his basic needs. However, he is very loving, knows what he likes and dislikes, has distinct preferences and lets you know what these are. He is inquisitive and loves exploring his world. Gladys says, “He has learned many things and our challenge is to help him learn many more.”

Will is medically very fragile and requires constant 24 hour care. When Will was five years old and his family could no longer provide this care, they sadly placed him in a local nursing home, as there were no other resources available. In 1987 he moved to Rivers Crossing, about 30 miles away from home. During his eight years at Rivers Crossing he required major surgery on three occasions with two of the procedures involving lengthy recovery with physical therapy. He also suffered a fractured clavicle and had numerous injuries. He was vulnerable to anyone who was overly active or aggressive due to his inability to move his wheelchair out of the way. The family could see that this was not a safe place for Will.
Will's mother, Carol, learned of a study tour group going to New Hampshire to visit some established community homes for persons with disabilities like Will's. She joined the tour and witnessed supported living working. She returned home with a renewed vow for Will to have that kind of life. Carol went to work making this happen and pressed for development of community alternatives for persons in institutions. As Rivers Crossing closure discussions began, funds were allocated and the family chose Georgia Options to support Will in his new home. Will's parents participated in every aspect of the planning including interviewing support staff. Carol was determined that Will should have a safe and secure home in his community.

A local contractor built the home specifically for Will with modifications for his wheelchair. The contractor now rents the home to Will. His parents approached the contractor with this request and not only did he agree, but he allowed them to help select the lot on which it was built.

Two of Will's real pleasures are freedom of movement and 'outside.' The great room/eating area is spacious and the furniture is arranged to permit him to move about freely. The windows are wide on each side of the door and reach low to the floor allowing him to easily see outside.

He has his own bedroom and sleeps in a regular bed for the first time. At the two institutions, he slept in a large padded 4-sided play pen type bed due to fear of him pulling up and falling. Will did not like a lot of touching initially and sometimes appeared fearful. Now, he loves to be touched and enjoys the playful tussling. He laughs and smiles most of the time.

Will likes to 'help' in the kitchen where he watches Gladys and knows that when the table is set, it's time to eat and he goes to the table. They know his favorite foods and some are served daily. When he's tired he goes to bed and when he awakens, he has a morning bath and begins his day.

Initially, Will would roll his chair to the TV and push on it. He would pull the chairs out from the table and pull over the tall house plants. Gladys says, "We had to teach him this is furniture, you leave it alone and this you can play with. Now he does not bother the chairs, hit the tv or pull over the plants."

Will attends the local public high school and is totally integrated into the community. He is accepted in his neighborhood and enjoys his neighbors. Will goes to the
Will grocery store, goes shopping, and enjoys eating out at least once a week. He bowls and soon will start swimming.

Carol states that Will is the healthiest that he's ever been in his life, he's eating well and does not require supplements as previously. This winter both Edgar, Gladys, and his housemate had the flu; Will did not. In the past he had constant upper respiratory infections and took numerous antibiotics. There have been no hospitalizations and he has had no injuries. Finding medical and dental services based on Medicaid coverage was somewhat challenging, but has been successfully arranged with local community practitioners.

Carol has this advice for others pursuing community placement:

1. Go for it, it works!
2. Select a care provider that you feel comfortable with, and who responds to your requests and attacks problems without delay.
3. Staffing is the most critical issue; be involved and stay on top of it.
4. Have your family person close to other family members so they have a fuller, more involved family life.

She says, "You must be strong for your family person who is not strong. Everything has been positive. I wouldn't change anything. Will is healthier, safer, and happier." Carol states, "Community living provides a quality of life that institutions can never match."

Will spends a lot of time outside and goes for strolls in the neighborhood. He sits and watches the movement in the trees and listens to the birds sing in the sunshine. Inside, he plays with Edgar and watches his favorite TV show, "Oprah". Sometimes he "sits on the sofa with us and with his arms across our shoulders and we're like....you know, family."

Carol sums up her feelings with "Will has a wonderful life and we have peace of mind."
Home, At Last!...Jason's Story

It was near dusk when I pulled into the driveway of the house. It was a neat wood stained house similar to others that were on the street that ended in a cul-de-sac. I was met at the door and relieved of pizzas, drinks, and cookies by Jason and his personal support staff, plus two friends. All were present for our pizza 'get together.' Jason went into the kitchen, got a plate, selected his pizza choice, put ice in a cup, poured his Pepsi, and returned to the living room. He sat on the sofa beside his friend as we all ate, talked, and socialized.

When he'd had enough and was becoming restless, using a communication board, he told us he wanted to go for a ride. We went to the car, he opened the back door, got in and fastened his seat belt. We turned on the music and enjoyed this quiet time at the end of the day.

