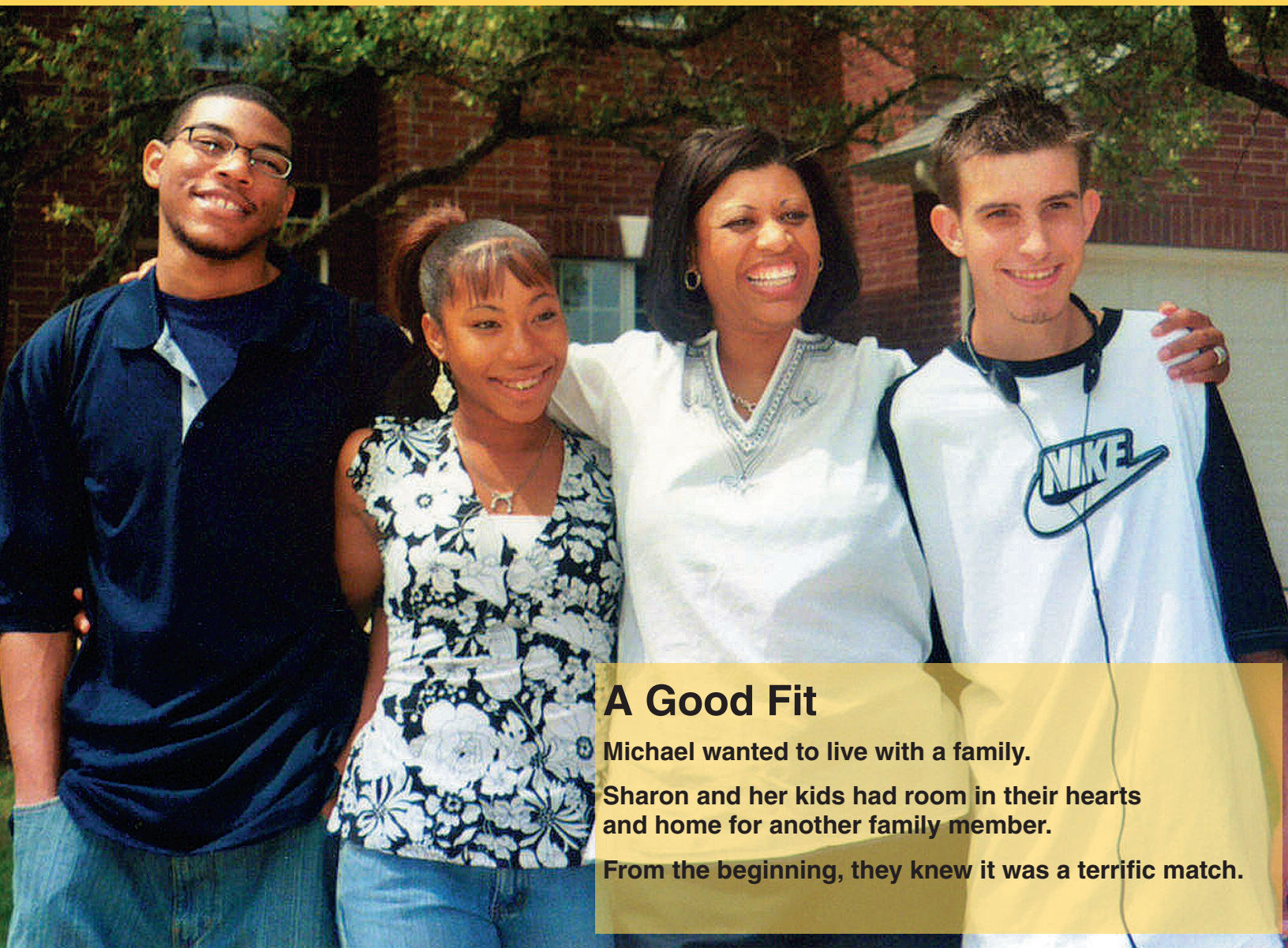




Summer 2005

family life for children with disabilities



A Good Fit

Michael wanted to live with a family.

