



# FOR ONE ANOTHER

Children's Freedom Initiative

## Children's Freedom Initiative

Our mission is to ensure that all children live with families in permanent, loving homes - not in nursing facilities, institutions or other congregate settings.

The Children's Freedom Initiative (CFI), established in 2005, works closely with families and stakeholders to advocate for access to home and community based services so children who experience disabilities remain with family or live in another permanent, loving home. Access to and the provision of services in the family home encourages children's development and the acquisition of life skills that lead to full community integration and more productive lives. Children who experience disabilities, like any child, thrive when in a loving home.

For a decade, CFI saw a decline in the number of Georgia's children with disabilities who were institutionalized in skilled nursing facilities and other congregate, segregated settings. Unfortunately, that trend has now reversed. Too often, even though on average it is more expensive for the state, families are forced to place their child in a congregate setting in order to access critically needed supports and services.

The solution rests with funding and wise state policies. The institutionalization of children and youth with disabilities can be avoided by ensuring that:

- Adequate funding is available for families to access necessary support services in the home or community.
- State policies focus on maintaining the family, enhancing the statewide network of providers, and removing barriers to keeping children with their families.

To learn more about the Children's Freedom Initiative, please contact the Georgia Advocacy Office at 404-885-1234.



## *Shoulders*

A man crosses the street in rain,  
stepping gently, looking two times north and south,  
because his daughter is asleep on his shoulder.  
No car must splash her.  
No car drive too near her shadow.  
This man carries the world's most sensitive cargo  
but she's not marked.  
Nowhere does her jacket say  
FRAGILE, HANDLE WITH CARE.  
His ear fills up with breathing.  
He hears the hum of a girl's dream deep inside him.  
We're not going to be able to live in this world  
if we're not willing to do what he is doing *for one another*.  
The road will only be wide.  
The rain will never stop falling.

Author: Naomi Shihab Nye

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## *Tobey Freck*

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Tobey Freck, a quiet fifteen year old, lives with his mom and dad and four brothers and two sisters. His eldest sister Sammy, eleven years old with long brownish hair in a bun on top of her head describes Tobey's helpers. "They go play tennis and to the pool with him in the neighborhood, see movies like the 'Avengers'. He had this really friendly helper who really cared about Tobey - he would talk to him - make sure he was happy. He listened to Tobey's gestures - could tell if Tobey was upset - Tobey would shake his head or not get out of the car. Mom talks to the new helpers a lot - tells them what to do when he gets upset - let him sit down and get a drink of water."

Tobey's mom Liz, with brilliant blue hair, describes her first born as she looks at Tobey's brown hair and deep brown eyes. "We had been on the long term planning list for a waiver forever but three years ago Tobey started vomiting and lost fifty pounds. The doctors put in a central line sticking out of his heart and said 'Take him home or to hospice. Good luck - if he starts to bleed out bring him back to the hospital.' We finally got thirty hours of support after school and Saturdays.

Tobey's helpers take him to the Aquarium and the Chattahoochee Nature Center; he loves the folk art paintings of faces in the High Museum. He will sit there for fifteen minutes gazing at the faces. Before we got support - when Tobey was ten he went to an ado-





“Since he’s had helpers he’s started going places, moving and he’s started to learn more - how to use an i-Pad, his speech device, the phone.”

lescent treatment facility; he sat at the end of a hallway for three weeks in a blanket. We brought him home.”

Liz’s eyes look fondly at her son, “When Tobey started to get depressed he sat in the chair all the time. He was listless and his muscles weakened - then he lost the ability to jump and run. He was on nine different psychiatric medications. He is his best self when he is at home. And I am my best self when I have help. Since he’s had helpers he’s started going places, moving and he’s started to learn more - how to use an i-Pad, his speech device, the phone. It was like a light switch went on. And we discovered the he understands so much more than we imagined. Now he takes just two medications mostly for sleeping.

Other families ask us how we got the waiver when Tobey was so young. How do you rank families that are completely individual in their needs?

Since we got the helpers he has gone the longest without a hospital stay. I know my children are more empathetic and sensitive and reach out to others because of their brother. The other day we were going down the long rows in Wal-Mart; Tobey saw an employee sitting on the floor stocking shelves. He hugged him from behind. The guy turned around with tears in his eyes, gave Tobey a big hug and said ‘Thank you.’”





