

## **PATHWAYS TO AND FROM CONGREGATE CARE FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES**

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### **Purpose**

The purpose of the study described here is to identify factors that contribute to admission and continued stay of children with developmental disabilities in congregate care and factors that contribute to achieving community alternatives, especially family-based alternatives to congregate care.

### **Research questions**

The study addressed three research questions:

1. Why are children with disabilities placed in congregate care?
2. Why do children with disabilities remain in congregate care?
3. What contributes to achieving alternatives to congregate care?

### **Background**

Texas legislation passed in 2001 requires permanency planning on a semi-annual basis for all children with developmental disabilities under age 22 who live in institutional settings in both the disability/longterm health care services system and the child welfare system. Permanency planning is defined in the legislation as “a philosophy and planning process to facilitate a permanent living arrangement with the primary feature of an enduring and nurturing parental relationship” to be achieved through either return home or placement in another family-based living arrangement.

The permanency legislation called for the Texas Health and Human Services Commission (HHSC) to contract with a community organization for the development and implementation of a system of family-based alternatives for institutionalized children with developmental disabilities who cannot live with their families. EveryChild, Inc. has contracted with HHSC for this work through the Family-Based Alternatives (FBA) project since 2002.

### **Study components**

The study involved three related components:

1. Literature review
2. Review of permanency planning records for 830 children and young adults living in congregate care
3. In-depth case studies of 30 children and young adults involved with the Family-Based Alternatives project.

Separate reports are available for each of the three elements of the study.<sup>1</sup>

### **Definition of terms used in report**

- Congregate care. Refers to facility-based living arrangements. The terms congregate care and facility are used interchangeably.
- Family-based alternative (FBA). Refers to any family living arrangement which serves as an alternative to congregate care including living with birth parents, extended family members, or adoptive parents as well as unrelated families such as foster care or support families. The phrase “FBA project” refers to the HHSC contract with EveryChild.
- Support family. Refers to families who are recruited, paid, and supported to care for children and young adults in their home under the supervision of a provider organization funded by the state’s disability services system. The term is used to distinguish support families from foster care families within the child protective services system.
- Legally authorized representative (LAR). For the purposes of this report, LAR refers to a person authorized by law to act on behalf of an individual, including the parent, guardian, managing conservator of a minor, or guardian of an adult.
- Medicaid waiver. Refers to a funding strategy that allows Medicaid funds which would otherwise be used for services in a Medicaid facility to be used for services in the community.
- Promoting Independence Plan (PI). Refers to the Texas plan developed in response to the 1999 Olmstead Supreme Court decision which requires states to offer community-based alternatives to institutionalized persons who wish to move to the community.
- Money Follows the Person (MFP). Refers to a policy whereby funds for institutional care are transferred to community care when an institutionalized individual moves to the community.

## **SUMMARY OF FINDINGS**

### **LITERATURE REVIEW**

The literature described the **precarious pathways** that lead to congregate care of children with disabilities living in congregate care arising from interacting ecological factors including characteristics of children, families, and the systems in which they are embedded.

#### **Children**

Research evidence from studies of early childhood development and attachment, and comparisons of outcomes of various caregiving arrangements suggest that a parental relationship characterized as readily available, responsive, nurturing, reliable, and consistent over time provides developmental advantage for children. Research evidence suggests risk of negative developmental consequences where this relationship is absent. It also suggests specific evidence of risk related to congregate care due to:

- Absence of a primary parental relationship
- Limitations in caregiving arrangements inherent in congregate care
  - Shift care
  - Turnover and understaffing
  - Competing needs of multiple other residents
  - Non-individualized responses to children
  - Interchangeable caretivers
  - Lack of continuity over time of a primary emotionally invested caregiver
- Higher incidence of maltreatment in congregate settings.

There is little research evidence that congregate care benefits children. Research evidence currently available suggests congregate care for children presents developmental risk without evidence of offsetting benefits.

#### **Families**

Research evidence describes families' daily life experience with a child with disabilities as variously shaped by multiple, interrelated factors including:

- *Circumstances* such as the child's care needs, the families' socioeconomic position, and other family members' needs
- *Interpersonal influences* such as culturally-shaped and professionally-influenced parental beliefs and appraisals of their child's disability and their situation
- *Services and supports* of varying availability and adequacy.

Research evidence suggests families operate in a variety of psychosocial and socioeconomic contexts that contribute to resilience and vulnerability that interact to affect decisions about placement. The ecological contexts that affect families raising

children with disabilities including the domains of family finances, access to health/education, home/neighborhood conditions, domestic workload, child care tasks, child play/peers, marital roles/responsibilities, social support, and information sources/goals.

Research studies describe wide variability in adaptation of families ranging from parents who report positive benefits from raising a child with disabilities to parents who experience great distress. Evidence describes some families as:

- Overwhelmed or exhausted or restricted by their child's extraordinary care needs and the extended duration of childhood dependency
- Stressed by financial burdens of increased expenses and/or lost income from forgone employment to care for their child
- Frustrated by inadequate, complex, fragmented services systems
- Anxious about the uncertainties of their family's and child's future.

Research identified three placement profiles leading to voluntary placement by parents:

1. Normative—age-related launching into adulthood
2. Anticipatory—seeking specialized care, protection, treatment, and training for children
3. Stress—seeking relief from chronic difficulties or crises.

Stress figures prominently in studies of families who have placed their children. Studies found that often no single factor or event leads to placement but rather that placement is the result of a combination and accumulation of multiple risk factors.