Sharon and her kids had room in their hearts and home for another family member.

From the beginning, they knew it was a terrific match.

The Family-Based Alternatives Project offers a new choice for families and a new life for children.

Family x 2 = love and security for Sheldon

Sheldon is a hugger. He loves to give—and get—hugs as often as possible.

Staff at the large residential facility he used to live in did their best to keep Sheldon well-stocked in hugs. But the demands of nearly 200 residents made it impossible to give him all the nurturing and attention he craved.

Patricia, Sheldon's birth mother, is ill and unable to provide daily care for her son, who has physical and mental disabilities. In 2000, when he was 10, she placed Sheldon in a large residential facility—the closest she could find—in another city. She visited him as often as her health and energy would permit the 75-mile trip—not nearly as often as Patricia or Sheldon would have liked.

EveryChild staff first met Sheldon while screening all the children in the facility. EveryChild has a contract with Texas' Health and Human Services Commission to find family-based alternatives for children living in institutions.

Family Support Coordinator Linda Thune contacted Patricia to discuss options for Sheldon. It was the first time, Patricia says, she was aware there *were* other options—especially any that would allow her son to live with a family.

The concept of shared parenting was attractive to Patricia, who wanted to continue to be involved in Sheldon's life as much as possible. When she learned there was a potential support family near her home, Patricia was ready to get the process rolling.



"I didn't know there were places Sheldon could be with a family. I'm glad to have him closer so we can do more things together. It means a whole lot to me to see him in a family that can care for him."

Patricia, Sheldon's Birth Mother

terminology

Shared parenting:

An arrangement where a child's care is jointly arranged between two households—the birth parents and a support family. It is an innovative and practical alternative to a facility, providing assistance to birth families while enabling the child to enjoy the benefits of family life.

Fast forward to today, two years later. Sheldon no longer lacks for hugs. He gets plenty of attention and love every day from his support family. His birth mom is welcome as often as she is able to visit. Support mom Brenda says it didn't take very long for Sheldon to settle into the "comfort of the everyday closeness of family."

Brenda's mother, Dorothy, and teenage son, Jonathan, are also part of Sheldon's support family. "My family has love and patience, and we enjoy sharing our home with someone who needs it," says Dorothy.

Sheldon, now 15, has his own room and enjoys spending time there listening to music and unwinding after school. As a full-fledged family member, he loves the freedom of moving around his home.

Being able to interact with family whenever he wants is a new experience for Sheldon—one, Brenda says, he seems to really enjoy. He also likes not having to be on a fixed schedule. He can take his time enjoying a meal. He can enjoy his favorite bath time ritual—a long, playful soak in a bubble bath.

By all accounts, Sheldon is thriving. He's developing confidence, new skills and relationships far beyond what could have been imagined for him in the institution.

And the family is thriving with Sheldon. Brenda acknowledges the changes that inevitably come with adding a new member to a family. By carefully learning everything they could about Sheldon and his support needs, they anticipated some of the changes to their own routines and planned accordingly.

Communication, Brenda says, is critical to the success of a shared parenting arrangement. The birth family and support family must be clear on goals for the child and expectations of each other. "All the parties have to work together," she says. "The most important thing is the well-being of the child."



Dorothy (left) and Brenda

Providers are important partners in shared parenting successes



No one is more pleased about Sheldon's new home than Elena Rogers. She is program director for Hill Country Support Services, the organization that provides support services for Sheldon.

Rogers says her agency shares EveryChild's view about the importance of family life for every child. "Our philosophy is to give preference to the most family-like setting possible," she says. "When you see how children blossom in a family, it's impossible to think otherwise."

Having worked with EveryChild for two years now, Rogers is complimentary of the organization's approach. "They are very thorough in making sure the match will work out. They don't hurry or take shortcuts just to get a child out of a facility."

