

EVERYCHILD ASSESSMENT PROJECT

FINAL REPORT

Submitted to:
EveryChild, Inc.

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**EveryChild Assessment Project
Executive Summary
Center for Social Work Research
March 13, 2009**

Background

This is the final report of a three-year project by the Center for Social Work Research (CSWR) to evaluate the progress of EveryChild, Inc. (EC) toward its mission to create a system that ensures that children with disabilities grow up in families instead of institutions. The findings are based on review of pertinent historical and archival data, conversations and meetings with EC staff, interviews with key informants, and tracking on a series of indicators developed to measure progress.

In 2001, Texas Senate Bill 368 (SB 368) laid out the general policy of promoting opportunities for family life for children with developmental disabilities under age 22 living in Texas institutions. The legislation required the state to do permanency plans for all institutionalized children with developmental disabilities to explore the possibility of either return to their own family home or placement with another family as an alternative to institutional care. As part of this legislative policy direction, EC has been contracted by the Health and Human Services Commission (HHSC) for six years to implement the Family-Based Alternatives (FBA) Project. In addition, EC has received grant and foundation funding, including substantial funding from the Texas Council for Developmental Disabilities. Together, these funds support ten full-time program staff.

At present, EC's funding directs the focus of their activities on children already placed in institutions. However, by demonstrating the viability of family life opportunities for these children, EC's goal is to pursue changes in policies and practices to enable family life for all children with developmental disabilities.

Evaluation Methodology

In the first year, the CSWR research team assisted EC in the development of a logic model to illustrate the relationships among EC's resources and activities and the benefits or changes that result. In the second and third year of the evaluation, the CSWR team then worked with EC to develop both quantitative and qualitative ways to understand progress toward the identified long-term outcomes:

1. System has capacity to provide family-based alternatives to all families/guardians who want them.
2. System has capacity to provide family-based alternatives to all children who need them.
3. System stakeholders demonstrate broad commitment to best practices regarding family-based alternatives.

Quantitative Indicators

Data from the one-year period from September 1, 2007 to August 31, 2008 provides an indication of the kind and level of activity engaged in by EC in pursuit of their mission and contract goals.

Identify, visit, screen and track children in targeted facilities. As of August 31, 2008, EC has identified 919 children with developmental disabilities in institutions. During the reporting year, EC maintained an average monthly caseload of 332 active cases of children in institutions and followed-up an average of 54 children per month after they moved to families. EC staff screened a total of 75 institutionalized children in the reporting year and engaged in significant activities for an average of 70 children per month. In the reporting year, EC assisted a total of 44 children to move from facilities to families, achieving family-based alternatives for an average of four children per month. Between August 1, 2002 and August 31, 2008, EC assisted 175 children with developmental disabilities to move from facilities to families.

Engage families and guardians in discussions about FBAs. During the reporting year, EC staff engaged in discussions with an average of 40 families or guardians per month. They obtained a total of 83 new consents from birth family/guardians to explore alternatives. Of 44 children who moved to families during the reporting period, 12 returned to their own families and 32 were placed with support families. Of 175 children assisted by EC to move from facilities since 2002, 50 of their birth families chose return home, 124 families or guardians chose placement with a support family, and one young adult moved to her own home.

Recruit and prepare potential support families. EC staff fielded a total of 240 new inquiries from potential support families during the reporting year that were generated from outreach activities. On average, they engaged in discussions with 18 potential support families per month regarding a specific child.

Collaborate with providers and develop support network. Altogether, EC staff has identified a total of 140 agencies that provide support family services as potential collaborators, growing from five in 2002. In the reporting year, EC staff engaged an average of 33 provider agencies per month in discussions or activities regarding development of FBAs. On average, EC staff engaged 29 providers each month in activities about a specific child. A total of 15 providers are closely aligned in collaborating with EC as allies and partners. EC hosts a consortium of support family providers that was attended on average by seven providers per month.

Collaborate with designated planners. EC staff work with service coordinators, caseworkers, and permanency planners who are responsible for coordinating and planning on behalf of specific children. During the reporting year, EC had an average of 88 contacts per month with individual planners/coordinators including 18 affiliated with the Texas Department of Family and Protective Services (DFPS), 38 affiliated with the Department of Aging and Disability Services (DADS), and 32 with facility providers.

Interact with policy and decision-makers and analyze trends and patterns. EC staff had at least monthly contact with DADS Access and Intake, Provider Services, the Promoting

Independence Advisory Committee, and DFPS Disability Specialists of Child Protective Services. In addition, EC staff have had regular contact with the Children's Policy Council, DADS Policy and Innovation, and HHSC Medicaid. They have participated in various stakeholder meetings and joint meetings of multiple state agencies and had intermittent contact with many subdivisions of a number of state agencies.

Organize outreach activities and develop and disseminate informational materials.

EC outreach activities tracked each month included a range of outreach activities -- presenting at conferences and community organizations, participating in community group meetings and informational fairs, contacting community organizations, placing ads in community newspapers, and distributing or posting informational materials.

Provide information, training, technical assistance, and consultation. On average, EC staff provided technical assistance and consultation to 68 organizations per month, including 33 support family provider agencies, 18 Mental Retardation Authorities (MRAs), and 17 other community organizations. In addition, EC staff provided formal training to an average of 34 individuals per month including support families and staff of provider organizations, families and professionals in the community, and state agency staff.

Network Map

These quantitative indicators suggest the multiple systems and the complex network within which EC staff work in trying to create family life for children with disabilities who would otherwise grow up in facilities. Building relationships with state agency staff, providers, and families is an essential part of EC's methodology. CSWR, in collaboration with EC staff, developed a network map of key contacts illustrating the number and variety of entities and individuals that EC staff routinely engage in carrying out their work. EC holds a unique position in this network working with network members to achieve FBAs and illuminating barriers to family-based alternatives for network members that need to be addressed at the administrative or policy level.

Network Analysis: Participant Perspectives

Six members of EC's network were interviewed by CSWR in order to better understand other perspectives about the growth and changes over time in creating family-based alternatives. These key informants represented senior staff with state agencies, MRAs, and community providers who were familiar with EC's mission and activities. They indicated that they understood EC's mission as facilitating system change and believed EC is succeeding in its efforts. All had positive things to say about their contacts with EC staff that they identified as knowledgeable, helpful, and skillful in their interactions with families and their role as system change facilitators. Informants identified strong leadership and an emphasis on building relationships as key attributes of EC that have contributed to positive influences on policy makers and facilitated increased opportunities for FBAs, but noted EC's ultimate success will depend on changes in laws, policies, financing and resources to fulfill their mission.

Case Log Analysis

To understand the complex and labor-intensive work of successfully moving children from facilities to families that is not fully captured through a simple count of children who have moved to families or activities engaged, the CSWR research team reviewed detailed case notes for seven children over 12 or more months detailing tasks, efforts, and obstacles to achieving family-based alternatives for children living in institutions. These cases illustrate the six stages identified by EC involved in moving a child from an institution to a family-based setting: (1) identifying; (2) screening, (3) developing, (4) exploring options, (5) transitioning, and (6) placing. Within these stages, the case analysis identified the routine functions that EC staff performed over the course of their work:

1. Initiating contact
2. Identifying needs
3. Identifying funding
4. Assisting parents/guardians in choosing providers
5. Assisting planners and coordinators who work with families
6. Locating services and supports
7. Supporting parents
8. Orchestrating transition and discharge
9. Advocating for family life

As a group, the case notes highlight the complexity of the systems and the extraordinary number of people with whom EC staff must coordinate to achieve children's movement from facilities to families, and obstacles to achieving FBAs including:

1. Policies that favor institutionalization
2. Size, scale, and multiple agencies of the bureaucracy
3. Complexity of policies and procedures, children's needs, and families' situations
4. Fragmentation of functions
5. Lack of resources

This case analysis reveals that the current system is large, complex, fragmented, has gaps, and lacks resources and policy priorities favoring family life, all issues which must be addressed to create the system that EC's mission envisions. EC staff use a case-by-case approach to assist in achieving FBAs and to inform policy recommendations targeted at system change. EC staff are not case managers, but work along side the various designated agency representatives who are responsible for permanency planning and service coordination for a particular child. However, EC staff are the only people who have the time and energy to persevere in complicated situations, and follow a case from start to finish taking on all of the issues it presents. Without this continuity and level of involvement, a number of opportunities for family life would likely have been forgone.

Legislative and Policy Changes

According to the most recent annual legislative report by HHSC on permanency planning and FBAs, approximately 1,200 children have moved from facilities to families in the past six years with a dramatic reduction in the number of children living in large facilities¹. Access to increased numbers of Medicaid waivers, improvements in permanency planning, and increased interest and capacity of providers in offering FBAs have all contributed to these changes. The report credits EC as the FBA contractor for their positive contribution to these trends through their advocacy, training and technical assistance efforts. Between August 2002 and August 2008, there has been a 77% reduction of children in large ICF/MR facilities and a 53% reduction of children in nursing homes, facilities where EC has targeted its effort. However, the legislative report also identifies increases in the number of children in state schools and DFPS institutions and indicates that the total number of children and young adults remaining in facilities is relatively unchanged since 2002.

Summary

The information gathered by CSWR from these multiple sources offers some evidence that outcomes identified in the logic model are being achieved. EC has worked with an increasing number of children, families, and collaborating organizations. They have created a growing network of policy and program contacts and relationships, and based on feedback from members of that network, they are well respected and their mission is gaining growing acceptance. Their case-by-case work highlights the multiple tasks and roles involved in successfully moving a child from a facility to a family home. These tasks and roles are currently dispersed across a variety of individuals in a fragmented system with gaps that make good planning challenging. The cases reviewed for this report suggest that without the continuity of EC staff who follow a child through all the various stages and activities required to achieve a family home, placements could have faltered at numerous points in the process. Working collaboratively with an expanding network of providers, MRAs, state agencies, and community groups, they have contributed to legislative and policy changes in the past six years that indicate that support for FBAs is growing, in part because of the unique role and expertise EC has brought to the collaboration. However, numerous obstacles present continuing barriers to achieving family life as evidenced by increases in the number of children in state schools and DFPS institutions and lack of reduction of the total number of children and young adults remaining in facilities. While significant progress has occurred in increasing opportunities for FBAs for institutionalized children, identified obstacles point to the need for continued effort to change policies, resources, and capacities to achieve a system that ensures children with disabilities grow up in families instead of institutions.

¹ Permanency Planning and Family-Based Alternatives Report in Response to Senate Bill 368, 77th Legislature, Regular Session, 2001, (January 2009). Available at: http://www.hhsc.state.tx.us/reports/SB368PermanencyPlanningReport_January2009.pdf

List of Acronyms

ADA	Americans with Disabilities Act
CBA	Community-Based Alternatives Medicaid Waiver
CLASS	Community Living Assistance and Support Services
CSHCN	Children with Special Health Care Needs
CSWR	Center for Social Work Research
CPA	Child Placement Agency
CPS	Child Protective Services
CRCG	Community Resource Coordinating Group
CSA	Casemanagement Agency
DADS	Department of Aging and Disability Services
DARS	Department of Assistive and Rehabilitative Services
DFPS	[Texas] Department of Family and Protective Services
DME	Durable Medical Equipment
DSA	Direct Service Agency
DSHS	[Texas] Department of State Health Services
EC	EveryChild, Inc.
FBA	Family-Based Alternative
FY	Fiscal Year
HCS	Home and Community-Based Services Medicaid Waiver
HCSSA	Home and Community Support Services Agency
HHSC	[Texas] Health and Human Services Commission
ICF/MR	Intermediate Care Facilities for Persons with Mental Retardation
MDCP	Medically Dependent Children's Program Medicaid Waiver
MHMR	Texas Department of Mental Health and Mental Retardation
MRA	Mental Retardation Authorities
SB 368	Texas Senate Bill 368: Permanency Planning and Family-Based Alternatives
TCDD	Texas Council for Developmental Disabilities
TCHCA	Texas Department of Housing and Community Affairs
TIFI	Texas Integrated Funding Initiative
TLC	Transition to Life in the Community funding through DADS

Introduction

This is the final report of a three-year project involving planning, research design, and data collection by the Center for Social Work Research (CSWR) to evaluate the program and policy implementation of EveryChild, Inc. (EC). It is based on our review of pertinent historical and archival data from EC, conversations and meetings with EC staff, interviews with key informants, reviews of case notes, and tracking on a series of indicators developed to assess progress.