Parental *appraisal* of caregiving burden and level of stress also figures in decisions about out-of-home placement. Studies suggest that variability in families' perceptions is not explained by the severity of the child's disability. Appraisals are shaped by:

- Socioeconomic circumstances
- Cultural influences
- Professional influences.

Although limited, studies of family involvement after placement suggest wide variation which is often influenced by facility practices and distance.

### *Systems*

The literature suggests that how systems have been organized and operate can affect whether pathways lead to congregate care. Availability, type, and access routes to services and supports vary. In disability services, most out-of-home placement of children occurs by parental decision as contrasted with child welfare services where children are removed from their families following abuse, neglect, or relinquishment.

Since the 1960s, the literature describes all child serving systems as undergoing trends away from institutional care toward increasing family support with notable exceptions:

- Institutionalization has recently been increasing for adolescents with behavior challenges and mental health needs and children with complex health care needs.
- Children with disabilities are over-represented in child protective services systems where they are more likely to enter care, less likely to leave care, and more likely to be placed in institutions than families.
- Funding for institutional care continues to exceed funding for family support.

Research literature regarding alternatives to congregate care revealed much work underway within and across child serving systems to better support family life and reduce institutionalization. Research identified evidence-based or promising approaches in five areas:

- *Alternate funding strategies* that redirect funds from facilities to community services through vehicles such as family subsidies, waivers, and family directed funding.
- *Alternate planning strategies* that involve families as partners using approaches such as wraparound, systems of care, and family group decision making.
- *Alternate living arrangements* that support various kinds of family-based alternatives including birth families, kinship care, and adoptive families as well as alternate family arrangements like treatment foster care and shared parenting.
- *Alternate practice approaches* such as Positive Behavior Support that assists individuals with challenging behavior to live successfully in the community and family homes.
- *Alternate frameworks* for organizing services such as permanency planning to guide child serving systems.

Common elements across the identified promising alternatives were:

- centralizing the importance of family life for children
- shifting from the child as recipient to the family as a unit
- shifting radically from traditional services paradigms that fit individuals into services to building supports to fit individual/family situations
- addressing organizational culture and relationships
- reconceptualizing the underpinning frameworks that guide services.

The literature reviewed suggests (1) some children with disabilities face risk related to their families' vulnerabilities and their placement in congregate care, (2) some families of children with disabilities face multiple, complex, and cumulative vulnerabilities, and (3) some systems are exploring family-based alternatives to congregate care with various levels of promising outcome evidence.

## PERMANENCY PLAN REVIEWS

The state developed and requires use of a form called a Permanency Planning Instrument (PPI) to capture uniform information from each permanency plan. The PPI provides information describing the child, circumstances that led to initial admission to a facility, placement history, family involvement since placement, wishes of the family or LAR regarding alternatives to the current facility, supports that would be needed for the child to live in the community, particularly at home or in another family-based living arrangement, and an action plan to achieve desired goals. Permanency plans were available for review for all children and young adults under age 22 living in including State Supported Living Centers (SSLC) (also known as state schools), Medicaid-funded Intermediate Care Facilities (ICF), nursing facilities, and facilities contracted by the Department of Family and Protective Services as General Residential Operations (DFPS/GRO) for children with intellectual disabilities. A database was constructed to analyze information taken from the PPIs. Data derived from narrative information was organized into categories to allow for aggregation. PPIs were reviewed for **830** children and young adults who lived in the identified facilities between October 2008 and October 2009.

### *Children and young adults in identified congregate care settings*

The PPIs offer a snapshot of residents of the four major types of Texas congregate care facilities serving children and young adults with developmental disabilities. Children and young adults admitted to congregate care for the most part had complex needs.

<i>Children and young adults in identified congregate care settings</i>	
Children and young adults living in the identified congregate care settings were generally older adolescents or young adults and disproportionately male.	<ul style="list-style-type: none"> <li>▪ Average age 17</li> <li>▪ 54% age 18-21</li> <li>▪ 69% male</li> </ul>
The majority of children and young adults had significant and/or multiple disabilities.	<ul style="list-style-type: none"> <li>▪ 90% had intellectual disabilities</li> <li>▪ 66% had challenging behavior</li> <li>▪ 54% had mental health needs</li> <li>▪ 27% had medical/physical needs</li> <li>▪ 27% had autism</li> <li>▪ 88% had multiple disabilities</li> </ul>
Facilities ranged in size from 6-beds to several hundred. The majority of children and young adults lived in large facilities of 16 beds or more.	<ul style="list-style-type: none"> <li>▪ 80% of minors lived in large facilities</li> <li>▪ 39% of minors lived in state schools</li> <li>▪ 51% of 18-21 lived in large facilities</li> <li>▪ 41% of young adults lived in small ICFs</li> </ul>
Many children and young adults lived at significant distance from their families.	<ul style="list-style-type: none"> <li>▪ 17% lived 200+ miles from family</li> <li>▪ 45% of minors lived 100+ miles from family</li> </ul>

**Initial facility admission**

Although there was individual variation, the most common admission pathways involved crises, hardships, chronic difficulties, and stress with little access to external support.