From a provider's perspective, Rogers says the most important thing about matching children with support families is putting the child's needs first. She believes small companies, such as Hill Country, may have an advantage. "We have the luxury of a little more time and flexibility when it comes to finding just the right match for a child and support family."

EveryChild Expands to Houston

Sharon Carey is a veteran when it comes to helping families. Since the late 1970s, she's guided them through the sometimes confusing, often cumbersome and always complex matrix of children's services and supports.

She started as director of the (then) Foster Parent Education Network at the University of Houston. Her work focused on foster families caring for kids who were abused and/or neglected. Later Carey worked for United Way agencies. Then she retired.

Or she meant to. When a former colleague, the current director of the Parent Education Project from the U. of H., called with news of a partnership with EveryChild, Inc., Carey was eager to sign on. In February 2005, she started work as EveryChild's family support coordinator in Houston. She is joined by UH-PEP part-time staffer Elaine Hime, a parent of a child with disabilities.

Carey's job is multifaceted. It begins with a list of children currently living in institutions who might be offered an opportunity to live with a family.

"I want to learn as much as possible about each child and family's circumstances," Carey says, "to help the parents make well-informed decisions about what is best for their child. It's difficult for the parents," she adds, "because often they've only been exposed to the gobbledygook and bureaucracy related to the process."

Carey says she tries to help families gain a good understanding of their options and confidence that their children can be supported in a family. Once they've understood what the funding really means, she continues, "several of the families have been interested in having their child return home."

Still, for a variety of reasons, some families feel it's just not possible for them to support their child at home. Carey says that many of these families had no idea there are options beyond an institution. "They may have been told their child needs to be in one of those big facilities or they may have heard of group homes," she says. "That's what's traditionally been available."



Meet EveryChild's Houston Staff! Sharon Carey (left) and Elaine Hime are helping Houston families of children with disabilities realize they have more options than they think.

"Our job is to talk with them about the idea of a support family and shared parenting arrangement," Carey explains. "Birth families are usually surprised to learn there are others willing—and able—to include the child in their homes and daily lives. It's not unusual for birth parents to question how another family can make it work when they can't."

It's a delicate conversation. Carey's wealth of experience helps her understand their perspective. "I listen to them and try to hear what fears and concerns their words convey," she says. "I try to use a lot of different examples to help them see how it works."

As birth parents become more open to the idea, Carey helps them explore available options—beginning with their own network of family and friends. If there are no prospects there, the search for prospective families continues through other, more established networks, like the provider community.

With just under six months under their belts, Carey and Hime have already arranged for seven children to move home or live with support families. They've talked with close to 50 families of children living in institutions. Of them, approximately 20 are in various stages of exploring family-based alternatives.

"I listen to families and try to hear what fears and concerns their words convey. I try to use a lot of different examples to help them see how it works." ~ Sharon Carey





Valerie and Ahlia. “The way she fits right into the family,” Valerie says, “makes us feel like we’ve known Ahlia all her life.”

terminology

Support family:

A family that is recruited, selected, prepared and paid to care for a child with a disability as part of an organized system of care which offers a family home as an alternative to residential facility care.

“Without EveryChild, we wouldn’t have known about Ahlia. Our family would not be complete.” ~ Valerie

Ah, the simple pleasures.

Ahlia, soon to be seven, just can’t get enough of the refrigerated air that blasts out of doors on the freezer aisle at the grocery store. The cool sensation is a guaranteed giggle getter, according to her support mom, Valerie.

The same is true for the speed bumps intended to slow traffic in her neighborhood. The thumping, jerky joy ride over them never fails to delight her.

Ahlia’s joy at discovering the world around her, Valerie says, brings joy to the whole family. Valerie’s children—Brandon, 23, and Korinne, 14—get a kick out of the little girl’s reactions to things that most people take for granted.