EveryChild's mission is to create a system that ensures that children with disabilities grow up in families instead of institutions. Its purpose is to participate in policy and practice changes designed to increase the opportunity for children with developmental disabilities to grow up in families. EC draws from previous models, in particular, one implemented by the state of Michigan, that shifted the focus from specialized services, which result in children's placement in shift-staffed facilities, to a focus on children's developmental needs, which require family-based care. The goal of this assessment is to:

- Assess context, by comparing its likely trajectory to those of related policies that have been implemented earlier (both in Texas and in Michigan);
- Assess the ways in which innovations implemented by EC reflect its original policy model;
- Assess the progression of steps in terms of adherence to the original policy model, as well as the model for implementation; and
- Assess the productivity of the practices in implementing system change.

In 2001, Texas Senate Bill 368 (SB 368) laid out the general policy of family life opportunities for children with developmental disabilities living in Texas institutions, including the values, policy intent, and proposed agency oversight. The legislation required the state to do permanency plans for all institutionalized children with developmental disabilities to explore the opportunity for them to move to family homes as an alternative. As part of this legislative policy direction, EveryChild has received continuous funding from the Health and Human Services Commission (HHSC) for six years on a roughly year-by-year basis to implement the Family-Based Alternatives Project. In addition, EveryChild has sought and received grant and foundation funding, including substantial funding from the Texas Council for Developmental Disabilities, including funding for this external evaluation.

At present, EveryChild's funding focuses activities on developing family life opportunities for children already placed in institutions. However, by demonstrating the viability of family life opportunities for these children, EveryChild's goal is to change policies and practices to enable family life for all children with developmental disabilities. EveryChild's strategy is to identify barriers and suggest new approaches or ways of operating to enable family life as an alternative to institutional care. Throughout this report, the term "family-based alternative" or FBA will be

used to include either return of a child to their own family home or placement with an alternate family (hereafter referred to as a “support family”) as an alternative to institutional placements.

In carrying out its contractual obligations and its mission, EveryChild works directly with children and families, but the organization must also interact with multiple agencies and individuals in a complex policy environment. In the first year the evaluation, CSWR staff assisted EC in the development of a logic model that illustrates the relationships among EC’s resources and activities and the benefits or changes that result. The overall scope of work is displayed graphically in the logic model in Appendix A.

The following definitions inform the logic model:

1. **Situation** is the problem or issue that the program is to address within its given context.
2. **Assumptions** are the beliefs held about the program and the people involved and the way the program is thought to work. Assumptions underlie and influence program decisions.
3. **External factors** include the cultural milieu, the climate, economic structure, housing patterns, demographic patterns, political environment, background and experiences of program participants, including media influences, and changing policies and priorities. The achievement of outcomes is both affected by and affects these external factors.
4. **Inputs** are the resources and contributions invested to achieve the desired outputs. These include time, people, money, materials, partnerships, research base, and technology, among other things.
5. **Outputs** are the activities, services, events, and products that reach people (individuals, groups, agencies) who participate or who are targeted. They include the processes, tools, events, technology, and actions used to bring about the intended changes; and the persons, organizations, communities, or other groups that the selected strategies/approaches are intended to affect.
6. **Outcomes** are changes or benefits for individuals, families, groups, businesses, organizations, and communities. Outcomes can be short-term, medium-term, or longer-term achievements. Outcomes may be positive, negative, neutral, intended, or unintended.

Given the scope and complexity of the work required for EveryChild to fulfill its mission, it is challenging to track changes over time. CSWR assisted EC in identifying indicators to create a consistent tracking process and the basis for ongoing evaluation of progress.

The logic model helped identify measurable outputs of EC’s work and practice model including:

1. Identify, visit, screen, and track children in targeted facilities;
2. Engage families and guardians in discussions about family-based alternatives (FBAs);
3. Recruit and prepare potential support families;
4. Collaborate with providers and develop support networks;

5. Collaborate with designated planners;
6. Interact with policy and decision-makers and analyze trends and patterns;
7. Organize outreach activities and develop and disseminate informational materials; and
8. Provide information, training, technical, assistance, and consultation.

The logic model also articulated the desired outcomes as follows:

Intermediate:

1. Children matched with support families or identified to return home.
2. Parents/guardians choose FBAs.
3. Availability of support families increased.
4. Provider's interests and capacity to offer FBAs increased.
5. Planning quality improved.
6. Needed changes implemented.
7. Increased awareness.
8. Increased stakeholder and community awareness, knowledge and understanding.

Long-term:

1. System has capacity to provide family-based alternatives to all families/guardians who want them.
2. System has capacity to provider family-based alternatives to all children who need them.
3. System stakeholders demonstrate broad commitment to best practices regarding FBAs.

During the second year, the CSWR research team assisted EC in developing mechanisms for tracking each of the above outputs (see Appendix B) and documented six months of EC's progress toward achieving program outcomes.

In the third and final year, the CSWR team continued to document EC's progress on the quantitative measures, and added several qualitative measures. In sum, this report includes information from the following sources:

1. **Quantitative Indicators.** We completed one full year of data collection on quantitative indicators developed in year 2 (Appendix C, Tables 1-9).
2. **Network Map.** To document EC's ties to various agency stakeholders and their extensive collaborations, we elaborated a network map of staff contacts (Appendix D).
3. **Network Analysis: Participant Perspectives.** To understand the views of network participants and document EC's efforts in achieving its mission, we conducted interviews with key participants in EC's network.
4. **Case Log Analysis.** In order to document the extensive efforts of time and personnel required to identify the needs of children in institutional care and their birth families, recruit appropriate support families and facilitate the movement of children with disabilities from institutional to family care, we analyzed seven cases selected by EC staff

and summarized key tasks, efforts, and obstacles to moving through the necessary stages to achieve family life for children currently living in institutions.

5. **Legislation and Policy Changes Affecting the Ability of Children with Disabilities to Move from Facilities to Families.** Appendix F illustrates relevant policy changes that have taken place since the inception of EC's Family-Based Alternatives Project in 2002. These policy changes indicate that support for FBAs is growing.

Each of these five methods of data collection is described in more detail in the following sections.

Quantitative Indicators

The CSWR research team developed several quantitative measures to track EC's progress in delivering key outputs and achieving key outcomes (see Tables 1-9 in Appendix C). The following section details the results of the first full year of this tracking, covering the period September 1, 2007 to August 31, 2008.

Table 1 shows the number of children who moved to family-based living situations. In the year covered during this assessment, EC averaged four placements per month, for a total of 44 children who moved from facilities to families, of whom 32 moved to support families and 12 returned to their own family homes. Table 2 tracks EC's work with children over the stages involved in moving a child from an institution to a FBA. As of August 31, 2008, EC has identified 919 children in institutions. The agency maintained an average monthly caseload of 332 active cases of children in institutions at any given time. Staff actively follow up with an average of 54 children per month after their move to a family. Between the inception of the FBA project in 2002 and August 2008, 175 children have been assisted by EC to move from facilities to families. Of these, 124 moved to support families, 50 returned to birth families, and one young adult moved to her own home.

An important part of EC's mission is engaging providers in the development of FBAs. Table 3 illustrates that an average of 33 are engaged every month in discussions or activities regarding FBAs every month and an average of 7 providers participate in consortium meetings. Table 4 tracks the growth in the number of providers and the progress of providers through successive stages of commitment to FBAs. Altogether, EC staff has identified a total of 140 providers, up from 116 in the first month of the year and up from 5 in 2002. Of these, over the reporting period an average of 43 were in the identification stage, 19 were in the screening stage, and 53 were in the development stage, 6 providers were considered allies, and 7 providers were considered partners. The proportion of providers in each stage remained relatively stable over the reporting year; however, the number of providers in the earlier stages of screening and development increased from 61 total in the first month of the year to 81 in the last month. A total of 15 providers are closely aligned in collaborating with EC as allies and partners. Nineteen providers with whom EC has worked most closely have collectively placed 99 children from facilities to families, or 57% of children placed since the project start.

Table 5 summarizes a number of targeted indicators for children, birth family/guardians, support families, and providers. EC staff screened a total of 75 children in the reporting year, obtained a total of 83 new consents from birth family/guardians to explore alternatives, and fielded a total of 240 new inquiries from support families. Based on a twelve-month average, EC's organizational caseload includes significant contacts with an average of 70 children per month, 40 families or guardians per month, 18 potential support families per month, and 29 support family providers contacted about a specific child per month.

Table 6 outlines EC's work with individuals within the service system who are charged with responsibility for coordinating and planning on behalf of specific children. During the reporting period, EC had an average of 88 contacts per month with individual planners/coordinators affiliated with DFPS, DADS, and facility providers. As many planning/coordination functions

are the responsibility of the state's 39 MRAs, the number of MRAs contacted is also tracked, and during this period, EC had contact with an average of 18 MRAs per month.

Table 7 illustrates the range of contacts with policy and decision-making entities. EC staff has had at least monthly contact and in some cases multiple contacts in a given month with DADS Access and Intake, Provider Services, the Promoting Independence Advisory Committee, and DFPS Disability Specialists of Child Protective Services (CPS). In addition, EC staff have had regular contact with the Children's Policy Council, DADS Policy and Innovation, and HHSC Medicaid. They have participated in various DADS stakeholder meetings and joint meetings of multiple state agencies. They have had intermittent contact with many subdivisions of a number of state agencies. The range of contacts is also illustrated in the Network Map in Appendix D.

Table 8 lists the various outreach activities of EC, including presenting at conferences and community organizations, participating in community group meetings and informational fairs, contacting community organizations, placing ads in community newspapers, and distributing or posting informational materials. The variety of outreach activities illustrates the ongoing and multi-faceted approach the agency takes to spread the word about FBAs. Table 8 tracks both contacts with individuals and circulation of materials.

Table 9 provides information about the training, technical assistance, and consultation activities of EC. On average, EC staff provided technical assistance and consultation to an average of 68 organizations per month, including an average of 33 support family providers, 18 MRAs, and 17 other community organizations. In addition, EC staff provided formal training to an average of 36 individuals per month including families and staff of provider organizations, families and professionals in the community, and state agency staff.

These quantitative indicators suggest the multiple systems and the complex network within which EC staff work in trying to create family life for children with disabilities who would otherwise grow up in facilities and illustrate EC's progress towards achieving the outcomes identified in the logic model.

