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RIVER'S CROSSING

Transition from Institution to the Community

Follow-up Study

Zolinda Stoneman and Beverly Al-Deen

"It's the relationships which really count: It is the people who make it work or not. . ."

— parent of a former River's Crossing resident

Institute on Human Development and Disability:
A University Affiliated Program

College of Family and Consumer Sciences
The University of Georgia
Athens, Georgia

It's the relationships which really count:
It is the people who make it work or not...

(Direct Quote from a River's Crossing Parent)

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February, 1999

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This publication produced under grant #90DD0477/02 from the Administration on Developmental Disabilities, Administration on Children & Families, U.S. Department of Health and Human Services, to the University of Georgia. If you have a disability and need assistance to obtain this publication in an alternative format, please contact the Georgia IHDD.

First Printing, February 1999

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Institute on Human Development and Disability:
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Dear Colleague,

When I first came to Athens, GA over 20 years ago, I accepted a position with the University of Georgia with a unit that was then known as the Athens Unit of the Georgia Retardation Center (GRC-Athens). This unit was a component of the University Affiliated Facility for the State of Georgia. The past 20 years were accompanied by dramatic changes for GRC-Athens (which became River's Crossing), for the University Affiliated Facility, and for people with mental retardation and similar disabilities.

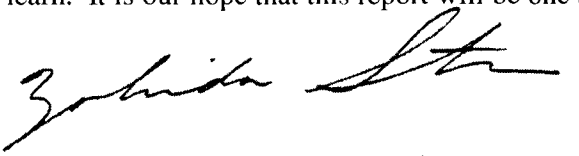
During that period, GRC-Athens changed from a short-term educational/diagnostic program to a 24-hour-a-day, 7-day-a-week institution. As a faculty member working with the unit's educational programs, I was strongly opposed to the creation of a new institution. Other advocates also expressed opposition, but the financial and political forces were too strong to overcome. In 1980, the change happened.

For me, the conversion was symbolized by the first weekend in which children stayed in the building rather than going home. Children had always stayed overnight during the week, but, each Friday evening, families arrived to pick up their children. Saturday and Sunday, the lights were turned off. After the conversion, the lights stayed on all weekend.

For many of us, it was an exciting moment when, once again, the lights were turned off in the residential unit. This happened on June 30, 1996.

River's Crossing employed many wonderful, dedicated staff who provided excellent care for the individuals living there. But, it was still an institution. As the time came for the closure, these staff, under the leadership of Dr. Sally Carter, Director of River's Crossing, were able to see a new vision for the residents. Under very difficult circumstances, they worked hard and unceasingly to create new lives in the community. Their efforts were successful. The River's Crossing focus people do, indeed, have new lives in the community. Not perfect lives, but life is a journey for all of us, with perfection always a distant goal.

This report also represents personal closure. Years ago, I was powerless to stop the creation of a new institution at my doorstep. Now, I have been given the privilege of documenting how the lives of the children and young adults who lived in that institution changed as they re-entered their communities. The stories are uplifting, but all of us have much yet to learn. It is our hope that this report will be one step in that learning process.



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Community inclusion is important for people of all ages. People with disabilities have the civil and human right to live and participate as equal citizens within their communities. We support the full inclusion of people with disabilities in all aspects of community life, work to eliminate barriers to inclusion, and assist in building the capacity of communities to be inclusive.

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Acknowledgments

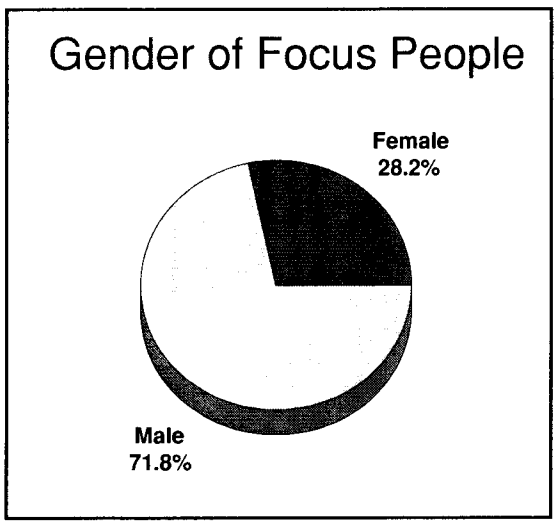
We want to thank the focus people and their families for inviting us into their homes and sharing their thoughts, dreams, and fears. We also want to thank the individuals we interviewed who were providing residential supports to the focus people. Without the creative ideas and logistical support of Dottie Adams, Judy Salmon, Gillian Grable, Jo Ann Cox, and Patsy Sailors, this work would not have been possible. We appreciate the helpful comments made by Dr. Sally Carter, former Director of River's Crossing, and Dr. Joyce Ringer and David Truran from the Georgia Advocacy Office, who reviewed an earlier draft of this report.

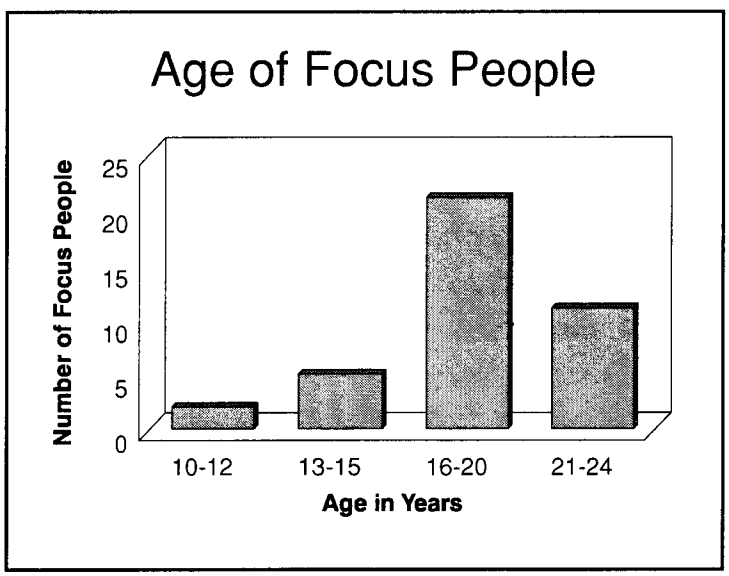
A special thanks to the interview team who worked very hard to acquire the information used to compile this study. They are as follows: Jorai Bailey, Bobby Brown, Kathryn Quattlebaum, and Martha DeHart.

Limited copies of this report can be obtained by writing to the IHDD. Copies of the companion book of stories, *Building New Lives in the Community,* are also available in limited quantities. To obtain either of these documents, write: John Weber, Dissemination Coordinator, Institute on Human Development and Disability/UAP, 850 College Station Road, University of Georgia, Athens, GA, 30602-4806 or send e-mail to jweber@arches.uga.edu.

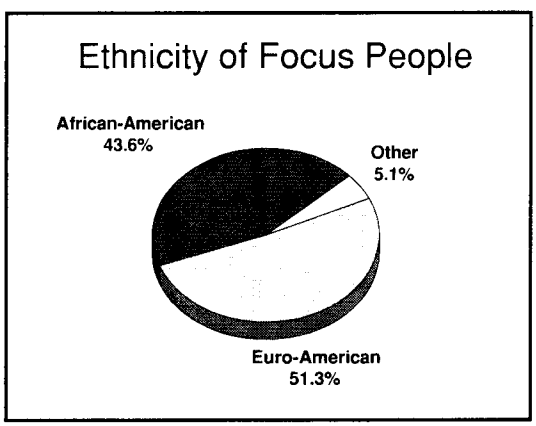
CHAPTER 1
WHAT IS RIVER'S CROSSING? WHO LIVED THERE?

On June 30, 1996, River's Crossing became the first institution to permanently close its doors in the state of Georgia. The closure was a landmark event. *(A brief history of River's Crossing is included at the end of this report.)* Many advocates hoped that the closing of River's Crossing would lead the way to further closures and downsizing of state institutions. This indeed has been the case. In December, 1997, Brook Run, an institution serving 326 people in suburban Atlanta, closed. Shortly thereafter, the Georgia Mental Health Institute in Atlanta closed its doors. It is important to understand how decisions made during the process of closing Georgia's institutions facilitate or hamper transitions to a new life in the community. It is also important to know how the lives of Georgia citizens change as they leave institutions and move into the community. This report presents information on the closure of River's Crossing, as seen through the eyes of the people who lived there, their families, residential providers, and the community staff who provide the focus people with daily support.



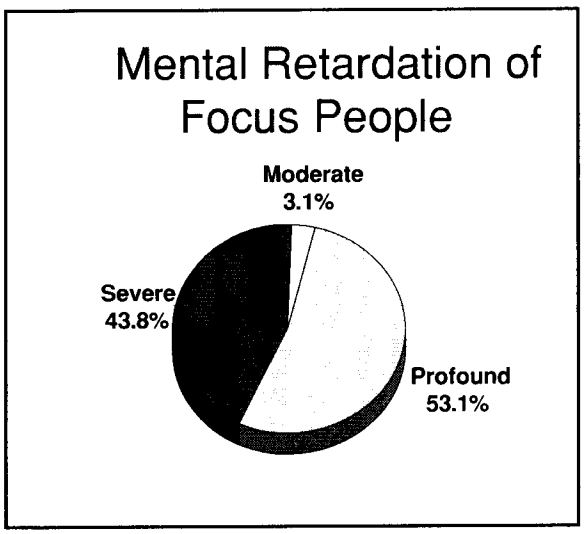


River's Crossing is located in Athens, Georgia. In the months before the closure, 39 youth and young adults lived there (28 males and 11 females). They ranged in age from 11 to 24 years with an average age of 19 years (see the CHARTS: *Gender of Focus People* and *Age of Focus People).* The ethnicity of the residents was primarily Euro-American and African-American with one Hispanic-American (see the CHART: *Ethnicity of Focus People*). One resident and his family had immigrated from Somalia.

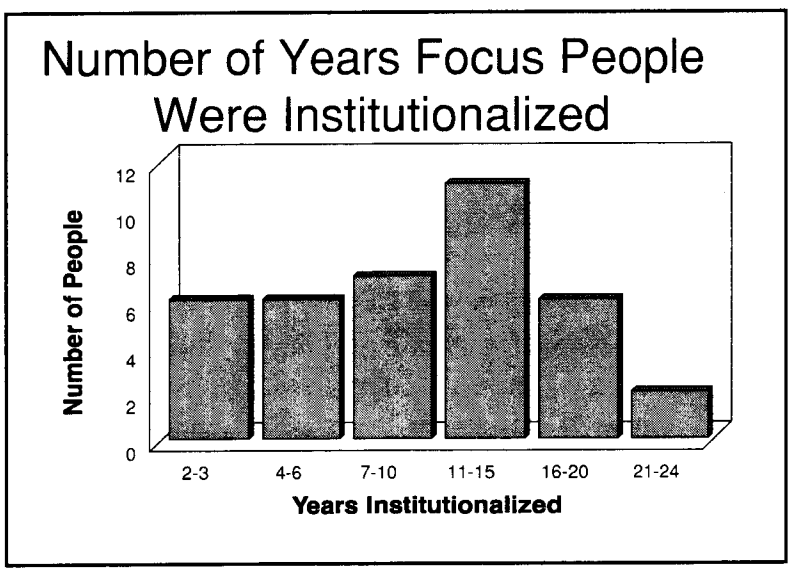


A large proportion of the River's Crossing residents had challenging behaviors that made many pessimistic that they could live outside the institutional setting. There was concern that the closure would instigate a "revolving door," in which residents would move to the community only to be returned to institutional care after a short period of time.

According to the medical records, almost all of the people who lived at River's Crossing were labeled as having severe or profound mental retardation (see CHART: *Mental Retardation of Focus People).* Almost half also were diagnosed as being autistic. Most of the residents had multiple diagnoses. Several engaged in severe forms of self-injurious behavior; others engaged in various forms of stereotypical behavior. One was blind as a result of self-injury. In addition to mental retardation and autism, labels that had been applied to the residents included: *PICA behavior, Rhett's Syndrome, microcephalus, hydrocephalus, explosive personality disorder, obsessive compulsive disorder, major depression, schizophrenia, seizure disorder, psychosis, bi-polar disorder, attention deficit disorder, and cerebral palsy.* Aggression and other forms of destructive behavior were common. Over 60% of the residents could not express themselves verbally. Most of the residents were ambulatory, with the exception of a few using wheelchairs for mobility. Many of the residents who could walk had quite unsteady gaits.



The average age at which the residents moved away from their family homes was 9.4 years. The youngest age at which a resident left home was during infancy; the oldest was 19 years of age when the out-of-home placement occurred. On average, over 10 years had passed since the residents lived at home with their families (the range was between two and twenty-four years; see the CHART: *Number of Years Focus People Were Institutionalized).* Some of the focus people lived at other institutions in the state before moving to River's Crossing. We asked family members/guardians to tell us the primary reason for the original out-of-home placement. Their responses are included in the chart on the following page.



What were the circumstances which caused the focus person to move from his/her home to an institution?	
Response	**Frequency**
Aggressive, destructive behavior	10
Caregiver's health failed	8
Seizures: strong medication requiring professional monitoring	4
Parents worked; could not give 24 hour care & monitoring	4
Problems in school; outbursts at home	4
Neglect: focus person removed from the family home	3
No family to care for him/her: placed in state custody	2
Developmental problems; very strong; didn't realize strength	2
No Data	2

The most frequent reasons for the original out-of-home placements were aggressive/challenging behavior and family circumstances that kept the family from being able to provide ongoing care. In general, when the individuals moved out of their family homes, no in-home support services (e.g. respite care, behavioral supports), or very minimal services, had been available to families to assist them in keeping their family member at home. For many families, the only way that they could receive the services that they needed was to institutionalize their family member, even if out-of-home placement was not what they wanted. Several families explained that the school system had encouraged an institutional placement for their child. The schools were not able to handle the child's behavior and convinced the parents that an institutional setting was their only option to receive educational and behavioral supports for their child.

CHAPTER 2
THE FOLLOW-UP STUDY

A. Preparation and Protocol

It was our intent to obtain information about the lives of former River's Crossing residents approximately a year after they moved to the community. Locating families and securing the needed interviews took longer than expected, therefore the time between moving to the community and the collection of data ranged between 10 and 18 months. This was partially due to the necessity to obtain written consent from the parent/guardian before visiting the focus person or the provider.

We developed a data collection protocol that attempted to obtain the perspectives of multiple people who were familiar with each individual in the focus group. Often in human relations it is difficult to define what constitutes "truth." Frequently, the best we can do is to obtain multiple points of view in order to see the situation from various perspectives. To achieve this goal, we developed three separate interview protocols that focused on the perspectives of: (1) the family member/guardian, (2) the focus person and/or a direct care worker who spent time with them daily, and (3) the residential provider. It was our intent to obtain as much information as possible directly from the focus person. In most instances, however, this was not possible because of the level of the focus person's cognitive disability. Instead, for most individuals, we interviewed a direct support worker. This interview occurred in the presence of the focus person so that responses of the focus person could be noted. Development of the interview protocols was a collaborative process, drawing upon the advice of numerous individuals familiar with River's Crossing and the people who lived there.

A rating form regarding the house/apartment in which the focus person lived was completed by the interviewer after visiting the focus person's home. For many of the interview questions and ratings, we drew upon our own past research. In addition, we also utilized interview questions from other studies of institutional closures (Conroy, 1995), architectural features of community residences (Thompson, Robinson, Dietrich, Farris, & Sinclair, 1996), and self-determination and choice (Stancliffe & Abery, 1997; Wehmeyer & Metzler, 1995). Whenever possible, a copy of the futures plan developed as a component of the transition from River's Crossing to the community was obtained. An attempt was made to obtain information on adaptive behavior from the River's Crossing records and to compare those data to adaptive behavior scores from instruments completed by community providers. Methodological problems made these comparisons impossible.

At the beginning of the follow-up process, there were nine focus people chosen to have stories written about their experience in the community. These were compiled into a book of stories entitled: *BUILDING NEW LIVES IN THE COMMUNITY - Hopes, Fears, & Dreams ... one year later* by Dottie Adams, Jo Ann Cox, Gillian Grable, Patsy Sailors, and Judy Salmon (published, June, 1997). (A copy of this publication is available by writing to: *John Weber, Dissemination Coordinator, IHDD/UAP, The University of Georgia, 850 College Station Road., Athens, Georgia, 30602-4806*).

B. The Interview Process

The first step in the follow-up process was to mail letters of introduction to families and guardians. We requested permission to interview them, the focus person and their residential provider. We asked to have access to the focus person's River's Crossing records and their futures plan. These letters, including written consent forms, were sent from Judy Salmon, an employee of the regional Community Support Services and a former social worker at River's Crossing, who was known to all the families. Families/Guardians were informed that all information collected would be strictly confidential. Families/Guardians who returned the written consent form were contacted to set up a date for a home visit. Follow-up telephone calls were made to those who did not respond by mail, or whose letter was returned undelivered. Judy Salmon and Dottie Adams from the Community Support Services worked closely with IHDD/UAP staff to help obtain information to locate family members whose addresses had changed or for whom no phone number was listed. It was emphasized that interviews were voluntary, and neither pressure nor inconvenience would be imposed upon the families/guardians. Permission was requested to use a tape recorder to record the interviews. If the individual was opposed to taping, detailed notes were taken, and the interview was conducted without the recorder.

When first approached, some families were reluctant to answer questions and did not understand the purpose of the interviews. When the purpose was explained in detail and they learned that Brook Run (an institution on the outskirts of Atlanta) was the next facility in Georgia to be closed, they began to talk freely and shared not only information, but their feelings, with the interviewers. Several parent/guardians who were the most reluctant to participate became the most willing to share their feelings when interviewed in person.

A team of interviewers was chosen and familiarized with the interview questions and the study protocol. We emphasized these goals: *(1) Dignity and Respect, (2) Relationships, (3) Choice, (4) Dreaming, and (5) Contribution and Community.* A central contact person was designated to coordinate the follow-up process and to conduct many of the interviews. Other interviewers were students of the University of Georgia. The team was to remain unbiased and receptive to any statements that the participants wished to share. Interviewers were instructed to emphasize that they were interested in hearing both pros and cons regarding the transition and the focus person's living situation. All participants were informed that should they be uncomfortable or opposed to answering any question, they were to tell the interviewer and the question would be skipped. Regular team meetings were held to share information. All data were coded with an identification number. The project director and the team contact person were the only individuals who knew which names corresponded to the ID numbers. When a team member completed an interview, the file was given to the central contact person who entered the information into a computer data base. Responses to open-ended questions were transcribed and coded according to content categories. The charts and information contained in this report are results of this collaborative effort.

C. Who Was Interviewed?

The follow-up process potentially included 39 former residents, 39 family members/guardians, and 39 residential providers, making a total of 117 visits/interviews, should all have participated. A guardian or family member was located and interviewed for all 39 focus people. Thirty-four of these interviews were with family members, four were with the Department of Family and Children Services (DFCS) caseworkers, and one was with a non-familial guardian (a close family friend). Of the family members interviewed, 29 were parents, two were grandparents, two were aunts, and one was a sister. One focus person's family consisted of two former River's Crossing staff members, who married and adopted the focus person.