Until June, Ahlia had spent almost her entire life in a large residential facility. When she was born with multiple physical and mental disabilities, doctors did not believe the infant could survive. They advised her overwhelmed, young mother that it would be best to admit Ahlia to the residential institution to receive hospice care. At least, Ahlia’s mom and doctors agreed, the baby’s basic needs would be met and she would be comfortable for (what seemed certain at the time) the short duration of her life.

More than six years later, Ahlia was still living in the facility, which was getting ready to close. Ahlia’s mother learned about EveryChild and the prospect of a family-based alternative for her young daughter. She agreed that a family environment—an option she had not imagined possible—would be much better for Ahlia.

At the same time, Valerie was exploring the prospect of becoming a support mother. Then—at almost the very last minute—she heard about Ahlia.

There was an instant connection. Within a few short weeks, Ahlia was discovering the love and comfort of a home. Ahlia’s birth mother is very pleased.

It’s only been a few weeks, but Valerie says the change in environment has resulted in significant changes for Ahlia. “Her limbs were so rigid before. Now they are more flexible. She used to dislike being touched. Now she loves to be held and hugged.”

Given the choice, Michael chose family



Ingredients of a strong support family: (from front) Briana, Michael, Sharon, Brandon

Sometimes it's the little things that offer clues about how people are going to "click." For Michael and then-prospective support mom Sharon, it was fried shrimp.

They met for the first time in the fall of 2004 at a seafood restaurant. Each ordered their favorite dish. When it turned out to be the same thing, Sharon says, they got the first inkling they would hit it off.

Brandon, Sharon's 23 year old son, was along for the meal and says he felt similar good vibes. Michael's gentle manner, joyful spirit and keen sense of humor won their hearts immediately.

The feeling was mutual. Michael was anxious to visit Sharon and Brandon in their home—and to meet Briana, Sharon's 15 year old daughter. On that visit, he also met some of the extended members of his soon-to-be support family. Three of Sharon's sisters live nearby. "Everyone was so impressed by Michael," Sharon recalls. "They just fell in love with him."

"Michael brings a positive energy to this house."

Michael continued to visit while Sharon worked with EveryChild, Michael's birth family and service provider to make the arrangement official. By early December, Michael joined his support family full-time.

For Michael, who has mental retardation, the move is an important step toward realizing his dream to live independently at some point in the future. He lived with his birth mom until he was 18. Then, typical of a young man seeking independence from family, he wanted to move out of his childhood home. Unaware of other options, he moved into a large facility with more than 150 residents, but that environment, he says, "wasn't comfortable." He was already considering moving to a group home when he learned it was possible to live with a family that would help him achieve his goals. After meeting Sharon and Brandon, the decision was easy.

For Sharon, including Michael in her family satisfies a desire to be useful to others—to put her nurturing nature to good use. For her children, she says, the experience opens their eyes and hearts to other people in the world and broadens their horizons. And while the family was prepared to give to Michael, they may not have anticipated how much Michael would give to them.

Michael stays in touch with his birth family. Sharon says his mother is pleased and supportive of the support family arrangement. Earlier this summer he flew to the East Coast to spend time with his father and grandfather—and plans to go back for more visits.

His plans don't stop there. In the fall, he will return to school to learn job skills. Eventually, he would like to work in construction or some other field where he can work with his hands. "He's excellent with technology, too," Sharon says with pride.

His plan also includes a home and family of his own. A current sweetheart makes a good prospect, he thinks. But that's all for later, after he's laid the proper foundation. For now he will enjoy being part of a family that will love and support him today and always.

NEXT ISSUE: Meet Draco Services, the provider that helped EveryChild connect Michael and Sharon. After years in the group home business, this provider is seeing the benefits of family-based alternatives.

Add another candle—EveryChild is three!

...by **Nancy Rosenau, Ph.D., Executive Director**

Where *does* the time go?