<b><i>Initial facility admission</i></b>	
Age at admission ranged from infancy to adulthood. Children were generally teenagers leaving home prior to normative age.	<ul style="list-style-type: none"> <li>▪ Average age at admission 14.2</li> <li>▪ 68% under age 18 at admission</li> <li>▪ 19% of young adults placed as step to independence</li> </ul>
Many admissions involved a lack of support or a perception that a facility offered services that were more readily available than in a family home.	<ul style="list-style-type: none"> <li>▪ 57% involved lack of external support</li> <li>▪ 37% admissions sought treatment, training, safety, stabilization, or improvement of child</li> </ul>
Reasons for admission were most often stress related. <ul style="list-style-type: none"> <li>▪ Some stress was specifically related to the child’s care</li> <li>▪ Some stress was not directly related to the child’s disability</li> </ul>	<ul style="list-style-type: none"> <li>▪ 96% of admissions were stress related</li> <li>▪ 84% stress related to child’s care</li> <li>▪ 60% stress not directly attributed to disability</li> </ul>
The source of stress not directly attributed to the child’s disability ranged from common situations that many families without members with disabilities face to extraordinary adverse circumstances.	<ul style="list-style-type: none"> <li>▪ 40% stress related to single parenting, work obligations, divorce, competing needs of other family members</li> <li>▪ 25% adverse circumstances such as death or illness of parent or serious financial difficulty</li> <li>▪ 30% protective services involvement</li> </ul>
Many children were not living with their parents when first admitted to congregate care.	<ul style="list-style-type: none"> <li>▪ 17% admitted from temporary settings</li> <li>▪ 12% living with other family members</li> <li>▪ 8% admitted from failed foster care</li> </ul>

**Post-placement experiences**

The PPIs suggest that once children are admitted to congregate care, they are at risk of extended stays, multiple facility placements, and limited contact with their families.

<i>Post-placement experiences</i>	
Although permanency planning legislation indicates congregate care placement should be considered temporary (not to exceed six months), the majority of children and young adults had lived in congregate care for extended periods.	<ul style="list-style-type: none"> <li>▪ 80% more than six months</li> <li>▪ 73% one or more years</li> <li>▪ 53% two or more years</li> <li>▪ 36% three or more years</li> </ul>
A large number of children and young adults experienced movement to other congregate care facilities after the initial placement.	<ul style="list-style-type: none"> <li>▪ 24% two or more facility placements</li> <li>▪ 7% three or more facility placements</li> </ul>
Contact with families varied widely but a significant number of PPIs documented little or no contact with families.	<ul style="list-style-type: none"> <li>▪ 53% contact at least once a month</li> <li>▪ 29 % contact 1-5 times in a six month period</li> <li>▪ 11% no contact</li> </ul>

**Future pathways**

The PPIs described planning for the future. The PPIs identified family/LAR preferences for remaining in congregate care for over half of children and young adults.

<i>Identified preferences</i>		<b>0-17</b>	<b>18-21</b>	<b>All</b>
Continued congregate care	Current facility	51%	52%	51%
	Other facility	7%	3%	5%
Family-based alternative	Return home	16%	7%	11%
	Alternate family	7%	2%	5%
Adult community living arrangement	Community group home	N/A	11%	6%
	Independent living	N/A	4%	2%
Unclear		19%	21%	20%

Future pathways were related to the perspective of the decision-maker responsible for choosing the goal.



<i>Decision-maker issues</i>	
Multiple reasons were identified where continued congregate care was indicated as preferred.	<ul style="list-style-type: none"> <li>▪ 73% families' beliefs</li> <li>▪ 51% family circumstances for minors</li> <li>▪ 29% professional influence</li> </ul>
A large number of PPIs indicated decision-makers were not parents.	<ul style="list-style-type: none"> <li>▪ 39% LARs for minors were not parents</li> <li>▪ 33% young adults LAR identified as self</li> <li>▪ 27% minors in CPS custody</li> <li>▪ 11% young adults had public guardians</li> </ul>
LAR status was unclear for many young adults.	<ul style="list-style-type: none"> <li>▪ 29% young adults LAR status unclear</li> <li>▪ 13% young adults had questionable capacity and no guardian</li> </ul>
For SSLC residents, interdisciplinary teams must recommend community placement and courts are involved in placement decisions for juvenile justice commitments	<ul style="list-style-type: none"> <li>▪ 36% SSLC placements</li> <li>▪ 9% juvenile court ordered commitment to SSLC</li> </ul>
For children in CPS custody, CPS and/or courts must approve community placement	<ul style="list-style-type: none"> <li>▪ 27% PPIs minors in CPS custody</li> </ul>

A variety of issues were identified which presented blocks or delays in achieving desired alternatives to facility placement

<i>Implementation issues when alternatives were desired</i>	
Service delivery barriers or inactivity identified in some PPIs hampered achieving a desired alternative.	<ul style="list-style-type: none"> <li>▪ 80% no activities documented</li> <li>▪ 29% lack of access to funding and services (often related to small and medium ICF or inability to locate a CPS foster home)</li> </ul>
Some families/LARs were not ready to act on preferred alternative.	<ul style="list-style-type: none"> <li>▪ 80% of children in CPS custody in DFPS/GRO facilities were identified as "not ready" by CPS caseworkers</li> <li>▪ 33% families wanted additional child training or stabilization or were willing to explore alternatives but not ready to commit</li> </ul>

Understanding decisions about continued use of congregate care or uptake of alternatives requires understanding the nature of the options, influences affecting choices, and the process of obtaining decisions about choices. The data (or lack of data) raised questions about preferences identified for future goals.

