

PERMANENCY PLANNING

TECHNICAL ASSISTANCE GUIDE



**Developed by EveryChild, Inc.
Family-Based Alternatives Contractor of
Health and Human Services Commission**

August 2017

TABLE OF CONTENTS

| | |
|--|----|
| PURPOSE | ii |
| | |
| I. OVERVIEW OF PERMANENCY PLANNING | |
| What is permanency planning? | 1 |
| The developmental basis for permanency | |
| Developmental benefits of family life | 1 |
| Developmental risks of facility living..... | 2 |
| The legislative basis for permanency planning | |
| The history of permanency planning policies..... | 2 |
| Permanency planning for children with developmental disabilities in Texas..... | 3 |
| Key elements of the Texas Government Code regarding permanency planning | 3 |
| Key elements of the Texas Government Code regarding family-based alternatives | 4 |
| Developing and implementing a system of family-based alternatives | 5 |
| | |
| II. GUIDANCE FOR DEVELOPING A PERMANENCY PLAN | |
| General guidelines | |
| The role of the permanency planner..... | 7 |
| Engaging families, legally authorized representatives, and young adults in exploring alternatives | |
| Building a relationship to enhance exploration | 8 |
| Decision-making..... | 8 |
| Imagining family life as an alternative to facility life | 10 |
| 1. Talking about returning home | 14 |
| 2. Talking about family life with another family | 17 |
| Achieving family life as an alternative to facility life | 22 |
| 1. Moving home | 23 |
| 2. Moving to another family | 25 |
| | |
| CLOSING | 29 |

PURPOSE

The purpose of this guide is to serve as a resource for individuals who are interested in permanency planning for children and youth with developmental disabilities served in the disabilities service system. The guide is intended to address children and young persons under the age of 22 with developmental disabilities who are not under the jurisdiction of the child protective services system. The guide is designed to first provide an understanding of permanency and then to provide specific suggestions for developing a permanency plan.

A WORD ABOUT LANGUAGE AND TERMINOLOGY

The guide uses the phrase “child or young adult” to assure attention is given to the distinction between minor children and young adults age 18 or older. The term “family/LAR/young person” is used to refer to the responsible decision-maker who may be a family member, a legally authorized representative (LAR), or a young adult over age 18 who does not have a legal guardian. The individual who is responsible for coordinating a permanency plan is referred to as the “permanency planner.”

ACKNOWLEDGEMENT

EveryChild, Inc., the Family-Based Alternatives Contractor for the Texas Health and Human Services Commission (HHSC), has developed this technical assistance guide. A companion HHSC *Permanency Planning Instruction Manual* is available that provides directions for completing the HHSC Permanency Planning forms and procedures. See Texas Health and Human Services Commission website hhsc.state.tx.us.

I OVERVIEW OF PERMANENCY PLANNING

This ***Permanency Planning Technical Assistance Guide*** is intended to help in understanding the role of permanency planning in enabling a child or young person with a developmental disability living in a facility or at risk of admission to achieve family life.

WHAT IS PERMANENCY PLANNING?

Permanency is the outcome intended by public policy to assure the emotional and physical security and continuity of family life for children who are unable to live with their parents and are served in a publicly supported out-of-home living arrangement. Permanency is based on two principles:

1. Children need the emotional security and continuity of a parental relationship.
2. Children need the physical security and continuity of a stable, safe living arrangement.

These needs are best met in a family.

Permanency planning is the process a service system uses to address a child's need for permanency. The planning task is to figure out how to achieve family life with its beneficial characteristics. The goal of permanency planning is to configure services and supports in such a way that they enable a child to experience a nurturing and enduring parental relationship in his or her daily life throughout childhood.

THE DEVELOPMENTAL BASIS FOR PERMANENCY

DEVELOPMENTAL BENEFITS OF FAMILY LIFE

We naturally think of children growing up in families. But more than just being typical, growing up in a family is developmentally necessary. The parent-child relationship is at the heart of family life. We know from child development experts and research evidence from studies of early childhood development, attachment, and comparisons of outcomes of various caregiving arrangements, that a parental relationship characterized as readily available, responsive, nurturing, reliable, and consistent over time provides developmental advantages for children. This parental relationship affects a child's sense of belonging and trust that affects his or her development in childhood and into adulthood. Permanency recognizes that a child's day-to-day experience of a positive parent-child relationship fulfills the developmental need for an enduring parental figure for healthy development.

Neuroscience research shows that parental nurturing and the resulting emotional attachment stimulates positive brain development in children. This research shows how the brain itself is shaped and changed by loving interaction, particularly in the early years of childhood. It shows how emotional interactions stimulate chemicals and neuron connections and reveals how caregiving patterns have a direct influence on the structure of the brain.

From a developmental perspective, the parent-child relationship is the “active ingredient” in optimal development. As development continues over the lifespan, the emotional foundation of childhood extends into adulthood. Permanency puts an emphasis on the developmental needs of childhood and directs activities to the assurance of family life anchored by a secure, responsive, and continuous parent relationship.

DEVELOPMENTAL RISKS OF FACILITY LIVING

Children with developmental disabilities are at higher risk of out-of-home placement than other children, and particularly at higher risk of placement in residential facilities. Permanency planning seeks to prevent facility admission or to enable children living in facilities to return to family life.

A family is much more than a caregiving arrangement. Infants and young children develop optimally through a specific relationship with a particular parenting figure. This relationship is not replicated by frequently changing caregivers. Research evidence suggests children raised in large congregate settings offering non-parental care by rotating shifts of caregivers experience poorer developmental outcomes compared to children raised in families.

Limitations are inherent in the very nature of congregate care facilities. Characteristics of congregate care that can be detrimental compared to family life include:

- Absence of a primary parental relationship
- Rotating shift care
- Turnover and understaffing

- Lack of continuity over time by an emotionally invested caregiver
- Competing caregiver demands of multiple children with similar needs
- Non-individualized caregiver responses to children
- Regimented daily schedules with limited spontaneity

Rotating caregivers in a shift-pattern of facility staffing, however affectionate, cannot replace the consistent nurturing parental figure required to fulfill the attachment bond necessary for a child’s optimal development. Like-wise, the countless opportunities for parental interaction in daily family life cannot be replaced by periodic visits of a parent to a facility.

THE LEGISLATIVE BASIS FOR PERMANENCY PLANNING

THE HISTORY OF PERMANENCY PLANNING POLICIES

Permanency planning has been a guiding policy in child protection services nationally since the 1970s and has been required by federal legislation since 1980. The *Adoption Assistance and Child Welfare Act of 1980* and its successors, the *Family Preservation and Family Support Act of 1993* and the *Adoption and Safe Families Act of 1997*, have mandated permanency planning for children in child protective service systems. The key principles of federal child protection laws require states to secure a safe and nurturing home for children with a permanent family in a timely manner. Current permanency efforts in child welfare systems focus on family preservation, family reunification, or adoption when parental rights have been terminated.

PERMANENCY PLANNING FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES IN TEXAS

Although permanency planning is not mandated by federal legislation in disability services systems which provide out-of-home placement for children outside the child protective services system, in Texas it is mandated by state legislation. Texas law underscores the importance of children with developmental disabilities living in a family by requiring permanency planning for each child living in an institution.

With the passing of Senate Bill 368 in the 77th Legislative Session in 2001, the Texas Health and Human Services Commission (HHSC) and designated health and human services agencies were charged by the state legislature with ensuring that a permanency plan is developed for each child with a developmental disability who resides in an institution in Texas. (See Government Code, Subchapter D, Sections 531.151 to 531.167.)

