

May 2003

family life for children with disabilities

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

# Two Families - Two Dreams Come True

Christmas 2002. It wasn't an ordinary Christmas present, but it was an ordinary dream— to live with a family. With the help of EveryChild, Inc., Bethany's mother helped her daughter move on Christmas Day from an institution with 110 children to a family home with Helena and Gabe.

"We've waited a long time for this," said Bethany's mom. "Bethany and I couldn't have asked for a better present. It's going to be a happy new year."

Just as excited as Bethany's family were the caregivers and managers of the institution where Bethany stayed for the past nine years.

Nine years ago, Bethany's mother found herself in an almost impossible situation. With a terminally ill husband and twin infant boys, she couldn't give Bethany the physical care she needed because of her disabilities.

Meanwhile, Helena was working as a case manager for people with disabilities but says what she really wanted was to provide a family for a person with a disability who needed one.



The two families were brought together by EveryChild as part of the Family-Based Alternatives Project. The Project recognizes the importance of family life for children, but also that there are families willing to care for children when circumstances prevent birth families from doing so. After finding families, the Project pulls together many pieces of a complex bureaucratic puzzle

"Bethany and I couldn't have asked for a better present. It's going to be a happy new year." Bethany's Mom

The Family-Based Alternatives Project offers a new choice to families.





Christmas Day: Bethany, her birth family and her new Support Family

to link families and multiple agencies and funding arrangements.

Bethany's mom was grateful for the facility, but she always knew it wasn't the family lifestyle she wanted for Bethany. After meeting Helena and Gabe, she and Bethany's brothers knew immediately that this was the family they were looking for.

"When birth families are not able to care for their children they want reliable, competent, loving caregivers. That is what a Support Family like Helena and Gabe can offer," said Nancy Rosenau, Ph.D., Executive Director of EveryChild, Inc.

"This new alternative of a support family means a child can have two families who love them and share in their care," added Rosenau. "The Family-Based Alternatives Project offers a new choice to families."





**Brown-Heatly Building** Offices of Texas Health & Human Services Commission

EveryChild has had tremendous response from individuals who want to be families for children with disabilities.

### **New Choices For Families**

"The Family-Based Alternatives Project is giving families a choice. In the past parents of children with disabilities haven't had a choice. Many times institutional care was their only answer," said Adelaide Horn, Director of Long Term Care and Support for the Texas Health and Human Services Commission (HHSC).

Horn, whose office oversees the Family-Based Alternatives Project, believes EveryChild has established a foundational foothold. She has been especially pleased at the response from families in the community who have called to inquire about providing a home for a child to move from an institution.

"The thing that keeps me excited is the tremendous response to this program from individuals who want to be families for children with disabilities." said Horn. "So many times we've heard you can't find families. This project is slowly and steadily showing there are many families out there."

As more support families become available, birth families will have more choices. Unlike traditional foster care, this new alternative represents a voluntary choice. Horn added, "It's important that families know they retain their rights when using a support family to share the care of their child."

Birth families and children and support families are carefully matched. "We're going for quality outcomes," Horn said. "We look for caring support families who fully understand the needs of children with disabilities, and understand that this is a long-term commitment. We want to place children in families that are successful for the children, successful for the support family, and successful for the birth family."

"Its exciting to realize there are individuals who want to be families for children with disabilities. This program provides a viable alternative and a true choice for birth families."

"? hope this small ripple turns into a wave and then becomes a tidal wave."

Adelaide Horn Director, Long Term Care Services and Supports Texas Health & Human Services Commission



# **Special Report: EveryChild**

Delivering on a commitment

EveryChild, Inc. is a nonprofit organization that came together in July 2000 in a coalition of people and organizations committed to family life for children with disabilities. The Texas Legislature has identified the importance of family life for children with disabilities as an important state policy.

As directed by the legislature in SB 368, the Texas Health and Human Services Commission (HHSC) contracted with EveryChild, Inc. to develop "a system under which a child who cannot reside with the child's birth family may receive necessary services in a family-based alternative instead of an institution." In Texas there are more than 1500 children with disabilities who don't live with families.