This was a culmination of a fantasy beyond his family's wildest dreams. Entered into with a great deal of anxiety, fear, and a tremendous amount of planning, but with the belief that with the right supports, Jason could live a fuller, freer, more independent life in the community with greater happiness.

Jason left his family for placement in an autistic group home at the age of six. From there he went to a state mental health hospital before being placed at Rivers Crossing in December 1983. It was anticipated that Jason would probably spend the rest of his life in an institution. He was considered to have such complex problems both medically, with uncontrolled seizures and behaviorally, that no other alternative would be possible. Indeed, he presented many, many challenges to all the specialists at Rivers Crossing. Many felt the community placement was doomed and genuinely feared for Jason's safety.

In medical lingo, Jason suffered from a seizure disorder, mixed type, autistic disorder with severe self injurious behavior, dysthymia manifested by crying episodes, decreased energy, decreased motivation, and decreased concentration. He functioned at the profoundly mentally retarded level, was non-verbal and visually impaired with essentially no vision in

"I think it's wonderful. I don't have to worry about how things are going. Everybody keeps me informed. At first I had my fears, but now I am very satisfied."

Sylvia W.
Jason's Grandmother
one eye. He has ear deformities from the self injurious behavior with frequent bouts of external otitis. He also experienced allergies that greatly exacerbated his hurting himself.

Jason has now been in his home about 8 1/2 months. When asked do you like living here, he immediately with facial emotion nodded up and down with a definite "yes." In his home, there are 24 hour awake personal support staff, all of whom had previous knowledge of Jason. Some transitioned out of Rivers Crossing with Jason and others joined later. They had previous training that allowed them to understand how to respond to the behaviors that are part of his autism, namely, his tremendous fears and anxieties that result in the self injurious behavior and his need for external psychological supports and his restraint dependency.

Jason has full medical supports in the community that include a physician of family practice, a psychiatrist who sees him at least monthly, an ophthalmologist, and a community dentist. Others have been identified but not yet needed - an ENT and a neurologist.

Jason makes choices within the context of his home, community, and relationships. When he gets up, he picks out his clothes, gets dressed, and walks out of his bedroom many mornings with no restraints. He watches his favorite television program and goes out to movies of his choice. He chooses when its bath time and when its bedtime. He often selects what he wants to eat. When he wants eggs for breakfast, he goes to the refrigerator and gets out eggs. If he wants cheese in them, he gets out the cheese. He lets you know he is hungry by going to the kitchen and getting out the skillet. He then helps with cooking. He goes to the grocery store, to the mall, and enjoys eating out several times a month. He is presently waiting for his friend, Michelle, to go with him to 'Star Wars'. He also enjoys his own tv and stereo.

Jason is doing volunteer work in three different locations in the community as a part of his job training. He loves "the earth" and soon is going to begin training in a greenhouse.

The challenges that existed have not disappeared in the community. He still faces every day frustrations and needs his personal and emotional supports. He is still comforted by his restraints, gloves, baseball cap, etc. However, he now is free of restraints at night and about 1/2 of each day. As he becomes more independent in meaningful activities and continues to learn to trust and feel safe, this dependency will hopefully decrease.
"Jason has let us know that he wants his circle meetings to be about friendship. He does not want it to feel like work or a staff meeting. It is about helping him enhance his life with meaningful activities and relationships. That is what is important to Jason."

Judy S.
Circle Member

There have been problems but his provider, Options in Supported Living, has shown a sincere commitment to making life better for Jason through community living. The initial staffing pattern of a live-in companion who slept at night did not work and Jason left the house on two occasions but was returned without negative consequences. There is now 24 hour awake staff. There has been some staff turnover, but his primary care staff have remained consistent.

Jason now has a case manager and a service coordinator who work for him. He also has a circle of friends as his personal agents. This circle consists of family, particularly his grandmother, his personal support staff, his advocate, and friends. Jason is the focus of the monthly meetings. Progress is reviewed and new plans are developed with Jason having as much control, independence, and choices as possible. This group has had a tremendous positive impact in making his life in the community successful.

Jason is still Jason. There have been no miracles. But he is learning about real life in the community. Those who know him best all agree that more of his personality is coming out, that he is happier, and has more periods of really good moods. He smiles often and is communicating more using his board, signs, and gestures.

Most important, when I asked, "Jason, do you like living here? Are you happy that you moved out of Rivers Crossing?" He responded with an instant, non-prodded signed, "Yes! Yes! Yes!"

Jason and Ann
"Everything is 100% better," says Mr. Bennie Roberson.

