Spotlight on Early Childhood Intervention (ECI) in Northeast Texas

TEXANS CARE for CHILDREN

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ABOUT TEXANS CARE FOR CHILDREN

We drive policy change to improve the lives of Texas children today for a stronger Texas tomorrow.

We envision a Texas in which all children grow up to be healthy, safe, successful, and on a path to fulfill their promise.

We are a statewide, non-profit, non-partisan, multi-issue children's policy organization. We develop policy solutions, produce research, and engage Texas community leaders to educate policymakers, the media, and the public about what works to improve the well-being of Texas children and families.

Funded by a variety of foundations and individual donations, our work covers child protective services, juvenile justice, mental well-being, health and fitness, early childhood, and the ways that each of those policy areas work together to shape children's lives and the future of Texas.

INTRODUCTION

The Texas Early Childhood Intervention (ECI) program contracts with community organizations to provide life-changing therapies and support to children under age three with disabilities and developmental delays. In November 2016, Texans Care for Children published a report, "Left Out: The Impact of State Cuts to Early Childhood Intervention (ECI) for Young Texas Kids with Disabilities," showing that thousands of Texas children were missing out on ECI services amid years of state funding cuts.

The report coincided with a statewide outcry about the Legislature's 2015 decision to reduce Medicaid reimbursement rates for therapies for children with disabilities and an expectation that the 2017 Legislature would reverse those cuts. Instead, the 2017 Legislature only restored approximately one-quarter of the lost funding.

This report builds on our 2016 report, taking a closer look at the Tyler-Longview area of Northeast Texas, which includes Smith, Gregg, Bowie, and other smaller counties. This report reflects data gathered on population and enrollment changes in the region as well as interviews with local ECI leaders, parents, pediatricians, child care directors, and social workers from March to June 2017. This report also includes new statewide information, including information on the partial rebound in ECI enrollment, additional program closures, and state policy updates. While the 2016 report used enrollment data through 2015 and population data through 2014, this report uses enrollment data through 2016 and population data through 2015.

KEY FINDINGS

Statewide Update and Context for Northeast Texas Developments

- State appropriations for ECI have fallen since 2011, decreasing from $166 million in FY 2011 to $148 million in FY 2018.[1, 2]
- In 2015 Texas legislators also reduced the Medicaid reimbursement rates paid to providers who offer speech, physical, occupational, and other therapies to children with disabilities.
- Three ECI contractors withdrew from the state program last year and three more withdrew this year.
- The number of children in ECI services in Texas fell 10 percent between 2011 and 2016, while the population of children under age three grew four percent across the state between 2011 and 2015.[3, 4, 5]
- ECI enrollment has partially rebounded in recent years, including a five percent increase between 2015 and 2016.[6, 7]
- ECI enrollment of Black children statewide decreased 30 percent from 2011 to 2016, compared to 10 percent among Hispanic children and 8 percent among White children.[8, 9]
- In 2016, 43 percent of contractors reported that they had eliminated dedicated Child Find outreach positions due to fiscal constraints.[10]

Northeast Texas

- Between 2011 and 2016, ECI enrollment in Northeast Texas fell from 1,896 to 1,458, a decline of 23 percent -- compared to 10 percent for the state -- despite the region's overall population of young children remaining flat.[11, 12, 13]
- ECI enrollment in Northeast Texas experienced a temporary, partial rebound in 2014 but fell by three percent in 2015 and another four percent in 2016.[14, 15]
- ECI enrollment of Hispanic children in Northeast Texas decreased 41 percent from 2011 to 2016 despite a four percent increase in the region's population of Hispanic children under age three from 2011 to 2015.
- ECI enrollment of Black children in Northeast Texas decreased 39 percent from 2011 to 2016 while the region's population of Black children under age three decreased two percent from 2011 to 2015.
- There were particularly steep ECI enrollment declines from 2011 to 2016 in Bowie County (33 percent), Cherokee County (46 percent), Henderson County (38 percent), and Smith County, the home of the City of Tyler (29 percent), while none of those counties experienced a decline in the population of young children.[16, 17, 18]
- Titus County and Gregg County fared relatively well compared to other counties, experiencing level enrollment and a six percent decline in enrollment, respectively, from 2011 to 2016.[19, 20]
- An erosion of ECI Child Find outreach efforts in Northeast Texas may have diminished community knowledge regarding ECI and referrals to ECI while contributing to greater stigma and fear regarding ECI.
- The closure of the Andrews Center ECI program in Tyler in 2016 provides an example of how closures can lead to gaps in ECI services for children, decreased enrollment, a loss of community knowledge regarding the availability of ECI, and other challenges that add up to children being left out of ECI.

EARLY CHILDHOOD INTERVENTION IN TEXAS

What is ECI?

Texas Early Childhood Intervention (ECI) provides targeted, high-quality interventions for children under three years old with disabilities and developmental delays, such as Down syndrome, speech and language delays, and autism. ECI providers work with families to help children meet developmental goals such as learning to walk, communicating with their families, or preparing for success in elementary school. ECI focuses on the first three years of life, when interventions are most likely to positively shape a child's brain architecture and trajectory in life, help them be school-ready, and reach their full potential.[21]

To ensure children have access to these critical services, federal law (Part C of the Individuals with Disabilities Education Act, or IDEA) requires state-administered early intervention programs to provide these supports to all eligible babies and toddlers.

Texas ECI fulfills these requirements by contracting with community organizations across the state. The contracted organizations provide evidence-based therapies, skills training, parent-coaching, and other tailored services to help children develop the skills necessary to meet their goals.

State Cuts to ECI and Medicaid Reimbursement Rates

While ECI has proven to be effective for participating children, in 2011 the state began to reduce program funding and reduced eligibility, requiring children to show a more severe developmental delay in order to receive early interventions. As a result, many families either waited many months until their child's developmental challenges became severe enough to enroll in ECI or they turned to private therapy that does not include the full array of effective parent supports and home visits. In both cases, families missed out on supports when and where they needed them and children's developmental challenges became tougher to address.

Legislators reduced ECI appropriations again in the 2013 and 2015 legislative sessions. In the 2017 session, lawmakers increased ECI appropriations, both for the remainder of the 2017 fiscal year and for the 2018-2019 biennium, but they did not fully fund anticipated caseload growth for 2018-2019. The ECI appropriation for 2018 is set at $148 million, compared to the $166 million appropriation for 2011, prior to the start of budget cuts.[22, 23]

Compounding these funding and eligibility cuts, in 2015 Texas legislators reduced the Medicaid reimbursement rates paid to providers who offer speech, physical, occupational, and other therapies to children with disabilities. The lower rates went into effect in late 2016 following a series of court battles. Because two-thirds of children in ECI are enrolled in Medicaid, the rate reduction further stressed ECI program finances all across the state. Despite many calls for legislators to reverse the rate cuts during the 2017 legislative session, lawmakers only restored 25 percent of the Medicaid funding cut in 2015. However, many stakeholders are concerned that the small restoration of funding will be eroded by state rules that went into effect September 1, 2017 reimbursing pediatric therapy providers based on 15-minute increments of care rather on a per-patient basis.