It was necessary to have the written consent of the parent/guardian to visit the focus person and the provider. We received permission to visit and interview residential providers for 34 of the 37 focus people who moved to the community (two families chose institutional placements). The three families/guardians who were not willing to have the provider service contacted gave very clear reasons for their decisions. For two parents, great dissatisfaction existed with the provider service and the families were in the process of changing providers. They were concerned that the timing was wrong for us to interview the providers under these circumstances. The third person who denied us the ability to talk with the provider was a DFCS caseworker who did not believe that a follow-up study would provide important information since she was already monitoring the living situation of the focus person. The interviewers accepted these decisions, appreciative for the family member/guardian's willingness to be interviewed and share their information.

All providers contacted were willing to participate in the study after they received permission from the family or were given a copy of the signed consent form from the family. When focus people had more than one provider in the year since moving to the community, we interviewed both the initial provider and the provider currently supporting the focus person. We received permission to visit with 36 focus people and their direct support workers. We were not able to meet with two focus people after repeated attempts because of scheduling difficulties. For one of these focus people, information was obtained from the direct care worker. *Thus, we interviewed 39 family members/guardians, 34 focus people, 35 direct care workers, and 34 representatives of the residential provider service supporting the focus person. We examined 32 medical records and 30 futures plans.* The provider services who participated in the transition from institution to community were: Augusta CSB, Cobb/Douglas CSB, Georgia Options, Housing Ideas, LADD, McIntosh Trail, Mentor, MiCasa, Milledgeville CSB, New Horizons CSB, OSL, River's Edge CSB, Star Choices, TOPS, and Trinity.

Editorial Note: *Thirty-nine (39) focus people participated in our research study regarding the closing of River's Crossing. Two of these individuals moved from River's Crossing a few months earlier than the others and were not officially counted as being a part of the closure.*

CHAPTER 3
LIFE IN THE COMMUNITY

When River's Crossing closed, families were given the option of having their family member move to the community or transfer to another institution. Of the 39 residents who moved from River's Crossing, families of 37 chose to have their family member move to the community. Two families chose a transfer to another state institution. All families were interviewed, including those choosing institutional placement. One of the focus people living in an institutional setting was visited. Because of issues of confidentiality (given that there were only two families who made the institutional choice) and the inappropriateness of many of the interview questions for institutional living, the data contained in the following sections of this report were compiled from the 37 former residents who reside in the community.

A. Where Do The People Live?

Families of the residents of River's Crossing resided throughout the state of Georgia. The objective at the time of the closing of River's Crossing was to place all focus people as close as possible to their families, preferably in the family community. The MAP: *Counties Where Focus People Lived At Time Of The Interviews* (see following page), gives a visual illustration as to where the former residents of River's Crossing now reside.

The housing options available in the community were as follows:

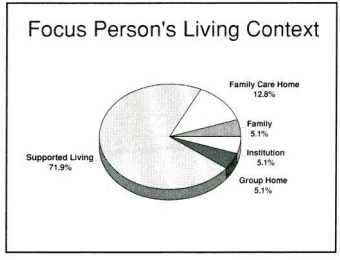
1. Group Home: These homes consist of several focus people residing in a single home under the watch care of one or more caregivers.

2. Supported Living: A focus person lives in a home or apartment, supported by one or more caregivers. Some focus people had a housemate who might also have a caregiver. The supported living housing includes: apartments, duplexes, and single family residential

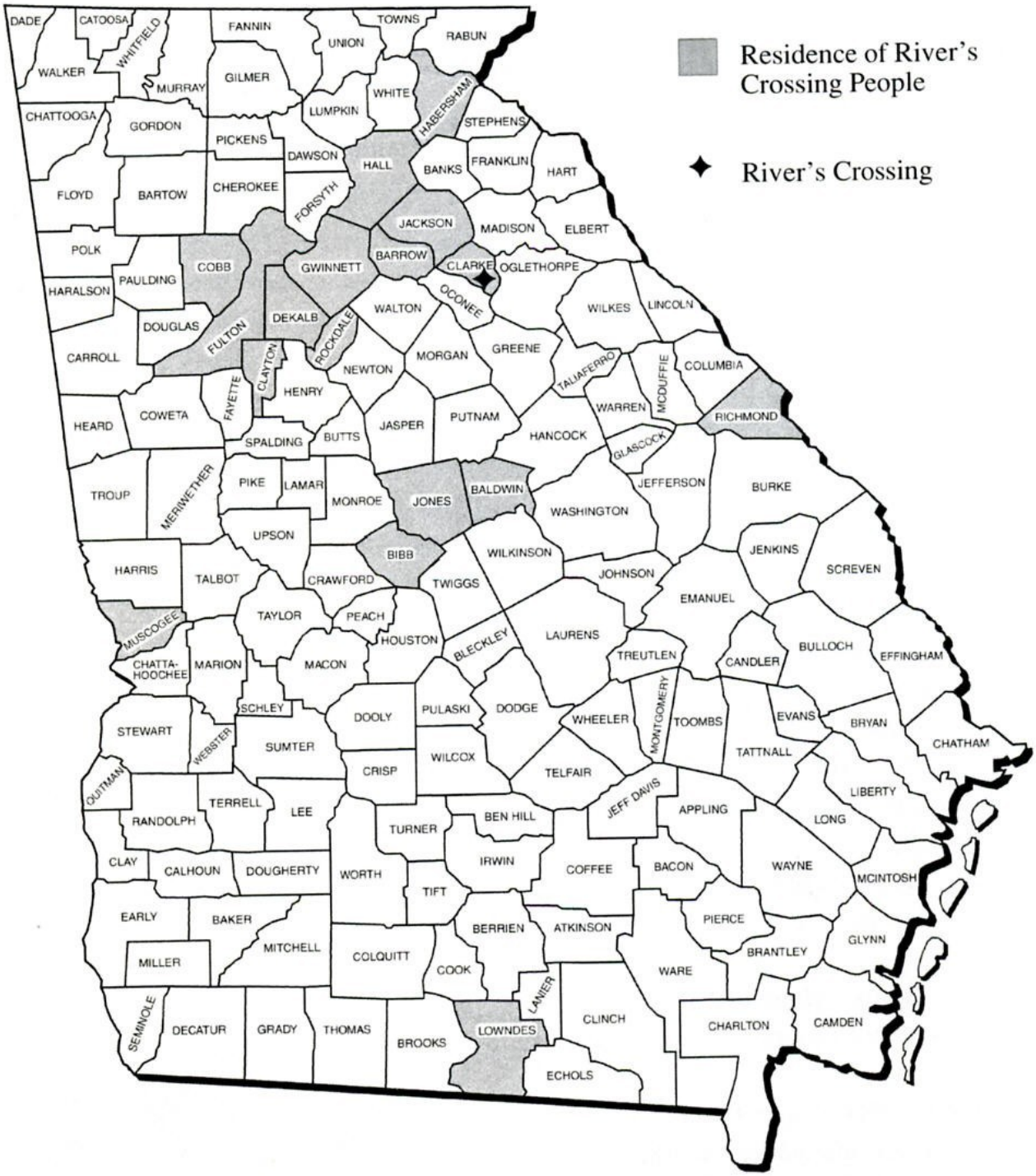
3. Family Care Provider: The focus person lives in the home of a family care provider.

4. Family Member: The focus person lives with a member of their natural family.

The CHART: *Focus Person's Living Context* provides information on where the focus people live (the chart includes the two focus people who moved to other institutions).



Counties Where Focus People Lived at Time of the Interviews



Over 70% of the focus people who moved to the community live in supported living contexts. Of the focus people in supported living situations, one lives in a home owned by her family. Twenty-two live in rental homes, duplexes, or apartments, and two live in homes owned by the provider service. A local contractor built a wheelchair-accessible home specifically for one of the focus people, and now rents the home to the focus person and his housemate. Twenty one of the focus people in supported living situations have their own homes or apartments with no housemates (but with 24-hour support staff); eleven have one housemate; four have two housemates.

The two focus people living in group homes live with two other people with disabilities sharing the home. Both of these group homes are owned by the provider services. Five focus people live with family care providers; four of these individuals live in homes owned by the caregivers and one lives with the caregiving family in a rented apartment. One focus person was able to move into a family care situation in which his mother's best friend is his family care provider. The family had hoped that he could eventually live with this friend after she retired. The closure caused this to happen a little sooner than they had planned. Two of the focus people live with members of their natural families; one lives with his mother in her home and another lives in a rented apartment with her grandmother.

We were interested in learning about the quality of the community settings in which the focus people were living. After interviewers completed their visits to each focus person's home, they completed a set of ratings of various aspects of the physical structure and the living environment. The following tables reflect these ratings. In general, the homes were judged to be quite homelike, both inside and outside.

Is the exterior of the structure homelike?	
Rating Choice	**Frequency**
Very homelike	25
Somewhat homelike	7
Not at all homelike	1
No Data	4

The interviewers rated the houses as being consistent with the neighborhoods in which they were located. Most (70%) of the focus people live in single family residential neighborhoods. Others live in neighborhoods primarily characterized by apartment buildings (11%), mixed residential dwellings (8%), or duplexes (6%).

How well do you think the structure blends into the neighborhood?	
Rating Choice	**Frequency**
Definitely blends in	32
Blends somewhat	1
Definitely not	0
No Data	4

In general, the houses had 6-7 rooms.

How many rooms are in the structure where focus person lives?								
# Rooms	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**No Data**
Frequency	1	1	4	1	8	3	1	9

Almost all of the focus people had their own bedrooms.

How many people share a bedroom?			
# Shared	**Private Room**	**One Shared**	**No Data**
Frequency	27	1	9

The interviewers completed a series of ratings concerning qualitative features of the interior of the home. These ratings are represented in the following chart:

What are the qualities of the living space?						
Description	**NO**	**No**	**Somewhat**	**Yes**	**YES!**	**No Data**
Interior is appealing	1	1	7	9	15	4
Interior is comfortable	1	1	4	17	10	4
Interior is cozy	1	2	6	16	8	4
Interior is impersonal	9	18	5	0	0	5
Interior is sparse	5	14	5	8	0	5
Focus person has privacy	1	2	16	14	0	4
Artwork/decorations on walls	1	2	12	11	6	5
Personal items of focus person present	8	2	15	6	0	6

The homes were rated as being quite pleasant and personally-decorated. One mother commented that her daughter lived in a "lovely brick home with a deck on the back," and that she had her own room that was furnished in a very feminine fashion, in "soft blue and mauve."

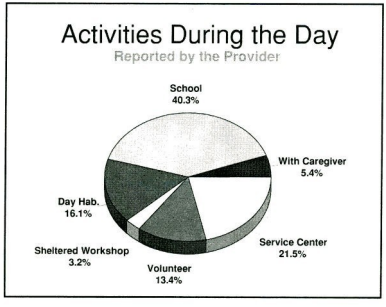
It was noted that for some focus people, PICA and other behaviors dictated that furnishings be more sparse than might be preferred in settings where those behaviors were not a consideration.

B. What Does The Focus Person Do During The Day?

When talking with the provider and the direct care staff, the interviewer posed the question: *How does the focus person spend his/her days?* The following possible options were presented:

How does the focus person spend his/her days?
Options
1. Employed full time (describe position)
2. Employed part time (hours per week, describe position)
3. Supported employment (hours per week, describe position)
4. Sheltered workshop
5. Developmental service center
6. Community volunteer work (hours per week)
Doing what?
At what location?
School: School Placement:
7. Public School - regular education - inclusive
8. Public School - special education - self-contained
9. Other (Day Habilitation)

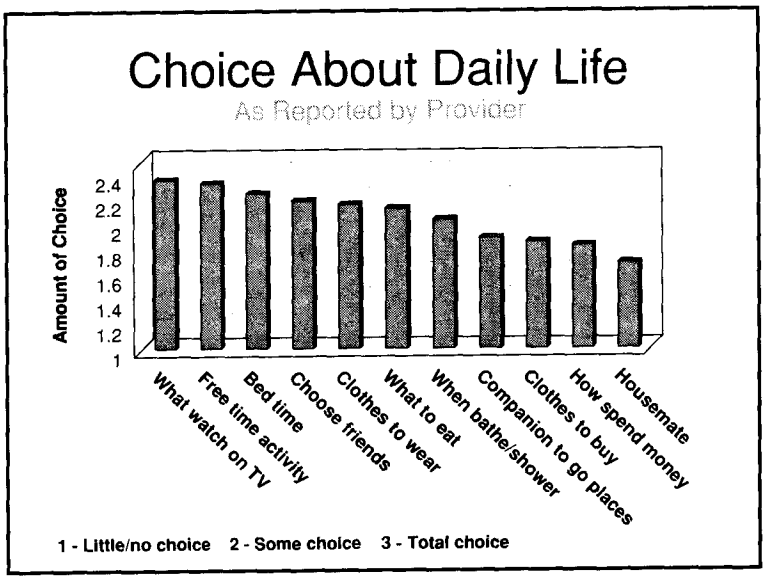
The CHART: *Activities During the Day* reveals that the largest group of focus people attend public school special education classes during the day. This is consistent with the young age of the focus people. Eight of the focus people receive day habilitation services or spend the day accompanied by a caregiver. Day habilitation can be both structured and unstructured. Some days there are events planned for the focus person, such as visits to the library, fire station, police station, etc. Other days the focus person accompanies the caregiver as they go about their daily activities. Five of the focus people participate in



community volunteer work. Several of the focus people involved in volunteer work are also receiving day habilitation services. The volunteer service is a component of the day habilitation activities. Eight focus people attend a Developmental Service Center during the day. These are work activity centers which serve adults with mental retardation. One focus person attends a sheltered workshop. *A year after moving to the community, none of the focus people are in supported employment, and none have full-time or part-time jobs.*

Since over 40% of the focus people are attending school, there is a strong need for providers to interact with the special education system. Most of the provider services were accustomed to providing residential support to adults. Several described difficulties in relating to the educational system. Working with the schools involves advocating for the student's educational rights, participating in IEP meetings, and serving as what might be considered "surrogate parents" for many of the focus people who are youth of school-age. In interviewing the providers, it became clear that many lack basic information about IDEA and other important special education laws. None of the focus people are in inclusive educational settings. A small number of focus people do not attend school because the schools communicated to the providers that they lacked adequate resources to meet the needs of the prospective students. These youth have challenging behavior that the schools were reportedly unable to handle in the educational setting. One provider withdrew a focus person from school because the school repeatedly called her during the day to come and pick up the focus person because of behavioral issues. A more thorough knowledge of the right to an appropriate education guaranteed to all children and youth under IDEA could have armed providers with information. With this information, they might have had more success in confronting these situations and advocating for the educational rights of the focus people.

C. Do The Focus People Have Choices Regarding Their Daily Lives?



Providers and direct support staff were given a list of aspects of daily life and then asked to indicate how much choice the focus person had about each aspect of their life. The list of choices were rated as follows: (1) *Little/No Choice*, (2) *Some Choice*, and (3) *Total Choice*. The responses of the residential providers and the direct support staff were almost identical. The CHART: *Choice About Daily Life* indicates that all of the focus people living in the community have some

choice about basic aspects of their lives. They are able to choose the clothes that make them happy and what activity they enjoy to occupy their free time. In general, most choice occurs for aspects of life that had the least consequences for the individual (what to watch on television, how to spend free time) and the least choice occurs in areas of greater consequence (spending money, selecting a housemate).

The amount of choice enjoyed by the focus people is considerably greater than it had been in the institutional setting. Still, many aspects of daily life are dictated by others. Few focus people, for example, had choice, concerning the selection of their housemate. Supporting the focus people to become involved in these choices may have precluded some of the difficulties that emerged when housemates were not compatible and one had to move. One mother described how her son's housemate's mother had requested that the two young men live together in the community. The mother had observed the young men interacting together at River's Crossing and thought that they seemed to enjoy each other's company. This perceptive mother provided support for her son and his friend to have choice concerning who they lived with, even though they could not communicate that choice verbally. Other housemates were placed together simply because two families living in the same area of the state selected the same provider service. In these instances, the focus people had no choice about who their housemate would be.

It was surprising that focus people who were viewed by providers as having challenging behaviors had significantly more choice about their lives than did other focus people (ratings averaged 2.2 for those with challenging behavior and 1.7 for other focus people, $t(30) = 2.80$, $p < .009$). It is possible that focus people with more difficult behavior were more assertive about having control over their lives. It is also plausible that this group of focus people had higher cognitive and functional skills than those without challenging behavior, causing staff to grant them greater choice.

All of the focus people included in this study have quite substantial developmental disabilities that may not allow them total freedom of choice. However, additional focus might be placed over time on assisting the focus people to assert greater self-determination over basic aspects of life, such as those included in the rating list.

D. Do The Focus People Know Their New Neighbors? Do They Have Friends?

Neighbors. When the focus people moved to the community, they were separated from their River's Crossing friends. The first year in the community was a time of adjustment. For many of the focus people, the first months were "getting acquainted" periods which were spent getting to know new staff. Often when we move into a new home, the first people we get to know are neighbors. We asked providers about the extent to which the focus people had become acquainted with their neighbors during their year in the community. Their answers are reported in the CHART: *Has the focus person become acquainted with the neighbors? Describe.* (See the following page.)

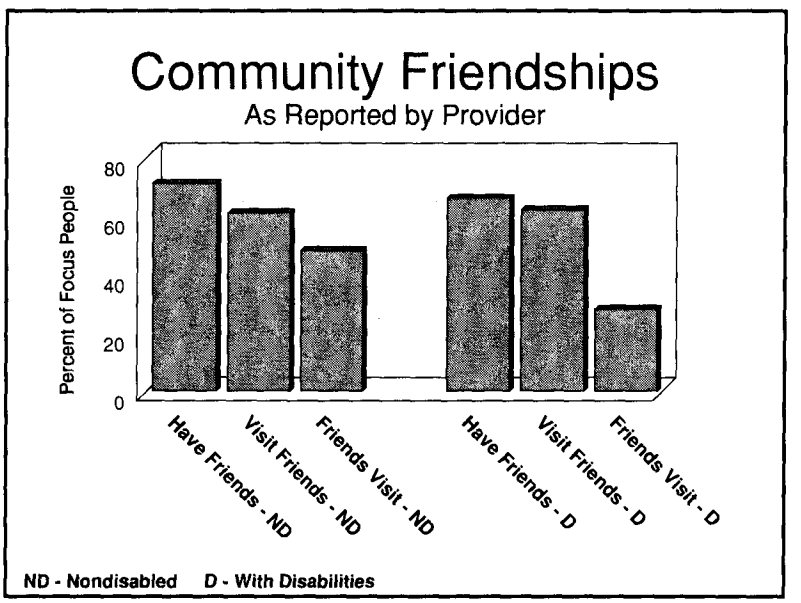
Nine of the focus people were reported by providers to be actively engaged with their neighbors. One focus person is paid each week by a neighbor to water her plants. They visit regularly. Another focus person is getting to know his neighbors as he walks his dog in the neighborhood.

Has the focus person become acquainted with the neighbors? Describe.	
Responses	**Frequency**
Visit each other in their homes	9
Wave or call out across yard/street	8
No interaction with neighbors	6
No Data	14

Neighbors visit another focus person each week, walking around with him and talking. He really enjoys those visits. One focus person got to know his neighbors by going into their house and eating their food. Now the neighbors invite him over to visit frequently. These neighbors also "keep an eye out" for the focus person when he is outside, monitoring his safety. For some focus people, interaction with neighbors is still minimal, or nonexistent. This is exemplified in a comment by a provider, "As they pass by they speak -- friendly, but not much interaction." Some of the providers were relieved that the neighbors accept the presence of the focus person. These providers seem to have relatively low expectations for inclusion of the focus person into the neighborhood.