"Everything in this house is his...It's not like being in jail any more," says Alicia Lester.

"Joel's high school classmates are jealous of his home and dream about living on their own some day," says Cynthia Harris, Joel's teacher.

Bennie, Alicia, and Cynthia all knew Joel very well while he lived at Rivers Crossing. They have all remained involved in his life. Bennie and Alicia both work with Joel in his new home as staff hired by Mentor, Inc., a private corporation which has the responsibility to meet Joel's residential needs via a Medicaid Waiver.

Before Joel's admission to Rivers Crossing in 1992, he had developed a complicated manner to meet his needs. He inconsistently used a variety of communication systems (manual signs, pictures, and gestures); but he consistently displayed a variety of inappropriate behaviors, many of which were very dangerous to himself and his family. Although he is still inconsistent with his communication systems, he is now individually supported in his own home where the staff working with him have the time to figure out what Joel is trying to communicate. The inappropriate behaviors are much less frequent and much less severe, and it has only been nine months since he began living in his own home.

As Joel was leaving Rivers Crossing, the residential provider, Mentor, Inc., investigated a variety of placement options. A very caring and experienced family with lots of room and land for Joel to explore was chosen for Joel to live with. Joel's mother, Cindy, was concerned about this option fearing it was too much to ask of a family, but her discussions with Mentor gave her the confidence to give approval for a trial visit. Cindy doubted that Joel would accept a family-type situation. Well, she was right and Joel very quickly communicated through his actions that this was not the right option for him. Mentor very quickly began
"My favorite part of being in Joel's Circle was when we got together in December and took Joel to a tree farm to pick out his own Christmas tree. Joel walked over acres of land till he found just the right tree. With support, he sawed down the tree and held tightly to it as we rode the hay wagon back to the car. He signed "saw," "tree," and "blinking lights" repeatedly. How nice to be a part of helping Joel develop his own holiday traditions!"

Dottie A.
Circle Member

developing a new alternative, one uniquely designed with and for Joel.

Joel's transition has been immensely aided by an active Circle of Support. It is a group of 10-12 people who work together to assist Joel in his pursuit of a satisfying life. Dottie Adams, his service coordinator from Community Support Services, staff from Mentor, ex-Rivers Crossing staff, his family, his public school teacher, and others meet monthly to not only problem solve big and little challenges, but to applaud and celebrate Joel's accomplishments.

The first few weeks were very intense and members of the Circle of Support were called on to do many things -- including spending the night or day to assist the staff in supporting Joel through a very rough transition phase. Without their help, Joel may have required temporary re-admission to a state institution while resources were further reinforced. Joel's Circle of Support continues to be a major strength in his life.

Everyone who knew Joel before and after his transition to community life has noticed positive changes in him. They comment that he seems proud of himself and he has grown in his sense of responsibility. Joel himself indicates that he does not miss living at Rivers Crossing. He signs he is "finished" with Rivers Crossing.

He likes his house, especially the kitchen. He proudly draws visitor's attention to his refrigerator, opens the door, and holds up a gallon of chocolate milk with a big smile on his face. This truly is Joel's home....and he knows it.

Joel loves to cook on the grill!
Saying "Yes" to Adrian

When Mrs. Parkins took Adrian for his first medical check up after leaving Rivers Crossing the doctor said to her, "This child belongs in an institution." Mrs. Parkins, Adrian's mentor remembers, "When I heard this I felt a whole heap of tears come up from inside. Why isn't there anyone to say 'yes'?'" Adrian, a dark brown haired, 15 year old young man with inquisitive eyes has lived with Mrs. Parkins for 10 months on a quiet street in south DeKalb County. Mrs. Parkins says, in a lilting voice that reveals her Jamaican heritage, "When Adrian first came to live with me, he would touch everything. I had to move his dresser drawers to the den because Adrian would climb on top of them. Now I can leave Adrian to watch tv or outside in the back yard." Adrian shares a bedroom with David, a teenager who has lived with Mrs. Parkins for several years.

Adrian went to live at Rivers Crossing when he was seven years old. Donna MacPherson, who worked at Rivers Crossing remembers, "When I met Adrian he was my first heart." After Rivers Crossing closed Donna found a job with Georgia Mentor, Inc., the provider chosen to serve Adrian. "When Adrian first moved from Rivers Crossing he had difficulty sleeping at night and he would take off his disposable diapers. He was tearing the mattress cover off his bed, coloring on the walls and breaking telephones. The mentor we first selected for Adrian to live with didn't work out. Since he has been living with Mrs. Parkins she has provided him with the structure he needs so that he feels calmer and makes attempts to communicate through signing."