The state cuts have placed a significant financial strain on ECI contractors. In 2014 alone, 22 ECI contractors (nearly half of the state's total) experienced shortages and used other organizational funds totaling $3.9 million to ensure kids received all the ECI services they needed.[24] Of those 22 contractors who were forced to pull from other local funding sources, seven have since closed their ECI programs.

The budget of the Texoma Community Center in Northeast Texas illustrates the impact of these state cuts. The program experienced a 28 percent decrease in Medicaid reimbursement rates in addition to a reduction of $300,000 in state funds in 2016 and $48,000 in FY 2017.[25]

As explained in the following pages, the financial strain caused by the state cuts has had significant consequences for ECI services for Texas children.

State Cuts Lead to Programs Closing Down

The financial strain on ECI has forced many contractors to drop out of the program or seriously consider it. In 2010, the state contracted with 58 organizations to provide ECI services to children across Texas. Currently, only 44 organizations provide ECI services.

Last year, three contractors – the Andrews Center in Tyler, the North Texas Rehab Center in Wichita Falls, and Emergence Health Network in El Paso – closed down their ECI programs. Two more ECI contractors, Easter Seals East Texas in Bryan/College Station and UTMB-Galveston shut down their programs on August 31, 2017. They were replaced on September 1, 2017 by Easter Seals of Greater Houston and Spindletop Center, respectively. Both are existing ECI contractors that expanded their service areas. Hill Country MHDD terminated its ECI program on October 11, 2017. Its service area is now divided among existing contractors Camino Real Community Services, Center for Life Resources, and Any Baby Can.

The closure of the Andrews Center on September 30, 2016 highlights how delays in HHSC's identifying and negotiating with a new ECI contractor, as well as the lag time in getting new ECI services up and running, are likely to cause children and families to go without ECI services for a period of time. For a child unable to walk or swallow, for example, gaps in ECI services may lead to developmental backsliding or further challenges in addressing the child's needs. The closure of the Andrews Center is addressed in greater details in the following pages.

Our research across the region and state has found that, even when a new ECI contractor is identified quickly, families may go without therapies for a period of time or fill the gap through private therapy services that may be more expensive and less comprehensive. The enrollment declines may be due to gaps in communication with referral sources and affected families, the time needed for hiring new staff and bringing them up to speed on each child's needs, a loss of confidence among referral sources, and other factors. For example, when North Texas Rehab ECI closed in Wichita Falls in Fall 2016, it was serving 240 children. It was quickly replaced by the Helen Farabee Center's ECI program, but it only serves approximately 150 children.[26] The ECI director of the Helen Farabee Center reports that it has taken many months to hire and train therapists, causing significant delays in evaluating children and providing them appropriate services.

Additionally, the closures have siphoned off scarce funding that could have gone to the numerous ECI contractors that were underfunded and struggling to stay afloat. In 2016, for example, the state allocated more than $2.2 million to provide start-up payments to ECI providers that agreed to replace programs that had closed their doors.[27] These payments occurred during a time when many other existing ECI agencies were struggling to keep their doors open.

State Cuts Lead to Lower Enrollment Statewide and Scaled Back Services

Due in large part to the state funding cuts, the number of children in ECI services in Texas fell 10 percent between 2011 and 2016, while the population of

children under age three grew four percent across the state between 2011 and 2015. The sharpest enrollment drops occurred after the 2011 cuts.

In recent years, there has been a partial rebound in ECI enrollment. Though enrollment dropped statewide by two percent in 2013, by 2014 nearly two-thirds of Texas counties began an upward trend in enrollment. **Across the state, enrollment increased three percent between 2013 and 2014, two percent between 2014 and 2015, and five percent between 2015 and 2016.**[28, 29, 30] Nonetheless, Texas has a low enrollment rate compared to other states. In 2015, Texas ranked 45th nationally for the percentage of children under age three enrolled in ECI.[31]

According to the consulting group that advised Texas in its decision to narrow eligibility in 2011, many other states that have reduced eligibility to save money experienced a temporary reduction in numbers, "but after one year the effect was mitigated… [and] the population of children served continued to increase." [32] Texas has been an exception to this pattern and, despite the recent rebound, continues to serve many fewer children than it in 2011.

Enrollment declines are even worse in some parts of the state and among certain demographic groups. In some of the state's largest urban counties, for example, enrollment declines between 2011 and 2016 are particularly severe: a 35 percent decrease in Collin County, 30 percent decrease in Harris County, 22 percent decrease in Travis County, and 22 percent decrease in Dallas County.[33, 34]

Additionally, statewide enrollment declines have affected Black children in Texas the most: **ECI enrollment of Black children statewide decreased 30 percent from 2011 to 2016, compared to 10 percent among Hispanic children and 8 percent among White children.**[35, 36]

The funding reductions have also forced ECI contractors to make their own damaging cuts. For example, there has been an erosion of Child Find outreach efforts, making it more difficult to boost enrollment of children in need of services. **In 2016, 43 percent of contractors reported that they had eliminated dedicated Child Find positions due to fiscal constraints.** The funding cuts have also affected the services provided to children who do enroll in ECI. Last year, over two-thirds of contractors expected to reduce the number (69 percent) and frequency (67 percent) of services to eligible children as a result of the Medicaid pediatric therapy rates, which went into effect in late 2016.[37]

BACKGROUND ON ECI IN NORTHEAST TEXAS

This report addresses ECI in the 23 counties that comprise Region 4 of the Texas Public Health System. The counties at the core of the region are Smith (home to the City of Tyler), Gregg (home to the City of Longview), and Bowie (home to the City of Texarkana). Nineteen less populated, more rural counties are also in the region. This report also refers to Region 4 as the Northeast Texas region.

