



Protect TX Fragile Kids

August 1, 2016

The Honorable Greg Abbott
The State of Texas
State Insurance Building
1100 San Jacinto
Austin, Texas 78701

Dear Governor Abbott,

We are requesting your help on behalf of our state's most vulnerable little citizens: our medically complex and disabled children. As constituents, taxpayers, concerned Texas residents, and parents of medically fragile children, we are writing to express our grave concerns regarding the STAR Kids managed care mandate. We request that you take immediate action to mitigate the pending negative impact to our state's medically fragile children. Our concerns are further outlined below.

We believe that there were significant legislative oversights associated with the STAR Kids Managed Care mandate (Senate Bill 7, 83rd Legislature). These concerns stem from the manner in which specialized waiver programs, specifically intended for medically complex children (such as the Medically Dependent Children's Program), have been lumped into this massive mandate, as well as the way the STAR Kids Program has been structured for implementation.

These waiver programs are comprised of children with severe, chronic conditions (often affecting multiple organ systems) who meet specific medical criteria for eligibility. These children have conditions which significantly impair daily functioning and require medical support to perform even the most basic necessities, such as eating and breathing. Caring for them is a considerable challenge and requires a delicate balance. According to Kidsdata.org, one-third of children with special health needs already receive inadequate services. STAR Kids will widen that gap.

Due to the complexity of these children's needs, many local doctors and clinicians are unable to provide appropriate support. **Immediate access to specialty care is critical to these children's well-being.** Evidence based research verifies that facilitating access to specialists and sub-specialists ("tertiary care") is highly effective. For example, one study found that children who were treated at pediatric tertiary centers had a 93% survival rate, while children treated outside of pediatric tertiary centers had a survival rate of 52%.¹

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. While we understand that managed care may be helpful for children who may not currently be receiving appropriate preventative care and whose needs are not as complex, *managed care is NOT a good fit for medically complex children who require tertiary care and a plethora of specialists, therapists, nursing agencies, medical equipment providers, specialty pharmacies, etc.*

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.

¹Journal of Medical & Pediatric Oncology, 1995



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Our families have been forced to turn to the Medically Dependent Children's Program out of desperation, *because the private managed care insurance system has failed to meet our children's critical medical needs*. Not to take advantage of the system, not due to a sense of entitlement: rather, we are desperate parents, simply trying to keep our children alive and our families together.

- **STAR Kids managed care is highly restrictive and less conducive to medically fragile children's welfare than the current fee-for-service system.** Under the STAR Kids managed care system, families will be forced to find a new in-network PCP who will accept their medically complex child as a patient. All access to care will now be required to go through a new PCP (who is not familiar with these children and their extensive medical history), in order to obtain any coverage through the managed care organization (MCOs). This restriction is applicable for all care, including physician's orders, such as prescriptions, procedures, and therapies.

Access to specialty providers will also require pre-authorizations or referrals, and those providers must now agree to each regional MCO's onerous terms and conditions to be "in-network" in order for children to obtain even secondary coverage. Continuity of care and immediate access to specialty care is vital for children with long-term medical issues and disabilities. It is crucial to prevent complications, promote long-term stability, and reduce the incurrence of higher acute care costs.

Many families have worked for years to identify clinicians who can appropriately and effectively treat their child. In many cases, these children have such rare conditions that most specialists have never treated a child with their condition which necessitates that families travel across the state or out of state in order to access appropriate care. Losing access to their extensive and established care teams will disrupt continuity of care and be life-threatening for these fragile children. *More restrictive, less appropriate managed care places medically complex and disabled children at risk and unable to maintain medical baseline.*

- **STAR Kids managed care impedes our ability to utilize primary private health insurance, resulting in significantly higher costs to the State of Texas.** More than 50% of the MDCP population maintains primary private insurance. Due to the complex and extensive nature of our children's medical needs, families are forced to rely on the MDCP program for secondary coverage in order to meet their child's complicated medical needs and maintain appropriate care at home.