Adrian enjoys Mrs. Parkins cooking, especially her bread pudding, and has learned how to chew his food more completely. Through careful and respectful communication she has taught Adrian how to take out the garbage, put his dishes in the sink and to pick up after himself. He has learned how to use a hand held shower to rinse himself off and to dress himself almost completely. They go to the mall on Saturdays where Mrs. Parkins shows him how to say "Hi" to people without grabbing them. Adrian and David often sit arm in arm on the couch together like brothers and watch tv. Adrian enjoys going out to eat several times a month and to the evening service at church where church members greet him every week. When he takes a walk with Mrs. Parkins in the neighborhood, he now waves at the neighbors, instead of grabbing them.

"Mrs. Parkins never communicates frustration to Adrian. That's important. We've provided her with training, respite support every weekend and emergency people as back up if Mrs Parkins needs it. We have been able to find more individualized medical care for Adrian than he was able to receive at Rivers Crossing. The medication he is now taking helps him sleep at night."

Donna
Mentor Coordinator
Donna describes the difficulty Mentor experienced in finding the right person for Adrian to live with. "We had to find someone who was not scared of Adrian; if he thinks someone is scared of him, he pulls out all kinds of behavior. Adrian used to rush out to cross a street and plugged things in and out of electrical sockets. Adrian needed someone within arms reach of him all the time initially. He would take anything to eat or drink from anyone, or go with them anywhere. We rearranged his home so that sharp or electrical objects were out of reach, and put the furniture in places where he could not climb up to reach things that were dangerous to him. Mrs. Parkins sewed the mattress covers together so he wouldn't rip them apart. We've bought Adrian a variety of things that he can use actively to focus his attention."

His high school teacher, Mr. Anderson, comments, "When I first saw Adrian at the beginning of the year I thought 'wild kid.' Adrian didn't know how to interact with people without grabbing; now he shakes hands with people he meets. He is beginning to use more signs for going to the bathroom, ice cream and tv. When we get a computer for the class, I'll be interested to see what Adrian can learn with it." Adrian's class goes on field trips several times a week to the grocery store and the mall.

Donna feels that Mr. Anderson's classroom of older boys provides the challenges that Adrian needs to learn. Students without disabilities from other classes come into his room at various times of the day to help. My proudest moment was when Adrian signed that he needed to use the toilet and actually used it! This means that he is communicating he has a need effectively. He is learning how to remain in his seat and stay with a task."

Mr. Anderson also provides respite for Adrian every weekend. "When Adrian is with my family he knows the rules. He asks to go into another room and goes everywhere with me and my three children. He watches what they do and plays games with them. When we're sitting down to eat, he prays along with everyone else."

Adrian's eyes light up when Mrs. Parkins' son comes to visit and gives him a "high five." Adrian's life now revolves around his home and neighborhood, his school and community, his church and camp in the summer. His love of being physically close to people has been mediated by adults who help him to approach others in a respectful way. As Adrian's home has been made safe for him, he has gained the freedom to express himself in positive ways. Adrian now hears the 'yes' of people who love him.
Before it was announced that Rivers Crossing would be closing, Deborah was talking to legislators trying to find a way to bring her son out of the institution. While he was in Rivers Crossing, she was faithful about visiting Dexter and brought him home for weeks at a time, but she was not certain if she could handle it full time without the right supports.

Dexter has a history of eating things that are not edible and it has been life threatening at times. During his nine years at Rivers Crossing there were several times when he needed medical attention due to his swallowing objects. This problem was one that was discussed at length as the plans were made for him to go back into the community. New staff had to understand how important it was to watch him continuously...his life depended upon it.

Deborah waivered between the time Dexter's futures plan was done and it was time for him to move. Her heart told her that she wanted him back home to live with her. She had several years of parenting to do that she had not finished. She was afraid of whether or not she could handle it. She remembered the difficult times when Dexter had tantrums and would break windows. Times when he refused to eat more than one meal a day. Times when the school bus drivers said that they couldn't handle him.

She decided that since he was 21, she would ask that he be placed in a home in the Gwinnett-Newton-Rockdale area since that was near where she planned to move. She went to a provider fair and met many providers. She asked questions. She listened closely to their answers. She talked with trusted staff from Rivers Crossing who knew what it took to care for Dexter. She took all she had learned and made a decision about LADD being Dexter's provider. Dexter moved into a group home setting on May 15, 1996.
"The Rivers Crossing staff were helpful in sharing information. It helped having start-up money so we could hire staff early. We made several visits to try to get to know Dexter, but you really don't know someone til you live with them."