Snapshot of the Region's Young Children

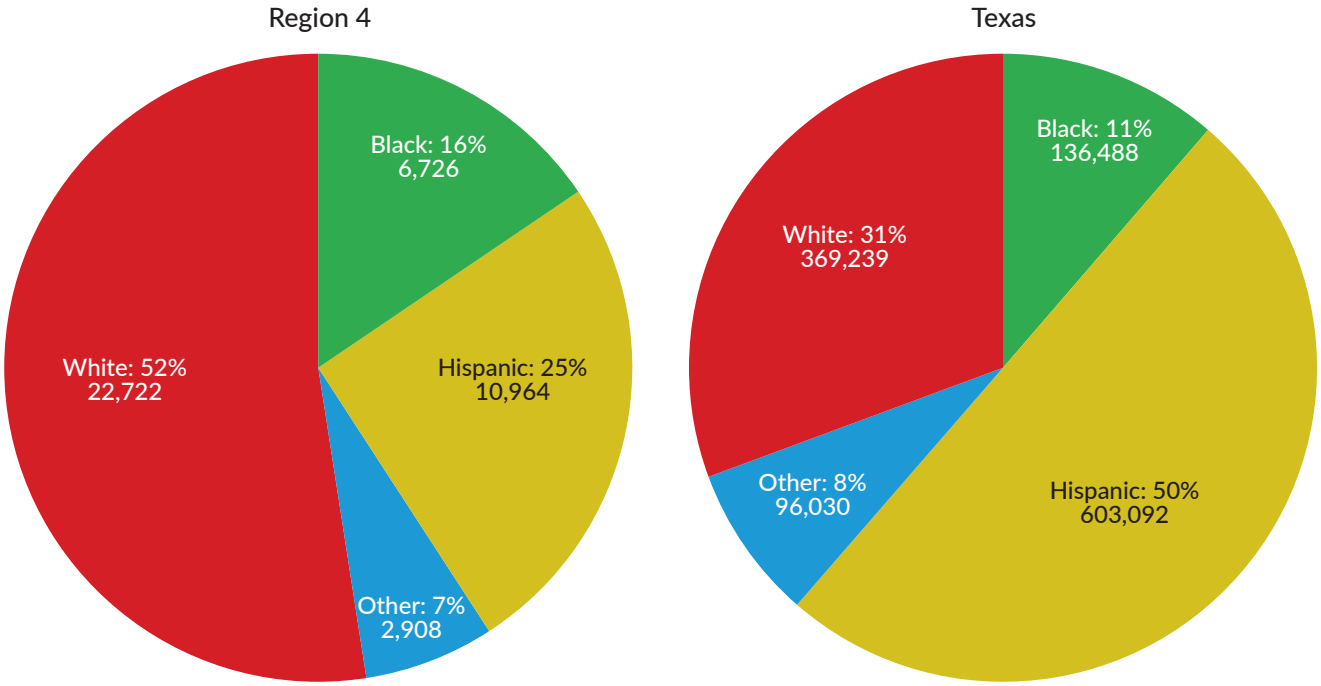
In 2015, the region was home to 43,320 infants and toddlers under three years old. Twenty-one percent of the children in the region reside in Smith County while another 38 percent of the region's child population under three years old live in counties bordering Smith County, including Cherokee, Gregg, Henderson, Rusk, Upshur, Van Zandt, and Wood.

Overall, the Northeast Texas region has a larger proportion of White children under age three (52 percent) than the statewide average (31 percent). The next largest racial/ethnic group in that age range in the region is Hispanic children, followed by Black children. The population of young children of color is concentrated primarily in the region's larger metropolitan counties, including Smith and Gregg. For example, just over 30 percent of Gregg and Smith County's children under three are Hispanic.

Snapshot of ECI Contractors in Northeast Texas

Currently, three community organizations contract with the state to provide ECI services to children in the 23-county area, which covers over 23,000 square miles. Community Healthcore expanded its service area to cover the communities that were served by the Andrews Center until last year.

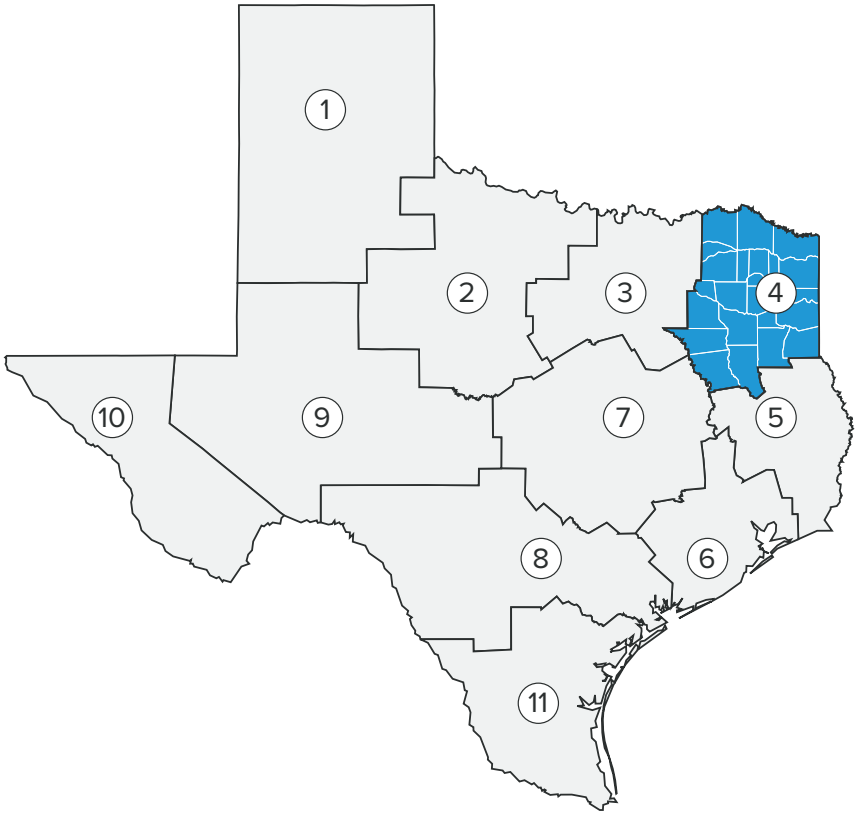
Figure 1: Population and Racial Distribution of Children Under 3 in Texas and Region 4



The Texas Demographic Center uses the "Other" population group to refer to all people who are Asian, identify two or more races, or otherwise fall outside of the Black, Hispanic, and White categories.