Friends. We asked providers and direct support workers about the focus person's friendships with individuals with and without disabilities (see CHART: *Community Friendships*). It might be expected that most of the friendships at River's Crossing were between individuals with disabilities or between the focus people and staff.

After moving to the community, focus people continued to have numerous contacts with other people with disabilities. They met their new friends in their special education classes and at developmental service centers. Almost 60% had visited the home of a friend with a disability at least once since moving to the community. Only about a quarter of the focus people had friends with disabilities come to visit them at their own homes.



The community provides opportunities for the focus people to make friends with people both with and without disabilities. Although a majority of providers responded that the focus people had friends without disabilities in the community, further

discussion revealed that for many of these individuals, the friends were really friends of the provider rather than friends of the focus person. These individuals visited the house and got to know the focus person, but were not visiting for the primary purpose of spending time with the focus person. Paid staff, or family of paid staff members, were often counted as nondisabled friends of the focus person. Thus, although the data represented in the chart on community friendships appear positive, the data are not as encouraging as they might seem at first inspection. A year after the closure, only a few focus people had the opportunity to be in included in the community to a sufficient extent to develop their own friends without disabilities -- friends that were not paid to spend time with them.

E. Participation In The Community

We asked the providers and direct support staff to indicate whether or not the focus people engaged in a set of community activities. When the provider or staff member said "Yes," we asked how often in a month that the focus person engaged in the specific activity. We also asked questions about who accompanied the focus person into the community, and how the person was transported. According to providers, the focus people engaged in the following community activities:

Community Participation		
Type of Participation	**% of Focus People**	**Times Per Month**
Grocery shopping	85	5.7
Retail shopping at the mall, K-Mart, Wal-Mart, etc.	82	5.6
Going out to eat (restaurant, fast food)	82	6.9
Recreation (movies, sports, park, swimming, etc.)	77	10.2
Religious services/worship	36	3.8
Other: Accompany caregiver with their daily chores and visits	75	12.0

The focus people are spending time participating in their communities. Like other citizens, they shop, go out to eat, and engage in leisure activities. One focus person has joined a walking club, another goes to the YMCA. Other focus people enjoy going to the mall or riding around the community in the car. In high school, one focus person has joined the marching band. All focus people visit the community at least periodically. The average focus person made 27 trips to the community per month; the lowest number of monthly community trips was 6, the highest was 55. Challenging behavior sometimes interferes with community participation. One provider described the behavior of a focus person who "falls to the ground and screams in public places." Additional behavioral supports may be needed to assist these focus people to become active participants in their communities.

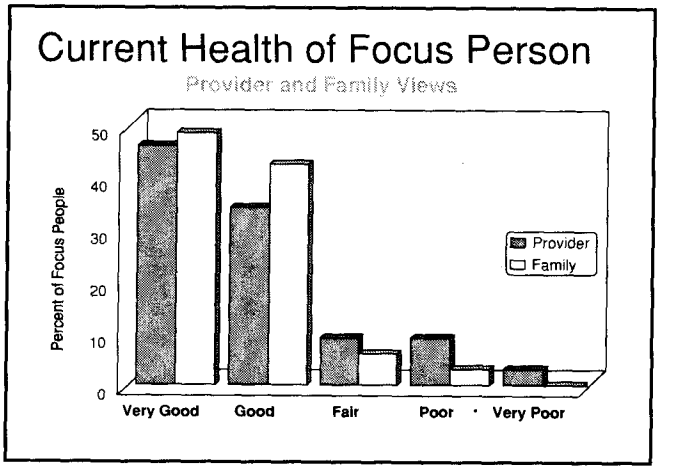
It is striking that as the focus people go out into the community, they are usually accompanied

by paid staff, rather than by friends. Perhaps as they live in the community longer, their friendship networks will expand, and they will spend more time engaging in community activities with nonpaid friends and other community members.

Transportation for community visits is provided by the staff and/or provider van. Family members participate in transporting some of the focus people, especially to and from medical services. One focus person owns her own car, which is driven by a staff person when she goes out. Most of the providers indicated that transportation is sufficient for the focus person's needs. One provider indicated that the focus person she supported loved to ride in a car, but unfortunately, she was one of the few providers who lacked adequate transportation.

F. Health And Safety In The Community.

As family members learned that River's Crossing was closing and thought about their family member living in the community, their greatest fears concerned the health and safety of the focus person.



Health. A year after the move, we asked family members/guardians and providers to evaluate the current status of the focus person's health and to indicate whether they thought the focus person's health had changed since moving to the community. The CHARTS: *Current Health of Focus Person* and *Changes in Health* reveal that most families/guardians and providers perceived the current health of the focus person to be either "very good" or "good." Only a small number of health concerns emerged from the interviews. Approximately half of the families/guardians and providers believed that the health of the focus person had *improved* since leaving River's Crossing. The following chart specifies the health improvements that the families/guardians and providers believed to have been experienced by the focus people. It should be noted that several family members and providers indicated that the health of the focus person had improved, but did not give a clear description of the nature of the improvement in response to the follow-up question. For that reason, the numbers on the

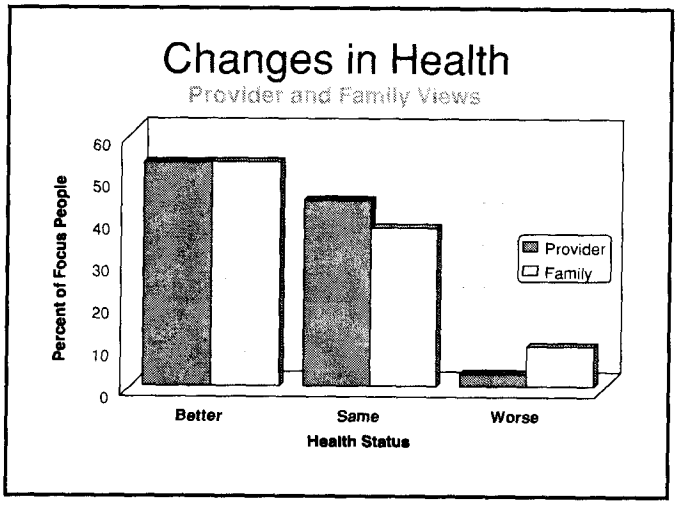
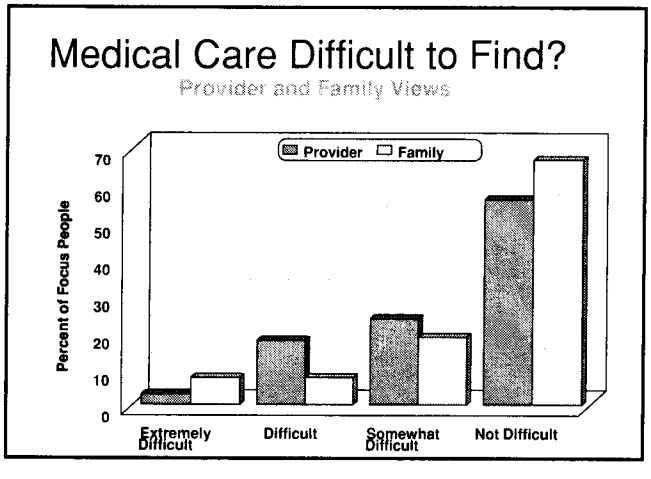


CHART: *Health Improvements* below are lower than the number of respondents who indicated a positive change in health. The most frequent positive health change, as perceived by both families/guardians and providers, was nutritional improvement, often accompanied by a weight gain.

Health Improvements	Frequency
Family Perceptions:	
Improved nutrition/weight gain	3
Sleeps better	1
Improved respiratory status	1
Individualized medical care	1
Improved vision	1
Provider Perceptions:	
Improved nutrition/weight gain	4
Less exposure to illnesses (flu, etc.)	3
More exercise	2
Skin improved/less dry	2
Medications stabilized	2
Fewer seizures	1

Less exposure to illnesses found in a congregate setting like River's Crossing was the next most frequently noted change. One focus person experienced an increase in the light/dark perception due to a community ophthalmologist who was successful in treating a corneal condition that compromised his vision.

A small number of families and providers indicated that the health of the focus person had declined since leaving River's Crossing. One focus person's sickle cell disease worsened, creating concern for both the family and the provider. Both noted that this decline in health, which is life-threatening to the focus person, was unrelated to the move to a community setting. One family was concerned that the focus person was gaining too much weight, while another thought the community setting provided less individualized medical attention.



Access to Medical Care. At the time of closure, some families/guardians and advocates were concerned about the ability of the focus people to secure adequate medical care in the community. This was particularly true for those people moving to rural areas of Georgia, where health care resources are limited. The CHART:

Medical Care Difficult to Find? (See page 17) summarizes the responses of families/guardians and providers to a question asking them how difficult it had been to find appropriate medical care in the community. Approximately half of the providers indicated that they had experienced some degree of difficulty in securing appropriate medical care. Somewhat fewer families/guardians perceived medical care to be a problem. Gynecological care was mentioned by several providers as difficult to find. The focus person with the most serious health problem (sickle cell disease) and another focus person with lupus had no difficulty finding appropriate health care in the community.

In examining the issues that made finding medical care difficult, several problems occurred across numerous focus people. These were:

(1) Behavior challenges presented by focus person

(2) Problems finding dental care

(3) Problems with Medicaid

(4) Limited specialized medical resources in rural areas.

Many families and providers noted that physicians were reluctant to serve individuals with aggressive or destructive behavior. This was the most serious barrier to medical access faced by the focus people. One provider noted that finding care was extremely difficult because she could not find a physician who was "not scared of" the focus person. The medical conditions of the focus people tended to be similar to those that physicians routinely treat, but the doctors were concerned about managing challenging behaviors in the medical context. Providers also expressed frustration about finding community psychiatrists who served individuals with severe disabilities.

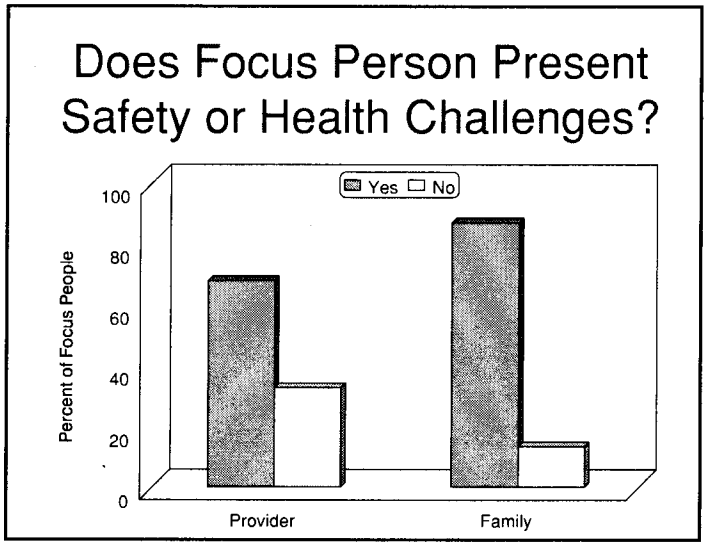
Access to dental care was also frequently mentioned as a problem, both by families/guardians and by providers. As with general health care, the primary barrier to dental care was the challenging behavior of the focus people. While living at River's Crossing, some of the focus people had been sedated in order to receive care (dental care was provided at another state institution). Few community dentists are comfortable using sedation to control behavior during routine dental procedures. A year after moving to the community, some providers still had not located a dentist who would provide ongoing care for the focus person.

Other focus people had their access to health care limited because of difficulties related to Medicaid. The most frequent challenge was a shortage of physicians who were willing to accept Medicaid patients. One focus person had difficulty receiving her Medicaid card. For an extended period of time after moving to the community, she had to travel several hours to a state institution to receive medical care because local physicians could not serve her without her card in hand.

Focus people experienced the same barriers to specialty medical care that are experienced by many other citizens living in rural Georgia. To receive specialty care, it is often necessary to commute substantial distances to the nearest urban center. Several providers noted the lack of orthopedists and other specialists and the need to travel to medical centers for certain types of care.

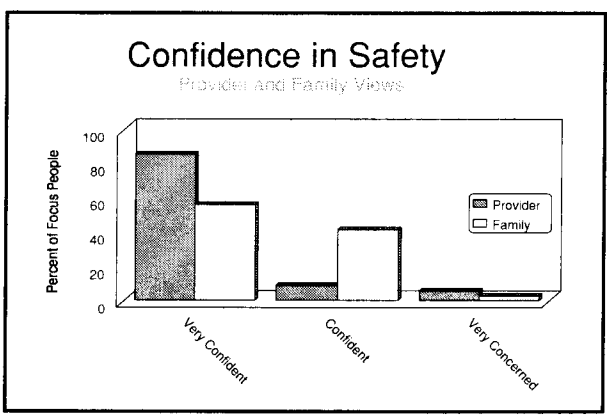
Safety. Safety of the focus people in the community was a great concern of families/guardians when the closure of River's Crossing was announced. We asked family members/guardians and

providers whether they believed that there were particular challenges related to the safety or health of the focus person. If they answered "Yes," we asked them to describe the challenges related to safety or health that concerned them. Over 80% of families/guardians and over 60% of providers indicated that there were safety or health challenges (see CHART: *Does Focus Person Present Safety or Health Challenges?*). The table below includes the responses of the families/guardians to the follow-up question asking for a description of particular safety and/or health challenges related to the focus person. Many challenges noted by the families/guardians concerned vulnerability because of the person's cognitive disability or safety issues created by violent or aggressive behavior.



Are there particular safety or health challenges related to the focus person?	
Family Member's Response	**Frequency**
Easily led, will do whatever he/she is told to do without question	11
Sometimes violent behavior	5
Wanders away from the house, does not realize danger	4
PICA behavior	3
Severe seizures	3
Eats raw and uncooked food	1
Ingests body fluids and products causing bacterial infections	1
Diabetic	1
No significant challenges	3
No Data	5

In general, both families/guardians and providers were quite confident that the focus people were safe in the community (see the CHART: *Confidence in Safety*). In part, this confidence occurred because the providers worked with families to adapt the living environment to maximize the well-being of the focus people. The table on page 20 describes some of the things that were done to eliminate concerns (data in the table



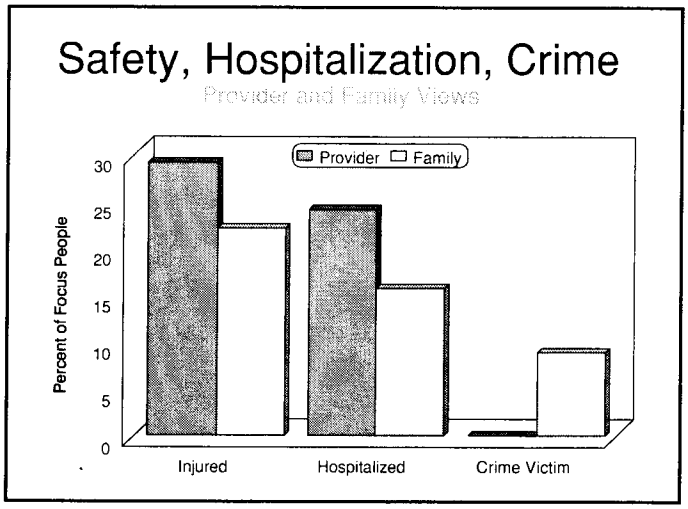
were obtained from the family/guardian interviews). Families/guardians viewed monitoring and supervision as the most important health and safety protections provided for focus people living in the community. Security systems and fencing were also noted as important. When providers were asked how they adapted the living environment to insure the health and safety of the focus people, they listed about the same safety behaviors that were communicated by families/guardians. In addition to the accommodations described by families, providers noted that they adapted the focus person's furnishings to meet their physical requirements. For example, when a focus person had difficulty with mobility, furniture was limited and sparsely placed to allow room for movement.

What has your provider service done to protect the safety & health of the focus person?	
Family Member's Response	**Frequency**
Provides constant one-on-one monitoring and supervision	16
Dead locks and/or security system, fencing around yard	5
No carpets or fringed cushions/pillows, leather fabric furniture, extra clean environment, clothing without buttons or zipper	2
Locks on kitchen cabinets and refrigerator	1
Monitors medication more closely making sure it is swallowed	1
Provider is not doing their job -- lot of concerns	1
No Data	11

Although confidence in safety is high, a few families and providers noted safety concerns. Two families expressed concerns about the safety of the focus person's housing. A mother whose son lived in a third-level apartment with large glass panels believed it was dangerous. She was concerned that her son might have a seizure or accidentally fall against the glass and get cut. She also worried that he might fall from the upper level because he stumbles and loses his balance from time to time. She said it was a very nice apartment, but was not appropriate for her son. Another mother voiced concern that there were no fire escapes on the back side of the house where her son's room was located (on the second story). One day-habilitation supervisor mentioned the inconvenience and possible safety hazard posed by a steep driveway to a house occupied by a focus person who uses a wheelchair. There is a wheelchair ramp off a back deck, which allows access to the carport, but both front and back yards are very steep with no level areas.

One family described an experience that caused them great concern. On two occasions, a focus person climbed out of a window and roamed about outside her house. On one of the occasions, the focus person knocked at the door to get back in the house before the staff person realized that she was gone. This frightened her family and the family of her housemate and resulted in the dismissal of the staff person. The family has since changed provider services and is more satisfied with the safety protections.

Injuries. Both the families/guardians and the providers were asked whether the focus person had been injured, hospitalized, or a victim of a crime since moving to the community (see the CHART: *Safety, Hospitalization, Crime).* If any of these events occurred, a follow-up question was posed asking for a description of what had happened and the cause of the event. As can be seen by the chart, the responses of the families/guardians and of the providers seemed to differ. We carefully analyzed the follow-up descriptions of the events to better understand the differing perceptions of these two sources of information. The chart below presents a summary of the descriptive information regarding injuries to the focus people. The data included responses obtained from both families/guardians and providers.



Injuries to the Focus Person (FP) since moving to the community.		
FP	**FAMILY REPORT**	**PROVIDER REPORT**
A	No injury reported	Focus Person fell walking up steps. (Emergency Room for stitches)
B	No injury reported (but noted Emergency Room visit for seizure)	Focus Person fell and hit his head during a seizure (Emergency Room)
C	No injury reported	Focus Person fell during a seizure (hospitalized for one night)
D	Focus Person fell getting on the school bus, chipped tooth	Focus Person fell getting on the bus, minor injury
E	Focus Person had claw & pinch marks, either from roommate or self-injury	Focus Person falls occasionally, not serious
F	Focus Person cut toe (Emergency Room)	No injury reported
G	Bruises and scrapes	Scrapes, happens when staff tries to control behavior
H	No injury reported	Focus Person falls occasionally, black eye was the most serious injury
I	No injury reported	Focus Person bites self. Minor injuries
J	No injury reported	Bruises from self-injury (hitting head on wall)
K	Sting or bite over eye, swollen	No data
L	No injury reported	Focus Person fell, fractured bone in foot
M	Focus Person fell in bath tub	Focus Person fell in bathtub
N	Focus Person got bite marks and bruises during short institutional stay	No injury reported
O	Focus Person fell and pulled neck muscle	No injury reported

Most of the injuries sustained by the focus people were the result of stumbling and falling or losing balance and falling in the bathtub, on the steps, or over furniture. Some of these falls were described as resulting from seizures. Other incidents involved self-injury. Providers were more likely than were parents/guardians to be aware of minor injuries experienced by the focus person. In one instance, an injury occurred at the family home, and the provider was unaware of the injury. In general, most injuries were minor, and only a few required medical care.