Paul B.
LADD

In July, Dexter was hospitalized in intensive care due to his swallowing a rag or part of some shoe inserts. His life was at risk. Deborah agonized over the thought of losing her only son. Dexter went through surgery and pulled through. She took him home to recuperate after his three week stay in the hospital.

It was during that time that Deborah listened to her heart. She wanted to bring Dexter home to stay. She met with Dave Mansell at LADD who helped her think about what support she would need to make it a reality. It was something that Dexter and Deborah had wanted for years.

Now Dexter is at home. He has support staff who come and take him out into the community. He loves to go the park, to the library, and out to eat at restaurants.

He has good medical supports who understand his needs. The hospital is familiar with him and Deborah doesn't have to explain his medical issues every time.

As far as Dexter is concerned, he is as happy as he could be. He has put on a few extra pounds enjoying mom's home cooking. He is calmer and quieter. He used to be bothered by the crowdedness and noise of the institution. He is more easily redirected. He is even talking more than he did before. His family has taken precautions to lock up things that he might try to eat. Deborah says, "It is better than I thought it would be." And that look on her face says, "My son is home where he belongs."
Marlon, a tall 18 year old young man, has settled in a pretty red brick house on a quiet street in Gray, at town near Macon. Marlon moved out of Rivers Crossing about ten months ago. His father, Joseph, speaks of the circumstances that led Marlon to live at Rivers Crossing: "As a child he used to bite, scratch, pinch, and grab anyone."

Marlon is Joseph's youngest son. Marlon's father, his older brother and two sisters were able to make the two and a half hour trip from Macon to visit Marlon several times a year, during the 10 years Marlon lived at Rivers Crossing. "When I couldn't get to see Marlon at Rivers Crossing like I wanted to, it bothered me. I feel great with him coming home because I get to see him more. I took the whole family out there one evening on Marlon's birthday, Valentines Day. Linda, his sister, lives in Gray so she can visit any time she wants.

"I was worried when they told me Marlon would be leaving Rivers Crossing. I didn't know if I could trust people who would take care of him like I had trusted the staff at Rivers Crossing. I worried about someone breaking into his house and if he would get his medication on time. I wanted him to remain at Rivers Crossing because I could rest at night knowing he was protected there. But the Rivers Crossing staff introduced me to different providers and I went to visit people they served. I decided Star Choices could serve him better because I found out they had a good reputation in the community. They take him to the doctor, stay with him overnight and keep a close eye on him. They really like Marlon; it's more than a job to them. I'm still concerned about Marlon hurting someone else or someone hurting him who doesn't understand him. His feet are unsteady and he falls sometimes."

Although Star Choices was not involved in the personal futures planning held with Marlon before he left Rivers Crossing, Ellen Goddard and Kinsey Walker from Star Choices learned from the plan Marlon's vision for his life in the community. Ellen describes what Star Choices did in a couple of months to prepare themselves to welcome Marlon into the community.
"We had visited four or five times with Marlon before he left; we stayed all night with him at Rivers Crossing and had an opportunity to talk with the staff who knew him well. We learned that Marlon wanted a house on one level with a front and back yard and a carport. He wanted a full pantry, a VCR and TV, and his own room with a double dresser without a mirror."

"We showed Marlon several houses he could rent and the one he chose has a back yard where he can put up a tent when he wants to sleep outside. He wanted to lose weight and in 10 months he's lost 20 pounds. Marlon goes grocery shopping several times a month and staff help him select food he likes to eat."

"Marlon wanted to have people around him he could trust to keep him safe. During the interview sessions with potential staff, Marlon would let us know if the man we were interviewing was big enough and fun loving enough to suit him. The guys who spend time with Marlon go over and visit with him on their days off. It's working because Marlon chose these guys."

Ellen and Kinsey notice that since Marlon left Rivers Crossing "he's able to be around crowds now; he goes to play ball, dance, cookouts and camping." Marlon no longer uses the straitjacket he wore at Rivers Crossing; it's been a learning experience for the staff who support him to know what makes Marlon upset to the point where he feels like he has to be restrained. Ellen observes that "It's a challenge to keep Marlon and other people safe and at the same time not restrict his choices. We've learned to pay close attention to his facial expressions and when he gets too quiet we know he is beginning to feel agitated. We help him to get a lot of exercise and when he shops or goes out to eat, two staff members are with him. We know when he says, 'I'm ready to go' that he means it."

Marlon spends his days visiting with Veronica, a neighbor who comes by every morning to greet him. Sometimes she cooks for him and takes him shopping; other days they sit in the carport. Marlon enjoys going over to the homes of friends he has met through the men he chose to support him. Last week a lady who lives across the street came over to introduce herself to Marlon and asked if she could drop by sometime. When he's feeling good Marlon laughs, jokes and calls out "heh" to the mail carrier and people who walk by his home. He likes to go to Checker's to get a hamburger and french fries and eat them in the park in Gray.