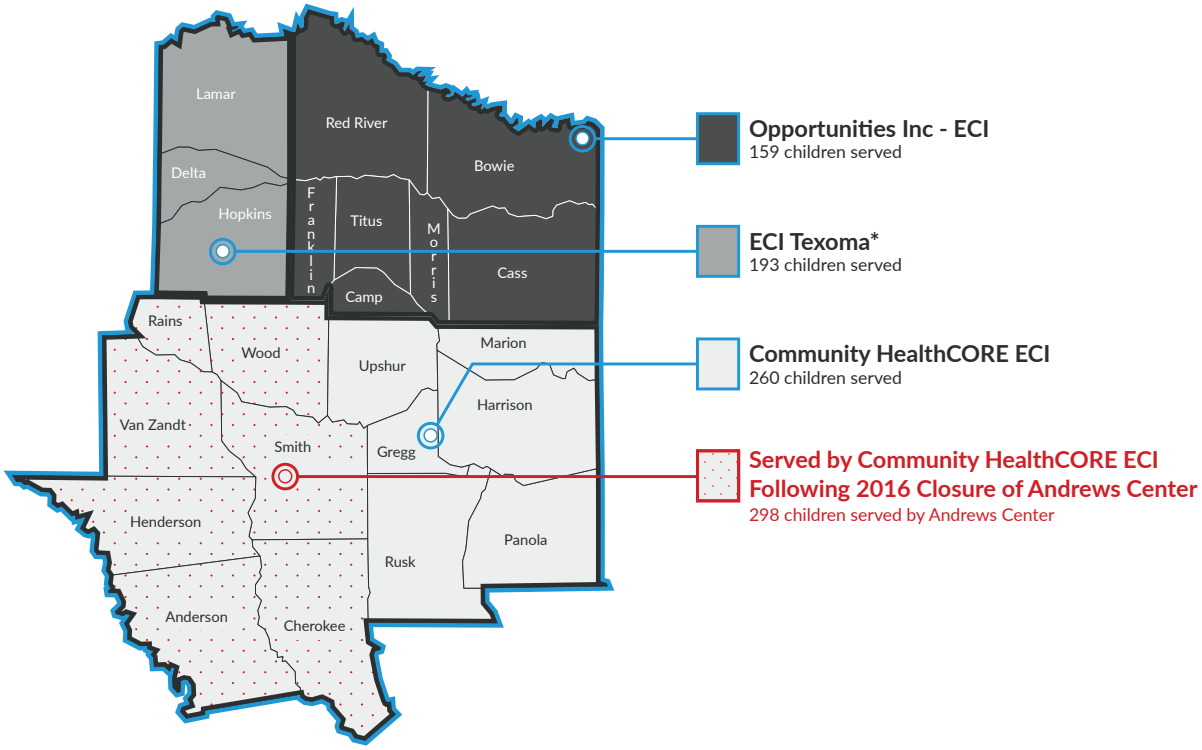
Source: Texas Demographic Center. (2016). Estimates of the Total Population of Counties in Texas by Age, Sex and Race/Ethnicity [2015 dataset]. Retrieved from http://osd.texas.gov/Data/TPEPP/Estimates/.

Figure 2: Texas Health Service Regions



Source: Texas Health and Human Services Commission. (2017). Center for Health Statistics Texas County Numbers and Public Health Regions. Retrieved from https://www.dshs.texas.gov/chs/info/info_txco.shtm

Figure 3: Region 4's Recent ECI Contractors and the Counties They Serve



* Texoma ECI is based in Grayson County in Region 3. It has a satellite office in Hopkins County that serves part of Region 4.

Enrollment numbers are a snapshot from August 31, 2015.

Source: Texas Department of Assistive and Rehabilitative Services. (2015) ECI Local Program Performance Reports (FFY2014-2015 Datasets). Retrieved from https://hhs.texas.gov/doing-business-hhs/provider-portals/assistive-services-providers/early-childhood-intervention-eci-programs/eci-data-reports/eci-local-program-performance-reports

JOHN'S STORY

John was born three months premature. The hospital told us to just wait and see and that his pediatrician would know if he's behind or not. We noticed that he wasn't walking, but weren't too concerned, thinking some kids walk a bit later than others.

When he wasn't talking like he was supposed to, I became really concerned.

Being new to Northeast Texas, I did not know what resources were out there, and then I found ECI.

Our ECI experience was amazing. The program was so important to us. I'm glad that I had the support of ECI.

When my son was transitioning out of ECI, I was scared and struggled with putting him into the Head Start program at the local district. I thought to myself, "My child is not special needs and he will be labeled special education for the rest of his life." It was scary for me to think he would have to carry that label throughout school. ECI addressed my fears, struggles, and stigma around special education services—they bridged the gap. Throughout his first year in Head Start, the ECI team checked in on us.

Today, John is 20 years old and a sophomore in college studying criminal justice. He graduated in the top 12 percent of his high school class, started college with 12 hours of college credits, and is thriving!

I believe the early intervention of his speech therapist and other ECI supports set him and our family up for success.

Looking back, the biggest takeaway from our experience with ECI is the guidance provided by ECI, which allowed me to be my child's best advocate throughout his school career. Like us, many parents of children of disabilities are probably scared and don't know where to begin. ECI is a valuable resource that can provide parents meaningful tools, support, and guidance.

- Herwanea, John's mom, in Tyler

LOWER ECI ENROLLMENT IN NORTHEAST TEXAS FOLLOWING STATE CUTS

Between 2011 and 2016, ECI enrollment in Northeast Texas fell by 23 percent. Enrollment decreased from 1,896 to 1,458, a decline of over 400 children.[38,39] During this time the population of young children in Northeast Texas remained flat, going from 43,578 in 2011 to 43,320 in 2015.[40] **The region's 23 percent enrollment decrease was worse than the statewide 10 percent decrease.**

There was a particularly sharp drop in enrollment, both in the region and the state, between 2011 and 2012 when Texas lawmakers cut funding and narrowed eligibility requirements for the ECI program, eliminating services for children with less severe developmental challenges. In that first year (2012), ECI enrollment dropped 17 percent across the state and 21 percent in Northeast Texas. Some counties were hit particularly hard during that first year, including Cherokee County (a 37 percent decrease), Henderson County (a 27 percent decrease), Smith County (a 24 percent decrease), and Gregg County (a 23 percent decrease).

ECI enrollment in Northeast Texas rebounded in 2014 with a six percent year-over-year increase but unlike the statewide trend, the rebound in Northeast Texas was temporary. Enrollment fell by three percent in 2015 and another four percent in 2016.[41,42]

The region's large enrollment declines affected children of all races and ethnicities, but there was a significant disproportionate impact on Hispanic and Black children. **While the population of Hispanic children increased in Northeast Texas by four percent, their enrollment in ECI plummeted 41 percent from 2011 to 2016.**

