



TEXAS CENTER *for*  
DISABILITY STUDIES

Understanding Successes and Barriers in  
Family-Based Alternatives:

Perceptions of Families, Facilities, and Agencies  
Final Report

By

The Texas Center for Disability Studies

at

The University of Texas at Austin

Penny Seay, Ph.D.

Denise De La Garza, Ph.D.

May 2006

## **Executive Summary**

Large numbers of children with disabilities do not live with families, and admissions to non-family residences continue to increase (Lakin, Aderson, & Prouty, 198; Anderson, Lakin, Prouty, & Polister, 1999). While it is socially expected that children grow up in families, this is not a reality for many children with disabilities. There are more than 1,500 children under age 21 residing in institutions in Texas.

The 77<sup>th</sup> Texas Legislative Session directed the Texas Health and Human Services Commission to contract with a community organization to develop a system of family-based alternatives for children with disabilities living in institutions. EveryChild, Inc. successfully won the contract to develop this program.

EveryChild's model was built on best practices of successful programs in other states and includes: (1) building trusting relationships with birth families, (2) assertively recruiting and preparing alternate families, (3) carefully matching children with families, (4) planning the child's transition from the institution, and (5) developing adequate supports to enable families to sustain children living with them over the long-term.

The Texas Center for Disability Studies conducted a qualitative research study to understand the impact of these activities on birth families and the support families recruited to care for children, as well as agency, facility, and provider staff currently involved in the care and placement of children in institutions. Understanding the successes and barriers to developing a system of family-based alternatives for children with disabilities and what helps families choose a family-based alternative over institutional care were goals of the study.

The research design involved in-depth interviews with two groups of participants: (1) families, including birth families and support families recruited to care for children with disabilities; and (2) agency, facility, and provider staff, including staff from state agencies, direct service provider agencies, institution and residential facility staff, Community Mental Health and Mental Retardation

(MHMR) center staff, and staff from EveryChild. The family interviews gathered information about perceptions, feelings, beliefs, and experiences of participants with the family-based alternatives model as implemented by EveryChild. The 39 agency, facility, and provider staff interviews gathered information about each person's role within their agency or facility as it related to the children involved with the family-based alternatives model, their concerns and suggestions, their views about the successes and barriers of the program, and their experiences with the EveryChild project and staff.

A total of 16 birth and support families were interviewed for the study. The birth families all expressed overwhelmingly positive experiences with EveryChild staff, and were very favorable toward family-based alternatives as well. The birth families recounted limited options, the lack of assistance from service providers, and the lack of coordination between programs that resulted in institutional placement for their children, and contrasted that with the ease of working with the EveryChild staff. Support families were also extremely positive and generally very enthusiastic about the process of becoming a support family. This group of participants experienced frustrations with policy-related barriers, especially with availability of funding for children to be supported in families. However, the placements of children that have been made were deemed very successful by the support mothers interviewed, their relationships with birth families were positive, and it was clear the children were integrated into the life of the support families fully and lovingly.

In analyzing the data from all of the participant groups, a number of themes emerge. Overall, all participants supported the concept that children belong in families. There was some disagreement about whether all children can live in families, but the concept was clearly supported. It was also clear that relationships between parents and staff within the system must be built on trust. This was eloquently addressed by several of the participants, including birth and support parents, as well as staff from the agencies, facilities, providers, and EveryChild. Additionally, all participants spoke to the dedication and

commitment of the EveryChild staff, and identified characteristics that are essential for this work to be successful.

Systemic, political barriers were the most clearly stated obstacles to developing and implementing a successful system for family-based alternatives. The rigidity of the existing system, difficulties with waiver programs and funding mechanisms, time limits for placements, existing policies and rules, lack of readily available accurate information, and other system barriers hinder the state from being able to fully implement a family-based alternatives model until policy changes occur that would support such a program. Leadership from the Texas Legislature and state agencies was noted as being critical to the success of the model and implementation in wider areas in the state.

Some participants identified a perceived lack of commitment to the model by agencies and facilities; participants who highlighted this issue felt that until the state leadership could ensure that changes would be made to encourage family-alternatives, little systemic effect would be felt. Failure to “close the front door” or end the admission of children into institutions and residential facilities by offering community alternatives was identified by state agencies, child placement agencies and the community MHMR centers as a barrier success.

The second category of barriers includes those that are related to the intense needs of children with significant disabilities, and the perception that the needs of children would be better served in facilities than they would in families. Some of the participants in the agency, provider, and facility staff groups felt it would be difficult, if not impossible, to find families who would be willing to accept children with intense needs for services and supports. This viewpoint was most strongly held by the facility staff, but a more moderate variation of this theme was at least mentioned by some state agency staff and some of the community MHMR staff. The direct providers and the EveryChild staff did not raise this as an issue, and instead expressed the feasibility of finding families for all children.

The need for a clear model and vision focused on the needs of the child is apparent. This will require a significant paradigm shift to begin thinking of what

it is that children need and what their experiences are, rather than focusing on the experiences of parents. Policies, rules, and procedures will need to be modified so that this focus will be supported. The leadership in the state will need to ensure that these changes occur to fully sustain a family-based alternatives model.

There was strong consensus across the groups regarding successes of the family-based alternatives project – seeing children in families, the development of new mechanisms for child placement, the expertise and technical assistance generated by the project, and changes in some policies. The most consistently identified measure of success was that children were moving from institutions and residential facilities into families. The positive responses from the birth and support families indicate that this type of system can work, but it must be carefully designed and managed. They are clear that the program designed by EveryChild addresses the key elements to make the process work effectively.

Analysis of the data gathered during this study from birth and support families; state agency, facility, and provider staff; and EveryChild staff generated strong themes that lead to the following recommendations. The comments from the birth and support families indicate that this type of system can work, but it must be carefully designed. It is clear that identifying people who care about children is a crucial part of successful placement of children. It is also critical that the people who work to match birth families, support families, and children are dedicated to the effort, and are not expected to manage large caseloads of children. Most of the birth families and some of the support families have worked with other child placement agencies and other health and human services programs in the past. They are clear that the program, as designed by EveryChild, addresses the key elements to make this process work effectively.

If Texas is to commit to the deinstitutionalization of children, and follow the spirit of SB 368 then clearly systemic changes need to occur that will support family-based alternatives. The rigidity of the waiver rules and the "front door" policy that makes institutionalization the primary option for children with severe disabilities must change. Additionally, the paradigm that

supports the concept that children with even the most severe disabilities belong in homes must be adopted by the state. These changes must occur from the top down, and infiltrate every level of management and direct care. It must be manifest in policies that truly support the concept that children with disabilities belong in homes, not institutions.

This type of systemic change is the work of all stakeholders, including political and agency leaders, community leaders in the judicial system, as well as front line workers. Caseworkers must be personally invested, as well as have the time and resources to develop meaningful family options for children. An inherent issue within this recommendation is that strategies to eliminate the potential for conflict of interest related to permanency planning must be addressed. These critically important plans should include the consideration of family options for children. Clearly one of the reasons EveryChild is successful is the personal commitment and passion of the staff. A culture within the state system that supports that type of personal investment in children is not unimaginable.

Parents of children with severe disabilities need options and information. All of the parents who had institutionalized their children felt they had no other option. This emotional and extraordinarily difficult decision was typically made without support, and with very limited information. Clear information that includes all of the rules about the waiver programs should be available to parents. Information about family-based alternatives should be given to every parent of a child with severe disabilities who is institutionalized or at risk of institutionalization, not only the ones who ask.

Training and education need to occur that help all of the stakeholders understand that children with disabilities, even severe disabilities, can be supported in homes. This philosophical shift of inclusion and compassion is essential for meaningful change to occur, and cannot be the sole responsibility of EveryChild staff. Developing mechanisms for internal training within agencies, training and information in institutions, and mechanisms for training and support of community stakeholders, including parents, would further the process of meaningful options for children with disabilities.

Clearly EveryChild is successful at what they do. The process is slow, and hindered by rigidity built into the system, however the successes were acknowledged by everyone interviewed. The families who were interviewed for this study were so grateful for the options afforded their children, and were relieved to see their children out of institutions. Parents felt their children were happier and better off with the support families. EveryChild should be able to continue and expand this important work for some of the most forgotten children within the state system.

The following comments, first from an agency staff person, then a support family, and finally a birth family, summarize the impact of the EveryChild approach and the development of a system of family-based alternatives:

*"This work is important in terms of issues that have to do with what's right for children and what's in the best interest in the long run for that child and for that family. ... Their dedication and their commitment to looking at services for children with disabilities in a different way...and push the state to make a difference for children. I think that's one of the best things, the most profound thing about the project." AFP16*

*"It is not like they are just looking for a home... What they are looking for is a family for someone. See anybody can live in a house, but they're looking for the whole... the atmosphere. You know, in other words making sure the right person's in the right place... it's not like big business." SF2*

*"I loved the program! I loved it! The only thing that could be done better is have more of them." BF 1*

## Table of Contents

Executive Summary .....	i
Introduction .....	1
Design of the Study .....	3
Introduction to Birth and Support Families .....	13
Birth Families .....	14
Support Families.....	26
Summary of Birth and Support Families .....	31
Agency, Facility and Provider Interviews .....	32
State Agency Staff .....	32
Direct Service Providers.....	47
Residential and Institutional Facilities .....	55
Community MHMR Centers.....	61
Overall Summary of Staff Interviews .....	68
EveryChild Staff.....	71
Summary of Research Themes.....	79
Recommendations .....	83
Appendix A: Birth Family Interview Guide .....	86
Appendix B: Support Family Interview Guide .....	88
Appendix C: Agency and Facility Staff Interview Guide .....	90

## **Introduction**

Large numbers of children with disabilities do not live with families, and admissions to non-family residences continue to increase (Lakin, Anderson, & Prouty, 1998; Anderson, Lakin, Prouty, & Polister, 1999). While it is socially accepted that children will grow up in families, this is not a reality for many children with disabilities. Parents have been, and continue to be, led to place their children with disabilities into specialized residential arrangements, and thus, these children do not experience a stable, nurturing family life (Rosenau, 2000). Family support systems that focus on the provision of services needed for children with disabilities to remain in the birth family are considered best practice for optimal child development.

There are more than 1,500 children under the age of 21 residing in institutions in Texas. Data from other states as well as recent experiences in Texas indicate that 80-90% of these children will not have the opportunity to return to their birth parents. While there are significant efforts in Texas to recruit and develop families to care for children who cannot remain with their birth parents, there are still huge shortages in the number of available placements for children with disabilities. EveryChild, Inc. was established to work towards the development of systems to remediate that discrepancy and provide the opportunity for every child to grow up in a family.

During the 77<sup>th</sup> Texas Legislative Session, Senate Bill (SB) 368 mandated that the Texas Health and Human Services Commission create a system of family-based alternatives for children living in institutions through the development of an award to a community-based group to pilot a program in a limited 12-county region of the

state; during the next Legislative Session, the county region was expanded. EveryChild successfully competed for the award to develop this program. EveryChild's long-term goal is to create a solid, reliable system of family-based alternatives in Texas that includes adequate support services for birth families and readily available alternate families, a system that will offer parents real alternatives to institutional care for their children with disabilities.

The family-based alternatives model is based on best practices of successful programs in other states and includes: (1) building trusting relationships with birth families, (2) assertively recruiting and preparing alternate families, (3) carefully matching children with families, (4) planning the child's transition from the institution, and (5) developing adequate supports to enable families to sustain children living with them over the long-term. The model works by bringing together an array of public and private entities to develop an effective system and facilitate implementation in a targeted area of the state. The system includes a continuum of family-based alternatives ranging from full-time foster care, to shared-parenting, to extended respite opportunities.

The Texas Center for Disability Studies (TCDS) conducted a two-phase qualitative research study to understand the impact of the family-based alternatives process on birth families and support families, as well as agency staff involved in the care and placement of children who reside in institutions. The study investigated the perceptions, feelings, beliefs, and experiences of the support parents and the birth parents of children with disabilities who had been placed in institutions or other residential facilities, and who participated with EveryChild in the Texas family-based alternatives project. Additionally, the study examined the perceptions, feelings, beliefs, and

experiences of personnel working in state agencies, child placement agencies, residential facilities and institutions, and community MHMR centers who were involved with care and placement of children residing in institutions and their families. The staff of EveryChild were included in the interviews of agency staff. Phase 1 of the study was conducted in the spring and summer of 2004; Phase 2 occurred in the fall of 2005.

This report includes information about the complete study, characteristics of the birth and support families and agency personnel, and findings from interviews with participants conducted during Phase 1 and Phase 2. The report is divided into five parts: birth and support family interviews; agency, facility, and provider personnel interviews; EveryChild staff interviews; a summary of the themes identified through the analysis; and, finally, recommendations based on the analysis.

### **Design of the Study**

While there is considerable research literature on foster care systems, research examining alternatives to foster care for children with disabilities is very limited, especially models that involve the voluntary choice by birth parents to use a long-term surrogate parent. For this reason, this study was exploratory. The purpose of the study was to understand the experiences, beliefs, and feelings of the participants without a preconceived idea of their responses, creating an opportunity for data to emerge that might be unexpected or unplanned. A qualitative design was used, based on principles of grounded theory, to develop an interview guide, and inform the data analysis procedures.

This section will include the data collection procedures, a description of the participants and data analysis.

### ***Data Collection***

The research design and all protocols for this project were submitted and approved by the University of Texas Institutional Review Board (IRB). Confidentiality standards were followed in the de-identification and protection of the raw data. A team of doctoral level researchers at the Texas Center for Disability Studies (TCDS) designed and supervised the study.

Researchers conducted in-depth, open-ended interviews with all of the participants. An interview guide was developed, piloted, revised, and then utilized to gather data from birth and support families, and from four distinct agency, facility, and provider groups. Each group will be described below in the Participant section.

De-identified participant information was given to researchers, who then selected participants for maximum diversity. EveryChild staff cooperated fully with researchers to provide necessary information, and contact families to obtain permission for the researchers to contact them about participating in the study. When permission was obtained from the families, researchers were given names and telephone numbers of potential participants. Potential participants were then contacted by telephone by TCDS interviewers, the study was explained, and consent was obtained.