<i>Questions raised</i>	<i>By PPI data</i>	<i>Beyond the scope of PPI data analysis</i>
<b>Clarity</b>	<ul style="list-style-type: none"> <li>▪ 20% unclear preference regarding goal</li> </ul>	<ul style="list-style-type: none"> <li>▪ Adequacy of documentation</li> <li>▪ Indeterminacy of family/LAR</li> </ul>
<b>Decision-maker</b>	<ul style="list-style-type: none"> <li>▪ 40% limited or no contact with family decision-maker documented in a six-month plan period               <ul style="list-style-type: none"> <li>* 10% no contact</li> <li>* 16% 1-2 visits</li> <li>* 14% 3-5 visits</li> </ul> </li> <li>▪ 35% young adults LAR identified as self not involved in plan</li> <li>▪ 29% young adults with unclear LAR status</li> <li>▪ 25% family/LAR not involved in planning</li> <li>▪ 13% young adults with questionable capacity and no identifiable LAR</li> </ul>	<ul style="list-style-type: none"> <li>▪ Adequacy of documentation</li> <li>▪ Plan based on second-hand information from third party rather than direct participation of LAR</li> <li>▪ Outdated information carried forward into current plan without new discussion</li> </ul>
<b>Decision-making</b>	<ul style="list-style-type: none"> <li>▪ 29% of PPIs identified professionals' influence as a factor in preferences for continued congregate care (including interdisciplinary team members, permanency planners, paid guardians, and facility staff)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Adequacy of documentation</li> <li>▪ Extensiveness and quality of description of alternatives</li> <li>▪ Influences outside permanency planning process</li> <li>▪ Relationship between family/LAR and individual responsible for describing alternatives</li> </ul>

**Summary from PPI analysis**

Although varying widely in details, pathways to admission were usually the result of a combination of interacting factors involving children with significant and/or multiple disabilities with families with difficult circumstances or chronic stress combined with a lack of resources.

For some children and young adults, the continued use of congregate care was the wish of their involved and active family or LAR. For others, it reflected ambivalence or reluctance of a family or LAR to consider an alternative. For others, continued congregate care reflected children and young adults who were disenfranchised by lack of participation in planning, lack of an active reliable informed decision-maker, having a decision-maker with little contact, or having no action taken on their behalf toward achieving a desired alternative to congregate care.

For a minority of children and young adults, living with a family or moving to a community alternative was an expressed desire. For a small number the pathway toward a desired alternative was underway, but for more, congregate care will continue until barriers or delays are resolved or action is taken.

### **CASE STUDIES**

Case studies were completed for thirty children and young adults with developmental disabilities known to EveryChild through the FBA project. Cases were selected to represent (1) a wide range of ages, disabilities, ethnicities, congregate care facilities, and placement histories; and (2) issues raised from the literature review and PPI reviews. The case studies tracked children and young adults over time who moved from congregate care to family-based alternatives and who remain in congregate care. A uniform case summary form was developed and completed to capture information from reviews of case files, database notes, and personal knowledge of staff familiar with the case. Themes and patterns within and across cases were identified. The case studies provide examples of factors which contributed to admission, continued congregate care, and alternatives to congregate care.

<i><b>Demographics of 30 cases</b></i>	
Age	<ul style="list-style-type: none"> <li>▪ Current age 7 to 23 with average of 15.2</li> <li>▪ Age at admission infant to 18 with average of 8.7</li> </ul>
Disability	<ul style="list-style-type: none"> <li>▪ 29 intellectual disabilities</li> <li>▪ 17 medical/physical disabilities</li> <li>▪ 14 behavior challenges</li> <li>▪ 12 autism/pervasive developmental disorders</li> <li>▪ 6 mental health disabilities</li> <li>▪ 18 multiple disabilities</li> </ul>
Race/ethnicity	<ul style="list-style-type: none"> <li>▪ 13 Anglo</li> <li>▪ 9 Hispanic</li> <li>▪ 5 African American</li> <li>▪ 3 other or multiracial</li> </ul>
Total years in congregate care	<ul style="list-style-type: none"> <li>▪ Range less than 1 year to 20 years with average of 5 years</li> </ul>

**Admission to congregate care**

Factors that contributed to **admission** to congregate care included:

- High care and support needs of child
- Difficult family circumstances
- Precipitating urgent events and protracted or chronic situations
- Lack of resources or fitting services and supports prior to admission

**Continued congregate care**

Factors that led to **continued congregate** care included:

- Parental rejection of alternatives or reluctance to consider alternatives
- Lack of parental involvement in planning and decision-making
- Lack of access to resources or fitting services and supports for alternatives to congregate care
- Lingering effects from earlier policies, practices, and service configurations.

**Family-based alternatives to congregate care**

Factors that contributed to movement from **family-based alternatives** after admission to congregate care included:

- Active engagement of family/LAR in planning and decision-making
- Family/LAR willingness to explore and accept alternatives
- Access to resources and fitting services and supports
- Assistance from a knowledgeable, active facilitator
- Reconsideration of previously declined alternatives after changes in family circumstances or beliefs
- Reconsideration of previously declined alternatives after facility closure or changes in satisfaction with facility
- Changes in policies, practices, and service configurations
- Time.

**Comparison of cases of continued congregate care and family-based alternatives**

The case studies enabled a comparison of children and young adults who remain in congregate care and those who moved from facilities to families.

Child/young adult characteristics (e.g., age, disability, support needs,) did not distinguish those who remain from those who moved to families.