Network Map

The development of a system of FBAs involves multiple state and local agencies and their respective programs, necessitating collaboration across and between them. Collaboration is a key element in EC's approach to increase FBAs for children. Building relationships with state agency staff, providers, and families is an essential part of EveryChild's methodology. During the first year of the contract, CSWR, in collaboration with EC staff, developed a preliminary network map of key contacts, including policy and decision makers.

In subsequent years, the CSWR research team focused on further developing this map to illustrate, not just the presence of relationships, but their nature and value to EC's activities, and the progress that EC makes in expanding and developing this network. The updated network map, along with a list of the organizational affiliations of individuals routinely engaged by EC, is in Appendix D.

The network map illustrates the number and variety of entities and related representatives that EC staff routinely engage in carrying out their work. They have a unique position in this network. They work both from the top down, filtering information about new policies and administrative changes to front line workers, but also from the bottom up, illuminating barriers to family-based alternatives that can be addressed at the administrative or policy level.

Network Analysis: Participant Perspectives

In year three, CSWR staff conducted a small number of open-ended interviews with members of EC's network, in order to better understand participants' perspectives about the growth and changes in creating family-based alternatives over time. The methods and findings of this effort are described in the following section.

Methods

This project utilized qualitative methods, namely open-ended interviews.

Sample participants included six members of EC's organizational network, identified by EC staff for their ability to provide rich information. Suggested participants included individuals who represent the three primary network member groups including three senior staff from state agencies, two senior staff from community-based provider organizations, and one senior staff from a Mental Retardation Authority (MRA). Each was selected because of his or her extensive experience in the field and with EC. Participants were recruited by email, with telephone follow-ups. One participant was interviewed in person and the rest were interviewed by phone. Interviews took place between September 25 and October 23, 2008. It was challenging to make contact with these busy executives and some interviews required three email reminders and multiple phone calls to make contact. As a result, some interviews were very short and rushed because of participant's time constraints. The interviews took between seven minutes and one hour. This resulted in a very different level of detail between participants in terms of their responses to the interview questions.

Interviews focused on participants' perceptions of EC's mission and how well the participant felt they were accomplishing it. The interview protocol included open-ended questions intended to trace any shifts over time in EC's progress and how and if the system had changed over time. Due to the diversity of relationships that some participants had with EC, the questions didn't work equally well with all the participants, and some questions had to be re-worded for clarity in individual interviews. For example, due to their extensive history with the agency, it was hard for some participants to remember their first impressions of EC and then contrast it with their current understanding.

The University of Texas Institutional Review Board (IRB) reviewed this study for protection of human subjects. In order to protect the identity of participants and their relationship with EC, a number of procedures were put in place. First, participants gave verbal, rather than written consent, so their names are not directly associated with data. Second, interviews were not audiotaped. Participant responses were recorded via handwritten notes and then transcribed electronically. Third, transcribed notes were identified by date, rather than by participants' name or other identifying information. Participants' name and agency affiliation were not included in the notes. Fourth, no demographic information was collected. Finally, responses are reported in a format that disguises the identity of a specific speaker as much as possible.

Findings

Overall, participants were very familiar with EC's mission and activities through various avenues, although one participant had not had significant recent contact. While half of the participants did not understand EC's mission when they first came in contact with them, they all currently identify it as system change to support family-based care for all children with disabilities. There was some confusion about where EC's child placing and individual casework fit into this mission by some participants. All agreed that the mission fits into the overall framework of services for children with disabilities. Five participants felt that EC was doing a good job of fulfilling their mission (the sixth had not had enough recent experience to comment). Several noted EC's dependence on changes in laws and financing to fulfill their mission. Two participants could not think of anything else that EC could do to further its mission. Three mentioned increasing resources and one suggested getting information about their program to different areas. Individual responses from each participant are categorized below by question. Most responses are paraphrased; those in quotation marks are exact quotes.

1. When did you first learn about/come into contact with EveryChild?

- Several years ago (not sure exactly) when asked for names of children in institutions. Over the years, participant has had frequent contacts with EC.
- About five years ago, but participant had previously worked with a member of the staff and knew about a similar program.
- Knew about them from a previous job some years ago, but has gotten to know them better in the past year because participant now supervises a program that works directly with EC.
- Before they came into existence as an organization (two participants).
- In 2005, when working with another agency.

2. What were your impressions of EveryChild?

- Initially, felt like they were not going to be very successful because they had an "ambitious" goal. Participant was initially "skeptical."
- They were experts in the idea that people with disabilities could live in families. They had good national contacts. They provided leadership in policy issues. They were working with an early, successful model.
- Impressed with the leadership and staff of EC and has been extremely happy with what they've been able to do.
- EC has helped state agency personnel and legislators identify the barriers AND identify sources of potential solutions.

- Didn't remember having a strong impression. Over time formed a positive impression.
 - Didn't understand it at the time, but once learned about it, thought it was great.
 - EC staff were "very helpful."
3. Can you tell me what your understanding of EveryChild's mission was at that time? (What is it you thought they were doing?)
- Their mission was to promote the idea that family environments are best for every child to grow up in.
 - Initially, was "fairly vague" on their mission -- thought they were an advocacy group focused on moving children from institutions to home environments.
 - "Their mission is to help facilitate moving kids from institutions to families." Their role is still one-on-one with families, but it now focuses more on facilitation of providers. At first, this participant saw EC as a child-placing agency, but in reality, that was a much smaller part of what they do because they had to develop a process in order to place children. It was always clear that they were not really a provider – they are a contractor to facilitate the movement of kids from institutions to family-based care.
 - "They (EC) have a broad mission to make sure that all kids with special needs have a family."
 - EC was there to look at the system and implement systems and make sure that all children were served, not just kids in institutions, and that there were families for all the kids. This included changing systems and involving state agencies in collaboration.
 - Promoting independence by individual contacts, education, strategic alliances, public testimony and encouraging agencies and providers to move from institution-based care to family-based care.
4. Tell me about your subsequent contacts.
- Comes in contact with EC at meetings participant attends with a supervisee.
 - Used to collaborate as a staff member of another agency with EC to find support families, but in current job doesn't have much contact. Still "visits" with EC director about how to translate the EC model nationally.
 - Very involved initially, but withdrew from direct involvement and is now involved in a different capacity.

- Doesn't typically deal with specific cases, but EC staff helped find placements for all of the children living in a particular nursing home when it was about to be closed.
 - Serves on the Children's Policy Council.
 - Member of the EC Provider Consortium and works with them to move children from institutions into family-based care.
5. How do you understand EveryChild's mission now? (Probe: Has it changed? If so, how?)
- From "flying solo" to making partnerships with other groups.
 - Their initial mission hasn't really changed, though the way they focus energy has evolved based on experience. The mission now is much bigger than locating support families – it's educating the system at the state and local levels.
 - Their mission is still about system change.
 - Didn't know if it had changed, due to limited recent involvement.
 - Initially, thought they had more of a global mission to shut down institutions, but came to understand that what they're doing is more individual casework.
 - Their mission is the same: all children should be cared for in a family-style environment.
6. Given what you know about services for children with disabilities, how do you think EveryChild's mission fits into it?
- While most people working in the system believe that all children with disabilities should be cared for in a family, there aren't sufficient resources for all children to do so. State agencies have to support parents' choice. The choices parents have are not always very good due to limited resources, so some children wind up in institutions.
 - EC fulfilling its mission depends on changes in laws, financing, and other participating agencies that provide services to children with disabilities to live in the community.
 - EC staff advocate and keep the issue of their mission as part of the debate at Department of Aging and Disability Services (DADS) and Texas Department of Family and Protective Services (DFPS).
 - EC's goal is to have all kids grow up in families, but there are not enough resources in the state to make that possible for all children.
 - "It fits really well and they've been really helpful."

- “EC’s mission is to put themselves out of business.” There will always be a need for children’s nursing homes for transitions and a temporary place for children who have severe behavioral issues, but “an institution is not a place for kids to grow up.”
- It’s an excellent mission, and what needs to happen, both in terms of advocacy and placing children in family settings. The mission is idealistic, not the “easy way out.”

7. What do you think about EveryChild’s efforts at fulfilling their mission?

- “I think they do a terrific job.”
- EC’s approach to parents is “very skillful.”
- “I think they’re doing a really good job. It’s slow because there are a lot of children and not a lot of resources and they have a small staff.” EC is limited because of their small staff and the lack of community resources, so they can’t make a huge impact quickly.
- “As far as I know” -- couldn’t answer specifically because of limited recent involvement.
- They have very strong leadership and they have been influencing legislators and policy makers, through their models and public speaking. However, waiting lists for community resources are growing in Texas, so families may give up and put their children in institutions because there are no resources. EC’s success can’t be judged on the basis of the number of children in institutions. EC has made progress in the ideological shift, but the money for the necessary services hasn’t followed.
- They are doing a relatively good job. There is a lack of support families.
- “I think they’ve done extremely well.” The number of children in large institutions has decreased by 85%, children in nursing homes has decreased by 40%. If you combine all the children with disabilities in institutions, overall there has been a 25% decrease.

8. What advice would you give EveryChild staff in furthering their mission?

- “. . . just keep on keeping on.”
- If they had more money, they could make more of an impact.
- “Nothing comes to mind.”
- Since the biggest barrier for moving some children into the community is the lack of resources such as funding and foster (support) families, perhaps they could work on increasing support for these services.
- Find strategic funding partners that will allow them to grow to the next step.

- Bring in speakers from the nine or ten states that no longer have state schools to assist Texas officials in figuring out how to do that.
- “It’s all about money,” in terms of their ability to advertise for what they do and advocate what the system should do.
- “Get the word out to different areas” – advertise who they are and what they do.

9. Other comments

- Positively disposed towards EC’s work, but given the lack of resources for community care, participant wonders about their ability to affect change long term.
- EC was “very helpful.”
- Supports EC 110%.
- At first, folks were not impressed with the number of children that EC was able to move from institutions to family-based care, but now they’ve seen how difficult it is to move kids.
- EveryChild staff “don’t make enemies out of bureaucrats.”
- Concern that the focus of moving children out of institutions might be like the move to de-institutionalize people with mental illnesses in the 1980s. Without adequate community supports, many people de-institutionalized in the 1980’s simply became homeless. Participant was concerned that similarly, moving children out of institutions now without proper community supports might result in a similar problem.
- EC staff have a lot of political savvy. They have good relationships with the agency staff and good boundaries.
- EC has been a key player in using the Medicaid waivers to get kids out of institutions.
- In evaluating EC program, should focus on outcomes of placements. It’s not that hard to place children in the community, but placing them in a situation that will last is the problem. If children eventually wind up back in institutions anyway, maybe it’s not worth the effort.
- Although children are best served in family situations, sometimes in the transition from a large institution to a FBA, it might be nice for there to be a “step down” process where the child moves from the larger facility to a smaller facility before actually going into a home as it’s often a very dramatic change for the child.

In summary, these network members understood EC's mission and praised EC efforts. In the complex system that provides services to children with disabilities, EC staff have sophisticated and complex skills that help them work within that system to facilitate more opportunities for family-based alternatives.