Interviews with the birth and support families were conducted at the location chosen by the participants for their convenience. Typically that was their home, although one interview was conducted in the office of the participant, and one was conducted by phone. Sixteen family interviews were conducted in total; eight with birth families and

eight with support families. Of the eight birth families, four had a support family, one had refused services, one had not yet decided whether to participate in the program, and two were waiting for placements. Five of the eight support families interviewed had children placed with them, one had been matched, and the final two were waiting for placements.

Interviews of birth and support families were conducted in Austin, Texas, and surrounding areas; including Houston, San Antonio, and East Texas. One birth family interview was conducted with the father; all other interviews were with birth mothers. One support family interview was conducted with a couple, the rest of the interviewees were women. All of the interviews were audio-taped after verbal and written consent was obtained from the participants. The interviewers made field notes after each interview; the audio-tapes were transcribed verbatim by research staff at TCDS, then reviewed and de-identified by the interviewer.

Interviews with the agency, facility, and provider staff were conducted either by phone or in person at the offices of the Texas Center for Disability Studies by research staff. A total of 39 staff interviews were conducted, including eight with EveryChild staff. Again, EveryChild cooperated fully with researchers to provide necessary information. EveryChild staff compiled a list of agency staff with whom they have worked. They contacted staff to obtain permission for researchers to telephone potential participants to explain the study, and obtain their consent to participate.

The agency and facility personnel interviewed were located in Austin and surrounding areas and worked with children who were living in facilities in the area of EveryChild's work. All of the interviews

were audio-taped after verbal and written consent was obtained from the participants. The interviewers made field notes after each interview; the audio-tapes were transcribed verbatim by researchers at TCDS, then reviewed and de-identified by the interviewer.

All of the interviews followed a similar format, although it should be understood that the interviews were conversations, not question and answer sessions. The interviews with the birth and support families gathered information about the structure of the family, descriptions of the child, and future plans, as well as information about participation and experiences with the EveryChild program and staff (see interview guide Attachment A). The interviews with the agency, facility, and provider staff gathered information about the participant's role within their agency or facility as it related to the children involved in the family-based alternatives program, their concerns and suggestions, and the successes of the program from their perspective, as well as information about participation and experiences with the EveryChild program and staff (see interview guide Attachment B).

### ***Participants***

Four distinct groups of participants were included in this study. Each of these groups is described in this section of the report. A total of 55 individuals were interviewed.

#### ***Birth Families***

Birth families are defined as the family of origin of a child with disabilities who made a decision to place their child in an institution or residential facility; two birth families were adoptive families. A total of eight birth families were interviewed; seven in person at a location of their choice, and one on the phone. Because these interviews had the potential to be sensitive, the interviewer was a qualitative researcher

as well as a licensed psychotherapist. Indeed, most of the interviews were emotional experiences for the birth parents. All of them appreciated the opportunity to tell their story and expressed gratitude for the interest in the well being of themselves as well as their children.

Six of the birth families were Anglo, one was Hispanic, and one was African American. All but one had other children, with a range of 1 to 4 other children, and an average of 2.33. Four families lived in rural areas, three in suburban areas, and one in an urban area. Of the eight families, two were waiting for their child to be matched, three had a child who had moved from a facility to a support family home (placed), one had moved their child back to their home, one had declined services, and one was uncertain as to whether she wanted to move the child to a support family. The average age of the children with a disability was 14.3, with a range of 7-22. Three of the children were elementary age, three were mid-teens, and two were young adults.

#### Birth Family Demographics

Ethnicity		Area		Other Children		Placements		Age of Children	
Hispanic	1	Urban	1	0	1	Waiting	2	6-11	3
African American	1	Suburban	3	1	2	Placed	3	12-18	3
Anglo	6	Rural	4	2	3	Returned Home	1	19-22	2
				3+	2	Declined	1		
						Uncertain	1		

#### ***Support Families***

For the purpose of this study, support families are defined as families who welcome a child with disabilities into their family with mechanisms in place to receive the necessary services and supports. These families receive training, go through an extensive matching process, and are compensated for their efforts. Eight support families

were interviewed in all; seven were interviewed in person in their homes and one was interviewed by phone after multiple attempts to interview the person at home had failed. The interviewers were qualitative researchers; one was a parent of an adult child with disabilities, and the other was a psychotherapist.

Three of the support families were Anglo, two were Hispanic, and three were African American. Two had no other children, five had one other child, and one had two other children. Six of the families lived in an urban area, and two lived in rural areas. Of the eight families, two were waiting to be matched with a child, one had been matched with a child and was waiting for the child to be moved into the home, and five support families had a child living with them.

Support Family Demographics

Ethnicity		Area		Other Children		Placements	
Hispanic	2	Urban	6	0	2	Waiting	2
African American	3	Suburban	0	1	5	Matched	1
Anglo	3	Rural	2	2+	1	Placed	5

***Agency, Facility, and Provider Staff***

There are five sub-groups within the agency, facility, and provider staff participant group. These were all staff in organizations providing services to children with disabilities and their families.

Agency, Facility, and Provider Staff Demographics

Type of Organization	Number of Staff Interviewed
State Agencies	15
Direct Service Provider Agencies	5
Residential Facilities & Institutions	3
Community MHMR Centers	8
EveryChild Staff	8
Total	39

*State Agency Staff.* The first sub-group worked in one of four state agencies with responsibilities for providing residential services for children with disabilities (Texas Health and Human Services Commission, Texas Department of Mental Health and Mental Retardation, Texas Department of Family Protective Services, and Texas Department of Human Services). A total of 15 interviews were conducted with this group, with at least one individual from each of these agencies.

The Texas Health and Human Services Commission is the agency that was charged by the Texas Legislature under SB 368 in the 77<sup>th</sup> Legislative Session to develop family-based alternatives in a limited county area of the state. Additionally, the Health and Human Services Commission oversees work of the other health and human services agencies in the state. In 2003 during the 78<sup>th</sup> Legislative Session, the Texas Legislature mandated agency reorganization under House Bill 2292. The transformation blended 12 agencies into five.

The Texas Department of Mental Health and Mental Retardation (TDMHMR) was the agency charged with providing services to children with developmental disabilities in the state; under the reorganization, the Department of Aging and Disability Services (DADS) administers these programs. This agency administers Intermediate Care Facilities for the Mentally Retarded (ICF-MR), where some of the children with disabilities in Texas reside. The Department of Protective and Regulatory Services (PRS) was the agency that administered the Institutions for the Mentally Retarded; under the reorganization, the Department of Family and Protective Services administers these programs. Children with disabilities who are under the conservatorship of the state are placed in these facilities. Decisions regarding placement involve the court system because the state serves as

guardians for these children. Finally, the Texas Department of Human Services was the agency that administered nursing homes; under the reorganization, DADS administers these programs. There are children under the age of 22 living in nursing homes, some of whom live in pediatric units of the nursing home.

*Direct Service Provider Staff.* The second sub-group of participants worked in direct service provider agencies that have experience in placing children with disabilities into a variety of community placements, including moving children from facilities into foster families (e.g., Lutheran Social Services, Handle with Care, Texas Mentor, CALEB). Five individuals from direct service agencies contacted by EveryChild were interviewed. Researchers contacted individuals from the third and fourth agencies on three occasions but were unable to secure appointments to conduct the interview.

*Institution and Residential Facility Staff.* The third sub-group of participants was administrative personnel from residential facilities serving children with disabilities (Willows, Children's Center, Casa Esperanza, Mission Road, Windcrest, Southland Villa, Trinity Care and Northwood). There were three types of facilities involved in the family-based alternatives process: ICF-MR facilities, which are administered by the Texas Department of Mental Health and Mental Retardation; Institutions for the Mentally Retarded, which serve children who are under the conservatorship of the state and administered by Texas Department of Family Protective Services; and nursing homes, which are administered by the Texas Department of Human Services. Administrative personnel from one of each type of facility were interviewed for the study.

*Community MHMR Center Staff.* The fourth sub-group of participants worked in one of the community mental health and mental retardation centers involved with providing services in the community to children, including those who have moved from institutions and facilities through the family-based alternatives process (Austin-Travis County MHMR, Center for Health Care Services, Hill Country MHMR, Bluebonnet Trails MHMR, Gulf Coast MHMR, and Burke Center). Eight interviews were conducted with staff from six community MHMR centers.

*EveryChild, Inc. Staff.* The final group interviewed for the study was the staff of EveryChild, Inc. This organization received the contract from the Texas Health and Human Services Commission to develop and implement family-based alternatives in one region of Texas. Eight interviews were conducted.

### ***Data analysis***

A phenomenological perspective, based on grounded theory, was used to analyze data in this study. This approach is used by researchers to determine the meaning, structure, and essence of the lived experiences of a certain phenomenon for the person or group of people in question, and explores how people make sense of experiences, both individually and collectively. It requires gathering data through in-depth interviews with people who have direct experience with the phenomenon of interest; those who have “lived experiences”.

During Phase 1 of the study, the research team at TCDS met weekly over a period of one month to develop the research design and interview protocols. After IRB approval and initiation of data collection, the team continued to meet weekly for approximately three months.

The team worked to solve operational issues and problems, as well as discuss preliminary impressions of the data as it was being coded. Preliminary codes, the conceptual names given to the events and incidents found in the raw data (the transcribed interviews) were developed by this team comprised of the interviewers and the transcribers. Data was uploaded into N6, a computer program used to organize qualitative data. Researchers then coded the data into themes using the initial codes. This level of coding reorganizes the data into primarily descriptive levels, and this report reflects that level of data analysis. During Phase 2 of the study, the research team analyzed the data using the themes that had emerged in Phase 1. Data was reviewed for new themes as well. A total of 38 interviews were conducted in Phase 1, and 17 in Phase 2.

## **Results**

Themes that emerged from the participant groups will be discussed in this section of the report. The process by which birth families came to place their child in an institution, concerns about the family-based alternatives process, and experiences with EveryChild staff will be highlighted. The decision by support families to become involved in the program, concerns about the process, and experiences with EveryChild staff will be also be included. Following the discussion of the birth and support family results, the themes that emerged from the interviews with agency, facility, and provider staff will be discussed. Their role in the family-based alternatives process in their agency, understanding of the family-based alternatives process, perceived barriers, possible improvements, and other concerns regarding the program, successes identified by the participants, and the experiences with EveryChild staff will be highlighted.

## **Introduction to Birth and Support Families**

The goal of the family based alternatives process is to generate options for children with disabilities who live in institutions that are both family and child focused. It was beyond the scope of this research to include the perspective of the children involved in EveryChild placements, however the perspectives of the parents of these children was critical to an understanding of the effectiveness of the project.

The birth families of children who had been placed in institutions were interviewed and audiotaped, in a conversational manner, typically in their own home about their experiences with their child. They were asked to describe their child and the circumstances that led up to the placement of that child in an institution, in an effort to understand what circumstance led a parent to this type of decision. The interviewer attempted to understand, from the parent's perspective, what family life was like for this parent, the experiences the parents had with the service delivery system in general, and the specific experiences parents had with EveryChild. Of particular interest was the parent's perception of the change that could occur with the integration of a support family into their life and the life of their child.

Individuals who had been approved by EveryChild as support families were also interviewed. Researchers were interested in what made that family want to incorporate a child with severe disabilities into their family, how they felt about the role sharing with a birth family, and how well prepared they felt for the tasks of caring for a child with severe disabilities. Researchers were also interested in the direct experiences these families had with EveryChild staff.

The following is a summary of the major themes that emerged from these interviews. It should be noted that these interviews were rich and sometimes emotional, particularly for the birth families. This

summary is not a complete account of the themes inherent in that data. The data from these interviews will continue to be coded and analyzed, to examine specific facets of the data for more subtle themes.

The researchers would like to acknowledge the families who welcomed them into their homes, and shared part of their unique life story. We were privileged to be allowed to share their experiences, hopes, and dreams for their children. The reader should be aware of the courage these parents demonstrated by participating in this study, and aware that their motivation was love for their children.

### **Birth Families**

The decision to place their child outside the home was extremely difficult for all of the eight birth families who participated in this study. This was overwhelmingly clear in Phase 1 of the study, and supported by the comments in Phase 2. Every family recounted, often emotionally, the impossible family circumstances that resulted in the painful decision to place their child in an institution. Many of the families had to seek residential placement because the behavior of their child had such a negative impact on other family members. Parents were put in a position of making impossible choices, trying to make a decision that would meet the needs of all members of their families, particularly young children.

*"And my little daughter started hiding in closets... she was so shy anyway that she wouldn't talk at school...it was just like too much. (My other son) didn't want to have friends over anymore..."* (BF5)

*"It got to the point that when (child) would come home from school and (younger child) would go and hide herself somewhere, so it was affecting her."* (BF2)

*“Really at that point we were feeling like we had to decide between whether we can meet her needs at home, ...or the other two kids, because we were having to isolate them from each other, she was so fragile that if they climbed on her or anything they could break her legs.” (BF6)*

These birth families lamented the lack of resources or support that would have allowed the child with the disability to stay home. One family attempted to obtain and provide the services their child needed before *“...it finally hit me...we were going to have to do something different, because she just keeps getting bigger. So what do you do?”* (BF7) In discussing the difficulty of this decision, this birth mother said:

*“Well even when I started looking at facilities, I went with the intention that if they can do it, I can do it. I just need to see what they have to help...you know, are there aides that will help lifting, and I saw real quick, that even at (facility) in a 30 minute time, there were ten different people that had their hands on her. Then they went home at the end of it. I watched two grown men try to change her diaper and when she doesn't want it...she is strong...So that's when I thought, that's why I can't do it any more.” (BF7)*

This family made the difficult decision to place their child in an institutional facility with the assistance of the local community MHMR center where her child received physical therapy services.

*“That's (the MHMR center) where they told us these facilities were our only options and it wasn't until (our child) had been there almost a year when we found other things. And there were like hundreds of other things, but apparently, you have to be in a large facility before you go on a list.” (BF7)*

This parent learned that it was necessary to place her child in order to obtain other services that were less restrictive. When the family was contacted by EveryChild, they were interested in seeing their child in a smaller setting, and in a home.