Hospitalization and Emergency Room Use. The chart below provides a comparison of the responses of the providers and families/guardians to a question asking whether the focus person had been hospitalized since moving to the community. For those who answered "Yes," to this question, follow-up questions asked for information about the reason for the hospitalization and the length of time the focus person spent hospitalized.

As was the case with injuries to the focus person, providers were more likely than were families/guardians to be aware of hospitalizations and visits to the emergency room. Several families expressed displeasure or anger that they were not immediately notified by the provider when their family member was hospitalized or taken to the emergency room.

The families felt it was very important that they know as quickly as possible when illness, injury, or hospitalizations occurred. Although this usually happened, there were times that families were not told, or were told belatedly. The types of illnesses or injuries that resulted in hospitalization

Has the Focus Person (FP) been hospitalized since moving to the community?		
FP	**FAMILY REPORT**	**PROVIDER REPORT**
A	No hospitalization reported	Fell (Emergency Room visit)
B	Seizures (Emergency Room visit for one hour)	Seizures, fell, hit his head (Stayed in the Emergency Room for one night)
C	No hospitalization reported	Fell during seizure (Hospitalized one night)
D	No hospitalization reported	Negative reaction to dental sedation (Hospitalized for three nights)
E	Throat culture: Ruminates-lung/stomach bacteria. (Hospitalized for one day)	Bacterial infection. (Hospitalized for one day)
F	Discovered diabetes: Hospitalized	Seizures and constipation
G	PICA - Sickle Cell (Hospitalized 3 times, lasting 2 days, 5-6 days, & 3 weeks)	Sickle Cell (Hospitalized 4-5 times, lasting 3 weeks at one stay, 1-6 days other stays)
H	No hospitalization reported	Seizures (Hospitalized for 2 days)
I	Cut toe (Checked at Emergency Room)	Seizures and constipation (Checked at Emergency Room)
J	High fever (Emergency Room visit)	No hospitalization reported

or emergency room visits appeared quite expected, with seizures, PICA behavior, and chronic illnesses accounting for most visits. There was no indication that lack of medical access resulted in increased use of emergency room services.

Medications. Over 90% of the focus people took at least one type of prescription medication for seizures or for mental health/behavioral reasons. The medications listed below are representative of those taken by the focus people, as reported by the providers.

Medications Named By Providers Which Are Administered To Focus People	
Azathioprine:50mg / 1 time per day	Luvox
Buspar:10mg / 2 times per day	Mellaril:25mg / 3 times per day
Canitor:330mg / 2 times per day	Moban:50mg / 2 times per day
Clonazepam / 2 times per day	Risperdal:1mg / 3 times per day
Cylert:37.5mg / once every a.m.	Prednisone:10mg / 2 pills every other day
Depakote / 2 times per day	Propranolol:20mg / 2 times per day
Depakote: 250 mg / 3 times per day	Propranolol: 3 times per day
Depakote:500mg / 2 times per day	Prozac:10mg / 1 tablet every other day
Dilatin:50mg /3-2 times per day	Risperdal:3mg / 2 times per day
Effexor: 2 times per day	Ritalin:5mg / 3.3.2 day
Elavil	Tegretol / 3 times per day
Hydroxyzine:50 mg / 2 times per day	Termoc:300mg / 3 times per day
Lorazepam (as needed)	Thioridazine:50 mg / 4 times per day

NOTE: *These are the medications which were named in the provider interviews and not necessarily all of the medications required by the focus persons. Use or dosage of medications was not verified by checking the focus person's medical records.*

Crime. None of the providers indicated that the focus person had been a victim of a crime. Three family members/guardians, however, reported that victimization had occurred. One family member reported that the focus person's home had been robbed. Another reported an unusual incident in which a direct care staff person had shaved a male focus person's body, resulting in the termination of the staff person. One father reported that he saw what he believed to be burn marks on his son. At the time of the interview, he had changed providers.

G. Provider Changes -- Stability of Housing

Twenty-six of the focus people moved to the community from River's Crossing and remained in the same house or apartment for the entire first year. Eight of the focus people experienced one residential move during that period; three focus people moved twice during the year. For each of the focus people experiencing dislocation during the first year in the community, we talked with the provider and the family/guardian about the nature of the move and why it had occurred.

One focus person lived in the community for several months and then moved home with his family. Two focus people stayed with their families for a while before their community housing was ready and their support staff hired and trained. One focus person was in DFCS custody when he left River's Crossing. After living in the community for a time, his family fought for and won custody. When that happened, he moved to another home and was supported by a different provider service.

Several of the moves were quite traumatic to the focus people. Two focus people had a particularly difficult time finding an appropriate community situation and were transferred from River's Crossing to another institution before finally moving to the community. For both, the transition from River's Crossing to the community was described as "chaotic" and "very rough." The reasons behind these problems related to insufficient time for planning and not enough start-up funds. Another focus person also did not have a community placement ready for him at the time of the closing of River's Crossing. He moved from River's Crossing to a respite home, for a placement that was only temporary and out of region (too far away from his family). He then moved closer to his family home, but this placement was also made on a temporary basis since it was still out of his home region. He was still living in this residence at the time of the interview.

After settling into her new home, one focus person was moved because her housemate was aggressive toward her, resulting in scratches, bruises, and bite marks. The focus person's mother was quite upset at this circumstance, since the house where the focus person originally lived was chosen for that focus person and furnished by her startup money. She believed the housemate should have moved, rather than her daughter. The provider explained the focus person was easy to get along with and could move in with another housemate immediately. They believed that this was the best solution under the circumstances as they were concerned for the focus person's safety. It would take time to find housing for the housemate with aggressive behavior; thus, relocating the focus person who was being victimized eliminated the possibility of her being further traumatized. Before moving in with this focus person, the housemate with aggressive behavior (also a former River's Crossing resident) had already moved twice because of issues surrounding her challenging behavior. In addition to the focus people described above, another focus person was also moved from one house to another because of problems with his housemate.

During the year, three focus people spent short periods of time in institutional settings because of challenging behaviors (these were not included in the above data concerning number of moves, since all three focus people returned to their original community homes after the short-term placement). One focus person was taken to an institution after a serious behavioral episode. A police officer took the focus person to the emergency room, where an intern had him transferred to a residential institution. He stayed there for three months. During that time, representatives of the provider agency visited him frequently and worked toward getting him released so that he could return to his home in the community. Another focus person was institutionalized after an outburst. The caregiver in his home was changed, and he returned to the community setting. The third focus person has had ongoing issues with challenging behavior since leaving River's Crossing, resulting in an unstable housing situation and time spent in a behavioral clinic for observation.

During the first year after the move to the community, five families changed provider services. There were communication conflicts which were irreparable, and the families felt that the providers were not doing their job. It was a frequent complaint of these families that the provider had not kept the promises that they made at the initial meetings prior to the closing of River's Crossing. In one instance, the family believed that the provider was placing more and more responsibilities on the family as time passed. The family had been told that they would be responsible for planning outings for the focus person and were to inform the provider of the outings as they were planned. The family responded by changing providers. At the time of the interviews, several other families were considering (or in the process of implementing) a change to another provider service.

F. Advocacy and Self-Advocacy

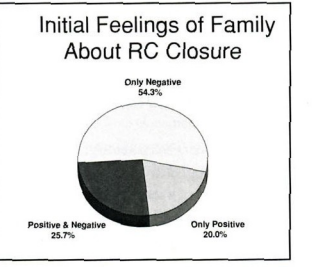
Providers and parents/guardians were asked whether the focus person was involved in a self-advocacy group, such as People First, which has active chapters across the state. Only one focus person was a member of a self-advocacy group. None were members of People First. We also asked whether the focus person had a Citizen Advocate. The Georgia Citizen Advocacy program provides trained lay-advocates who work to support the inclusion of people with disabilities into the community and advocate for their rights. Seven focus people had Citizen Advocates. Many family members and providers were not familiar with either People First or Citizen Advocacy and had difficulty responding to these questions.

CHAPTER 4
PERSPECTIVES OF THE FAMILIES

A. Initial Attitudes/Feelings About Moving To The Community

Family members/guardians were asked about their initial feelings and thoughts when they heard that River's Crossing was going to close. The CHART: *Initial Feelings of Families About RC Closure* shows that for over half of the families/ guardians, the first reaction to the news was negative. About a quarter of the families/guardians had a mixed reaction when they first heard about the closure, experiencing both positive and negative emotions.

The following chart provides more specific information on the initial reactions of the families:

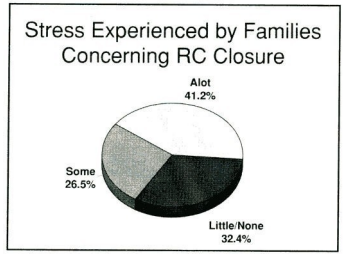


What were your feelings or thoughts when you first heard that River's Crossing was going to close?

Families Initial Attitude/Feelings	Frequency
Distressed - disturbed - anxious - fearful	14
Did not want closing - better at River's Crossing	7
Happy and thankful for closing - wanted community	7
At first concerned; after informed, felt more positive	5
Concerned about medication and well-being	1
Should have targeted larger, less effective institutions for closure, not RC	1
No Data	2

Feelings expressed included fear, anxiety, anger, and concern. The families who were happy about the closure were pleased that they now would be able to secure a Medicaid waiver for their family member to live in the community. These families did not want an institutional placement for their family member in the first place, but were unable to find services to meet their needs while the focus person was living at home. The closure assured their family member the support that they needed to live in the community. Families/guardians were asked how much stress and worry the closing of River's Crossing caused them. The CHART: *Stress Experienced by Families Concerning RC Closure* on the following page, shows that about 70% of the families/guardians experienced stress or worry about the closing. When families/guardians were asked to describe what caused them stress, they

mentioned safety and staffing concerns as the primary causes of this stress (see the CHART: *Things That Caused Stress and Worry*).



Family concerns about safety took many forms, including concerns about whether they could trust the community caregivers, whether someone could sneak into a community residence and harm the focus person, whether staff would fall asleep while they were responsible for supervision, how nonverbal focus people would be able to call for help, whether focus people would wander outside alone, what kind of neighborhood the focus people would live in, who would have access to the community residence, what type of direct care staff would be hired, and who would monitor the focus person's needs. They worried about the hiring and training of caregivers and whether the caregivers would be properly trained to administer and monitor medications.

What things caused particular stress and worry for you during the closing of River's Crossing?	
Things That Caused Stress and Worry	**Frequency**
Safety	10
Finding and keeping the right caregivers	6
Medication issues	4
Stress of the unknown	4
Broken promises	3
Afraid of losing quality of life	2
Locating proper housing	2
Funding problems	2
Problems with legal papers, transportation	2
Normal parental fears	2
Roommate problems	2
Lack of choices in providers (only one to choose from)	1
Lack of involving the parent in decision-making	1
Political structure: lack of interest in human well-being	1

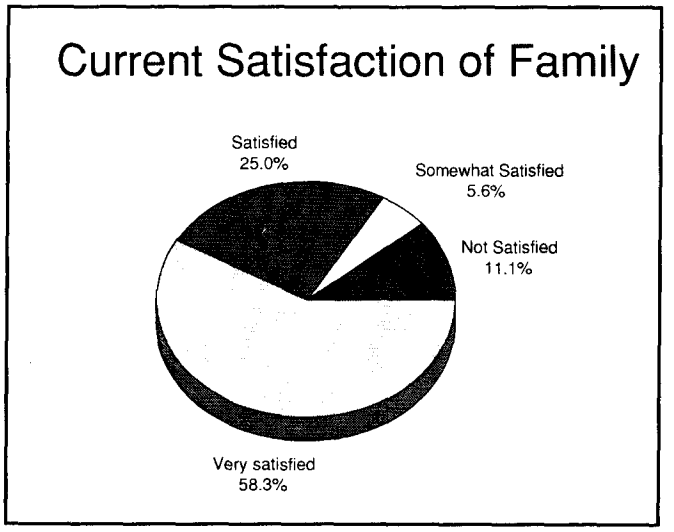
***Note**: Some families/guardians had more than one stress factor listed. Thus the total number of comments exceeds the 37 community families/guardians contacted.*

The three caseworkers from the Division of Family and Children Services (DFCS) who responded to the question were mixed in their initial reactions to the closure. One caseworker saw community living as a positive option for the focus person and experienced no stress over the closure.

The other two caseworkers, however, initially had negative feelings about the closure and were concerned that the focus people could not live in the community. They both indicated that they experienced a great deal of stress concerning the closure.

B. Current Family Satisfaction With Life in the Community.

After the move to the community had taken place and the focus people were settled into their new homes, the families/guardians were overwhelmingly satisfied with the community living situations experienced by the focus people (see PIE CHART: *Current Satisfaction of Family*). *Although most families/guardians were quite concerned when they heard of the closure and experienced stress as they planned for their family member, they were supportive of community living a year after the closure.*



Their outlook was positive that things would continue to get better for the focus person. The misgivings when the news of River's Crossing's closing came had dissipated into thankfulness that their family member could enjoy a better quality of life. One year later, all three DFCS caseworkers who were interviewed were highly satisfied with the focus people's lives in the community. A year after the closure, only a few families were not satisfied with the focus person's life in the community. These families had specific concerns/conflicts with the residential providers. In general, these families were in the process of exploring options for changing their provider service.

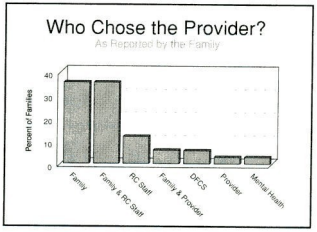
Families who expressed satisfaction with the focus person's life in the community were asked what they particularly liked about the community living situation. Results are reported in the following table:

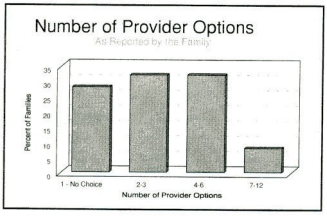
What about the community living situation do you particularly like?	
Response	**Frequency**
Lives closer to home, more visits	10
Likes his/her being in a home and not in an institution	10
More supervision (one-on-one)	8
More love and caring - male and female figures to emulate	3
Better supervision of medication and food intake	2
Nice housing	2

The four families who indicated that they were not satisfied with the focus person's current life in the community were asked about their reasons for dissatisfaction. They had multiple complaints/concerns. Some of the families were unhappy that the focus person was still living too far away from the family home and wanted them to live closer. One of these families lived 60 miles away from River's Crossing, and now lives 60 miles away from the focus person's new home. The other family who was dissatisfied is now much closer to the focus person, who lives approximately 50 miles away (compared with over 200 miles from River's Crossing), but they still want their family member closer. Two families wanted the focus person to live at home with them and, for different reasons, this had not happened. Families complained that staff turnover was too high, causing inconsistent monitoring of medications, that staff supervision was insufficient, and that they were not being kept informed by the providers about what was happening in the lives of the focus people. One mother complained that she knew more about her daughter's life while she was at River's Crossing. Now, in the community, she has difficulty getting information from the provider. One family had been promised by the provider that their daughter would live in a house with a fenced yard; the yard at the house where she moved did not have a fence, and they were concerned for her safety when she was outside. Two of the dissatisfied families had asked providers for an accounting of how the focus person's Medicaid funds were being spent, but had been denied this information. One dissatisfied family complained that things kept breaking down in the focus person's apartment, and, at one point, the water was cut off. Another dissatisfied family was concerned that their daughter had gained 20 pounds and was eating at fast food restaurants too often.

C. Process Of Choosing Providers

For about three-quarters of the focus people, family members were actively involved in choosing the residential provider (see CHART: *Who Chose the Provider?*). Families reported that the number of provider options available to them varied a great deal depending upon where the families lived (see CHART: *Number of Provider Options*). Almost 30% of the families had only one provider available to them, and, as such, had no choice of provider service. In general, these families were unhappy that they





were not offered a choice of provider service. Families were asked to describe how they obtained information about the provider services and how they chose the provider for their family member.

Most families received information about providers from River's Crossing staff and from meetings with representatives of provider services. Some families participated in a study tour of the community living options in the state. Most families benefited from information about the providers made available to them by the River's Crossing staff and appreciated meetings set up by staff that allowed the families to discuss living options with representatives of the provider agencies.

How did you choose the primary provider for residential support?	
Response	**Frequency**
Lists provided to family by RC & meetings held to introduce providers	23
RC staff helped family choose	7
Looked for provider closest to home with the best qualifications	3
Circle of Support helped find & choose the best provider	1
No Data	3

D. What Went Right During The Transition?

We wanted to understand the process of the transition, as viewed by families/guardians. During the interviews, families/guardians were asked to describe the things that went well during the transition to the community, as well as areas that created problems for them or for the focus person. Their responses to the question about what went well are listed in the following table:

What went well in transitioning your family member from RC to his/her new home?	
Response	**Frequency**
Everything went well - smooth transition	24
Staff accompanied focus person to community	13
Team effort: Family/RC staff/provider	12
Minor setbacks - contacted RC staff for help and information	11
RC social worker counseled with families to help prepare them	10
Finding the right housing and community	8
New staff got acquainted with RC staff before the actual move	7
Nothing worked well - Lot of loose ends	5
Meetings before RC closing to introduce provider to family and give information regarding their services	2
RC staff became the caregiver for the focus person in the community	2
No Data	1

Note: *Some families/guardians had more than one factor listed. Thus the total number of comments exceeds the 37 community families/guardians contacted.*

In general, families/guardians were quite positive about the transition experience. They had high praise for the River's Crossing staff for their help and wise counsel. They cited instances where a "team effort" made the transition easier, with providers, families, and River's Crossing staff working together to plan for the transition and to solve problems as they arose. River's Crossing staff accompanied the focus people and families to visit community living options, meeting new staff, getting to know the neighborhood, and easing the stress of moving to a new home. Open communication and easy access to information were also described as important components of a positive transition, as viewed by the families/guardians.

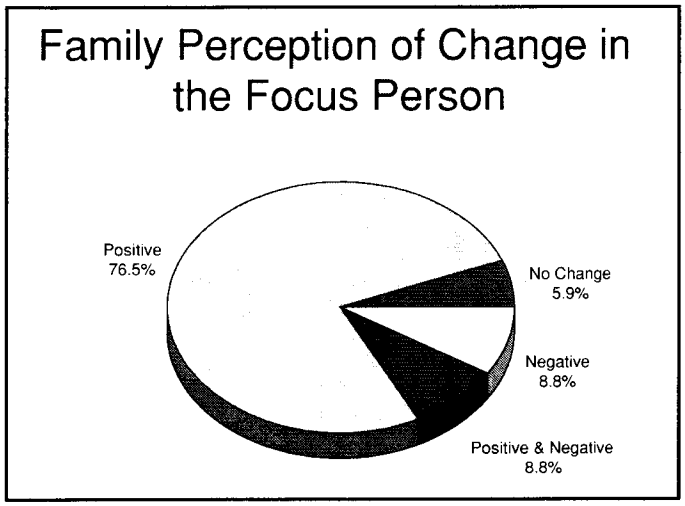
E. What Could Have Been Done Better During The Transition?