For Marlon the biggest change he's experienced since he left Rivers Crossing is having the opportunity to vacuum his home, shop, go to basketball practice with the guys, and "whistle at the girls."
He is learning how to help out with cooking, cleaning and keeping his house tidy. He enjoys seeing Mook, Bug, Karen and Tony (his family) more. He now chooses when he goes to bed, when he eats, the clothes he wears and when to take a bath. He says it's quiet at night and that he likes sleeping in his own bedroom. Marlon speaks of the men he chose to support him: "Dean, he's big and helps me go places and helps me when I fall. Willie jokes with me and rents movies I like." Sometimes Marlon says he feels empty inside. He wants a job at a car sales lot. Ellen took him to a car lot to show him the kinds of jobs available but he said he didn't want to wash or clean cars to get them ready for sale.

Ellen, Kinsey and their teammates Pat and Clara have pulled together a Circle of Support that currently meets twice a month to brainstorm ways to help Marlon feel safe in his community and to find him a job. The Circle includes everyone from Star Choices who spends time with Marlon, his neighbor and the Sheriff and Deputy Sheriff in Gray. Ellen, who facilitates the Circle meetings, comments, "Everyone in the Circle has committed to call people they know to find a job for Marlon. The Deputy Sheriff visits Marlon regularly and at times when he's upset, helps him get focused without calling an ambulance or the police."

"After Marlon grabs someone, he hits his head against the floor and says 'I'm sorry.' You have to love Marlon to put up with your fear of being hurt. As a team we've learned that we can dig down deep and still prevail."

Kinsey W.
Star Choices

On one occasion in the past (before the Circle was established) Marlon was not able to control himself and the police took him to a hospital emergency room. Once there, a hospital intern sent Marlon to Central State Hospital in Milledgeville. During the three months Marlon spent at Central State, Star Choices staff drove almost daily the hour long trip to visit him and to advocate for his return to community living.

Star Choices staff are constantly listening to "hear" what direction the team needs to follow in order to support Marlon. They are listening to the men who support Marlon so that they don't experience "burnout." Two of the men whom Marlon chose 10 months ago are still with him. Ellen feels that the choice to schedule the men for no more than eight hours of support at a time with Marlon has made a difference. The men feel supported by Star Choices in the decisions they make with Marlon on a day to day basis.

Star Choices is trying to help Marlon understand himself and bond with other people in his community. Keeping him, as well as others safe has required Star Choices to reach way down inside themselves -- way beyond their fear of being spit upon or hit by furniture, scratched or grabbed -- to find the place where they can stand in solidarity with Marlon.
So often we buy into the reasons not to try something new or different; so often we settle for less than we can and should expect and strive for. Judson’s adoptive parents just would not let that happen for him. Judson, soon to be 19 years old, had lived in a state institution since he was 4 years old. The state (through DFCS) had severed all parental rights as Judson was admitted to Rivers Crossing. Judson had never known the nurturing presence of parents in his life. Then, two wonderful people, Kevin and Karen, came to work at Rivers Crossing. Kevin came to know Judson in 1987, while working at Rivers Crossing in provision of daily care giving supports to Judson and his dorm mates. A bond began to grow between Judson, who never spoke using words, and Kevin who was jovial and always had a joke or greeting for everybody. Karen, a special educator with a knack for seeing beyond the easy and obvious, came to Rivers Crossing in 1989. Life created a wonderfully combustible mixture when Karen, Kevin, and Judson were brought together. An explosion of powerful relationships and love have been the result. Kevin and Karen were married on 6/13/92, and Judson was a groomsman in their wedding, handsomely attired in a tuxedo. Judson’s participation in this special moment for Kevin and Karen happened in spite of Judson’s need for one-on-one support within arms reach. (His seizures and unpredictable falls to the floor were so challenging that Judson required a person standing next to him, prepared to help him, if needed, at all times.)

Shortly after their wedding, Karen and Kevin moved to Augusta so Karen could begin attending the Medical College of Georgia to become a physician; but Judson continued to experience their love and their visits. Every chance they could find, they made their way to Athens to visit “Jud” and to take him to his favorite pizza place, “Mama Sid’s.” Within a few months, Karen and Kevin began to ask questions about how to go about becoming Judson’s legal parents, and on 3/24/94, Judson was adopted -- legally, officially and forevermore their son. At a party in Augusta, he celebrated his new identity, his new opportunities, and his new life with those who saw a glimpse of the future for him. From that point on, Karen and Kevin knew that they would not rest until Judson lived in the community with them--in a situation uniquely designed to meet his intense support needs.
and to fully acknowledge his personhood. And so, the explosion based in belief in the power of relationships continued, as Kevin and Karen continued to develop Judson's future along with their own. As they looked to the future, they saw Karen in medical practice and Kevin in recreational therapy practice--roles in the community where they could shape the definition of supporting people to have life in it's fullest measure; and they saw Judson there with them, making his contribution along with them. Today this is a reality. Judson moved out of Rivers Crossing to live in the Augusta community on May 9, 1996.