Case Log Analysis

The complex and labor-intensive work of successfully moving children from facilities to families is not fully captured through a simple count of children or activities engaged. The CSWR research team reviewed the detailed staff notes on five cases that have been documented by EC staff from January 2008 to December 2008. Two additional cases, which had been tracked over a longer period, were added to capture cases where the plan for the child was placement with a Support Family. Analysis of these logs provides a narrative summary of the tasks, efforts, and obstacles to moving through the necessary stages to achieve family life for children currently living in institutions. These cases were chosen for convenience, and so may or may not be representative of the range or proportion of cases that EC works with; however, they provide extensive detail about the process of working with different kinds of cases. The examples include:

- Case 1: Father actively involved in child's care and wanted to bring him home – child returned to his home from a nursing home.
- Case 2: Child returned to mother's home from a nursing home.
- Case 3: CPS case – EC assisted in locating a support family, and was working towards transition from a large DFPS facility at the time of the last entry.
- Case 4: CPS case – EC requested to assist in finding a support family. CPS withdrew because family decided child should remain in institution.
- Case 5: CPS case – EC contacted by MRA about locating a support family. EC recruited a family, but CPS and institution decided that child should be moved to a group home due to behavior problems. EC staff advocated for a family placement. There were problems with the child's behavior in the group home and at the time of the last entry, EC staff was again involved in trying to locate a support family.
- Case 6: EC assisted mother in locating a support family and transitioning child from the institution.
- Case 7: EC staff assisted mother of a 21 year old in selecting a support family and transitioning the child from a nursing home.

These cases illustrate the six stages identified by EC involved in moving a child from an institution to a family-based setting:

- Identifying child in institution and gathering initial information.
- Screening child by gathering information from medical records and institution files, visiting with the child, contacting birth parents or guardian (such as CPS), and prioritizing children on whom to focus.
- Developing family-based placements by working with birth families or guardians to help them imagine an alternative for the child and gaining their consent to explore options.
- Exploring options by beginning to identify the funding and community resources needed to either bring the child home or establish a support family.
- Transitioning to a chosen family-based option by assuring all the necessary services for home or support family care are arranged.
- Placing child at home or in a support family.

Tasks and Roles

Within these stages, EC staff functions as connectors, linking families with resources and linking the various participants [institution, MRA, provider agency, CPS, etc.] with the family and with each other.

Initiating contact. EC staff is pro-active, often initiating first contacts with families and providers to begin conversations about family-based care, as they did in Cases 1, 3, 6, and 7. Further, they keep the process moving forward by participating in the planning process and following up with the various participants. This sometimes involves prodding them to complete their assigned tasks, keeping them in the loop regarding changes in the plan, and reminding participants of aspects of the plan. Linking and negotiating with various providers are key activities. In Case 1, the EC staff member coordinated the efforts of two MHMR centers (one in the child's home county and one in the county where the child was institutionalized) to obtain a determination of mental retardation to establish eligibility for services. In Case 5, EC staff maintained the focus of the large number of participants involved of key aspects of the child's permanency plan.

Identifying needs. EC staff helps identify the needs of the child and family in order to know what services, funding, waivers, and providers to seek. The plan of care in the facility does not address what a family needs, so EC staff initiates discussions with the family about what it would take for the child to live in a family home, either their own or with a support family. For example, in Cases 1, 6, and 7 the children had been placed in institutions far from the birth families, making it hard for them to be part of their child's life. In Case 1, the birth father actively wanted his son at home. In Case 6, when given the opportunity for the child to be placed in a support family closer to their home, the birth mother and her extended family were very positive about this option and actively participated in the transition. In all the cases, EC staff was proactive about identifying the financial, social, medical, educational, and equipment needs required to move a child to a family-based setting. For example, the child in Case 6 had very complex medical needs. EC staff followed up to make sure the support family could manage the child's medical needs and could secure adequate backup nursing and care.

Identifying funding. EC staff plays a key role in identifying and assessing sources of funding and explaining the options to parents and to the various participants. For example, in Case 2, Home and Community-Based Services Medicaid Waiver program (HCS) and Community Living Assistance and Support Services (CLASS) were both available to pay for care at home, but they pay for different things at different rates, so the family considered both. In Case 6, after considering a number of potential support families, it became clear that the CLASS waiver funding for a support family was not adequate for a child with such complex medical needs and the process was halted. Over a year later, the Texas legislature passed Rider 41 which allowed children living in nursing facilities access to the HCS Medicaid waiver which would provide more appropriate services and funding, making it possible for this child to live with a support family in the community. EC staff again contacted the birth mother to see if she was interested in trying again, and their efforts eventually resulted in this child moving to a family-based placement.

Assisting parents/guardians in choosing providers. As children are enrolling in waiver programs, their parents/guardians are given the names of providers for waiver services, but may not be given names of providers of other Medicaid service providers. Parents/guardians are given only names and addresses, and are expected to determine which provider would best suit their preferences and their child's needs. EC staff assists them in learning about providers who might suit their preferences for FBAs. In Cases 1 and 2, EC staff worked with birth families to choose providers so the child could come home. In cases 6 and 7, EC staff worked with both birth families and support families to choose the necessary providers to enable the child to move to a support family. The birth mother in Case 6 worked two jobs and without the support of EC staff would probably have discontinued the effort to locate and arrange a support family.

Assisting planners and coordinators who work with families. EC staff are not case managers, but instead work along side the various designated agency representatives who are responsible for permanency planning and service coordination for a particular case. Staff work with, but have no direct authority to address the numerous gaps or impediments to the successful transition of a child from institutional to family-based care. EC staff are the only people who follow a case from start to finish and take on all of the issues it presents. EC staff fill gaps, facilitate communication between the disparate entities, and have the time and energy to persevere in complicated situations. Without that, a number of opportunities for family life would have been forgone. For example, in Case 7, EC staff accompanied the child's mother on visits to ten support families with multiple providers.

Locating services and supports. In all but Case 4, EC staff were key to locating the services necessary to successfully transition to a home-based situation. The EC staff member in Case 2 made numerous calls to locate nursing and attendant care providers and equipment for the child's return home. Due to problems arranging for providers and equipment, the discharge date had to be moved, and the EC staff member took responsibility for assuring all the involved parties were contacted about the change. EC staff took on a similar role in Case 6, where numerous delays in getting needed equipment and services and even a hurricane delayed the discharge. EC staff also assisted the birth parents/guardians in searching for potential support families and visits to support families in Cases 3, 4, 5, 6 and 7.

Supporting parents. At times, EC staff provide supportive counseling to parents and support parents as they deal with the child's needs, his or her care, or interactions with other agencies. For example, in Cases 1 and 2, EC staff members listened and problem solved when parents were upset about the care their children were receiving in the institution. EC staff also accompanied parents to meetings with provider agencies. In Case 7, EC staff helped to negotiate differences in caregiving preferences between the birth parent and the support parent. After the child in Case 1 was returned home, EC staff provided supportive counseling to the birth parent.

Orchestrating transition and discharge. Timing is critical to the transition process. There is considerable complex work involved in discharging a child from a facility. Often the responsibility for transition planning within agencies and institutions is fragmented and thus inadequately done. In the cases examined, EC staff members helped orchestrate the timing of the various activities required for discharge and kept all the participants on task. For example, in Case 2, the EC staff member was present for the discharge, and double-checked last minute

details that could disrupt the discharge. The child in Case 6 had very complex medical needs and it was critically important that all equipment, providers, and supplies be in place in the support family home before the child was discharged from the institution. EC staff persevered through several bureaucratic glitches to make sure that the receiving home was ready for the child. In Case 7, there were several issues with providers that threatened to delay or derail the placement without EC staff prodding and problem solving.

Advocating for family life. EC's mission involves advocating for FBAs, so advocacy for children and families is a thread throughout all their efforts. The advocacy role presents a dilemma when EC staff feel that a course of action decided by parent or guardian is not in the best interest of the child, because the state honors the right of parents/guardians to choose the type of care for the child, and does not make a separate determination of what is best for the child. In both Cases 4 and 5, EC staff advocated for a family-based placement while the CPS worker or birth parent decided on an institutional placement. In deference to the state's policy of parent/guardian choice, EC's role in such circumstances is to assure the parent or guardian is fully informed about the benefits of FBAs and about the resources available to accomplish it.

Effort

With so many moving parts, the connecting role is very time-consuming. Connecting requires contacts with many agencies including various kinds of facilities, numerous community providers, MRAs, and state agencies. It involves contacts with many individuals including permanency planners, service coordinators, provider agency administrators, nurses, policy-makers, Medicaid administrators, and waiver program managers. Glitches frequently occur requiring contacts with regulatory and administrative offices of state agencies. The case notes for individual children document dozens of entries per month in active cases with each note reflecting multiple telephone calls and emails, or participation in meetings or home visits. Since EC has only nine program staff to cover the entire state of Texas, their efforts often require extensive travel and coordination with their counterparts in other regions.

Obstacles

In pursuing their mission of a family-based placement for every child with a disability, EC staff faces a number of obstacles:

Policies that favor institutionalization. Chief among these obstacles is a system that disproportionately favors institutionalization. Currently, institutional care for children with disabilities is an entitlement, but family support is not. Therefore, many parents who might wish to care for their children at home are not able to because of lack of supportive services. Further, the state honors parent/guardian choice of institutional care, and does not make or promote a separate determination that a family-based alternative might better meet the child's needs. Moving a child from an institution to a FBA is a complex process. It involves a large number of participants including the institution, agencies that determine funding, Medicaid, MRAs, local providers, and the family. Not all of them are firmly committed to family-based care for every child. For example, in cases 4 and 5, the transition process broke down because the family/guardian ultimately decided on an institutional rather than an available home-based

placement. In Case 4, the CPS case involving parental neglect was dismissed because the parents assured adequate care by consenting for the child to remain in a health care facility, but the child's need for family life was unaddressed. In Case 6, the nursing home staff and administrators both actively and passively impeded the progression of the family-based placement, even though the birth mother had clearly expressed her desire for it.

Size, scale, and multiple agencies of the bureaucracy. Another obstacle has to do with the multiple sub-systems and professionals within the system. Three large state agencies are involved in the development of FBAs: HHSC, DADS, and DFPS. There are 254 counties with 39 MRAs. Different state agencies use different regional configurations of counties. There are hundreds of provider agencies with different contracts with different state agencies. Large bureaucracies with overburdened staff put additional drag on the exploration and transition process. In Cases 4 and 5, considerable EC staff time was taken up simply trying to contact agency representatives for information. In Case 6, two EC workers in different regions were constantly following up on tasks, even agreeing to remind someone before a scheduled conference call. Obtaining Transition to Life in the Community (TLC) funding through DADS took nearly three months rather than the two weeks as originally promised. Bureaucratic delays made the move nearly impossible, as the support family could have decided to take another child.

Complexity of policies, procedures, children's needs, and families' situations. Large bureaucracies operate based on complex policies and procedures. For example, policies and procedures regarding Medicaid waivers require extensive knowledge and expertise to navigate. One of the roles of EC staff is explaining this system to parents and providers and smoothing the navigation process. In Case 2, the EC staff member spent hours trying to determine if Medicaid would repair or replace a damaged bed needed for the child to return home. In Case 2, determining whether an HCS or CLASS waiver would provide the best coverage for the child's needs required a detailed understanding of two different waiver programs. In Case 4, the EC staff member spent considerable time trying to ascertain the child's legal status with CPS. In Case 1, the EC staff member coordinated the efforts of MRAs in two regions. The sheer number of participants involved becomes an obstacle, one that EC addresses through its coordinating role. Communication across state agencies and between regions within state agencies can be problematic in such a large and complex system.