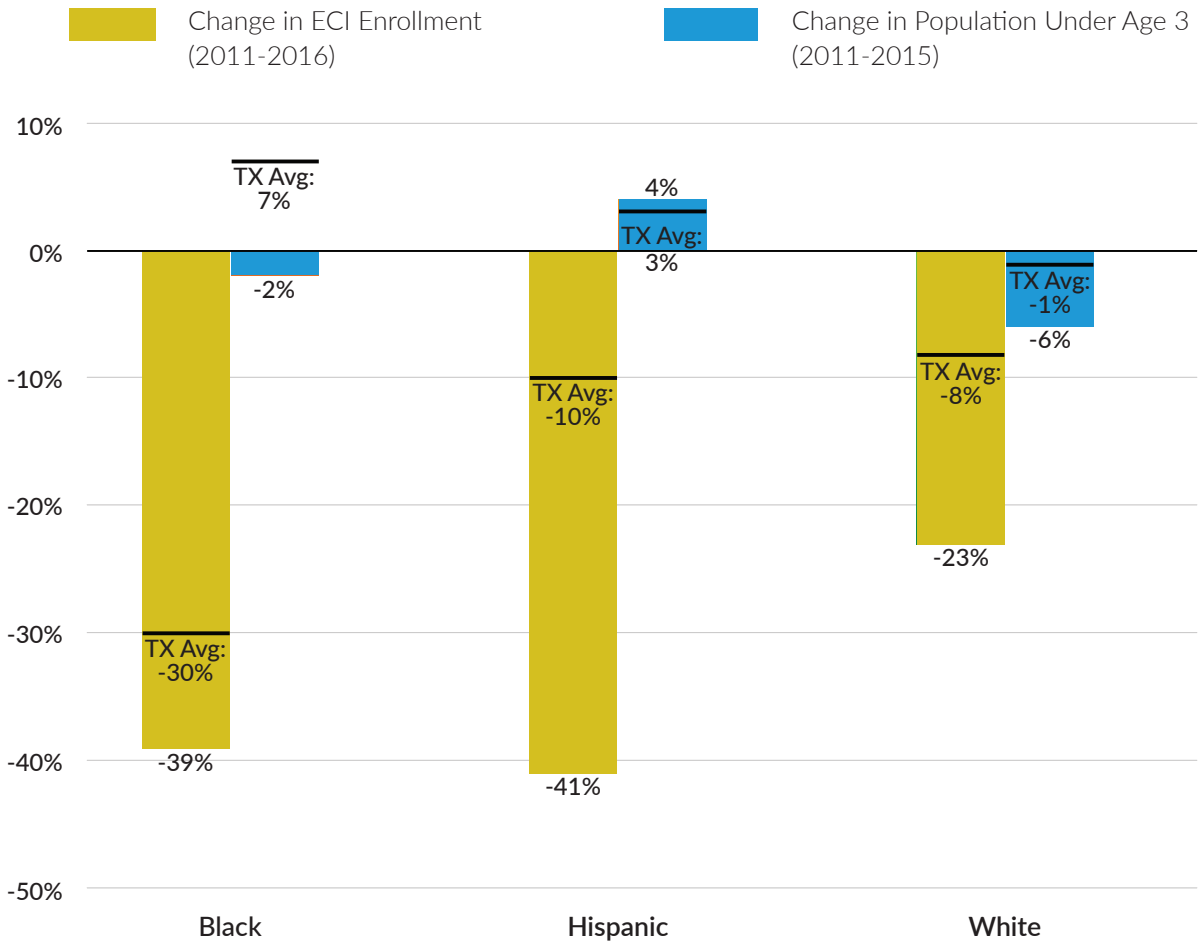
Similarly, while the population of Black children under three living in the region during that time decreased two percent, ECI enrollment among Black children fell 44 percent. Enrollment of the region's White children fared better, falling only 23 percent between 2011 and 2016, while the population of young White children decreased 6 percent between 2011 and 2015.[43, 44, 45]

Among the six counties that had more than 100 children enrolled in 2011, there were particularly steep enrollment declines in Bowie County (36 percent), Cherokee County (54 percent), Henderson County (41 percent), and Smith County, the home of the City of Tyler (29 percent).[46, 47] None of those counties experienced a decline in the population of young children.[48]

Among the six counties that had more than 100 children enrolled in 2011, Titus County and Gregg County fared the best. Titus County enrollment remained even at 103 children from 2011 to 2016 despite a decline in population. In Gregg County, the home of the City of Longview and one of two largest counties in the area, the enrollment decrease was not as steep as it was in the region as a whole. ECI enrollment in Gregg County decreased six percent from 2011 to 2016, a concerning decline but not as severe as the region's 23 percent decline.[49, 50] The population of young children in the County and the region remained fairly flat during this time. Enrollment of young white children in Gregg County fared particularly well, dropping only two percent from 2011 to 2016 while the County's population of White children under three decreased nine percent from 2011 and 2015. The Hispanic enrollment decline in Gregg County is concerning, but it's better than the Hispanic enrollment declines that occurred in the region in the midst of similar population growth: Gregg County's enrollment of Hispanic children declined 10 percent (amid a nine percent increase in the population of young Hispanic children from 2011 to 2015) while Smith County, for example, saw a 21 percent decline in ECI enrollment of Hispanic children (amid an 11 percent population increase from 2011 to 2015).[51, 52, 53]

Figure 4: Change in ECI Enrollment and Population Under Age 3, By Race/Ethnicity, in Region 4

Black and Hispanic enrollment declined disproportionately.



Sources: (1) Texas Department of Assitive and Rehabilative Services. (2016). Dataset from Public Information Request made by Texans Care for Children. (2) Texas Health and Human Services Commission. (2017). Dataset from Public Information Request made by Texans Care for Children. (3) Texas Demographic Center. (2016). Estimates of the Total Population of Counties in Texas by Age, Sex and Race/Ethnicity [2011 and 2015 datasets]. Retrieved from http://osd.texas.gov/Data/TPEPP/Estimates/.

WAYS THAT STATE CUTS CONTRIBUTE TO DECLINING ECI ENROLLMENT AND OTHER ECI CHALLENGES IN NORTHEAST TEXAS

Closing of the Andrews Center ECI Program in Tyler

The number of ECI contractors in the region fell from five in 2009 to three in 2017. In 2010, Region 8 ESC ended its ECI program. It had served Franklin, Camp, Cass, Morris, Red River, and Titus Counties.

In 2016, the Andrews Center, a well-known and established presence in Tyler, closed down the ECI program it had managed for more than 20 years. It had served the Tyler-Jacksonville area of Region 4 (Smith, Henderson, Cherokee, Van Zandt, Wood, and Rain Counties).

State and local experts interviewed for this report cite the fiscal and administrative burdens as the primary reasons for the closure of the Andrews Center ECI program. The organization's participation in the ECI program led to the loss of over one million dollars over a three- to four-year period due to unreimbursed costs, the need to transfer funding from the rest of the organization to cover ECI costs, and other financial pressures.[54] Local stakeholders also described the ways that the financial strain on the Andrews Center undermined the quality of ECI services they provided prior to closing their program. A former Early Intervention Specialist for the Andrews Center said that they struggled to meet the deadline to develop an Individualized Family Service Plan within 45 days.[55] Many pediatricians in the Tyler-area told us they were frustrated by unreturned phone calls and the lack of follow-up after a referral, believing those factors impacted family engagement. "In general, if a family doesn't hear back within two weeks about ECI referral, they don't think there's a problem," says Dr. Valerie Smith.[56]

The closure of the Andrews Center has hurt ECI services and enrollment in three key ways that we have also seen in other regions of the state.