<b>Children with similar disabilities and support needs</b>	
<b>Remains in congregate care</b>	<b>Returned to family</b>
<b>DIEGO</b> is a 22 year old who has cerebral palsy and a profound intellectual disability. He uses a wheelchair for mobility and is dependent for all of his care needs.	<b>CHRIS</b> is a 23 year old with complex medical problems which require a ventilator for breathing and a feeding tube for nourishment. He has a profound intellectual disability and needs assistance for all his needs.
<b>Remains in congregate care</b>	<b>Moved to extended family as support family</b>
<b>JESSE</b> is a 15 year old with an intellectual disability, autism, and mental health needs.	<b>RAUL</b> is a 15 year old with a mild intellectual disability, ADHD, a mental health diagnosis, and a history of juvenile justice involvement
<b>Remains in congregate care</b>	<b>Moved to support family</b>
<b>JUAN</b> is a 7 year old boy whose premature birth resulted in significant health care problems. He is fed through a gastrostomy tube and uses a wheelchair for mobility.	<b>KIM</b> is a 13 year old with complex medical needs resulting from an illness as an infant. She uses a ventilator for breathing and is fed by a gastrostomy tube. She uses a wheelchair for mobility.

*Family characteristics* (e.g., circumstances, households, histories) did not distinguish children or young adults who remain in congregate care from those who moved to families. The families of children and young adults who remain in congregate care had similar demographic characteristics and histories to those where a family-based alternative was achieved. Differences between stayers and movers were seen, however, in the level of family involvement and the nature of their beliefs and appraisals of congregate care and alternatives.

<b>Families with similar circumstances and histories</b>	
<b>Remains in congregate care</b>	<b>Moved to support family</b>
<b>DARIUS</b> was 8 years old when his parents died. He was cared for by a relative who was a single parent struggling to work and raise her own two sons.	<b>PAT's</b> parents were killed in the same accident which caused his disabilities. He was raised by his grandmother until she died suddenly when he was eleven years old.
<b>CARL's</b> single mother has chronic fatigue syndrome and has difficulty providing care related to Carl's physical disability.	<b>TONY's</b> mother is a widow with a serious health condition who is too frail to lift and provide care needed due to Tony's physical disability.
<b>JESSE</b> was removed from his family by CPS at age 4 due to neglectful supervision.	<b>CODY</b> was removed by CPS from his family at age 10 due to neglect.

<b>Similar children with different family beliefs and engagement in planning</b>	
<b><i>Remains in congregate care</i></b>	<b><i>Moved to support family</i></b>
<p><b>JUAN</b> is a 7 year old boy who was born prematurely with significant health care problems. Juan was placed directly from the hospital in a pediatric nursing home with the expectation that his condition was terminal. His health improved but he continues to have medical needs and significant developmental delays. He is fed through a gastrostomy tube and uses a wheelchair for mobility. He has never lived at home and his family believes he needs nursing facility care. The facility staff encourage this view. Juan's residence in a nursing home entitles him access to Medicaid waivers which offer services and supports for him to return home or live with an alternate family. His family has not participated in permanency planning, has not responded to waiver offers, and has elected to continue his care in the nursing home.</p>	<p><b>ERIC</b> is a 9 year old who has physical, intellectual, and medical disabilities. He was not expected to live at birth. He was transferred from the neonatal intensive care unit at 4 months of age to a nursing home. He has a tracheostomy for breathing, a gastrostomy tube for nourishment, and a wheelchair for mobility. Because he lived in a nursing home, Medicaid waivers were available which could provide support for him to return home or live with another family. The Family-Based Alternatives project met with his mother and her extended family in their home to explore alternatives. Eric's mother felt she couldn't bring him home but indicated willingness to consider an alternate family. The FBA project staff assisted in finding a potential support family and facilitating visits and transition planning. Eric was placed with a support family near his extended family in 2008 after eight years in the nursing home.</p>

<b>Similar children with different family appraisals of alternatives</b>	
<b><i>Remains in congregate care</i></b>	<b><i>Moved to support family</i></b>
<p><b>PHIL</b> is a 16 year old who has a profound intellectual disability. He is dependent for all his care needs and uses a wheelchair for distance. His parents were overwhelmed by his need for round-the-clock supervision. Phil was placed at age 2 in a large ICF, six years before the permanency planning legislation. Phil has lived in congregate care for fourteen years. Since 2001 Phil has been offered Medicaid waivers which would provide supports for an alternative to congregate care but his family has turned them down. They believe large group settings offer more monitoring and access to nurses and other professionals. The FBA project arranged for Phil's father to visit three community-based group homes with individuals similar to his son, but he continues to believe that the large facility is the only setting that can meet his son's needs.</p>	<p><b>TONY</b> is a 19 year old with a profound intellectual disability. He is dependent for all his care needs and uses a wheelchair for mobility. Tony's mother is a widow with a serious health condition. He was placed at age 4 in a large ICF facility, seven years prior to permanency planning. He lived in congregate care for eight years. In 2003 he was offered a Medicaid waiver. With assistance from the Family-Based Alternatives project, his mother learned about the support family service which could provide Tony the opportunity to live with an alternate family. His mother elected that alternative because she believed it would be better for her son to live with a family. The FBA project located a family near her home and Tony was placed at the age of 13 where he has now lived for six years.</p>

System characteristics played a role in admission and continued stay in a facility. Features which distinguished children and young adults who remain in congregate care from those who moved to family-based alternatives were access to resources and fitting services and supports, involvement of a decision-maker, and involvement of a facilitator.