In addition to the complexity of the system is the complexity and intensity of medical and behavioral needs of individual children, and the complexity of family dynamics and situations. The seven cases provide a glimpse of this complexity. Children ranged in age from 5 to 21. The range of diagnoses among the children in the seven cases included: mental retardation, encephalopathy, microencephaly, blindness, hearing impairment, traumatic brain injury, cerebral palsy, seizure disorder, developmental delay, bipolar disorder, quadriplegia, autism and attention deficit disorder. Many used g-tubes, tracheostomies, and wheelchairs. All of these children had multiple diagnoses. The children's complex medical needs require numerous specialists, medications, equipment, and supplies. EC staff has sophisticated knowledge of various diagnoses and their care requirements. They also deal with the complex situations and needs of the children's families. Families' histories included divorce, adoption, single parenting and step-parenting, poverty, parental illness, competing parental responsibilities for other family

members, and multiple household moves. In Case 4, CPS had removed the child from the family due to neglect. EC staff encouraged the families' involvement with their child and in the process of moving the child to a support family. When the family decided to leave the child in the institution and CPS withdrew, EC continued to try to work with the family to encourage a placement for the child that would better serve the child's needs for family life. In Case 6, the birth mother was a teenager when her child was born with multiple health care issues. She has close extended family that had a positive, but complex relationship with the child. In Case 7, one of the main challenges was the birth mother's preference. As her child had been abused by a man, she was very reluctant to have male caregivers. However, the child weighed over 150 pounds, making that a challenging preference to accommodate.

Fragmentation of functions. In addition to the programs and policies that serve children with disabilities being complex, they are also fragmented. Many programs are "siloed" and staff within them do not know much about or communicate with other programs. Because of the fragmentation of the system, no single individual is charged with overall responsibility across time. Functions are compartmentalized across large bureaucracies. For example, the function of permanency planning is carried out by a different person than is enrollment in a waiver, which is carried out by a different person than is the development of an individual plan of care, so there is opportunity for "slippage" of information. For example, in Cases 2 and 5, EC staff had to explain funding to provider and state agency staff. In Case 5, EC staff had to remind members of the team involved in the planning the child's discharge about key aspects of the child's permanency plan. The multiple tasks and roles involved in successfully moving a child from a facility to a family home are dispersed across a variety of individuals in a fragmented system with gaps that make good planning challenging. In the cases reviewed for this report, the only consistent professional involved was the EC staff person working the case. Without the continuity of someone who followed the child through all the various stages and activities required to achieve a family home, these placements could have faltered at numerous points in the process.

Lack of resources. Another obstacle is the lack of community-based resources for children with complex medical and/or behavioral needs. While a waiver may be available, it may not provide the right services, or adequate amounts of the right services. In Case 6, a support family home fell through because the available CLASS waiver would not pay for services adequate to the child's needs. The child could not be moved to a support family until Rider 41 was passed in 2007, which made a different waiver available to pay for the needed services. Further, appropriate services may not be available in some locales, even if funding is available. The staff working in Cases 1, 2, 5, and 6 made numerous phone calls with local providers attempting to organize at-home nursing care for these children

Summary

This case analysis highlights the complexity of the systems within which EC must work and the extraordinary number of people with whom EC staff must coordinate to achieve children's movement from facilities to families. The number of acronyms cited in this report highlights the various policies and programs that staff must understand and navigate. Staff must work with, but have no direct authority or control over, these systems, which have numerous gaps and

impediments to the successful transition of a child from institutional to family-based care. EC demonstrates the comprehensive tasks that must be done to enable a child to move from a facility to a family. EC are the only people who follow the case from start to finish and take on all of the issues it presents. Appendix E presents a graphic summary of the tasks and roles required to facilitate the movement of children from facilities to families, and identifies the major system representatives responsible for each of them. The current system is large, complex, and fragmented and lacks resources and policy priorities favoring family life, all issues which must be addressed to create the system that EC's mission envisions.

Legislation and Policy Changes Affecting the Ability of Children with Disabilities To Move from Facilities to Families

As illustrated in the Logic Model, one of the external factors that both motivate and constrain EC's activities is the legislative and policy environment relative to children with disabilities.

Appendix F illustrates relevant policy changes that have taken place since the inception of EC's Family-Based Alternatives project in 2002. These policy changes indicate that support for FBAs is growing.

According to a legislative report by HHSC on permanency planning and FBAs², approximately 1,200 children have moved from facilities to families in the past six years, including a dramatic reduction in the number of children living in large facilities where EC targets most of its effort. Between August 2002 and August 2008, there has been a 77% reduction of children in large ICF/MR facilities and a 53% reduction of children in nursing homes. Access to increased numbers of Medicaid waivers, improvements in permanency planning, and increased interest and capacity of providers in offering FBAs have all contributed to this reduction. The report goes on to credit EC as the HHSC FBA contractor for their positive contribution to this trend, through their advocacy, training and technical assistance efforts. However, these successes are tempered by continuing barriers. The legislative report identifies increases in the number of children in state schools and DFPS institutions. Furthermore, while 1,200 children and young adults are reported to have moved from facilities to families since 2002, the total number of children and young adults remaining in facilities is relatively unchanged, although the types of facilities have changed to smaller facilities.

² Ibid.

Summary

During the three years of this evaluation contract with EC, CSWR staff have assisted EC staff in identifying key indicators for the agency's success and have helped develop tools to measure outcomes.

While much of EC's staff time is spent working one-on-one assisting individual children with disabilities to move from institutions to family-based care, their work is part of a much larger vision: that all children with developmental disabilities can live in a family with sufficient support. So in complement to the individual work with children and families, much staff time is also spent at the system level in capacity building and policy development using individual casework to inform both. Such a sweeping mandate requires substantial change in the systems that provide care for these children and, in some cases, the ideas and attitudes of the people who are part of those longstanding systems. Necessarily, this kind of systemic change is much harder to assess.

The first step in the evaluation process was assisting EC staff to articulate their immediate, intermediate and long-term goals. After a year of reviewing archival reports and documents and numerous discussions with EC staff, this process resulted in a Logic Model, contained in Appendix A, which outlines the activities the agency engages in and the outcomes EC seeks to accomplish.

In the second year, CSWR staff began identifying ways to measure progress toward these outcomes. The tables in Appendix C outline this progress. In the period September 1, 2007 – August 31, 2008, EC assisted in a total of 44 placements to either birth families or support families. Compared to fiscal year (FY) 2003, the first year of operation when EC assisted with a total of 9 placements, this is nearly a 400% increase. However, as one of the key informants noted, EC's success cannot be judged on the basis of the number of children in institutions. EC has made progress in the ideological shift, but the resources for the necessary family-based services are still lacking, although there have been some important changes in funding as result of the legislation and policy changes, outlined in Appendix F.

An important part of EC's mission is engaging providers in the development of FBAs. In FY 2003, EC listed a total of five providers who assisted in a family-based placement. In FY 2007, that number is 140. Fifteen providers are considered allies or partners, those who are most closely aligned with EC's mission.

In their work to change the system in which these activities take place, EC staff works with individuals within the service system who are charged with responsibility for coordinating and planning on behalf of specific children. During the period September 1, 2007 – August 31, 2008, EC had an average of 88 contacts per month with individual planners/coordinators from DFPS, DADS, and facility providers as well as contact with an average of 18 out of 39 MRAs per month. They also have monthly contact with DADS Access and Intake, Provider Services, Promoting Independence Advisory Committee, as well as the Disability Specialists at CPS and intermittent contact with many divisions of a number of state agencies and important policy and decision-makers in the systems that impact children with disabilities. They also conduct ongoing

outreach to spread the word about family-based alternatives to the general public as well as provide training, technical assistance, and consultation to state agencies and providers.

With a mission as broad as EC's, numbers by themselves do not do justice to their efforts. Therefore, in addition to measuring the number of children placed, providers contacted, support parents identified, trainings provided and other aspects of EC's work that can be counted, CSWR staff also developed qualitative measures that "flesh out" these numbers and begin to explain the process and the possible impact of their work.

In the second year, CSWR worked with EC staff to develop a network map of all the agencies and organizations with whom they must coordinate to achieve their mission. In the third year, we conducted a small number of telephone interviews with key members of EC's network to gain a sense of how these participants understood EveryChild's mission, and how it was succeeding. Overall, participants were very familiar with EveryChild's mission and activities through various avenues. While half of the participants did not understand EveryChild's mission when they first came in contact with them, they all currently identify it as system change to support family-based care for all children with disabilities, indicating that EveryChild is succeeding in its efforts to educate these systems about FBAs. All agreed that the mission fits into the overall framework of services for children with disabilities and had positive things to say about their contacts with EC staff that they identified as knowledgeable, helpful, and skillful in their role as agents of system change. As one participant said, EC staff members "don't make enemies out of bureaucrats." Most participants felt that EC was doing a good job but noted EC's dependence on changes in laws, policies, and financing to fulfill their mission.

Also, in the third year, CSWR took on an analysis of case logs to illustrate the tasks, efforts and obstacles involved in taking a case from intake to outcome. This case analysis highlights the complexity of the systems within which staff must work and the extraordinary number of people with whom EC staff must coordinate to achieve their mission of family life for children. Staff must work with, but have no control over, these systems, which provide numerous impediments to the successful transition of a child from institutional to family-based care in the form of policies that favor institutionalization, bureaucracy, complexity, fragmentation, and lack of resources for FBAs. While EC staff are not designated case managers, they do track all the moving parts in a case, as well as keep it moving forward towards a family-based placement. As Appendix E illustrates, in the cases we followed, EC staff were the only professionals who followed the case from start to finish and took on all of the issues it presented. In documenting the individual case approach used by EC to inform its policy work, this analysis highlights aspects of the current fragmented system that must be addressed to create the system that EC's mission envisions.