First, there was a gap between the end of the Andrews Center's ECI contract with the state and the start of the state's contract with the program that replaced it. The Andrews Center ended services on September 30, 2016 for the approximately 300 children it served. On November 1, 2016, Community Healthcore, located in Longview (about 40 miles east of Tyler) absorbed the service areas of the closed program. By January 2017, some of the children previously served by the Andrews Center started to receive services.[57] Because of the gap, Disability Rights Texas filed a complaint in December 2016 on behalf of a child in Smith County previously served by the Andrews Center. The complaint alleged that the child's gap in ECI services violated the federal Individuals with Disabilities Education Act (IDEA). The hearing officer for Texas HHSC issued a formal decision in early January 2017 that the interruption did violate IDEA and ordered the state to resume full services to the child within seven days.[58]

Second, services are interrupted due to the time needed to hire and train staff, evaluate children's needs, and take other steps to launch a full-functioning ECI program. According to media reports, in December 2016, Community Healthcore was only staffed at 50 percent.[59] Our research shows that similar delays have occurred following closures in other parts of the state.

Third, in the case of the Andrew Center's closure and in other closures around the state, there were gaps in communication with families and community referral partners, a loss of confidence in the community, and other difficulties. One former ECI program staffer that worked in the areas served by the Andrews Center described the transfer process following the closure of the Andrews Center's ECI program as a "nightmare," explaining that children fall through the cracks because procedures for connecting families and referral sources with a new provider are unclear.[60] A Tyler-area physician reported to us in May 2017, "We were without ECI October through January or February. There was a care gap in services to families. When ECI was disbanded no one even knew about it. An organization in Longview has the contract now and many people don't know they have the contract."[61]

Erosion of "Child Find" Outreach Efforts

ECI contractors' Child Find staff work with pediatricians, child care providers, social service agencies, neonatal hospital staff, and others to ensure that parents of

young children with disabilities and developmental delays are aware of ECI and have the support necessary to enroll their children. Federal regulations require all states to have a robust Child Find effort in place, which is critical for enrolling children in need of services.

Unfortunately, as the state has cut ECI funding, there has been a significant erosion of Child Find efforts across Texas. **According to our 2016 survey of all ECI contractors in Texas, 43 percent eliminated their dedicated Child Find staff positions in the previous four years.** As of 2016, only 22 percent of the state's ECI contractors had a dedicated Child Find staff person.[62]

The deterioration of Northeast Texas Child Find efforts – and its impact on community knowledge of ECI and referrals to ECI – is clear. Years prior to closing the ECI program, the Andrews Center had a director of Child Find; however, funding reductions in 2011 forced Andrews Center to utilize staff in other ways, undermining community enrollment. A Community Health Worker (CHW) in Tyler told us, "For years I've thought we didn't have an ECI program because you just don't hear about it."[63] Other community members we spoke with from May to July 2017 in Northeast Texas noted that many newer, younger directors and staff of child care centers appear to be less knowledgeable about ECI because ECI staff visit with child care centers staff less than they used to.[64]

The closure also affected relationships between ECI and pediatricians and other health providers. One local pediatrician said, "Honestly, I started doing direct referrals to Occupational Therapy (OT) and Speech because I got so used to not getting a response from ECI and months without a provider."[65] Child Find efforts are now needed to educate community partners in the Tyler area about the availability of ECI through Community Healthcore, the replacement for the Andrews Center program. Several local social service providers and pediatricians in the Tyler area informed us that they did not know how to submit a referral to Community Healthcore.[66]

The region's Child Find efforts also face the challenge of keeping up with the changing demographics in Northeast Texas. The number of White children under three in the region is declining while the number of children of color is increasing.[67] Further research would be required to determine whether local Child Find efforts have been able to deploy Child Find staff and resources that reflect the cultural and linguistic diversity of the region.

This deterioration of Child Find efforts undermines any efforts to reverse some of the particularly concerning enrollment trends, including the disproportionate enrollment drop among children of color. Given the other demands of taking on more service areas and other responsibilities, it may be difficult for the new ECI contractor, Community Healthcore, to address the problem.

Stakeholders report that the most at-risk, underserved, and hard-to-serve children are more likely to be "missed" when Child Find efforts deteriorate. In Texas, these children include those living in rural areas, in poverty and/or unstable conditions, in households where English is not the primary language, and with parents reluctant to seek services for a variety of reasons.

Greater Stigma and Fear

Anecdotal reports suggest that ECI-related fears and stigmas are gaining momentum in the absence of meaningful ECI outreach.

Many community stakeholders in the region perceived a growing caution among some families about enrolling their child in ECI based on distrust of government-related healthcare interventions; stigma around mental health challenges; assumed association of ECI with Child Protective Services; fear of getting involved in a public program, particularly among immigrants; and sometimes even guilt or denial regarding a child's disabilities or delays.

A former ECI staffer shared her perspective saying, "African American families faced a lot of fear around admitting their child's delay and felt a lot of worry when asking for help….We tried to help address fears, stigma and bias around disabilities through community outreach and education and our efforts were successful, but it got harder when we couldn't spend as much time in the community."[68]

One example noted by stakeholders was ECI contractors' previous visits to child care centers to conduct universal screenings. A former Child Find Director in the region said the "screenings for everyone" approach was effective in opening the door for a conversation about any concerns, easing fears among families, and reducing some families' perception that they were being targeted. Unfortunately, we heard from community members that these efforts have waned as dedicated Child Find activities could not be sustained.

Families may be more likely to overcome the fear or stigma when ECI programs are able to conduct comprehensive community outreach, employ ethnically and linguistically diverse staff from the communities they seek to reach, and develop strong relationships with families, physicians, and child care centers.

Fig 5. Change in ECI Enrollment and Population Under Age Three in Region 4 Counties

EAST TEXAS COUNTIES	2011 ECI Enrollment	2016 ECI Enrollment	Change in ECI Enrollment 2011-2016	Change in Population Under Age 3 2011-2015
Smith*	339	240	-29%	3%
Gregg	314	296	-6%	0%
Bowie	161	108	-33%	4%
Henderson*	143	89	-38%	3%
Cherokee*	104	56	-46%	1%
Titus	103	103	0%	-5%
Van Zandt*	83	60	-28%	-1%
Anderson*	80	40	-50%	-4%
Upshur	77	47	-39%	-7%
Harrison	75	65	-13%	-5%
Rusk	68	64	-6%	-9%
Lamar	60	40	-33%	2%
Hopkins	53	49	-8%	-3%
Camp	45	25	-44%	3%
Wood*	43	49	14%	-2%
Cass	33	37	12%	4%
Panola	32	18	-44%	-4%
Morris	20	19	-5%	-2%
Rains*	19	9	-53%	-6%
Franklin	18	17	-6%	-13%
Red River	13	16	23%	-2%
Marion	8	4	-50%	-6%
Delta	5	7	40%	-1%
EAST TEXAS TOTAL	**1,896**	**1,458**	**-23%**	**-1%**
STATEWIDE TOTAL	**59,092**	**53,077**	**-10%**	**4%**

* ECI program closure occurred in these counties in 2016.

