

STAR Kids Managed Care is Harmful for Medically Fragile Texas Children

In response to "STAR Kids will provide better health care for the state's needy children" published in the SA Express-News on 09/13/16

We agree, Commissioner Smith: let's set the record straight about the STAR Kids managed care mandate. As parents and advocates for our state's medically fragile children, our goal in approaching the Texas Health & Human Services Commission (HHSC) has been to work with the agency to address serious concerns associated with the legislature-mandated transition to managed care--ultimately, to ensure that no child is harmed. To paraphrase a recent statement by Governor Abbott: "Maybe the best way to start would be with the simplest and most profound idea. No [...] child deaths."

It is a sad day in the state of Texas when parents who are simply advocating for their sick children to receive the vital and appropriate care necessary to keep their child alive are belittled and maligned by public servants: the very policymakers whom they have trusted to protect the health of their children. There are no "tall Texas tales" here, only Texas parents gravely concerned about the facts and conflicting information, as put forth by HHSC and the managed care insurance companies.

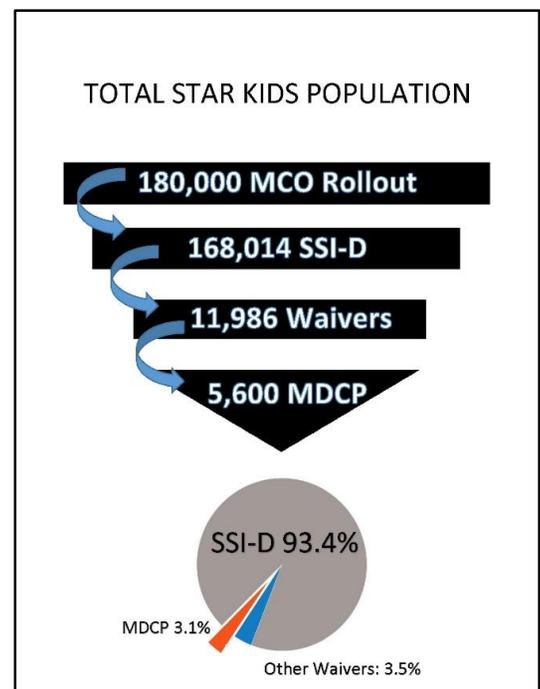
We invite you, Commissioner Smith, to sit down directly with our families and truly listen to the sincere concerns associated with this managed care mandate as it relates to medically fragile children. Listen to the informed parent testimony provided at the recent [STAR Kids Advisory Committee Meeting](#). Come spend a day in our lives and understand what our children require to keep them alive on a daily basis. Our lives are filled with change: in fact, change is the only constant when you have a medically fragile child. **We are not scared of change, but we are concerned about the STAR Kids Program and what it means for our complex children.** The lack of readiness and the highly restrictive nature of this program will be harmful to medically fragile children.

Significant Oversights Associated with the STAR Kids Mandate

The 1200+ families of medically fragile Texas children represented by the non-profit grass-roots organization Protect TX Fragile Kids **are not "fearful" or "anxious": these are informed and engaged parents** who have researched the STAR Kids program based on the facts provided by HHSC and the insurance companies contracted under this program. As we have peeled back the layers of this legislative mandate, we have learned there were significant oversights associated with the STAR Kids mandate. The current structure of this managed care program will be harmful for our state's medically complex children and will threaten their stability.

Platitudes and vague generalizations about the STAR Kids managed care 'product' do not change the facts. These are the facts:

- The STAR Kids Program was mandated by Texas Senate Bill 7, 83rd legislature, as a cost containment measure, forcing 180,000 Texas children from a PPO-type Medicaid system into an HMO-style managed care system. Of those 180,000 children, 11,986 access Medicaid through needs-based (non-income) medical criteria, and approx. 5,600 of those are part of the Medically Dependent Children's Program which has a strict medical eligibility criteria (*see graphic breakdown*).