"It is the policy of the state to strive to ensure that the basic needs for safety, security, and stability are met for each child in Texas. A successful family is the most efficient and effective way to meet those needs. The state and local communities must work together . . . to ensure that each child recieves the benefits of bing part of a successful and permanent family as soon as possible." Sente Bill 368 (77th Texas Legislature)



EveryChild's Austin based team: Linda Thune, Family Support Coordinator and Julie Benoit, Recruitment Coordinator



EveryChild works under the contract with HHSC, the umbrella organization that includes three state agencies: Texas Department of Mental Health and

Mental Retardation (MHMR), Texas Department of Protective and Regulatory Services (DPRS), and Texas Department of Human Services (DHS).

"There are two significant resources needed to move children out of institutions—money and families. EveryChild has been finding the families. As for money for this project, it's basically already there—but it is currently being spent on institutional care for these children. In the face of our current budget crisis, it is more critical than ever that we consider value for money," said Terry Beattie, Director of Children's Long Term Care with HHSC. "The legislature and the Project recognize the value of family life for children with disabilities."

"Families and children in institutions have been waiting a long time for us to create opportunities for them to experience a family life again," said Nancy Rosenau, Executive Director of EveryChild. "And families across all segments of Texas life are telling us they're willing to help."

"Children grow up fast and every day we delay is a day of family life they miss," added Rosenau. "These kids are waiting on us. They're counting on us."



EveryChild's project management team: Nancy Rosenau, Executive Director and Lisa Sheppard, Program Administrator

*EveryChild's San Antonio based team: Karla Auten, Family Support Coordinator and Roddy Baker, Recruitment Coordinator* 

### Luis Goes Home

Two years ago, Luis's life and that of his family changed forever. A horrific car accident put Luis in a coma and in a nursing home. His mom, Yolanda, spent 18 hours a day by his side for the past two years. His brothers, their wives, babies, and girl friends regularly crowded into the tiny room Luis shared with a roommate.

On January 21, Luis went home.

Amidst the tears of joy and goodbye hugs from almost every caregiver in the nursing home, Luis wheeled out into the fresh January air for home.

"It's ironic. Larry, who walks, talks, and takes cares of himself is staying, while Luis who's in a coma is going home." said Lisa Sheppard, Program Administrator who helped orchestrate the move. "This shows it's not always the disability, but the support a family gets, that marks whether people stay in nursing homes."

For Luis's family, the fact that Luis was in a coma was not what prevented him from going home. When Linda Thune, Family Support Coordinator with EveryChild, met Yolanda in August of last year, she asked a simple question, 'What would it take for Luis to come home?' Thune discovered that the biggest barrier was accessible housing. So she set in motion the many activities that culminated on this winter afternoon.

"The family has been waiting for so long. Now Luis is home. This simple fact of being home is at once powerful yet so ordinary. That's the beauty of it—the sheer ordinariness of being home." said Nancy Rosenau, Executive Director. "This is about moving the extraordinary things like special equipment and supplies and nursing care, to the ordinary place Luis's family wants him to be-home."

"Now instead of sleeping in a chair next to his bed, Yolanda can sleep in her own bed, and so can Luis," added Sheppard. "Now they don't have to make special arrangements to visit. Luis is home."

"Our strategy is to help one family at a time and hope that this family's story will help another family realize their dream," said Rosenau. The strategy seems to be working. Yolanda introduced the EveryChild team to the mom of a young woman in a room down the hall from Luis' who had been asking Yolanda how she did it.

"How do you like being home, Luis?" asked Rosenau. Luis moved his closed eyelids ever so slightly. "I don't know what Luis understands about being home, but I know absolutely what it means to his family."



*Home at Last. Mom Yolanda spent 18 hours a day by Luis's bedside in the nursing home for two years.* 

EveryChild works to move extraordinary things like special equipment, supplies, and nursing care to the ordinary place families want to be--home.



## Families' Loving Decisions

Christy Dees is a strong supporter of families. With her 17 year old son, she knows first hand what its like to have a child with a disability. And she knows from years of working with families the difficult decisions they sometimes have to make.

Dees is a Child Developmental Disabilities Specialist with the Texas Department of Mental Health and Mental Retardation (MHMR), one of the three state agencies supporting the EveryChild Family-Based Alternatives Project.

"When support is unavailable, families are sometimes forced to make some hard but loving decisions to place a child," says Dees. "For some there is a viable alternative that hasn't been an option in the past— the opportunity for their child to live in an alternate family's home."

"A good support family is one that will open their arms to a child and welcome them as part of their family and also welcome the birth family's continued involvement," says Dees. "They support one another."