*"When we met (support family), we were really happy with her and she seemed to love (our child) and at her house (our child) would have her own room and her own things and just get a lot of attention."* (BF7)

An issue that was discussed by birth families both in Phase 1 and Phase 2 of the study dealt with the relationship with the support family. This birth family was comfortable with this relationship *"because we've had a year or two to get used to it – that we're going to have someone helping us...and I try to even think it's kind of an extension of our own family...And we've talked about maybe there would be times we could even have (support family) and (our child) do some things together because they're an important part of our family because they care for our baby."* (BF7)

In discussing the relationship with EveryChild, this birth family stated: *"I wish there was some way that families could find out about EveryChild before they get to a point of crisis and that would be the only thing I think would make it better...early intervention."* (BF7) This family also praised EveryChild for providing them with good and reliable information, as well as helping them to feel comfortable with their decision.

*"I would like to have somebody come and help me at home instead of sending her somewhere. But we were not offered that kind of option."* (BF2)

*"I felt in a way it was selfish by keeping him and the resources weren't there for us and I was like, I cannot do this, at least if he is*

*there he will be ...have around the clock care, everything he needs is there and he doesn't need to be taken out. On the other hand, he's so far away from home and the same thing the nurses do, I have been doing and I know how to do."* (BF3)

When families needed options and assistance with their child, it was difficult to find. The limited options, the lack of assistance from service providers, and the lack of coordination between programs often resulted in institutional placement for their children.

*"There was not an option."* (BF2)

*"The expert told me he have to go to a nursing home."* (BF1)

*"I got very frustrated and I talked to my mom and we looked for alternatives... so I battled a while about it because I didn't want him to go... I didn't want him to leave home and I was never away from him. .... I was worried about them coming in and taking him from me so I placed him where he is, and he's been in there ever since."* (BF3)

There are so few options for children, even with institutional placements, that most often the children had to go live in a city away from their family. This made it very difficult for parents to be involved with their children, pick them up on weekends, and check on them during the week.

*"...it's one, and the other closer will be Temple for me, and the next closest will be Port Arthur and that is bad as Temple. So I decided to go to Temple. (note: Temple is about 3 hours from her home)"* (BF3)

*"There was one place in Houston that had openings, I forgot the name now. But we got so excited about it, Houston is too far, you know, but it was something, because there were no options in Austin."* (BF2)

*"...having to drive fifty miles north to go pick her up, to bring her, so she could participate in family stuff on the weekends or*

*whatever, and it was like, if we go there, then I was driving like two hundred miles, three hundred miles..." (BF6)*

Finding any kind of placement was not a simple process. Parents were generally astonished at the limited options available for their children, and the difficulty in finding out about those options. The Internet and other parents were important resources. Parents generally reported doing the exploration of options themselves, with limited support from caseworkers.

*"I was calling Easter seals, MHMR, the state, the county...I was on the Internet one morning and read an article ... so I called Ohio and she connected me with somebody in Florida... and the lady in Florida connected me with the lady in Forth Worth that found me a place in San Antonio..." (BF5)*

*"...and the other case manager had been promoted, so she wasn't working directly on the case. And we kept calling and doing our part, I mean, I would call and find out what sites, there is a website..., so we called some of those places..." (BF2)*

*"I dug and dug and I went to the library to look on the Internet and there was not anything... I have a friend who was a caseworker and she was not (my child's) caseworker but I would ask her a lot of questions and get a lot of information about what course to take and where do you go for doing this, and where do I go from here? And we stayed in touch with each other and she helped me a lot too." (BF3)*

The complicated waiver system, with stringent time limitations, created enormous difficulty for parents who were already making impossible decisions. Parents sometimes felt they had to learn the unwritten rules, "the game", in order to get needed services for their child.

*"They said you just got to play the game and I said 'what is the game?' And they said you will go at the top of the list if you put ...your (child) in an institution and the closest institution that I could find was \_\_\_\_\_" (BF5).*

*"(My child's) name had come up on the list and so she met with me and we talked about what (my child's) needs were, how much nursing care she would need, how much recreation, how many hours she was in school, medications, all these kind of issues, and what it would take to take care of her in the community in a foster home. And... she gave me this list of foster care providers in the state of Texas and it's like twenty, thirty pages thick. And so I said, 'So I just kind of look for the ones that are in San Antonio?' and she goes 'Well, you know, some of them might be based in Corpus but have homes in San Antonio'. So how are you supposed to know, it's not broken down... But I kept running into... them being geriatric, not providing any transportation, being stuck in a room smaller than this and I know that they meet with the regulation; it's like ten by ten or eight by eight. It looked like a cell." (BF6)*

*"And so I didn't want that one, and um, just it seemed like...everything we were...and they were like 'make a decision, make a decision, hurry up, hurry up, hurry up, we're going to get in trouble we've got to get this money spent' yadayadayada...the lady that was working with me was getting in trouble with her supervisor, the supervisor was getting written up by, you know, whoever the program directors for the HCS funds are because they hadn't spent the money, and I wrote a long letter, I wrote like a two page letter saying you cannot expect this person to be on a waiting list for seven years, who is quadriplegic, who can't speak, who can't defend herself, or anything, ... You know, I can't just move her in anywhere. I have to know that*

*she's going to be safe, and she's going to be well cared for and she's going to be included in a family. That's what foster care is! So anyway, they didn't close her, I mean, they were telling me that she would lose her place on the waiting list and that she would have to wait until funds were available again. And I said 'this is not even fair', I mean, you can't...if this person had, if she needed just a place to stay, that would be one thing, but this is someone who needs all these services. She has multiple disabilities and that's why she's been on this list! ...and I'm going to find a place in thirty days?" (BF6)*

*"And I mean I'm a smart person, well-educated and whatever and I think, 'what about the parents who like, don't speak English, you know? Who are not well educated, who have, you know other kind of barriers economically and stuff' because I have resources! I knew people all over the city and I still couldn't do it by myself." (BF6)*

One parent was particularly eloquent about what was needed to remediate this problem.

*"How come, there's not some system in place to help, you know, where every opening is? I mean, they should have some sort of...not just a directory that they hand you but, now the systems can be more automated and I'm sure that they could set up ...Just set up where they have a list of their providers, they know the good things about them and the bad things, which population they prefer, what level of clientele they prefer to have or that they're able to manage best, and what works best for their families and stuff. And be able to narrow it down to...be specific about what your needs are...I was like, we needed everything! I mean, we needed transportation. There was a lot of them that couldn't transport. It was like ...you're just calling everybody, you know? And whether they had an opening, or didn't have an opening, or whether the opening ...would fit for a kid her age*

*and her needs and that kind of stuff. I mean, that one place...her roommate was going to be a 64 year old woman! I'm like, she's 17! I said 'she's 17; you think it's normal to have a 17 year old with a 64 year old roommate?'...It would have helped if they would have had a better system in place for...first of all knowing that your name was coming up, so that you would have more time...instead of a thirty day deadline and as we were approaching September 1, because of that fiscal year crossing...that was like just a huge issue...'if we don't find this by September 1, we're going to lose it'....'I was supposed to make you do this for thirty days and I let it go on, and we've let it go on.' Like they had done me this big favor to let it go? Ninety days and stuff? Um...it still was unreasonable!" (BF6)*

It was a telling feature of these interviews that every one of the birth families, when queried about a perfect placement for their child said "home!"

*"Perfect? I would like her to be home again, I want to be a family together" (BF2).*

*"That will be ideal for me. If I have to work from home, I will work from home just to have him home...with enough support. I will love to have him home" (BF3).*

*"And I told them 'I don't want that you take my son. I don't want that you raise my son, I want that you help me raise my son' "* (BF5).

Had adequate supports been available earlier, it is possible that these families might have made other decisions.

The family-based alternative model involves finding a support or foster family for children who have lived in institutions. Understanding what helps people choose a program like EveryChild over institutional care was one of the goals of the research. One question interviewers

explored was the concerns or barriers birth families experienced during the process. There was one concern or drawback that families consistently cited: the fear the placement wouldn't work out.

*"So we feel a little insecure of having her with one person that can actually quit anytime. You know, you can make the commitment ...but something can happen. I just don't like to have that fear that somebody can call me one morning and say 'come pick up \_\_\_ because her provider is gone or whatever'...."* (BF2)

*"I tell her if I am or get sick that is the only thing that worries me but (EveryChild staff) already told me that we have to make plans in case that happens."* (BF1)

At least one family expressed concern over the role delineation. However, she felt those concerns were manageable.

*"It's hard for me to see somebody taking over our place but at the same time I think it's best for \_\_\_\_\_. I tell you, my main goal is to have her happy, we work around the other stuff."* (BF2)

The family who decided against a family-based alternative was very clear about the importance and value of the program, but the mother's personal choice for her child was a group home.

*"I want other parents to come see their kids, I want them to come play at my house, and I want that kind of environment. I would like to be able to check on him anytime I wanted and I don't want to be in somebody's home. I would like to take a nap with him if I feel like it."* (BF5)

This mother reported she found a group home that was near their home, and worked well for the needs of her child and the other members of the family. The arrangement allows her to go to his school regularly, and have him home whenever she wants. Her perspective was that *"EveryChild is so wonderful and I think for other families it*

*would be ideal*". (BF5) However, at this time, it didn't meet her needs. She appreciated that EveryChild was still a resource for her, and that staff still checked in with her.

The families all reported positive experiences with EveryChild staff, although some families who were further along in the process had more extensive experience than others who were just beginning. Prompt return of telephone calls, personable and committed staff who often went beyond what was expected, were routinely reported.

*"Very, very easy. They seem to be very available. We email each other. They are very supportive and it's really fun to work with them."* (BF2)

*"(EveryChild staff) even gave me her home phone number if I have a question or I need anything I can call her at home."* (BF1)

*"She has been a real support, like a real person, not just an agency like a (quote) 'job'...She's looking for the interest of the kids and the family...When (EveryChild staff) contacted me, she stayed in contact with me and it's not like I heard from her and six months this and six months down and I don't hear from her."* (BF3)

*"(EveryChild staff) were with me every step to find a place that will be OK for (my child)."* (BF1)

*"The paperwork, like they sent all the information, you can read through it and you can actually understand like everything. You don't need to use a dictionary!"* (BF3)

Even the family who didn't use the family-based alternatives process reported support from EveryChild:

*".... If anything it exceeded my expectations when I had that first phone call. Still (EveryChild staff) stays there for support, I had e-mail, phone, cell phone for her".* (BF5)

One birth parent, whose child was living with a support family, was enthusiastic about the process. The open communication, the genuine love and concern the support mother demonstrated for her child as well as her, the complete trust she had in the support mother to care for her child, and the happiness of her child were important features of the relationship. This comment speaks clearly to the trust the birth parent has in the support parent.

*“(The support mom) and I are real open in terms of communication. We do emails, phone calls and touch base with each other and like...I make curtains for (my child’s) room, and bulletin boards and stuff like that. She’ll hang up stuff for her... and it’s totally (my child’s) home. I mean, it’s totally (my child’s) room! That room is so (my child) it’s not even funny...(support mom) has been, like anytime that there’s a problem...and she’s been at the ARD meeting, which she knows everybody up there (school)...It’s almost embarrassing to me because I don’t know all of them. I haven’t even met all the teachers you know?...but she’s in contact with them all the time. If there’s a problem, I will know... (I) feel like (I) have that support. You know, and there was just like, for years and years that I felt like I was just in there by myself...” (BF6)*

The enthusiasm and joy of the birth family who was empowered by EveryChild to bring their child home is clear. This mother desperately wanted her son home, and out of a nursing home.

*“What is the best thing about him being home? I am happy, and...(my child) is happy and everybody else is happy...I loved the program! I loved it! The only thing that could be done better is have more of them.” (BF1)*

### ***Summary of Birth Family Interviews***

The birth families had overwhelmingly positive experiences with EveryChild staff and, in general were favorable towards the premise of the family-based alternatives program. The difficult experiences families had with the service delivery system were evident, particularly the stringent requirements related to finding placements. Limited options and information were typical, with families working to find information through informal networks and the Internet. These circumstances compounded the difficulty in managing everyday family life with a severely impaired child.

The importance and value of families for all children, including children with severe impairments, was captured eloquently by this mother. *"She needs that... oh, what's the word? That place in the world, that place she belongs to, so I want for her to have her bedroom, her home, her address is not an institution, and she'd still be close to me, ... you know, I will always be her first family, you know. I'm her mother."* (BF2) The perception that we all need to belong, and that our mothers will always be our mothers, make family-based alternatives a humane and viable option for people who simply can't raise their child with a disability in their home.

## Support Families

The support families, as a whole, were very enthusiastic about the family-based alternatives program and process. This report will focus on their decision to participate in the program, concerns about the process, and communication and interaction with EveryChild.

The decision and desire to be a support parent seemed to stem primarily from philanthropic reasons; many individuals felt “called” to do this type of work, and felt their contribution was valuable. People also felt they had specific skills or experiences that allowed them to do this well.

*“I just feel like (pause) it's my calling I guess, like I want to help somebody that has disability.” (SF3)*

*“We both quit our jobs now to do this full time. We decided to devote our time 24/7 to this... that's our mission.” (SF1)*

*“I guess it's the patience and the willingness that we have that this we want to open our doors to anyone that comes here.” (SF1 P2)*

*“We feel real good about doing this...just to see that the client is happy and feels safe. You get that feedback from the client, maybe not verbally, but once in a while you get it from a hug, a smile, you do things together, you laugh, you know, or even if you have a client that's nonverbal that doesn't show any emotions, just to know that you're helping. That's what makes the difference.” (SF1 P2)*

*“It keeps me grateful. And a lot of joy. A lot of joy. A lot of love. And I'm, I've got a real maternal instinct...and I had never had any children so it kinda helps me there...satisfies that need.” (SF2)*

Finding a child was a serendipitous event for two of these support families. One support family talked about meeting the child

now living with them in this way: *"We're real pleased that we ran across him...because he's great, he's wonderful! ...We went to (facility) to meet a younger child, and he was like four and a half, and it was just instinct. While we were there we happened to see this other child and my husband and I both had the same instinct when we left that this (younger child) was not the right kid...and we saw this other one that kind of peaked our interest."* (SF7) The facility staff discouraged the support family from bringing this child into their home as he had lived in a facility for more than seven years, and had a history of aggressive behavior. This behavior has not been evident in the home.