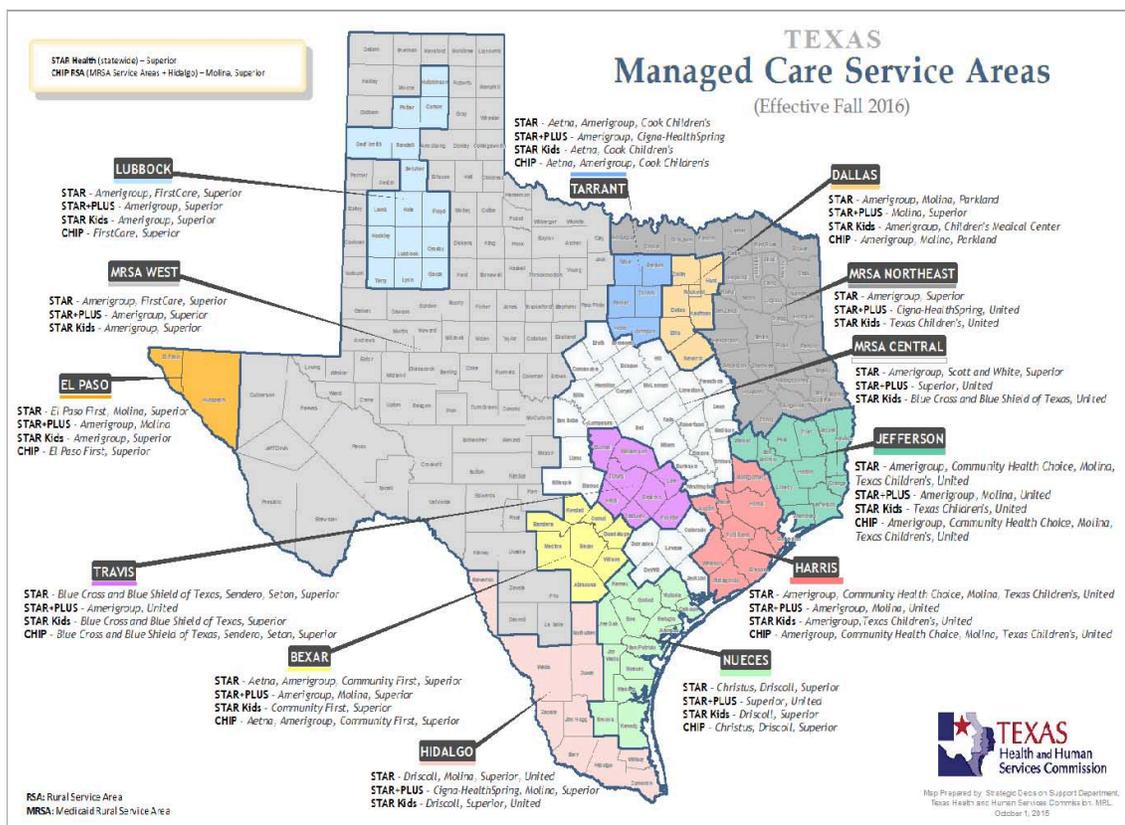


These are medically fragile children who are ventilator-dependent, have tracheostomies, require oxygen and feeding tubes to sustain their lives, are on dialysis, have uncontrollable seizures and

immune deficiencies, and children with terminal illnesses—**truly sick children with rare and complex disorders who require an intensive, hospital-level of care to sustain their life outside of a medical institution.**

We are Texas taxpayers and hard-working parents in overwhelming circumstances—simply trying to keep our children alive and families together. We are not “entitled” or taking advantage of the system.

- The majority (greater than 50%) of families with medically dependent children carry private commercial insurance; however, due to the catastrophic nature of their child’s illness, commercial insurance is not sufficient to meet their child’s significant medical needs. *This legislation made no provision for use of primary private insurance, which will result in higher costs to the state of Texas.*
- As of 11/01/16, ten (10) private managed care companies, with conflicting interests rooted in profitability (7 of which are for-profit entities), will receive a capitated budget per child and will now have full authority for these children’s access to care. Under STAR Kids, agents of these private insurance companies will take the place of neutral state caseworkers to determine eligibility and medical necessity for all services, including access and eligibility for the waiver program itself. These private entities will now regulate and allocate children’s access to all medical care as they see fit.
- Restrictive county-based geographic service areas inhibit access to major pediatric medical facilities and specialty care, and will now require families to select from two regional insurance companies based on where they reside (*see HHSC managed care map below*). Although HHSC has stated that these insurance companies have the “flexibility” and “freedom” to contract outside of their regional service area, they are not compelled or contractually obligated to do so. Where is the flexibility and freedom for the children and their access to care?



- The new needs assessment/screening tool, which helps to determine what services, such as nursing care, each child needs, has not been fully tested for reliability as recommended by Texas A&M. HHSC's response? "We have run out of time." This is absolutely unacceptable. Children's lives are at stake.
- Some families have still received absolutely no communication from HHSC about this mandated transition or have received inaccurate communication informing them they must join the wrong program.
- Families are required to select from one of two plans within their regional service area by 10/12/16, yet the insurance companies are not required to post their online provider directories until 11/01/16. STAR Kids managed care provider networks will not be finalized until an even later, unspecified date.
- As a result of families' advocacy efforts, HHSC has promised a 6-months continuity of care to continue seeing existing providers, but it is only 6 months OR until the insurance company comes out to complete their assessment OR until existing authorizations expire, whichever is soonest--not a full 6 months. At the end of that period, children will still be in the same situation--losing providers and no longer able to access the most appropriate care and treatment.
- Under the terms and restrictions of the STAR Kids mandate, many medically complex children will lose access to the highly-specialized care teams of physicians and providers whom families have worked years to assemble in order to keep their child alive and medically stable because the providers will not or cannot contract with the managed care organizations. Loss of these critical facilities and carefully structured care teams will lead to increased incidences of acute care, more hospitalizations, and will be harmful to medically complex little Texans.