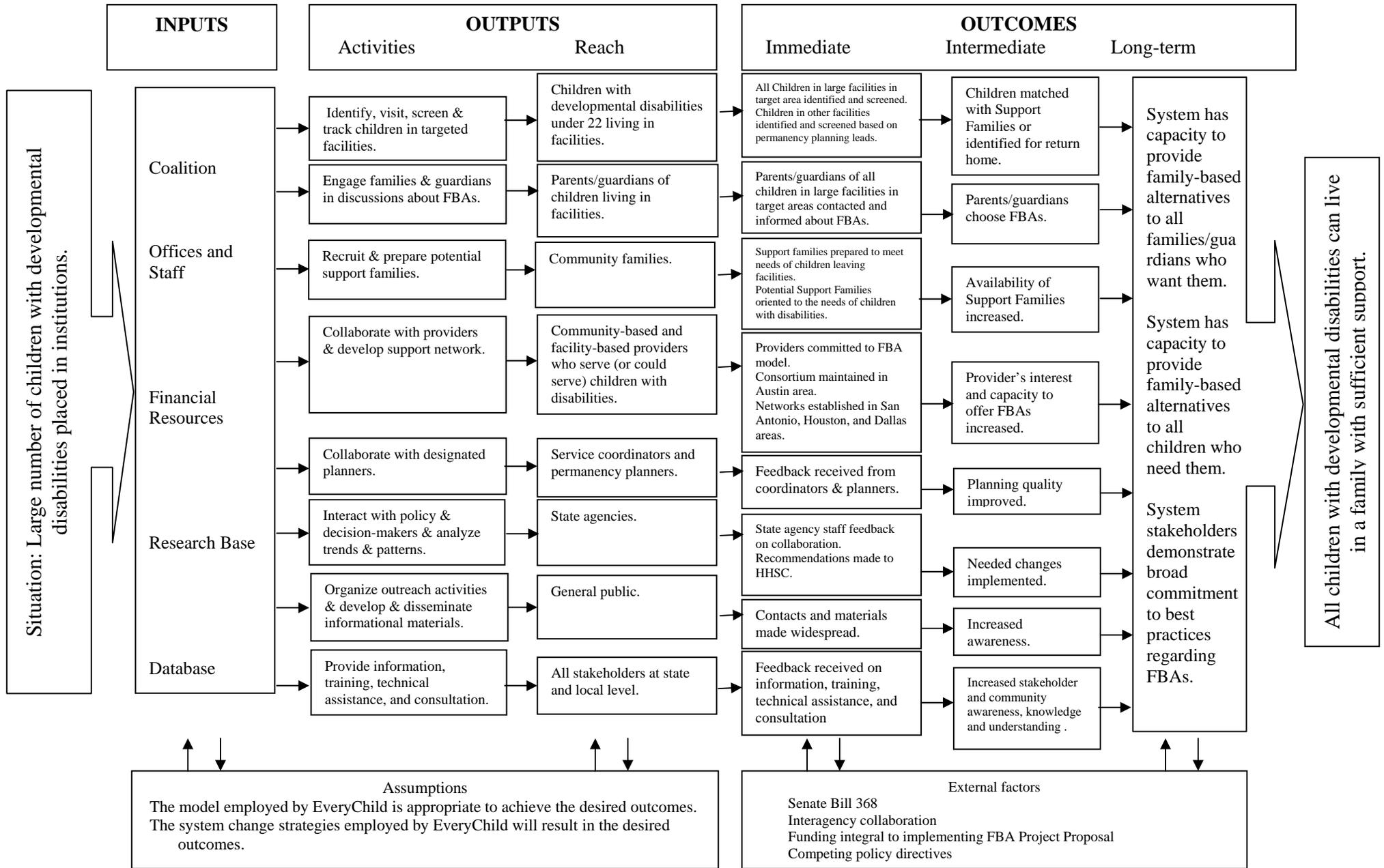
Through persistent effort, EC has contributed to the trend in Texas of children with disabilities increasingly using family-based alternatives to institutions. According to a legislative report on permanency planning and FBAs³, approximately 1,200 children have moved from facilities to families in the past six years, including a dramatic reduction in the number of children living in large facilities where EC targets most of its effort. Access to increased numbers of Medicaid

³ Ibid.

waivers, improvements in permanency planning, and increased interest and capacity of providers in offering FBAs have all contributed to this reduction. The report goes on to credit EC as the FBA contractor for their positive contribution to this trend, through their participation, training and technical assistance efforts. While much progress has been made, the legislative report also identifies increases in the number of children in state schools and DFPS institutions. These increases point to the need for continued change in policies, resources, and capacities involving collaboration across the complex network in which EC works.

In summary, in the past three years of the CSWR's work with EC, they have continued to articulate their mission and intended outcomes and the work required to achieve them. Furthermore, as a result of their work with CSWR, EC has developed and implemented more sophisticated data management and tracking systems, which will allow for ongoing assessment of their future progress. In every arena, their impact has continued or expanded over the long run. They have created a growing network of policy and program contacts and relationships, and based on feedback from members of that network, they are well respected and their mission is gaining and growing acceptance, as more people know about FBAs. They have worked with an increasing number of children, families, and collaborating organizations. Working case by case, they are more clearly articulating the obstacles to FBAs and targeting those for system change. Collaborating with an expanding network of providers, MRAs, state agencies, and community groups, they are striving to make those changes. Legislative and policy changes in the past six years indicate that support for FBAs is growing.

Appendix A: Logic Model*



*<http://www.uwex.edu/ces/pdande/evaluation/evallogicmodel.html>

Appendix B: EveryChild Outputs and Measurement Indicators

	Output	Measurement Indicator
1	Identify, visit, screen, and track children in targeted facilities	Tables 1, 2, and 5
2	Engage families and guardians in discussions about FBAs	Table 2, 5; case logs
3	Recruit and prepare potential support families	Case logs; Table 5
4	Collaborate with providers and develop support network	Tables 3 and 4
5	Collaborate with designated planners	Table 6
6	Interact with policy and decision-makers and analyze trends and patterns	Table 7; network map; interviews with members of the network
7	Organize outreach activities and develop and disseminate informational materials	Table 8
8	Provide information, training, technical assistance, and consultation	Table 9

Appendix C: Quantitative Indicators

Table 1. Family-Based Outcomes Achieved for Children Assisted by EveryChild

Categories	September 2007	October 2007	November 2007	December 2007	January 2008	February 2008	March 2008	April 2008	May 2008	June 2008	July 2008	August 2008	12Month Average	12 Month Total
Children returned home	1	1	3	1	0	0	1	0	2	0	2	1	1	12
Children moved to alternative families	2	2	5	3	2	5	2	3	2	3	1	2	3	32
Month Total	3	3	8	4	2	5	3	3	4	3	3	3	4	44

Table 2. Stages in Movement of Children Toward Family-Based Alternatives⁴ September 2007 – August 2008

Status	Stage as of the end of each month	Sept. '07	Oct. '07	Nov. '07	Dec. '07	Jan. '08	Feb. '08	Mar. '08	Apr. '08	May '08	Jun. '08	Jul. '08	Aug. '08	12Month Average
Active	Identifying	73	62	58	66	72	79	70	61	62	85	81	78	71
	Screening	99	100	94	91	93	103	95	92	89	86	88	91	93
	Developing	92	93	99	95	91	87	70	73	71	73	72	82	83
	Exploring support family placement	60	64	64	67	67	71	67	66	64	64	61	59	65
	Exploring return to birth family	10	7	5	7	7	11	14	14	18	19	18	14	12
	Transition	6	13	11	6	8	4	7	12	10	5	9	6	8
Subtotal	Active	340	339	331	332	338	355	323	318	314	332	329	330	332
On hold	Family/guardian unable or unwilling to discuss or low priority residence	109	114	110	114	113	114	140	139	139	134	135	140	125
Subtotal	Active & on hold: known children currently in institutions	449	453	441	446	451	469	463	457	453	466	464	470	457
Follow up	Moved to family – actively following up	52	42	48	53	57	59	55	57	54	56	59	59	54
Inactive	Moved to families – not following up	110	119	136	138	139	138	149	148	156	158	158	158	142
Closed	Moved out of state, aged out, deceased	197	198	190	191	194	201	209	215	217	226	227	232	208
Subtotal	Follow-up, inactive, closed: known children no longer in institutions	359	359	374	382	390	398	413	420	427	440	444	449	404
Total	All children known to EC since project start	808	812	815	828	841	867	876	877	880	906	908	919	

⁴ This table indicates the number of children in each month. As these are duplicated counts, they do not include yearly totals.

Table 3. Provider Activities⁵ September 2007 – August 2008

Providers	Sept. '07	Oct. '07	Nov. '07	Dec. '07	Jan. '08	Feb. '08	Mar. '08	Apr. '08	May '08	Jun. '08	Jul. '08	Aug. '08	12Month Average
Participation in consortium meetings	5	9	3	7	4	6	4	14	3	13	10	8	7
Providers contacted regarding FBAs	32	35	42	32	33	38	32	34	28	31	33	25	33

⁵ This table indicates the number of providers for each activity each month. As these are duplicated counts, they do not include monthly or yearly totals.

Table 4. Provider Stages of Development⁶ September 2007 – August 2008

Stage	Sept. '07	Oct. '07	Nov. '07	Dec. '07	Jan. '08	Feb. '08	Mar. '08	Apr. '08	May '08	Jun. '08	Jul. '08	Aug. '08	12Month Average
Identify	43	41	45	43	42	43	42	43	44	44	44	44	43
Screen	13	13	15	16	17	17	22	22	22	23	25	25	19
Development	48	50	52	52	53	53	54	54	53	55	56	56	53
Ally	5	5	5	5	5	5	6	6	6	8	8	8	6
Partner	7	7	7	7	7	7	7	7	7	7	7	7	7
Total providers	116	116	124	123	124	125	131	132	132	137	140	140	

⁶ This table indicates the number of providers in each stage at the end of each month. As these are duplicated counts, they do not include yearly totals.

Table 5. Targeted Indicators September 2007 – August 2008

Category	Indicator	Sept. '07	Oct. '07	Nov. '07	Dec. '07	Jan. '08	Feb. '08	Mar. '08	Apr. '08	May '08	Jun. '08	Jul. '08	Aug. '08	YTD Totals	12Month Average
Child	# screened	5	10	0	0	0	26	10	2	3	3	4	12	75	6
	# for whom there was significant work	77	71	61	75	83	93	73	66	67	56	58	54	834 ⁷	70
Birth family / guardian	# of new consents obtained	10	11	6	1	11	14	9	10	0	0	2	9	83	7
	# for whom there was contact	44	47	51	38	36	45	31	45	31	33	37	36	474 ⁸	40
Support family	# new inquiries	4	10	7	10	10	13	32	41	28	43	22	20	240	20
	# contacted re: a specific child	8	22	24	18	27	20	17	13	19	14	17	20	219 ⁹	18
Support family provider	# of allies and partners	12	12	12	12	12	12	13	13	13	15	15	15	15	13
	# contacted re: a specific child	26	31	31	33	27	38	27	22	30	32	29	21	347	29

⁷ These YTD totals include duplicated counts.

⁸ These YTD totals include duplicated counts.

⁹ These YTD totals include duplicated counts.

Table 6. EveryChild's Contacts with Planners / Coordinators¹⁰ September 2007 – August 2008

Target	Sept. '07	Oct. '07	Nov. '07	Dec. '07	Jan. '08	Feb. '08	Mar. '08	Apr. '08	May '08	Jun. '08	Jul. '08	Aug. '08	12Month Average
DFPS	21	15	23	17	13	22	15	20	14	21	16	20	18
DADS	32	47	39	27	31	41	35	44	50	42	34	38	38
Facility providers	31	28	25	28	23	36	33	27	35	36	47	31	32
Total significant contacts (individuals)	84	90	87	72	67	99	83	91	99	99	97	89	88
Total MRAS represented by contacts (organizations)	21	22	20	15	17	19	15	15	18	17	15	17	18¹¹

¹⁰ This table indicates the number of contacts with planners/coordinators at the end of each month. As these are duplicated counts, they do not include yearly totals

¹¹ Rounded.

