

Medicaid: A Lifeline, Not Just a Line Item

*Written by Karen Carlton, guardian to
Joey Tucker, residents of Durham, NC*

Karen has spent a significant part of her career advocating for individuals with disabilities. In her spare time, Karen enjoys spending time with Joey, a young man with Down syndrome, whom she met over 30 years ago and has grown to love deeply. In early 2025, Karen became his guardian. This is their story.

Joey is 34 years old and has Down syndrome. He's funny, charming, spirited, and, according to Karen, the most amazing person she knows. Joey has received Medicaid waiver services most of his life—services that have allowed him to greet everyone he meets in store aisles, attend public school arts performances, volunteer at local nonprofits, learn to cook, join a handbell choir, play on a baseball team, take ballet and Zumba classes, and thrive in his local community rather than an institution.

At just 20 months old, Joey entered the foster care system and faced placement in a nursing home due to his extensive medical needs. He spent most of the first 20 months of his life in the hospital. It was then that his adoptive mother, Dawn, stepped forward to foster and eventually adopt him. Because of Medicaid waiver services, she was able to provide him a loving home while continuing to work. Karen came into Joey's life when he was 3 ½ and later on became one of his Medicaid-funded direct support staff when he was 5 years old. It was through this that Karen got to bear witness to the beautiful life that Dawn had created for Joey with the support of Medicaid-funded services.

On December 21, 2024, tragedy struck. Joey and Dawn were involved in a head-on collision when their car was hit by an impaired driver. Joey sustained serious injuries, and sadly, Dawn did not survive. The family recently found out that in her dying moments, Joey's mother wrenched the steering wheel as far to the right as possible, placing herself in the line of the oncoming vehicle to protect Joey. Those extra few inches of space took Dawn's life but ultimately saved Joey's.



When she heard about the accident, Karen rushed to the hospital and remained with Joey during his stay. After discharge, Joey went home with her, and she is now his legal guardian. Karen shares that she will never replace his mother. She's his "KK" and she is doing her best to honor Dawn's strong legacy of loving and advocating for him.

Without Medicaid waiver services, Joey would have faced state care and placement with strangers during the most traumatic time of his life. Instead, he lives with someone he has known and trusted for over 30 years, maintaining his routines with familiar caregivers and continuing to thrive, while Karen continues to work.

While they both grieve deeply for Joey's mother, Joey and Karen are building a new family together. This transition was made possible by continued access to these critical services.

Thanks to Medicaid waiver services, Joey has been able to live a full life in a vibrant community of family and friends who love him deeply. **As Congress makes budgetary and policy decisions, we urge you to protect and strengthen access to Medicaid programs. For some, these programs may be just a line item. For Joey, they are a lifeline.**

Shortly after the wreck, Joey and Karen wrote this creed:

*At OUR house...
We are a TEAM.
We LOVE each other.
We can do HARD things.
We can be SAD if we need to be sad.
We can do FUN things.
We can have iPad time.*



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