The law also requires the state to report semi-annually on permanency efforts. The results of permanency planning as documented in reports to the legislature have shown a steady decline in the use of facilities since 2002, especially ICF-IID facilities (Intermediate Care Facility for Individuals with Intellectual Disabilities or Related Conditions) and nursing facilities.

| Facility Use by Children under Age 22 since Permanency Legislation | Decrease between 2002 and 2016 |
|---|---------------------------------------|
| Nursing facilities | 68% |
| Large ICFs | 93% |
| State Supported Living Centers | 24% |

KEY ELEMENTS OF THE TEXAS GOVERNMENT CODE REGARDING PERMANENCY PLANNING

Following are excerpts from the Texas Government Code developed to implement the permanency legislation.

■ Permanency planning is defined as “a philosophy and planning process that focuses on the outcome of family support by facilitating a permanent living arrangement with the primary feature of an enduring and nurturing parental relationship.” (Section 531.151)

■ “It is the policy of the state to strive to ensure that the basic needs for safety, security, and stability are met for each child in Texas. A successful family is the most efficient and effective way to meet those needs. The state and local communities must work together to provide encouragement and support for well-functioning families and ensure that each child receives the benefits of being a part of a successful permanent family as soon as possible.” (Section 531.152)

■ A “child” is defined as a person with a developmental disability who is younger than 22 years of age. (Section 531.151)

■ “Institutions” are designated (Section 531.151) to include:

- An Intermediate Care Facility for Individuals with Intellectual Disabilities or Related Conditions (ICF/IID)
- A nursing facility
- A group home operated under the authority of a Medicaid waiver program
- An institution for individuals with intellectual disabilities licensed by the Department of Family and Protective Services

■ Preadmission information is required to be provided to ensure parents or guardians are fully informed of all community-based services and supports (Section 531.1521). The development of comprehensive information is required for parents or guardians considering placing a child in an institution to explain:

- The options for community-based services
- The benefits to the child of living in a family
- That placement of the child in an institution is considered temporary
- The requirement for an ongoing permanency planning process

■ Placing the child's name on a waiting/ interest list for waiver program services is required after notice of placement in an institution (Section 531.157).

■ An offer of services is required (Section 531.155). Each entity receiving notice of the initial placement of a child in an institution may contact the child's parent or guardian to ensure that the parent or guardian is aware of:

- Services and support that could provide alternatives to placement of the child in the institution
- Available placement options
- Opportunities for permanency planning

■ Monitoring of permanency planning efforts (Section 531.159) and permanency reporting (Section 531.162) are required. HHSC monitors placements to ensure ongoing permanency planning for each child and submits semi-annual reports to the legislature.

KEY ELEMENTS OF THE TEXAS GOVERNMENT CODE REGARDING FAMILY-BASED ALTERNATIVES

An important mechanism to assure permanency for children with developmental disabilities is the availability of a system of **"family-based alternatives"** to facilities for situations where children are unable to live with their own families. The Texas permanency planning legislation requires the development and implementation of a system under which a child who cannot reside with the child's birth family may receive necessary services in a family-based alternative instead of an institution. Key elements of the Texas Government Code, Subchapter D, Section 531.060 include:

■ "Family-based alternative" means a family setting in which the family provider or providers are specially trained to provide support and in-home care for children with disabilities or children who are medically fragile.

■ "The purpose of a system of family-based alternatives is to further the state's policy of providing for a child's basic needs for safety, security, and stability through ensuring that a child becomes a part of a successful permanent family as soon as possible."

■ "The system shall encourage parents to participate in all decisions affecting their children and shall respect the authority of parents, other than parents whose parental rights have been terminated, to make decisions regarding their children."

- “The system must provide for:
 1. recruiting and training alternative families to provide services for children;
 2. comprehensively assessing each child in need of services and each alternative family available to provide services, as necessary, to identify the most appropriate alternative family for placement of the child;
 3. providing to a child’s parents or guardian information regarding the availability of a family-based alternative;
 4. identifying each child residing in an institution and offering support services, including waiver services, that would enable the child to return to the child’s birth family or be placed in a family-based alternative; and
 5. determining through a child’s permanency plan other circumstances in which the child must be offered waiver services, including circumstances in which changes in an institution’s status affect the child’s placement or the quality of services received by the child.”

■ “In placing a child in a family-based alternative, the system may use a variety of placement options, including an arrangement in which shared parenting occurs between the alternative family and the child’s birth family.”

■ “Regardless of the option used, a family-based alternative placement must be designed to be a long-term arrangement, except in cases in which the child’s birth family chooses to return the child to their home.”

DEVELOPING AND IMPLEMENTING A SYSTEM OF FAMILY-BASED ALTERNATIVES

The Texas Health and Human Services Commission has contracted with EveryChild, Inc. since 2002 to assist in the development and implementation of a system of family-based alternatives. (See EveryChild’s website at everychildtexas.org.)

The first priority of permanency planning is energetic and creative exploration of supports to enable families to resume care of their children who are living in facilities. Where that is not possible, permanency planning seeks the possibility of family life with another family, i.e., a family-based alternative.

Assuring permanency requires service systems to develop and promote family-based alternatives to facilities. Recruiting families for children who cannot remain at home provides them the opportunity to live with another family and provides a developmentally sound alternative to the limitations of residential facility care.

Development and implementation of a system that assures family life, operates on the following principles:

1. It is generally in the best interest of children to remain at home with their family with adequate supports.
2. Remaining at home may be contingent on having adequate family support.
3. Long-term living in a congregate care facility is not an appropriate permanency planning option when a child cannot remain at home.

I. OVERVIEW OF PERMANENCY PLANNING

4. When placement in a residential facility has occurred, the provision and coordination of services and supports that will facilitate reunification of the child with his or her family (including extended family) should be given priority attention.
5. If a child cannot return home, priority attention should be given to finding another family home in which the family is prepared to provide care and support on a long-term basis.
6. Moving to another family is contingent on effective recruitment and available families having adequate support.
7. Finding the right alternate family depends on an effective matching process that takes into account the child's needs, the preferences of the child's family, and the preferences and capabilities of the alternate family.
8. Engaging families who have placed their children in facilities in exploring ways to enable family life requires helping them imagine the possibility and providing them the assistance needed to achieve it.
9. The specific elements of a permanency plan to achieve family life must be tailored to the individual circumstances of each child and family.

The policies and principles outlined so far provide the context for permanency planning. Guidance for developing an individual permanency plan is provided in the next Section.

II GUIDANCE FOR DEVELOPING A PERMANENCY PLAN

GENERAL GUIDELINES

Permanency planning focuses on the outcome of family life—a permanent living arrangement with the primary feature of an enduring and nurturing parental relationship. Permanency planning is not a single event or meeting—it is a goal-directed process that occurs over time.

Permanency planning involves:

- Understanding the child’s developmental, social, emotional, cognitive, physical, and mental health needs; history; and current and past relationships.
- Engaging the family/LAR/young person in exploring the benefits of family life and ways to achieve it.
- Helping the family/LAR/young person to imagine family life as an alternative to facility care.
- Determining goals and preferences and envisioning the specific services and supports needed to enable living with a family.
- Identifying actions to achieve family life by activating access to needed services and supports and providing for a careful transition from a facility to a family.

Permanency planning for children and young persons with developmental disabilities under age 22 begins when admission to a facility has occurred or is sought, and continues with at least semiannual reviews until the age of 22 as long as the child remains living in a facility.