Another support family described a similar situation. When EveryChild staff took the support mother to a facility to meet a child who had been identified as a potential match, the support mother saw another child and *"it was just love at first site! So I said to (EveryChild staff), what about this child? What about her?"* (SF8). EveryChild located this child's birth family, explained the program, and the child was eventually moved to the support family's home.

The families interviewed in Phase 2 were very positive regarding the assistance they received from EveryChild in completing the licensing process and working with the providers to make the placement of the child. Two of the families praised EveryChild, both the staff and the philosophy of the program. They found them to be very helpful in working through the maze of the system and answering questions that they had, and particularly in dealing with funding issues.

Families were asked about their concerns about being matched with a child. Operational concerns, such as time delays and funding problems with the process, were discussed, as well as some concerns about the child will integrate into the family.

*"We got the paperwork ready...but I don't know how long it's going to be till they actually place someone in your home, because it hasn't happened to us yet, so for some reason, it hasn't happened... we filled out the application, the paperwork, everything. Did the inspection of the home and he said 'I'm going to contact you in a couple of weeks.' This was back in October. It was before Christmas. So we haven't heard since then....so I don't know if he didn't have any kids for us or just paper ...to be honest with you, I don't know if he thinks we're not qualified, or I'll just be honest with you, I don't know what's going on. But I was going to call him and ask him, 'Be honest with me. We did not qualify?'" (SF1)*

*"I have already visited the child twice and I went once with (EveryChild staff) ...and I met the child, and then last spring when he was off from school, I went there again to see him, just to see him...he had been asking me 'When do I go home with you?' And I say, we have to talk ...to your mom and besides there is other stuff that we need to get involved. I didn't really make him excited because we're not sure...we don't want to get him excited because we know there is no budget yet." (SF3)*

*"The only request we had is a child that's nonaggressive, that's not aggressive with others, because the two clients we have now are not aggressive at all." (SF1)*

The matching process was discussed very positively by several support families. This response captures one aspect of the relationship between birth and support parents that can lead to a successful placement.

*"We did have an interview with the birth mom and she told us about herself, we told about ourselves... It really does (need to be a*

*match too)... And I do call her, especially when he comes back from the doctor, and she's fantastic. I'm not trying to be (his) mother, you know, I'm not trying to take that away from his mom. I'm just a provider, taking care of (him), trying to provide the best I can for him. ..I mean, I fell in love with (him) the first day I seen him, and that's something you just have to have.....you can't not like them and have them in your house...So you have to extend the same courtesy and love as you do your own natural family." (SF5)*

Families were also queried about their overall experiences with EveryChild staff and the family-based alternatives program. Other than the one support family who hadn't heard whether they were qualified for the program, the responses were overwhelmingly positive.

*"The person that came to us first and told us about the program was very professional, very kind, and gave us as much information as he could, informed us about the program and the children..." (SF1)*

*"I'll be honest with you it was real nice to have them... It was an asset... 'cause they were real... I'm used to in this field, I'm used to a lot of turn over...and it's nice to be able to call and still talk to (the same EveryChild staff) But, but, like I said, I worked in the other...where all of a sudden you call and its not the same person and they don't know a thing about you." (SF2)*

*"So (EveryChild staff) is organizing the classes and the things like they kind of training ... I was delighted that they have so much available to you at this day and time." (SF4)*

*"The very best thing is that they are getting them out of an institution...That is number one...that's something that we need and we need more of. You know, that is my very, very top thing and then the second thing is consistency. I can call today and (EveryChild*

*staff)...know what's going on. They're very aware of what's going on...they follow through. They were there on Christmas day. That's not a day that everybody needs to be out. They're supposed to be with their family. But yet they were with our family. You know...when they say they're going to do something, they do it... and, I believe them. That's another thing. I believe them. Yes. I trust them."* (SF2)

The spirit of family-based alternatives and the commitment of the EveryChild staff was captured by this support mother.

*"It's not like they are just looking for a home...for someone...what they're looking for is a family for someone. See anybody can live in a house but they're looking for the whole...the atmosphere. You know, in other words making sure the right person's in the right place. Rather than just find a home... 'okay, here's your house. Here's where you're going to live.' Yes. They follow through, they call...they remember (your) name. You know...that's real important ...it's not like big business."* (SF2)

### **Summary of Support Family Interviews**

The responses of support families to the family-based alternatives program were extremely positive. Negative comments were related primarily to policy-related issues that hindered moving children and ensuring reimbursements to families. The placements that have been made were deemed very successful by the support mothers interviewed; relationships with birth families were positive, and it was clear the child was integrated into the life of the support family fully and lovingly.

## **Summary of Birth and Support Families**

Both birth families and support families were interviewed and queried about their experiences with EveryChild. All of the families interviewed expressed positive feelings about EveryChild and felt that the support generated by EveryChild staff was above and beyond what they expected. Both birth and support families expressed that the process was time consuming; however the birth families seemed to have a better understanding of the complexity regarding funding streams involved in the matching process. Policy related concerns particularly about the waiver process were a significant issue for birth parents. Clearly the easiest path for a parent is to keep their child in an institution.

Both birth and support families need ongoing information, communication and support for successful placements. The families who had made placements were extremely pleased with the results, and felt that the children were significantly better off than they had been in institutions. All of the families believed in the philosophy of a family based alternatives process. All of the birth families, given enough support, stated they would have preferred to have their children at home with them. However, even with additional available supports, most of these families did not choose to bring their children home.

## **Agency, Facility and Provider Interviews**

The four groups of participants in this study will be discussed separately.

### ***State Agency Staff***

The agency staff interviewed represented the Texas Health and Human Services Commission, Texas Department of Mental Health and Mental Retardation, Texas Department of Family Protective Services, and Texas Department of Human Services. Three of the participants were interviewed in Phase 1 and in Phase 2. The participants included state agency policy level personnel as well as individuals in field offices in Austin, Houston, and surrounding areas who worked more directly with children and facilities. Data regarding staff perceptions of role change due to the family-based alternatives process; barriers, concerns, and suggestions for improvements to the process; the relationship with EveryChild staff; and the successes of the program will be discussed.

### ***Staff role change***

In general, agency personnel reported minimal change in their roles because of the family-based alternatives process. The changes that were reported were primarily related to being the contact person for EveryChild staff, and a person who would help EveryChild get information that they needed.

*"I think I just became more active when I realized that I needed to play a more active role. I can't speak for other DD specialists throughout the state ..., but I am kind of like the broker for the children that we have here, and pretty much I'm the go-between with anything that EveryChild needs from staff or information that they*

*need so that if it's something that I can retrieve from the computer, I can probably do it faster and more efficiently than them trying to contact the actual case manager for the child because they're handling too many children; they won't give it priority." (AFP24)*

In discussing the ways in which their role within their agency changed, at least one participant spoke about a collaborative relationship with EveryChild staff regarding the family-based alternatives model. This included being trained by staff from EveryChild as well as direct actions on the part of the agency.

*"I think from there [the initiation of the partnership] we just kind of worked together to figure out what the best way was to get the word out and educate the rest of the staff across the state, since it's such a large program...There are several different avenues we have taken. One is through ...sending out what we call PSAs, which are broadcast through our system to notify staff of a new service or any kind of new entity." (AFP7)*

*"I think what they look to me for many times is the knowledge of Medicaid and Medicaid programs, and understanding how the reimbursement for Medicaid purposes works" (AFP37).*

While state agency staff reported minimal change in their roles since the initiation of the family-based alternatives model, one role change highlighted by several participants was their involvement with the re-approval for continued placement of children in facilities. While this activity is not directly related to the family-based alternatives program, it was one of the new mandates of SB 368 which also mandated the creation of the alternatives process. This also relates to the permanency planning process for children, which is often carried out by facility or agency staff.

Permanency planning is a philosophy and a process aimed at helping families secure optimum services and supports to enable their child to meet his or her potential. It is based on the philosophy that children should grow up in families and seeks to secure permanent living arrangements that enhance a child's growth and development.

Several state laws exist that require Texas health and human services agencies to develop permanency plans for all children residing in nursing homes, state schools, or intermediate care facilities for the mentally retarded. Permanency planning also benefits children at risk of institutional placement.

As stated in Senate Bill 368 (77<sup>th</sup> Texas Legislative Session), "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 provide encouragement and support for well-functioning families and ensure that each child receives the benefits of being a part of a successful permanent family as soon as possible...the commission and each appropriate health and human services agency shall develop procedures to ensure that a permanency plan is developed for each child who resides in an institution in this state on a temporary or long term basis."

*"And, we have to approve the, what we call the permanency plan for these children every six months. Then we send this information to HHSC because they also have to re-approve the continued placement of the kids in these programs. And so, my hands have been involved in that process." (AFP5)*

*"I work very closely with \_\_\_\_\_ who is our placement section supervisor, who works with four staff members up here who assist staff in the field with obtaining permissions for the children to be placed in some of these settings...so we're closely with her to keep up with some of the referrals that we're getting." (AFP5)*

### ***Barriers, concerns, and suggestions***

Participants identified several barriers to the success of the family-based alternatives process. Political barriers were frequently stated, including lack of funding, problems with waiver programs, rate differences between programs, and other systemic issues. These participants also frequently stated that as long as institutions and facilities continued to admit children, the system would not change. Preventing the admission of children into institutions and facilities by offering effective alternatives to families, a concept known as "closing the front door", was a consistent concern identified.

*"I don't see in the near term effectively closing the front door without some major policy and funding changes...and I don't see that happening..." (AFP1)*

*"...then of course there is a statute that's kept the door open. And until we develop and have statute that prevents the front door, and insures when a child, when a family reaches the point of needing support to prevent institutionalization we have them available." (AFP8)*

One participant expressed initial concerns that this process would be duplicative of existing state efforts because of established work with child placement agencies. This participant acknowledged the existing focus on children without disabilities, and suggested increasing efforts with child placement agencies as a way to expand the success of this process.

*"I think that the ways that they could better support and work with the child placing agencies ...would be in the long run more effective. I mean the child placing agencies are more focused for the ...well, I won't use so much the term 'more normal' children, but they're not as focused on the children with developmental disabilities, but I think many of them could expand to do more in this arena."*  
(AFP5)

Political and systemic issues were discussed in the state agency interviews. Participants identified non-supportive priorities in the Texas system, funding issues, and the need to shift leadership priorities as significant barriers to the process.

*"...the system isn't fully ready for family-based alternatives because there's not a consistent payment mechanism to pay for the support the child needs to remain in a home."* (AFP1)

*"In Texas we are trying to increase the number of support services to families. We are looking at some models that have worked real well up north in Michigan, Pennsylvania, and some other places, where the government agencies have been more supportive of families trying to care for these type of children... and so we're in a long-term, probably 10-year process here in Texas trying to increase, re-arrange, I should say really, along the way the government functions, or works, for some of these children to be more supportive of helping these children stay in families..."* (AFP5)

*"...some of my concerns are not things that are within their control. One is that we have an incredibly heavy private provider lobby that isn't particularly thrilled that the family-based alternatives project is here. And they feel threatened by the fact that we believe children belong in families and not living in their institutions."* (AFP8)

*"...we are trying from the top down and the bottom up...to make this better understood...and a question from rather high management people saying 'well, why can't we just leave them there?'" (AFP6)*

Consistently, agency personnel stated that they felt the family-based alternatives process was too slow, and this was an issue that created strong feelings among participants. While several participants recognized that the matching process used by EveryChild was good in terms of making a successful placement, it was also seen as unrealistic.

*"Unfortunately in our system here in \_\_\_\_\_ we don't always have the luxury of being able to wait a couple of years to kind of groom a family before we make a placement." (AFP5)*

*"I am told that they signed a family and there was a match and it just moves too slowly and either the foster family doesn't want to wait because they want kids in their home now or...I don't know what happens. It, they never, it never happens...It's a good thing that they want to move slowly to make sure that the placement...is going to work. But the family, when they get the license, they want a kid because they want money." (AFP25)*

Another consistent concern from the agency personnel was that the children in the facilities being considered for a family-based alternative were children with very intense needs. Consequently, according to several of these participants, the families needed for children with these high needs would also have to be special families. Five of the ten participants in this group identified the severity of the disability and the resultant service and support needs for the children as factors in the process.

*"Some of the kids have intense needs though...and because of the disabilities we have to place them in physically fragile foster homes or homes specialized to handle habilitative care...Many times we have tried other placement situations and they haven't worked out. And so, by process of elimination, we have had to resort to placing kids in some of these more structured programs. Again, because of the child's needs at the time." (AFP5)*

*"I think the concepts are great. I just don't think we have the level of families that these children need and I don't think there's enough of them out there to meet the demand...these children have extraordinary needs and it's going to take extraordinary people to be able to deal with those needs." (AFP26)*

*"I think it is a pretty tough job to find families who are willing to take children who have these special needs." (AFP3)*

*"It's not an easy thing, especially when you're dealing with kids who have these needs for special services...it takes a special type of individual to be able to handle this on a daily basis." (AFP6)*

*"I think one of the barriers is that families are ill equipped to handle kids with these problems. It's hard to find a family who's willing to, because they are going to have to commit their whole, entire lives to that child. I mean, they won't hardly be able to go anywhere, or do anything, their every second is going to be taking care of this child." (AFP25)*

When asked by the researchers about the success of the family based alternatives process, participants consistently stated that children growing up in families represented success and what was best about the process. *"The main successes are the kids who are now living in families" (AFP8); and "I think it's a great idea to get a child*

*out of a facility and into a family environment” (AFP3). Additionally, participants identified other benefits the state has gained through the development of the family-based alternatives model, including being a training resource for the state, creating opportunities to discuss the experiences of children who live in institutions, and focused recruiting of families for these children.*

*“The best is just the simple fact that it allows a mechanism for a child to grow up in a family instead of an institution and...all the studies and what not are very conclusive that kids do a lot better in families. And they need that sort of emotional attachment and bonding with a prominent adult relationship...without the family based alternatives we haven’t really had a structure in place to facilitate that.” (AFP1)*

*“The best thing is they are the folks that have the words that can help families understand and be OK with exploring other options for their child other than coming back to the birth family. The other success they can claim is that they’ve provided invaluable technical assistance to the state agencies as they standardized the process across agencies.” (AFP8)*

*“I think the project has been real helpful as far as being a resource, being able to bring their expertise, being able to help our staff think of new options, perhaps, re-think how they are approaching trying to find resources for the children.” (AFP5)*

*“Well I think the best thing is that they are actually going out and recruiting families that want kids with disabilities...because they deserve to be in a family environment too.” (AFP25)*

EveryChild was seen as a significant resource in terms of increasing knowledge and skills of a myriad of professionals who are

involved in children's services in Texas. The on-going need for training and technical assistance to broad groups was highlighted in many of the interviews. Several of the participants stated that EveryChild should be training case workers, judges, lawyers, legislators, families, and the general public on the effects of institutionalization on children.