<b>Similar children with different access to resources and fitting services</b>	
<b>Remains in congregate care</b>	<b>Moved to support family</b>
<p><b>ALEX</b> is an active 8 year old with autism, severe intellectual disability, and ADHD. He was removed from his family by child protective services at the age of six and placed in a large DFPS/GRO facility where he has lived for two years. The goal is reunification with his family. CPS has been unable to find a foster care agency or foster family near his family willing and able to care for a child with Alex's disabilities while his mother works for his return. Disability services providers might be willing to serve Alex in a family-based alternative but he is on a waiting list for a Medicaid waiver and does not have access to the waivers available to other children with disabilities who live in large facilities because the facility where he lives is not included in the Promoting Independence Plan.</p>	<p><b>TOM</b> is an energetic 9 year old. He has autism, severe intellectual disability, and ADHD. Tom was adopted as an infant. He was placed in a large ICF facility at the age of four when his family felt they could not protect his younger sibling from inadvertent injury due to his behavior. No community services or supports were available. After admission Tom was able to access a Medicaid waiver due to the state's Promoting Independence Plan. The Family-Based Alternatives project identified disability provider agencies and potential support families near Tom's family. The FBA staff assisted in pre-placement visits and transition plans to ensure adequate preparation of the support family, a smooth transition, and support after the placement.</p>

<b>Similar disabilities and similar lack of family involvement with different levels of facilitation</b>	
<b>Remains in congregate care</b>	<b>Moved to support family</b>
<p><b>FRAN</b> is 20 years old. She has a severe intellectual disability and cerebral palsy. She uses a wheelchair for mobility, is dependent for her care needs, and receives nourishment through a gastrostomy tube. Her family had no support when she lived at home and struggled financially. As Fran grew older, her size and dependency made her care more difficult. At age 14 she was placed in a nursing home two hours away from her family. Fran has lived in congregate care for six years. Her parents visited at first but over the years their visits and calls stopped. They haven't visited for the past three years and have not responded to attempted contacts for permanency planning or Medicaid waiver offers which could support an alternative to congregate care. Fran is unable to make competent decisions on her own but has no one external to the facility to consider alternatives on her behalf.</p>	<p><b>SEAN</b> is 12 years old. He has a profound intellectual disability, gastrostomy and tracheostomy tubes, and uses a wheelchair. He was placed in a nursing home at seven months of age. He lived more than two hours from his mother who was unable to visit due to her inability to find child care for her other children for the extended time required for the trip. She frequently moved residences without notifying the facility and was unable to maintain a working phone number. She could not be contacted for semi-annual reviews and waiver offers went unanswered. The Family-Based Alternatives project staff visited her last known address and employer to try to locate her. They were able to connect and develop a relationship through face-to-face contact. They located a support family and Sean was placed with the support family at the age of 10. The FBA project helped the mother arrange a power-of-attorney to make decisions in her absence.</p>

*Time-related factors* played a role in admission, consideration of alternatives, and uptake of alternatives. Lack of resources and services *prior* to admission was a key factor in many admissions. Access *after* admission was a key factor in uptake of alternatives for some cases. However, new access to previously unavailable resources and services did not necessarily result in immediate uptake of alternatives.

- In some cases, moves to families occurred fairly quickly after admission with access to previously unavailable resources and services.
- In some cases, moves to families came many years later when family-based alternatives which had previously been available but rejected were reconsidered as the result of closure of the facility.
- In some cases the instigation for a move was a change in the family's circumstances over time (e.g., remarriage, aging of siblings).
- In some cases, consideration of an alternative was the result of a slow process of shifting parent/LAR ideas through experience and exposure to alternatives, often facilitated by active engagement with someone who was knowledgeable and experienced with family-based alternatives.

#### **System changes over time**

**SARA** is 23 years old. She has severe physical and intellectual disabilities. She uses a wheelchair and needs assistance with all of her needs. Sara's disabilities were the result of a traumatic brain injury at fifteen months of age due to abuse by her father who was subsequently imprisoned. After a year in the hospital Sara was admitted to a large facility at age 2. She stayed for eight years then moved to a large ICF for five years. She then moved to a nursing home for five years. Sara had already been living in congregate care settings for ten years in 2001 when Texas' permanency planning legislation was enacted. She became entitled to Medicaid waivers by virtue of her residence in a nursing home and the money-follows-the-person policy, but no offered waivers at that time provided for a support family living arrangement. Sara's mother was unable to care for her at home but was willing to consider a family-based alternative to congregate placement. In 2007 a waiver with support family services was made available to children in nursing homes. The staff from the Family-Based Alternatives project took Sara's mother to visit ten alternate families until she found the family she considered right for Sara and her. Sara moved to a support family at age 21 after 20 years in congregate care.

The thirty cases described many tragic situations that led to congregate care, but also provided examples where system responses went beyond simply removing children and young adults from difficult situations. The benefits of family life were reopened to children and young adults with high support needs and families with difficult circumstances through active and assertive (re)direction of resources, services, and supports toward family-based alternatives to congregate care.



## **THEMES ACROSS THREE COMPONENTS OF STUDY**

Eight themes related to congregate care of children and young adults with disabilities were evident across the three components of the study.

1. Ecological perspective. The literature, PPI reviews, and case studies identified multiple interacting factors regarding children, families, and services systems that contributed to admission and future pathways.
2. Resource access. The literature review described historical changes in services and funding from institutions to the community. The histories of children and young adults in the PPIs and case studies reflected this shift. Inadequacy of services was indicated in 57% of PPIs as a contributing factor to initial facility admission. The case studies provided examples of the importance of access to resources enabled by the Promoting Independence Plan and money-follow-the-person policies in providing alternatives to congregate care. But the case studies also highlight the role that waiting lists for community services and lack of access to waivers as a diversion strategy played in admissions to facilities.
3. Family appraisals and beliefs. The literature review suggested that family perceptions and interpretations of disability, care giving burden, and stress are shaped by interpersonal, cultural, and professional influences and play a role in their decisions regarding placement in congregate care. Studies showed that unmet need and fragmentation of services undermine families' sense of control and affect their appraisal of their ability to maintain their child at home. Research suggests that differences in appraisals are often unrelated to the severity of disability. The PPIs and case studies provide examples where children with very similar disabilities have families with very differing views about the appropriateness and desirability of congregate care or alternatives.
4. Family engagement in planning. The literature review described three planning approaches with emerging evidence as promising practices: wraparound, system of care, and family group decision making. A common feature of all three is engagement of parents and extended family members in planning. Research on family group conferencing found that marshalling the ideas and resources of extended family networks generated more creative and wide-ranging solutions to support a child within their community than traditional service planning approaches. The PPI reviews provided examples of minimal or no family participation in planning. The case studies provided examples where extended families who were engaged in planning were facilitated to assume care of a child as an alternative to congregate care.
5. Young adults engagement in planning. The literature review raised questions about the absence of the perspective of young adults in research about congregate care. One of the few studies seeking the views of youth living in congregate care found differences between parents and youth. Where families focused on services attributes, youth focused on relationships and community links. The PPIs reflected a significant