As with any other endeavor, the transition from River's Crossing to the community could have gone more smoothly for some of the focus people. Some things went well, but others did not. Family/guardian responses to questions about what could have been done to make the transition easier for themselves and for the focus person are listed in the table below:

What about the transition could have been done better? What problems were experienced?	
Response	**Frequency**
Nothing - Everything went as well as could be expected	11
Miscommunication between family & provider/promises not kept	5
Should have visited home before moving in, prepared better	5
Community home not ready at the time of the closure	4
Staff not well trained and prepared for this type of care	3
Time frame was too short	3
Wanted focus person close to home - nothing available	3
Family member wanted to be caregiver	2
Wanted ground level apartment (not 2nd/3rd floor)	1
Knowing about funding in advance would have relieved some stress	1
Minor issues about furniture and personal items	1
Parent should stay involved and monitor	1
No Data	8

Note: *Some families/guardians had more than one factor listed. Thus the total number of comments exceeds the 37 community families/guardians contacted.*

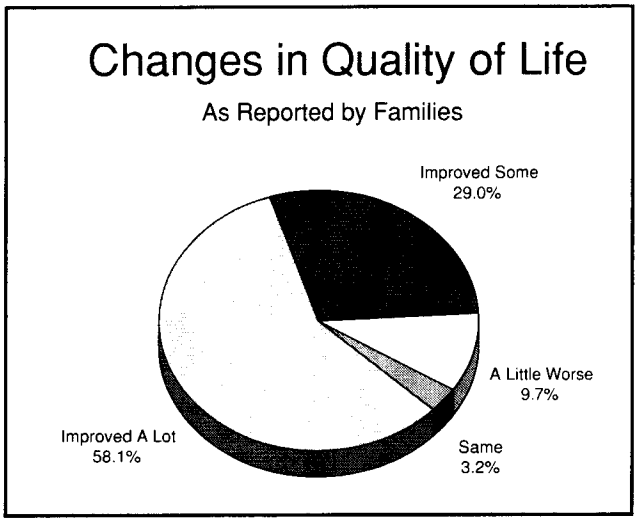
Miscommunication between the families and the providers was the most frequently mentioned problem. Some families believed that they had been made promises that were not kept after the provider was selected. The time frame for the transition was viewed by some as being too short, and families/guardians were concerned that support staff were hired and began work with little if any training. The homes for several of the focus people were not ready when River's Crossing closed. These people had to move somewhere else temporarily, until arrangements for their home could be



completed. Families viewed this as being very unsettling and disruptive to their lives. A few families had hoped that their family member could move closer to the family home than was possible, given the restraints on the provider services. One mother described how her son cried the first week or so in his new home. He had only visited the home once before the move. The mother believed that the transition would have been easier for him if he had the opportunity to visit more often and become comfortable with the new setting before the final move took place. The desire to have the focus person visit the new home more often before the move was echoed by several of the families.

F. Changes In The Focus Person

Family members/guardians were asked whether or not they saw a change in the focus person since the move to the community (see CHART : *Family Perception of Change in the Focus Person*). Ninety-four percent of families/guardians noted a change in the focus person since leaving River's Crossing. Over three-quarters of the families/guardians perceived that the focus person had changed in a *positive* way.



A question was also posed to family members/guardians asking them if they believed the focus person's quality of life had changed since moving to the community (see CHART: *Changes in Quality of Life*).

Over 85% of families/guardians believed that the focus person's quality of life had *improved* since leaving River's Crossing. Over half believed that his/her quality of life had improved "A lot." The table below describes the types of changes that the families/guardians perceived in the focus person.

Families/guardians reported a decrease in challenging, disruptive behavior after their family members moved to the community. The focus people were described as being calmer than they were when living at River's Crossing. It is important to note that many families believe that the focus people are *happier and more joyful* in their new homes in the community.

Changes the Family Observed in the Focus Person Since Leaving River's Crossing	
Positive Changes	**Frequency**
Less disruptive behavior - calmer	18
Happier - shows more joy	16
Health better: i.e., fewer seizures, medication monitored to health needs, etc.	9
Made progress in personal skills and personal hygiene	7
Walking, recreation and getting outside makes them happy.	6
Responds well to the caregiver, 1-1 ratio much better.	5
More verbal, using more words	3
Feels safer	2
Improved in school	2
Much longer attention span	1

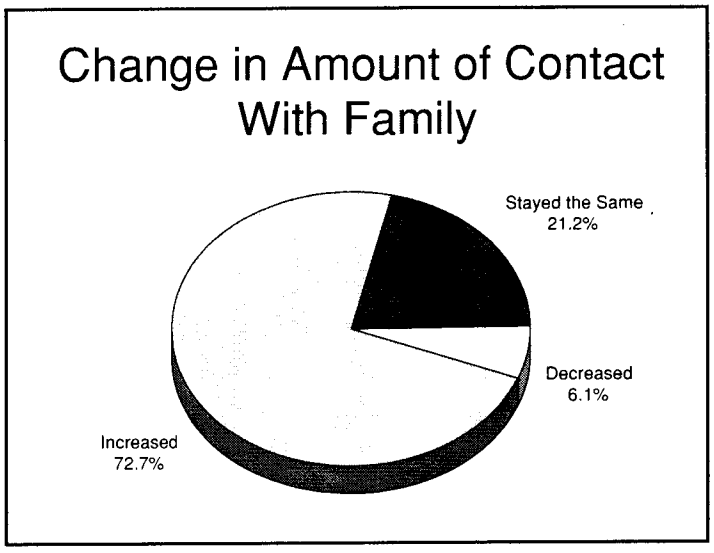
A father noted how his son now "smiles a lot." Another father said that his son "seems a lot happier and seems to be getting more affection."A grandmother stated that her grandson "is more satisfied, calmer, more at peace; he doesn't whine or cry as much." One mother described how happy she was that her son was now having "a normal life." Interviewers visiting the focus person confirmed the perceptions of the families, frequently noting the "broad smiles" of the focus people during the interview visits. One focus person becomes agitated when hearing about River's Crossing, wanting to be reassured that River's Crossing is closed, and he won't be going back.

Health and hygiene improvements were described, as were increases in skills and use of language. One family commented that their daughter is beginning to dress more like a teenager, and doesn't think of herself as a "little girl" anymore. Focus people enjoy increased recreational opportunities and greater opportunities to spend time out of doors. Relationships with family are improved for some of the focus people.

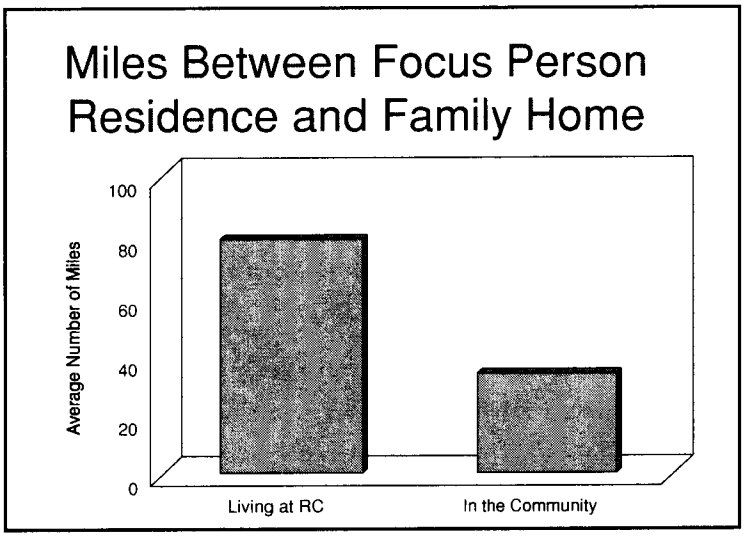
For three family members who noted a negative change in the focus person, the most frequent problem was an increase in challenging behavior. One family was concerned that the focus person had lost skills in his initial community placement. After moving to another home, served by another provider, this family believed that those lost skills were slowly returning. One family was concerned that lax supervision was allowing their family member to ingest body fluids/products, causing bacterial infections and health problems, decreasing her quality of life. Another commented that she was concerned about her son's gums and potential tooth decay without dental services.

One focus person was obviously missing his friends at River's Crossing. He still talks about wanting to go back to River's Crossing and brightens his affect when River's Crossing is mentioned. He seems to particularly miss certain members of the River's Crossing staff. His mother believes his quality of life has improved since moving to the community, but she is concerned that he misses his friends. When focus people/direct support staff were asked whether the focus person was happy that he moved out of River's Crossing, this was the only person for whom the answer was "No."

G. Family Visits And Contacts Since Moving to the Community



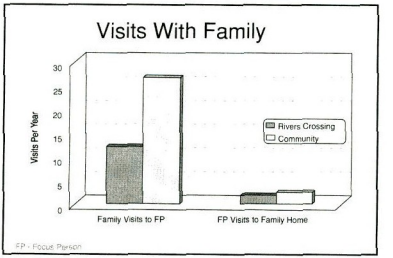
One of the hopes of the families and advocates supporting the closure of River's Crossing was that the move to the community would increase the amount of time that focus people would be able to spend with their families. Families were asked a series of questions about their amount of contact with the focus person, both while the focus person was living at River's Crossing and since the move to the community. Almost three-quarters of the families said that their contact with the focus person had increased since the move to the community (see CHART: *Change in Amount of Contact With Family*). There were three family members who saw the focus person less often after the move from River's Crossing. One mother worked very long rotating hours; she said she knew that the focus person was only a mile from her and she could get to him should something happen. There were two instances where the primary parent figures were incarcerated and could not visit the focus person in the community. A guardian had been assigned for both focus people.



The distance between the residence of the focus person and the family home decreased substantially after the focus person left River's Crossing (see the CHART: *Miles Between Focus Person Residence and Family Home).* Families lived an average of 79 miles from the River's Crossing facility. The closest family lived 15 miles from the facility; the most distant family lived over 200 miles away. Families lived an average of 28 miles from the focus person's home in the community. A small number of families, however, still lived far from the focus person. The most distant family lived 100 miles away from the focus person's community residence. The focus person's family hoped that things could be worked out over time so that he could live closer.

All of the families/guardians had visited the focus people in their new home in the community. While living at River's Crossing, focus people were visited by their families an average of 12 times

a year. *After the move to the community, visits to the residence of the focus person more than doubled in frequency* (see CHART: *Visits With Family*). Although a few families had visited the focus person only once or twice, other families visited up to 300 times in the year since the focus person moved to the community.



Most of the families arranged for the focus people to come to their homes for visits. These visits to the family home increased modestly after the move to the community (see CHART: *Visits with Family*). The following chart provides more detailed information on the frequency and duration of visits to the family home:

Since leaving River's Crossing, has the focus person come to visit you at your home? If Yes, how often? For how long a stay?

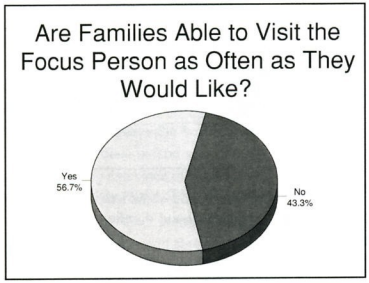
Visit At Home?	Frequency	If Yes, How Often?	Frequency	How Long Were the Visits?	Frequency
Yes	27	Occasionally	14	Few hours	12
No	4	Weekly	7	Day	10
DFCS	4	Monthly	4	Weekend	3
No Data	2	Frequently	1	Overnight	1
		No Data	1	Week or more	1

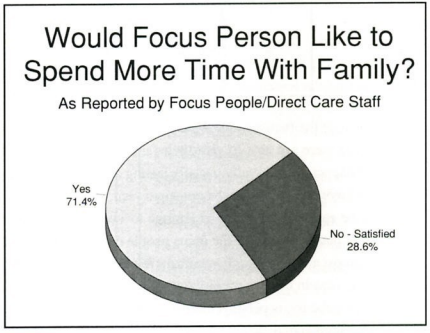
Four of the focus people were in the custody of the Division of Family and Children Services (DFCS) and were not able to visit their families of origin. For the other focus people, visits home tended to happen occasionally, usually lasting a day or less. One mother described how she prepares her son's favorite foods when he comes to visit, since he enjoys eating them so much. In general, it seems to be easier for families to arrange to visit their family members at their new homes in the community than it is to have the focus people come to the family home to spend time.

Almost all of the family members felt there was greater knowledge of what was going on with the focus person in the community setting than when they lived in River's Crossing. Parents voiced joy in having the focus person closer to home where more frequent visits were possible.

> A parent stated: *When we had a family dinner at her place for her birthday, my parents came. I never envisioned being able to do that. To be able to say, I'm going to have dinner at my daughter's house. ..... She is a young lady.*

We asked family members if they were able to visit the focus person as often as they would like. Over 40% of the families answered "No" to this question (see CHART: *Are Families Able to Visit the Focus Person as Often as They Would Like?*). These families were asked what barriers kept them from visiting. Conflicts with work schedules were the most frequently mentioned barrier. One of the parents mentioned that she had only short amounts of time after work to visit and was concerned that arriving and leaving quickly would be more upsetting to her daughter than not visiting at all. Other barriers to more frequent family visits were due to personal/family reasons, lack of transportation, lack of time, and health problems. Some providers are willing to drive the focus person to see their families; other providers are not. One family indicated that the provider did not make them feel welcome when they visited, and that the provider had asked them not to bring the focus person's brothers to the focus person's home to visit. This angered the family because they wanted their daughter to have the opportunity to get to know her brothers. Another family speaks only Spanish. They can only communicate with the provider and staff supporting their son when another of their sons or their daughter can go with them and translate.

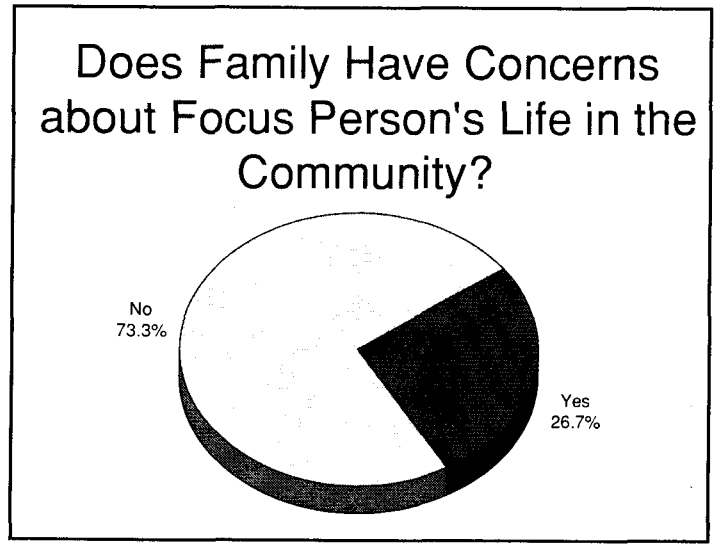




We asked the focus person/direct support staff if the focus person was satisfied with the amount of time they were able to spend with their families, or whether they would desire more time together, or less time together (see CHART: *Would Focus Person Like to Spend More Time With Family?*). Over 70% of the responses indicated that the focus people would like to spend more time with their families. Thus, although family contact increased after the move to the community, all concerned wished for even more time to spend together.

H. Remaining Fears

A year after the move to the community, families/guardians were asked if they had any remaining concerns about the focus person's current home or about community life. The CHART: *Does Family Have Concerns about Focus Person's Life in the Community?* indicates that almost three-quarters of the families have no remaining concerns about the focus person's community life. For those families with remaining fears, the following chart describes their continuing concerns:

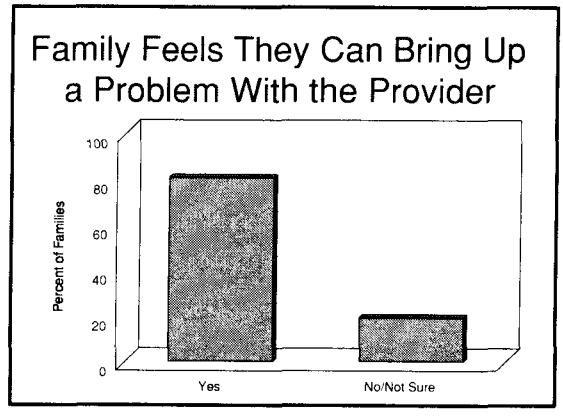


What are your fears or concerns regarding the focus person in his/her current home?	
Response	**Frequency**
Safety: Getting hurt or sick	4
Adequate supervision	4
Always worry about health/normal parental concerns	4
Safety from abuse	1
Quality of interaction with staff	1

Safety concerns remained the families' strongest fears. They feared injuries to the focus people and worried about whether supervision and monitoring in the community residences was adequate.

I. Relationships Between Family and Providers in Addressing Problems

The CHART: *Family Feels They Can Bring Up A Problem With The Provider* suggests that almost 80% of the families reported that they were comfortable bringing their problems or concerns to the attention of the providers. One family changed providers during the first year due to the provider's unwillingness to listen to her suggestions about the support needs of the focus person. For most families, however, communication with the provider agencies seemed to be working well.



CHAPTER 5
PERSPECTIVES OF THE PROVIDERS

A. What Went Right During The Transition?

One of the reasons for conducting this follow-up study was to determine the things that were done well during the closure, as well as to identify ways in which the process could have been improved. In the previous section of this report, we described the responses of families/guardians to our questions about the strengths and weaknesses of the transition process. We asked providers a similar series of four open-ended questions, inquiring about what went right during the transition for the focus person and for themselves as providers, as well as about things that could have been done to make the transition easier for the focus person, and for themselves. The following table summarizes their responses to the questions concerning what went right in the transition process:

What things went right during the transition to the community?	
Responses	**Frequency**
Team effort. Having family involved and active, strong support from RC staff	20
Finding housing before closing, able to furnish/prepare house before the move	8
Finding the right community support staff	7
Being able to have RC staff accompany the focus person to the community	5
Provider visited RC and got to know the focus person before the move	4
Having focus person visit the community before the actual closing	3
Nothing, except that RC closed and the focus person moved to the community	3
Provider was not involved at the time of closure	2
No Data	3

Note: *Some Providers noted more than one factor that went well in the transition. Thus the total number of comments exceeds the number of providers interviewed.*

The providers had glowing praise for the staff who worked at River's Crossing. They lauded the dedication of the staff to making the transition go smoothly and the willingness of staff members to go "above and beyond the call" to work on behalf of the focus people. Although their jobs were at risk because of the closure, most River's Crossing staff strongly believed in the right of the residents to live in the community and were excited about the new lives the focus people could have after the facility closed. Provider comments included: "River's Crossing staff did a fine job," "River's Crossing staff helped a lot," "We could call and ask questions of River's Crossing staff," "River's Crossing staff gave a lot of input and a team effort made the transition easier," "River's Crossing staff helped make it smooth." Providers described instances in which staff were called upon for assistance even

after the facility had closed and the staff were working at other employment. Staff encouraged providers to call them and provided ongoing support and assistance.

Families of the focus people also received praise from the providers for their efforts in behalf of their loved ones. Many families became actively involved in finding housing, selecting support staff, and planning for the move to the community. Good communication between the providers and the families was viewed as a critical element of a successful transition. Providers and families worked together to try to find housing for the focus people as close to their family home as possible. Furnishings and personal items were provided by some families to enhance the hominess of the new houses and apartments. The team effort among the providers, River's Crossing staff, and families was viewed as the most positive aspect of the transition process by many providers. Another key to success was the ability of the providers to secure appropriate housing well before the move and to identify and hire appropriate support staff.