*"...we work with such a variety of child placing agencies...and the more education they can get about who EveryChild is and what they do and how they work, the better off it is for our workers that are going forward and using family-based options." (AFP7)*

*"Well I don't know that as a group if they understand the fact that the court system is at the core of our particular care of the child. And if the judge says we want the child to stay in this situation because we, with the information that we have, feel that with their needs they provide the best setting...either being terminal or being high risk of infection or whatever...And they were having some trouble accepting the fact that we don't move without the judge." (AFP6)*

While it is recognized that the court system is unique in its process of working with children and families, and in making placements, the participants saw EveryChild as being in a position to educate individuals within that system. Case workers are not the decision-makers in making placements, and while they recognize the importance of informing decision-makers, they did not perceive this type of education as their role.

*"I am not the deciding factor as to whether or not the placement will occur. All I can do is make the recommendation..." (AFP26).*

Researcher question: "and they're not in your sphere of influence?"

*"Well, I mean, I can talk to them...and I can tell them about the program and about how EveryChild feels that the placement would be*

*beneficial for the child...But I can't tell them that they have to do it...or that they have to accept it." (AFP26)*

*"the other thing in the CPS system is, we've got a ways to go in training judges, you know, who often will make recommendations for institutional care when they don't really...they're not really familiar with... you know, the fact that there are alternative family arrangements for kids with significant disabilities. I think we still have a long ways to go in terms of educating the community at large in terms of the alternatives...and the legislature in terms of the fact that institutional care is...detrimental to children." (AFP1)*

Additionally, permanency planning was highlighted during Phase 1 of the study as a critical factor in moving children from institutions and residential facilities into families. Families, case workers, and others need training on permanency planning to facilitate moving children. The issue of a potential for conflict of interest was raised because permanency planning is often done by institution and facility staff. Changes in the 78<sup>th</sup> Texas Legislative Session removed the potential for conflict of interest in permanency planning.

*"...we've got a lot of training to do with the case workers, with permanency planning. We've got a lot of training to do. There's nobody to do training. ...the permanency plans are done by... the institutional staff in the ICFMRs, which is maybe not the most efficient way to do it, in that, you know, there's a potential conflict of interest there." (AFP1)*

When asked by a researcher about presenting the option of alternative family placement, one participant responded *"right now my program works with, does the permanency planning for children in nursing facilities. And, any of the parents who seem to be looking at a*

*possible alternative family, we do refer them to EveryChild.” (AFP3)*

Referrals to EveryChild regarding family-based alternatives are apparently not done routinely in some facilities.

Finally, this group of participants suggested that EveryChild better support and educate child placement agencies on how to more effectively work with children with disabilities. Training in order to increase numbers of potential support families would increase the participation in the program, and is an activity that should be increased by EveryChild staff.

*“And train more of these families. You know, support more of these families. And, if they do care for these kids, develop support systems for the foster parents with these agencies, also that they can continue to offer family alternatives for kids.” (AFP5)*

### ***Relationship with EveryChild***

The relationships among agency staff and EveryChild staff were complex and sometimes impeded by conflicting views. While participants generally praised EveryChild for the work they were doing, there were some concerns raised about the way that the staff interacted with the agencies. Differences of opinions regarding the ability of all children to live in families contributed to the conflicts with some agency staff. Additionally, a perceived lack of respect by EveryChild staff for the work that has been underway in Texas for several years with children with disabilities was seen as a barrier.

*“I don’t think that they were initially very savvy at meeting the providers and the system in our state where they were. And not making them feel bad about what they do. I think they’ve gotten much, much more savvy about that...about how to work with the agencies...But they are much better at that than they were at first.*

*They turned a lot of people off initially, a lot of providers, a lot of people who philosophically agreed with them but didn't like the high moral ground approach." (AFP8)*

*"You know I understand the advocacy role, and they are functioning out of their expertise, but, given the volume of cases that different child placing agencies work with, they do look at they do consider all the options available, but then they make decisions and then need to move on. And I think that sometimes the project has had difficulty in letting go and looking at other cases...Sometimes the project hasn't been happy with [the placement decision]." (AFP5)*

Additionally, while participants understood the need for the time involved in the process of matching, it was identified as being too slow. This was especially true for participants from the Texas Department of Family Protective Services, who are often working on an immediate crisis situation and require a much quicker resolution. During Phase 2 of the study, there was some confusion regarding the role of EveryChild; the family-based alternatives process is not designed to assist in crisis situations. However, this concern was voiced by at least one participant.

*"...the process takes a long time, and we totally understand that and agree with that philosophy, but the reality is that we have a crisis and sometimes we have children with no place to go. That's our reality. And so we don't always have that kind of time. I don't know what the answer is here. Except that sometimes we're in this position where we have to make hasty plans. We do the best we can to match them...They're not that much help to us when we have a crisis." (AFP38)*

As three of the state agency personnel had been interviewed before, they were asked if they had seen any changes since their

interviews were conducted in Phase 1. One agency staff member commented:

*"I think they've been very constructively trying to address and improve upon the things that were noted in the last evaluation that they could improve upon. I've seen them trying to focus on building relationships with the state agencies so that they will be viewed as a resource to the state agency and not so much from an advocacy standpoint, because they were hired to help us implement this. I think that they're seeing their place as a resource for state agencies, more than what seemed like in the beginning was almost sort of this advocate role."* (AFP40)

Another agency staff member saw changes in the knowledge of the system, particularly in the area of funding:

*"There are positive changes that I see with EveryChild that I think will better enable them to advocate for children... I think they're beginning to see more how the rates work, what payment rates are based on, how services are funded, and ... better understanding that they need to have knowledge about funding because very often that's going to drive the service you get...they're putting themselves in a better position to be able to advocate for children and children's services, because once they have that knowledge, then they'll be able to participate in discussions around that and then advocate for an appropriate rate for the service for the child...I think they're both providers and advocates."* (AFP37)

### **Summary of State Agency Staff Interviews**

The state agency staff, especially those who were in the field and working directly with children and facilities, were generally less positive overall than either birth or support families about the family-based alternatives process. In addition, they understood less about the

process itself and were confused about the relationship of the process, their role, and EveryChild. In general, they did not report that their role had changed significantly through their involvement with the family-based alternatives process. While they seemed to agree that a measure of success was children growing up in a family rather than an institution, there were also many comments about the lack of available foster families, especially for children with high levels of needs. They also expressed frustration that the EveryChild staff seemed unwilling to accept the system under which they worked: that the case workers were not the final decision makers, that some of the decisions would be made by the court system for some children, and that the most they could do was to make placement recommendations.

This group also identified a strong need for more training on the family-based alternatives process itself, permanency planning, and the effects of institutionalization on children. The interviews suggested that the agency personnel saw this as the role of EveryChild.

It should be noted that the agency staff who held the more negative opinions of the process itself and of EveryChild staff were responsible for children who were under the conservatorship of the state. These individuals indicated that the system they worked under was quite rigid, requiring orders from a judge to make any changes in a child's placement, and expressed frustration that EveryChild staff did not seem to understand this issue. These agency staff did not seem to feel that educating individuals within the legal system about family-based alternatives was their role.

There was considerable support for the family-based alternatives process voiced by all of these participants, although differences about whether it was feasible to identify sufficient numbers of families who

were willing to make a commitment to the children were expressed. This was another issue that was seen as falling to the staff of EveryChild: that of doing focused recruiting of families for children who were perceived to be more difficult to move into families. State agency level policy staff were generally much more positive about the family-based alternatives project, the benefits this program brought to the state, and the expertise of the EveryChild staff, than were the case workers and other front line staff interviewed.

## **Direct Service Providers**

Five direct service provider agencies were contacted to request participation in the study. Three of these agencies have been involved with EveryChild before the award of the Texas Health and Human Services Commission contract to establish family-based alternatives, and had a history of placing children with disabilities with foster families; the remaining agencies have a long history of providing services to children with disabilities and their families, and had worked with EveryChild. Five interviews were conducted. Information regarding staff role change due to the family-based alternatives process; barriers, concerns, and suggestions for improvements to the process; the relationship with EveryChild staff; and the successes of the program will be discussed.

### ***Role change***

When asked by the researchers about how their roles had changed when they began working with the family-based alternatives process, the participants reported a significant change in how they worked with children and families. There was an increase in the workload with the greater coordination of efforts.

*“My role changed a lot in that I had to be very involved with the coordination and the process to make sure everybody was on the same page. It took a lot of time and energy.” (AFP29)*

Additionally, direct service providers had a role in recruitment of families, and at least one participant discussed efforts to keep others in the agency motivated to work with this process. Both of these efforts were made more difficult by the length of time required to complete a move.

*"I think it was an effort we tried to do as far as the recruiting of families and educating families on to serve this population that do need homes and we had numerous families that were ready to do that and because there were no placements they left or gave up." (AFP 29)*

*"...and I guess on our part, on my part from an agency perspective you know I was the one in our own agency keeping everybody motivated and going when staff would get frustrated with a placement that's not happening...I would have to keep them going and after three years, it was, it didn't make sense to continue to recruit families to take the population when we weren't seeing that population come into our facility." (AFP29)*

Some of these participants discussed the changes in their roles due to the family-based alternatives process more in terms of having an additional resource to assist in placing a child into a family. The process allowed the agencies to explore more options for children even if they did not result in a family placement. Staff commented that they considered a wider variety of options for all children because of their experiences with this process

### ***Barriers, concerns, and suggestions***

Barriers were also discussed by these providers; those identified were primarily systemic issues, including licensing issues, inequities between various waiver programs, and lack of commitment from agencies. The following response captures the complexity of the waiver programs and the difficulties that providers encounter when trying to move children to families.

*"The problems were that I've seen and that I've been a part of trying to figure out what to do is the funding stream. People didn't put enough effort into figuring out how that was going to work. Like I said,*

*these kids can come out of a nursing home and the Medicaid money can follow them to DHS. All DHS has to offer is CLASS and CLASS has no family component. They wouldn't let the money go to MHMR where they had HCS which did have and does have a support family component...what we had to do to bring...a ten year old boy with cerebral palsy [out of the nursing home]...he had this money that would follow him out of the nursing home, but CLASS couldn't serve him. So what we had to do was take a home health license. We had to get a license to be a home health agency. And then with that we had to contract with DHS through the MDCP program.” (AFP9)*

In addition to the problems of trying to serve children through the different waiver programs, these agencies also worked with families who faced barriers because of reimbursement issues. During Phase 1 of the study, it was not unusual for reimbursements to be reduced when children moved from institutions and residential facilities into homes, which could result in fewer families who are able to accept a child into their family because of their continued need for services and supports. Changes in the 78<sup>th</sup> Texas Legislative Session addressed these issues, and reduced the barriers related to reimbursements.

*“...the barrier is that it is still very therapeutic based. ...agencies like ourselves are afraid to venture out and to take the population and the barrier in the level of care system ... and how kids are evaluated and determined on a reimbursement. That still is a major barrier that I may get a child who is extremely medically fragile and in three months the child's level drops which is a reimbursement drop for the family and it's a major ordeal and a fight to get them raised up again and I can't expect families to take care of some of these children with the reimbursements they are getting.” (AFP29)*

Lack of facility support for moving children out was also discussed. This was sometimes attributed directly to staff within facilities who didn't want a particular child to be moved, while in other situations it reflected an unwillingness to consider the possibility of any child moving.

*"...we had numerous kids that we had seen and were ready to place and it never happened. And that wasn't because we didn't want it to happen...there were two or three or four different people involved in the process and they were not all on the same page. A worker may have said well I don't really want them to leave. They've been here in this place two years and they don't need to leave." (AFP29)*

*"Gaining access to these institutions was very difficult, and there are still some that they can't set foot in. And if they do, they won't give you any information...Even working with [state agency] meant dealing with a lot of skepticism...so there's still reluctance on the part of [agency] in some areas and some particular staff to even consider any of these kids ...going into foster families." (AFP9)*

The length of time required for a good family – child match was identified as a barrier by one participant. Processes within the state were identified as a conflict with the family-based alternatives process. *"[It's] not easy, though, under Promoting Independence because it doesn't give you enough time to develop homes." (AFP43)* Conflicts related to licensing standards were also raised as barriers to the process in some situations.

According to the these providers, the delicacy of working with birth families and the difficulty of presenting options to them that were potentially threatening was sometimes compounded by the residential facility staff. "Closing the front door" on facility admissions by

developing and offering family alternatives was again identified as being a critical component to effecting systems change.

*“But it was getting into the door of all these places and building some trust with these folks, and quite frankly in some of these [facilities] these kids are their bread-and-butter...” (AFP9)*

Other waiver rules create problems for providers to overcome. One of these rules states that children under CLASS cannot be placed in a home with more than three unrelated people living in the family. According to one of the participants *“that’s going to knock out pretty much all of our families who are willing to take children with severe disabilities and medical needs” (AFP9).*

Another significant problem dealt with the rules regarding time limits for taking specific actions. After a child’s name comes up from a waiting list, the family must notify the agency that they want to use the waiver services within 30 days. The family then has 45 days to select a provider for the services. Delivery of services must begin within 90 days. One family whose child became eligible for a waiver that would have allowed her to come home, could not use the waiver because their house was inaccessible, but there was not enough time for the family to relocate within the strict time limits for the waiver.

The direct service providers had suggestions for improving the family-based alternatives process, and these were primarily about working on rule changes. The frustration of dealing with the inflexibility of the funding streams is apparent in this comment.