Table 7. EveryChild’s Contacts with Policy and Decision-Making Entities September 2007 – August 2008

Target	Sept. '07	Oct. '07	Nov. '07	Dec. '07	Jan. '08	Feb. '08	Mar. '08	Apr. '08	May '08	Jun. '08	Jul. '08	Aug. '08
HHSC												
Policy & Analysis			X	X	X		X	X	X	X	X	
Medicaid	X	X		X						X	X	
Health Coordination & Consumer Services			X	X	X	X	X	X	X	X	X	X
Regional Medicaid office				X		X						
Stakeholder meeting or workgroup	X									X	X	
DADS												
Policy & Innovation		X	X	X		X	X	X	X	X	X	X
Access & Intake	X	X	X	X	X	X	X	X	X	X	X	X
Provider Services	X	X	X	X	X	X	X	X	X	X	X	X
Regulatory Services	X								X			X
Stakeholder meeting or workgroup	X					X	X	X	X		X	X
Other						X						
DFPS												
Licensing						X						
DFPS Disability Specialist of CPS	X	X	X	X	X	X	X	X	X	X	X	X
Other										X		
DSHS	X	X			X	X						
Joint meetings with multiple state agencies	X		X	X	X		X			X		
Other									X	X	X	X
Children’s Policy Council	X	X	X	X	X	X	X	X	X			
Promoting Independence Advisory Committee	X	X	X	X	X	X	X	X	X	X	X	X

**Table 8. EveryChild’s Outreach Activities and Dissemination of Informational Materials
September 2007 - August 2008**

September 2007	<ul style="list-style-type: none"> • Ads and articles in community publications with circulation of 38,500 • Four presentations made to community groups with a total audience of 53 • Contacts with 10 community organizations
October 2007	<ul style="list-style-type: none"> • Ads in community publications with circulation of 34,000 • Distributed information and materials to 70 people at two conferences • Presentation to 40 people at two events • Contacts with 11 community organizations
November 2007	<ul style="list-style-type: none"> • Talked with 40 people at two conferences • Presentation to community group with audience of 35 • Ads or articles in community publications with circulation of over 34,000 • Contacts with 4 community organizations to solicit assistance in posting or circulating information about FBAs
December 2007	<ul style="list-style-type: none"> • Presentation to a community group with audience of 45 people • Contacts with 3 community organizations to solicit assistance in disseminating information about FBAs
January 2008	<ul style="list-style-type: none"> • Presentation to 20 Regional Managers of CSHCN at DSHS • Contacts with the 9 community organizations or groups to solicit assistance in disseminating information about FBAs • Hosted Project Advisory Committee for Texas Council for Developmental Disabilities
February 2008	<ul style="list-style-type: none"> • Presentation to 15 contractors of CSHCN at DSHS • Presentation to three community groups with total audiences of 47 individuals • Contact with 20 people at information meeting • Contacts with 9 community organizations • Distributed 365 informational items to community groups or posted in public locations
March 2008	<ul style="list-style-type: none"> • Contacts to 11 community organizations or businesses • Participated in 2 community informational fairs • Attended an interagency foster care provider association meeting • Ad in community newspaper distributed to 338 households • Distributed 505 informational items to community groups or posted in public locations
April 2008	<ul style="list-style-type: none"> • Contacts with 9 community organizations • Participated in 4 community informational fairs • Presentation to 35 members of Chamber of Commerce • Presentations at 2 community organization events • Hosted meeting with Project Advisory Committee of the DD Council • Attended interagency foster care provider association meeting • Ad in community newspaper distributed to 1867 households • Distributed 373 informational items to community groups or posted in public locations

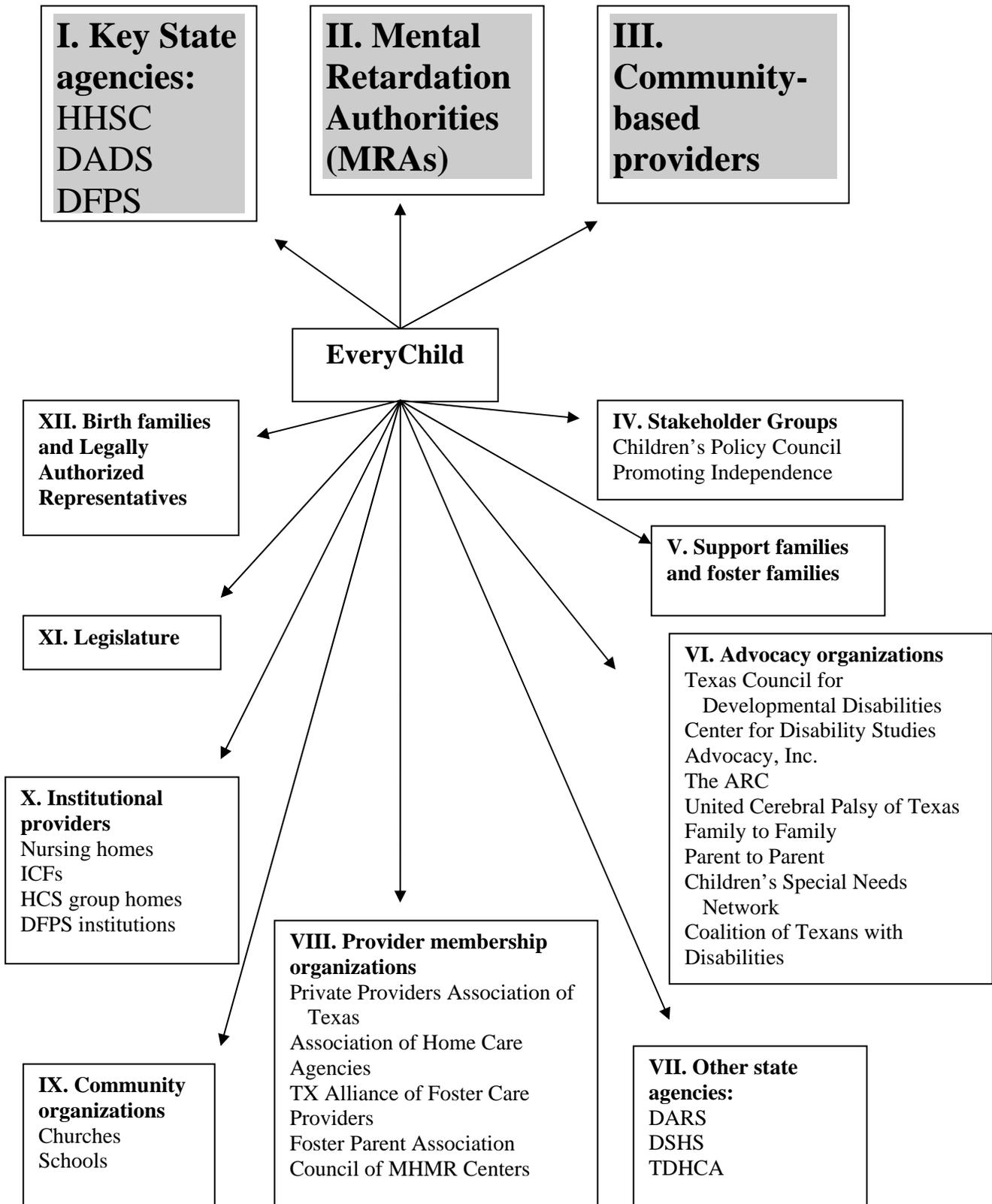
Table 8. (Continued) EveryChild’s Outreach Activities and Dissemination of Informational Materials September 2007 - August 2008

<p>May 2008</p>	<ul style="list-style-type: none"> • Contacts made with 24 individuals representing 14 community groups or businesses • Participated in 2 community informational meetings with total of 45 participants • Hosted community “meet and greet” event attended by 80 people • Presented to 35 members of Chamber of Commerce • Presented to 120 health care professionals at conference • Attended interagency foster care provider association meeting • Ads in community newspapers distributed to 1870 households • Distributed 402 informational items to community groups or or posted in public locations
<p>June 2008</p>	<ul style="list-style-type: none"> • Contacts with 20 individuals representing 15 community organizations • Presentations to 43 members of 2 community groups • Presentation to 90 staff of residential facility • Ads in community newspapers distributed to 2282 households • Distributed 260 informational times to community groups or posted in public locations • Hosted table at 2 community information fairs
<p>July 2008</p>	<ul style="list-style-type: none"> • Contacts made with 12 individuals representing 10 community organizations • Presentation to 15 members of community group • Participated in mixer hosted by Chamber of Commerce • Ads in community newspapers distributed to 1482 households • Distributed 153 informational items to community groups or posted in public locations • Hosted tables at 2 community information fairs • Participated in interagency foster care consortium • Hosted Project Advisory Committee for TCDD
<p>August 2008</p>	<ul style="list-style-type: none"> • Contacts with 19 individuals representing 16 community organizations • Presentation to 55 participants in a community resource fair for children with special needs • Ads in community newspapers distributed to 400 households • Distributed 175 informational items to community groups or posted in public locations • Hosted a table at community information fair

Table 9. Training, Technical Assistance and Consultation Provided by EveryChild – September 2007 to February 2008

Activity	September 2007	October 2007	November 2007	December 2007	January 2008	February 2008	March 2008	April 2008	May 2008	June 2008	July 2008	August 2008	12 Month Average
Technical assistance or consultation to organizations:													
SF Provider	32	35	42	32	33	38	32	34	28	31	33	25	33
MRA	21	22	20	15	17	19	15	18	18	17	15	17	18
Other (nursing, ISD DME, ILC, AI, therapist, day habilitation, etc.)	6	8	20	14	17	32	19	9	22	17	24	16	17
TOTAL organizations	59	65	82	61	67	89	66	61	68	65	72	58	68
Training:													
Provider staff and support families	23							47	19			26	
Community families, state agency staff, health care professionals		40	180										
CRCGs			35								25		
CSHCN staff					20	15							
TOTAL number trained	23	40	215		20	15	0	47	19	0	25	26	36

Appendix D: Network Map
Figure 1: Network Map



Organizational Affiliations of Individuals Routinely Engaged by EveryChild¹²

I.) Key State Agencies:

A. HHSC (Health and Human Services Commission)

- Health Coordination & Consumer Services
 - Program Coordination for Children and Youth Office of Health Services
 - TIFI/CRCG Office
- Policy Analysis & Program Coordination
- Medicaid/CHIP
 - TMHP Claims Administration Operations
 - Managed Care Operations
 - Policy Development and Support
 - Medicaid Long Term Care
- Office of Family Services
 - Medicaid for the Elderly and People with Disabilities

B. DADS (Department of Aging and Disability Services)

- Commissioner
 - Deputy Commissioner
 - Center for Policy and Innovation
 - Policy Development and Oversight
 - Quality Assurance and Improvement
 - Policy Analysis and Support
 - Long Term Care Policy
 - MFP Demonstration
 - Center for Consumer and External Affairs
 - Stakeholder Relations
 - Center for Program Coordination
 - Provider Services
 - Institutional Services
 - Policy Development and Support
 - Community Services
 - Policy Development and Support
 - Contracts
 - Waivers for Persons with MR & DD
 - Consumer Direction

¹² Sources of Organizational Charts:

HHSC: http://www.hhs.state.tx.us/OrgChart/HHS/HHSC_OrgChart.html

DADS: http://www.dads.state.tx.us/news_info/executives/dads_org.pdf

DSHS: <http://www.dshs.state.tx.us/orgchart/default.shtm>

DFPS: http://www.dfps.state.tx.us/Documents/About/Executives/DFPS_Org_Chart.pdf

- Survey and Certification
- State Schools
 - Management Support Oversight
 - Continuity & Service Coordination
- Access and Intake
 - MR Authorities
 - Local Procedure Development and Support
 - Program Enrollment
 - Utilization Review and Utilization Control
 - Guardianship
 - Oversight and Community Supports
 - Regional and Local Services
 - Program Enrollment
- Regulatory Services
 - Survey Operations
 - Waiver Survey & Certification
- Chief Operating Officer
 - Consumer Rights and Services
 - Consumer Rights/Surrogate/Decision Making

C. DFPS (Department of Family and Protective Services)

- Child Protective Services
 - CPS Support Manager
 - Director of Policy and Program
 - Children with Disabilities Program Specialist
 - Regional Directors
 - DD Specialists
 - Director of Special Services
- Adult Protective Services

II. MRAs 39 MRAs covering 254 counties

- Directors
 - Supervisors
 - Permanency planners
 - HCS Waiver enrollment
 - HCS Waiver case managers

III. Community-Based Providers

- Support Family Providers
 - Home and Community Services (HCS) (107 identified providers)
 - Community Living and Support Services (CLASS) (3 identified providers)
 - Child Placement Agency (CPA) (39 identified providers)
- Other Community Services (100+ providers)
 - Home and Community Support Services Agency
 - Nursing