It seems like only yesterday we were hiring EveryChild, Inc.'s first staff members. Back In May 2002 we were taking the first steps to create a strong system of family-based alternatives for kids with disabilities living in residential facilities and institutions throughout Texas.

It's been three years since then, and a lot has changed. Originally we focused on twelve counties in the Austin/San Antonio corridor; now we've expanded to Houston and beyond. Three years ago there was no program offering support families for children leaving nursing homes; today there's not only a program, there's a group of providers who are recruiting support families. When we started out, birth families hadn't heard of shared parenting. Now we have birth families and support families who have been in shared parenting relationships for two years. And the stories of their successes are attracting the interest of other families.

By far the most exciting and rewarding accomplishments are reflected in the positive changes in the children who are experiencing the love, support and comfort of family and home. To date, a total of 47 children have moved out of institutions and into the loving arms of family—and more are poised to make the move.

The chart below highlights some of the statistics that indicate our progress since the beginning. We're very proud of the numbers for this still-fledgling

endeavor—particularly in light of the many challenges that come with introducing a new concept to a state the size of Texas.

What you don't see in the numbers are the many people and organizations who have joined forces with EveryChild to assure that children with disabilities grow up in families. The list begins with our Board and staff members, for whom this work is more than "just another job." Words do not do justice to their passion and determination.



We're also deeply indebted to the service providers who have joined as allies in this important work. Without providers who understand the importance of home and family in a child's development, EveryChild would be hard-pressed to help children make lasting transitions to family life.

Finally, we are most grateful to the birth families and support families who are willing to set aside a more traditional concept of family to consider arrangements that will allow children to thrive amidst people who truly love and care for them. These families are the essence of EveryChild.

EveryChild Update

CHILDREN

- *Currently known to project: 516*
- *Total number of children who have moved out of institutions into family life: 47*
(Six returned to live at home with their birth families; 41 moved from facilities to live at home with support families)

FAMILIES AND GUARDIANS

- *Known to be willing to explore family life for their children living in facilities: 82*
- *Ready to look for a support family: 41*

POTENTIAL SUPORT FAMILIES

- *Currently known to EveryChild via inquiries: 1000*
- *Completed home visit with EveryChild staff as first step toward becoming a support family: 400*
- *Referred to providers for verification as a support family: 84*

Help Wanted: Loving Families

EveryChild continues to generate a great deal of interest in family-based alternatives. How do we know? Because we're still getting a lot of inquiries from people who are interested in learning how to be a support family.

Some are calling in response to our recruitment messages in the media. Happily, others are hearing about us through their networks of family, friends and colleagues. All the calls are keeping project staff plenty busy and mighty grateful.

"With all that's going on in the world today, it's easy to think people would be too busy or involved with their own lives and problems to consider caring for a child with a disability," says Nancy Rosenau, executive director. "That is simply not true. An amazing number of families are ready, willing and able to extend their love and support to a child who really needs it."

"It reinforces EveryChild's firm conviction that every child needs a family and there is a family for every child."

About EveryChild

EveryChild, Inc. is a nonprofit organization created in July 2000 by a coalition of organizations and advocates committed to family life for children. In Texas there are more than 1500 children and young adults with disabilities who don't live with families. The Texas Legislature and the Texas Health and Human Services Commission (HHSC) have identified the importance of family life for children with disabilities as an important state policy. HHSC has contracted with EveryChild, Inc. to develop a system of family-based alternatives to facility care.

To learn about becoming a support family, call 512-342-8844 (Austin area) or 877-742-8844 (toll free).

Birth families or guardians who want information are invited to call:

Austin area: Linda Thune—512-342-6810
San Antonio area: Karla Auten—210-663-2272
Houston area: Sharon Carey—713-743-0608
Other areas: Elizabeth Tucker—512-342-0543

Nancy Rosenau, Executive Director: 512-342-8846
Lisa Sheppard, Program Administrator: 512-342-8847



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