Sources: Texas Department of Assistive and Rehabilitative Services. (2016). Dataset from Public Information Request made by Texans Care for Children. (2) Texas Department of Assistive and Rehabilitative Services. (2017). Dataset from Public Information Request made by Texans Care for Children. (3) Texas Demographic Center. (2016). Estimates of the Total Population of Counties in Texas by Age, Sex and Race/Ethnicity [2011 and 2015 datasets]. Retrieved from http://osd.texas.gov/Data/TPEPP/Estimates/.

ADDITIONAL CHALLENGES FACING ECI IN NORTHEAST TEXAS AND ACROSS THE STATE

State Contracts Underestimate the Number of Children Served

Individual ECI agencies often serve many more children than anticipated in their state contract. In FY 2017, for example, 54 percent of ECI contractors served more children than they were contracted to serve.[69] HHSC's financial contract with each provider is based on the state's annual estimate of how many children that provider will serve. The state is obligated to provide additional mid-year funds to the contractors to cover unexpected additional enrollment. Contractors are required to use those additional funds before the end of the fiscal year, but the payments are often made so late that contractors are unable to use the funds before the deadline.

ECI Contractors' Transportation Costs Are Not Fully Reimbursed

Another financial challenge pointed out by ECI agencies in Northeast Texas and across the state is the transportation time needed to reach families to provide in-home supports, which is not fully reimbursable to insurance or the state. This is critically important for rural areas given the large service areas of ECI programs in the region. Moreover, a former Early Intervention Specialist told us, "Caseloads should not just be based on numbers but also driving times—that impacts everything."[70] More information is needed to determine how caseloads are calculated for contracting purposes and if any changes would help ECI agencies in rural areas reach all children in need.

Providing Translation Services Amid Financial Strain

The financial strain on contractors may have an impact on their ability to meet the diverse needs of families, including the ability to provide culturally and linguistically appropriate services. In Tyler, a former Early Intervention Specialist shared, "There was only one therapist who spoke Spanish and one translator for seven counties—scheduling become chaotic and the delivery of services was impacted." In addition to workforce issues and challenges recruiting bilingual staff due to low pay, she added that the ECI program paid for the translator's time to drive long distances to families, which was a non-billable cost.[71]

More information and research is needed to determine how best to support translation services to ensure all eligible children, regardless of their family's home language, can be effectively served.

Gaps in Developmental Screenings

In many cases, children are referred to ECI when a doctor identifies a possible disability or delay after conducting a developmental screening during routine check-ups. The American Academy of Pediatrics (AAP) recommends eight of these well-child check-ups within the first 15 months of life and developmental screenings for children at 9 months, 18 months, and 24 or 30 months.

Unfortunately, it appears that a large proportion of Texas children are not being screened for possible developmental or social delays. For instance, according to the National Survey of Children's Health 2011-2012, only 30 percent of Texas children age 10 months to 5 years received a standardized screening for developmental, social, or behavioral concerns.[72]

Additional data is available regarding the low screening rate for Texas children enrolled in Medicaid and the Children's Health Insurance Program (CHIP). While over three million Texas children – or 45 percent of Texas children – are enrolled in Medicaid or CHIP coverage, it is important to note that this plan-reported data does not include children in private insurance or those who do not have coverage. The data reported by Texas Medicaid and CHIP health plans reveal:

- Among Texas children under age three enrolled in Medicaid or CHIP, only 45 percent were reportedly screened during the previous year with a standardized tool for risk of developmental, social, or behavioral delays;

- Just 41 percent of Texas children under 12 months, 50 percent of one-year-olds, and 45 percent of two-year-olds received developmental screenings during the previous year.[73]

These screening rates are based on a developmental screening measure endorsed by the National Quality Forum ("Developmental Screening in the First 3 Years of Life"), which identifies whether, during the past 12 months, a child was screened for risk of developmental, behavioral, and social delays using a standardized screening tool. The data take into account the number of children *eligible* for a developmental screen. In other words, screening rates are based on the number of young children in Medicaid or CHIP who *should have* been screened according to American Academy of Pediatrics recommendations to screen children at 9 months, 18 months, and 24 or 30 months.

It is important to highlight that this data may underrepresent the number of Texas children being screened because the measure includes some – but not all – screening tools used by doctors.*

A relatively high percentage of Texas children enrolled in Medicaid and CHIP are going to well-child visits, suggesting that the low screening rate is not due to a lack of well checks. Among this population, 96 percent of children 12 months to 24 months and 90 percent of children 25 months through 6 years had at least one visit with their primary care physician in the last year, according to 2015 data. For those children 15 months old or younger, 55 percent received six or more well-child visits during the year. (The AAP recommends eight well-child visits in the first 15 months of life; Medicaid and CHIP plan-reported data tracks the percentage of children receiving six or more well-child visits within the first 15 months of life).[74]

Northeast Texas has a low screening rate compared to other parts of the state. Compared to the statewide average of 45 percent, only 34 percent of children under age three enrolled in Medicaid and CHIP in the Northeast Texas Managed Care Service Area were screened during the last 12 months for developmental, social, and behavioral delays. With screening rates ranging from 29 to 58 percent across Texas regions, Northeast Texas underperforms compared to the El Paso region (56 percent), the Bexar region (44 percent), and the Dallas region (52 percent), among others.[75]

On the other hand, Northeast Texas is in line with other regions when it comes to young children receiving well-care check-ups, according to Medicaid and CHIP plan-reported data. In the region, 97 percent of children 12 months to 24 months and 88 percent of children 25 months through 6 years had at least one visit with their primary care physician in the last year (compared to 96 percent and 90 percent statewide, respectively). Likewise, 56 percent of Northeast Texas children enrolled in Medicaid and CHIP received six or more well-child visits during the first 15 months of life, similar to the statewide average of 55 percent.[76]

Physicians we spoke to in the region highlighted some of the possible reasons for low screening rates. Physicians working in the Tyler-Jacksonville area noted that developmental screenings are a "newer practice" for general physicians, and in rural areas like Northeast Texas, more children are often seen by family practice physicians rather than pediatricians who may be more familiar with developmental screening, monitoring, and community resources.