Recently Karen told a story about how some of the medical practitioners around her in her pediatric residency are re-thinking the way they view serving persons with profound mental challenges, and she credits her son's presence in her life and in the community with this. If she, Kevin, and Judson had not lived the reality of seeing beyond the disability to the person, she could not have impacted the medical community in the powerful way she now does on behalf of all persons with mental retardation. Karen, Kevin and Judson are a team and they are proving that all persons have a valued role in the community. Judson is a person with significant disability issues-- a diagnosis of profound mental retardation, a very fragile and serious seizure disorder, and a need for total support in activities of daily life. What Kevin and Karen and many who worked with them to help plan for Judson believe is that none of these issues should keep a person in an institution. Judson and other persons with similar challenges need community life and communities need their gifts and their friendships.

Judson lives today in a peaceful Augusta suburb of brick homes, near his parents. He lives with three housemates who share expenses, and they often do things together for fun. A church nearby has a community-wide party one Saturday a month, and Judson likes to go. Judson and his housemates all need support which is provided by staff who work in shifts. Staff cook meals and attend to the running of the household, in addition to providing safe supervision and attention to Judson's personal needs. Judson does not communicate using words and it is important for staff to be attentive to how he demonstrates his needs and preferences. Judson's home is a warm, friendly and comfortably decorated place, and Judson's room is furnished with a beautiful dark cherry double bed and matching pieces.
Judson's mom says, "The best part is he has his own room; he has his own stuff and nobody messes with his stuff. He has lots of stuff that belongs to him and he has control over it."

Judson attends Greenbriar High School and he attends the after school and evening functions which teenagers enjoy, such as the football games and an evening pizza party. He has found a favorite restaurant in Augusta--CiCi's--a place with a pizza buffet, and he goes there with his parents, staff, and housemates. Kevin says he thinks Jud would like to attend some musical concerts--maybe Jazz or MoTown. There are still some services which Judson's parents are working on securing, such as speech therapy and dental care. They are still pursuing this and see some possibilities emerging.

The dream of having Judson in the community is a reality. Kevin, Karen and Judson would probably say that their story does not mean that life is perfect, but it illustrates that achieving a good life in the community for a person with significant cognitive and medical disabilities is a journey worth traveling. Recently, as Karen and Kevin told their story again, Judson was with them, sitting peacefully in his favorite soft arm chair in their den, with the backyard pool visible behind him through the glass doors. Karen and Kevin have a strong desire to relate their story and their hope to other parents of persons whose disabilities are at the most taxing end of the spectrum. Karen says, "It's the relationships which really count; it is the people who make it work or not, no matter what the needs of the person being supported are."

Kevin and Karen are so pleased to have Judson closer by
Family Support Makes It Possible - Lakeisha's Story

Their voices filled with emotion, Eddie and Althea Parker describe their efforts to get help for their 18 year old daughter, Lakeisha. "We called everyone we could to get help. We started when Lakeisha was four; the Macon School for the Blind would not serve her because we didn't live in Macon so she attended a school for children with disabilities in DeKalb County. Some of the problems she developed were because of the situations she was in. She had to ride two or three hours on the bus to school in a strait jacket and she was placed in "time out" a lot during class. The summer Lakeisha was thirteen her body was becoming a woman; she was at home during the day with our younger daughter Latoya and our son Jonathan who were trying to take care of her. She was a danger to other people and herself. The day she broke a fifty-five gallon fish tank was the last straw."

Althea remembers, "I didn't want to lose it and strike back at my child. The social worker from the school presented Lakeisha to the MATCH committee and they recommended we file a "deprived child" order. We had to go to the jail with the prisoners to file the order. We had to give up custody of our child to DFACS to get her help. My husband was allowed to ride in the police car with Lakeisha to Georgia Mental Health Institute. When they got to GMHI they asked him, 'Why didn't you institutionalize her before now?' We never wanted to put her in an institution but Lakeisha went to Rivers Crossing when she was thirteen.