Dees has personal experience with the benefits of shared parenting through her son. "Without help I don't know what choices I might have made," she adds.

"My family uses an informal shared parenting arrangement. We have another family who will take care of our son when we need a break," said Dees. "This is a family where he has parents who love him. Their care is unquestionable. That has been the greatest amount of support for me" For children in facilities Dees explains, "MHMR needs to make sure all families understand all the options. We need to go back and reach out to families. Obviously our first choice is for the child to be in their birth home. But the reality is that is not possible for all families. Shared parenting is a viable option, a loving option. The shared parenting alternative is something we have not explored enough with families." says Dees. "We haven't understood until recently that there are families out there who are interested in taking in children with special needs."

" The truth is we're too late for many birth families," says Nancy Rosenau, of EveryChild. "But we're not too late for their children. What we need to do is help their parents think through the idea of another family."

" The most frequent question we hear is 'What makes you think a support family can do this when the birth families couldn't?'" says Rosenau. "Birth families naturally and rightly wonder about that. The differences lie in their circumstances. A key difference is that support families take on their role fully and carefully prepared and well supported. But they're also making this a vocation and they get financial support that enables this choice. We get the best of both worlds: the reliability of a paid caregiver and the love of a family."

With shared parenting, an alternate family provides the best of both worlds: the reliability of a paid caregiver and the love of a family.

"The shared parenting alternative is something we have not explored enough with families."

Christy Dees Child Developmental Disabilities Specialist, MHMR







### **A Dallas Cowboy**

When Karla Auten, Family Support Coordinator at EveryChild, talks to families she speaks with a special kind of authority. She knows first hand what it's like. Two years ago a routine pregnancy turned into an emergency delivery that threatened both Karla's and baby Erik's lives.

The Emergency Room Nurse that night remembers saying "a man is going to lose his wife and baby tonight." She was wrong but that night was the beginning of Auten's journey as the parent of a child with disabilities.

Now Karla works with other families helping them to consider loving family alternatives to institutional care for their children. "There is an unspoken bond between parents," said Auten. "You know you've spent a lot of days and nights in the hospital wondering if your kids are going to be okay. The fact is it's not easy. But you can go on with your life." "And there's all kind of 'ups' everyday." added Erik's father, Robert Auten.

Erik's father remembers before Erik was born he daydreamed that his son would grow up to be a Dallas Cowboy football player. In the face of almost losing his son, his perspective changed.

"They said 'He might not be able to see.' I don't care. 'He might not be able to walk.' I don't care," said Auten as he smiled with a father's affection, winning a smile from Erik sitting in his lap. "I thought I wasn't gonna have him at all. If he's not gonna give up, then neither are we."

"Karla's job requires respectful discussion of very emotional issues. Having Erik has given Karla an extra insight and connection with families." said Nancy Rosenau, Executive Director of EveryChild. "She doesn't assume her experience is the same as other parents but when Karla talks to a birth family and they learn about her personal experience, they say 'oh, you really do understand!'"



*Eric, Dad Robert and Mom Karla Eric nearly died during birth. Mom Karla almost died, too. Two years later Mom helps other birth families of kids with disabilities.* 

Helping birth families consider alternatives to institutional care for their children requires respectful discussion of a very emotional issue. Being a parent of a child with disabilities, gives EveryChild Family Support Coordinator Karla Auten insight and connection with other families.



"There is an unspoken bond between parents.

Karla Auten Family Support Coordinator EveryChild

### **Children Deserve Families**

Thomas Chapmond, Executive Director of the Texas Department of Protective and Regulatory Service (PRS), is a strong advocate behind the unique collaboration of state agencies behind EveryChild's Family-Based Alternatives Project. The Project is working to realize the vision of family life for children with disabilities.

"One of the things that's critical to this project, I believe, is not only that we recruit families and find places for these children to live-good loving families—but that we monitor and ensure that those families are able to fulfill the kinds of obligations that they've made and that we support them to make this a success," stated Chapmond.

On any given day, Chapmond's agency cares for more than 12,000 children in foster care, giving the agency an extensive backround in recruiting, licensing and training foster families. PRS brings considerable knowledge to the collaboration, but Chapmond believes his agency will also learn from the other agencies and from the children and families.

In contrast to many children who come into care with PRS, Chapmond realizes that many children with disabilities moved into institutional care because their families had insufficient support. "This is about making sure that all children have families and that certain groups of children aren't denied that opportunity."