Moreover, some stakeholders in the region suggested that low-income and minority populations are more likely to visit physicians who, for a variety of reasons including time constraints, may not spend the necessary time screening for developmental delays and connecting families with helpful programs. Dr. Valerie Smith shared, "There's a variability in the quality of providers serving Medicaid patients. In high volume

* Additional research is needed to determine if screening rates may potentially underrepresent the number of screenings conducted in health settings. It is possible that more young Texas kids are being screened for potential concerns when they visit the doctor, but plan-reported data may not reflect these screenings if the Ages and Stages Socio-Emotional Questionnaire (ASQ-SE) tool or other screens are performed.

To be part of the "Developmental Screening in the First Three Years of Life" measure, the health provider must use a screening tool that covers the full array of developmental "domains" – motor, language, cognitive, and social-emotional aspects of a child's development. Tools that only focus on assessing a child's mental health, for example, are not counted for this measure. Currently, about seven standardized screening tools meet this criteria and cover the full array of developmental domains.

While AAP does not endorse any specific screening tool, Texas Medicaid and CHIP reimburses health providers when three specific developmental screening tools are used: the Ages & Stages Questionnaire (ASQ); the Parents' Evaluation of Developmental Status (PEDS); and the Ages and Stages Socio-Emotional Questionnaire (ASQ-SE). While ASQ and PEDS screening tools are part of the developmental screening measure, the ASQ-SE tool is not because it focuses on a specific element – a child's social-emotional or mental health.

In addition, the developmental screening measure includes children enrolled in the Medicaid or CHIP plan continuously for 12 months prior to the child's first, second, or third birthday. Data is excluded if there is an enrollment gap of more than 45 days during the measurement year, meaning that some children who lose insurance during the year may be receiving a screening during check-ups but are excluded from the data.

practices, providers are seeing kids every 10 minutes and things can get missed."[77]

More research is needed to better understand screening tools used by providers, gaps in screenings, reasons behind regional differences, and how screening practices affect ECI enrollment.

Relationships with Managed Care Organizations

Managing the critical relationships with Managed Care Organizations (MCO) is an additional challenge for ECI contractors. HHSC contracts with MCOs, such as Blue Cross Blue Shield of Texas, Parkland HEALTHfirst, Superior Health Plan, and others, to coordinate health services for most Texas children enrolled in Medicaid and all Texas children enrolled in the Children's Health Insurance Program (CHIP).

ECI contractors must maintain contractual relationships with each MCO in their region. The contractors negotiate reimbursement rates and contracts with each MCO. They also ensure children have a coordinated care plan and receive all medically necessary services. In many states, the state agency overseeing ECI programs has the contractual relationship with MCOs, a more centralized and efficient approach.

Additionally, MCOs have a critical role to play in ensuring families of children with disabilities know about ECI and consider the option of participating in ECI. Texas HHSC has found that, in some cases, families have been told by MCOs or private therapy providers that they must choose between ECI and private therapy, which is not correct. Texas HHSC recently sent out guidance to all MCOs explaining that families enrolled in Medicaid can participate in ECI and seek additional medically necessary services from other Medicaid service providers, such as private therapy providers. The guidance also states that HHSC expects MCOs to "ensure that their providers are not creating barriers to accessing medically necessary services, including ECI services."[78]

POTENTIAL FEDERAL POLICY CHANGES MAY FURTHER JEOPARDIZE ECI

ECI services for Texas children could be hurt by upcoming federal decisions on the future of Medicaid and Children's Health Insurance Program (CHIP) funding; the requirement that Medicaid cover provide comprehensive services for children (the requirements is known as Early and Periodic Screening, Diagnostic, and Treatment benefit, or EPSDT); and the Individuals with Disabilities Education Act (IDEA).

ECI providers bill children's health insurance plans, including Medicaid and CHIP, to help cover the costs of ECI services. Medicaid is a particularly important source of funding. About two-thirds of children served through Texas ECI are enrolled in Medicaid. Medicaid reimbursement makes up about 40 percent of ECI program funding.[79]

Any reductions in federal Medicaid funding would likely hurt ECI services in Texas. For example, the deep Medicaid cuts proposed in versions of Affordable Care Act (ACA) repeal legislation would significantly reduce children's access to ECI. Those and any other proposals to cut Medicaid and establish a block grant or per capita cap would shift the costs of health services from the federal government to the states and counties. In practical terms, they would put states in a position to either increase state spending on Medicaid to replace lost federal funds or, in a more likely scenario for many states, cut Medicaid eligibility, benefits, and/or provider payments. Those decisions could drastically reduce access to ECI services for children enrolled in Medicaid.

Additionally, if Congress were to cut the EPSDT benefit or allow states to waive or cut this benefit, young Texas children with disabilities would suffer. The EPSDT benefit – known as Texas Health Steps in Texas – ensures that children with Medicaid coverage can receive health screenings, developmental screens, and treatments to address conditions discovered through screenings and diagnostic tests. The EPSDT benefit is one of the hallmarks of the Medicaid program and critical for children with disabilities or developmental delays.

Moreover, Texas ECI services could be harmed if Congress were to cut IDEA Part C funding or change IDEA requirements on states. Compared to other states, Texas relies more heavily on the federal government

to fund our ECI program. (Nationwide, states cover about two-thirds of the costs of ECI while the federal government covers about one-third, but in Texas state funding only covers about one-third.) Further, under Part C of IDEA, all babies and toddlers whose disabilities or delays fall within the state-defined eligibility criteria are entitled to receive the full array of ECI services they need. Any loosening of the requirements to serve all eligible children would weaken the Texas ECI program and threaten a young child's access to critical early interventions.

It is clear that decisions made by federal policymakers on Medicaid, CHIP, and IDEA policies could have ripple effects on the future of Texas' ECI program and children's access to ECI services.

RECOMMENDATIONS

For State Policymakers:

- Ensure that existing ECI contractors have the financial and other resources they need to remain in the ECI program and be financially sustainable, including adequate and timely mid-year funding to cover enrollment beyond their contracts.
- Fully reverse the Medicaid therapy rate cuts enacted in 2015.
- Utilize the state's ECI advisory committee to assess and recommend options to strengthen the ECI program, boost Child Find efforts, support translation services, reduce administrative burdens on ECI contractors, and improve transitions following closures.
- Evaluate and address the causes of the disproportionate decline in ECI enrollment of children of color.
- Enhance data collection on developmental screenings and implement strategies to increase screening rates.

For Federal Policymakers:

- Fully fund Medicaid, CHIP, and IDEA Part C.
- Maintain protections for children in Medicaid, including EPSDT.
- Maintain IDEA requirements for states to provide early intervention services to all eligible children under age three.

For Community Leaders:

- Build on successful local efforts to improve community coordination and outreach regarding developmental screenings, ECI awareness, and ECI enrollment.

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1106 Clayton Lane #111W, Austin, TX 78723
512-473-2274 | txchildren.org | @putkids1st