Managed care inhibits access to appropriate care for many complex children who will lose access to specialized doctors, providers, and hospitals critical for their survival

The majority of these children require large teams of specialists and providers who work together to treat their complex multi-system conditions and medical needs. Consider the case of Christina Gregory, age 2. Christina was born with CCHS (Congenital Central Hypoventilation Syndrome), a rare disorder where her brain does not tell her body to breathe. She is one of 400 people in the U.S. with this disorder. Many doctors have never heard of her condition and do not know how to treat it. Christina is 24/7 ventilator dependent, and currently sees 9 local specialists and 1 primary care physician through her primary private health insurance plans. She resides just over the line of the Tarrant County service area--but the majority of her physicians and her PCP are located in the Dallas County service area, as is her hospital. These providers are not Medicaid providers, but they keep Christina medically stable and provide the most appropriate care for Christina's complex medical needs. **Under the STAR Kids managed care mandate, many of her doctors as well as her hospital are no longer "in-network" with the two regional insurance companies in her designated service area.**

When services or procedures are performed by one of these physicians, Christina's family pays out of pocket, but often the supporting services (such as nursing care), facilities and necessary equipment are covered by Medicaid, making it possible for the Gregory family to afford and access the



Christina Gregory, age 2, requires skilled nursing, treatment by highly-specialized physicians, and hospital-level care to remain at home with her family.

extensive care that Christina requires to stay at baseline. With this move to restrictive managed care organizations, this will no longer be possible, thereby forcing further reliance on Medicaid, increasing Medicaid costs, and moreover threatening Christina's very well-being.

There are those who will say that this mandate is about providing a “better standard of care for all children on Medicaid.” Perhaps that is true for families who do not have medically complex children and are not currently receiving adequate or appropriate care. If the goal truly is to improve the standard of care for ALL children, **then families of medically complex children should be empowered to work with their existing care teams to make their own decisions in the best interests of their child’s health.** They should not be constrained by restrictive geographic county service areas determined by government bureaucracy or have care rationed by private entities with conflicting interests rooted in profitability. *Forcing medically fragile children into a managed care system designed to keep people well is like forcing a square peg into a round hole: it does not fit medically fragile children’s needs.*

Exempting Medically Fragile Children from STAR Kids Managed Care is in Texas’ Best Interest

We understand and appreciate the need to balance our State’s budget and be fiscally responsible with our tax dollars. To that end, *we have proposed a working group of knowledgeable Texas parents and providers to identify more appropriate ways to reduce spending costs.* Ensuring access to appropriate and effective medical and rehabilitative care for our State’s most vulnerable population should not simply be an attempt to further cut a line-item on the budget, but a demonstration of our State’s moral emphasis and priorities.

We understand that HHSC is required to implement this legislative mandate and is only able to make minimal alterations and tweaks to the STAR Kids managed care program. Even if the agency could implement all of the potential changes that have been discussed, at best these are temporary band-aids to underlying systemic issues associated with this managed care mandate. They are not functional, long-term solutions.

In order to ensure that no children are harmed in this transition, and to allow legislators time to re-examine the provisions of this legislation specifically as it relates to the most vulnerable little Texans, **we are asking the Texas legislature to take action to:**

- (1) *delay implementation of the STAR Kids Program for the waiver program population; and***
- (2) *take legislative action in January to exempt this medically fragile population from the managed care mandate.***

The bottom line is that the STAR Kids managed care mandate threatens the stability of our state’s fragile children. As taxpayers, citizens, and parents who fight every day to keep our children alive, **we believe that it is in the best interests of the State of Texas—financially, politically, ethically, and morally—to exempt the Medically Dependent Children's Program from the STAR Kids managed care mandate.**

When government listens and responds to the people they represent to ensure that policies and programs are appropriate and effective, and make changes to avoid unintended negative consequences, our state can be more successful. On behalf of our children and the thousands of other medically complex children throughout the State of Texas who are adversely impacted by the STAR Kids mandate, we appeal to our lawmakers: **please help to protect our State’s most valuable asset--our children.**