B. What Could Have Been Done Better During The Transition?

When the providers were asked about things that could have gone better in the transition, two overarching issues emerged: *the need for additional time and for additional communication/ information*. In many ways, these two issues are interrelated. A rush to move the focus people into the community quickly sometimes precluded sharing of important information that could have facilitated the transition process. The short time frame compromised the ability of the provider, family, and River's Crossing staff to work together to plan for the move. Communication problems were also created, as exemplified by a provider who was not able to supply some of the things that a family believed that they had been promised by River's Crossing staff.

While many providers lauded the efforts of the River's Crossing staff, a few providers needed more assistance from the staff than they received. One provider captured the lack of information by stating, "Lots of questions...No answers!" Although communication with River's Crossing staff was cited as a problem for some providers, it was clear that much of the information void experienced by providers did not result from River's Crossing staff failing to share what they knew. Rather, there were systemic information problems that created a context in which neither the providers, families, nor River's Crossing staff had all the information they needed to proceed in a planful fashion.

The providers listed the following concerns that, if addressed, could have helped make the transition smoother. (See the CHART: *What could have been done better during the transition?* on the following page.)

Providers attributed many of the problems that they experienced to a lack of time to plan for the transition. Some providers were not given specific information about when the focus person would be leaving River's Crossing, creating problems in adequately planning for the move. One issue mentioned by providers was a need for additional time and additional information to assist in a more informed selection of support staff. They were not able to visit River's Crossing as often as they would have liked or were not able to get to know the focus person sufficiently to make key decisions about

the person's support needs in the community. A few providers were not able to even meet the focus person's family before the move to the community.

What could have been done better during the transition?	
Response	**Frequency**
More communication between the families and the staff would have helped	10
More observation at RC of what would be needed for day/night activities	8
Nothing that I can think of	7
Time frame: Very rushed and chaotic toward the end	5
More information about the challenges they might be facing to better prepare	4
Choosing the right support staff, providing training for support staff	3
Housemate problems	3
Time frame - more specific information about when to expect the focus person	3
Startup money was a problem (not sufficient or no money available)	2
Difficult to get medical specialists for about six months	2
Tax questions and finding the solutions	1
Housing closer to family, but outside family community (now closer than RC)	1
Limited records: needed more detailed information than discharge packet	1
Focus person experienced loneliness due to inability to communicate	1
Paperwork was not complete and required a lot of time	1

Note: *Some Providers noted more than one factor that created a problem or could have been done better in the transition. Thus the total number of comments exceeds the number of providers interviewed.*

Some providers were selected very late in the closure process. These providers experienced particular difficulty in having time to get to know the focus person and to plan for the transition. Providers also differed in their experience and expertise in planning transitions. More experienced providers, particularly those who valued collaborative planning, made greater efforts to work as team members with families and River's Crossing staff. Some providers were more knowledgeable than others about the questions they needed to ask and the information they needed to obtain to be prepared to support the focus people in the community. As described in a later section of this report, some providers were able to take advantage of the personal futures plans that were done for focus people leaving River's Crossings, while other providers were unfamiliar with this process and did not draw upon the information in the futures plan to facilitate the transition.

Lack of sufficient start-up funds was a problem for some providers. One provider described that at the time of the move, the focus person's house was unfurnished. The provider scrambled to pull together donated furnishings, resulting in a house where "nothing really matches." Other providers had difficulty finding housing and support staff close to the focus person's family and had to compromise in choosing the location of the person's home. As reported earlier, this was of serious concern to those

families who remain physically separated from their family member because of distance. For those focus people who moved to the community with housemates, there were some problems in selecting an appropriate housemate. Some housemate matches failed because of aggressive behavior on the part of one focus person or general incompatibility.

Since the timeline for closure was primarily determined by the budgeting process of the Georgia legislature, it presented all participants in the closure process with constraints that could not be altered. The closure was a component of the Governor's requirement that all state departments redirect 5% of their budgets into programs that had high priority or were underfunded. Monies were being redirected from the institution into community supports. To have extended the closure beyond the end of the fiscal year would have put the financial basis for the closure in jeopardy. The process was driven by the knowledge that on June 30, 1996, *the lights would be turned off in the building* and everyone who lived there needed to have moved to another home.

C. How Did the Providers Become Acquainted With The Focus Person?

One of the first steps in moving to the community was for the focus person and representatives of the provider service to become acquainted. We asked the providers how they met and got to know the focus person. Their responses are included in the following chart:

Getting to Know Focus Person.	
Response	**Frequency**
Met at time of closing/visited focus person at RC	16
Provider involved in futures plan/acquainted at RC prior to closing	7
Worked at River's Crossing	3
Did not know prior to move to the community	3
No Data	8

Most providers indicated that they met the focus person for the first time shortly before the closure. For some, this occurred at the futures planning meeting held at River's Crossing. Some providers were able to visit the focus person several times before the move. Some focus people were able to go into the community to meet the providers. A few providers, however, reported that they did not meet the focus person until the move to the community actually happened.

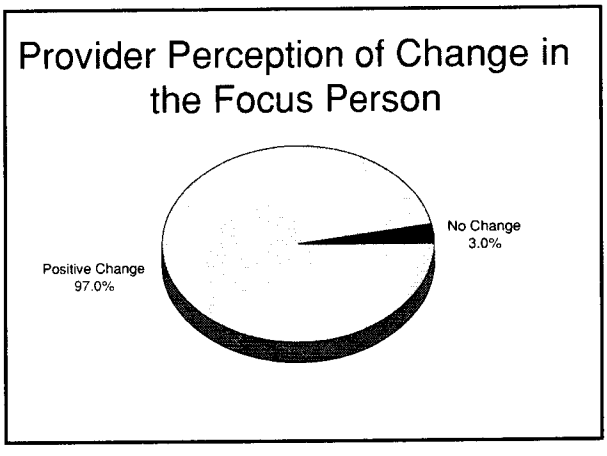
D. Changes In The Focus Person Since Moving To Community

Providers were asked whether they noticed any changes in the focus person since moving to the community. Almost all of the providers indicated that the focus people had changed in the past year (see CHART: *Provider Perception of Change in the Focus Person* on the following page). As with the

family perceptions, the providers who noticed changes viewed these changes as being overwhelmingly *positive*. The most frequent changes perceived by the providers were decreases in challenging behavior, improved hygiene, increased self-esteem and happiness, and greater independence.

Provider's Perception of Change in the Focus Person	
Responses	**Frequency**
Less aggressive, fewer behavior problems	8
Better hygiene, improved grooming and dress	6
Feels better about himself, happier, laughs more	4
More independent/better self-care skills	4
Improved sleep	3
More relaxed/calmer	3
More lively/outgoing/confident	2
More community participation	2
Uses more words, talks more	2
More tolerant of physical contact	1
Less self-injurious behavior	1
No change	1

E. Staffing Patterns



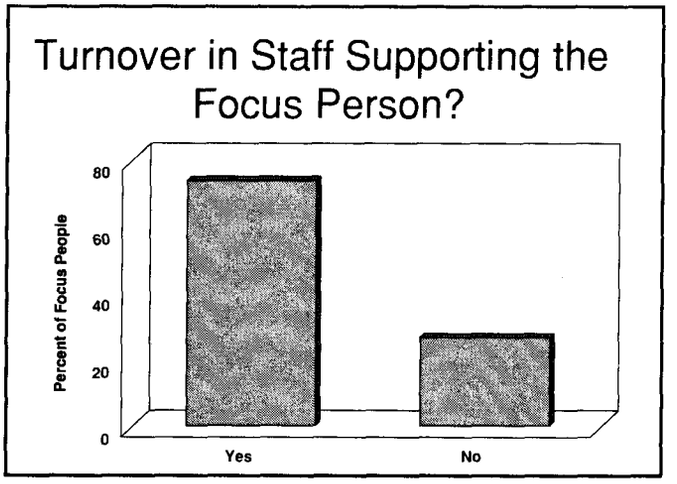
River's Crossing employed 54 direct care workers to provide 24-hour support for the residents who lived there. After focus people moved to the community, individualized support needs were assessed and different levels of staff support were secured based on the needs of each focus person. We asked the providers about the number of day and night staff who were available to the focus person. For 21 of the focus people, one day staff member was assigned; for three focus people, there were two designated day staff. Other focus people shared support staff with their housemates, resulting in a 1:2 or greater staff to focus person ratio (no data were available for 4 of the providers). At night, 19 focus people were supported by one staff member; one person had two staff people assigned to them at night. Others had less than a 1:1 staff to focus person ratio at night. Staff support was greatest for those focus people who were restless and did not sleep through the night.

The number of support staff was increased or decreased during the first year in the community for several of the focus people. Twelve of the focus people needed more support staff than were originally assigned, so that staffing intensity was increased after the person settled into their new home.

Providers attributed this need for additional staff to the presence of more intense challenging behavior and aggression than was originally anticipated, as well as to the need for one-on-one support. For three focus people, fewer staff were required than originally anticipated. This was primarily due to decreased need for night staff.

For 19 of the focus people, River's Crossing staff followed them to the community, changing jobs and geographic locations to support the focus people in their new community homes. The focus people whose staff accompanied them to the community adapted very quickly to their new homes. Staff already knew the habits of the focus people, understood their support needs, and were able to facilitate a smooth community transition. One provider noted that staff were "like family" to the focus person. In two instances, River's Crossing staff were not successful in making the changes needed in moving from an institutional to a community support setting. One provider commented that the staff person was not able to work with the loose supervision found in community contexts -- a change from the more structured institutional setting. Another provider perceived that a staff member was not able to leave the institutional mind set behind and adapt to providing community support.

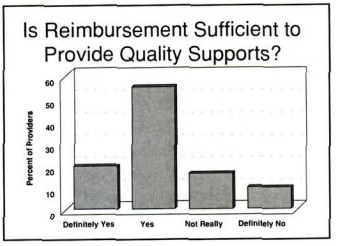
Two-thirds of the focus people had experienced at least one change in support staff during their first year in the community (see CHART: *Turnover in Staff Supporting the Focus Person?*). This staff turn-over was caused by a variety of reasons. Some staff resigned because of personal reasons (returned to school, found a better job, pregnancy), while others experienced burn-out or frustration with the challenging behaviors exhibited by the focus person they were supporting. At times, provider agencies moved staff from one focus person's home to another in order to find a better match between the staff person and the focus person. Some direct support staff were terminated during the year. This generally occurred because of a lack of fit between the skills/characteristics of the staff member and the support needs of the focus person. One staff member was terminated due to behavior that was viewed to be inappropriate and potentially abusive to the focus person. Generally, the termination decisions were made by the provider agencies, but, upon occasion, staff were terminated based on the request of the focus person's family.



High staff turnover does not allow the focus person to really get to know their support staff or to become accustomed to the same person for long periods of time. Learning to communicate and building trust are more difficult when staff are not stable over time. Some focus people experienced multiple changes in staff, creating stress for all involved. These issues presented a challenge for the provider agencies, for newly hired support staff, and for the focus people. Staff turnover was a major concern for families.

F. Reimbursement Issues

Providers were asked about their daily reimbursements for providing support. They were also asked whether these rates were sufficient to provide quality supports for the focus person. Most providers received $118.26 per day, which is the rate for Personal Support under the Mental Retardation Medicaid Waiver Program. Higher reimbursement rates were negotiated for a small group of focus people with particularly intense/challenging behavior. Some of the providers received an additional $70 per day, for 240 days during the year, for day habilitation services. Most providers indicated that the reimbursement rates were sufficient to provide needed support (see CHART: *Is Reimbursement Sufficient to Provide Quality Supports?).* The most frequent complaint was the lack of day habilitation funds to plan meaningful days for the focus people. A few providers had concerns that sufficient funds did not exist to provide needed supports for focus people with very aggressive or otherwise challenging behavior. For some of the focus people, their providers believed that the reimbursements were only sufficient to meet their needs because the focus people had one or more housemates. Providers commented that if these people lived by themselves, the funds would not be sufficient to pay for their support. Another provider noted the staff approached her with a list of needed "extras" that are needed in the focus person's house. These requests must be denied because the funds are too tight. One provider noted that funds were not sufficient for her to "rent a movie or go for a pizza" and sometimes were insufficient to purchase needed clothing for the focus person. Donated items supplement what can be provided for the focus people from the reimbursements received by providers. For other focus people, funds are sufficient only because families pick up part of the expenses and pay some of the focus person's bills.

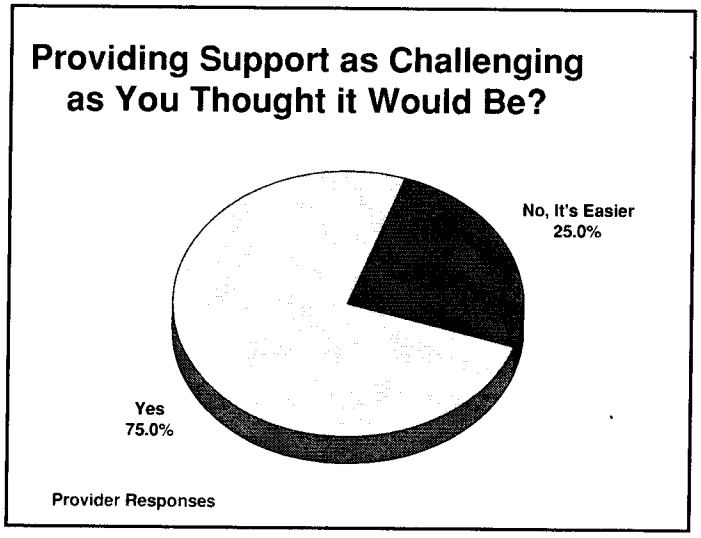


The data indicated that all of the providers who stated they did not have sufficient funds to provide quality supports for the focus person were providing support for individuals with challenging behavior. Thirty-seven percent of the providers supporting focus people with challenging behavior found the reimbursement rates insufficient. None of the providers providing support for people without challenging behavior indicated a problem with the adequacy of reimbursements they received.

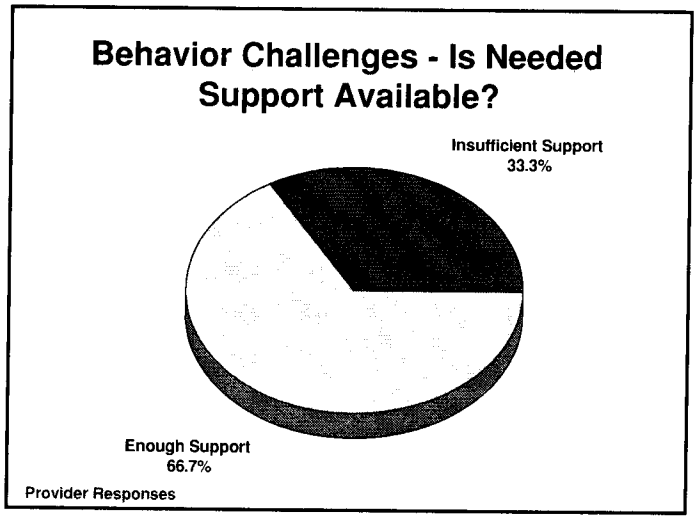
The flow of funding created problems for a number of providers. In some cases, startup money was not available during the initial transition. We interviewed one provider who was continuing to keep a focus person in her group home without reimbursement. The provider contract had expired and the local provider service had been sold. The caregiver did not want to send the focus person away, so she continued to keep him without funds. This provider paid staff from her own pocket until a new agreement could be reached.

G. Challenging Behavior - And Other Challenges

Many of the focus people leaving River's Crossing had quite negative "reputations" that caused concern that their support needs might not be able to be met adequately in the community. At the time of the closure, some of the provider services shared these concerns and were anxious about their ability to support individuals with negative histories like those of the people living at River's Crossing. This was a new frontier for some of the provider services and they did not know exactly what to expect until they had actual experience with the focus person in the community. We asked the providers a year after the closure whether supporting the focus person in the community had been as challenging as they thought it would be. The responses are graphed in the CHART: *Providing Support as Challenging as You Thought it Would Be?* About two-thirds of the providers answered "Yes." A third of the providers, however, found that the unknown challenges of providing support had not been as great as they had expected. Many providers were surprised at how well the focus people adapted to their new surrounding and caregivers. There had been problems, but they were faced as they materialized and solutions were sought.



According to the service providers, approximately three-quarters of the focus people had behaviors that could be considered as challenging, including aggression, self-injurious behavior, and destructive, angry outbursts. Several of the focus people reacted to the initial transition with intensified challenging behavior, which leveled off after the person became more comfortable with their new surroundings. For providers faced with these behaviors, we asked about the adequacy of behavioral support that they received to assist them in responding to challenging behavior. *It is of concern that one-third of the providers perceived that the behavioral support available to them was not sufficient to meet the focus person's needs* (see the CHART: *Behavior Challenges - Is Needed Support Available?*).



CHAPTER 6
FUTURES PLANNING AND CIRCLES OF SUPPORT

A. The Planning Process

The Governor's Council on Developmental Disabilities for Georgia funded Dottie Adams of Community Support Services in Athens to facilitate a futures plan for each focus person before the person moved from River's Crossing. The process was based on the work of Dr. Beth Mount. Detailed information about the futures planning process for residents of River's Crossing can be found in *Children Are Our Future: Alternatives to Institutions for Children and Adolescents*, by Dottie Adams, 1996, available from the Governor's Council on Developmental Disabilities (Suite 210, Third Floor, 2 Peachtree Street, N.W., Atlanta, Georgia, 30303). The introduction to that document states, "Futures planning became a tool to help families, friends, and staff focus on each individual to examine what they might want for their future. Details were discussed about the type of support that would be needed; priorities were set and a timeline of activities was laid out."

We were able to obtain and analyze 30 of the futures plans. Participants in the meetings were listed on the plan. There were between 5 and 21 people participating in each of the futures planning meetings (the average was 10 participants). The focus people were always present. Twenty-eight of the 30 focus people for whom we had plans had a parent, other family member, or guardian present. River's Crossing staff were present for all of the planning meetings. Twenty-two of the meetings included a representative of the provider service that would be providing community support for the focus person after the move.

Each futures plan provided important profile information which created a picture of the focus person. (See FIGURE: *Futures Planning Format* on the following page.)

B. Use of the Futures Plans

Examining the 30 futures plans available to follow-up, we found that the plans were rich with information and dreams. They were very detailed and carefully documented a wealth of information about the focus people. Those who were closest to the focus people and knew their habits and preferences had spent many hours creating in-depth personal profiles. The plans outlined the gifts each focus person brings to community life, their strengths, positive qualities, and capacities. Supports that the focus people would need to live in the community were delineated, as were preferences concerning housemates (or lack thereof), desirable characteristics of support staff, intensity of staffing needs, important relationships with friends and family, and activities enjoyed and disliked by the focus person. Many of the challenges and barriers to reaching the focus person's dreams were summarized in the plan, documented by those who knew the focus people the best.