*“Changing this rule at DHS would make a huge difference...the thinking is the flexibility of funding...it’s so segregated...we’ve said, and EveryChild really was the leader of this, to DHS, we’ll take the money and then transfer to MHMR so we can get a HCS slot. Well no they*

*don't want to do that because the Medicaid match and the general revenue of the federal dollar match for CLASS is different than the general revenue federal dollar match for HCS and...they were going to lose...money. The legislature says that this money is supposed to follow the child but nobody made a system for it to happen...I don't see any flexibility or any instruction to those agencies...to get them to do this."* (AFP9)

### ***Relationship with EveryChild***

Participants from the direct service provider agencies reported very positive relationships with EveryChild, presenting the work being done as quite collaborative. The philosophies of these agencies and EveryChild were closely aligned.

*"I think now that we've got EveryChild, we, the collective we in the state, are far better off than we were before, and there are huge success stories. I think that EveryChild has just done a tremendous job in devising a system, given the constraints and the uncooperativeness that they experienced."* (AFP9)

Phase 2 of the study revealed lingering confusion regarding the role of EveryChild in the state system. One participant commented: *"...a colleague of mine who works for another agency that's an HCS provider was complaining about this agency that messed up a placement that she had been working on and she said...it was EveryChild. I spent about a good hour explaining the benefits and the good things they do, and...after she understood it, she was able to accept it. Before what she thought was some renegade advocacy group at the last (minute), messing things up."* (APF 43)

Participants saw EveryChild as a needed advocate for alternatives in the state that benefit children. They valued the

contributions made by EveryChild in helping children move into families, and saw a need for more EveryChild staff. *"...it's just so hard to develop families; it takes a lot of work and there's only one person in a community this size with that many children...it was very difficult for (EveryChild staff) to do. And we were working and helping as much as we could too, but it's a lack of resources not the people involved."* (APF42)

### **Successes**

The direct service providers cited successes in the family-based alternatives process in very child-focused ways. Seeing children and families grow was the most positive impact.

*"Well, it's getting children into a nuclear family...and being able to provide them with the kind of family activities and nurturing, and just being part of the family that most of these kids were without...It's incredible to watch them blossom in these families."* (AFP9)

*"Well, I believe there is a home for every child. I think kids growing up in institutions or facility-based is not OK...most of our situations have been long-term with this population where the family has made the child a part of their family and that's the difference that makes it work."* (AFP29)

Additionally, one provider cited that the increased identification of children in nursing homes, children who had not been previously identified, was a success of the family-based alternatives process. The model developed and implemented by EveryChild was praised as a success.

During Phase 2 of the study, the expansion of the program into other areas of the state was seen as a positive step, and one that

would benefit many more people. One participant experienced successes with family-based alternatives when a residential facility closed, and several children who were living there were moved into support families or back to their birth families with supports, rather than moving to another facility.

One participant who has shifted from providing residential services to providing support families commented:

*"...it's also one that makes sense financially. I don't have to worry about the bricks and mortar. I don't have the large number of staff getting paid depressed rate wages because of funding issues and dealing with all the training turnover...It's get the family, get them trained and provide the support; that's much more productive than it is to maintain an eight, nine, ten employee group home. So, I've told my staff that as we grow...we want to go in the direction of supported home living, supporting people in their family homes or in mentoring alternative families or support families...and I wouldn't have had this philosophy had I not been exposed to EveryChild." (AFP44)*

### **Summary of Direct Service Provider Interviews**

Philosophically, the direct service providers were closely aligned with the family-based alternatives process, and strongly supported the efforts of EveryChild staff to match children with families. While they saw an increase in their workload as they worked with children and families through this process and experienced some delays in the process, their frustrations were primarily with the systemic barriers created by inflexible rules and difficulties reported in working with residential facilities. They clearly saw that all children could live in families if the systemic barriers to delivery of services could be resolved.

## **Residential and Institutional Facilities**

Although eight facilities were contacted to participate in this study (two ICF-MR facilities administered by TDMHMR, two institutions for the mentally retarded administered by DFPS, and four nursing homes administered by DHS), only three agreed to participate despite numerous attempts to schedule an interview. The three facilities included one ICF-MR, one institution for the mentally retarded, and one nursing home. The contacts at the eight facilities were called at least three times; in some cases, calls were not returned. In one situation an appointment for a telephone interview was set, but when the researcher called, the individual was not available. This is an obvious limitation in this data set. However, themes did emerge in the analysis of the data. Information regarding staff role change due to the family-based alternatives process; barriers, concerns, and suggestions for improvements to the process; the relationship with EveryChild staff; and the successes of the program will be discussed.

### ***Role change***

Two of the programs indicated that they heard about EveryChild and the family-based alternatives process through a direct contact from EveryChild, in one situation, *"I believe they just came over one day and told us what they were and showed us their card"* (AFP 12). The third participant, however, had a different introduction to EveryChild and the family-based alternatives process. They were contacted after a child in their facility had been identified to possibly move.

*"We received a letter from [agency A] and we also received a letter from EveryChild explaining their role and what they was doing, and then I received a call from \_\_\_\_\_ who requested to come out for a*

*visit, and also received a call from [agency B] who came out and we completed the paperwork...and then provided the information with the names of the parents so they can make contact with them to see if this child would be better in a family environment or if the parents would be interested in placing the child in a family environment."*

(AFP14)

Two of the programs also stated that the involvement with EveryChild and family-based alternatives changed their roles at their agencies by adding responsibilities to their work.

*"The only difference is probably time, a lot of time has been with the EveryChild people when they come in. So that was probably the biggest thing, especially the time for the case managers...they come in to do their research and look into the chart and do things like that and it's very time consuming for the case managers. A lot of the stuff that they're coming in and asking about could be sent to them, mailed to them and it would probably save us half a day that nothing's really been accomplished...we just kind of let them come in and just trying to be professional. And, I mean we have a really good working relationship with them, so ...if they've got the time to burn we just try our best to send them in the right direction to the things that they need to have access to...they ask a lot of questions, they constantly come back...if you take away the amount of time that it takes sometimes, it's not a bad experience at all."* (AFP12)

One program had a very different perspective on role change. *"We were still supportive because really what EveryChild's done is they've cut my workload to be honest...this agency came up and cut a lot of my leg work out for which I was grateful for because it allowed me to devote my time to other things"* (AFP14).

One facility connected the requirement for permanency planning to the family-based alternatives model. This segment describes the process used to possibly identify children for the program. In this situation, it was the facility that determined whether to discuss the possibility of a family-based alternative with the child's birth family. This comment represents the potential conflict of interest that existed during Phase 1 of the study when family-based alternatives are initiated through a residential facility rather than with a systematic process within the state.

*"...we received a letter from (agency A) that we had to do the permanency planning where we submitted the name [of a child] to a regional facility that's in the region of (agency A) and we sent information out to the parents and they ... that permanency planning is looking at possibly placing your child,...talking with you...placing your child in a home environment. Into your home or either in a home environment or ... foster type of parenting. Then basically what we've done is sit down and review each child in the facilities and went over the pros and the cons of if that child, particular child, was able to go into the home environment or does that child need to be placed in a medical facility. And we identified the children that was able to be placed into homes." (AFP14)*

### ***Barriers, concerns, and suggestions***

In terms of concerns and barriers to success, these facilities identified several. One facility was concerned about *"making sure that the family understands the type of children that we serve and their needs"* and saw barriers in that the family would need considerable support (AFP13). The second facility expressed stronger concerns.

*"I don't think the time is spent to get to know the children that they're working with. I think it is more so of numbers. It really seems to be a numbers thing as far as trying to get a child moved...I've had a lot of children that have been discharged and a lot of times the situations that they went into were not as good as the situation that they were in before here at \_\_\_\_\_" (AFP12)*

*"...we have nursing staff here and a lot of our kids are very much in need of that nursing care, and my direct care staff here are really catered to kids with the increased medical type needs...often you run into people who have a hard time dealing with those kinds of kids...so you get legs and arms broken, just by accident not necessarily by something the kids did...so I think that sometimes EveryChild just kind of comes in and looks and hopes to put a kid in a better situation, and actually they're not putting that kid in a better situation." (AFP12)*

This participant indicated that the staff in the facility were extensively trained to avoid injury to the children living there, and felt that the facility was best able to provide the services needed by the children because of the training. However, in a situation where a child was moving to a foster family, the facility did not provide any training for the foster parents, nor see that as their role.

*"We don't do very much training with the foster parents at all...we basically just have a meeting with the parents when come in and just kind of go over some things with them. But as far as the training my staff gets? No, foster parents are not getting that training...I feel that's more the responsibility of the individuals that are coming in to take those children to get that training... why would that be our responsibility?" (AFP12)*

Other concerns raised by the facility administrators involved the continued security of funding and funding availability in the community. Experiences with previous programs in which funding was lost after children were moved and then had to be returned to the facility, resulted in strong cautions about family-based alternatives.

### ***Relationship with EveryChild***

The relationship with EveryChild was generally reported to be positive. The participants viewed EveryChild staff as being very dedicated to the children and families with whom they worked.

*"The people I've worked with so far with EveryChild are very, they're very upbeat. They believe in what they're doing and they're positive – they bend over to help you and one of the things is just the communication back and forth with them. They visit a child not only during the weekday, but they make special visits on their time to visit with the child and they visit the children at their schools as well as here at the facility." (AFP14)*

### ***Successes***

When asked what these facilities saw as the best quality of the family-based alternatives project, one stated *"they have a good focus, they really have the child's best interest in mind. They want to make sure the transition will be as good as possible in the sense that it's successful"* (AFP13).

*"...the effort that's being made is probably the best thing about it. I think that the people are involved. I think they have the right people involved as far as the kind of staff that they bring in to look at each case and look at the children. They really seem to care about what they are doing." (AFP12).*

One facility described the success in this way:

*“We have a couple of children that have left our facility and gone into home environment and who have been very happy...and they have been placed into the foster home and they finally know what it is like to have someone who loves them, someone who they can call on, someone who is there 24/7 with them.”* (AFP14)

### ***Summary of the Residential and Institutional Facility Staff***

This group of participants was the most divergent from the philosophy of the family-based alternatives model. They identified numerous barriers preventing the success of the process, and indicated fairly directly the process was not always a good one for children. They were outspoken about the difficulty of finding families with the desire, skills, and abilities to provide the care needed by children from their facilities. However, they perceived EveryChild staff as trying to do something positive even though at least one participant wasn't sure if the children's best interests were being addressed. One participant, however, was generally positive about the family-based alternatives process, the staff of EveryChild, and the impact for children of living in a family. In spite of some of the negative views of this group, all three participants spoke positively of EveryChild successes.

## Community MHMR Centers

Four community MHMR Centers in central Texas and the Houston area participated in the study. Three of these centers were involved from the outset with EveryChild and were considered partners; two centers provided space for some of the EveryChild staff and/or other administrative support; one center came into contact with the family-based alternatives process after EveryChild requested services for a child being moved from a facility into a home. A total of eight interviews was conducted with this group of participants, six during Phase 1 and two during Phase 2. The Phase 2 participants had been aware of the family-based alternatives process for at least 18 months. Neither of these participants had been interviewed before. Information regarding staff role change due to the family-based alternatives process; barriers, concerns, and suggestions for improvements to the process; the relationship with EveryChild staff; and the successes of the program are discussed.

### ***Role change***

There was little identified role change with the involvement in the family-based alternatives process in that these agencies were performing some of this work already. One community MHMR center did discuss collaboration with the family-based alternatives process in helping to move a child.

*"No, I was already involved in helping ...working with families to bring about the services." (AFP30)*

*"No, our role changed a little bit in that we did a lot of work up front with EveryChild." (AFP18)*

*"Not really, but it's just that it gave us another option." (AFP17)*

*"We recently had a case where a minor was in the HCS program. And the mother came in and visited with us and we, did a lot of consulting with EveryChild, Inc. on this. It's been a really complicated case. And it was like, she wanted to choose another provider, we helped her with that and EveryChild was very instrumental because, with a minor you can imagine, you know,...and the mom was very much involved, but mom had mental health issues of her own. So it was a real collaborative effort. And that was probably the first case where they had to come back in and assist us." (AFP17)*

The Phase 2 participants interviewed were involved in the closing of a facility that housed children with disabilities, and they worked with the family-based alternatives process to find new placements for some of these children. They were able to access additional resources for these children through EveryChild, and this represented a change in their roles. Neither participant commented more specifically regarding this issue.

### ***Barriers, concerns, and suggestions***

Barriers identified by the community MHMR centers often involved funding, funding streams, and waivers. Issues of parental abandonment were also discussed by one agency.

*"The barriers? It's the lack of resources out there and you have to take time to make a good match. The lack of resources just drags it and bogs it down." (AFP30)*

*"Funding is the main one...another barrier I see...and EveryChild's trying to address this and so are we. But where families don't seem to be...families and guardians prefer group homes versus what we have which is alternative living, the foster home. They seem to think that group homes are better, more stable, or they just...maybe*

*it's because of the term foster home, that there's a barrier because they associated it with somebody's abused...but a lot of times families are resistant to placing their loved ones in another foster home or homelike setting. And maybe part of it is the guilt."* (AFP21)

*"There's still a lot of kids in Texas living in institutions and we can't prevent that at this point...even though they're [the CRCGs (Community Resource Coordinating Groups)] supposed to serve as a gate keeping function, that doesn't always happen. Realistically, because a lot of these ICF-MR places, nursing home places are privately operated, kids can go in those places without going through anybody."* (AFP16)

*"I think they may not use foster. They try to do the shared parenting stuff and we've not had that experience with anybody that's had a [birth] family member involved."* (AFP20)

*"...there isn't any way to stop kids from going into institutions in the first place. So how do we try to address issues like parental abandonment which is a huge issue...in two ways. One is leaving them at the institution, not hearing from them again, but the first thing is getting to that point where they feel like they have to give their children up. So there would be decreases in family support and some of these other avenues. It makes it harder for families to take care of their children if they have significant disabilities. They need significant support."* (AFP16)

One participant discussed the difficulty some birth families have consenting to the process.

*"I think by the time they (the birth families) get to me, they are holding on by a string, you know, a thread, and they are wanting something as quick as possible and it just doesn't happen that way,*

*especially with folks that are just looking for something and they don't have any Medicaid waiver or anything else to fall back on that supports that placement...It's two things that families have talked to me about. Their fear of the unknown and they're still saying if I can't do it, what makes you think another family can do it. Or how can I justify allowing another family to do what I couldn't do." (AFP45)*

Other concerns cited by some of the agencies involved the amount of time required to make placements. Some agency personnel indicated that potential foster (support) families had been lost due to the extended time needed to make good family matches.