When asked about the biggest barriers for children with disabilities Chapmond said, "We have got to advance the notion that these children can be cared for in a family home. But they're going to need different kinds of services and supports."

Chapmond is particularly interested in learning more about shared parenting through the Family-Based Alternatives Project where birth families and support families share the care of a child.

"One of the things I'm really excited about is the notion of Shared Parenting," added Chapmond. "Just think how scary it would be if the needs of your child were such that you think as a parent you can't meet them. And think how comforting it would be to have another family say, 'I'll partner with you. I would be happy to help you raise this child." " said Chapmond. "I'm looking forward to further exploring this idea to make it a reality in Texas for families."



Offices of Texas Department of Protective and Regulatory Services

It is critical not only that we recruit good loving families, but that we that we support them to make this a success.

"Children deserve families ..We believe that all children can be with families given adequate supports."

Thomas Chapmond Executive Director Texas Department of Protective and Regulatory Service





# **Oprah, Move Over!**

Move over, Oprah, there's a new kid on the block. Twelve-year-old would-be television talk show host, Elizabeth, cornered her foster mom, Sharon Kiely, with a video camera to get the inside scoop on being a foster parent. Elizabeth asked the tough questions.

Q Elizabeth: What is your favorite TV show? A: Mom: Trading Spaces, no doubt.

Q. Elizabeth: Okay, what is your favorite time of season?

A. Mom: Christmas, you guys are all happy and well.

Q. Elizabeth: Do you like doing foster care? A. Mom: I love doing foster care because it's all about children. It's what I was called to do.

Q. Elizabeth: What is your most favorite part about it? A. Mom: Probably the loving, the hugging...even the tears.

But it's just all about you guys.

(Off camera announcer) - WRAP in 3, 2, --)

...This is Elizabeth and thanks for joining me and .....uh...Mom!

From a simple wish to make a home for one child, Sharon and Al Keily of Wimberley have created families for many children. When two-month-old Elizabeth came to the Keily's, she wasn't expected to live because of her medical problems. Mary Abigail, who uses a ventilator to breath and has a rare syndrome which makes her health precarious, also joined the Keily home. They not only survived, they thrive.

Handle with Care, a partner organization in the EveryChild Family-Based Alternatives Project, has 43 medically fragile children in 16 foster families and is adding new families.

"It's what I was called to do.

Sharon Kiely Executive Director and Foster Parent Handle With Care





Elizabeth, Mary Abigail, Sharon and Al Kiely, Toto and Spot enjoy famiy life at the Kiely home.

Sharon and AI had found their calling. They decided to open a foster care agency to find families for other medically fragile children.

The Kiely's know there are many more Texas families who can provide a family home for children with complex medical needs. Handle with Care does not advertise for families, but Sharon says they can barely keep up with the calls that come just by word of mouth. Foster families who love what they do tell other families. Other families see the tremendous need and learn that they can do it too.

# 340 Families Strong And Growing

Irene Clements wrote the book on caring for children in Support Families. As Associate Vice President of Family Services for Lutheran Social Services of the South (LSSS) she wrote the Foster Parent Handbook that guides families serving over 750 children in foster care. After 27 years as a foster mom, adopting four children including a daughter with a disability, and serving for seven years as the President of the Foster Parent Association, Clements has a lot to say in the book.

LSSS recruits, certifies, and develops foster families for children. Since joining LSSS to develop its foster program six years ago, Clements reports it now has 340 families and 25% of the children have a disability.

" The really exciting thing is we're attracting a lot of new families." Clements reports not only finding numbers of interested families, but very qualified caregivers. "We have been attracting folks who have worked in nursing homes and are interested in staying home taking care of their own child and fostering another child," added Clements.

As one of the founding partners in the EveryChild Family-Based Alternatives Project, LSSS brings a wealth of experience. But Clements also notes the differences between the EveryChild approach and foster care. "We need to change what the public knows," said Clements. "Many of the children in institutions are not victims of abuse or neglect. They are victims of family circumstances. We need to educate the public that there is a difference. Families get discouraged and feel like they're alone and there is nobody to help them. A lot of times that's why families had to opt for placement."

"The really exiting thing is we're attracting a lot of new families."