THE ROLE OF THE PERMANENCY PLANNER

Permanency planning requires a joint effort between families/LARs/young persons and representatives of state services. While one individual is designated as a permanency

planner with responsibility for developing a plan, permanency planning is not done by a single person in a single encounter. The process involves multiple contacts with multiple parties over time.

The permanency planner is responsible for developing the plan. This requires engaging others in both *gathering* and *providing* information and viewpoints. Importantly, exchanging information involves both facts and ideas and perspectives. Information and viewpoints may be gathered from meeting and observing the child or young adult, reviewing records, and talking with the family/LAR and significant others, and current, past, or prospective caregivers or service providers. Information and viewpoints also need to be provided to the family/LAR/young person about the benefits of family life, family living options as alternatives to facility living, and services and supports that can enable family life.

Permanency planning is not intended to substitute for requirements for the individualized planning for services and supports required for residents of a facility or a Medicaid supported home and community-based living arrangement. Permanency planning and individual service planning should be integrated with each other.

HHSC has developed the Permanency Planning Instrument (PPI) form for documentation of permanency planning. (See ***HHSC Permanency Planning Instruction Manual*** at hhsc.state.tx.us.) The permanency planner is responsible for completing the PPI based on record reviews, observations, and conversations with the family/LAR/young person and relevant others.

ENGAGING FAMILIES, LEGALLY AUTHORIZED REPRESENTATIVES, AND YOUNG ADULTS IN EXPLORING ALTERNATIVES

Engaging families, LARs, and young persons in exploring family life as an alternative to facility life is at the heart of permanency planning.

BUILDING A RELATIONSHIP TO ENHANCE EXPLORATION

Helping families/LARs/young persons to consider an alternative to the facility requires permanency planners to build a trusting relationship to encourage exploring options. Trust comes from engaging in active listening and respectful interaction, honoring their experiences, providing useful information, being approachable and friendly, remaining engaged over time, working hard on their behalf, persevering and problem-solving in the face of obstacles, attending to details, and inspiring a realistic expectation of success.

Permanency planners need to be, or become, familiar with the child or young adult, with their family/LAR, and with possible services and supports to be able to share meaningful information and effectively explore options with families/LARs/young persons. Permanency planners need to fully understand the family/LAR/young person's perspectives to be able to find alternatives that fit their views, but also need to fully understand the possibilities for family life that can be created to be able to help them grapple with their concerns and envision solutions.

Whenever possible, discussions with the family/LAR/young person should be done in person. However, when not possible, every effort should be made to enable participation by other means

of personal communication (e.g. phone, videoconferencing, or email).

The permanency planner should make every effort to explain permanency planning in a way that encourages families/LARs to participate. The permanency planner's relationship with the family/LAR as a trusted guide is critical to their discovery and understanding of the possibilities for achieving family life.

DECISION-MAKING

Permanency planning respects the decision-making authority of families, legally authorized representatives, and young adults without guardians. Informed decision-making requires:

1. Knowledge about what is important to and for the child or young adult, and
2. Understanding the benefits and availability of services and supports for family living arrangements.

Permanency planning should incorporate the principles and practices of self-determination. This means that children and young adults should be engaged and their views solicited to understand the life-style they prefer. Young adults over age 18 should be assumed to be competent to make decisions unless a guardian has been appointed. Even when authority for decisions is held by a parent or guardian, every effort should be made to include and honor the wishes of the child or young person. For young adults who do not have a guardian, a volunteer advocate may be engaged to assist them in understanding their options and making decisions. For children under the conservatorship of the child welfare system, the child protective services (CPS) caseworker serves as the LAR in the planning process. The CPS caseworker will determine, based on court direction, whether or not the family of the child may participate in the planning process.

Tips & Considerations

FOR ENGAGING FAMILIES/ LARS/YOUNG ADULTS

- Families/LARs/young persons will be more inclined to consider the idea of an alternative to the facility if they can work with a permanency planner who they believe understands them.
- Considering the possibility of change requires much more than information. It requires intentional, thoughtful, guided exploration of new or different ideas and sometimes challenging previously held ideas.
- Understanding and being able to inform families/LARs/young persons about alternatives will be difficult for permanency planners who have not had experience with family-based options. Inability to present an accurate and complete picture of family-based options influences whether families/LARs/young people see them as viable. In particular, permanency planners should be knowledgeable about services available through Medicaid and Medicaid waivers including the host family service option in the Home and Community-based Services (HCS) Waiver.
- Systems are complex and can be difficult to navigate. Families often need help from someone who has the time, energy, know-how, and persistence to figure out how to “work the system” to achieve a family living option.

Experience has shown that moves of children from facilities to family homes become the preferred choice under three conditions:

1. When families have access to adequate services and supports.
2. When system representatives collaborate to provide access, and remove barriers to needed services and supports.
3. When someone who is knowledgeable and capable actively assists families in imagining alternatives and exploring how to achieve them.

The role of the permanency planner in fulfilling the third condition is critical.

“My daughter’s living in a facility was weighing heavy on my heart. I didn’t know what to do. Then when I met you, it was an answer to my prayers. I had talked with a service coordinator before who told me about waivers, but I didn’t understand that a waiver meant I could choose a family. She gave me this list of providers and it’s twenty pages thick! I mean, how are you supposed to know? With you, I could actually understand everything. You were with me every step to find a family that will be good for my child. You will always be treasured by our family.”

Because of the central role of the family/LAR/young person in permanency planning, extensive guidance is provided below for how to engage them in understanding options for family life and how to achieve it. First are suggestions for talking about family life in general, followed by separate specific suggestions for talking about each of the pathways to family life—returning home or moving to an alternate family.

IMAGINING FAMILY LIFE AS AN ALTERNATIVE TO FACILITY LIFE

Families/LARs/young persons may have a range of perspectives about other living arrangements. Some families/LARs/young persons are comfortable with the current facility living arrangement. Others prefer a change. Permanency planning begins with “meeting them where they’re at.” The task of permanency planning is simultaneously to respect past or current decisions while also facilitating reconsideration of family life. Deeply understanding the family/LAR/young person’s perspectives can provide clues about how to facilitate achievement of family life as soon as possible.

Families/LARs/young persons may be uninformed or misinformed about the risks of facility living compared to the benefits of family life.

Davon was placed by his mother in a pediatric nursing facility at the age of four on the recommendation of the family doctor. When he was ten, permanency planning was instituted and the benefits of family life and the support available to support it were explained to her. She hadn’t understood there was a downside to facility life in ever-changing staff. She elected to take him home. When asked why she hadn’t taken him home earlier, she replied simply, “Nobody asked.” She said she felt she was being responsible by following a professional recommendation for specialized care in a specialized place and no one had suggested otherwise.

Tips & Considerations

FOR IMAGINING FAMILY ALTERNATIVES

- Families/LARs/young persons will be more likely to choose return home or a family-based alternative to facility care when they believe that the benefits of a change outweigh the current facility living arrangement.
- Family life needs to be seen by families/LARs/young persons as realistic, not just an abstract idea. They need to be able to imagine that family life is feasible.
- Families may not initiate or welcome consideration of an alternative to the facility. They may be too leery or too weary to consider a change after the emotionally charged decision they made to place their child, or they may finally feel settled after a difficult time.
- Families/LARs/young persons will be more likely to choose family life instead of facility care when they are assured access to good, reliable supports for return home or well-qualified alternate families from whom to choose when return home isn’t possible.