*"I would like for it to be faster. But I realize this is a complex thing and it's difficult to find – and you know I guess I'm talking out of both sides of my mouth – I'd rather they be slow and thorough and make a good match...but of course I'd like for it to be more readily available." (AFP30)*

*"My only gripe is that there is not necessarily funding and people ready...you know you identify a provider and then they get all excited and then nothing happens for months and months and months...so it kind of ends up I think giving false expectations or hopes or whatever." (AFP20)*

When questioned about ways to improve the family-based alternatives model, these agencies primarily spoke of the funding issues, problems with waivers, lack of information, and increasing the understanding of the system by providers as well as families. Additionally, the level of care reimbursement structure created barriers identified by one agency.

*"...one of the things that concerns me is that sometimes the kids that are brought out of the facilities into another program, or into an*

*alternate home program...sometimes you can't access, you can't get some of the adaptive aides or special needs. Like if they need specialized reading equipment, or something special that they need to come with them. Because the funding, those items belong to the program that they are with. But the funding doesn't start here until they've entered, so you can't get them until they come to your program and sometimes that causes a delay in service." (AFP30)*

*"We've been given information that when people do get funding to come out and they are identified for an HCS slot that the MRAs are changing people's level of needs. So when you get the information from the state school you may have someone that needs intensive supervision and needs help with every task in a day...and someone that works at an MRA in \_\_\_\_\_ that they are instructed to decrease people's levels of needs by one level when they come out of an institution. So you think you have a level of need eight and you have your supports built in...if someone in an institution at a level of need eight, they are not going to miraculously turn into a level of need five just because you're in a community." (AFP20)*

### ***Relationship with EveryChild***

The MHMR centers had generally positive views about working with EveryChild. Even if they were somewhat frustrated by the time it took to do a placement, they understood the reasons for the time involved. The dedication and caring of the EveryChild staff was well-known by this group.

*"I think I would have hoped that we would have caused more kids to get out, but I think that's building for that." (AFP16)*

*"This work is important in terms of issues that have to do with what's right for children and what's in the best interest in the long run*

*for that child and for that family...Their dedication and their commitment to looking at services for children with disabilities in a different way...and push the state to make a difference for children. I think that's one of the best things, the most profound thing about the project." (AFP16)*

### **Successes**

Many successes were identified, and these were generally very child-focused. One agency reported a change in their structure for serving children.

*"This consumer is looking forward to going and living with the provider. I visited with him in the provider's home last week...and he just looked at home! The thought that he won't live in a large 206-bed institution – that he'll live in a community with a family." (AFP18)*

*"Oh gosh! I think it's wonderful! I think being able to move a child from a large facility into a more home like setting, I think it really is beneficial to the child. He can get a lot more individual attention, a lot more, you know, hugs and love from somebody who's there all the time." (AFP21)*

*"I just think if they get one kid placed, that's one kid that's not living in an institution." (AFP20)*

The Phase 2 participants expressed that their work with the family-based alternatives process was successful in moving some children from the facility that was closing. However, other placements happened more slowly, and while seen as a success, the issues around availability, funding, and waivers were critical factors that negatively impacted the process.

### ***Summary of Community MHMR Center Staff Interviews***

The MHMR centers held generally to very positive perceptions about the family-based alternatives process and the work with EveryChild. Those that seemed more comfortable working with this model tended to have more experience in developing and providing community supports for children in foster care placements. These agencies were united in their belief that families were better places for children. While they indicated a general shortage of foster families, they did not indicate that these particular children would be more difficult to care for in general than other children. They also recognized many of the systemic issues that the other participant groups have addressed.

## **Overall Summary of Staff Interviews**

The analysis of the staff interviews revealed a number of themes regarding staff roles, barriers, concerns, and suggestions to improve the process, the relationship with EveryChild staff, and successes. All of the staff, regardless of the agency, organization or facility, talked about the systemic barriers that they faced on a daily basis, and how these barriers made their work more complex and difficult. Generally, involvement with the family-based alternatives model did not create a significant role change for most of the participants. For those who did report a significant change, it was primarily in the level of communication with the EveryChild staff and in organizing, coordinating and sharing information. It was also noted that most of the staff who were interviewed placed the responsibility for developing family-based alternatives primarily on the staff of EveryChild.

Barriers identified can be categorized into three areas. The first are the systemic barriers, including issues with funding, waiver programs, program inequities, reimbursement, and licensing. These systemic barriers restrict the full implementation of a family-based alternatives model until policy changes occur that would support such a program. Leadership from the Texas Legislature and state agencies was noted as being critical to the success of the model and implementation in wider areas in the state. This is an area of enormous importance.

Some participants identified a perceived lack of commitment to family-based alternatives by agencies and facilities; participants who highlighted this issue felt that until the state leadership could ensure that changes would be made to encourage family-alternatives, little systemic effect would be felt. Failure to “close the front door” or end

the admission of children into institutions and residential facilities by offering community alternatives was identified by state agencies, child placement agencies and the community MHMR centers was seen as a barrier to success.

The second category of barriers is related to children and the intensity of their need for services. Some of the participants clearly felt that the needs of children would be better served in facilities than they would in families. In fact, some participants felt that placement in a family would be dangerous to the child. Along the same reasoning, some participants felt that it would extremely difficult, if not impossible, to find families who would be willing to accept children with such intense needs for services and supports. This viewpoint was most strongly held by the facilities, but a more moderate variation of this theme was at least mentioned by some of the state agency staff and some of the community MHMR staff. The child placement agencies did not raise this as an issue, and talked more about finding families for all children.

The final category of barriers involves the difficulties of developing relationships between all the entities in this process, including agencies, institutions, residential facilities, birth families, support families, case workers, and all others. This is a critical barrier that cuts across all of the participant groups and one that must be addressed. These relationships are important to the process and they will take time and energy to build and sustain. The issue of trust and positive working relationships is also related to the barrier cited by all of the groups regarding the length of time that is required for placements to be made. While there are reasons for the slowness or the speed of the process, depending on the system and the

circumstance, it will not be understood or accepted by all of the stakeholders without trust and cooperation.

Relationships with EveryChild were generally positive in all groups, although they have not always been so, and are not positive in all situations. The dedication, caring, and commitment of the staff is widely recognized, even if there is dissatisfaction about the process being used. The knowledge and expertise of the staff is also respected by most of the groups, although some feel EveryChild still doesn't completely understand the system that exists in Texas. Interestingly, the group that perceived EveryChild as being inflexible also reported that they worked in a system with very little flexibility which prevented them from fully implementing the family-based alternatives program. This may be an indication of a system-imposed barrier that hinders the creativity often required to successfully solve problems.

Improvements to the process were focused primarily on addressing the political barriers of funding, changing rules, and amending waivers. Additionally, increased training for both awareness and implementation was identified as beneficial.

And finally, there was strong consensus across the groups regarding successes of the programs – seeing children in families, the development of new mechanisms for child placement, the expertise and technical assistance available to those serving children with disabilities, and changes in policies. The most consistently identified measure of success, however, was that children were moving from institutions and residential facilities into families.

## **EveryChild Staff**

The final group interviewed by the researchers was the staff of EveryChild, Inc., the agency charged with developing and piloting a family-based alternatives process in a limited number of counties in the state. During Phase 1 of the study, there were six staff members at EveryChild: an executive director, a program administrator, two family support coordinators, and two recruitment coordinators. All six were interviewed. Two additional staff were added after Phase 1 and interviewed during Phase 2. The themes that emerged from the analysis focused on the barriers, concerns, and suggestions; successes and what makes the system work; and relationships and experiences with agencies, facilities, birth families, and support families. Additionally, seeing the process as child-centered emerged as an important element of the process.

### ***Barriers, Concerns, and Suggestions***

The EveryChild staff identified systemic barriers that hindered the work of the process. These barriers included a number of systemic barriers that hinder the state leadership, including state-level bias toward institutionalization and facility placement, funding streams, waiver programs, program inequities, and others. Once again, the systemic issue of preventing new admissions to residential facilities and institutions was raised; “closing the front door” by adequately supporting community living is critically important.

*“One of the difficulties is the incongruity of having the state say its policy is, its stated preference, its stated guide is children belong in families, and yet the structure of the system and funding is in many ways not set up to do that.” (EC35)*

*“To become a licensed foster home is a tedious process – it is 30 to 40 hours of training, a lengthy application, psychosocial home study, you have to get all kinds of paperwork: proof of address, proof of insurance, just all kinds of stuff...if the CPA is offering training they do a three month cycle and they’ll do their training...if something happens and they can’t attend a training one night sometimes they’ll have to wait until the next cycle.” (EC34)*

*“For example home studies – there’s a great deal of protection around a home study in one system, and in another system you don’t even have one. This is a protective rule that’s absent in one but then in the system that doesn’t have home studies you can place only three kids in a home so it stays small enough to feel like a home and in the other system that has great home studies you can place 11 kids and call it a family.” (EC36)*

Policies that support family-based alternatives are needed. Systemic barriers that hinder the process were most frequently identified. Not all Texas state leadership supports the family-based alternatives model and those who do are often hindered by the existing state program and policy restrictions.

*“We’ve any number of times lately said, ‘oh, wouldn’t so-and-so be good for so-and so. Yeah but they’re not – you know they’re HCS and that person’s going to have to have CLASS or they’re CPS and that person has an HSC slot, you know?” EC35*

Often, children with extremely complex needs are identified by providers, agency and facility staff, and others as reasons why the process won’t work. Policies in Texas do not support the belief that all children can live in families. And, the process of why certain children are identified for placement is interesting and fairly intangible.

*“You know my feeling about that is, OK, well, if we have 1,500 kids let’s do the other 1,499 and then we’ll put our heads together about [number] 1,500 because, yeah, he sounds pretty difficult.”*  
(EC35)

*“I know for me sometimes I’ll just look at a kid and something about that kid reminds me of something or someone that gives me some pleasure and I make a connection – a chemical, I mean I really think it’s chemistry like you just make that connection. That kid’s cute to me! So it’s about the match and it’s about the fit because sometimes families will come forward who have the skills that make the kid that seems difficult not difficult to them.”* (EC35)

### **Successes**

Clearly, the success of the family-based alternatives model is seen each time a birth family considers the option of a family-based alternative, a support family agrees to be matched with a child, and a child is moved from an institution or facility into a home. This is accomplished by following the steps of the model: (1) building trusting relationships with birth families, (2) assertively recruiting and preparing alternate families, (3) carefully matching children with families, (4) planning the child’s transition from the institution, and (5) developing adequate supports to enable families to sustain children living with them over the long-term. Additionally, the model works by bringing together an array of public and private entities to develop an effective system and facilitate implementation in a targeted area of the state.

Regarding building trusting relationships with birth families, one of the most critical components of the model, an EveryChild staff member stated *“we’re very careful to talk in a different way than*

*system folks typically talk. We try hard not to use jargon...but I think the simplest way to put it is that we always try to talk to families person to person, human being to human being. Not worker to client, not professional to parent, not somebody who is outside their experience, but somebody who's willing to enter their experience with them and walk down that path with them." (EC35)*

EveryChild staff described a system that would be more successful in moving children from institutions and facilities into families. Some of characteristics of a successful system included the importance of keeping the focus on the experiences of the child first rather than the perspective of the experience of the parent, and of encouraging families to consider family-based alternatives early in the process, even at the first approach to the system for services.

*"So what should happen in a system is more emphasis in every conversation with a birth family who approaches the system about family life so that it would be part and parcel of any conversation way from the beginning ... when somebody first approaches the system they obviously want or need something." (EC36)*

*"You are more willing to make compromises when you don't have a picture of a real person in your head that you saw yesterday or talked to yesterday. And I know \_\_\_\_\_ has told us that all along; she tells the recruitment coordinators all the time you have to meet these kids even if your work isn't directly with them. You have to meet them and you have to meet families too." (EC35)*

### **Relationships**

All of the EveryChild staff discussed the importance of building relationships with the entities involved in this process: the children, birth and support families, state agencies, child placement agencies,

facilities, and community MHMR centers. These relationships are critically important, and building them takes time and effort. Phase 2 of the study revealed more positive comments about relationships with stakeholders and partners.

*“Well in the beginning it was just a lot of relationship building. They were kind of trying to figure out who we were...” (EC31)*

*“So we work with a number [of agencies] and increasingly my job has frankly become more related to partner relationships with other agencies that we can work collaboratively with them to get the kids out.” (EC34)*

*“You know, why should I trust you? What do you mean I need to be thinking about what’s good for my kid? Where were you? That’s a conversation built on trust and we don’t have that without work.” (EC35)*

Another aspect of relationship building is that it requires time. The participants identified many important tasks that are accomplished during this time that contribute to the success of the process.

*“Time! Some say we are too slow and others say we move without really knowing the issues. Discrepancies are sometimes out of our control. Like the worker who places a kid we would have preferred to go slower with. But this attention to pre-placement is not just about speed, it’s about what you do during that time – like getting to know the child, giving the support family a chance to get to know the child, giving the birth family and support family time to get to know each other, taking the time to get equipment and training and logistics worked out, giving the child a chance to make a transition – it all has to be done.” (EC36)*

*“What we discovered was this is very time consuming, difficult work that isn’t always easy to figure out what the right thing to do is and it’s new in Texas and it’s also work that requires not only for [support coordinators] to go out and do the core thing they’re supposed to do, which is to get to know the kids and get to know the families, but also to get up around the system all the time while they are doing that.” (EC35)*

*“in terms of matching the kids and moving the kids and that kind of thing – it really was more around the relationship building I think...and figuring out how we work together and what similar goals we have. You know, how does the EveryChild process of wanting to move slowly and wanting to be careful fit with the \_\_\_\_\_ system of you know hurry up and got to do it emergency-wise – so it was just a lot of figuring it out.” (EC31)*

*“You know I work with birth families and guardians of children with disabilities to talk with them some to explore the options of family-based alternatives and meet the children and see them and get information about them and get that information to our family [recruitment] coordinator and the support families that she recruits so that they have that so that we can pursue that matching process if they want to.” (EC32)*

### ***Child-centered thinking***

Thinking about the experiences of the child in a different way strongly emerged as a theme in this group. Because the traditional systems are not organized around the experiences of the child, and do not always provide sufficient supports for families to keep their children at home, parents often have not been supported to think about their child’s perspective on being in a family, and this can be

quite difficult to do. A paradigm shift is needed to begin to see life from the perspective of the child, and to recognize what the child is experiencing, rather than the more traditional perspective of parents. Permanency planning should be a way to begin to accomplish this.