FUTURES PLANNING FORMAT

FUTURES PLANNING FORMAT

Planning For: _____ Date: _____

People Participating In The Planning Process:

_____ _____
_____ _____
_____ _____
_____ _____
_____ _____

Personal Profile Information For:

Home	Places	Choices	Skills
Health	People	Images	Dreams

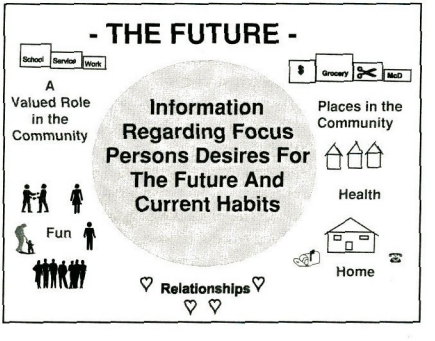
PERSONAL PREFERENCES

Name: _____

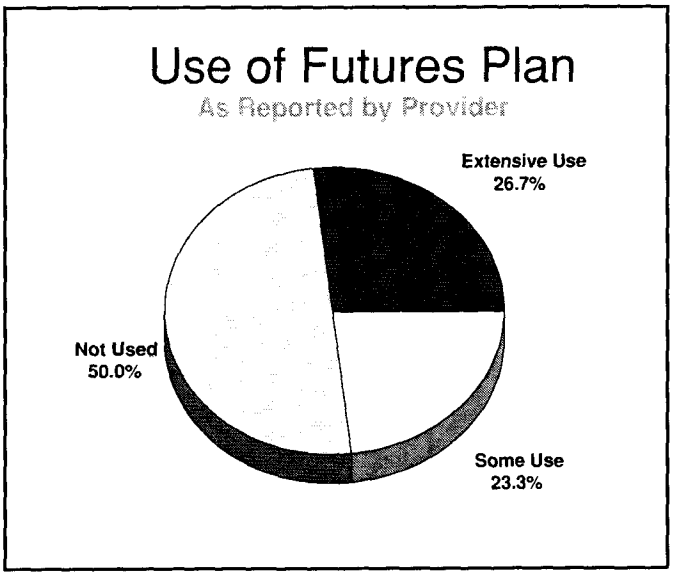
Things That "Work", That Create Interest, Motivation, Engagement	Things That "Don't Work", That Create Upset, Frustration, Depression

OBSTACLES	OPPORTUNITIES	STRATEGIES
Priorities:		Timeline:

- THE FUTURE -



the information in the futures plan as they worked with others to design the community living environment for each focus person. The futures plan would only be expected to have a positive impact on the focus person's life if it were studied and used by the provider to assist in making key decisions about the focus person's new home. Unfortunately, only a minority of the providers utilized the rich information in the futures plan (see CHART: *Use of Futures Plan*). Slightly over 25% of the providers indicated that they were currently, or had in the past, made extensive use of the information contained in the plan. A smaller number of providers had used the plan to a limited degree. Half of the providers had not used the plan at all. River's Crossing staff reported that each provider service was given a copy of the futures plan. Nonetheless, some of the providers reported that they couldn't remember ever having seen the futures plan; others were not sure if they had seen the plan or not. It was obvious from the interviews that some of the providers did not know what a futures plan is, and were not clear what the interviewer was asking. Other providers had a copy of the plan on file, but had not used it.



Participation in the futures planning meeting at River's Crossing increased the likelihood that the representative of the provider service would know what a futures plan is and utilize the information contained in the plan. Of those who reported that they utilized the futures plan extensively, 87% of the provider services had a representative who participated in the River's Crossing meeting. For those who did not use the plan at all, or did not know that it existed, approximately half of the provider services were not represented at the River's Crossing meeting. It appears that the futures planning meeting helped the providers gain an understanding of the importance of the information in the plan and created a context for interpreting the drawings and notations that comprised the plans. Being present and helping to develop the plan increased its meaning and created a degree of "buy-in" from the providers.

Several providers commented that they had used the futures plan to assist them in developing the Individualized Service Plan (ISP), but now use the ISP to plan for the focus people. These comments, in effect, communicate that the providers switched paradigms, moving from a support paradigm, represented by the futures plan, to a more traditional, professionally-focused service paradigm, represented by the ISP. Providers making this paradigm-shift made use of the information in the futures plan to assist in the transition process. However, the futures plan does not achieve its potential impact when only used to facilitate the development of the ISP. One of the providers indicated that it had been a mistake to ignore the futures plan in the beginning, and noted that she had recently begun to appreciate its importance. She stated: "If we had paid closer attention to the

information provided in the futures plan, it would have eliminated some problems for both the focus person and our staff. There were some vital facts listed in the WHAT'S WORKING and WHAT ISN'T WORKING that should have been heeded."

One of the shortcomings of the futures planning process, as implemented in the River's Crossing closure, was that success depended on the community providers having an understanding of person-centered planning and skill in implementing this approach. The transition plan would only work if the providers and families/guardians could understand and use the futures plans and were knowledgeable about the next steps to take in the planning process. Unfortunately, this assumed a level of skill and knowledge on the part of many of the providers that did not exist. For the process to be successful, it would have been critical for the providers to receive intensive training in person-centered planning. This did not happen. Most providers did not receive any training or continuing support to assist them in using the information in the futures plan or to help them identify and implement the next steps in the person-centered approach. Funding was available to develop the futures plans, but funding was not available to teach providers and families how to use the plans.

For a few focus people, the futures plans fell upon a receptive environment in the community setting. In these instances, providers endorsed the support paradigm, were knowledgeable about person-centered approaches, and used the futures plan to facilitate the focus person's entry into the community. For these focus people, the futures plan was an important road map to community living. For most of the focus people, this was not the case. Frequently, the person-centered planning process was not understood by the provider services. The futures plans were completed in an extremely competent manner, but at the community provider service, they fell on dry, rocky soil. They died and did not thrive. Providers looked at the "funny drawings" on the plan and did not take them seriously. They did not know how to interpret the information. The professional ISP model was respected and considered to be effective; the person-centered approach may have seemed unnecessary and irrelevant. For some providers, the ISP model and person-centered planning were indistinguishable and viewed as being the same thing. As the case with providers, many families/guardians were unfamiliar with the person-centered approach and uncertain how to use the plan to advocate for the focus person's future.

One of the lessons of the River's Crossing closure is that developing a futures plan, in and of itself, is not sufficient to foster a better life in the community. Developing a plan is only the first step. This is not a new lesson. It has been an important tenet of those who have developed and implemented person-centered approaches. Futures planning raises expectations and encourages dreams, but these expectations and dreams will not be realized if the plan is put in a closet or filed away. Unfortunately, for the majority of focus people leaving River's Crossing, the futures plan was the first *and last* step in the person-centered planning process.

C. Circles of Support

If ideally implemented, the futures planning process would lead to the development of a circle of support for each of the focus people. After the move to the community, a designated facilitator

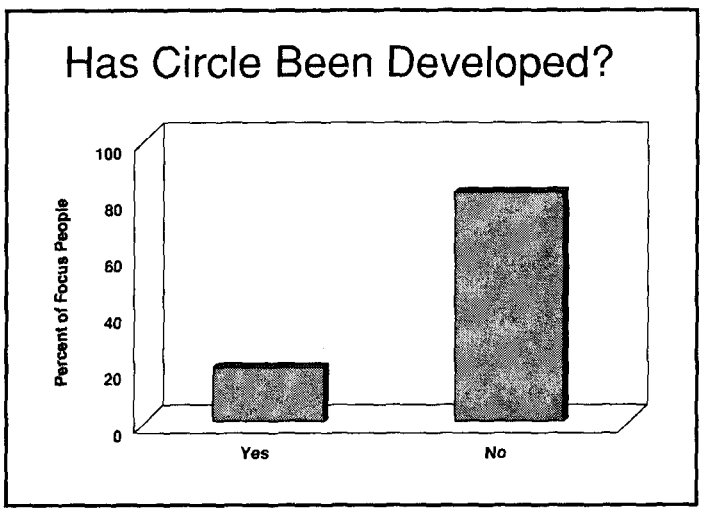
would convene a meeting including family/guardians, staff, friends, neighbors, and others in the community who are a part (or who want to become a part) of the focus person's new life. The circle would use the futures plan as a stepping-off point, working with the focus person to constantly revise the plan and to work toward a desired, meaningful life in the community. Beth Mount (1994) describes this process, "Personal futures planning is much more than a meeting; it is an ongoing process of social change. The effectiveness of a plan depends on a support group of concerned people who make a dream reality by learning to solve problems, build community, and change organizations together over time (p. 97)."

To ascertain whether this component of the futures planning process occurred during the first year in the community, we asked parents/guardians and providers if the focus person has a circle of support. If the respondent indicated that a circle exists, we asked whether the circle was currently active, how often it met, who are members of the circle, and how it operates.

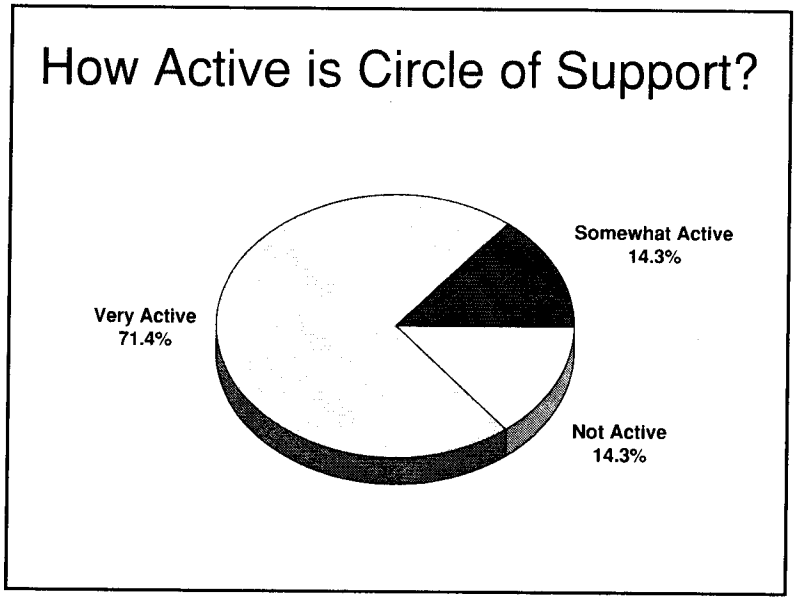
In analyzing the responses we received, several things became clear. First, many families and providers had a difficult time understanding what a circle of support is, and, therefore, had a difficult time determining whether a circle exists for the focus person. Families, in particular, seemed to consider participants in the futures planning meeting at River's Crossing as constituting the focus person's circle. They answered "Yes" to the question about whether or not the focus person has a circle, and then indicated that the circle had not met since more than a year before, when the focus person was still at River's Crossing.

Second, many respondents, especially providers, thought that the interdisciplinary team that is mandated to meet quarterly to work on the ISP was the same thing as having a circle of support. Examining the data more closely, these "circles" all met quarterly, as required for an interdisciplinary team, are composed almost exclusively of professionals and staff, and are usually facilitated by the service coordinator. Twenty-two of the providers and 12 families/guardians indicated that the focus person has a circle of support, using this loose, imprecise definition.

For respondents who indicated that a circle of support exists, we analyzed each description of a "circle" in order to remove those which were really interdisciplinary teams or which had not been active since the futures planning meeting held at River's Crossing. After these analyses were completed, only seven of the focus people were judged to have a true circle of support developed around them in the community. Of these seven circles, five were active at the time of the interview, and one was somewhat active (see CHARTS: *Has Circle Been Developed?* and *How Active is Circle of*

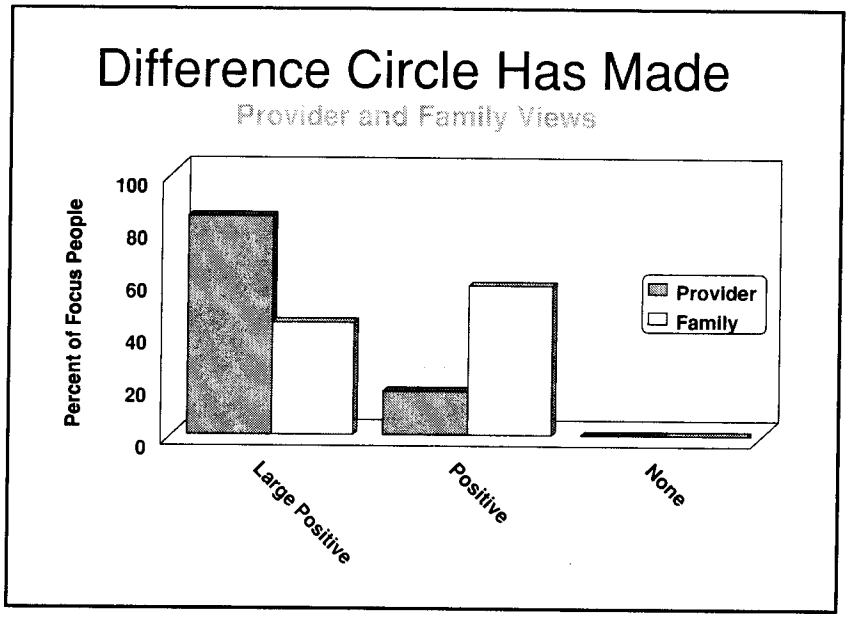


Support?). One circle was not meeting any longer but members hoped to reactivate the circle in the future.



Circles primarily were facilitated by people outside the provider service who were skilled in person-centered planning. Families participated in the circles. Where family were not involved in the focus person's life, caseworkers from DFCS were active participants in the circle. Neighbors were frequent participants. One provider described the circle members as "non-paid overseers." For one focus person, who has challenging behavior that has brought him to the attention of community law enforcement, the local sheriff participates as a member of the circle of support. Most of the circles meet monthly; one meets every two weeks. The frequency with which the circles meet tends to depend on the nature of the issues being worked on at the time.

For the seven focus people who have a circle of support, there is a strong belief on the part of both families and providers that the circle has made an important positive difference in the life of the focus person (see CHART: *Difference Circle Has Made*). For one focus person, the circle helped locate appropriate medical care in the community. A provider described the circle as "keeping everyone tied together." Another provider commented that the purpose of the circle was, "to try to make dreams a reality." For one focus person, the circle has developed a "Dream Catchers Fund" to gather donations to help him build toward desired goals. One provider noted that she believed that "time and energy would have been saved" if a support circle had been formed in advance of the behavioral interventions instituted to address the focus person's challenging behavior.



CHAPTER 7
SUMMARY AND RECOMMENDATIONS

A. Many Wonderful Things Happened for the Focus People

- People are happier and more joyful
- People have nice homes in the community
- People have an improved quality of life
- People have more choice about their daily lives
- People see their families more often
- People go into their communities to shop, to eat, and to recreate
- Many of the focus people are healthier
- Self-injurious and other challenging behaviors occur less often for many people
- People are starting to get to know their neighbors and to make new friends
- No one returned to an institution to live

B. But Life Isn't Perfect

- Some focus people did not have stable housing during the first year
- There was high turn-over among support staff
- None of the focus people are employed
- Challenging behavior compromises life experiences for some people
- Schools have denied an education to some of the younger focus people
- Some focus people do not have access to needed dental and medical care
- Some focus people still live too far away from their families
- Some people's homes were not ready for them when River's Crossing closed
- Some focus people did not get along with their housemates, forcing one person to move
- People have little choice about some of the most important aspects of their lives
- People have few friends
- People go into the community accompanied by staff, but seldom go with friends
- People spend a lot of their time in segregated settings (special education classes, service centers, etc.)
- Some people miss their friends from River's Crossing

C. What We Learned

- Families experienced much stress, fear, and anxiety when they learned that River's Crossing was going to close
- Families were quite positive about the move to the community after they saw how the focus people's lives had changed; this is similar to what has been found in numerous other states where institutions have closed
- The quality of life of people improved after moving to the community
- It is important for families, providers, institutional staff, and focus people to communicate openly and to work together for a smooth transition
- When the transition is too rushed, people are harmed - their support needs are not met, the wrong support staff are hired, homes in the community are not ready for them when they must move, behavioral supports are not in place, and families are stressed and angered
- When homes were not ready for people leaving River's Crossing, and those people had to be temporarily moved to a temporary residence, group home, or another institution, their lives were disrupted; they experienced a difficult, chaotic transition
- Providers serving children and youth were often not informed about educational laws such as IDEA; they needed support in working with the school system
- A positive relationship between the provider and the focus person's family is critical to success; when this was not present, the families often changed provider services
- When River's Crossing staff went with the focus people to support them in their new homes, the transition to the community tended to go smoothly; not all River's Crossing staff, however, were able to leave the institution behind and be successful in adapting to life in the community
- Most of the injuries experienced by the focus people were caused by falls
- Providers and families need training on futures planning and on building circles of support; creating a futures plan before the transition is an important first step, but does not guarantee that the plan will be understood or used in the community setting
- People need to be supported in making new friends
- People need jobs
- Community physicians, dentists, and other medical personnel are frightened of people with challenging behavior and sometimes refuse to serve them
- Behavioral supports available in the community are inadequate to meet the needs of many of the focus people

D. Challenges We Will Face in the Future --Issues and Recommendations

- **CHALLENGE -- THE IMPORTANCE OF TIME TO PLAN:** Closing an institution too quickly causes harm to some of the residents. Although long-term outcomes were positive for focus people leaving River's Crossing, the rush to meet the arbitrary timeline for closure caused unnecessary chaos and disruption in the lives of a few of these people. Time is needed for families to learn about community living options, to adjust to the changes that are about to happen, and to select a residential provider. After the provider is chosen, time is needed for them to get to know the focus person, to learn about their needs and desires, to get to know members of the focus person's family, to hire appropriate support staff, and to select and furnish the new home. Time is needed for the focus person to visit their new home several times and get to know their new support staff before moving in.
- **RECOMMENDATION:** *Key policy makers, including members of the Georgia legislature and the Governor, need information that helps them understand the importance of sufficient time for closing an institution. Time must be available to complete individual planning for each person who will leave the institution. No person should have to move to another institution or to a temporary residence because their community home was not ready the day the institution closed its doors.*

- **CHALLENGE - LIMITED CHOICE ABOUT HAVING HOUSEMATES:** Some providers make limited funds stretch further by requiring focus people to have housemates, even if this is not the desired living situation.
- **RECOMMENDATION:** *Financial supports need to be sufficient to support focus people to live alone in their own homes/apartments (with support staff), if that is their choice or the choice of their families/advocates. People should not be forced to have housemates if they want to live alone.*

- **CHALLENGE - FAMILY FEARS AND CONCERNS:** Families of individuals living in institutions often assume that their family members will live in an institutional setting for the rest of their life. They are comforted by their belief that institutions are safe places for people to live that offer a positive quality of life. These families are shocked when they learn an institution is going to close. As would be expected, some families react with fear and anger. Yet, it has been the experience in many institutional closures, including River's Crossing, that most families are pleased with community life for the focus person after the institution closes.
- **RECOMMENDATION:** *Families of individuals living in institutions need information about community living options long before an institution is targeted for closure. Families need support in dreaming about what is possible for their family member. They need to have the option to have their family member move to the community at any point in time, without having to wait for the institution to close. This requires increased funding for community living options.*

D. Challenges We Will Face in the Future (Continued)

- **CHALLENGE -- LIMITED COMMUNITY SUPPORTS:** Some focus people originally were placed in River's Crossing because it was the only way that their families could obtain services for them. These families would have preferred to have their son or daughter continue to live at home, but agreed to an institutional placement because it was the only way that they could get assistance. Georgia families who want their family member with a disability to live at home, or to live in the community, still face inadequate support for these life choices. Families continue to be forced to consider institutionalization for family members because no other choices exist.
- **RECOMMENDATION:** *Families should never have to give up their son or daughter to an institution in order to receive services. Georgia families should not be penalized because they want their family member to live at home. The large number of families on the waiting list for services (and those who are not on the waiting list because they have become discouraged and lost hope) need to receive the services that will allow the focus people to continue to live in the community. Avoiding institutional placement should be one of the highest priorities for the allocation of resources. This may mean supporting the family so that they can continue to provide the needed care, or it may mean creating a community living option for the focus person.*

- **CHALLENGE -- PARTNERSHIPS WITH SCHOOLS:** Some local school systems are not prepared to educate children and youth with challenging behavior. Schools have denied an education to a small number of focus people of school age leaving River's Crossing to live in the community.
- **RECOMMENDATION:** *IDEA mandates a free appropriate education for every child, regardless of the nature or severity of their disability. The schools need support in serving children with challenging behavior. No child should be denied an education. Residential service providers, accustomed to serving adults, need information and training concerning the educational rights of children and youth with disabilities.*

- **CHALLENGE -- LIMITED BEHAVIORAL SUPPORTS:** A substantial number of focus people moving to the community from River's Crossing have their life choices and opportunities limited by challenging behavior. This behavior includes aggression toward others, destructive behavior, and self-injury. Challenging behavior limits educational and vocational opportunities, community participation, medical and dental care, friendships, and overall quality of life. Many providers do not have the behavioral support they need to assist focus people in overcoming the negative effects of these behavioral challenges. Providers supporting focus people with challenging behavior sometimes do not have the funds/resources that they need to provide quality supports to these individuals.