Individuals serving as LARs who are not family members, such as public guardians serving multiple individuals, may not know the child or young adult or their history well if they have not spent significant time with them. Non-family LARs who are part of the public service system may not necessarily be aware of family-based options. They may be more familiar with group living arrangements than family supports or alternate families. Like families, non-family LARs may have concerns about disrupting a child or young adult, especially one who has lived in a facility for a long time. Non-family LARs will be more likely to opt for alternate family living arrangements if they have experience with, or can become familiar with, their feasibility and benefits.

*Maria was employed by the program that provides guardians for adults when no family member is available. She had three years of experience as a case manager for individuals with intellectual disabilities living in group homes. She participated in the permanency plan for **Anthony**, a 19-year-old young man living in a large ICF. She was familiar with other young adults with similar behavioral support needs who lived in group homes but she had not seen host family situations caring for similar individuals. She knew Anthony could not return home, but she was uncertain whether it was feasible for Anthony to live successfully with another family so she was reluctant to consider it. After the permanency planner introduced her to some alternate families, she began to see the potential benefit for Anthony.*

Young persons who are unable to return home may have had little experience or exposure to other living arrangements, especially to alternate families. In addition, they may be influenced by staff of the facility who likewise may have minimal experience or exposure. Young adults may be hesitant to make a change in their living arrangement, especially if they have lived in a facility for a long time. Conversely, they may be hesitant about a change if they have moved recently or have had frequent moves in the past. Young adults who cannot return home will be more likely to opt for alternate families if they can become familiar with their benefits.

***Michael** was 18 years old and living in a large ICF facility. He had moved there from his mother's home because he wanted to be independent. Through permanency planning, he learned about other alternatives. He was offered the opportunity to visit small group homes and host families. One of the families he met was Sharon and her young adult son and teenage daughter. They "clicked" immediately. He could see how they shared his interests and perspective about becoming an independent adult while also enjoying the warmth and encouragement of a family environment. Michael chose to live with Sharon's family and has stayed for ten years. Since then he has taken classes at the community college, gotten a job, made friends, and volunteered in the community. He still loves coming home.*

II. GUIDANCE FOR DEVELOPING A PERMANENCY PLAN

Permanency planning for children and young adults currently living in facilities will require revisiting previous decisions and choices with sensitivity and respect in order to open consideration of different alternatives. It can be helpful to think of decision-makers as falling along a continuum of comfort with alternatives to the facility. Your approach should reflect where the family/LAR/young person falls along the continuum.

ACTIVITIES RELATED TO FAMILY/LAR/YOUNG PERSON COMFORT WITH FAMILY-BASED OPTIONS

| | | ← CONTINUUM → | | |
|---|--------------------------|---|---|---|
| COMFORT WITH FAMILY-BASED OPTIONS: | | Unwilling to consider moving to a family | Uncertain about family life but willing to explore | Prefers return home or move to alternate family |
| | GENERAL APPROACH: | Help family/LAR/young person sustain relationships and participation in permanency planning | Help family/LAR/young person to imagine possibilities and learn more about family options | Help family/LAR/young person know about and connect to services and supports to achieve family life |

Seth is an active 13-year-old with a profound intellectual disability and autism. He has a history of challenging behavior including being agitated and disruptive and sometimes striking out. As a result, he needs constant supervision and support. In seeking help, his family faced a years-long waiting list for support at home but found that placement in an ICF was readily available. After placement, Seth's parents were offered permanency planning and a Medicaid waiver to access community-based services and supports. The permanency planner helped his family to see how waiver resources could be used to provide staff trained in behavior support to help in their home with direction from a behavior support specialist. Seth's family was able to bring him home with the supports they needed.

Gaining support of families/LARs/young persons for consideration of a goal of family life will likely be the result of multiple factors. Motivation to change a previous decision for facility placement to a decision for family living (either returning home or moving to another family) can come from two major sources:

1. **System changes.** Changes may have occurred in available options since the initial placement. For example, there may now be more family supports to enable return home or increased availability of alternate families. Changes may also have occurred in the way families are engaged in discussion of alternatives. There may be more regular opportunities to explore options since placement and availability of a trusted guide to explore possible alternatives to a facility.

2. Family changes. Changes may have occurred in family circumstances or the make-up of the family household (e.g., remarriage or siblings grown and moved out). Changes may reflect decreased parental responsibilities (e.g., siblings older) or changes in family perspectives (e.g., decreased satisfaction with the facility, increased exposure to other possibilities, or awareness of other families with positive experience with alternatives).

Jessica is beautiful 13-year-old with complex medical needs. She uses a ventilator and is fed by a gastrostomy tube. When she lived at home, her mother struggled to manage Jessica's needs, coordinate home nursing schedules, attend school, and meet the needs of Jessica's younger sibling. Jessica was placed in a nursing facility. While Jessica lived in the facility, her mother completed her degree, was divorced, and remarried. With a new home and supportive husband, she was ready to explore bringing Jessica home.

Whether the family/LAR/young person's view is one of total satisfaction with the current facility or less, the strategy is to explore how to improve life for the child or young adult. The logic goes something like this:

If you found something better, wouldn't you want it? Wouldn't you hate to learn that there was something out there that was better and nobody told you about it? To be better, I know it has to offer things that you value more than the current arrangement. I'd like to help you consider whether there is something better.

You can put such an invitation in your own words. For a family/LAR/young person inclined to maintain the current facility living arrangement, you can then invite an open-ended response that honors that preference. For example:

Tell me what it is about this living arrangement that works for you and your child.

You may hear answers such as:

- *I feel secure. I know my child is safe.*
- *My daughter is comfortable. She seems happy.*
- *I have access to medical and specialized support.*
- *I like the staff. They understand my son and his disability.*

Once you get an understanding of what they like you can reflect and confirm:

Everything you've mentioned makes sense. These are things I'd want for myself or my child. Let's begin to look at how it might be possible to have those desirable things in a different living arrangement and whether it's also possible to have other desirable things that aren't available in the facility.

By positioning your conversation this way, you may open the door to consideration of family living. The point is not that a skeptical family will change their view in a single conversation, but that the possibility of thinking differently might open up exploration.

The next two sections will look at the two pathways to family living in more detail. Following are separate sections with guidance for talking about (1) returning home and (2) moving to another family's home.

1. TALKING ABOUT RETURNING HOME

Considering return home is essentially about envisioning the kind of support that would make home life feasible. The work at this stage is not to *plan* return home but rather to *imagine* successful return home. At this point you should not be first presenting a list of services or programs or providers or funding sources—rather you are seeking to understand what would enable the possibility of return home. You need to help the family visualize what would be supportive before you figure out how it can be provided. This means resisting the impulse to start with available services and providers.

Talking with a family about the possibility of their child returning home to live will be met with a variety of responses from families. It may well be emotionally charged. Most families will express the wish that their child could come home—the task is to sort out whether that is a feasible option or a dream they desire but don't view as realistically achievable. Some families will be very clear about what they need to enable them to consider their child coming home. In those cases, the task will be trying to find ways to get the right services and supports to the family. For other families, the sincerity of their wish to have their child return home will not (or at least not yet) be expressed in terms of a set of concrete identifiable services and supports. In those cases, the task will be trying to help the family become clearer about what it would take for their child to return home.