"Rivers Crossing was an hour and a half drive from our house but even though we both work full time we went to visit her once or twice a month. Everytime we left her after visiting it was hard; we got to the point where we didn't say good-bye because it would upset her so. We bought land in Newton County thinking we would move there so we could be closer to Rivers Crossing. When we heard they were going to close we were upset thinking about all we had gone through to get her what she needed."

Eddie describes how he and Althea interviewed five providers and visited the homes of people the providers served in order to choose what they wanted for Lakeisha. "We want a
"Lakeisha has an understanding now that she has a right to make choices; she's not Momma's little girl anymore, she's a young lady. She's matured a little - she doesn't think of herself as a little girl much anymore. Since she has more choices she's learning what she wants and doesn't want to do." 

- Althea Lakeisha's mom

Althea describes her feelings during the frantic two weeks the family and TOPS had to prepare for Lakeisha's move. "I saw a dream come true I thought would never be fulfilled for my teenaged daughter. I knew I was never going to see Lakeisha walking down the steps in her prom gown, but never did I think I'd be shopping for my daughter's new apartment! I told everyone in the store I was shopping for my baby's new apartment. I didn't think she would be the first one to leave the coop."

Althea and Eddie chose an apartment twenty minutes drive from their home and was close to shops, movies and other activities Lakeisha enjoys. Eddie comments, "We put dead bolts on the locks and now I can say my prayers and go to sleep at night knowing she's okay." Monica Terry of TOPS comments that initially a staff person served as a live in companion for Lakeisha. "Although we had met Lakeisha and talked with her family for several months before she left Rivers Crossing we were notified that the budgets were ready two weeks before the date she was moving out. We went through several staff changes trying to find the right person to support Lakeisha. Every time a staff person changed it was very difficult for her. We meet monthly with her parents and it was their idea to hire her grandmother and her aunt to provide support for Lakeisha."

Lakeisha walks with her Aunt Shannon outside on a wide park in the center of the apartment complex in Conyers where she has lived since she left Rivers Crossing. Shannon reflects: "Lakeisha loves to run, shoot the ball and dance so we spend a lot of time in the park. Sometimes the neighbors come over to visit and all the children in the complex know Lakeisha's name." Lakeisha rents her apartment with her grandmother who stays with her at night and several weekends a month. During the day Lakeisha and her aunt visit the mall, go bowling, and on the weekends spends time with her niece, Dawn and sister Latoya. Lakeisha has joined a walking club at Stone Mountain. At home she helps her grandmother and her aunt with washing clothes and cooking. Although she cannot see, Lakeisha has learned to move up and down the stairs in her new apartment.
Lakeisha's sister Latoya says, "The best thing about having my sister close by is that I get to see her more often. We play hand games and dance." Latoya enjoys spending the weekends at her big sister's apartment. Her father Eddie reflects: "Latoya and Jonathan attended Lakeisha's futures planning with us; we wanted them to be with us every step of the way because someday when we're gone, they will have to monitor the services Lakeisha receives.

"Lakeisha seems happier now — to be the center of attention. She doesn't catch as many colds as she did at Rivers Crossing and she's more willing to learn and stay on task. I would never have thought Lakeisha could learn how to wash clothes. We wanted soft/firm people with Lakeisha who didn't mind her touching them. We're looking for a job coach now who can help her get a job." She misses her friends at Rivers Crossing; it's been hard to find activities Lakeisha enjoys where she can meet friends without grouping her with other people with disabilities.

Lakeisha likes to be on the go and enjoys driving to shops and restaurants with her aunt. Lakeisha claps her hands when she is feeling good and loves to sing and listen to music. When she announces, "I like liver" her aunt tells her when they will be having liver for dinner that week. Since she left Rivers Crossing Monica observes that Lakeisha eats well and is no longer constipated. "Finding a doctor who had time to give Lakeisha and would accept Medicaid, was difficult at first. We are now able to take her to a good doctor once a month and have found the food that Lakeisha likes to eat which keeps her healthy. We've contracted with a behavior specialist to learn how to help Lakeisha redirect her attention when she feels upset. Several times a month Monica comes over to help her aunt and grandmother with Lakeisha. Her mother comes for several hours three times a week to visit. Both her parents come over if there's an emergency. Lakeisha's family is very dedicated to her.

Eddie and Althea plan to move to their land in Newton County and give Lakeisha their home; the home she grew up in. "We want Lakeisha to have the deck on our house to sit and a swing in the back yard because she likes to be outside. We didn't have time to move out of our house when Lakeisha first left Rivers Crossing but by the summer she'll be in her own home. Once we got hold of the idea that Lakeisha could live in her own home, we were like a dog on a bone. We fought too long and too hard to get what we have in place now, to let it go."
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