## *Dionna Allen*

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Penny Jones and daughter Dionna live with her dad Dion for whom she is named. “God gave her to me - she is my blessing” Penny says in a soft Guyanaian accent. “It’s an amazing journey. She taught me about myself - self-discipline and stability.” Dionna’s pony tails in twists frame her smooth brown skin - she gazes at the sign on the wall at the foot of her bed “The Princess Sleeps Here.”

Dionna receives 84 hours of nursing assistance during the week. “If I had 20 hours more I could get a full time job and help my husband - maybe we could buy a house.” Penny describes how she has to climb up and down ten stairs in their rental home in order to bring Dionna to the family room where everyone gathers - her two brothers, three sisters, two nieces and nephew. “Eventually no one will be able to lift Dionna - she weighs sixty-two pounds now.”

Penny picks up Dionna’s beautifully manicured fingernails - deep blue with a little flower on one finger. “When her monitor starts to beep I know her heart is racing a little. That’s when she wants me to come dance with her because Beyoncé is on the radio!” Penny smiles at her princess and says, “I hold up a sexy outfit and say blink once if you want to wear this, blink twice if you don’t. Well you know she always blinks once!”

“After Dionna was born they said give her up to hospice - I took



her home. She's here for a reason. I have had to appeal every year for eleven years to Medicaid to get her hours - that means getting three or four doctor's letters every year. The blood sweat and tears mothers like us go through."

*"It's an amazing journey.  
She taught me about myself,  
self-discipline and stability.*







## *José Escobar*

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José Escobar, seven years old, lives with his mother Ady and his grandmother. His sharp haircut and dark eyes with long lashes sparkle when he says “Yeah I go to school here and my girlfriend is Sidney.” José is bilingual - as he looks around his living room decorated for Halloween he exclaims, “I am going to be Batman for Halloween!” Mom will take him trick or treating in the neighborhood.

Ady, petite with curly auburn hair explains “I used to work as a safety manager for hospitals and construction sites - I would like to go back to work. I made a request using the letter from the hospital for thirty-five hours during the week and twenty-one hours on the weekend. I need to request more hours for night because sometimes I wake up twelve times a night; José’s breathing machine starts beeping or he is taking out his nutrition tube. The company that provides the nursing and certified nursing assistant hours doesn’t come reliably. I have to teach someone new every week - I don’t have stable people. Why does the company send people who aren’t strong enough to lift him?”

When asked if she and José go places in their community Ady’s deep brown eyes moisten with tears. “We go to the hospital and back.” As Ady lifts José, who weighs forty-nine pounds, she expresses “I am the mother, the lawyer, the doctor, the advocate and





the nurse. I will fight for his rights no matter if I have to go all the way to the moon. My family sees José as a champion, a guerrero - a fighter. Someday José is going to be a speaker - telling people 'If I can do it, you can do it. Yo sí puedo.'"

*"I am the mother, the lawyer, the doctor, the advocate and the nurse. I will fight for his rights no matter if I have to go all the way to the moon.*





## *Sareena Kahn*

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Sareena Kahn celebrated her third birthday at home where she lived with her mom and dad, Gul and Amir and her twelve year old brother Aiyan. Her name means “princess”; when Aiyan used to call “Sareena” her long dark hair streaked with gold shook and smiles lit up her face. She loved the cartoon “One Little Finger” and when she heard her mom’s voice on the i-Pad recording her family had made her dark eyes sparkled.

In the past four months her mom hadn’t slept; that’s how long Sareena had been awake all night. Her mom, whose soft quiet voice echoes her Pakistani heritage appealed to the Medicaid agency for more hours of help so she and her husband could sleep.

Sareena received 84 hours of nursing services when she was born. Abruptly when she was one year old the Katie Beckett waiver she received stopped. In order to keep her at home, mom who graduated from Georgia Tech as an engineer and worked for the GA State Department of Transportation had to leave her job. The family lost their health insurance. Her dad, who runs convenience stores, rose at 5:00 AM to go to work and then returned home after fifteen hours to help with Sareena at night.

Her mom had to appeal the reduction of Sareena’s skilled nursing services. After several months of negotiations, Sareena’s family





accepted the state's offer of thirty-two hours of unskilled support and twenty-four hours of skilled nursing supports.

Sareena died on the autumn morning of October 14, 2018. Later that afternoon family and friends came to visit her one last time before her parents and brother went to the mosque to pray. Her Uncle Kahn laments "Sareena was a blessing from God. He has taken back his gift."

*"Sareena was a blessing  
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