It is useful to think about engaging the family in a conversation rather than conducting a survey. Instead of asking

Tips & Considerations

WHEN TALKING ABOUT RETURN HOME

- Families may be skeptical about the idea of their child returning home, especially if they were unable to get the kind of support they needed before they sought placement. They may view returning home as re-experiencing the difficulties that led to placement. Consideration of return home will be dependent on their coming to believe that services and supports are more readily available or more reliable now than then.
- The possibility of a child returning home is directly related to the match between the family's perceived needs and the availability of services and supports. Families will be more likely to opt for return home if they can see how resources can solve the problems that led them to place their children.
- Support for returning home needs to be realistic and include the right kind of services and supports, in the right quantity or frequency, reliably delivered, amenable to change as needed, and sustainable over time.

closed-ended questions (e.g., *Do you want your child to return home?*), asking open-ended questions can be more conducive to exploring possibilities.

The starting point of the discussion needs to be an open invitation posed in such a way that it doesn't seem judgmental.

II. GUIDANCE FOR DEVELOPING A PERMANENCY PLAN

One way to open the topic of return home is to follow up on a discussion about what led to placement out of the family home and satisfaction since then. Questions that logically flow from those circumstances can be posed in a way that acknowledges experiences then and since. The discussion should serve as an opportunity for the family to feel heard and understood. Depending on their description of what led to placement, an approach might be to first reflect and acknowledge their experience and then introduce a related open-ended follow-up question. For example:

Wow, it sounds like you really had your hands full. It seems like you've been pretty happy with the facility for your son. What is it you like best and least about your son living in the facility?

It sounds like the facility was there when you needed it. But it seems like you are pretty unhappy that a facility was your only option. What are some things about your situation at home that are different now?

These kinds of questions won't necessarily tell you directly that a family prefers bringing their child home, but they can give you leads to follow up.

Helping families to understand available services and supports is necessary but is not a discussion to be had only *after* a decision to bring their child home. Rather, it may be the motivation that *precedes* the decision. While the family should be provided with written informational materials, they need much more than a list of services and providers. They need a discussion that is tailored so they can see how services and supports can be put together to fit their specific situation. The discussion can be thought of as discovering the kinds of *people, things, and arrangements* that could help. Discussion of *people* includes identifying others who can provide hands-on assistance in the home or offer particular kinds of expertise such as nurses, behavior support specialists, or physical therapists. Discussion of *things* can include housing, home modifications, furnishings, equipment, supplies, and adaptive devices. Discussion of *arrangements* can include coordination, training, respite, or financial support.

***Raul** is a handsome 15-year-old with a mild intellectual disability, attention deficit and hyperactivity disorder, and a mental health diagnosis of Oppositional Defiant Disorder. He was placed in a State Supported Living Center (SSLC) at the age of 12 after several incidents of hitting a teacher. Permanency planning began with admission. His family wanted him to come home but knew that something had to change. The SSLC interdisciplinary team developed behavior support strategies that could be used in the community and recommended placement in a group home instead of return home. Raul was placed in a group home through a Medicaid waiver. The permanency planner continued to pursue family life. She met with Raul's mother and his extended family to help them visualize what might be possible. Together they began to see a realistic possibility where Raul and his mother moved in with her sister's family to help each other out. Family members learned about effective behavioral supports. They learned how the waiver could bring supports and services into the shared family home. Raul was successfully reunited with his extended family.*

II. GUIDANCE FOR DEVELOPING A PERMANENCY PLAN

It can be useful to pose "What if" questions to open a discussion that suggests possible kinds of supports that might enable return home. For example:

You describe how difficult it was to lift and carry your daughter as she got older. What if you could have equipment that could do the lifting for you?

It sounds like you are comfortable that staff know how to work with your son but you miss being able to see him regularly. What if you could have staff who were as competent as the staff in the facility who could come to your home?

Your task in these discussions is to tap into meaningful possibilities.



Next Steps... Families responses to the discussion so far will vary from readiness to return home, to having reservations, to being reluctant.

If the family expresses *readiness* for their child to come home and describes what they need, even if tentative, then the next step is to engage them and others in figuring out together what specific resources exist and what it would take for their child to return home. (See the section on "Moving Home" below.)

If the family expresses *reservations*, then the next step might be identifying how to help them gently continue to explore possibilities. Rather than trying to get a final decision in a single conversation, it might be more productive to say something like:

It sounds like there are lots of things to think about as you're considering your child's future and your own. You don't have to make a decision today. I'd like to help you in thinking this through. I know some people who might be helpful for you to talk to. I also know some families who could describe their experience with their child returning home. What if I introduce you?

Tim is a 16-year-old with autism and a severe intellectual disability. He is very active and needs constant vigilant supervision because of his lack of safety skills. His parents struggled with his need for constant supervision while also caring for his four siblings. He was placed in a large ICF facility. In permanency plan reviews his parents indicated they believed the facility was the only setting that could serve their son. They didn't see how it was possible for him to live at home. Then the facility announced it was closing. Faced with the need to find another placement, his family reconsidered options that had been introduced but dismissed in previous permanency planning. They felt Tim needed someone to work directly with him who understood his challenging behavior and dual diagnoses. The permanency planner helped the family to see how competent staff could come to their home and work as part of a team in coordination with his clinicians and school staff. This option had been available while Tim lived in the facility, but the imminent closure led to reconsideration of his living arrangement and willingness to consider alternatives. His mother now says, "I wish I had listened earlier. Thank you for not giving up on me."

If the family feels *reluctant* about return home, then the topic of another family caring for their child should be opened. (See “Talking about Family Life with Another Family” in the following section).

The goal of the discussion about returning home should be to open the door to further dialog and activities rather than close the door until the next permanency plan review. If the family is unwilling to entertain any options other than the facility, then the conversation can focus on figuring out how to help them be as engaged as possible in their child’s life.

2. TALKING ABOUT FAMILY LIFE WITH ANOTHER FAMILY

Exploring the possibility of another family is essentially about helping a family/LAR/young person to envision how it would be beneficial and how it would work. The task at this stage is not to *plan* moving to another family, but rather to *imagine* another family as a successful living arrangement. At this point you need to help the family/LAR/young person visualize another family with whom they would be comfortable.

The idea of another family may be greeted with a range of responses. Most families will express that they wish their child could come home but when that is not realistically possible in the relatively near future, the permanency planning task is to explore how their child would be able to enjoy family life with another family. Some families whose circumstances prevent them from resuming care of their child may find the idea of their child living with another family appealing. In those cases, the task is to find the right alternate family. Other families may be hesitant, skeptical, or

outright opposed to another family caring for their child. In those circumstances the task is to gently explore and address their concerns.

Experience with many families who have faced consideration of another family as an alternative to a facility has shown that agreeing to an alternate family is dependent on three conditions:

1. Availability of alternate families who are carefully assessed, selected, trained, and prepared to care for children with developmental disabilities.
2. Understanding that parents do not lose their rights by placement with an alternate family and can remain engaged in the child’s life.
3. Understanding that families/LARs/young persons can choose the particular family who will provide care.

It will be important to pay attention to terminology when talking about another family caring for a child. How another family is presented, and the terms used to do so, will influence willingness to consider it as an option. For the discussion here, the term “alternate family” is used to distinguish it from the child or young person’s family. The term “family-based alternative” is used to distinguish an alternative to a facility. Neither are terms that families may find appealing. The term “foster care” applies only in the context of child welfare custody. An alternate family living arrangement in the disability services system is different from traditional foster care. The term “host family” is used to reference the waiver service arrangement that supports another family.