*“So they [permanency planners] have a difficult job. But that’s what they’re supposed to do, is help these families think differently about what their options might be for their child and for some of these families to help them think about this from their child’s perspective for the very first time, rather than from their own perspective as a parent.” (EC35)*

*“... people that were hired to be permanency planning specialists to train other permanency planners that thing that seemed to turn them around a bit was to stop thinking in terms of the parents’ life and start thinking more in terms of the child’s life. Start talking about the child’s experience of being parented in the daily life. Not parent visits once a month. It’s the everyday experience of feeling parenting that when you can see that and feel that and touch that, you’re probably on the right track to permanency.” (EC36)*

*“Family is essential for all of us and ... if the thing that brings them pleasure in life is the sound of a kind voice or the touch of their mother’s hand on their arm or rubbing their head or their dad singing to them and hearing familiar people laughing and talking or having the familiar scent of their home... if that’s what’s meaningful for them then why take that away from them?” (EC35)*

### **Summary of EveryChild Staff Interviews**

The analysis of the interviews with the EveryChild staff revealed several themes regarding barriers in the state to the successful implementation of a family-based alternatives process. One of the

strongest themes that emerged focused on the need for the process to be driven by child-centered thinking and planning. The EveryChild staff consistently talked about looking at life through the eyes of the children, and about the power that comes with that focus.

A second theme deals with systemic barriers to developing, implementing, and expanding a system of family-based alternatives in the state. Texas leadership has much work to do to make significant changes in policies, rules, and procedures so that the system that has been demonstrated can be realized.

The EveryChild staff discussed relationship building as a critical factor in the family-based alternatives process. Relationships with facility and agency staff were not always positive, sometimes related to differences of opinions about how to best provide services to children with disabilities, and sometimes because family-based alternatives were not seen as positive. The relationships were made more difficult at times when dealing with some of the policies and procedures that do not support family-based alternatives.

## Summary of Research Themes

In total, 55 participants were interviewed in the study: eight birth families; eight support families; 15 state agency personnel; five providers; three residential institution staff; eight community MHMR staff; and eight EveryChild staff members. Phase 2 of the study did not reveal any additional themes, and not all of the themes from Phase 1 appeared in the Phase 2 analysis. However, the additional interviews reconfirmed the analysis of the original study.

In analyzing the data from all of the participant groups, a number of themes emerge. Overall, all participants supported the concept that children belong in families. There was some disagreement about whether all children can live in families, but this concept was clearly supported. Relationships between parents and staff within the system must be built on trust. This was eloquently addressed by several of the participants, including birth and support parents, as well as staff from the agencies, facilities, providers, and EveryChild. Additionally, all participants spoke to the dedication and commitment of the EveryChild staff, and identified characteristics that are essential for this work to be successful.

A number of barriers and concerns were also clearly identified across the data sets. Systemic, political barriers were the most clearly stated obstacles to developing and implementing a successful system for family-based alternatives. The rigidity of the existing system, difficulties with waiver programs and funding mechanisms, time limits for placements, existing policies and rules, and lack of readily available accurate information obstruct family-based alternatives from becoming a reality.

One of the systemic barriers voiced was that the process of developing and matching families simply took too long and was not realistic in the system that exists. The EveryChild staff clearly identified some of the issues that are addressed during pre-placement time, which include the birth family, support family, and child all getting to know each other; ensuring that equipment, services, and supports will be available when needed; and allowing time for a smooth transition. The birth and support families expressed that the time and availability of the EveryChild staff was a critical necessity.

While the matching process was identified as being important by staff from all but one of the sub-groups, interviewees did not seem to understand the complexity of merging different systems and the way that this contributed to the time for creating matches. Matches are complicated: the child, birth, and support family must be well matched; in addition, the support family must be licensed as a provider in the same waiver program where the child receives services. This component of the matching process is driven by systemic issues within the funding system that creates significant barriers. It was not discussed by any participant group other than EveryChild staff, and it is one that clearly adds time, complexity, and complication to the process. If this model is adopted, the system will be charged with developing a process so that placement workers have the time that is needed to make careful matches, and the ability to move children and families across different systems for funding.

The second category of barriers includes those that are related to the intense needs of children with significant disabilities, and the perception that the needs of children would be better served in facilities than they would in families. Some of the participants felt it would be difficult, if not impossible, to find families who would be

willing to accept children with intense needs for services and supports. This viewpoint was most strongly held by the facility staff, but a more moderate variation of this theme was at least mentioned by some state agency staff and some of the community MHMR staff. The direct service providers did not raise this as an issue, and instead expressed the feasibility of finding families for all children.

The need for a clear model and vision focused on the needs of the child is apparent. This will require a significant paradigm shift to begin thinking of what it is that children need and what their experiences are, rather than focusing only on the experiences of parents. Policies, rules, and procedures will need to be modified so that this focus will be supported. The leadership in the state will need to ensure that these changes occur to fully sustain a family-based alternatives model. This issue is tied to the final theme in the analysis, that of the use of language.

A significant theme related to the use of language addresses the issue of ownership. Agency staff, child placement agency staff, facility staff, and community MHMR staff acknowledged various levels of ownership of the process in their comments, but primarily saw the family-based alternatives model as being the responsibility of EveryChild, rather than a process of systemic change in Texas. This lack of ownership by the stakeholders creates significant difficulties in implementing this or any other model. Frequently, agency, facility, and provider staff participants commented that “they”, referring to EveryChild staff, should do more training, recruit more families, be more available so that family-based alternatives could be created for children. On the other hand, EveryChild staff also expressed the wish to retain ownership of the process, stating that the agency, facility, and provider staff did not believe it could work, and in fact, did not

think it was appropriate for all children. The original legislation that mandated the development of a family-based alternatives program, envisioned this as systems change; however, the work of EveryChild was viewed as a grant project in many ways by the participants.

Finally, in reviewing all of the transcripts, researchers noted that the different participant groups used different language to describe the placement of a child. State agency, facility, and provider staff talked primarily of children being placed in “family environments”. Child placement agencies were much more likely to use the word “home” when discussing placement issues for the children they served. Residential facilities and institutions very seldom used the words “family” or “home”; in fact, in one exchange between the researcher and the participant regarding the consequences of placing a child in the community without the specialized care that the participant felt was only available in the facility, the following language was used:

*Researcher: “And that [happened] in the home?”*

*Participant: “That was in the place he was discharged to”  
(emphasis added). (AFP12)*

EveryChild not only talks about “homes”, “families”, and being a “member of a family”, they also were the only group that looked at the family-based alternatives process with a concerted effort to experience this from the eyes of the child. The issue of language is consistent with the level of divergence from the philosophy of the family-based alternatives process, with the child placement agencies being closest in beliefs and practices to EveryChild and the facilities and institutions being the most divergent. Significant amounts of time will be required to reach common ground on this issue and come closer to working collaboratively to create family-based alternatives.

## Recommendations

Analysis of the data gathered during this study from birth and support families; state agency, facility, and provider staff; and EveryChild staff generated strong themes that lead to the following recommendations. The comments from the birth and support families indicate that this type of system can work, but it must be carefully designed. It is clear that identifying people who care about children is a crucial part of successful placement of children. It is also critical that the people who work to match birth families, support families, and children are dedicated to the effort, and are not expected to manage large caseloads of children. Most of the birth families and some of the support families have worked with other child placement agencies and other health and human services programs in the past. They are clear that the program, as designed by EveryChild, addresses the key elements to make this process work effectively.

If Texas is to commit to the deinstitutionalization of children and follow the spirit of SB 368, then clearly systemic changes need to occur that will support family-based alternatives. The rigidity of the waiver rules and the "front door" policy that makes institutionalization the primary option for children with severe disabilities must change. Additionally, the paradigm that supports the concept that children with even the most severe disabilities belong in homes must be adopted by the state. These changes must occur from the top down, and infiltrate every level of management and direct care. It must be manifest in policies that truly support the concept that children with disabilities belong in homes, not institutions.

This type of systemic change is the work of all stakeholders, including political and agency leaders, community leaders in the judicial system, as well as front line workers. Caseworkers must be

personally invested, as well as have the time and resources to develop meaningful family options for children. Clearly one of the reasons EveryChild is successful is the personal commitment and passion of the staff. A culture within the state system that supports that type of personal investment in children is not unimaginable.

Parents of children with severe disabilities need options and information. All of the parents who had institutionalized their children felt they had no other option. This emotional and extraordinarily difficult decision was typically made without support, and with very limited information. Clear information that includes all of the rules about the waiver programs should be available to parents. Information about family-based alternatives should be given to every parent of a child with severe disabilities who is institutionalized or at risk of institutionalization, not only the ones who ask.

Training and education need to occur that help all of the stakeholders understand that children with disabilities, even severe disabilities, can be supported in homes. This philosophical shift of inclusion and compassion is essential for meaningful change to occur, and cannot be the sole responsibility of EveryChild staff. Developing mechanisms for internal training within agencies, training and information in institutions, and mechanisms for training and support of community stakeholders, including parents, would further the process of meaningful options for children with disabilities.

The importance of this type of education and training to support this shift in service delivery was clearly expressed by one participant:

*"...it's also one that makes sense financially. I don't have to worry about the bricks and mortar. I don't have the large number of staff getting paid depressed rate wages because of funding issues and dealing with all the training turnover... So, I've told my staff that as we*

*grow...we want to go in the direction of supported home living, supporting people in their family homes or in mentoring alternative families or support families...and I wouldn't have had this philosophy had I not been exposed to EveryChild." (AFP44)*

Clearly EveryChild is successful at what they do. The process is slow, and hindered by rigidity built into the system, however the successes were acknowledged by everyone interviewed. The families who were interviewed for this study were very grateful for the options afforded their children, and were relieved to see their children out of institutions. Parents felt their children were happier and better off with the support families. EveryChild should be able to continue and expand this important work for some of the most forgotten children within the state system.

This support parent eloquently talked about why the EveryChild model is working:

*"It is not like they are just looking for a home... What they are looking for is a family for someone. See anybody can live in a house, but they're looking for the whole... the atmosphere. You know, in other words making sure the right person's in the right place... it's not like big business." (SF2)*

## **Appendix A: Birth Family Interview Guide**

*Tell me about your family:*

- a. How would you describe your child ?*
- b. What kind of living situation has he/she been in? When did that arrangement occur? What were the circumstances around that decision? What do you like or dislike about that living arrangement?*
- c. What kind of goals do you have for your child? What do you want to see in his/her future?*

*How did you hear about the Family-based Alternatives Program?*

*Tell me about your decision to participate?*

- d. Did anything make it easy to participate?*
- e. Did anything make it difficult?*
- f. Was there anything that worried you about changing your child's living arrangement?*
- g. Was there anyone in your family or life who objected to the change? (what did other people tell you about doing this?)*
- h. Did the FBA staff give you the info you needed to make the decision? What info was most helpful? Was any info not helpful?*

*If you decided to participate in the program, where is your child living now?*

- i. What is the best thing about those changes?*
- j. What is the worst thing about those changes?*
- k. If you didn't change, what is the best thing about keeping your child there? what is the worst thing?*
- l. If there was a perfect placement for your child, what would it be?*

*Who has been most helpful to you in making this change? (role)*

- m. What did you like the best about the FBA program?*
- n. Was there anything you didn't like about the program?*
- o. Anything you would change about it?*
- p. Is there anything that could be done to make this program better?*

*What would you tell other families about this program? Is there any advice you would give other families with children like yours?*

## **Appendix B: Support Family Interview Guide**

*Tell me about your family:*

- a. What are your family goals right now?*
- b. What is it about your family that makes it possible to include a child with a disability*
- c. What would that child be like, if you have a choice?*
- d. How will that child fit into your family life?*
- e. What kind of goals do you have for your family with a child with a disability ?*

*How did you hear about the Family-based Alternatives Program?*

*Tell me about your decision to participate?*

- a. Did anything make it easy to participate?*
- b. Did anything make it difficult?*
- c. Was there anything that worried you about changing your child's living arrangement?*
- d. Was there anyone in your family or life who objected to the change? (what did other people tell you about doing this?)*

- e. *Did the FBA staff give you the info you needed to make the decision? What info was most helpful? Was any info not helpful?*

*Do you have a child living with you now?*

- a. *What is, or will be, the best thing about those changes?*
- b. *What is, or will be, the hardest thing about those changes?*
- c. *What is, or will be the best thing about having a child here?*
- d. *What is, or will be the worst thing?*
- e. *What would make this placement a perfect place for the child?*
- f. *What child would fit best with your family?*

*Who has been most helpful to you in making this change? (role)*

- q. *What did you like the best about the FBA program?*
- r. *Was there anything you didn't like about the program?*
- s. *Anything you would change about it?*
- t. *Is there anything that could be done to make this program better?*

*What would you tell other families about this program? Is there any advice you would give other families with children like yours?*

## **Appendix C: Agency and Facility Staff Interview Guide**

*What is your role in your agency?*

- a. Are you directly involved in placement of children?*
- b. Do you work with parents of children in facilities?*

*How did you hear about the Family Based Alternatives Program?*

*Did your role change within your agency after the Family-Based Alternatives program was introduced?*

- a. How did it change? Did it require more or less time to do the work needed?*
- b. Did you work differently with children and/or families because of the Family-Based Alternatives program?*

*What are the barriers to successful implementation of this program?*

*What could be done to improve the program?*

*What successes do you see in the program?*



Financial support for this evaluation of the EveryChild, Inc. Family-Based Alternatives Project is provided by the Texas Council for Developmental Disabilities, with federal funds\* made available by the United States Department of Health and Human Services, Administration on Developmental Disabilities. The views contained herein do not necessarily reflect the position or policy of the TCDD. No official endorsement should be inferred.

\*{\$140,000 (80%) DD funds; \$35,000 (20%) non-federal resources}