number of young adults who were not involved in discussions of alternatives to congregate care, in some cases even when they were identified as their own LARs. The case studies provided examples where no one was available to consider the merits of alternatives or act on behalf of young adults with questionable capacity.

6. Role of facilitator. The promising planning approach of family group conferencing identified in the literature review highlighted the important role an active independent facilitator can play in assisting families in planning. The facilitator role extends beyond linking to pre-existing services to focus more broadly on positive desired outcomes. The case studies highlighted availability of such a person as a significant factor contributing to the uptake of alternatives to congregate care. The literature on promising practices and the case studies emphasized that facilitation is significantly different from traditional service coordination strategies that offer slots, beds, and menus of services from which to choose.
7. Cross system issues. The literature review identified promising approaches to working with children who have needs that cross service systems. The PPIs identified that 51% of children and young adults had both an intellectual disability and a mental health disability, 27% of minors had both a developmental disability and child protective services involvement, and 19% of minors had both a mental health disability and child protective services involvement. The case studies provided examples where traditional silos of disability and child welfare service systems blocked access to the most fitting services.
8. Challenging behavior. The literature review, PPIs, and case studies were consistent in identifying challenging behavior as a frequent factor involved in admissions to congregate care. The literature identified Positive Behavior Support (PBS) as an evidence-based approach for working with individuals with challenging behavior in community settings, and specifically in family homes. In 66% of PPIs, children and young adults were identified as having challenging behavior. In 8 of the 19 case studies which involved movement from a facility to a family setting, children and young adults had challenging behavior. In two cases of children and young adults with challenging behavior who remain in facilities, support families were tentatively identified who were willing to provide care and plans were underway to prepare them and determine whether adequate supports could be developed to assure success. In two other cases, however, despite considerable effort, no family-based living arrangements had yet been identified. Potential willingness of a family to care for a child with challenging behavior is related to both competence and confidence in their abilities and the support they can expect to assist them. Potential success is related to the ongoing reliability and adequacy of supports.

## DISCUSSION

The purpose of the study was to better understand the use of congregate care for children with disabilities in Texas. Themes across the literature review, PPI reviews, and case studies suggest pathways that lead to admission, continued stay, and uptake of alternatives.

### Pathways

The literature review suggested *precarious pathways* that put children with disabilities at risk of institutionalization. The PPI reviews suggest *predictable pathways* in Texas that lead to admission, continued stay, or alternatives to congregate care. The case studies suggest *alternate pathways* that resulted in family-based alternatives to congregate care.

Pathways leading to admission to congregate care almost universally involved stress-related situations exacerbated by lack of resources and/or lack of alternatives to facility admission. A question can be raised as to whether access to alternatives would have been successful in averting congregate care admission. The current study, however, suggests that the existence of resources and choice of alternatives alone do not assure uptake of alternatives to congregate care. Beyond the scope of this study is understanding to what extent families are influenced by policies and practices which treat continued congregate care and family-based alternatives as equally acceptable choices despite research evidence of the benefit to children of family life and substantial risks associated with congregate care.

After admission, the PPIs identified pathways leading toward continued congregate care as more likely than alternatives. While continued congregate care may represent the informed choice of some engaged legally authorized decision-makers, given the findings of the PPI reviews and case studies, it is unreasonable to conclude that all PPIs which indicated lack of interest in alternatives were a reflection of active, fully informed legally authorized decision-makers. PPIs and case studies provided examples where absence of a decision by an informed and legally authorized representative resulted in continued congregate care by default.

Based on the findings, whether a future pathway leads to continued congregate care or uptake of an alternative is dependent on a complex set of factors including:

- Existence of a legally authorized representative (LAR)
- Level of involvement of the family/LAR with the child or young adult
- Level of involvement of the family/LAR in planning
- Clarity or determinability of decision-makers' preferences
- Effects of decision-makers' interpersonal influences, experiences, beliefs and appraisals
- Access to fitting services, supports, and resources
- Level of action after an indication of interest in an alternative
- Timing of system changes in the life cycle of a child or family.

Problems related to these factors raised questions for a significant portion of 830 PPIs where continued congregate care was identified as the “preferred” pathway. The case studies provided examples of alternative pathways where resolution of problems in some of these areas resulted in placement in a family-based alternative to congregate care. Factors involved in consideration and uptake of family-based alternatives included:

- Extensiveness of discussion of family-based alternatives
- Quality of description of family-based alternatives
- Experience of the individual describing family-based alternatives
- Energy devoted to engaging the family/LAR or young adult
- Type of relationship and level of trust between the family/LAR and the individuals involved in planning.