Tips & Considerations

WHEN TALKING ABOUT ALTERNATE FAMILIES

- Families may be skeptical about another family caring for their child. They may worry that another family's ability or desire to care for their child is a negative reflection on their own parenting. They may worry about the motivation of another family.
- Alternate families need to be seen by families/LARs/young persons as providing a similar or better quality of care as they believe the facility provides. The qualities of a particular alternate family need to be obvious to the family/LAR/young person.
- Families/LARs and young adults who cannot return home will be more likely to opt for alternate family living arrangements if they can become familiar with their benefits through interactions with others who have chosen them or through extended visits with a proposed family before making a decision.
- Families may believe an alternate family means foster care, even if that term is not used. The idea of foster care and the child welfare system where it is used, may elicit negative reactions from families. It is important to help families understand how an alternate family is different in that they maintain their parental rights and can remain actively engaged in their child's life.
- EveryChild, Inc. is available to help. The organization has many years of experience in connecting families and alternate families that has enabled many children with developmental disabilities to move from facilities to alternate family homes.

Bryan is an adorable 10-year-old who was born with multiple disabilities and complex medical needs. He was placed directly from the hospital in a nursing facility far from his family. His parents wanted him to return home but struggled with housing, finding a job, and not speaking English. The doctor at the nephrology clinic seeing Bryan suggested he would do well in medical foster care like other children he treated. Bryan's father feared that meant giving up his son. The permanency planner met with the family in their home along with a Spanish-speaking service coordinator. Bryan's worried father was only willing to consider another family when he was assured they were not trying to take his son from him. He challenged the permanency planner to "Show me." She took him to visit several host families. When he met one Spanish-speaking family, they hit it off right away. It was clear the family would welcome Bryan's family's involvement. Bryan was able to move and the two families have become like one big extended family. They get together regularly and share the ordinary activities of daily life, like when Bryan's two dads took him to get his first "big boy buzz" haircut. For Bryan's family, the care of another family did not mean losing their son—it meant gaining a closer place in his life.

Sheldon is an affectionate 14 year old with a profound intellectual disability. He is dependent for all his care needs and uses a wheelchair for mobility. Sheldon's mother is a widow with serious health conditions which leave her too frail to lift and care for her son. He was placed in a large ICF facility prior to the permanency planning legislation. Sheldon was subsequently offered permanency planning. When his mother learned about the possibility of a host family she said, "I think that sounds great. Nobody told me there were families who could do this. If he can't live with me, I would rather have him with a family." She was able to choose a family close to her home to care for her son.

For families/LARs/young persons who are ready to find an alternate family, see the section on "Moving to Another Family" below.

For families for whom the idea of another family caring for their child is greeted with skepticism or outright rejection, you need to be able to effectively address their concerns. A typical source of their wariness is some variation of the question:

Why would another family be able to do what we, who love this child, have been unable to do?

Whether asked outright or left unspoken, part of the process of considering another family will be helping to find a satisfactory answer to this question.

An answer can sometimes be found by working through a comparison between the child's family's experience and the circumstances of alternate families. On close examination, there are many ways in which differences between the two families can help explain how circumstances might position another family to be able to raise a child with significant disabilities. Differences between the two families may lie in the choices and opportunities that an alternate family has that were not available to the child's family. If presented carefully and respectfully, these differences can offer a way for a family to come to understand another family's ability or willingness to do what they have struggled to do.

Alternate families have *choices and opportunities* to decide whether, how, when, and under what circumstances to be a parents.

CHOICES AND OPPORTUNITIES

Alternate families have CHOICES that many birth families have not had:

- to become a parent of a child with a disability
- to decide the type of disability they feel comfortable supporting
- to adapt their lifestyle

Alternate families have OPPORTUNITIES that many birth families have not had:

- to be ready and prepared to parent a child with a disability
- to begin caring for a child with disabilities when they are emotionally strong
- to become comfortable with the child's disability and needs gradually and in advance of the child entering the family
- to have financial support to assist with child and family needs
- to receive adequate supports and services to assist with child and family needs

By working through these comparisons, the child's family may begin to imagine how another family could do what their own circumstances prevented. You can also work through comparisons of family life and facility life to help the family imagine the day-to-day realities of their child living with an alternate family.

SIMILARITIES AND DIFFERENCES

Similarities between facilities and alternate families:

- Caregivers undergo thorough background checks
- Caregivers have specialized training regarding children with disabilities
- Caregivers are paid to provide services
- Living arrangements are subject to periodic inspections to assure health and safety
- Professional services are available to caregivers

Differences between facilities and alternate families:

- The number of caregivers with whom the child interacts
- The availability of a consistent caregiver
- The opportunity for the child to spend time primarily with a preferred caregiver
- The extent to which the preferred caregiver's time is shared with other children
- The extent to which caregivers change from day to night and week to week
- The extent to which caregiver relationships extend beyond a shift
- The likelihood of a relationship that continues into adulthood

In addition to the relationship between the child and alternate family, you will also need to address the relationship between the family and the alternate family. You can point out how their involvement represents a kind of **"shared parenting"** where they can maintain their parenting relationship in partnership with the alternate family. It can be useful to suggest how shared parenting is somewhat like parenting between two households by extended family members or following a divorce (without the parental discomfort that led to the divorce).

JaQuincy is an energetic 12-year-old. He has autism, a severe intellectual disability, and attention deficit hyperactivity disorder. He requires close supervision due to his level of activity and lack of awareness of safety issues. JaQuincy was placed in a large ICF facility when his family felt they couldn't protect his younger siblings from unintended consequences of his behavior. A facility several hours away was the only option available. After placement, JaQuincy's family participated in permanency planning where they were introduced to the idea of another family caring for JaQuincy. His mother's initial response was, "It'll never work." But she was willing to consider it so JaQuincy could be closer. Visits with potential families near JaQuincy's family were arranged. To her surprise, JaQuincy's mother was immediately attracted to one family who she subsequently chose for her son. The two families have since built a shared parenting relationship. JaQuincy's mother says "She's like a sister." The two extended families socialize together with JaQuincy spending time with his two loving families.

"It was hard for me to see somebody taking our place, but at the same time, I think it's best for my son. My main goal is to see him happy. We work around the other stuff."

Of course, considering an alternate family is more than just the idea of one—it is about finding a specific acceptable alternate family.

Discussion with families/LARs/young persons should preview how alternate families are recruited, evaluated, approved, monitored, and supported. Helping families/LARs/young persons to understand the services and supports involving alternate families is not a discussion to be had only after their decision to consider another family. Rather, it may be the motivation that precedes

Tiffany is a sweet 22-year-old who loves country music and hates scary movies. She has cerebral palsy and an intellectual disability. At 16 she was placed in an 8-bed ICF facility. She had been living with her grandmother who was awarded custody when Tiffany's parents' rights were terminated by CPS. Her grandmother struggled financially and with Tiffany's care as she was getting bigger. Tiffany wanted to live with a family. They were introduced to Carol who was a special education teacher and a host family. Tiffany's grandmother describes Carol: "She is an absolute godsend. Tiffany absolutely loves Carol and they have a very close bond. It is a perfect match. It's not like they were just looking for a home—they were looking for the whole atmosphere of a family. It's not like big business."

the decision. While the family/LAR/young person should be provided with written informational materials, information needs to reflect more than waiver funding, program eligibility, and provider lists. The discussion needs to be tailored so they can see how services and supports involving an alternate family can be put together to fit their specific situation and preferences.



Next Steps... Family/LAR/young person's responses to the discussion about alternate families will vary from readiness, to reservations, to reluctance. If the family/LAR/young person expresses *readiness* in finding an alternate family, the next step is to plan out activities to find a suitable alternate family (see the section on "Moving to Another Family" below).

