



Bumps in the Road

By Rylin Rodgers, Training Director, Family Leadership Coordinator,
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Looking back to my now teenage children's early childhood, my first thought was my "white limo" fantasy. When my son was hospitalized as an infant, and the complexity of his condition was not yet clear, my husband and I saw another family leave the children's hospital in a limousine. That family was celebrating a successful surgery, resolution of the child's issues and a return to life as normal. This would be their last hospitalization, and they were going home for good in style. We turned to each other and pledged to do the same when our turn came, which would surely be soon. We would get through this current crisis, and we would move on with the normal life we had planned for our son. But that limo ride never came for our family, and it never will. In fact, in many ways we have instead been on a very different and unexpected road, with wide variance in vehicles and driving conditions.

What I have learned from this journey is immense. First, while raising children who have special health care needs is the road less traveled, we were not alone. The families before us forged a path. The families currently on the road with us are the most wonderful traveling companions: giving, resourceful and resilient. And after a while I started to notice the families who followed, and hoped we were smoothing some of the bumps on the road for them. And while some sections of our road are built by families alone, most of our journey has been supported by professional builders.

The providers who partner with individual families and those who are working on system-level road design have both a tremendous impact. Home visiting systems give families access to tricycles and training wheels with the support they need to travel their own paths. Primary care medical homes are more than a roadside tune-up shop. They provide whole child medical care and the partnership each family needs to navigate its course. Subspecialty providers give the critical care for very complex needs when sudden breakdowns occur. Financing the raising of my children has been a part of the journey in a constant state of change. At the moment families have increased chances of being insured on the road, but too many still can't meet minimum coverage standards. Care coordination pilots are building the network needed to turn on the GPS system for families. The pit crew that supports our journey is extensive and endlessly important: therapists, medical equipment suppliers, teachers, community partners, even political leaders. It takes them all!

Texas Parent to Parent

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In the beginning, I didn't know what I would need to effectively parent Matthew and Laura. Frankly, I had little knowledge of the world of systems and supports that would be crucial to their success in growing and learning. What I know now is that the road system out there is not yet perfect – there are bumps, potholes, unpaved stretches and detours – but it is there, and amazing folks are working every day to smooth the journey and to build new and better highways. I thank you for putting on the work vest, even in less than ideal conditions. I urge you to continue to be alert to the needs of the travelers, point out the shortcuts, move the barriers and cheer the journey. Sometimes, I still wish for the limo ride, more often I am aware of what I would have missed and that my family was meant to be on this road.

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