The case studies provide examples which showed how time, energy, knowledge, and experience with family-based alternatives contributed to a child’s movement to a family after reconsideration by a parent or LAR who had previously been reluctant to consider an alternative, rejected alternatives, or been uninvolved. The case studies provide examples where access to an active facilitator made the difference between continued stay in congregate care and movement to a family-based alternative.

The findings suggest that uptake of alternatives is not just dependent on options being offered, but on *how* options are offered. An example of the importance of the description of alternatives was evidenced in the case studies. PPI narratives of explanations of family-based alternatives sometimes described alternate families as “foster care” and stated the family did not want foster care. It is unclear to what extent the family’s only reference point to foster care was the child welfare system. Open to question is the possibility that a voluntary family-based alternative described in different terms (e.g., shared parenting) might have resulted in a different level of interest. Several cases provided examples where families initially rejected an alternative referred to only as “foster care” but subsequently accepted an alternate family described and understood differently.

### **System change**

The literature review suggests the permanency planning effort undertaken by Texas within the voluntary disability services sector as unusual in state services. A particularly relevant study in the literature examined an exceptional attempt in another state to implement permanency planning for children with disabilities in the developmental disability services system. Barriers to implementation in that state were identified as:

- Philosophical tensions around family versus government responsibility and intervention
- Fiscal limitations in making an array of family support available
- Absence of leadership
- Lack of clear responsibility

- Resistance of institutional providers
- Resistance of parents who had become content with residential care over many years or had little contact or emotional connection to their children
- Resistance to treating absence of parents as abandonment if they had placed based on professional input
- Lack of practice knowledge of caseworkers about the range of possible options.

A number of these elements were suggested in the PPIs and case studies as applicable in Texas.

In combination, the three components of the current study suggest the complexity of issues involved in continued use of congregate care by children with disabilities. A most important “take away” from this study is caution about overly simplistic conclusions about continued use of congregate care. The complex and interacting factors identified in the study suggest that reduction of congregate care must deal with how alternatives are facilitated for current residents as well as future children and young adults *at risk* of admission. The PPIs and case studies described many difficult situations where congregate care provided the only available solution. But they also provided examples of feasible family-based alternatives which could provide a solution other than institutionalization. If the benefits of family life suggested by the literature review are to be open to children with high support needs and families with difficult circumstances, then systems must actively and assertively direct resources, services and supports, and active facilitation toward family-based alternatives to congregate care.

### **Conditions for a successful system of family-based alternatives to congregate care suggested by the findings**

1. Access to adequate resources and fitting services and supports
  - Accessed and activated as soon as possible after admission
  - Available for children at risk of facility admission rather than requiring facility admission to access
  - Flexible and comprehensive enough to fit the unique and changing needs and circumstances of a child and family
2. Active engagement of families, LARs, and young adults
  - Investment of their time and energy in exploration
  - An external counter balance to offset possible facility biases (e.g., information primarily from individuals who are unfamiliar with community alternatives)
  - A mechanism for substitute decision-making for minor children and young adults unable to give consent who have no family or LAR who is actively involved with them and willing to participate in planning and decision-making on their behalf

### 3. An active facilitator

- With knowledge, experience, and connections
  - With experience with family-based alternatives to congregate care
  - Who understands resources and processes across disability services and child protective services
  - With connections with local services, providers, and networks of support families and foster families
- With time, energy, identified responsibility, and contact
  - Who assumes responsibility to assure all necessary actions are taken with to assist in exploration of possibilities; exposure to actual alternatives; matching needs with services and supports; and preparing, transitioning, and following up
  - Who has personal contact and develops relationships with families
  - Who provides continuity over time

### 4. Time and timeliness

- The timing of access to resources, services, and supports for alternatives is critical to whether congregate care is used and for how long.
- The process of assisting a family, LAR, child, or young adult to consider an alternative requires time to fully understand possibilities, explore ideas and beliefs, and be exposed to actual examples.
- The process of achieving a desired alternative requires time to find or create, adequately prepare, coordinate transition, and follow up.

## **SUMMARY**

The study suggests that pathways leading to admission to congregate care of children and young adults with disabilities involve interactions between characteristics of children, families, and systems. Children were most often admitted to congregate care when they had high support needs, their families faced difficult circumstances, and systems responded with no alternatives other than facility admission.

The study suggests that future pathways from congregate care to the community are tied to family/LAR decision-makers' beliefs, willingness to explore alternatives, and level of engagement combined with access to resources, services and supports, and a facilitator. Continued congregate care is most likely when (1) family/LAR's appraisal of satisfaction with congregate care and skepticism of alternatives goes unexplored or (2) family/LAR's are uninvolved in planning. Uptake of alternatives is most likely when (1) family/LAR's appraisal is that family life is preferred to facility life or (2) family/LARs are willing to be involved in exploration and participate in planning even if initially skeptical of alternatives.

Resources for alternatives that enable movement to the community from institutional care have become more readily available through the state's Promoting Independence Plan and money-follows-the-person policies. Future use of congregate care by children will be related to resources available for *diversion* prior to admission. Alternative approaches described in the literature review as promising in the areas of planning, family-based living arrangements, supporting children with challenging behavior, and prioritizing family life as a guiding framework may yet be more fully explored.

Future uptake of alternatives to congregate care will require policies, activities, and resources that solve the problems that lead to congregate care but do so in ways that give preference to family life over congregate care for children with disabilities in order to achieve the benefits and avoid the risks outlined in research about children's well-being.

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<sup>1</sup> Separate reports of the three components of the study providing additional details are available at [www.everychildtexas.org](http://www.everychildtexas.org).