If the family/LAR/young person has *reservations*, the next step might be identifying ways to help them gently explore the possibility in continuing conversations. Rather than trying to get a final decision in a single conversation, it might be more productive to say something like:

It sounds like there are lots of things to think about as you're considering your child's future and your own. I'd like to help you in thinking through the possibility of an alternate family. You don't have to decide today. I know some families who were hesitant like you but changed their minds when they had a clearer picture. I know the people who helped them who might be helpful for you to talk to. What if I make arrangements to connect you? You've got nothing to lose but a few hours of your time.

If the family/LAR/young person is *reluctant* to entertain options other than remaining in the facility, the conversation should also focus on how to help them maintain engagement in each other's lives. It might be productive to offer your availability to help by saying something like:

Sometimes things change. I'm available to talk again before our next six-month review. In the meantime, is there anything that would help you and your family and your child to be able to spend more time together?

The goal of the discussion of alternate families should be to open the door to meaningful continuing dialog and activities, rather than close the door until the next review of the plan.

Tips & Considerations

TO ACHIEVE FAMILY LIFE

- “The system” is large, complex, and challenging to navigate. It involves multiple state agencies and a variety of programs with various eligibility criteria. Beyond disability services, it may include other systems such as health, housing, and income assistance. Families may need help figuring out how to use these many components of the system effectively.
- As the Family-Based Alternatives contractor for the Health and Human Services Commission, EveryChild can help with advice and technical assistance to permanency planners, service coordinators, and families/LARs/young persons. EveryChild staff can serve as a resource and may be able to assist at any of the steps needed to achieve family life.

ACHIEVING FAMILY LIFE AS AN ALTERNATIVE TO FACILITY LIFE

Achieving the permanency goal of family life requires action to move from intentions to implementation. The task requires drilling down to get at all the details necessary to achieve a successful move from facility life to family life. At this point, your exploration discussions with families/LARs/young persons and others should have (1) enabled envisioning the possibility of family life, (2) identified the preferred family living arrangement, and (3) previewed resources generally available to support it. Achieving family life now requires arranging for the actual needed services and supports and preparing for the transition from a facility to a family.

Facilitation of this stage is essential to success. In reviews comparing children and youth who remained in facilities with those who moved to families, the availability of an active facilitator—a person with the knowledge, time, and energy to follow through on multiple and complex details—was found to be a key factor in achieving family life.

The permanency plan needs to be integrated with an ongoing individual plan of services and supports and service coordination. Participation by the permanency planner will depend on the way the local service system is organized. Ideally, the permanency planner would participate in the development of the individual plan of services and transition to the proposed family living arrangement. If not able to participate directly, at the least, the permanency planner's responsibility is to assure a smooth “hand off” of their relationship with the family/LAR/young person to the designated coordinator and to assure their understanding of the family/LAR/young person's perspectives developed during the process of permanency planning.

II. GUIDANCE FOR DEVELOPING A PERMANENCY PLAN

Building on the permanency plan, activities required to implement it generally involves coordination, accessing resources, and transition activities, including:

- Coordinating services and supports
 - Identifying the individual responsible for ongoing service coordination
 - Identifying a team to assist
 - Understanding services and supports needed
 - Identifying responsibilities for completing processes and procedures to activate services and supports
 - Arranging assessments if needed
- Accessing resources
 - Identifying informal supports in the desired locale
 - Identifying formal services and supports and providers available in the desired locale
 - Identifying funding sources and access pathways
 - Identifying eligibility and enrollment requirements
 - Making contacts on behalf of the child/family/young person or providing contact details to help them obtain services and supports
 - Matching a child/family's needs for return home with available services and supports OR
 - Matching a child or young adult with an available alternate family
- Facilitating transition
 - Arranging child/young person-specific training for caregivers and providers
 - Arranging pre-move visits
 - Arranging schedules for specific services and supports
 - Coordinating a timetable for moving

These general activities are directed toward one of two pathways: (1) moving home or (2) moving to another family which are addressed in separate sections below.

1. MOVING HOME

Returning home depends on working through many details and dealing with multiple moving parts. The extent and type of coordination assistance needed will vary (1) from family to family and (2) with the level of supports and services needed by the child or young adult and family. Responsibilities for coordinating and delivering supports and services will need to be clearly established in order to move from a permanency plan to actual delivery of ongoing services and supports. The task in facilitating return home is to establish a comprehensive "package" of personal, community, and service system resources that will work for the child and the family.

It is important to envision what would be supportive before figuring out how it can be provided. The exploring stage provides clues. The implementing stage requires moving from the general to the specific. It is still important to resist the impulse to start with a list of available services and programs—instead it can be useful to think first about support more generally as identifying types of people, things, and arrangements that are needed.

People: the kind of help needed from others

- Hands on help at home and/or in the community
- Advice and/or assistance from individuals with expert knowledge
- Socially/emotionally supportive relationships
- Problem-solving assistance

Things: the kind of tangible items needed for the child and/or the home

- Housing
- Household goods and furnishings
- Vehicle
- Home and/or vehicle modifications
- Equipment, devices, supplies

Arrangements: the kind of preparations and measures needed to be put in place

- Training
- Financial resources
- Contracts/agreements
- Transportation
- Coordination/scheduling
- Respite
- Backup/contingency plans

Applying knowledge of sources of support can fill-in the details for identified needs. Returning home requires figuring out how needed supports can be organized and whether they can be provided at the level and intensity that a child or young person and their family needs. This requires knowledge of the family's personal resources, knowledge of local community resources, and knowledge of the service system.

Generally, support will come from some combination of the family's personal network, their community, and the formal system. Community support is not some idealized concept but consists of specific people, things, and arrangements with a specific function.

Tips & Considerations

FOR MOVING HOME

- Families/LARs/young persons need to know how to get what is needed for return home and who will be helping them initially and on an ongoing basis when permanency planning ends.
- Given the relationship developed with the family/LAR/young person, the permanency planner may want to be available to check back informally after their permanency planning role has ended.
- While some families can articulate clearly what they need for their child to return home, other families will need a good deal of assistance to envision how specific services and supports could be structured to meet their needs and their child's needs.
- Not every kind of support is a "service." Support includes more than services. Some supports involve concrete useable things like backyard fences or grocery delivery. Sometimes support means problem solving. Sometimes it means social networks that provide both emotional support as well as tangible benefits.

Two key resources from the formal system to supplement the family's personal resources and local community resources that are likely to be particularly helpful are Medicaid and Medicaid waivers. Services and supports available in the waiver should be matched to the identified needs. Service coordination involved in the waiver will play a key role in developing and ongoing monitoring an individualized plan of services and supports.

For children and young persons who cannot return to their families, arrangements for moving to another family living are covered next.

2. MOVING TO ANOTHER FAMILY

Moving to an another family requires addressing many details and considerations similar to returning home but importantly involves two additional activities: (1) finding potential alternate families and (2) determining whether a particular alternate family is a "good fit" from both the child or young adult's perspective and from the family/LAR's perspective.

It means finding the right family with the right attributes to fit the needs of the child or young adult and the preferences of their family or LAR.