- Community-Based Alternatives (CBA)
- Medically Dependent Children’s Program (MDCP)
- CLASS
 - Direct Service Agency (DSA)
 - Case management Agency (CMA)
- Durable Medical Equipment (DME)
- Independent Living Center--Relocation Specialists
- Individual Professional Specialists
- Independent School Districts

IV. Other State Agencies

A. DARS (Department of Assistive and Rehabilitative Services)

- Center for Consumer & External Affairs
- Stakeholder Relations
- Early Childhood Intervention

B. DSHS (Department of State Health Services)

- Division of Family & Community Health Services
 - Office of Title V & Family Health
 - Children with Special Health Care Needs (CSHCN)
 - Specialized Health Care Services
 - Health Screening/Case management
 - Children and Pregnant Women Case Management
 - Purchased Health Services Unit

C. TDHCA (Texas Department of Housing and Community Affairs)

- Community Affairs
 - Section 8 Housing
- Housing Resources Center

Appendix E: Tasks and Roles to Achieve Family-Based Alternatives

Table 10: Tasks and Roles to Achieve Family-Based Alternatives

Stage	Task/Role	Locus of Responsibility									
		EC	Permanency Planner	Waiver enroller	Mental Retardation Authorities	State Office	State DD Specialists	State Agencies	DFPS caseworkers	Community-based providers	Facilities
Identifying	Identify names of children in facilities	X				X					X
Screening	Gather information	X	X				X	X			
	Review previous permanency plans	X	X				X	X			
	Visit child	X						X			
	Initiate contact with parent/guardian	X	X								
Developing	Help parent/guardian imagine family-based alternative	X	X								
	Identify child’s needs	X	X					X			X
	Identify family’s preferences	X	X								
	Provide emotional support for parents	X									
	Determine interest in exploring options	X	X								
Exploring options	Identify funding for needed services	X	X								
	Explain funding and waiver options	X	X								
	Identify best-fitting waiver	X									
	Identify providers for needed services	X		X	X						
	Locate providers willing and able to provide needed services	X									
	Assist in selection of providers	X									
	Locate support families within provider organizations	X								X	
	Screen potential support families	X								X	
	Visit potential support families	X									
Transitioning	Arrange pre-placement visits	X									
	Assure all needed services and supports are arranged prior to placement	X									
	Coordinate enrollment in waiver	X		X							
	Develop individual plan of care	X								X	
	Follow-up and assure communication across all parties	X									
	Problem-solve barriers	X				X					
	Orchestrate discharge	X								X	X
Placement	Problem-solve post-placement issues	X								X	
	Assure all needed supports and services after placement	X								X	

Appendix F: Legislation and Policy Changes Affecting the Ability of Children with Disabilities to Move from Facilities to Families

FY 2002 (9/1/2001)

- **SB 368** – Permanency planning legislation for children with developmental disabilities residing in out of home shift staff settings. Allowed for the creation of the family-based alternatives project. Noted that institutionalization of children is temporary and that an appropriate chief executive officer or the officer’s designee approves an extension of an additional 6 months.
- **Rider 37 of the General Appropriation’s Bill (SB 1) - Promoting Independence** – This rider allowed children who were living in nursing homes to access one of the Texas Department of Human Services Medicaid waivers to move back home to family. The waivers that were made available to children were CLASS, MDCP and DB/MD. These waivers did not have a mechanism to pay for Support Families therefore children in nursing homes that needed Support Families were unable to move. *“It is the intent of the legislature that as clients relocate from nursing facilities to community care services, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services.”*

FY 2004 (9/1/2003)

- **Rider 7. b. (2) of the General Appropriation’s Bill Z(SB 1) - Nursing Home Program Provisions** – This rider allowed individuals who were receiving services in a Medicaid waiver through the Texas Department of Human Services to exceed the cost cap if they needed the extra services to remain living in the community. *“The department may not disallow or jeopardize community services for individuals currently receiving services under Medicaid waivers if those services are required for that individual to live in the most integrated setting and the exemption complies with the federal Health Care Financing Authority Centers for Medicare and Medicaid Service’s cost-effectiveness requirements.”*
- **Rider 28 of the General Appropriation’s Bill (SB 1) - Promoting Independence** - This rider was a continuation of rider 37 from the 77th Legislative Session. *“It is the intent of the legislature that as clients relocate from nursing facilities to community care services, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services”*

FY 2005 (9/1/2004)

- **Amendment to the Home and Community-Based Services (HCS) Medicaid waiver** adding a targeted eligibility group of 10 children in nursing homes to the waiver. The roll-out of the slots officially got underway in the spring of 2005.
- **Amendment to the Community Living and Support Services (CLASS) waiver** adding Support Family Services to the Medicaid waiver service array.

FY 2006 (9/1/2005)

- **Rider 18 of the General Appropriation's Bill (SB1) - Promoting Independence-Client Services.** This rider was a continuation of rider 37 from the 77th Legislative Session and Rider 28 from the 78th Legislative Session. *"It is the intent of the Legislature that as clients relocate from nursing facilities to community care services, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services."*
- **Rider 46 of the General Appropriation's Bill (SB1) - Promoting Community Services for Children.** This rider allowed funding for 50 children to move from small (6-bed) and medium (7-13 bed) Intermediate Care Facilities to move into the community. SB 627 was proposed to create a pilot project to allow 100 children living in small and medium ICF to access "money-follows-the-person" A proposed bill did not pass, so Rider 46 was added to SB 1. *"It is the intent of the Legislature, to provide opportunities for children (under the age of 22) residing in community intermediate care facilities for the mentally retarded to transition to families during the 2006-07 biennium. To facilitate such transitions when requested by parent/guardian, funding for up to 50 children residing in community intermediate care facilities for the mentally retarded may be transferred from the ICF/MR strategy to Community Care Services Strategies to cover the cost of the shift in services. The Executive Commissioner may develop rules that would allow decertification of the ICF/MR beds upon such transition to prevent additional costs being incurred."*
- **Rider 54 of the General Appropriation's Bill (SB1) – CPS Reform Plan.** This rider allowed over the course of the biennium for 62 children aging out of CPS foster care to receive HCS services. *"Out of funds appropriated in Strategy A.3.2, Home and Community-Based Services, \$1,182,270 in General Revenue Funds, and the associated federal funds, are set aside each fiscal year for children aging out of Foster Care."*
- **SB 626** – clarifies the ability of an individual in a Medicaid waiver to exceed the cost cap of the waiver if the services are necessary for the person to live in the most integrated setting. Individuals who were over the cost cap in 2005 may continue to exceed the cost cap and those that were not a part of that protected group may go up to 133% of the cost cap.
- **SB 40** - The bill requires that a party other than the institution where the child lives be responsible for permanency planning. The intent is to minimize the conflict of interest that is present when a facility is responsible for permanency planning for children in their facility. The bill allows for permanency planning to be done by the local mental retardation authority, a private entity other than an entity that provides long-term institutional care.
- **HB 2579** – requires that parents of children are given information about community services prior to placement in an institution. Also requires parents upon admission to provide contact information including driver's license number. Requires facilities to

notify the local MRA of a request for placement of a child in the institution. Requires facilities to notify DADS within 30 days of inability to locate the child's family and if after 1 year from that date, DADS is not able to locate the family, then CPS is notified and a referral is made. If CPS can't locate then they are to petition the court for temporary conservatorship.

- **HB 1867** – codified into law “money-follows-the-person” for individuals in nursing facilities to provide community-based services. This bill only applied to those individuals moving from nursing facilities to the community and only allowed access to the legacy Texas Department of Human Services waivers including CLASS, MDCP, CBA and DB/MD. The law was not applied to the HCS waiver.

FY 2008 (9/1/2007)

- **Rider 37 of the General Appropriation's Bill (SB1) - Promoting Independence Plan.** This rider continued Rider 54 of the 79th Legislative Session and increases to 120 the number of children over the biennium that can access HCS if they are aging out of CPS foster care. *“Out of funds appropriated above in Strategy A.3.2, Home and Community-based Services, \$1,699,464 in General Revenue Funds in fiscal year 2008 and \$4,859,969 in General Revenue Funds in fiscal year 2009, and the associated Federal Funds, are set aside from funds appropriated for interest list reduction, for 240 individuals moving out of large intermediate care facilities and 120 children aging out of foster care.”*
- **Rider 41 of the General Appropriation's Bill (SB1) - Services Under a 1915c Waiver.** This rider allowed children living in nursing facilities to access the Home and Community-Based Services (HCS) Medicaid waiver in addition to the waivers offered under previous riders and HB 1827. *“It is the intent of the Legislature that, from the funds appropriated above, the Department of Aging and Disability Services shall provide service under a Section 1915(c) waiver program, other than a nursing facility waiver program to an individual, 21 years and younger, leaving a nursing facility if the individual: a. meets the eligibility requirements for that Section 1915(c) waiver program; and b. in order to leave the nursing facility, requires services that are available only under that Section 1915(c) waiver program.”*
- **Rider 42 of the General Appropriation's Bill (SB1) - Services under HCS Waiver Program.** This rider allowed for children living in Intermediate Care Facilities to access other 1915(c) Medicaid waivers if they did not meet eligibility for the HCS Medicaid waiver. Children living in an ICF/MR and whose IQ is higher than 70 or 75 may access CLASS instead of HCS. *“It is the intent of the Legislature that, from the funds appropriated above, if an individual 21 years and younger, seeking to leave an intermediate care facility for the mentally retarded, has been offered services under the HCS (Home and Community-based Services) waiver program, the Department of Aging and Disability Services may provide services to the individual under another Section 1915(c) waiver program if the individual leaving the facility: a. is determined to be ineligible for the services provided under the HCS waiver program; and b. meets the*

eligibility requirements for and needs services provided under another Section 1915(c) waiver program.”

- **Rider 43 of the General Appropriation’s Bill (SB1) - Promoting Community Services for Children.** This rider was a continuation of Rider 46 from the 79th Legislative Session that allowed 50 children over the course of the biennium to move from small and medium Intermediate Care Facilities into the community using the HCS Medicaid waiver. *“It is the intent of the Legislature, out of funds appropriated above, to provide opportunities for children (under the age of 22) residing in community intermediate care facilities for the mentally retarded to transition to families during the 2008-09 biennium. To facilitate such transitions when requested by parent/guardian, funding for up to 50 children residing in community intermediate care facilities for the mentally retarded may be transferred from the Strategy A.7.1, Intermediate Care Facilities - MR, to Community Care Services strategies to cover the cost of the shift in services. The Executive Commissioner may develop rules that would allow decertification of the ICF/MR beds upon such transition to prevent additional costs being incurred.”*
- **Rider 45 of the General Appropriation’s Bill (SB1) - Waiver Program Cost Limits.** This rider raised the individual cost caps in the CLASS, HCS, CBA and DB/MD waiver to go up to 200 percent of the reimbursement rate that would have been paid for that same person to be served in a facility. Part b of the rider allowed individuals to exceed the newly established cost cap if there is no other available living arrangement in which the person’s health and safety can be protected and the person’s health and safety cannot be protected by the services provided within the individual cost cap.
- **Medicaid State Plan for Personal Care Services** – Texas implemented the new Personal Care Services benefit in the Medicaid state plan for children under the age of 21. Personal Care Services allow individuals to receive both delegated and non-delegated personal care services in their homes. The beneficiary group expanded to include children with cognitive and behavioral support needs.