This mandate makes no provision for those utilizing primary private insurance. It will force parents to choose between accessing the most appropriate providers to care for their child or obtaining coverage for their child's plethora of critical medical needs. *Not allowing stakeholders to fully utilize primary private health insurance will force increased reliance on Medicaid and translate into even greater costs for the State of Texas.*

- **No reciprocity between many major facilities and networks across STAR Kids service areas within or outside of the State of Texas.** (see attached map – Exhibit A)
Example: Families within the Tarrant service area will no longer be able to use their current hospital and providers across town in Dallas, because that hospital is now only in-network for acute care purposes. The managed care "service area" now requires them to go to the hospital in Ft. Worth, and vice versa for those in the Dallas service area. This scenario is repeated across the state. Families from across Texas who travel to Dallas or Houston for specialty care are being told that their providers will no longer be considered in-network, because they are not part of their geographic service area.



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Families in the MRSA NE service area (near the Red River) are being told that they will have to drive over 400 miles to Texas Children's in Houston, despite the fact that all of their child's care has traditionally been with Cook Children's in Ft. Worth or Children's Medical Ctr. in Dallas, only 70-80 miles away. This change alone will greatly increase costs to the State through reimbursement of mileage, hotels, and per diems for each trip these families have to make to obtain care for their child. *Traveling 400 miles each way for routine medical care, as well as forcing a change of facilities and providers, is highly likely to cause a significant decline in health, safety, and welfare for these already fragile children.*

- **STAR Kids managed care mandate represents a political dichotomy for the State of Texas as well as a considerable conflict of interests.**

As a state, we are suing the federal government over the Affordable Care Act (or "Obamacare" mandate)—*and yet the State of Texas is doing the very same thing to its weakest and most vulnerable little citizens.* Chronically ill children will lose their current providers and their access to highly trained specialists. Private insurance companies and their agents will now replace neutral state caseworkers in an exceedingly restrictive situation. Under STAR Kids, these private insurance companies are given full authority to determine eligibility and medical necessity for all services, including access and eligibility for the waiver program itself. *These private entities with conflicting interests rooted in profitability will now regulate and allocate children's access to all medical care as they see fit.*

- **STAR Kids greatly increases the burden on parents and places unnecessary restraints on the caregiver's ability to create and maintain an appropriate plan of care at home.**

Medically fragile children and their families already face enormous daily challenges. The disruption of care and increased restrictions associated with the STAR Kids mandate will compound the stress levels for primary caregivers and their families, who are already functioning in multiples roles and at maximum capacity, while also caring for other children, maintaining jobs, and providing for their families. This proposed change greatly increases their burden and places unnecessary restraints on the caregiver's ability to create and maintain an appropriate plan of care.

It is important to note that as our families have become aware of this mandate, we have been working with HHSC to address these issues (*see enclosed letters – Exhibit B*), and to request a 12-month delay in implementation due to readiness issues. Because this is a legislative mandate, however, HHSC is only able to make minimal short-term alterations and tweaks to the STAR Kids managed care program. *While we appreciate the effort HHSC has made to work with us, these changes are not long-term solutions. Even if HHSC could implement all of the potential changes that we have discussed with Medicaid Director Gary Jessee, at best these are temporary bandaids to underlying systemic issues associated with this managed care mandate.*

If the goal is truly to cultivate a culture of life within the state of Texas, then this should be a priority. All life is endowed with intrinsic value from our Creator, and our State's disabled and medically fragile children, while requiring extra medical care and provision, add considerable value to our society, community and families. Ensuring access to appropriate and effective medical and rehabilitative care for our State's most vulnerable population little citizens should not simply be an attempt to further cut a line-item on the budget, but a primacy demonstrating our State's moral emphasis and priorities.

The bottom line is that the STAR Kids managed care mandate threatens the stability of our state's most vulnerable little citizens. 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.**



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We understand and appreciate the need to balance our State's budget and be fiscally responsible with our tax dollars. To that end, *we are proposing a working group of knowledgeable Texas parents and providers to identify more appropriate ways to reduce spending costs.*

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 and disabled children throughout the State of Texas who are adversely impacted by the STAR Kids mandate, we appeal to you both as a parent, and as the leader of our great state of Texas: **please help to protect our State's most valuable asset-- our children.**

We welcome the opportunity to meet directly with you and your staff to discuss these concerns, as well as possible solutions. We look forward to working with you to ensure that the Medically Dependent Children's waiver Program remains effective and successful for all Texans, big and small.

Sincerely,

7,170 concerned Texas parents, taxpayers and residents

512 concerned out-of-state family & friends

Protect TX Fragile Kids

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