John is a 21-year-old with complex medical issues and a profound intellectual disability. He uses a ventilator for breathing and a feeding tube for nourishment. John was placed in a nursing facility at age 15 when his family did not have enough support to manage his health care on their own. John's family was clear in permanency planning that they desperately wanted him home. When John became eligible for a waiver, with assistance from EveryChild, a complex plan was put together to enable him to be reunited with his family. The plan involved John and his parents moving together to a new home and organizing a team of competent people to assist in his care. The plan required accessing a housing voucher, finding an accessible house, completing minor home modifications, procuring equipment, and arranging private duty nursing. The plan involved John's father quitting his job to be reliably available through employment as John's attendant (an option because John is an adult). After four years in the nursing home and many months of planning, John was reunited with his family. His father said "His medical needs were met to a certain extent, but all of his other needs weren't met. His spiritual needs, his emotional needs are just as important. They're being met now. So, he is a whole person now. It has been a real blessing to us to have him home."

Josh is a friendly 19-year-old with an intellectual disability. He needs assistance for all activities. His single mother struggled financially. She needed to work but her son's needs conflicted with her work obligations and schedule. Josh was placed in a large ICF. In permanency planning, his mother continued to feel she couldn't resume care for him at home but she was also reluctant to consider an unknown family. The permanency planner helped her to see an option she hadn't considered possible. Josh's mother learned how his favorite uncle could be supported to care for him in his home, including receiving financial support. This arrangement enabled Josh to live with his extended family near his mother.

There are two general strategies for finding an alternate family:

1. Personal-network-based search. This strategy involves helping the family consider individuals in their personal network or in their child's network of significant others and current and former caregivers and service providers who might be approached about becoming an alternate family. An interested alternate family could then be assisted to become a host family with an HCS waiver provider.

2. Provider-based search. This strategy involves connecting the family/LAR/young person with provider organizations that recruit and support alternate families in the preferred geographical location.

Potential families identified through either type of recruitment effort should initially be considered as leads to be further pursued. Matching is the process of determining whether a potential family is a good fit for the child or young person and for the family and/or LAR. Matching is a process of discovery. Matching includes consideration of another family's characteristics (e.g., household composition, experience, motivation, and lifestyle), location, housing, expectations regarding interactions with the child's family or LAR, and availability of support. It also requires thinking through what supports and services might enable a potentially willing family

***Molly** was placed in an 8-bed ICF at age 10 when her parents felt her care was getting too much for them and the aide they had been using quit. Her parents were reluctant to consider another family. They had turned down a waiver offer because they wanted her to stay at the group home and didn't believe in her living with an unknown host family. Through permanency planning, they were encouraged to think about people close to Molly. They identified Amanda, Molly's teacher for the past three years who she adored. Amanda was approached and indicated she was interested in considering Molly living with her. She learned how she could be supported through a waiver as a host home. Molly's parents had not imagined she could live with Amanda. They agreed to Molly living with Amanda because they trust her and know that Molly loves her.*

***Bethany** is a friendly 20 year old young woman who uses a wheelchair and requires help with all of her needs due to physical and intellectual disabilities. She was placed in a large ICF facility when her father died and her mother was struggling to care for her and her younger brothers. Her mother was pleased with the care and security provided by the facility. She participated in permanency planning. Although she trusted the facility, she found the vision of a family sitting down together at the dinner table more appealing than the noisy dining room Bethany shared with 100 other people with disabilities. She was helped to meet with provider agencies to find possible host families. She was introduced to five potential families. She particularly liked a family with experience working in facilities caring for individuals like her daughter. When she visited them, the photos of family life scattered throughout their home mirrored her own home and the lifestyle she wanted for Bethany but hadn't thought possible. Bethany moved to the host family her mother chose. She now enjoys the smell and taste of home cooking, the intimacy of family life, and the love of a second family.*

to become a capable family. A promising family needs to be connected to a provider agency for assessment, background checks, and preparation through training and support.

Resources to support another family will likely include the Medicaid Home and Community-Based Services (HCS) waiver which provides funding and support for host families.

Families/LARs/young persons can be assisted in selecting a specific alternate family by being offered descriptions of potential alternate families and visiting those that seem promising.

Determining if a potential family is a good match requires weighing multiple factors including the child or young adult's needs, the family/LAR's preferences, and the alternate family's abilities, preferences, and access to support. In addition to family/LAR visits with a potential alternate family, visits between the child or young adult and the alternate family are needed to assure the alternate family's ability to meet his or her needs and to be prepared to make a commitment to the child or young adult becoming part of their family. Visits, including overnights and extended stays, can be critical in making a final selection. Deciding to go forward will depend on how closely available resources come to meeting essential needs. It will also depend on how a family/LAR and/or young person feels about the alternate family.

Jackie suffered a traumatic brain injury due to being shaken as an infant. She was hospitalized and then transferred to a series of congregate care facilities. She had lived in facilities for many years before permanency planning was instituted. Her mother had never cared for her at home and wasn't willing to assume that responsibility. She hesitantly agreed to consider another family caring for Jackie. She met ten different families before she found one she felt would be good for Jackie and would welcome her to continue to be part of her life. It took several years, but Jackie was able to move to a family at the age of 21.

It is not uncommon for families to be somewhat hesitant about the idea of another family, only to find complete comfort when they meet an actual family.

Karina, age 17, had lived with her mother after her parents divorced. Then her mother died. Her father and stepmother tried to care for her but their military careers meant constant moving. Karina was placed in a nursing facility. Though hesitant to consider other families, her father worked with EveryChild and a number of provider organizations to meet their host families. He met two promising families where the mother was a pediatric nurse. Both families' homes and experience were a good fit for Karina's needs, but he clearly preferred Nancy. He knew right away that hers would be the perfect family. He said "It just felt right."

Tips & Considerations

FOR MOVING TO ANOTHER FAMILY

- Many families who were initially doubtful report finding the right alternate family has been comforting to them as well as beneficial to their children.
- It may take a pool of good families to be able to find the right family for a particular child or young person. Accessing a sufficient number of adequately prepared alternate families requires knowledge of the provider community and tapping into their host families.
- EveryChild, Inc. is available as the HHSC Family-Based Alternatives contractor with many years of experience in connecting families and alternate families. EveryChild has extensive knowledge about provider agencies and host families (See EveryChild website at everychildtexas.org for contact details.)
- Development of a written **Shared Parenting Agreement** may be helpful to a family in assuring parents that their rights are intact and thinking through their relationship with the chosen alternate family. The agreement can be used to help the two families identify and work through expectations about their interactions around all aspects of the child or young person’s life. The signature of a service system representative on the agreement can serve to assure both families that their wishes have been acknowledged and will be honored.

After agreeing to a specific family, there still needs to be attention to a thoughtful transition. The transition process involves not only setting up the specific supports and services, but also addressing the sequence and pace of a move. Pacing and sequencing should allow for increasing experience between the child or young person and the alternate family and between the alternate family and the child’s family or LAR.

Many parents of children who once lived in congregate facilities were initially doubtful about the idea of another family caring for their child but subsequently found a successful match. Parents who found the right alternate family report that the experience of having another family who loves and values their child has been tremendously supportive to them as well as their child.

CLOSING

The purpose of permanency planning is to set in motion a set of specific activities that will contribute to the possibility that a child or young adult currently living in a facility (or at risk of admission) will be afforded the opportunity to grow up in a family. Understanding a child's developmental need for family life underpins permanency planning. Achieving the permanency goal of family life involves moving through a process from *imagining* family life to *exploring* the resources to make it possible, to *activating* supports and services to make it happen. Critical to the permanency planner's role is knowing how to engage families/LARs/young persons, how to talk about options for family life, and how to link them to supports and services to achieve family life. The ultimate test of a permanency plan is how well it furthers the opportunity for a child or young person to experience family life with the primary feature of an enduring and nurturing parental relationship.



everychildtexas.org