D. Challenges We Will Face in the Future (Continued)

- **RECOMMENDATION:** *Access to positive behavioral support is critical for focus people with challenging behavior as they move from the institutional setting to the community. Providers need to have sufficient funds to provide the intensity of staffing needed to support the focus person when behavioral episodes occur and to keep them, and those around them, safe. Community support resources need to be enhanced. Behavioral support should be on-call to providers/families/focus people at all times, with trained staff available to respond quickly when a behavioral crisis occurs. Increased collaboration with mental health providers, including psychiatrists, is needed. Direct care staff need additional training in understanding why challenging behaviors occur and in providing positive behavioral supports.*

- **CHALLENGE -- LIMITED SYSTEM CAPACITY FOR PERSON-CENTERED DEVELOPMENT:** Time and resources were invested in developing rich, detailed futures plans for focus people leaving River's Crossing. These plans captured the dreams of the focus people, as well as the obstacles they faced and the supports they needed. Those who knew the focus people best shared their knowledge and hopes for the person in their new community home. For many of the focus people, these futures plans were not extensively utilized, or not utilized at all, by the community residential providers. Only a small number of focus people have a circle of support developed around them. Many providers are unfamiliar with person-centered development, futures planning, and circles of support.
- **RECOMMENDATION:** *Person-centered approaches are values-based and require a dramatic shift in attitudes and beliefs from traditional service-delivery models. For that reason, person-centered approaches cannot be mandated or required of all providers without subverting their value. Nonetheless, the River's Crossing closure provided an opportunity for developing community transitions using these approaches because funding existed to develop futures plans for all residents involved in the closure. Futures planning, in and of itself, is not sufficient. In order for futures planning to have its intended impact, it is critical that community providers have an understanding of person-centered development, that they accept the values on which these approaches are based, and that the focus person have an advocate who is skilled in developing and facilitating a circle of support. This requires a comprehensive approach which links futures planning to the development of a circle of support after the move to the community has taken place. Implementation of a more comprehensive approach would have strong benefit for focus people leaving institutional settings, but would require funding and commitment beyond that available for the River's Crossing closure. It also requires intensive training for providers and families.*

Appendix A

THE VOICES OF THE PARENTS

The parents/guardians of each of the focus persons were asked what advice they would give to another family who was not sure whether or not they wanted their family member to move out of an institution like River's Crossing into the community. They were asked to share what they had learned from their experiences that might help another family in a similar situation.

Their responses were:

ADVICE: Choosing the right caregiver makes all the difference. I now am more secure about this son's safety than I am about my other two sons who are in public school and college.

ADVICE: Stay involved and make sure you choose the right caregiver. The caregiver is the reason everything has worked out so well for our family member. I feel very fortunate.

ADVICE: Look at all the aspects, an institution is an institution. There has to be something better.... There is something better. We learned that system sucks. You have to fight for what you want, get on the phone, keep bothering people.

ADVICE: Stay involved with your children and keep asking questions. Don't let anything pass by. Always tell them that you love them and will be there for them.

ADVICE: Our son has an ideal situation. He is living with my best friend who had planned to take him when she learned of the closing of River's Crossing. Just enjoy her as if she were my big sister.

ADVICE: Make sure they follow up, meet the family, check for safety.

ADVICE: It was good for him to get his own place.

ADVICE: Definitely "move," can't emphasize that enough. Really look at the Service Provider, hopefully, there will be more than a visit at different times of day. Go with your gut.

ADVICE: Explore all options with the providers, check all of them out thoroughly; explore options with spouse and get consistency of information; locate provider with same interest in meeting child's needs; talk it over between parents; parent support group of future closings; attorney information when custody/rights violated.

ADVICE: Personal Care Home (Recommended this scenario). Our son is doing better (behaves better).

ADVICE: Stay involved. Stay in decision-making loop. Stay informed of what is available. Ask questions. Get what you want for your child.

ADVICE: Be careful and questionable. Get feel of provider through conversation. Visit other families who are under the care of the provider. Pray a lot for someone with a caring heart. Don't judge the book by the cover. All that glitters is not gold. Be prepared and ready for the prejudices and stares from other people.

ADVICE: Really proud of our son and people who helped him get where he is and the staff from River's Crossing.

ADVICE: Tell them it was a very plus move for our son. Be involved in community placement. Select provider that you feel comfortable with. Opportunity to be more involved with your family member if circumstances permit. Family atmosphere, provides a quality of life that institutions can never match.

ADVICE: Give it a try. Better for person. Fears usually are normal. Give it a try for child's sake. Child will learn more in community and will have really more normal life. Faced with more problems in community but worth it. Better care.

ADVICE: Might be alright.

ADVICE: Make surprise visits on your child. Pick a provider well and investigate them, be sure about child's needs, match the home well with the child (same age/size), make a safe arrangement. Call the provider's bluff -- not get manipulated.

ADVICE: Go for it, try it. You can always go back to an institution. Your biggest fear is just fear itself. Just go ahead and take the plunge and see what happens.

ADVICE: You have to watch these people carefully and stay up with what they are doing.

ADVICE: Once we got hold to the idea that she 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. We never wanted her in an institution anyway. She seems happier to be the center of attention. More willing to learn and stay on task. I would have never thought she could wash clothes.

ADVICE: "Go for it." They can do it. There are homes. There are people to take care of them. They have a much better life.

ADVICE: Get involved.

ADVICE: I would tell them to ask around about the different providers or find other families who have their family members in the community. Visit the providers supporting someone.

ADVICE: We are glad our daughter will do better. Parents need to be really involved. Let the provider know that you intend to be really involved. Don't be afraid to speak up and tell people of your concern.

ADVICE: I was positive all along. I moved our daughter before the closing came about as I never believed that she belonged in an institution. I did not want her there to begin with. My health contributed to not having a choice. I felt like it could be better. It is scary as a parent. She is more isolated in the community. There is less opportunity to know what goes on in community. There could be better programs. I want her to have life experiences at her own pace. Understand that my first choice still is the community, and I feel she belongs in the community, but I have a lot of concern.

In closing, the parent/guardian was asked if they had any other things that they would like to share. Their responses were:

SHARE: Trust in the Lord and communicate with those that you need to work with.

SHARE: Community placement is better, even though it is hard to think about leaving structured environment, it is worth trying.

SHARE: I hope someday to have my son at home. I have become very active in church. I now rely on God for my strength. In my circumstances, I have to work....there is no choice. I am glad that my son is closer and I can have him home when I am off work, but it still isn't the same and I worry. I always worry about him. My family has grown closer to the Lord and found some inner peace so we can work with this situation. I just want what is best for my son. I'm so afraid he will be hurt and won't be able to tell me or cry out for help. I pray all the time that God will protect him against the world and make him happy. He is such a joy in my life. I want to tell others to look for the joy rather than dwell on the problems.

SHARE: I learned a lot more about people with disabilities living in the community, and the enrichment of their son's life is tremendous (DFCS Caseworker).

SHARE: Relationship!

SHARE: We are just glad about our son's medical progress.

SHARE: The situation is not at all what we want. We can't understand why we are not allowed to have our daughter live here except that financially we can't give her all the services, but we realize the direct care staff is paid to do work and we wonder why we can't do it for her with some monetary assistance. The staff at her home does not make us feel welcome and has asked us not to bring her brothers to visit. We just don't understand why things have turned out like it has. It has helped to have someone listen to how we feel.

SHARE: Nothing.

SHARE: Overall, I am happy with the situation.

SHARE: I work so many long hours that I don't get to see my daughter. I work approximately three or four miles from her house, but I have two other daughters other than this daughter. One is younger and one older. She is very hyper and had to have restraints at River's Crossing. I was reluctant to give her up, but I knew I couldn't continue taking care of her. She was growing up and needed constant supervision and care. She needed more that I could give and work out side of the home. Then I had to consider my other two daughters and their needs. It was a hard decision and I tried to check out alternatives with the thought in mind that she would be better with total one on one care. I wanted her to have a chance to get better opportunities in her life than I could provide for her. I work all the hours that I can so there will be enough money. I'm afraid to stop by her house for pop-calls....afraid it will upset her that I don't have time to stay longer, and it will make it worse on her after I leave than if I didn't come at all. I want her home on holidays when I can be off work. It is just so hard to stop by for five minutes and have to leave her. She is so loving and I just don't want her upset. It hurts me, too.

SHARE: She has very good body language to let her us know what is going on. She expresses her feelings from the heart and is so genuine. I can tell when something is wrong, and I can also tell when the caregiver tells me about something that has happened, and I ask her about it....she lets me know if it is the truth or not. She can react in a way that I know immediately if the caregiver is deceiving me or not.

SHARE: Get with the right people and ask questions. Ask a lot of questions and don't let them make you feel bad about asking.

SHARE: You must be strong for your person who is not strong. The rewards for our son have brought peace of mind, and he is having a wonderful life.

SHARE: It is easier to see what is going on in the community. People can drop in any time to visit. It is consumer's home after all. Consumer has privacy in community. This is a good thing to have their own home. I am glad. If there had been any other way, there would have been no institution placement in the first place.

SHARE: Have surprise visits regularly. This is to ensure safety and accountability. They have to stay on their toes if they expect you to drop in anytime.

SHARE: We were very sad of the circumstances that our son had to endure. We want him back with us and hope that someday he will be able to live in the house with his brothers and sisters. Now that we have regained custody, we feel that it will someday be possible to have him back full time. He is doing so much better now, and we have sayso in what happens to him. The new caregiver has brought him a long way, and she is good to him. We can tell that he is happy with her. He smiles a lot and looks real good.

SHARE: *Mother:* Favorite story and most proud moment with focus person: "I saw a dream I thought would never be fulfilled for her. 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 Galsy's apartment. I didn't think she would be the first one to leave the coop." Most proud that my teenage daughter is settling in her own apartment. Having her own apartment. I was never going to see her walking down the steps in her prom gown.

Father: When we had a family dinner at her place for her birthday, my parents came. I never envisioned being able to do that. To be able to say, 'I'm going to have dinner at my daughter's house.' Her understanding that she has a right to make choices. Not Mama's little girl anymore. She is a young lady.

Both: Need to train the families, and have on-going training with the staff. Start programming parents for what is on down the road. Left hand needs to know what the right hand is doing.

SHARE: I feel great with him coming home because I get to see him more. When I couldn't get to see him at River's Crossing like I wanted to, it bothered me.

SHARE: I am so thankful that my son has this. It is like that he knows what is going on. Not treated like: "you don't know what you are talking about."

SHARE: We are in the process of changing Provider Services. My daughter is hard to motivate, needs encouragement, is hard to keep up with, loves to swim. Glare bothers her. She is the 3rd child of 4 daughters. Severe autism/profound mental retardation, non-verbal. She loves to swim free without a life jacket and is like a fish in the water. None of the swimming facilities will allow her to swim without a life jacket. This is a real problem and upsets her. In addition, the agency sent a caregiver that does not swim and does not like to take her around the pool which is her first love. These things bothered me because I had specifically requested that she be able to go swimming. This was the one thing that brought her pleasure. They seemed to ignore my requests.

Appendix B

RIVERS CROSSING: HISTORY

The five story red brick building in Athens, Georgia, known as River's Crossing, was built in 1968 through a joint effort between the Georgia Department of Human Resources and the University of Georgia. When it first opened, River's Crossing, then known as the Georgia Retardation Center (GRC) -- Athens campus, was a satellite center of the University Affiliated Facility (UAF) for the state of Georgia. In September, 1965, an application was made to fund construction of two mental retardation facilities in Georgia. One was to be located in Chamblee, Georgia, on the outskirts of Atlanta, and the other (River's Crossing) on land owned by the University of Georgia in Athens. Funds were appropriated from the 1963 Mental Retardation Facilities and Mental Health Centers Construction Act (PL 88-164) for this purpose. The University of Georgia agreed to transfer land to the State Hospital Authority for construction of the facility in Athens, which would then be leased to the Georgia Department of Public Health for operation. The University of Georgia and the Georgia Department of Public Health contracted for shared responsibilities in the operation of the program in Athens, with the Georgia Retardation Center in Chamblee established as primary grantee for the University Affiliated Facility. Ten academic departments at the University of Georgia participated in the planning for what was then called the Athens Unit of the Georgia Retardation Center: Special Education, Child Development, Vocational Rehabilitation, Speech Pathology and Audiology, Recreation, Social Work, Psychology, Counselor Education, Reading, and Sociology.

In 1967, the Board of Regents deeded 4.5 acres to the Georgia Department of Public Health for the Athens Unit GRC. With a cost of 1.7 million dollars, the building that housed the Athens Unit GRC was completed in 1969. This 76,000 square foot, five-story building was located on 13.5 acres in the Research Park section of campus. It was designed specifically to be multi-functional and fulfill a variety of service and training functions. A grant was submitted to the predecessor agency of the Administration on Developmental Disabilities for a Core grant to support the Georgia University Affiliated Facility (UAF). This grant was awarded, to be administered by the Superintendent of the Georgia Retardation Center at Chamblee. A portion of the requested funds were to support activities at the Athens Unit GRC.

The Athens facility included approximately 40 staff/faculty, 12 secretarial employees, carrels for 48 graduate students, seminar rooms, a well-equipped library (a component of the University Library System), a school containing eight classrooms with adjoining observation rooms, kitchen and dining areas, numerous individual or small group therapy/assessment rooms with adjoining observation facilities, and three dormitory floors providing living space for 40 children. A specially designed "apartment" for parents to stay overnight, and for family interactions to be observed, was also included in the building.

A section of the building was designed for short-term (approximately 4 months) residential care of children with mental retardation, with services focused on intensive diagnostic evaluation. These

programs predated PL 94-142 and mandatory public school education for all children with disabilities. Residential care was provided since many families lived too far away to commute daily to center programs. The center closed on weekends and holidays, with children returning home during these periods. Other children were served as day students, receiving evaluative services delivered in classroom and therapy contexts. Reports developed by interdisciplinary teams would follow the child back into the family/community to facilitate appropriate programming. No children were to be placed in long-term residential care at the facility. The first non-residential classroom students arrived at the Athens Unit GRC in September, 1969; and the first residential students began occupancy in December, 1969. University of Georgia students began training at the site in Fall Quarter, 1969.

In 1979, the Department of Human Resources relinquished its role as grantee for the Georgia UAF, turning that role over to The University of Georgia. At that time, the Athens Unit GRC became the University Affiliated Facility for the State of Georgia. GRC Chamblee remained a clinical training site for the newly reorganized UAF, continuing to share a portion of the Core ADD budget. Over time, the role of the Chamblee unit in the UAF was phased out completely.

In 1980, a major change occurred for the Athens Unit GRC. The facility became a seven-day 40-bed ICF-MR for children. This change expanded the funding base for the center, but brought with it many other changes as well. When the unit initially became an ICF-MR, approximately 60 children continued to be served in the day-only school programs. The goals that the Department of Human Resources (who initiated the move to become an ICF-MR) and The University of Georgia held for the Athens Unit GRC began to drift apart. Some of the university faculty pulled back from the revamped structure of the unit as a state residential institution for children.

The non-residential day students were gradually phased out of the Athens Unit GRC programs after its conversion to an ICF-MR. By 1984, the program served 40 residential students. Approximately 12 preschool children were served in the only non-residential program still operating at the facility. In 1986, the UAP preschool program was moved from the Athens Unit GRC to the McPhaul Child and Family Development Center on the University campus. At this point, the Athens Unit GRC, as a service program, became solely a 40-bed ICF-MR serving children and adolescents. Over time, the children and youth served by the unit changed such that the residents were some of the most challenging children/youth in the state. More children with autism lived at the unit, as well as an increased number of children with negative reputations because of aggressive behavior and severe self-injury.

In 1985 the Georgia University Affiliated Facility became The Georgia University Affiliated Program (UAP), and the executive offices of the UAP were moved from the Athens Unit GRC to the University of Georgia campus. All day-to-day activities of the UAP, however, continued to be conducted at the Athens Unit GRC, where faculty and staff had offices. The year 1986 brought about a revised Memorandum of Agreement which was signed between the University of Georgia and the Department of Human Resources. This further clarified and reorganized the relationship between the University and the state regarding programs at the Athens Unit GRC. The Memorandum acknowledged the increased gap between the goals and interests of the two agencies and stipulated that

all administrative responsibility for the ICF-MR (now synonymous with the Athens Unit GRC) be placed with the Georgia Department of Human Resources. Although the Memorandum dealt most directly with the relationship between the University of Georgia and the residential service programs at the Athens Unit GRC, the indirect effect of this memorandum was to create what amounted to a "divorce" between the Georgia University Affiliated *Program* and the facility which was constructed in 1965-69 to be the Georgia University Affiliated *Facility*. This "divorce" allowed the UAP to pursue a community-based mission, more consistent with ADD mandates and allowed the Athens Unit GRC to function under state agency supervision as an ICF-MR. Provisions for continued occupancy of office space for university personnel at the Athens Unit GRC were built into the Memorandum, but these personnel no longer had a relationship with the service programs housed in the building.

On July 1, 1991, the name of the facility was changed from the Athens Unit GRC to River's Crossing. This was an effort to show respect through language to the residents who resided in the tall brick building on the banks of the Oconee River. When an article was printed in the Athens Banner-Herald, the local newspaper, on Monday, July 1, 1991, with the headline: ***Center Changes Name to 'River's Crossing'***, it included a quote from Dr. David Braddock, Director of the Institute on Disability and Human Development at the University of Illinois at Chicago, which read:

> *The only downside is if ... the state merely changes the name of a facility, but does not follow through with development of appropriate supported community living, so one day... (the facility) ... no longer needs to exist,*

Another quote from Zebe Schmitt, who was then the Executive Director of the Georgia Governor's Council on Developmental Disabilities, expressed a similar thought:

> *We should be working toward having places for people to live in the community ... small enough they don't need to be named.*

Five years after the name change, River's Crossing was closed.

The closure occurred as a part of Georgia Governor Zell Miller's redirect budget request that would provide $1.03 million in savings by relocating residents into community-based care.

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