Irene Clements Foster and Adoptive Mom Associate Vice President of Family Services Lutheran Social Services



" The long term commitment," added Clements. That's another difference the public needs to know about." Foster care often means an emergency placement and is usually temporary. The Family-Based Alternatives Project, in contrast, takes the time to place carefully and looks for long term commitments.

"Those differences are the very things that are attractive to families thinking about becoming a Support Family," said Julie Benoit, Recruitment Coordinator for EveryChild. "Support families are attracted to the idea of a carefully planned placement and making a lasting home for a child."

Sometimes the arrangement between a support family and a birth family can be shared. Clements wants LSSS to be part of figuring out how to organize care for children in this new way. "Shared parenting is a way for children to have lots more people caring about them" stated Clements. "Shared parenting can be anything from checking once a week by phone, to coming by every day. Shared parenting can enrich the child's life many times over."

Lutheran Social Services, a partner organization in EveryChild's Family-Based Alternatives Project, has 340 foster families and is attracting many new families.





Linda Thune and Nancy Rosenau of EveryChild, Terrie Beattie of the Health and Human Services Commission, and Colleen Horton of the Texas Center for Disability Studies are working to change the system for Kyle.

## **Ready and Waiting**

"Kyle doesn't like to be left behind," said Colleen Horton, of the Texas Center for Disability Studies, getting ready to go with the staff of EveryChild to visit 10 year-old Kyle

Kyle's father couldn't care for him at home but wanted Kyle to be part of a family. When no family was available, the only option was the nursing home.

In August last year a Support Family was found for Kyle. EveryChild hoped that Kyle could be in a family before Thanksgiving. But Thanksgiving and Christmas both passed. Complicated funding rules have, so far, prevented Kyle and many other children with disabilities like him from moving into families.

"It seems impossible that it's taking so long to figure this out, but it's taken years to create this system, so unraveling it is no small task." said Nancy Rosenau, Executive Director of EveryChild. "It's hard, but it's do-able."

EveryChild is charged with the task of finding ways to make it easier for children with disabilities in institutions to move back with their birth families or into Support Families.

"We can do this," said Nancy Rosenau. "But we need more champions, leaders who will cut through the bureaucracy to get children into ready and waiting loving families."

Meanwhile, the EveryChild team continues to visit Kyle, as they did on this spring evening. They spent several hours of playing with Kyle, talking about school and listening as Kyle recited the Pledge of Allegiance. But then, it was time to say goodbye again.

Rosenau reflected on Kyle's recitation of the Pledge of Allegiance. "He clapped his hand over his heart when he got to the part about 'liberty and justice for all,'"she remembered. "From the way he emphasized the word 'all' I think he knew it included him. We have to make sure it does."

EveryChild is charged with the task of finding ways to make it easier for children with disabilities in institutions to move back with their birth families or into Support Families.

"Kyle is ready and waiting to move to a family that is waiting for him."



# Help Wanted: Loving Families

EveryChild has sparked a great deal of interest because of the volume and quality of phone calls responding to recruitment messages in the media. In Austin and San Antonio and the surrounding counties, hundreds of families have called EveryChild to find out about becoming Support Families, pleasantly overwhelming EveryChild staff.

"After years of thinking that there were no other options, birth families are starting to have hope that there is a family alternative when they can't care for their child," said Julie Benoit, Support Family Recruitment Specialist with EveryChild.

"It's a myth that you can't find families to care for children with disabilities," added Roddy Baker, also a Support Family Recruitment Specialist with EveryChild. "I have to admit I was skeptical at first too. But we've been inundated with calls from Texas families willing to open their hearts and homes to children with disabilities."

### For information about becoming Support Family:

In the Austin area call Julie Benoit at (512) 483-5830 In the San Antonio area call Roddy Baker at (210) 358-3227

For birth families or guardians who want information: In the Austin area call Linda Thune at (512) 483-5872 In the San Antonio area call Karla Auten at (210) 358-3077

Website: www.everychildtexas.org Program Administrator, Lisa Sheppard, (512) 232-0768 Executive Director, Nancy Rosenau, (512) 232-0756

"We've had over 350 calls in six months. We can hardly keep up with the calls from families who want to provide a family for a child with a disability. And best of all, many of the families that call have experience with people with disabilities and they especially want to help a child who lives in an institution. But we still need more families. "

Julie Benoit, Recruitment Coordinator, EveryChild, Inc.

**OLD LOGO** 

